AVISO

SPRING 2012 | ISSUE NUMBER 68

THERE IS STILL TIME TO REGISTER FOR THE 2012 LEARNING INSTITUTE!

Are you interested in advancing your skills and making valuable connections? There is still time to register for the Canadian Hospice Palliative Care Association's 2012 Learning Institute! The best and brightest faculty in the hospice palliative care field have worked these past months to create an intimate and intensive Learning Institute. Join the CHPCA and many of your peers across the country from June 1-3 at the Banff Centre in Banff, Alberta. Attendees are able to register in five intermediate to advanced learning streams that will include presentations, case studies, workshops and small group work.

There will also be a Lunch Symposium for Physicians and Nurses, presented by Purdue Pharma. The Symposium is entitled Post Cancer Treatment Pain Management: Assisting Patients to Have Less Pain on their Road to Recovery.

The CHPCA has negotiated a group rate at the Banff Convention Centre. Staying on the Banff Center's campus is convenient, affordable and beautiful. For room rates and booking information please *click here.*

Still not convinced? The Banff Centre is nestled in the Rocky Mountains. While in Banff, why not explore the wilderness around you. To book with Discover Banff Tours, please *click here*.

Registration is still open! *Visit our website* to learn more. Don't miss out on what promises to be an eye-opening weekend.

STREAM 1	ADVOCACY, KNOWLEDGE TRANSLATION, LEADERSHIP AND ORGANIZATIONAL DEVELOPMENT
STREAM 2	INTER-PROFESSIONAL EDUCATION AND PRACTICE
STREAM 3	AWARENESS, INFORMATION, SOCIAL MEDIA AND ADVANCE CARE PLANNING
STREAM 4A	CLINICAL PRACTICE - PAIN
STREAM 4B	CLINICAL PRACTICE - GENERAL

PRESIDENT'S LETTER

SARAH WALKER, PRESIDENT OF CHPCA

What an exciting time to be working in hospice-palliative care! We are making headlines across the country whether with poignant stories related to care or controversial issues causing us all to think about how we approach 'end of life.' We are sharing new ideas and reaffirming best practices in everything from symptom management to program development. Our area of expertise is increasingly in demand for many reasons including the aging of our population. I'm sure you all have received calls recently from friends asking for help as they try to navigate the illness of a family member—your knowledge is a lifeline for the community.

Albert Einstein was quoted as saying, "The only source of knowledge is experience." If you agree with that—CHPCA has made your life much easier! We have gathered together some great people with diverse experiences, a fresh platform for in-depth discussions and a beautiful environment—it's the CHPCA's Banff Learning Institute! We're sharing ideas around advocacy, clinical practice, advance care planning, education (and we've got mountains, great food and bears)-- what more could you want?!

If you haven't attended a CHPCA event in the past, I hope you'll consider joining us in Banff. We'd love to have your voice become part of the ongoing dialogue. If you were with us in Newfoundland or for other CHPCA conferences, I encourage you to come to the Learning Institute. It's a new approach for CHPCA and we'd love your feedback!

Before I end, congratulations to all of you who participated in Hospice Palliative Care Week events—great job! The number and variety of events were fabulous. Thanks for taking the time out of your hectic schedules to celebrate and share our work.
Hope to see you in Banff!

Sarah L. Walker

CHPCA BOARD OF DIRECTORS

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Dr. Heather Mohan
North Vancouver, British Columbia

News From The Provinces

Alberta

RURAL ROADSHOW MORE THAN JUST ANOTHER COURSE

Alberta Hospice Palliative Care Association is in the midst of presenting our 3rd Annual Palliative Care Workshop in rural towns and cities throughout Alberta. The topics range from 'We're All in This Together', to 'This Thing Called Grief', and 'Talking about the Tough Stuff'. The AHPCA Rural Roadshow has been successful on so many levels!

Rural participants have told us that the Workshops provide more than just learning opportunities. Rural workshops, on their own turf, provide unique community building opportunities and many other advantages over bigger conferences in central locations. These benefits include:

Rare Networking Opportunities
We have learned that participants from many rural areas are unaware of the services and support groups in nearby towns and cities. - These workshops provide a great opportunity for networking and regional community building in palliative care.

Training Customization
Through prior consultations and discussions with community stakeholders, the workshops are customized to meet the unique needs of each community.

Compassionate and Caring Support
Statistics indicate that each participant brings their experience and training to at least 6 other community members. As a result - professionals, volunteers and family caregivers are better able to alleviate the suffering of those facing the end-of-life experience in their own communities, and to develop stronger support ties and services for those left behind.

Collaboration with Local Hosts
We work hand-in-hand with a palliative-related organization in each area, and AHPCA couldn't bring these important workshops to rural locations without help from these hard working 'host partners'. Hosts value the opportunity to bring training to their community with no costs to their organizations, and have reported that the workshops enhance their profile within the community.

Palliative Awareness Building
Even those who don't attend hear about the workshops through community newspaper articles, posters and interviews. When the need arises they are aware that palliative and hospice care offers support and services to experience end-of-life with comfort, peace and dignity.

This year the Workshops are also building our AHPCA Membership roster. The full day Workshop fee includes an AHPCA Membership. As a result, we expect our Membership to grow by as many as 300 individuals. Our challenge as always is to keep our new and existing Members happy, engaged and prepared to renew again next year!

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Follow us on Twitter and stay in the loop!

@CanadianHPCAssn

NATIONAL OFFICE UPDATE

SHARON BAXTER, EXECUTIVE DIRECTOR

You have to love this time of year in Canada. Flowers are blooming and snow is gone. We are all looking forward to being in Banff in early June.

As you may have noticed -- Hospice palliative care in Canada is getting more media attention. The Canadian Hospice Palliative Care Association, the Champion's Council, the Quality End-of-Life Care Coalition of Canada and many other partners are working on the national scene to raise the profile and attention to this under funded and under represented part of our health care system.

The increased attention could be due to our aging population; or it could be due to more of us living with a chronic disease or conditions; or the reality that more and more of us are being called upon to be caregivers for aging family members. But for whatever reason, the media is paying more attention and Canadians appear to be more open to talking about death and dying or as we like to say, "how would you like to live your life right to the end?"

Last year over 260,000 Canadians died. Each person's journey varied greatly depending on the programs and services they were given like their settings of care, how much care their family and friends could assist with, what they were dying of but also it was dependent on where they lived in this vast country. It really does depend on where you live.

In many areas of the country, services are not integrated well. People wait in hospitals for home care and long term care beds – they wait no matter where they want to die! The Quality End-of-life Care Coalition of Canada under the management of the Canadian Hospice Palliative Care Association is starting work on a national initiative funded by the federal government advancing the integration of hospice palliative care across all settings of care.

How can we better integrate hospice palliative care into our health care system? How do we create seamless transitions between settings of care and how do we encourage specialists or primary care to refer patients to hospice palliative care in a timely fashion? Also, how do we fund a health care system that includes hospice palliative care? These questions concern all of us. We hope that this initiative acts as a catalyst for change in health system renewal.

Another issue I wanted to bring to your attention today is what we call advance care planning. This is often referred to as power of attorney for health, advance directives or health proxies depending on where you live in this country. Most importantly, advance care planning is about the conversation and not necessarily about the written directives. CHPCA and its partners have launched a campaign called "Speak up: start the conversation about end of life care." April 16th was advance care planning day in Canada and five provinces declared the day.

In March 2012, the CHPCA and its ACP partners conducted an Ipsos-Reid poll that found that 86% of Canadians have not heard of advance care planning, and that less than half have had a discussion with a family member or friend about healthcare treatments if they were ill and unable to communicate. Only 9% had ever spoken to a healthcare provider about their wishes for care.

We have lots of work to do! I encourage you to get engaged in this campaign and issue. Consider becoming an Advance Care Planning champion and speak up.

The National Hospice Palliative Care Week campaign was a few weeks ago now and the theme for 2012 was "Let's Work Together." As Canadians approach the end-of-life, it is increasingly important for pathways of communication to remain open between family and all professionals including volunteers involved in a patient's continuum of care. This year's theme encouraged us all to maintain open communication and work together.

The CHPCA Champion's Council is busy working on a few high profile initiatives.

The Life Blanket campaign will be launched this fall so stay tuned.

The National Fact Sheet on Hospice Palliative Care has been revamped and expanded to include more relevant statistics and facts. This fact sheet is a key advocacy resource and terrific to engage the media with. The fact sheet can be found at www.chpca.net.

The National Directory has been re-developed and some of the information we are seeking has changed. One of our summer students will be in touch to update your information if they haven't already done so. This info is used for referrals but also for better defining the work that we do. Please go online to look at your listing, you can now update your form directly at www.chpca.net.

2012 CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION ANNUAL GENERAL MEETING

The CHPCA Board of Directors invites you to attend the Association's Annual General Meeting taking place on:

Thursday October 11th, 2012
5:40 – 7:00 pm
Palais des Congrès, Montreal, Quebec

Highlights include:
Presentation of the Annual Report and Audited Financial Statements
President's Report and Executive Director's Report
Election of Members-at-large
Presentation of the Award of Excellence, Balfour Mount Champion Award and Media Award

Please join us as we celebrate our achievements and reflect on the future of hospice palliative care in Canada. For more information please ***contact us***.

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

You may have also noticed that we have relaunched www.chpca.net with a new look and feel. Our website is now more interactive than ever, so please take a look around and let us know what you think!

In closing, enjoy a wonderful summer.

Sharon Baxter

IN MEMORIAM

She was known internationally for helping thousands of dying patients through their final days, and now the "grand-dame of palliative care" has made the journey herself.

Dr. Elizabeth Latimer, passed away at the age of 68 at the Juravinski Hospital on April 28. Dr. Latimer will be remembered as an internationally renowned leader in the emerging area of palliative care. She lectured around the world and frequently wrote scholarly articles on the subject.

Dr. Latimer was an active member of the Canadian Hospice Palliative Care Association, and constantly strove to improve the access to and quality of hospice palliative care for all her patients. In 1999, Dr. Latimer was honoured with the Award of Excellence by the CHPCA for her tireless dedication to end-of-life care.

Dr. Latimer grew up in Hamilton and became a nurse before going on to medical school at McMaster University.

We thank Dr. Latimer for her dedication to hospice palliative care movement and making a difference in the lives of many Canadians.

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BRITISH COLUMBIA

BCHPCA has had a busy few months leading up to our annual conference and Annual General Meeting. This year's conference theme, Reconnecting and Sharing Wisdom, acknowledges our 26th year of service to people in British Columbia and the Yukon. The conference will provide an opportunity for over 200 attendees to reconnect with friends and colleagues from all over the province and to make connections with those who are new to the organization.

A new board was elected and affirmed by the members with Meg Milner as our incoming President. Our structure provides for representatives elected from each of our 6 health regions in addition to the executive positions. We find ourselves with a great mix of returning board members and new directors.

As we look ahead, we are strengthening our administrative infrastructure and hope to be hiring new staff in the near future. We have plans to engage our members in a number of areas including membership structure, education, communication and advocacy.

ONTARIO

ADVANCING HIGH QUALITY, HIGH VALUES PALLIATIVE CARE IN ONTARIO. A DECLARATION OF PARTNERSHIP AND COMMITMENT TO ACTION.

In April 2011, the Hon. Deb Matthews, Minister of Health and Long-Term Care announced a review of hospice palliative care in Ontario. The review was completed in December with the issuance of a report titled Advancing High Quality, High Value, Hospice Palliative Care in Ontario, Declaration of Partnership and Commitment to Action. The declaration of partnership is between the Ministry, Local Health Integration Networks (14 networks are the local funders for most healthcare in Ontario), and provincial association partners representing health service providers. The report and supporting documents are available at *www.qhpcco.ca*

The review process involved 87 individuals from across Ontario from all care settings and professions, from CEOs to front line staff, large institutions and small agencies, rural and urban geographies, came together with the common goal of advancing quality hospice palliative care. Consumer consultations were also conducted to gather the perspectives and experiences of patients/clients and family caregivers. Hospice palliative care was examined from four perspectives: Integration and Shared Care; Accountability and Governance; Education, Mentorship and Specialized Support; and Care Pathing across the Continuum of Chronic Disease Management.

The Declaration is a seminal document for hospice palliative care in Ontario and will guide policy development at the Ministry, inform best practice, and act as a call to action for everyone working in the field to lead real change. Change that will result in high quality, person and family directed integrated care delivery. This change will improve system performance and sustainability; improve population health outcomes; and most importantly improve the quality and value of hospice palliative care for the people of Ontario. The vision for hospice palliative care in Ontario is "Adults and children with progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to help them live as they choose, and optimize their quality of life, comfort, dignity and security."

Hospice palliative care is now recognized as a priority for system transformation. One desired outcome of system change is to position hospice palliative care within the provincial chronic disease framework. The majority of people with advanced chronic disease should be identified and offered care and support through collaborative, extended inter-professional teams based on the new delivery model outlined in the report. To support system transformation the report calls for standardized outcome indicators, integration of care across the continuum of care, care coordination, and regionalized hospice palliative care programs. There is no question that this is a large and complex task but there is also a willingness to move forward and effect change wherever possible and through an iterative process. The participants in the review process committed individually and collectively to move forward immediately with a targeted focus to evolve hospice palliative care in Ontario to a more integrated future state.

The question for hospice palliative care providers in Ontario is: How will you lead change?

PRINCE EDWARD ISLAND

Prince Edward Island continues to make strides towards a quality palliative care program that is comprehensive across the Island. In January Minister Currie, the Health Minister assured us that the stand alone hospice was still on the books with all the programs that we had advocated for. There would be a slight delay in the opening because of the new LTC facility that was being built but Premier Ghiz was committed to the stand alone facility. At Christmas we had launched a Christmas Card Campaign wishing the Premier and Liberal Party well but also stating how we must continue with the new facility and the Minister and Premier got the message.

The provincial hospice palliative care program have begun to look at the number of people who are hours from death (up to 48) being transferred to acute care facilities. Although the number is small we see this as a place to reduce such transfer and provide more supports to families and care providers in the home.

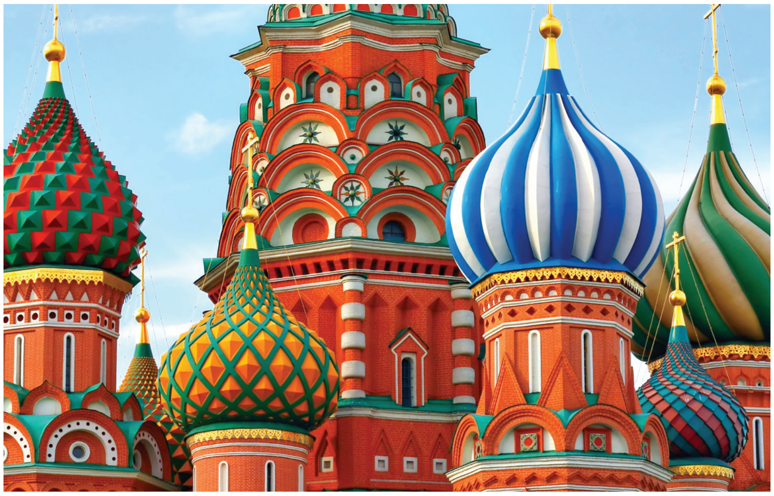
The provincial program has also begun to have the Integrated Palliative Care Nurses visit to provide education and support to nursing staff in two government LTC facilities. This will help bring consistency to end of life care across the continuum and the good principles of palliative care will be taught to the staff as well.

There is also a pilot to have the nurses from the Integrated Palliative Care Team follow a person who is registered in the Integrated Program but has to go to acute care. The nurses will see the person on a daily basis. This again allows for consistency in care and education for acute care nurses in palliative care practices.

A new four bed Palliative Care Unit is opening in O'Leary PEI. This is attached to the hospital there. Staff have been trained by Dr. LeCour and her team so quality palliative care will be available for people in that area of the Island.

The second Provincial Palliative Care Conference is June 21-22 in Summerside. Last year we had a waiting list and we expect the same this year as knowledgeable speakers will bring current up to date information in their presentations.

HPCA of PEI has completed some restructuring. We welcome Joanne Ings as our new ED and Jodi Swan as our new president.



Champion's Council
Conseil des Champions

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

THOUGHTS FROM A CHAMPION

BY MICHAEL SANGSTER

When I was asked to join the Canadian Hospice Palliative Care Association's Champion's Council in 2010, I had not spent much time contemplating that final stage of life - that word we try very hard not to use. Death. We like to think that it won't happen to us or our loved ones. But, in reality, we know better. Admittedly, I had limited knowledge of hospice palliative care then, including the comfort, dignity and humanity that surrounds it. Little did I know that I would be experiencing it first hand within that coming year. Thankfully, my beloved mother-in-law died peacefully in a residential hospice, with her family and with her dignity, surrounded by love and compassion. I personally commend the entire hospice palliative care community across Canada for the exceptional work they do in providing the care and comfort for both the patient and family in such a difficult time. I am now a passionate supporter who is actively engaged because of my own experience, and as I become increasingly familiar with just how difficult this topic is for most people.

Talking about death won't kill us. My role, and that of my other fellow members of the Champion's Council, is to advance the profile of hospice palliative care across Canada; and we are doing so by talking. Some of the recent activities of my fellow Council members include a keynote address to the Canadian Club of Toronto by Paul Lucas, President and CEO of GlaxoSmithKline who challenged corporate Canada to embrace compassionate care; a workshop at the Human Resources Professionals Association Conference by Kathy Butler Mallette, Chief of Human Resources at the House of Commons, who brought to light workplace implications of employees caring for critically ill family members; and a keynote address to the Rideau Club in Ottawa by recently-retired Senator, Sharon Carstairs, who eloquently defined hospice palliative care as the essence of the human spirit.

Within the next few months, you will also be hearing about a thought-provoking campaign for which I am co-chairing with fellow Champion's Council member, Russell Williams, President of Rx&D, that will challenge Canadians to view death and dying a little differently.

Together, we will continue to break the silence and help create dialogues and meaningful conversations surrounding end of life issues.

Maurice Sendak died recently. He was 83 years old. And while most of us know him best as the author of the popular children's book Where the Wild Things Are, he also had a great quote that I wanted to leave with you:

> ***"I cry a lot because I miss people. They die and I can't stop them. They leave me and I love them more." - Maurice Sendak***

Michael Sangster is Vice-President, Federal Government Affairs at TELUS Communications.

The Canadian Hospice Palliative Care Champion's Council is a group of dedicated community and business leaders who have come together to lend their voice and be champions in advancing the profile of hospice palliative care across Canada. They are dedicated advocates and supporters, and the Canadian Hospice Palliative Care Association is very proud to call them friends. For a list of Champions, please click here.

Circle of Caring. *Circle of life.*

The Canadian Hospice Palliative Care Association's Circle of Caring shares a common hope – that when the end of life comes to us or a loved one, that it may be peaceful and free from pain.

Join us. Join other compassionate community leaders in the Circle of Champions in Caring and help the Canadian Hospice Palliative Care Association (CHPCA) ensure that every Canadian has access to quality care at the end of life.

Stay informed. As a member of the Circle of Champions in Caring, you will have access to various subscriptions, resources, tools and connections that will keep you apprised of what is possible at the end of life.

Share your compassion. Participate in our of the CHPCA's annual events and receive discounts on registrations. Explore volunteer opportunities in your local community.

Honour a loved one. Dedicate your gift in the precious memory of someone whose life has touched you.

Our commitment to you. Each Circle member will receive the following:

- Quarterly electronic updates of your gift at work
- Copy of 'A Caregiver's Guide – A Handbook About End-of-Life Care'
- A guide all Living Lessons® resources
- Recognition on the CHPCA Donor Wall at the National Hospice Palliative Care Conference
- One year subscription to the CHPCA Newsletter, AVISO
- Recognition in the CHPCA Annual Report (for donations over $500)
- A printed copy of the CHPCA Annual Report (for donations over $500)
- Bi-annual letter from the Chair of the Board of Directors (for donations over $100)

Introducing the Circle of Caring Virtual Garden.

This virtual garden has been created as a place to come together to celebrate friends and family, a place to honour the memory of a loved one and a place to pay tribute to hospice palliative caregivers across Canada. It is a place to celebrate life and a place to come together in solace.

For more information, please contact Caroline Kayll, Partnerships and Development at (613) 241-3663 ext. 224 or email ckayll@bruyere.org.

THANKS FOR HIKING WITH US FOR 10 YEARS!

On May 6, 2012, thousands of Canadians of all ages gathered on walking paths, parks, and hiking trails across Canada to celebrate the 10th Annual Hike for Hospice Palliative Care. Although organized as a national event, each Hike is hosted locally.

“We created this event so that local hospice palliative care programs across the country without the capacity or staff to organize an event of this scale on their own are able to raise much needed funds,” stated Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association (CHPCA). “In May 2011, over 100 hike sites participated across Canada and raised $1.6M, with 100% of those funds remaining in their local communities.”

This year, the CHPCA created the Hike for Hospice Palliative Care Power of 10 Campaign, to mark the 10th anniversary of the Hike. This campaign encourages Canadians to speak to 10 people – friends, family, co-workers, and family doctors – about the importance of hospice palliative and end-of-life care. It encourages us all to tell 10 friends, who tell another 10, who each tell 10 more, effectively growing the hospice palliative care community.

Thank you to all of our hike sites for 10 years of the Hike for Hospice Palliative Care! Together we can make a difference. We hope to see you all at the next Hike for Hospice Palliative Care, May 5, 2013! For more information on how to get involved, please click here.

NATIONAL HOSPICE PALLIATIVE CARE WEEK:
LET’S WORK TOGETHER!

As National Hospice Palliative Care Week launched on May 6th, CHPCA encourged hospice palliative care professionals, patients, caregivers and their families to work together, to ensure the best possible care for Canadians nearing the end of life.

“Support networks are there to help! Health care teams, caregivers, volunteers, family and friends are valuable resources, keep them in the loop,” said Sarah Walker, “quality hospice palliative care offers a flexible set of services. It includes physical, psychological, social, spiritual and practical support to people with life-threatening illnesses, and to their families. It focuses on what people need and want at any given time, both prior to death and during bereavement.”

“As Canadians approach the end-of-life, it is increasingly important for pathways of communication to remain open between family and all professionals including volunteers involved in a patient’s continuum of care. This year’s theme encourages us all to maintain open communication and work through a difficult time together” added Sharon Baxter.

The responsibility of caring for someone with a life-limiting illness is one that needs to be shared collectively within the hospice palliative care team and the family. Together we can all make a difference in the lives of those who are living with a life-limiting illness and those affected by it.

Thousands of organizations across the country celebrated the 2012 National Hospice Pallaitive Care Week with meetings, celebrations, and other events. Over 200 people joined us for our first National Hospice Palliative Care Week Webinar, “Teamwork: The sum is greater than the parts,” hosted by Fred Nelson, Mike Harlos, and Brenda Hearson. To view the event recording and download the powerpoint slides, please *click here*.

THE OTTAWA DEAF PALLIATIVE CARE TEAM

BY CHRISTINE WILSON AND ELAINE CAMPBELL

One afternoon in a palliative care unit at Elizabeth Bruyere Continuing Care in Ottawa, a palliative care doctor walked into a patient's room, gently placed the patient's right hand on the doctor's long braids to feel them and then moved the patient's hand to touch the doctor's stethoscope. The patient smiled and recognized the doctor. The patient had Usher's Syndrome – a genetic condition that caused retinitis pigmentosa and deafness. The patient at that time was surrounded by some members of the Ottawa Deaf Palliative Care Team providing support to the patient and her spouse, using American Sign Language.

The Ottawa Deaf Palliative Care Team was officially formed in the winter of 2009 after it's eight members received a 13 week training program at The Hospice at May Court with access to American Sign Language interpreting services. The Deaf Palliative Care Team has provided support to Deaf individuals receiving care from various health care facilities or Hospice Palliative Care professionals. Also, the team has provided support to persons referred from other agencies or organizations.

The team has provided assistance, as well, to individuals, friends and families in and of the Deaf Community who ask for support for end of life issues, including long term care for themselves or their families and friends.

The team also has liaison with a long time, deaf volunteer at Roger's House. Members of the team volunteer regularly at The Hospice at May Court and Friends of Hospice of Ottawa.

Whenever a member of the Deaf Community needs palliative care, the team of volunteers will be ready to assist the staff of various facilities to provide culturally sensitive care. The team can also assist Deaf/Blind individuals as well as hard of hearing, deafened and oral deaf, who rely on speaking and speechreading.

Through the ongoing involvement of the Deaf Palliative Care Team in various existing programs in Ottawa-Carleton Region, staff and other volunteers can become familiar with the team and comfortable working with Deaf colleagues. Should a Deaf person subsequently need services, a core group of knowledgeable people will be made available.

The inclusion of the Deaf Palliative Care Team paves the way for breaking down communication, cultural and institutional barriers that limit Deaf people's access to hospice palliative care and other end of life issues.

The cost of interpreting services for workshops and meetings as well as the Volunteer Orientation Course at The Hospice at May Court has been covered by Sign Language Interpreting Associates Ottawa INC. (SLIAO) who have generously provided interpreting, at no cost, for more than 51 events since 2008. The Deaf Palliative Care Team is hopeful that funds can be secured to provide interpreting (for the Deaf) and intervening (for the Deaf/Blind) services on an ongoing basis.

For more information about the Ottawa Deaf Palliative Care Team's work, you may contact:

Christine Wilson 613-864-7040 Cell (Voice)
wilsonchristine@rogers.com
M. Elaine Campbell
613-729-1612 TTY via Bell Relay Service for the Deaf at
mecbell@rogers.com

LONG TERM CARE AND HOSPICE PALLIATIVE CARE
BY MARY LOU KELLEY AND THE QPC-LTC TEAM

Front Line Staff Experiences of Grief and loss in a Long Term Care Home

Front Line Staff Experiences of Grief and Loss in a LTC Home, is a sub-study of the QPC-LTC Alliance. The goal of this sub-study is to describe the experiences of grief and loss of nine front line workers in LTC and to report on recommendations of how the organization can offer support to staff after a resident dies. Please click ***HERE*** to view the presentation or click ***HERE*** to view a Powerpoint presentation of the findings.

Personal Support Worker Competencies

Given that Personal Support Workers provide most of the bedside care in LTC, the empowerment and education of Personal Support Workers is key to the development of a palliative care philosophy of care. The development of palliative care competencies for PSWs is a key step in the development of the palliative care team in LTC. To view a draft toolkit outline the competencies highlighted by Personal Support Workers please click ***HERE***.

Training Toolkit for Educating Families, Volunteers and Staff on the Snoezelen ® Room

Snoezelen® (snooze–e–len) is a combination of two Dutch verbs – snuffelen, meaning to explore, and doezelen meaning to relax. Snoezelen® is a registered trademark of Rompa, Chesterfield, England. Since Snoezelen® is proprietary, the therapy is often referred to as Multi-Sensory Stimulation. Snoezelen® can be described as an emotional and intellectual vacation. Snoezelen® involves the stimulation of the senses and provides an alternative way to interact with your client. It is a failure free interaction without the demand for rules, memory or intellectual functioning. Snoezelen® provides the opportunity to bond and connect when past methods of communication have not been effective. Please click ***HERE*** to view the toolkit.

QPC-LTC Alliance Recommendation to Ontario Long Term Care Association

Dr. Mary Lou Kelley has been invited to present recommendations to the Ontario Long Term Care Association's expert panel on the Future of Long Term Care in Ontario. On October 24, 2012 Mary Lou will present recommendations on the need to incorporate high quality palliative care in long term care homes. Please click ***HERE*** to view the brief.

The CHPCA and the QPC-LTC Alliance believe that we need to:

1) Expand Advance Care Planning
2) Promote Palliative Care Programs in Long Term Care Act
3) Enhance Resources to allow Long Term Care Homes to create hospice palliative care programs
4) Strengthen Interprofessional Collaboration within LTC homes and with Community
5) Integrate hospice palliative care Philosophy into Resident Centred Care

The CHPCA, in partnership with the Quality Palliative Care in Long Term Care Alliance (QPC-LTC) aim to change the common view of long term care and hospice palliative care through knowledge translation and communications initiatives. Please ***click here*** for more information and how you can get involved.

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CHPCA 2012 AWARD OF EXCELLENCE

NOMINATION DEADLINE: JUNE 29, 2012

Do you know someone in hospice palliative care who is making a difference? Take time to recognize their efforts – Nominate them today!

AWARD PURPOSE:

- To recognize the outstanding national contribution of a CHPCA member who exemplifies professional and/or personal commitment and achievement in the field of hospice palliative care within Canada.
- To publicly acknowledge, celebrate and highlight exemplary efforts in the field of hospice palliative care.

AWARD SPIRIT:

Accomplished, Dedicated, Committed to Excellence, Champion, Compassionate and Knowledgeable

AWARD ELIGIBILITY:

The nominee is an exemplary CHPCA member whose excellence is devoted to hospice palliative care in Canada in either a paid or voluntary capacity. To be a recipient of this award, the nominee must have made an impact at the national level and contributed to the mission of CHPCA by enhancing the quality of life for individuals and their loved ones who are facing a life threatening illness and bereavement.

The Awards Selection Committee will also review nominees' contributions and leadership in the following areas:

- Key accomplishments in hospice palliative care
- Personal and/or professional commitment
- Volunteerism in service of advancing hospice palliative care in Canada
- Leadership in areas of hospice palliative care program development, policy and advocacy
- Development and involvement in hospice palliative care educational initiatives
- Community hospice palliative care outreach and development
- Advancement of hospice palliative care in areas such as best practices, interdisciplinary team and service delivery
- Research impacting hospice palliative end-of-life care

The award will be presented to only one individual in a given year and it is possible that it may not be granted every year.

NOMINATIONS:

For further details and to nominate an individual for this award, please go to www.chpca.net and follow the link to the Award of Excellence.

Submitted nominations must include the nomination form (including the signed consent of the nominee), two letters of support (i.e., from team members, families, colleagues) and a current CV of the nominee.
Click here to submit your nomination today!

Speak Up

Start the conversation
about end-of-life care

Advance care planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences in the event that you become incapable of consenting to or refusing treatment or other care.

An advance care plan is more than a document outlining your wishes for care at the end of life. It's a conversation that you have with the person who will represent you.

Our second National Advance Care Planning Day was April 16, 2012. We had many organizations spread the word but we still need your help.

JOIN THE SPEAK UP TEAM* &
HELP US PROMOTE NATIONAL ADVANCE CARE PLANNING DAY 2013

For more information on advance care planning visit our website *www.advancecareplanning.ca* to find the resources and tools such as:

- Why make a plan?
- Learn how to make your advance care plan
- Help others make a plan
- How can your organization and community become engaged in the National Advance Care Planning campaign?

Download our Toolkit - distribute our tools and resources such as:
- New ACP video
- ACP Workbook
- Wallet cards, bookmarks, pamphlets, posters, button and sticker templates

*For more information on Join the Speak Up Team contact *gfernie@bruyere.org*

THE CHPCA MARKETPLACE

Your one-stop shop for hospice palliative care resources and information materials for health care providers, volunteers and family and informal caregivers.

Visit us online at www.chpca.net to place your order.
Questions? Call Laureen at 1-800-668-2785 ext. 221
or by email: lnickerson@bruyere.org

Who Will Care: The Pan-Canadian Study of Palliative Care Providers

by Dr. Arminee Kazanjian and Winnie WY Chan

Despite the increasingly crucial role of the healthcare workforce and volunteers working in palliative care, very little is known about their numbers or the personal attributes they bring to their work. Funded by the Canadian Institute of Health Research (CIHR), Who Will Care in the End: A Pan-Canadian Study of Palliative Care Providers is the first and only study to look at the national picture regarding the palliative care workforce. This research included the development and administration of a new survey to collect data on palliative care providers in Canada, as well as to examine and assess compassion satisfaction and compassion fatigue among them. The survey included validated scales that measure these phenomenon as well as questions to describe socio-demographic profile, work characteristics and practice culture.

Compassion Fatigue has often been referred to as the emotional "cost of caring" for others and has led professionals to abandon their work with traumatized victims in their care. However, a demonstration of compassion in the long term does not always lead to negative emotional states or outcomes. Compassion Satisfaction stems from the emotional rewards of caring for others in a health care context; clinicians feel a sense of return or incentive by seeing a 'change for the better' in patients and families. These constructs heretofore have seldom been applied to health personnel in palliative care.

After follow-ups with health care institutions and their officials, we obtained 630 usable surveys from the palliative care workforce across Canada. The average age of the respondents was 52.34 yrs (55.01 for male and 51.75 for female). Our analysis yielded important insight: Compassion Satisfaction is found to be negatively correlated with both Compassion Fatigue and Burn Out, and there is a positive association between Burn Out and Compassion Fatigue. That is, workers experiencing Compassion Satisfaction are less likely to experience Compassion Fatigue and Burn Out. Full time staff and RNs were more likely to experience higher Compassion Fatigue and Burn Out. Therefore, Practice Status and Professional Affiliation appear to denote the intensity and frequency of exposure to secondary stress, and may be considered as a dose-response measure. In addition, the impact of Principal Institution of practice was discernible on levels of Compassion Fatigue and Burn Out but not of Compassion Satisfaction. Details of overall results have been published in the journal of Palliative Medicine in December 2011: (***http://pmj.sagepub.com/content/early/2011/12/16/0269216311431311***). Further analysis is in progress and will involve modelling to determine the impact of types of organizational culture and how they can make up for any deficit in professional culture as well as the impacts of individual attributes on Compassion Satisfaction.

To share our study findings, a two day meeting of various stakeholder leaders was held in Vancouver last year. Discussions were held among participants to 1) determine which messages held value for the palliative care workforce, 2) determine who the audiences for each message were and 3) outline tools, venues, and platforms for bringing these messages to the target audiences. A two-fold approach, targeting both broad and specific audiences was decided upon. The broad approach incorporates leveraging existing platforms, forums and educational programs to disseminate the main messages at a national level. The targeted approach will involve specific workplaces (eg. Canuck Place - Vancouver, Victoria Hospice, Winnipeg Regional Program and Edmonton Regional Palliative Care Program), among others, to act as early adopters, and use the survey, discussion guides and vignettes as they become available. The second phase of this KT activity is the development and delivery of meaningful and applicable tools for dissemination of the research evidence. This end-of-grant KT phase was also funded by the CIHR.

Mark Your Calendars!
National Hospice Palliative Care Week
May 5-11, 2013
go to www.chpca.net for more details!

Need to know more about Canada’s Compassionate Care Benefit?

Research overwhelmingly points to the need to share knowledge about the Compassionate Care Benefit (CCB) via front-line health professionals in order to increase awareness and understanding about the Benefit and its application process. The CHPCA now has available a number of informational tools (posters, pamphlets, bookmarks and magnets) which inform health professionals about the CCB.

Please order yours today by emailing vsherry@bruyere.org!

CANADIAN
Virtual Hospice

A Story About Care

A Story About Care is a persuasive personal account and a compelling teaching tool for everyone working in health care. This 15 minute video is one man’s reflections on the power of the caring relationship that can exist when people working in health care see the “person and not a pathology.” Jim Mulcahy shares his heart touching story of what it has been like to be cared for as he lives with end stage lymphoma while caring for his wife Sarah who has Huntington’s Disease. Through his story Jim talks of the care that made a difference and the health providers “whose behaviour towards me.... encouraged and cultivated my recovery of me.”

In the two months since its launch, the video has garnered over 18,000 views. It is already being used to train student nurses and as a professional development tool for health providers. It was chosen as the opening plenary at the national Whole Person Care Conference in Sydney, Australia because in the words of conference organizers “it epitomized the philosophy of care giving.” View the video on ***www.virtualhospice/Gallery*** or on Canadian Virtual Hospice’s YouTube Channel. A Story About Care was produced by the Canadian Virtual Hospice and the Canadian Association of Schools of Nursing in cooperation with the Health Design Lab at St. Michael’s Hospital and with ongoing support of the Canadian Partnership Against Cancer and the Winnipeg Regional Health Authority.

FROM DATA TO ACTION: DRIVING QUALITY OF PALLIATIVE CARE IN THE HOME

BY VICKI LEJAMBE, SAINT ELIZABETH

Saint Elizabeth has been a trusted name in Canadian health care for more than a century and is a leader in responding to client, family and system needs. As an award-winning not-for-profit and charitable organization, Saint Elizabeth is known for its track record of social innovation and breakthrough clinical practices in home and community care. Our team of more than 6,000, made up of nurses, rehab therapists, personal support workers and crisis intervention staff deliver nearly five million health care visits annually.

Saint Elizabeth's desire to understand and improve the client experience resulted in a renewed energy and focus on moving from data to action. In keeping with the organization's vision "to honour the human face of health care" the Senior Leadership team made a significant strategic commitment to support evidence based decision making at all levels of the organization. This was achieved with the development and implementation of new mechanisms to collect, examine and act upon data.

The organization began by reviewing indicators in palliative care used internally and externally, conducting a literature review and internet searches and consulting experts. Palliative care indicators were selected based on a balanced scorecard approach and including such items as client satisfaction, client outcomes related to symptoms and safety and risk. Indicators needed to be: linked to corporate strategy and objectives; reflective of the palliative care client perspectives; measurable within existing or potential systems and resources; and, have the potential to be actionable.

Saint Elizabeth recognized there was a need for strong data collection and analysis. While existing information systems were used, new technology was initiated including the use of Blackberry devices to collect client outcomes and information. In fall 2011 over 1,000 nurses were trained on this new application. Drop down menus were included in the software to ensure quick and easy data entry. Reports were generated weekly, monthly and quarterly depending on the type of data.

Accurate and consistent data was one of our success criteria in using data to improve care. Clinical leaders in the organization initially worked closely with information services to refine and automate the reports. Analysis of the Blackberry symptom data was completed weekly by the Advanced Practice Nurse (APN) to turn data into information. The Clinical Leadership team also supported regional teams with understanding what the data showed and how it could be used to improve client care.

We continue to use this practice to drive quality palliative care. The APN can identify high risk clients who have high symptom burden and/or distress levels. The data also reveals nurses who may need additional education and training on using palliative care assessment tools. The APN connects with members of the regional leadership teams to review the data and, if needed, develop an improvement plan.

The impact on client care has been significant. Front line nurses have shared that the symptom data provides them with a weekly picture of who the palliative clients are and possible clients who may require access to Saint Elizabeth's Palliative Care Resource Nurses. Nurse Supervisors and Clinical Educators have expressed how the data allows them to connect with nurses to better understand clients' needs – and support nurses with the right information and resources to meet those needs.

As one supervisor shared, "the data has opened the discussion with staff and in the end improved the client's experience. The data has given us the power to improve the care provided to clients and this is being noticed by others as we are now getting more referrals." Nurses have repeatedly shared that it is nice to know that the data [they enter on their Blackberry] is being used to benefit clients.

In our experience this innovative way of collecting and sharing data is significantly improving the quality of palliative care at Saint Elizabeth. It provides the evidence for client-centred care discussions and decisions to take place and increases team engagement, and confidence in their practice. We will continue to explore new ways of using data in palliative care, and in the community.

Communication in Palliative Care: How to talk to your family about a loved one passing on

Listen to We Care's podcast discussion hosted by Sue Kelly, RN, with Erin Bezemer, RN and Beth Gray, RN addressing some of the most difficult questions caregivers and families face when their loved ones are approaching end-of-life. *Click here to listen now.*

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Quality Palliative Care in Long Term Care: Tools for Change

On Wednesday October 17th, 2012 the Quality Palliative Care in Long Term Care (QPC-LTC) Alliance will be hosting a national conference to showcase evaluated strategies and tools that can support Long Term Care Homes to develop and deliver palliative care programs. Decision-makers in long term care homes or community partner organizations that support palliative care in long term care are encouraged to attend.

The following objectives have been set for the conference:

- Provide a forum to promote palliative care innovations for long term care homes
- Showcase effective practices developed through the QPC-LTC Alliance and by international collaborators
- Generate strategies to address gaps and barriers for developing palliative care programs in long term care homes
- Identify effective ways for decision makers to be catalysts for change in long term care homes.

This conference will be held at Chestnut Conference Centre, 89 Chestnut St. Toronto Ontario.

Registration for this event will begin in late May. For more information please visit our project website ***www.palliativealliance.ca*** or contact Jessica McAnulty at ***jmcanult@lakeheadu.ca*** or 807-766-7268.

2012 ANNUAL NICE KNOWLEDGE EXCHANGE

Join us at the NICE Knowledge Exchange – May 24th, Hart House, University of Toronto – for a stimulating day featuring an exceptional program of experts in knowledge exchange in the field of aging.

KEYNOTE ADDRESS:

Dr. Marion McMurdo - Physical Activity in Later Years: an Exercise in Common Sense

INTERACTIVE WORKSHOPS:

Adverse Drug Reactions & Older Adults with Dr. Patricia Keys
Early-Onset Dementia - the Experience of Family Caregivers with Adriana Shnall
...and much more!

Registration includes breakfast, lunch and Scientific Director's Reception. Space is limited so register now at ***www.niceke.ca*** If you have any questions, contact us at ***anke@nicenet.ca***

See you all on May 24th!