

A MESSAGE FROM THE CHAIR: BETH ELLIS

It has already been one year since the inception of the Hamilton Niagara Haldimand Brant (HNHB) Hospice Palliative Care (HPC) Network. And in this short period of time, I could not be more pleased with the level of cooperation, collaboration and communication across all hospice palliative care stakeholders within our LHIN area.

Interdisciplinary service providers, and care settings across the continuum are now identifying and considering the big picture, system wide issues that impact and affect all of us to provide the very best patient centred care.

This collective partnership united by one common vision of “Quality Hospice Palliative Care for all individuals in the HNHB LHIN area” enables the network to work together collaboratively to plan, coordinate, implement and evaluate a system of quality hospice palliative care across the HNHB LHIN area. It is this working together as a “system” of hospice palliative care providers that has enabled us to begin the first steps in the development of the first ever HNHB HPC System Design process.

I wish to thank the entire Network membership for their involvement and support of the Network activities over this last year. It is this level of cooperation that will enable us to move forward in achieving our HNHB HPC goals and objectives.

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HNHB HPC SYSTEM DESIGN

For a growing number of people suffering from progressive life-limiting illness in today’s aging society, there is an obvious need for high quality hospice palliative care that will relieve suffering and improve their quality of living and dying. Now, more than ever before, it is important to ensure that people in the Hamilton Niagara Haldimand Brant region have access to the best possible system of hospice palliative care. It is estimated that there are 486,597 people aged 50 and over living in the region today and that this number will increase to 595,212 in 2016. Projections, based on the incidence of cancer, for example, among numerous other life-limiting illnesses in this demographic, show that approximately 3,080 will require hospice palliative care in 2008 and 3,782 will need these services in 2016. This is a conservative estimate based on the assumption (expounded in the Romanow Commission’s 2002 report on the Future of Health Care in Canada) that just under two thirds of those who could need hospice palliative care will actually want it.

But what will it take to ensure quality hospice palliative care for all individuals who require it?

This is a complex question with often differing answers depending on the sector of care (i.e. long-term care, home or hospital), care settings and disciplines. However, based on the Canadian Hospice Palliative Care Association’s *A Model to Guide Hospice Palliative Care, Based on National Principles and Norms of Practice*, hospice palliative care is defined as care that aims to relieve suffering and improve the quality of living and dying. This is what the HNHB HPC Network endorses as its overarching definition of HPC. As with any progressive life-limiting illness there is an obvious end-of-life phase that hospice palliative care emphasizes, but it does not do so to the exclusion of issues that occur prior to this point, nor to the exclusion of care that emphasizes prolonging life.

This care can be delivered in any one or more locations – hospital, home and long term care – but, now, relatively new on the health care system

landscape, community residential hospices. During the course of illness, patients often move one or more times between these sectors, where understandings of hospice palliative care and ways of doing things can differ widely. Similarly, care is usually delivered by a variety of health care providers, including, but not limited to: hospital physicians and staff, family physicians, volunteers, nurses, social workers, physiotherapists, pharmacists, occupational therapists, among others.

What is often lacking in the big picture and what often results is confusion and stress to patients and families (at usually an already stressful time), is a way of bringing all these disparate aspects of hospice palliative care together so that patients and families experience one cohesive system of care that they perceive as working together for their benefit. The importance of this can not be underemphasized; patients who are approaching or at the end-of-life are some of our health care system's most medically complex and society's most vulnerable - people who deserve the very best that our universal health care system can offer. Doing this means finding ways to promote collaboration, to exchange information, and to develop common standards and a coordinated system of care. Responding to this challenge is the overarching goal of the Hamilton Niagara Haldimand Brant (HNHB) Hospice Palliative Care (HPC) Network (the Network).

The Network has been working diligently over the past two years to design an HNHB hospice palliative care system that will enable people to receive quality hospice palliative care throughout their illness trajectory with a possible emphasis on the end-of life phase. This **system design** is now at a stage where members of the Network would like to share their ideas with the broader health care community and to hear what people think about this proposed approach.

Why invest energy in developing a system design?

It is envisioned the system design will provide the framework that the Network and its membership can use to help guide development of hospice palliative care services. It will support health care organizations in their own decision-making and in the development of their own internal hospice palliative care strategic plans. It will also help inform the LHIN about priority requirements and support a multi-staged implementation plan for hospice palliative/end-of-life care in the HNHB LHIN.

Priority HNHB HPC System Components

Through an extensive literature review of HPC system best practices along with key informant consultations, five essential building blocks that will help promote and enhance the development of an integrated service delivery model throughout the HNHB area were identified, which include:

1. Shared Care Model;
2. Coordinated access;
3. Common standards of practice;
4. Collaborative information systems; and
5. Comprehensive education and mentorship.

Next Steps

The HNHB HPC Network is now seeking feedback from HNHB HPC Stakeholders with a view to enabling us to collectively investigate and act on opportunities and build partnerships to move forward with the further development of the shared care model and supporting system components, including coordinated access, common standards of practice, collaborative information systems and comprehensive education and mentorship as quickly as possible.

For further information about the HNHB HPC system design process, or to receive a full version of the HNHB HPC System Design final report please contact the HNHB HPC Network at 1-800-263-5480, ext 432. We welcome your comments and input by email or fax by **August 8, 2008**.

NEW AD HOC COMMITTEE OPPORTUNITY

The Network recently established a Communications Working Group, under the leadership of Brother Richard MacPhee, Chair. The committee will be reviewing, finalizing and recommending next steps for the draft communications plan which was recently completed. The committee is currently seeking interested representatives from the network membership to participate on this committee. If you are interested please inquire for further information at 1-800-263-5480, ext 432.

Other Network Ad Hoc Working Groups currently include:

- HNHB HPC Service Delivery Working Group
- HNHB HPC Education Working Group
- HNHB Residential Hospices Working Group
- HNHB Aboriginal HPC Services Working Group

We always welcome Ad Hoc Committee applications from the membership for your involvement in future initiatives. If you are interested please inquire for further information.

HNHB HPC WEBSITE

Another important vehicle for ongoing Network communication is the new HNHB HPC website which is now live and located at www.hnhbhpc.net. The new website has the potential to be a dynamic and interactive environment to enable timely communication to and from the Network members. We also hope to use the website for easier online registration to upcoming educational courses as well as on-line surveys. We encourage you to provide us with your input and feedback on the new site and to provide your suggestions for continual improvements and upgrades. Please save the new site to your favourites to visit us regularly.

NEW HNHB COLLABORATIVE WORK

PPCIP Steering Committee

The Provincial Palliative Care Integration Project (PPCIP) has a new name and new goals and targets for 2008/2010. Cancer Care Ontario has renamed the project the *Ontario Cancer Symptom Management Collaborative*. Some of the new goals and targets for the project are to:

- Continue to spread to other patient populations and care sites;
- Expand patient access to ISAAC (electronic kiosks in the cancer centre foyer where people can enter their Edmonton Symptom Assessment Scores);
- Seek engagement of others in the *Collaborative*;
- Examine opportunities to expand ISAAC to other hospitals and care settings;

Locally within the HNHB, the Juravinski Cancer Centre (JCC) will continue to help sustain the projects successful implementation within the community sector. To support this on-going roll-out the JCC has now partnered with the HNHB HPC Network to Co-Chair the local project Steering Committee. New Chairs are Dr. Sharon Russell, Regional Palliative Care Physician Lead, and Julie Darnay, HNHB HPC Network Director. The committee, which includes all key system partners, will continue planning the implementation strategy for the ongoing rollout of the common tools (ESAS and PPS), along with the Collaborative Care Plans (CCP) and Symptom Management Guidelines (SMG) across this LHIN area.

Division of Palliative Care, Department of Family Medicine, McMaster University, Life Long Learning Committee

The HNHB HPC Network is very pleased to be jointly working with the Division of Palliative Care through a cross sharing of roles on our education

planning committees. This joint venture has identified many opportunities for collaboration with the Division, including the co-sponsorship of the Innovations Day and Network Annual Membership meeting. Mark your calendars for **Wednesday, November 12, 2008** for a day long HNHB interdisciplinary conference to be held at the Hamilton Convention Centre. Stay tuned for further registration and program details.

PALLIATIVE PAIN AND SYMPTOM MANAGEMENT AND EDUCATION UPDATE

The ongoing partnership with the Palliative Pain and Symptom Management Program (code 24A) and the Facility Palliative Care Interdisciplinary Community Education (23A) has enabled HNHB HPC activities and projects to rapidly move forward through many joint initiatives.

We would like to extend our appreciation to the HNHB transfer payment agencies, including the HNHB CCAC, Hospice Niagara and Acclaim Health for making this relationship work in the best interests of the community. Their flexibility and solid working partnership along with the Network is a solid example of thinking outside the box and acknowledging opportunities that provide enhanced services.

As a result of this working partnership, we would like to welcome Mickey Turner as a part-time PPSM Consultant covering the area of Burlington within our LHIN. Along with Chris Sherwood, serving the Haldimand Norfolk and Brant communities, we will be hiring 2 new consultant positions within the next few weeks to service the areas of Hamilton and Niagara.

UPCOMING EDUCATIONAL ACTIVITIES

• Fundamentals

The Fundamentals of Hospice Palliative Care is an interdisciplinary introductory education program based on the foundational concepts from A Model to Guide HPC (Ferris et al., 2002).

Fall 2008 Sessions being offered starting the weeks of October 6 and October 14 and running for 8 weeks in the following locations:

- Hamilton (3 locations),
- Haldimand, Simcoe and Brantford,
- St. Catharines, Grimsby and Niagara Falls,
- Burlington.

The Fundamentals course is a prerequisite for the Advanced Hospice Palliative Care Education (AHPCE) and Comprehensive Advanced Palliative Care Education (CAPCE) courses noted below. Stay tuned for Fall registration details.

- **Advanced Hospice Palliative Care Education**

The AHPCE Program is specifically designed as a next step following the Fundamentals to meet the learning aspirations and needs of unregulated health care providers (e.g. Personal Support Workers and Volunteers) who care for people living with life-limiting illness and their families. This program extends beyond the eight “Domains of Issues” described in the CHPCA Model (and explored in the Fundamentals) by exploring the “Process for Providing Care”, to round out the complete “Square of Care” – the framework that describes the essential components of comprehensive hospice palliative care.

Stay tuned for anticipated Fall 2008 course locations, times, dates and registration details.

- **Comprehensive Advanced Palliative Care Education**

CAPCE is a new program for regulated health care professionals and as with AHPCE, extends beyond the eight “Domains of Issues” described in the CHPCA Model (and explored in the Fundamentals) by exploring the “Process for Providing Care”, to round out the complete “Square of Care” – the framework that describes the essential components of comprehensive hospice palliative care. One of its primary objectives is to develop HPC Resource Professionals in LTC homes, agencies and communities. The 7-month program takes place from September to March. Applications are accepted once a year in the spring.

Stay tuned for anticipated Fall 2009 course locations, times, dates and registration details, which will commence February 2009.

- **Pallium LEAP**

This course is offered in collaboration with the Division of Palliative Care, McMaster University. The 2.5 day LEAP course offers an opportunity for advanced active learning about current best-practice in caring for patients with life-threatening and life-limiting illness, with a special focus on family practice and community settings.

Sessions being offered in:

- Haldimand, Norfolk Brant - Fall 2008
- Niagara - Winter 2009

- Hamilton/Burlington - Spring 2009

For further information, details or registration, please contact Kim at 1-800-263-5480 ext. 432.

PROVINCIAL END-OF-LIFE CARE NETWORK

Currently there are 14 End-of-Life (EOL) or Hospice Palliative Care Networks across the province, each aligned, or in the process of aligning to its respective Local Health Integration Network (LHIN) catchment area. The Directors / Coordinators of each EOL/ HPC Network comprise the Provincial EOLC Network (PEOLCN), which works together in areas of common interest across the province.

Recently, the PEOLCN worked collaboratively with the Ontario Palliative Care Association (OPCA) and the Hospice Association of Ontario (HAO) to advise the Ontario Ministry of Health and Long-Term Care in its response to a survey that was conducted by the Quality End-of-Life Care Coalition of Canada (QELCCC). This survey assessed each provincial Ministry of Health’s perception of the status of implementation of the CHPCA’s Pan-Canadian Gold Standard for Palliative Home Care within their respective jurisdictions.

This national survey was done in response to commitments made by the provincial and territorial Ministers of Health regarding palliative home care programs and services in the 2004 Ten-Year Plan to Strengthen Health Care. The information gathered was compiled into a national report card and released to the public in May 2008. For more information on the Hospice Palliative Home Care in Canada: A Progress Report, please go to: <http://www.chpca.net/qelccc.htm>

A CELEBRATION OF HNHB HPC SUCCESSES

The Brant County Hospice Palliative Care Team (BCHPCT), housed out of the Stedman Community Hospice, is a community-based shared care outreach team that provides medical, clinical, pain and symptom management, emotional/spiritual and bereavement support, and hospice volunteers, as an interdisciplinary and cross-care setting team.

The purpose of the BCHPCT is to improve hospice palliative care for individuals and their families by providing quick response intervention in whole person care. The BCHPCT provides hospice palliative care in the comfort of individual’s home or location of choice. The BCHPCT works in partnership with formal and informal service

providers to support the full spectrum of the individual (and their families) needs.

The new team is comprised of Dr. Andrew Trever, Dr. Bernadette McNeil, Jennifer Dennis, Advance Practice Nurse and Jennifer Budd, Psychosocial/Spiritual/Bereavement Advisor. It is our hope that together we will enhance the services available to our community to provide continuity of care through an interdisciplinary team to support our patients and their families through their end of life journey.

IMPLEMENTATION OF THE HNHB NETWORK MODEL

The Network Advisory Committee and three Community Committees, including Haldimand Norfolk Brant, Hamilton Burlington, and Niagara, now have full representation, with the exception of only a few available spots remaining. (See the following Committee Lists and current vacancy opportunities).

The calibre and diversity of individuals that have been nominated or who have volunteered to fill these roles is outstanding and forms the essence of the HNHB HPC Network's collective knowledge and strength! This amazing group is highly interdisciplinary and crosses multiple care settings and sectors. To each volunteer we thank you for your dedication and involvement.

Please feel free to contact your regional or local sector representative on the Network for further information or details on how you can become more connected to the Network. Current HNHB HPC Network representatives include:

ADVISORY COMMITTEE

HNHB Knowledge Expert Lead	Representative
Chair	Beth Ellis Executive Director Bob Kemp Hospice
Network Host & Transfer Payment Agency	Ingrid Fell, HNHB CCAC Director of Client Services HNHB CCAC
Service Delivery	Dr. Denise Marshall Associate Professor and Director Division of Palliative Care McMaster University
Education	Dr. Alan Taniguchi Palliative Care Physician Specialist and Education Director, Division of Palliative Care McMaster University
Research/Evaluation	Dr. Kevin Brazil Associate Professor, Department of Clinical Epidemiology and Biostatistics, McMaster
Advocacy/Communication	Brother Richard MacPhee Executive Director Good Shepherd Centres

HNHB CCAC	Janet Noble Client Services Manager- Palliative Care HNHB CCAC
Aboriginal Services	Lori Monture Manager, LTC/Home & Community Care Six Nations Health Services
French Language Services	Micheline Wyld French Language Services Hamilton Health Sciences
Regional Cancer Centre	Dr. Sharon Russell Head, Palliative Care for Regional Cancer Program, Assistant Clinical Professor Faculty of Health Sciences McMaster University
HNHB OPCA Rep	Lesley Hirst Nurse Practitioner
HNHB Sector Lead	Representative
Long-term care	James Miller (Haldimand Norfolk Brant) Administrator/Director of Care Delhi Long Term Care Centre
Acute Hospital	Debbie Smith (Niagara) Health Program Director – Medicine/Palliative Care. Regional Director Hospitalists Program Niagara Health System
CCC Hospital	Carol McKenna (Hamilton) Program Director for Palliative Care St. Peter's Hospital
Residential Hospices/ Visiting HPC Volunteer	Margaret Jarrell (Niagara) Executive Director Hospice Niagara
Visiting Professional Community Service Organizations	Angela Brewer (Burlington) Chief Executive Officer Acclaim Health
Family Physicians	Dr. Nadia Plach (Burlington) Family Physician
Bereavement Support Organizations	Janet Devine (Niagara) Bereavement Support Professional Niagara West Palliative Care Team
Funeral Homes	Jan Nichols (Burlington) President Bay Gardens Funeral Home
Consumers/Family Caregivers	Vacant
Pastoral care/spiritual community	Jane Smith-Eivemark (Hamilton) Manager, Spiritual and Religious Care Hamilton Health Sciences
Community Support Services	Janie Fraser Regional Director of Operations Canadian Red Cross Society
Pharmaceutical	Janie Bowles Jordan Clinical Pharmacy Resource Marchese Health Care
Member-at-Large	Suzanne Leece (Haldimand Norfolk Brant) Nurse Clinician CCC and Inpatient Rehabilitation Brant Community Healthcare System

HALDIMAND NORFOLK COMMUNITY COMMITTEE

Sector	Representative
Long-term care	Joan Andrews Director of Care John Noble Home
Acute Hospital	Elizabeth Hawthorne Nursing Director Medicine Norfolk General Hospital
CCC Hospital	Sherry McKnight Manager, Complex Continuing Care and Palliative Care Brant Community Healthcare System

HNHB CCAC	Vacant
Residential Hospices	Cheryl Moore Executive Director Stedman Community Hospice
Visiting HPC Volunteer Service Organizations	Vacant
Visiting Professional Community Service Organizations	Amanda Heron Occupational Therapist Community Rehab
Family Physicians	Dr. Robin Martin Godelie Family Physician
Bereavement Support Organizations	Vacant
Funeral Homes	Gary Callitis Funeral Director Dennis Toll Funeral Home
Consumers/Family Caregivers service	Vacant
Psychospiritual	Camillia Galezowski Pastoral Care Stedman Hospice
Community Support Services	Vacant
Pharmacy	Guy Cuerrier Lead Dispensary Pharmacist Marchese Health Care
Member-at-Large	Ellie Sly Director of Care Dr. Bob Kemp Hospice

HAMILTON COMMUNITY COMMITTEE

Sector	Representative
Long-term care	Rev. Kevin Baglole Administrator Brantwood Lifecare Centre
Acute Hospital	Idico Tettero Advanced Practice Nurse, Outpatient Palliative Care Program Joseph Brant Memorial Hospital
CCC Hospital	Sue DiSabatino Clinical Nurse Specialist St. Peters Hospital
HNHB CCAC	Melissa Chadwick-Popp Case Manager/RN, Palliative Team HNHB CCAC Burlington
Residential Hospices	Sandy Street Executive Director Carpenter Hospice
Visiting HPC Volunteer Service Organizations	Mae Radford Manager VON Volunteer Services
Visiting Professional Community Service Organizations	Lori Strickland Clinical Resource Nurse/Supervisor Saint Elizabeth Health Care
Family Physicians	Vacant
Bereavement Support Organizations	Brenda Symons-Moulton Social Worker
Funeral Homes	Tyson Webber Funeral Director Donald V. Brown Funeral Home
Consumers/Family Caregivers	Vacant
Psychospiritual	Pat Finnigan Pastoral Coordinator Good Shepherd Centres, Emmanuel House
Community Support Services	Vacant
Pharmacy	Kathleen Leach Owner/Pharmacist, Sutherland's Pharmacy

Member-at-Large	Vacant
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NIAGARA COMMUNITY COMMITTEE

Sector	Representative
Long-term care	Andrea Spiridi Staff Educator/PPSM Coordinator Bella Senior Care Residence LTC Home
Acute Hospital	Joyce Smith Clinical Manager, Inpatient and CCC West Lincoln Memorial Hospital
CCC Hospital	Diane Reid Manager, Complex Continuing Care & Geriatrics, Hotel Dieu Shaver Health and Rehabilitation Centre
HNHB CCAC	Paola Lawrence Palliative Care Case Manager HNHB CCAC Niagara Branch
Residential Hospices	Executive Director McNally House
Visiting HPC Volunteer Service Organizations	Terry Mactaggart Program Coordinator NOTL Community Palliative Care Service
Visiting Professional Community Service Organizations	Jan Wright Clinical Resource Educator, Palliative Care St. Elizabeth Health Care
Family Physicians	Vacant
Bereavement Support Organizations	Marny Atkinson Vice-President Niagara Bereavement Resource Council
Funeral Homes	Jim Fyfe Prearrangement Counsellor Morgan Funeral Home
Consumers/Family Caregivers	Alyce Sutherland Consumer Caregiver
Psychospiritual	Maureen O'Connor Psychospiritual Advisor Niagara West PC Team
Community Support Services	Marlene Slepkov Interim Branch Manager VON Niagara
Pharmacy	Leslie Chappell Lead Infusion Pharmacist Marchese Health Care
Member-at-Large	Mary Catherine Rilett Advanced Practice Nurse Niagara West PC Team

HNHB Hospice Palliative Care Network Staff

<p>Julie Darnay, Director julie.darnay@hnhb.ccac-ont.ca</p> <p>Kim Glenn, Administrative Assistant kim.glenn@hnhb.ccac-ont.ca</p> <p>Chris Sherwood, HPC Consultant, Haldimand Norfolk and Brant chris.sherwood@hnhb.ccac-ont.ca</p> <p>Mickey Turner, HPC Consultant, Burlington mturner@acclaimhealth.ca</p> <p>Currently being hired HPC Consultants for Hamilton & Niagara</p> <p>149 Hartzel Road, St. Catharines, Ontario, L2P 1N6 1-800-263-5480 x432</p>
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