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ONTARIO COLLEGE OF FAMILY PHYSICIANS

Improving the Quality of Hospice Palliative Care Across Ontario: A Summary of the Results of the Strategy Development Workshop

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Executive Summary

The Ontario College of Family Physicians partnered with Cancer Care Ontario to plan and host a strategy development workshop aimed at improving the quality of care delivered in Ontario for patients with end-of-life conditions. We are grateful to the leadership of the Ontario Association of Community Care Access Centres and the Provincial End-of-Life Care Network for their input, guidance and advice and are particularly grateful to the key stakeholders who actively participated in the workshop. Their input and ongoing support will ensure that our overall goal and vision for the workshop of accelerating movement towards an integrated hospice palliative care service delivery system in Ontario will become a reality.

The main messages from the workshop are as follows:

- There is consensus that an integrated hospice palliative care (HPC) service delivery system is needed throughout Ontario. The vision for the system needs to be provincial; however, the implementation needs to be regional and locally driven using a grassroots, community development approach.
- Since the primary care sector is key to an integrated hospice palliative care delivery system, the dynamics of how palliative care is planned and delivered needs to change. It will be important to establish the supports needed by family doctors, advance practice nurses, community care case managers and home care nurses and to ensure adequate linkages between family practices, family health teams and community health centres and secondary and tertiary care providers.
- A comprehensive and integrated Hospice Palliative Care Delivery System should include:
  - Seamless linkages between primary, secondary and tertiary care health service providers
  - Easy and timely access to all services in the ***Square of Care*** in all care settings
  - An inter and intraprofessional collaborative care service delivery model (including intraprofessional education)
  - An appropriate system to support patient/family navigation
  - A health human resource strategy
  - Common assessment and communication tools including electronic health record that are easily accessible by the patient, family caregivers, family physician and all other members of the patient's care team.
  - An accountability framework that includes benchmarks/quality indicators and includes a public reporting framework
  - A population based registry
  - Population based funding for health human resources, information technology, physical space, pharmaceuticals, supplies, tools, etc.

The Square of Care:
A Conceptual Framework

		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical			Patient and Family Care			
	End of life/ Death Management						
	Loss, Grief						

Participants also identified the fact that, as a key priority, there is need to establish provincial leadership to assist the Ministry of Health and Long Term Care to develop and implement a mandated strategic plan for Ontario's Hospice Palliative Care Delivery System. To that end, concrete next steps were identified; namely, to establish a Hospice Palliative Care Coalition and relevant Action Teams to support the advocacy agenda and to further support strategy development begun so effective at the workshop thanks to the active participation of our 130 participants.

In summary, the partners committed to the following actions:

1. to circulate the report on the results of the Strategy Development Workshop to all participants and to the stakeholders who were invited but unable to attend;

2. to organize the first meeting of the Hospice Palliative Care Coalition; and,

3. to establish action teams to develop work plans in the following areas:

    - system accountability
    - funding models, policy development and guidelines
    - addressing the full continuum of care
    - defining the palliative care program
    - linkages through common practices, processes and structures
    - health human resource strategy development

4. To inform the MOHLTC in regards to the recommendations from the workshop and to establish a forum for ongoing discussions regarding a provincial strategy and implementation of an integrated hospice palliative care delivery system throughout the province.

Palliative care "is a program of care for the patient and the family that encompasses disease management, pain and symptom management, psychological, social, and spiritual needs, end-of-life care and planning, and dealing with mourning, loss, and grief" (Kelley, 2009) (www.agora.lakeheadu.ca).

Acknowledgements

Special thanks to the trailblazers who were involved in the planning and facilitation of the Strategy Development Workshop and for their enthusiasm and commitment towards improvement of hospice palliative care in Ontario. The planning committee members were as follows:

Dr. Sandy Buchman (Chair), OCFP
Ms. Julie Darnay, Hamilton Niagara Haldimand Brant Hospice Palliative Care Network
Ms. Lisa Droppo, OACCCC
Dr. Deborah Dudgeon, Cancer Care Ontario
Ms. Esther Green, Cancer Car Ontario
Dr. Amna Husain, Temmy Latner Centre for Palliative Care
Ms. Elaine Kachala, OCFP
Ms. Jan Kasperski, OCFP
Dr. Cheryl Levitt, Cancer Care Ontario
Dr. Denise Marshall, McMaster University
Ms. Andrea Martin, Waterloo Wellington Hospice Palliative Care Network
Ms. Margaret Mottershead, OACCAC
Dr. Jeff Myers, Cancer Care Ontario
Ms. Georgina White, OACCAC

The thought provoking presentations of our hosts and speakers were key to the success of the day. Our gratitude is extended to:

HOSTS:
Dr. Sandy Buchman
Dr. Denise Marshall
Dr. Jeff Myers

SPEAKERS:
Ms. Julie Darnay
Dr. Carol Sawka
Ms. Margaret Mottershead
Ms. Esther Green
Mr. Chris Sherwood
Dr. Deborah Dudgeon
Ms. Andrea Martin
Dr. Hsien Seow
Dr. Denise Marshall
Ms. Cathy Fooks

We are particularly grateful to our facilitator, **Tazim Virani, RN, MScN, PhD** for her leadership and insights as we prepared for the workshop and for her excellent work in supporting our participants in their efforts to provide their insights into the development of our key messages.

Introduction

The Ontario College of Family Physicians (OCFP) and Cancer Care Ontario (CCO) conducted a review of the extensive body of literature that provided evidence of what constitutes a safe, equitable and quality hospice palliative care (HPC) delivery system. In addition, the partners reviewed the systems already in place in Ontario, especially in communities where investments in pilot HPC projects had received excellent support from the Ministry of Health and Long Term Care. We concluded that Ontario was on the right track; however, there were inequities across the province that needed to be addressed. The partners, in collaboration with the Ontario Association of Community Care Access Centres (OACCAC) and the Provincial End-of-Life Care Network (PEOLCN) planned and hosted a strategy development workshop with close to 130 key stakeholders in attendance. The overall goal and vision for the workshop was to accelerate movement towards an integrated service delivery system in Ontario. In preparing for the workshop***, we firmly believed that an integrated HPC system would allow for appropriate, effective and efficient health care services and other supports to individuals and their loved ones who were experiencing a progressive life limiting illness.***

Objectives

The specific objectives were to:

- Present the evidence and pilot experience of various HPC initiatives undertaken in Ontario;
- Engage momentum and facilitate agreement to work towards a vision/gold standard of a fully functioning integrated service delivery model; and,
- Discuss the roll out of a provincial HPC integrated service delivery model.

Key Outcomes

The following were the outcomes anticipated:

- Consensus on key elements of the various frameworks for developing an integrated HPC service delivery system
- Identify key factors or actions required in order to move forward towards an integrated HPC system
- Develop a set of priorities, actions and stakeholder engagement in relevant working groups.

Background

Although much work has been accomplished to date in HPC in Ontario, it is believed that there is much more that needs to happen in order to improve HPC as a system of care. The need to continue to develop a shared vision and concrete action were the key drivers for developing the Strategy Workshop.

Three key questions were summarized in Chris Sherwood's presentation which provides the overall summary questions that need to be addressed:

- How do we know if someone needs hospice palliative care?
- What skills do health care providers require to provide this care?
- What systems need to be in place within an organization (or region) to enable it to deliver quality hospice palliative care?

Vision: Every Ontarian living with progressing life limiting illness will be able to receive care that aims to relieve suffering and improve their quality of living and dying (Sherwood, 2009)

In addressing the above questions, it is hoped that Ontario will move forward towards having a quality and integrated HPC service delivery system.

Strategy Development Workshop Methodology

Planning

Over several months, a group comprising representatives from the following organizations met to brainstorm and conceive a process whereby various stakeholders would be engaged in developing a strategy and movement towards an integrated HPC service delivery system:

- Ontario College of Family Physicians
- Cancer Care Ontario
- Ontario Association of Community Care Access Centres
- Provincial End of Life Care Network

Workshop Framework

The Strategy Development Workshop was designed to enable a wide range of stakeholders to form a common understanding on key concepts and ideas by listening to several presentations and discussing relevance, connections between ideas and initiatives and developing recommendations on building an integrated HPC system. (See Appendix A for the workshop agenda).

Dr. Stephen Wetmore (OCFP's President) and Dr. Carol Sawka (CCO's Vice-President, Clinical Programs and Quality Initiatives) warmly welcomed the guests and introduced the hosts for the day, Drs. Sandy Buchman, Denise Marshall and Jeff Myers. The hosts provided an overview of the progress made

to date, the rationale for the workshop and the goals that had been set for the day (see Appendix B: Hosts' speaking notes).

Following the "setting the stages" presentations by three hosts, Dr. Buchman led a panel consisting of Ms. Julie Darnay who presented on MOHLTC's End-of-Life Care Strategy, Dr. Carol Sawka who provided a statistical update, Ms. Margaret Mottershead who reviewed the MOHLTC's ER/ALC Wait time Strategy and the Aging at Home Strategy and Ms. Esther Green who updated the participants on Interprofessional Care and Education.

Dr. Denise Marshall then introduced Mr. Chris Sherwood, President of the Ontario Palliative Care Association who provided an inspiring vision for hospice palliative care in Ontario.

Mr. Sherwood's presentation was followed by a panel discussion led by Dr. Jeff Myers. Dr. Deborah Dudgeon presented a paper on regional models of care that served as the basis for much of the discussion that followed in our small groups. Dr. Dudgeon was followed by a joint presentation on the Provincial End-of-Life Network by Mr. Julie Darnay and Andrea Martin. An overview of End-of-Life Home Care Services in Ontario was presented by Dr. Hsien Seow, followed by a presentation by Dr. Denise Marshall on the Shared Care Team Model in the Hamilton Niagara Haldimand Brant LHIN. Ms. Cathy Fooks from the Change Foundation presented as the luncheon time keynote speaker on palliative care from the patient's perspective. (See Appendix C: Presentation Slides).

While the presentations were important in setting the tone for the day, the small group discussions were seen as key to the success of the day. Great care was taken to ensure that the list of participants was inclusive to ensure that the small group discussions reflected the views of diverse groups of stakeholders. Over 350 individuals from the following groups of stakeholders were invited to the workshop:

- Ontario College of Family Physicians/Family Physicians
- Cancer Care Ontario/Regional Cancer Centres
- Community Care Access Centres
- Hospice Palliative Care/End-of-Life Network Chairs/Directors
- Canadian Partnership against Cancer/Community
- Ministry of Health and Long Term Care
- Palliative Care/EOL Network Physicians
- Provincial Palliative Care Leads
- University Chairs/Program Directors
- Nurses
- Pharmacists
- Other key leaders

While we were anticipating 70 to 80 key leaders and practitioners to be in attendance, the workshop was over-subscribed. More than 130 participants were in attendance with several others on a wait-list who we were unable to accommodate. The overwhelming interest in the workshop was heartwarming for those on the planning committee (See Appendix D: Participants List).

Following the two small group discussions, time was allocated to form working groups; however, participants requested time to address broad-based questions including issues concerning the roles of various existing structures and how the outcomes from the workshop will align with activities and actions already undertaken by these structures. Close to 50 participants in the workshop indicated their interest in continuing to participate in post workshop working groups.

Key Findings from the Strategy Development Workshop

First Breakout Session: Connecting the Dots

The participants were organized into 12 breakout groups and were asked to report back on one *Key Idea* that resonated at their table. The majority of the reported ideas were congruent with those presented by the various presenters and reflected broad based consensus on the themes amongst the invited participants.

The main themes arising from the 12 table discussions are as follows:

- Participants recognized that the current timing is appropriate to stimulate a concerted effort towards development of a strategy for integrating the HPC service delivery system. A number of key initiatives provide the opportunity to leverage and spring forward improvements in HPC. These include:

    - MOHLTC Provincial End-of-life strategy
    - End of Life Networks (provincial and 14 regional)
    - Primary health care renewal
    - Primary Health Care Transition Fund demonstration projects (e.g. shared care/mentorship models in palliative care)
    - Family Health Teams
    - Role of Advance Practice Nurse
    - Research studies demonstrating needs/gaps in hospice palliative care
    - Alternate level care strategy
    - Enhanced acute care services through home care
    - Long term care reform
    - Interprofessional education (IPE)
    - Stakeholders' interest, readiness and engagement for action
    - Evidence on patients' preference for place for dying
    - Building community capacity model for palliative care (Kelley et al, 2007)

- Participants agreed with the evidence that there are numerous issues with system navigation, communication between health care providers as a result of lack of effective and efficient tools and lack of common tools (especially lack of common and shared electronic health records) across health care settings that results in redundancy, duplication and waste of time both for patient and for health care providers. These issues also created disjointed care experiences for the patient, particularly as they transition from one care setting to another or from one care provider to another; with many examples of situations where their needs were not met.

- The vision for an integrated HPC service delivery system should include:
    - Collaborative and coordinated provincial leadership
    - Consensus on a strategic plan

- Population based planning for palliative care
- Common tools (assessment, care plans, guidelines, care maps)
- Electronic health record
- Navigation
- Multi or Interdisciplinary care teams
- Health human resource strategy including need for interprofessional education and collaboration
- Integration of primary care with rest of system – access to primary, secondary and tertiary care in each region
- Benchmarking/quality indicators and quality improvement processes with focus on system integration e.g. at points of transition (quality indicators from patient perspective)
- Care maps across health care settings that are supported by common standards and continuity of care

Second Breakout Session: Building the System

Participants at the second breakout sessions were asked to discuss strategies in building an integrated HPC service delivery system and to identify three key priority action areas. The breakout group spent a great deal of discussion time focusing on the need to build system level accountability for HPC. This included the need to work simultaneously on defining and agreeing on a common vision and components for an integrated HPC service delivery system, establishment of a provincial strategic plan for HPC, consensus on the infrastructure under which the building blocks of an integrated HPC system can be directed or steered, and, establishment of quality indicators that can help to drive change.

Participants discussed the need to have a mandatory provincial framework for HPC that included the continuum of care, utilizing all 14 EOL/HPC networks. A mandatory framework would ensure a common driving mechanism or driver; however, it was important to participants that the implementation process uses a community development, grassroots approach while addressing barriers that were systemic and/or system wide in nature. An integrated HPC system was needed in order to ensure there was equitable and effective access of health care services to individuals who were living with a progressive life-limiting illness.

Similarly, it was reported by several breakout groups that it would be important to define and share accountability for HPC in family practices and the primary care sector in general. Embracing the notion that primary care is a key place in the health care system for HPC would change the dynamics of how HPC is planned and delivered. Giving priority to primary health care should include family physicians, nurse practitioners and other healthcare professionals practicing in family practices, Family Health Teams and Community Health Centres.

Other breakout groups agreed and endorsed the need to integrate primary, secondary and tertiary care settings and strongly recommended the need to establish appropriate infrastructure and system supports in order to promote collaboration, communication and coordination between the sectors.

In order to ensure that key stakeholder groups were informed about the principles, components and needs of an integrated HPC service delivery system, it would be critical to “market” these ideas to key stakeholders including policy makers. Key stakeholders would include but not limited to MOHLTC, LHINs, patients and their families and the public at large. Additionally, using common language based

on current health care system priorities would help to contextualize HPC in the broader health care system reform (e.g. reduction of wait times, aging at home strategy, primary care transition). Many of the breakout groups also indicated that monitoring and reporting of quality indicators sensitive to HPC would be key to drive change, provided that there were mechanisms in place for data collection, analysis and reporting.

In order to ensure an integrated HPC system, there was a clear desire indicated for a direct strategic and communication link between the HPC community and MOHLTC. Several structural ideas (e.g. Hospice Palliative Care Ontario – HPCO) were proposed but there was inadequate time for a thorough discussion and consensus.

Additionally, there was discussion on the need to clearly define what an HPC team should be and what supports would be required by the teams. Several suggestions were made in terms of key elements of an effective HPC team. These included:

- Development of trust and working relationships – inter and intra-professional collaboration
- Defined competencies, scopes of practice
- Communication systems that work – need for electronic health records/databases
- Key role to support – Advanced Practice Nurse working in partnership with Physicians and others (navigation, coordination, collaboration) – must be accountable to the team no matter where the funding is coming from or where the patient is located.

In establishing an integrated HPC system, there were also recommendations in the area of funding models, guidelines and policies. Specifically, the discussions highlighted the need to establish population based funding for HPC. Overall, it was important to revisit how resources (financial and human) could better be deployed in the health care system for more effective and efficient processes and outcomes.

Attendees prioritized two key recommendations for the short term. These were:

1. Establish an infrastructure such as a HPC coalition in order to continue the discussions and to establish direct communication and discussions with MOHLTC.

2. Establish relevant working teams in order to support the HPC coalition's work in advocating and developing a strategy for HPC service delivery integration.

(See Appendix F: Breakout Session #2)

Committing to Action: Next Steps

In order to move forward with the high priority recommendations, the following activities were identified:

a) Circulate the *Strategy Development Workshop Report* to all attendees.

b) Invite those who have shown interest in participating in the coalition and the working groups to identify areas of activity they would be interested in pursuing. Potential areas to establish Action Teams and develop detailed work plans include:

   i. System Accountability
   ii. Funding Models, Guidelines & Policy
   iii. Full Continuum of Care
   iv. Defining Palliative Care Program
   v. Linkages through Common Practice, Process and Structures
   vi. Human Resources

c) Invite suggested organizations (Ontario Palliative Care Association, Hospice Association of Ontario) to participate in the coalition.

d) Organize meeting with MOHLTC contacts to debrief and establish forum for ongoing discussions regarding a provincial strategy and integration of HPC.

Appendix A:

Strategy Development Workshop Agenda

IMPROVING THE QUALITY OF HOSPICE PALLIATIVE CARE (HPC) ACROSS ONTARIO
A STRATEGY DEVELOPMENT WORKSHOP

Date & Time: Tuesday June 23, 2009 7:15 AM - 3:30 PM (Toronto - Victoria Ballroom)

Location: Metropolitan Hotel 108 Chestnut Street Toronto, ON M5G 1R3 (Ph: 416- 977-5000)

7:15 - 7:45 AM	**Registration and Breakfast – Workshop will begin promptly at 7:45 AM**
7:45 – 7:55 AM	**Welcoming Remarks and Introduction of the Co-Hosts** **Stephen Wetmore,** MD, CCFP, FCFP, *President, The Ontario College of Family Physicians (OCFP)* **Carol Sawka**, MD, FRCPC, *Vice-President, Clinical Programs & Quality Initiatives, Cancer Care Ontario*
07:55-8:10 AM	**Setting the Stage** Co-Hosts: **Sandy Buchman**, MD, CCFP, FCFP, *Regional Primary Care Lead, CCO for Toronto Central & Past-President, Ontario College of Family Physicians* **Denise Marshall**, MD, CCFP, FCFP *Associate Professor, Division of Palliative Care, Dept. of Family Medicine & Assistant Dean for Faculty Development, Faculty of Health Sciences, McMaster University* **Jeff Myers**, MD, CCFP, MSEd**,** *Regional Palliative Care Co-Lead, CCO for Toronto Central & Associate Head, Division of Palliative Care, University of Toronto*
8:10-9:00 AM **5 min** **15 min** **15 min** **15 min**	**Provincial Strategies Panel: Setting the Workshop Context** Co-Host: **Sandy Buchman,** MD, CCFP, FCFP - Panel Introduction **Ms. Julie Darnay**, B.A., M.Ed., *Co-Chair Provincial End of Life Network:* MOHLTC End-of-Life Care Strategy **Carol Sawka,** MD, FRCPC **and Ms. Margaret Mottershead**, *CEO, The Ontario Association of Community Care Access Centers (OACCAC):* The ER/ALC Wait-time and the Aging at Home Strategies **Ms. Esther Green** RN, Msc(T), *Provincial Head, Nursing and Psychosocial Oncology, Cancer Care Ontario*: Interprofessional Care and Education
9:00-9:25 AM **5 min** **20 min**	**Developing a Common Vision for Hospice Palliative Care (HPC) in Ontario** Co-Host**: Denise Marshall,** MD, CCFP, FCFP – Panel Introductions **Mr. Chris Sherwood**, *President, Ontario Palliative Care Association*

09:25-10:45 AM **5 min** **15 min** **15 min** **15 min** **15 min** **15 min**	**Moving Forward with the Evidence** Co- Host**: Jeff Myers,** MD, CCFP, FCFP, MSEd – Panel Introduction **Deborah Dudgeon**, MD, FRCPC, *Provincial Program Head, Palliative Care, Cancer Care Ontario, W. Ford Connell, Professor of Palliative Care Medicine, Queen's University*: Regional Models of Care: Recommendations for the Organization & Delivery of Palliative Cancer Care **Ms. Julie Darnay,** B.A., M.Ed., **and Ms. Andrea Martin,** RN**,** *Co-Chairs Provincial End of Life Network*: Hospice Palliative Care Integrated System Design Framework - A PEOLC Network Perspective **Hsien Seow,** PhD, Cancer Care Ontario Research Chair, Health Services Research, Dept of Oncology, *McMaster University,* Use of End-of-Life Home Care Services in Ontario **Denise Marshall,** MD, CCFP, FCFP**:** Haldimand Niagara Hamilton Brant (HNHB) HPC Shared Care Teams **Questions and Answers**
10:45–11:00 AM	**Break**
11:00-12:00 **5 Min** **55 min**	**Connecting the Dots** **Facilitator: Tazim Virani**, RN, MScN, PhD, *Principal Consultant, Tazim Virani & Associates* **Key Outcomes:** 1. Define the key strengths in the current system and best practices 2. Identify key drivers of success and opportunities that would lead towards an integrated delivery system for hospice and palliative care **Facilitator's Instructions for Small Groups** **Small Group Break-Out Discussion**
12:00:-1:00 PM	**Lunch - Key Note Speaker** **Ms. Cathy Fooks, President & CEO, The Change Foundation: *The Patient's Perspective***
1:00 – 1:10 PM	**Tazim Virani: Facilitator's Report from Morning Discussion**
1:10- 2:30 PM **5 min** **60 min**	**Tazim Virani: Building the System – What should the system look like in 2015?** **Key Outcomes:** 1. Identify broad based actions that would move towards an integrated service delivery system 2. Define roles and responsibilities/accountabilities for these actions 3. List 3 key priorities **Facilitator's Instruction for Small Groups** **Small Group Break-out Discussion**
2:15-2:30	**Stretch Break**
2:30 – 3:05	**Tazim Virani : Moving into Action – Establishing Action Teams**

10 mins **25 mins**	**Key Outcomes:** 1. Identify 5-6 Action Teams to develop detailed plans 2. Participants to self-define which Action Team they wish to participate and/or support 3. Action Teams to meet and establish their first meeting date **Facilitator's Instructions to the Participants: Self-Select Action Team to Participate in Small Group Break-out Discussion**
3:05 – 3:30 PM **15 min** **10 min** **3:30 PM**	**Summing Up & Next Steps** Facilitator & Co-Hosts: Highlights of the Day & Key Decisions Closing Comments – **Stephen Wetmore,** MD, CCFP, FCFP **& Deborah Dudgeon,** MD, FRCPC **Adjourn**

Appendix B:

Speaking Notes

- Dr. Sandy Buchman
- Dr. Denise Marshall
- Dr. Jeff Myers

Dr. Sandy Buchman

My name is Sandy Buchman, and along with my co-hosts Dr. Jeff Myers and Dr. Denise Marshall, the three of us - on behalf of the planning committee for this event - will serve as hosts for today We too welcome you to this workshop and thank you for taking the time to participate in what we know will be a very stimulating and productive day. Each of us wears a few hats which have led us to being selected for our hosting roles this morning. Jeff is representing the secondary and tertiary level of palliative care as he is a full-time Palliative Care Physician and Program Head of the Odette Cancer Centre's Patient and Family Support Program under which Palliative Care falls at Sunnybrook Health Sciences Centre here in Toronto. He has recently been appointed Associate Head of University of Toronto's Division of Palliative Care and with Dr. Camilla Zimmerman shares the responsibility of Palliative Care Lead for Cancer Care Ontario in the Toronto Central LHIN. Denise's 20 year career as a Palliative Care physician has allowed her to work in all care settings from rural to tertiary, and as the Inaugural Director of the Division of Palliative Care at McMaster, as well as an Assistant Dean in their Faculty of Health Sciences, she also brings an academic perspective. She has published several papers in Palliative Care, most recently with regard to system design and Family Physician engagement. I represent the community perspective as I am a family physician with a full time practice these days in home-based palliative care working under the auspices of the Temmy Latner Centre for Palliative Care here in Toronto. I wear a couple of hats as a host of today's events, representing our organizational hosts - the Ontario College of Family Physicians and Cancer Care Ontario as I also currently serve as Past Past President of the Ontario College of Family Physicians and as Primary Care Lead in Toronto Central LHIN for Cancer Care Ontario. Jeff, Denise and I will take a few minutes before we get started this morning to set the context for what we know will an exciting day.

This workshop would not have happened if it wasn't for the work of an incredible steering committee, who has worked together for several months in preparation for this day. In addition to my colleagues Jeff and Denise, I would like to acknowledge the contributions of Julie Darnay, Esther Green, Deb Dudgeon, Amna Husain, Jan Kasperski, Lisa Droppo, Andrea Martin, Prabhjot Minhas, Raquel Shaw Moxam, Georgina White, Carol Sawka, Cheryl Levitt, Teresa Martin and Margaret Mottershead. In particular, Elaine Kachala of the OCFP has worked phenomenally hard in bringing us all together to plan on numerous occasions and has been responsible for the most effective administration and co-ordination of this complex event. I would be remiss if I did acknowledge and thank as well the System Design Working Group consisting of Paul Cavanagh, Beth Lambie, Julie Darnay, Andrea Martin, Maggie George and Cate Root for their marathon effort in finalizing 2 of our main pre-reading documents on HPC System Design Framework & Preliminary Inventory Review in time for this workshop today and which will serve to kick off our discussions. In addition I would like to note the efforts and contribution of CCO's Provincial Palliative Care Program under the able direction of Dr. Deborah Dudgeon, who prepared the excellent paper on the Regional Models of Care for Palliative Cancer Care and which will serve as a foundation for today's discussions. And finally I would like to acknowledge our expert facilitator for the day Tazim Virani, principal consultant with Tazim Virani and Associates, a consulting firm specializing in health and social services, research and management as well as strategic planning and facilitation, whom I will be honoured to formally introduce prior to our working sessions. I must also gratefully acknowledge the OCFP and CCO as our hosting organizations both of whom have been incredibly generous in providing financial and administrative support in allowing this event to come to fruition.

I would bet my last dollar that each and every one of you here today has had a personal, compelling reason or reasons for having become involved professionally in palliative care. Please take a moment to reflect on those reasons and your subsequent experience in palliative care, and keep those thoughts in mindful awareness as you carry out your task today. For me, a family physician, who entered medical

school in 1978 – when all I learned about palliative care was in a brief reference to a relatively new book called "Death and Dying" by Elisabeth Kubler-Ross – and to which nobody at my school paid much attention - it was my early experience with the HIV/AIDS epidemic in 1984 when my first patients arrived on my doorstep and begged me to look after them. AIDS of course was a rapidly terminal diagnosis in those days and I soon realized that the end-of-life care of these patients required a lot more skill than just the attention and compassion I was eager to impart. Indeed, as my medical career progressed, I witnessed many horrendous deaths in our hospital and emergency room which I knew, deep in my heart, could have been managed a whole lot better than they were. What about home deaths I hear you ask? Essentially non-existent – unless sudden and unplanned of course. Much of the needless suffering I witnessed was not only due to a lack of fundamental knowledge about the care of the dying, but also due to the absence of a program or a system that supported the needs of these patients and their families.

Over the intervening years, so much time and effort and study by so many people, here in Ontario and indeed around the world, has led to the creation of the discipline of Hospice Palliative Care (HPC) – an interprofessional approach to the care of the dying – which has progressed so far, yet as we all are keenly aware, not yet far along enough along here in Ontario as to support a fully integrated service delivery system of palliative care, that can meet the needs of every dying person and his or her family in Ontario in a timely and equitable manner. As is noted in the HPC System Design Framework Knowledge Synthesis Report, right now in Ontario, the concept of integration presupposes the presence of several functioning independent programs linking across sectors. Right now in Ontario we have a "System of Systems." So we gather here today, to envision and plan a future integrated and seamless, interdependent and accountable system of care, to come to a consensus of what that system should look like, how it should function, how it can realistically be created.

Why now you might ask? Well it is similar to when a patient comes into the office with a long standing complaint. Why now? It usually meant that there was an imperative, a compelling reason for that individual to show up. The suffering had gone on too long. So too it seemed to those of us on the planning committee for this event, and indeed to many others we know, that the time for further study is past. That enough pilot projects and studies and have been completed, and that there is sufficient evidence, from around the world and from right here in Ontario, that the time to take action on this issue is now. That the culture of interprofessional collaboration in healthcare in Ontario has matured to the point where we are ready as a group to embark upon this bold initiative. That we, as leaders and professionals in Palliative Care in this province, based on the information and evidence which we have pre-circulated and about which you will hear more today, can come to consensus and agreement of the kind of system of palliative care delivery that can work successfully and efficiently and provide the highest quality of care that we can realistically sustain. So we now have this unprecedented opportunity - Carpe Diem – seize the day. There is no time like the present.

But although we need to act now, what we are doing is envisioning the future - an audacious vision of a fully integrated Palliative Care Delivery system for the people of Ontario. This vision must be clear, focused and compelling. It must engage us all, unify our efforts and catalyze our team spirit. It must be concrete and have a clear finish line, so we know when our goal has been achieved.

So as you reflect on this vision, and as you remember your personal reasons for being involved in palliative care, bring your perspective forth. Let us begin the process of achieving consensus, and ending with a commitment to see this project through to the finish line.

I will now turn the podium over to Denise and then Jeff, who will share with you their perspectives on "Setting the Stage" for today's events.

Dr. Denise Marshall

- Personally, there is a 20 year career saturation, heaviness, and restlessness-that I am not practicing as part of either a regional, or provincial system of care
- Thus my sense of service, stewardship, or accomplishment for our patients, if solely resting on local innovation , small exemplars or pockets of excellence starts to feel inadequate, inauthentic, greedy, and myopic in the context of the provincial and national needs
- These feeling intersect with this time of profound opportunity and readiness;
    - CCO signature event in 2006- first discussions
    - Vast data and projects- the work of Duggleby, Wilson and Robinson around Canadian access to care etc
    - EolcNetwork and LHIN maturities, integration and CCAC alignments
    - Renewed primary care mandate, Romanow, Kriby and all the rest
    - An engaged and mobilized cancer care system in Ontario
    - Tools, patient identification (especially non cancer-improvements here)
    - Prognostication abilities and understandings
    - Passionate pleas of our primary care learners and colleagues (Lehman et. al …"first and foremost a primary care discipline")
    - Specialty status for Pall care in both the specialty of fam med and the royal college
    - Processes for change that help us understand capacity – antecedent conditions, catalysts for change- the Kelley model
    - There is a critical mass of us who wish to see this change happen
- My accumulated awareness of these wonderful exemplars provincially, nationally and internationally has become burdensome not to act upon
- I am also aware of the vast inequities in the spaces and places "outside' the pockets of excellence-it becomes a social justice issue – to know of the possibilities and to not act becomes untenable
- "Wait times" for setting of care, transition in care that fall below any accepted standard of " patient safety" – ie, seeing palliative care systems planning via the current consumer and MOHLTC lenses
- I am well aware now of what Ontarians say they want and need in PEOLCare- they are weary and despair with poor transitions in care and too many of them; they plead for continuity of care; care close to home, the right setting at the right time
- Social innovation is the only acceptable response- this is a calling, no question- the kind where we feel we have no choice but to act and are pulled (often kicking and screaming)into a process of change
- Move from Desire- to Doing, close the gap, connectivity
- Focused on compromise, not just consensus- we all don't get what we want, but together we move something forward that we can live with.
- Let's envision the end of "don't you people talk to each other?"

Dr. Jeff Myers

Good morning – it is an honour for me to be here with you this morning. Sandy and Denise have done a wonderful job of setting the stage and I thought I would take my few minutes and share with you the story of a patient and his wife whose care I had the unexpected privilege of participating in.

A friend of mine called telling me about his uncle who was living with CA and in horrible pain. He asked if I would call his uncle and his wife. It became clear within ten minutes of talking with the wife that she was going to ensure that her husband's final wish of dying at home was honoured, that he likely had days to weeks left to live, that his pain was not well controlled and that they had a willing family physician who's office was across the street but who was feeling out of this league with respect to both pain management and the EOL care. The couple lived about an hour and a half away from Toronto and had in place maximum home care support but the geographical area was not served by a palliative care physician or group.

For me, being primarily immersed in in-patient care, what emerged over the next three weeks was a deep understanding of the hour to hour challenges facing patients and families when death at home is desired and the almost insurmountable impact when absent is a fully supportive system and infrastructure. The wife was a self-described bull in a china shop and was the kind of caregiver and human who was going to make this work for her husband…no matter what. I agreed to participate in the gentleman's care because the family physician was initially keen on partnering with me in the co-management of his pain. As the days went on however, despite the communication plan we had arranged, the physician became less and less responsive, in particular when I brought up the issue of pronouncement of gentleman's death. The physician did not take call and did not belong to an on-call group.

Because of an astounding commitment by the wife, her husband did die at home and was relatively comfortable at the time. I was out of town that day, it was of course 2AM and the family doctor could not be contacted which meant the back up plan we had been put in place was to be initiated. The paramedics were called and our expectation was the "Expected Death" protocol would be initiated given our background work and having followed to the best of our ability the process as it had been outlined for us. The wife tells it like it is and I believed her when she informed me that she needed to literally throw herself on her husband to prevent the EMTs from beginning CPR and taking him to the hospital.

The coroner was not called that night and the EMTs, firemen and policemen did finally and relatively uneventfully leave after two hours of paperwork. The funeral home then picked up gentleman's body without a signed death certificate. The day after husband died, the wife was called by the funeral home and was told a police officer had indicated on the paperwork that fingerprints needed to be taken of the husband and that the coroner needed to sign the death certificate. This led to three days of the wife running around attempting to facilitate these two outstanding issues feeling very confused the entire time as to why this was necessary. Understandably so, the wife was eventually told the coroner had not been called at the time of death and as such would not sign the death certificate. The wife was also informed that lone police officer who could attain her husband's fingerprints was on vacation for two weeks. The wife was 42 and the husband was 45. They were high school sweet hearts and had been together for over 25 years. Can you imagine if this is what you were doing in the three days after caring for the actively dying love of your life?

In the end, the death certificate was signed, the need for finger prints was waived and the husband's memorial service took place four days after he died at home. That night, this impenetrable advocate of a human being, the wife, left a voice mail for me and at the risk of sounding dramatic in almost of wimper of a voice, a voice that had been beaten down said, "My husband's last wish of dying at home shouldn't have been this difficult".

The kicker in all of this story?….had the couple lived a few blocks away…their experience would have been completely and utterly different.

This is why I stand before you today as I believe, as you will see, we have enough background information, enough pilot projects, enough lessons learned, enough capacity, enough knowledge of the landscape and enough patients and families that deserve excellent palliative care throughout the course of their illness that we have a duty to act. It is now an issue of action, mobilization and equity. The three of us have outlined the sense of urgency as I hope for the sake of the couple that their remarkable story doesn't have to be my story or Sandy's or Denise's or anyone else's in this room – because it doesn't have to be. I tell the story not to instill a sense of fear or drama. To me, the story is compelling as it inspires me to seek justice. I believe that today comes with an enormous opportunity to take a large step forward and capitalize on each story of inspiration that I'm certain we all carry.

Appendix C:

Presentation Slides

- Ms. Julie Darnay
- Dr. Carol Sawka
- Ms. Margaret Mottershead
- Ms. Esther Green
- Mr. Chris Sherwood
- Dr. Deborah Dudgeon
- Ms. Julie Darnay/Ms. Andrea Martin
- Dr. Hsien Seow
- Dr. Denise Marshall
- Ms. Cathy Fooks

Ministry of Health and Long-Term Care End-of-Life Care Strategy (2004-2008)

Presented by Julie Darnay
Co-Chair, Provincial End-of-Life Network

MOHLTC Transformation Projects (2004)

Goals

- Sustainability of the health system
  - Reducing the cost curve of hospitals
  - Appropriate investment in the other sectors
  - Improving access to services
- Reducing wait times across the system
- Quality care in the most appropriate setting

"Getting the right care, in the right place, at the right time, for the right person, at the right price"

(Reference - MOHLTC 2004)

2

Investing in the Community

Key Projects:

- Alternate Level of Care Strategy
- Enhanced Acute Home Care
- Increasing Community Mental Health Care
- Long-Term Care Home Reform

(Reference - MOHLTC 2004)

3

Enhanced Acute Home Care

Priorities:

- Implementation of a comprehensive four-year provincial strategy to reduce hospitalizations, where appropriate, including enhanced short-term acute home care services, improved acute community mental health services, and **development of a comprehensive end-of-life strategy.** (Reference - MOHLTC 2004)

4

End-of-Life Care Strategy

Strategy Investment

- Four-year provincial end-of-life strategy that spanned the care continuum
- $115.5M investment
- Funding targeted for 2004-05 to facilitate end-of-life planning at 3 levels:
  - regional networks
  - local service delivery models for integrated end-of-life care
  - development of comprehensive provincial end-of-life strategy
- Implementation over three years ending in 2007/08
- $70,000 annual base funding provided thereafter for ongoing palliative care planning, development and leadership within each LHIN area
- Provincial HPC Advisory Committee established

(Reference - MOHLTC 2004)

5

End-of-Life Care Strategy

Goal

- Comprehensive, consistent and high quality of end-of-life care across the province

Objectives

- Shift care of the dying from the acute setting
- Enhance/develop a client-centred and interdisciplinary end-of-life service delivery capacity
- Improve access, coordination and consistency of services and supports

(Reference - MOHLTC 2004)

6

End-of-Life Care Strategy

Deliverables

- Establish in each district planning area end-of-life regional system networks by March 2005 for:
  - broad system design
  - coordination and integration of services at a system level
  - monitoring and assessment of community needs
  - promotion of service innovations
- Build on strengths of existing networks
- Members representative of those who coordinate/ deliver care

(Reference - MOHLTC 2004)

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End-of-Life Care Strategy

Deliverables (Continued)

- Establish local interdisciplinary and integrated end-of-life care service delivery by 2005/06 to enhance home care and respite services and avoid hospital admission and caregiver burn-out
  - improve access to appropriate services, including pain and symptom management, 24-hour on-call health services, and home care services
  - coordinated-point of entry
  - apply technology in innovative ways

(Reference - MOHLTC 2004)

8

Provincial Advisory Committee

- Representation from 13 provincial associations and 16 regional network planning groups
- Champions for the strategy
- Forum to advise on planning and implementation
- Foster collaboration and partnerships
- Information sharing
- Establishing common ground
- Input into the Ministry communication plan
- Advisory Committee sunset in 2006

(Reference - MOHLTC 2004)

9

HPC Networks

- Are a strategic alliance of providers of hospice palliative care in which all participants, and the group as a whole, benefit
- A group championing a strategy for the EOL/HPC system
- The network does not provide direct service delivery itself although its member organizations do
- A relatively inexpensive and effective way of mobilizing problem-solving resources
- A system of shared values, identity and goals

10

Who is included?

- Consist of a balance of decision makers, consumers and those with clinical expertise
  - Be representative of current palliative networks/ committees, hospitals, CCACs and contracted service providers, physicians, hospices, Cancer Care Ontario, MOHLTC Regional Offices (now LHINs), pharmacists, LTC facilities, community support service agencies, informal caregivers, Palliative Care Initiatives #1-4 (i.e. PSM Coordinators)

(Reference - MOHLTC 2004)

11

Network Functions & Skills

- Advice
- Connect
- Support
- Influence
- Promote
- Strategize
- Reach Out
- Link
- Share
- Inform
- Convince
- Rally
- Inspire
- Facilitate
- Engage

12

Shared Accountability

- Shared Accountability means organizations are accountable not only within their organizations, but to other organizations and the public for the care received by individual consumers.
- Principles of effective accountability include:
  - Clear roles and responsibilities
  - Clear performance expectations
  - Balanced expectations and capacities
  - Credible reporting
  - Responsible Communication
  - Reasonable review and adjustment

Reference: The Change Foundation (2004, November) Accountability, Continuity and Effectiveness: Health Networks in Ontario
Reference: December 2002 Report of the Auditor General of Canada

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Network Representation

- Erie St. Clair
- South West
- Waterloo Wellington
- Hamilton Niagara Haldimand Brant
- Central West
- Mississauga Halton
- Toronto
- Central
- Central East
- South East
- Champlain
- North Simcoe Muskoka
- North East
- North West Ontario

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Provincial End-of-Life Care Network (PEOLCN) 2005

Provides a forum to:

- Facilitate the exchange of information
- Identify and recommend areas of common interest for shared project planning and implementation
- Improve system coordination, decrease duplication and increase efficiencies.
- Promote consensus building and consistency in best practices to provide a common interface with the MOHLTC and other stakeholders on key policy issues wherever possible
- Participate in evaluation processes to identify key projects where joint work plans can be created

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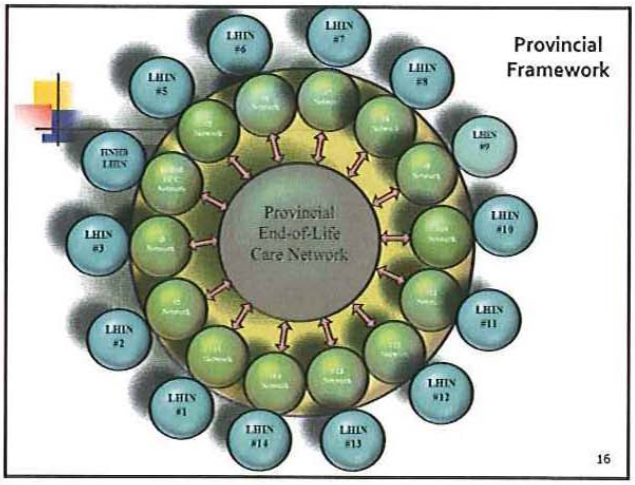

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In Summary

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Benefits of HPC Networks

- **Consumers:**
  - Improved access and more timely and appropriate services, information and support
  - Smoother transition between care settings
- **Service Providers:**
  - Better access to information and support
- **Organizations:**
  - More effective and efficient services (i.e., best practices)
  - Better utilizing scarce resources
- **System:**
  - Providing a unified forum for HPC system-wide planning, problem solving and integration

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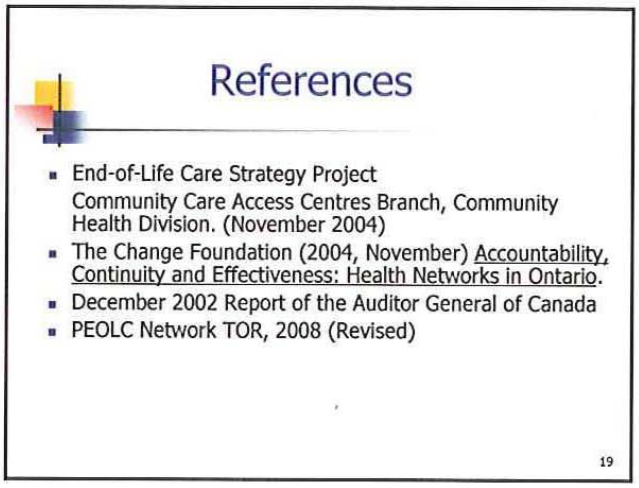
References
End-of-Life Care Strategy Project
Community Care Access Centres Branch, Community Health Division. (November 2004)
The Change Foundation (2004, November) Accountability, Continuity and Effectiveness: Health Networks in Ontario.
December 2002 Report of the Auditor General of Canada
PEOLC Network TOR, 2008 (Revised)
19

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20

cancer care ontario | action cancer ontario
celebrating 65 years

Advancing Provincial Strategies

Carol Sawka, MD, FRCPC
VP Clinical Programs and Quality Initiatives, Cancer Care Ontario
Professor, Faculty of Medicine, University of Toronto

Hospice Palliative Care Strategy Development Workshop
June 23, 2009

Better cancer services every step of the way

Increase in cancer incidence

83,220

The yearly total of Ontarian's expected to be diagnosed with cancer in 2017.

This breaks down to 228 per day, compared to 172 per day in 2007.

Increase in cancer survival

406,000

The estimated number of Ontarians who will be living with cancer diagnosed within the past 10 years.

Over the next decade, Ontario will see a 40% increase in the number of people living with cancer.

Aging cancer population and probability of dying of cancer

Of all new cancer cases in 2007, 87% were in people over the age of 50

Estimate 27,900 deaths due to cancer in 2009

Approximately 1 in 4 Canadians will die of cancer

Why is this important?

- Over half of Ontario cancer deaths in 2005 (51%) occurred in an acute care hospital setting
- 314,519 ED visits in 2007/08 were by cancer patients and approximately 84,000 of these visits were related to pain and symptom management
- Over 40% of cancer patients (approx 10,000) visited the ED in the last two weeks of their life in 2005
- Average LOS for last admission - 14 days

Aligning care with patients' needs and wants

- Acute care settings are generally not designed to provide the best possible end-of-life or palliative care
- We now have data on most common presenting complaints to ER - amenable to earlier intervention
- Visits to the ED for those reasons at the end-of-life may be associated with poorer quality of care and may signal a need to improve symptom management

Contributing factors to ED volumes and acute care admissions

- Patients needing symptom management/ palliative care are not identified early enough
- Symptom changes are not communicated to the care team in a timely fashion
- Care teams lack expertise in palliative care and have difficulty accessing off-hours expertise

What is being done?

- CCO Initiatives
  - Launched Provincial Palliative Care Strategy in 2005
  - Integrated Palliative Care Programs in every region
  - Models of Palliative Care
  - Education and mentorship in collaborative practice and palliative care
  - Improved measurement of quality standards
  - Ontario Cancer Symptom Management Collaborative

Ontario Cancer Symptom Management Collaborative (OCSMC)

- Opportunities for:
  - Better and earlier identification of physical and psychosocial symptoms
  - Earlier treatment
  - ED and inpatient avoidance
  - Better multidisciplinary care
- Spread use of common tools across all cancer patients and settings
  - Access to ISAAC

Moving forward: System wide improvements

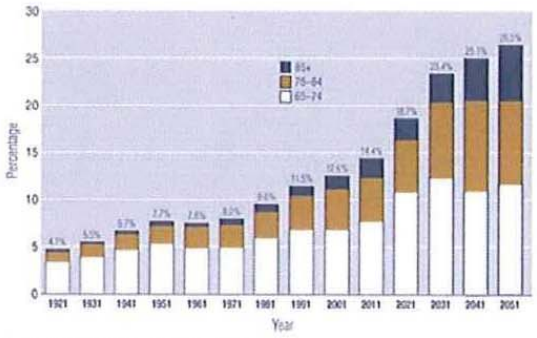
Much has been done, much more we can do by working together. Ontario needs to:

- Meet the realities of the growing cancer burden while improving quality, access and capitalizing on innovation
- Develop a system to effectively meet symptom management issues
- Implement an integrated model of hospice palliative care to accommodate long-range needs and the projected increase in palliative care treatment

Ontario's Aging at Home Strategy

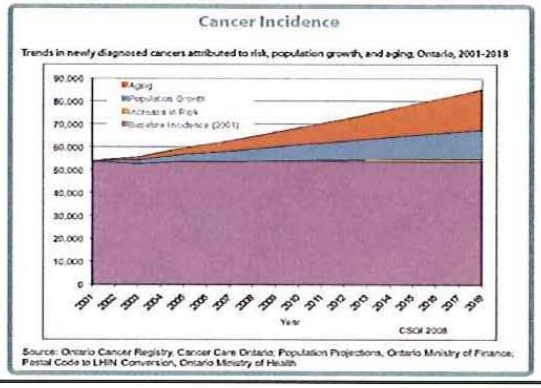
Margaret Mottershead, CEO, OACCAC
Improving the Quality of Hospice Palliative Care
Strategy Development Workshop
June 23, 2009

Ontario's Aging Population



Source: Ministry of Health and Long-Term Care
Aging at Home November 2007

Related Growth in Cancer and other Chronic Diseases



Source: Ontario Cancer Registry, Cancer Care Ontario; Population Projections, Ontario Ministry of Finance; Postal Code to LHIN Conversion, Ontario Ministry of Health

Ontario's Aging at Home Strategy August 2007

- First major LHIN-led strategy
- Goal to expand community living options, home care and community support services to allow people to continue leading healthy, independent lives in their own homes
- Focus on innovation, non-traditional partnerships, cultural diversity, prevention and health promotion
- LHINs conducted community consultations in Fall 2007

Aging at Home Strategy (2007)

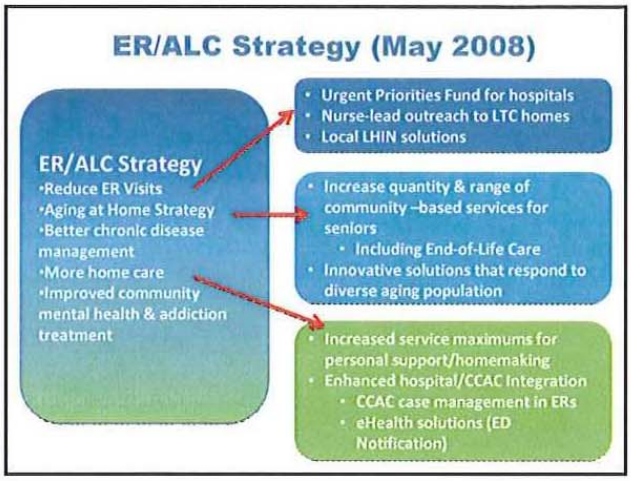
Health Care Priorities (April 2008)

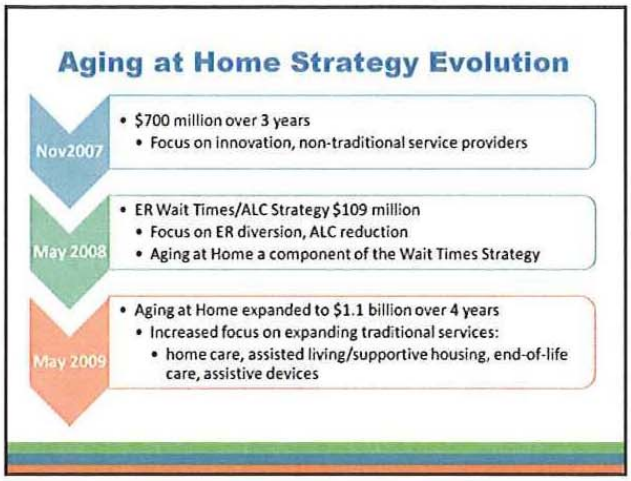
ER Strategy

- Reducing ER visits
- Aging at Home Strategy
- Better chronic disease management
- More home care
- Improved community-based mental health and addiction treatment

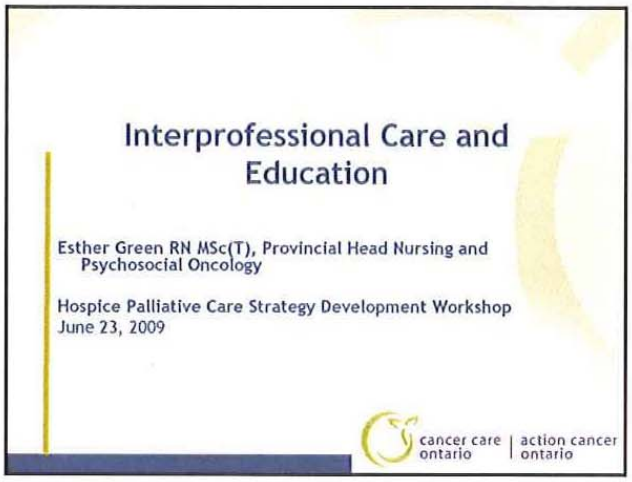
Family Health Care Strategy

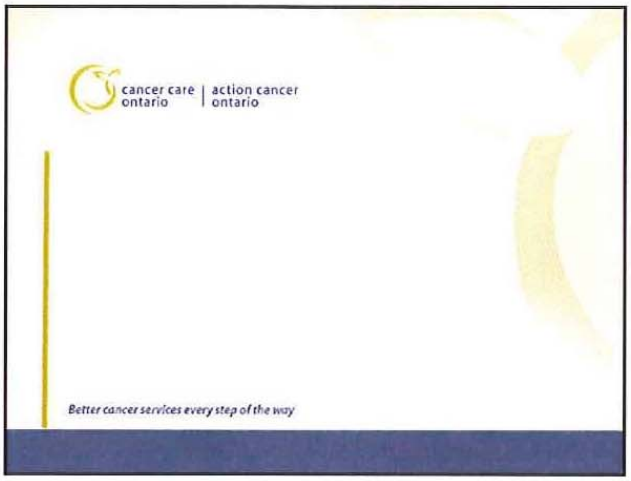
- 50 new Family Health Teams
- 25 Nurse Practitioner-led clinics
- 9,000 new nurses

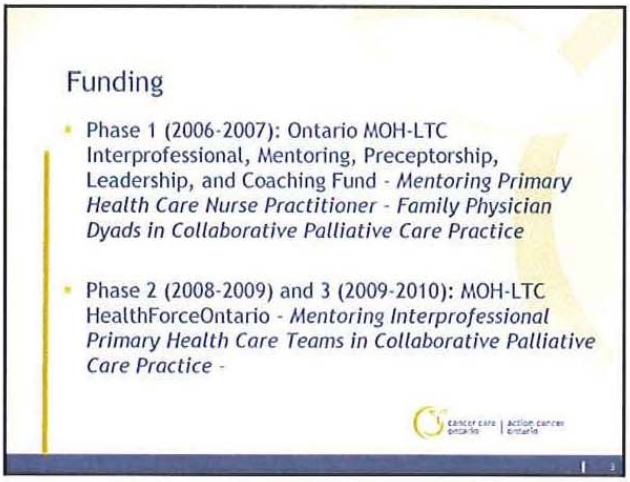

ER/ALC Strategy (May 2008)
ER/ALC Strategy
•Reduce ER Visits
•Aging at Home Strategy
•Better chronic disease management
•More home care
•Improved community mental health & addiction treatment
• Urgent Priorities Fund for hospitals
• Nurse-lead outreach to LTC homes
• Local LHIN solutions
• Increase quantity & range of community –based services for seniors
• Including End-of-Life Care
• Innovative solutions that respond to diverse aging population
• Increased service maximums for personal support/homemaking
• Enhanced hospital/CCAC Integration
• CCAC case management in ERs
• eHealth solutions (ED Notification)

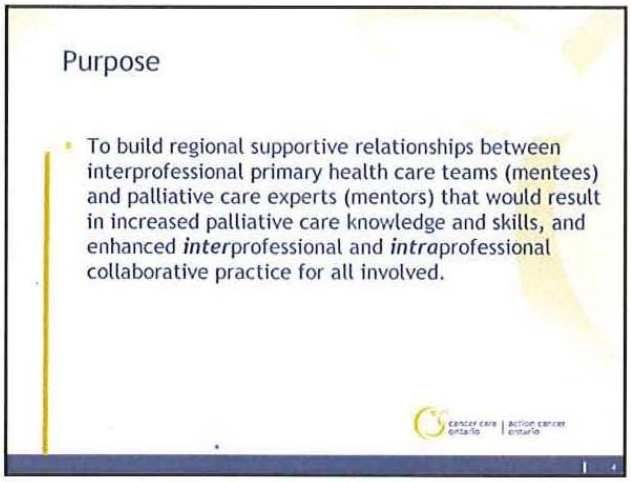

Aging at Home Strategy Evolution
Nov2007
• $700 million over 3 years
• Focus on innovation, non-traditional service providers
May 2008
• ER Wait Times/ALC Strategy $109 million
• Focus on ER diversion, ALC reduction
• Aging at Home a component of the Wait Times Strategy
May 2009
• Aging at Home expanded to $1.1 billion over 4 years
• Increased focus on expanding traditional services:
• home care, assisted living/supportive housing, end-of-life care, assistive devices

Our Challenges
• Coordinating and integrating care across the continuum
• Building service models that provide real value for our patients
• Capitalizing on models and investments already made (Aging at Home, Family Health Teams and other LHIN initiatives)
• Seizing new opportunities (e.g., Integrated Client Care Project), leveraging expertise and partnerships, forging new relationships and actually implementing best practices


Interprofessional Care and Education
Esther Green RN MSc(T), Provincial Head Nursing and Psychosocial Oncology
Hospice Palliative Care Strategy Development Workshop
June 23, 2009
cancer care ontario | action cancer ontario


cancer care ontario | action cancer ontario
Better cancer services every step of the way


Funding
Phase 1 (2006-2007): Ontario MOH-LTC Interprofessional, Mentoring, Preceptorship, Leadership, and Coaching Fund - Mentoring Primary Health Care Nurse Practitioner - Family Physician Dyads in Collaborative Palliative Care Practice
Phase 2 (2008-2009) and 3 (2009-2010): MOH-LTC HealthForceOntario - Mentoring Interprofessional Primary Health Care Teams in Collaborative Palliative Care Practice -


Purpose
To build regional supportive relationships between interprofessional primary health care teams (mentees) and palliative care experts (mentors) that would result in increased palliative care knowledge and skills, and enhanced interprofessional and intraprofessional collaborative practice for all involved.

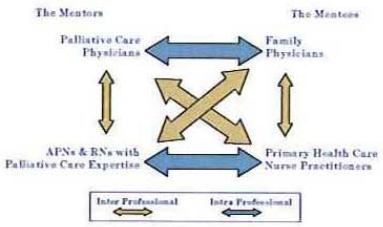
System Goals and Impacts
Improved collaboration among interprofessional primary health care teams and palliative care specialists
Increased palliative care knowledge and skills e.g., symptom management for pain, nausea & vomiting, etc.
Improved patient and family satisfaction
Improved symptom management allowing patients to be managed "closer to home"
Improvements in educational practice, attitudes and self-reported preparation to provide and teach end-of-life care

Project Sites
Kingston, Hamilton, Thunder Bay (Phase 1) (LHIN 4,10 and 14)
Kingston, Hamilton, Moose Factory, Timmins, Kitchener-Waterloo, Sudbury, London (Phase 2) (LHIN 2, 3, 4, 10, 13)
Kingston, Sudbury, North Bay, Kitchener-Waterloo, London, Erie St Clair (Phase 3) (LHIN 1, 2, 3, 10, 13)

Participants

- Mentees
  - Interprofessional primary health care teams consisting of primary care physicians, primary health care nurse practitioners or registered nurses, pharmacists, social workers, dietitians, etc.
- Mentors
  - Interprofessional palliative care teams consisting of palliative care physicians, advanced practice nurses or a registered nurse with advanced palliative care training e.g., CHPCN(C)
- Number of participants
  - Phase 1 - 50
  - Phase 2 - 95
  - Phase 3 - 130

Overview of Interactions



Methods

- Mentor workshop (one day) and mentee (2 ½ day) workshops:
  - *L*earning *E*ssential *A*pproaches to *P*alliative and End of Life Care (LEAP) developed by the Pallium Project© (10 modules)
  - Collaborative Practice Module (Jones and Way)
- Regional Facilitators
- Mentorship Phase

Mentorship Phase

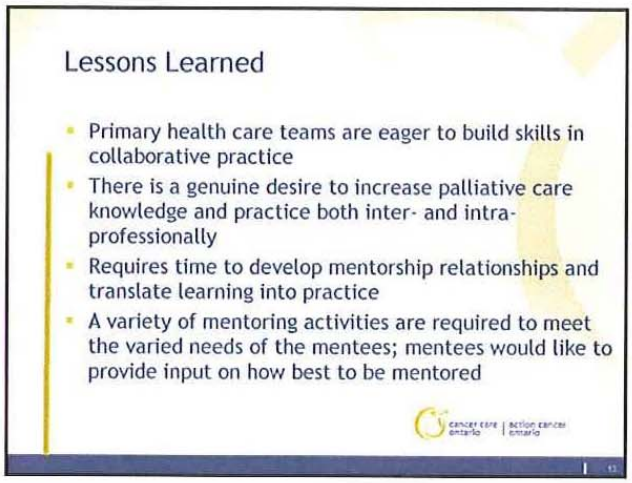
- 6 months following mentee workshops (8 weeks in Phase 1)
- Tele-conferences & video-conferences (case-based)
- Face-to-face meetings
- Shadowing opportunities
- Community rounds
- Telephone consultation
- Collaborative electronic space (Sagelink.ca)
  - Online discussion forum
  - Posting of resources
  - Asynchronous online case studies

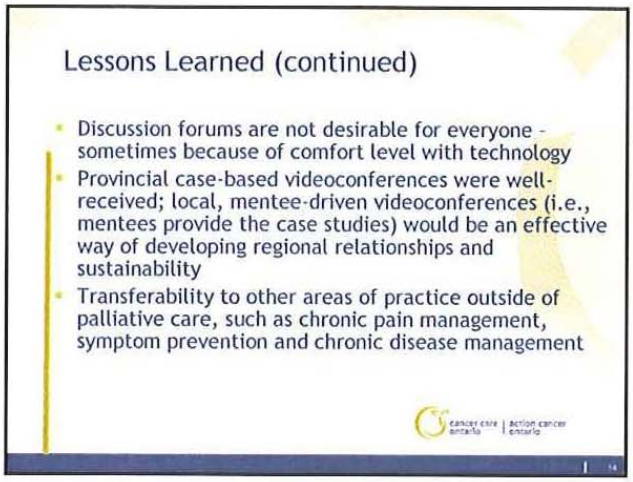
Evaluation Design

- Qualitative and quantitative
- Pre, immediately Post, 'long term' Post (e.g., 2 months follow-up)
- Assessed
  - Collaborative practice and self-assessed competencies
  - Clinical practice and palliative end-of-life care knowledge
  - Satisfaction with education component
  - Satisfaction with mentorship and collaborative practice experience

Key Results

- Improved palliative care knowledge
- Improved collaboration
- Increased confidence in:
  - Communicating effectively and collaborating when deciding the best course of action in diagnosing and managing the treatment of patients
  - Assisting patients/families with issues related to intimacy/sexuality
  - Supporting patients/families experiencing complex reactions such as anger or denial
  - Providing guidance to patients in coping with emotional responses and reactions to dying


Lessons Learned
Primary health care teams are eager to build skills in collaborative practice
There is a genuine desire to increase palliative care knowledge and practice both inter- and intra-professionally
Requires time to develop mentorship relationships and translate learning into practice
A variety of mentoring activities are required to meet the varied needs of the mentees; mentees would like to provide input on how best to be mentored


Lessons Learned (continued)
Discussion forums are not desirable for everyone - sometimes because of comfort level with technology
Provincial case-based videoconferences were well-received; local, mentee-driven videoconferences (i.e., mentees provide the case studies) would be an effective way of developing regional relationships and sustainability
Transferability to other areas of practice outside of palliative care, such as chronic pain management, symptom prevention and chronic disease management

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Kathy Coulson RN MScN
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Ingrid Harle MD
Mary Lou Kelley MSW PhD
Andrew Knight MD
Glen Maddison MD
Denise Marshall MD
Linda Pisco MA
Jane Sanders RN, MHSc
Cori Schroder MD
Joshua Shadd MD
Raquel Shaw Moxam MSc
Alan Taniguchi MD
Lewis Tomalty PhD
Janice Van Dijk RN MHSc MSc
Donna Ward MD

"OUR MODEL OF HOSPICE PALLIATIVE CARE: THINKING OUTSIDE THE BOX!"

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Palliative Care Consultant
Brant, Haldimand and Norfolk Counties
President, Ontario Palliative Care Association

Disclaimer

All information contained within this presentation has been shamelessly stolen from any number of brilliant minds (not mine… er um… of course). This presentation, therefore, contains not one original thought (at least not mine) and any resemblance to one, is unintentional and purely coincidental.

If today you were diagnosed with a life-limiting illness and you knew that at the most you had a year or two to live…. would it take you by surprise?

What is Life?

Hypothesis

Life is a sexually transmitted disease that ends in death…

- Mr. B
- 53 year old
- Lung cancer
- Not receiving treatment that aims for cure
- Prognosis 3 – 6 Months?

Is Mr. B "palliative"?

- Mrs. R
- 67 year old
- ALS
- Newly diagnosed
- Prognosis estimated as 2 – 5 years…

Is Mrs. R "palliative"?

- Joey
- 11 year old
- Duchene's Muscular Dystrophy – diagnosed 5 years ago
- Wheelchair bound X 1 year
- Prognosis estimated as 8 - 15 years…

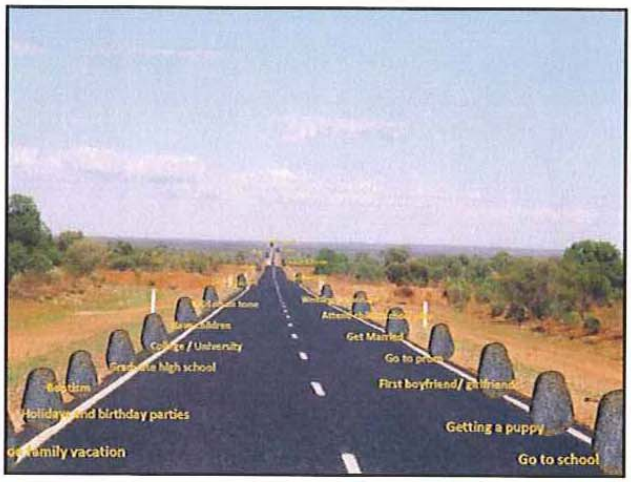
Is Joey "palliative"?

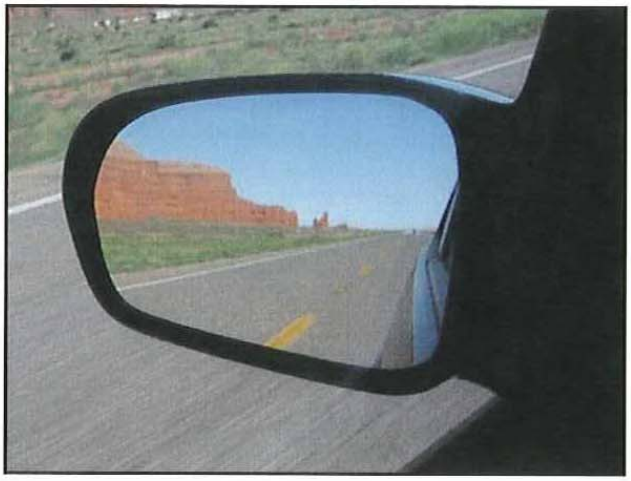
Questions

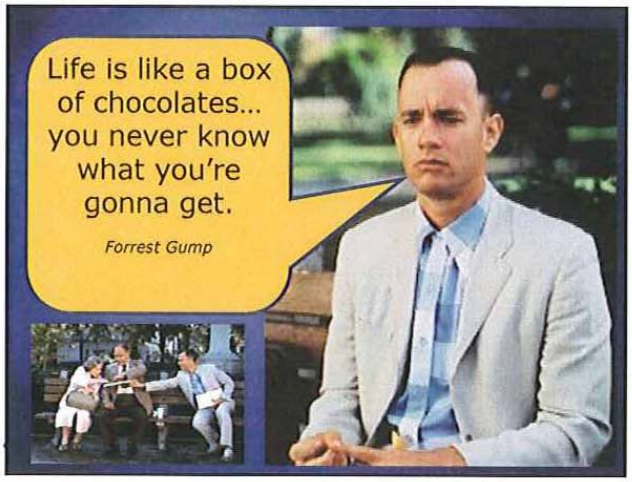
- How do we know if someone is "palliative"?
- Who decides?
- If all stakeholders in a given situation were allowed to answer this question, would each choose the same answer?
- What does it mean to be "palliative"?
- If you are "palliative", are you dying?
- If so, when does a person "start" dying?
- If you are dying, are you not living?
- If you are receiving care from a "palliative care program", are you "palliative"?
- Is it important to have answers to these questions?

Questions

	True	False
Palliative care is provided ONLY by specialized programs.	☐	☐
If health care providers take care of people who are dying, they provide palliative care.	☐	☐
If a health care organization takes care of people who are dying, it provides palliative care.	☐	☐

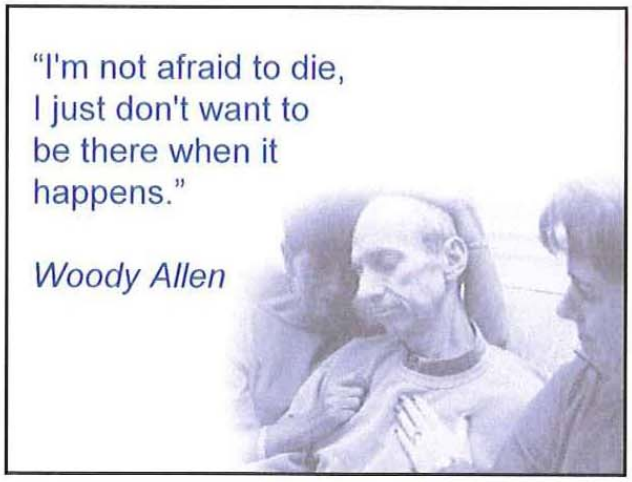


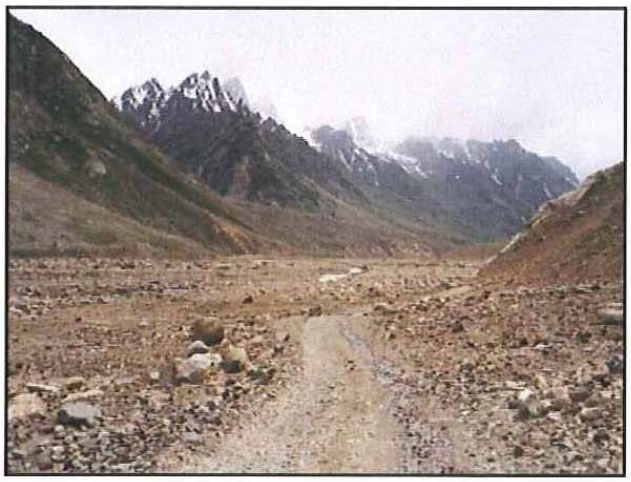


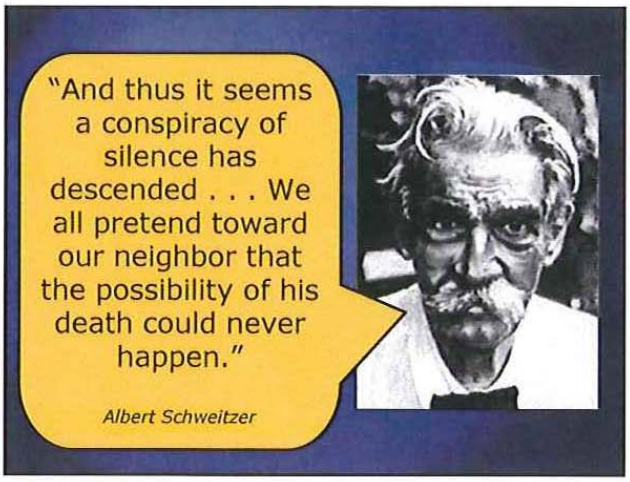


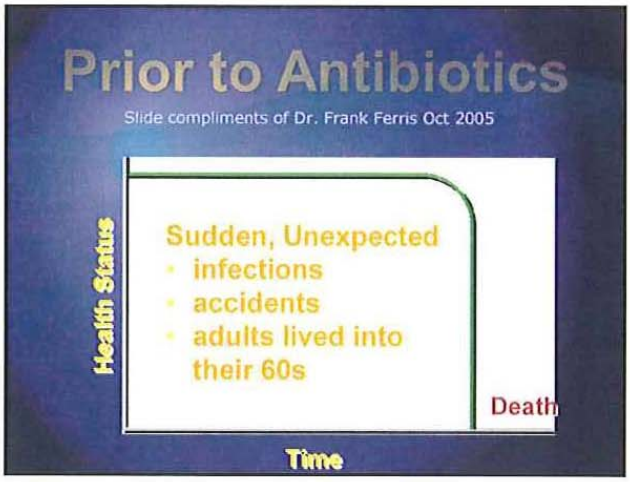
STATISTICS CANADA 1997 Data
CANADA'S NATIONAL STATISTICAL AGENCY

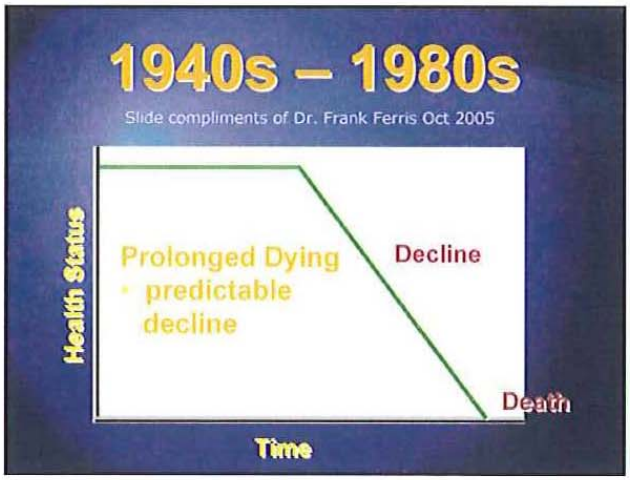
	Number	%	Total
All causes	215,669	100.0	658.7
Cancers	58,703	27.2	181.5
Diseases of the heart	57,417	26.6	173.0
Cerebrovascular diseases	16,051	7.4	47.8
Chronic obstructive pulmonary diseases and allied conditions	9,618	4.5	29.0
Unintentional injuries	8,626	4.0	27.6
Pneumonia and influenza	8,032	3.7	23.7
Diabetes mellitus	5,699	2.6	17.4
Hereditary and degenerative diseases of the central nervous system	5,049	2.3	15.0
Diseases of arteries, arterioles and capillaries	4,767	2.2	14.3
Psychoses	4,645	2.2	13.6
Suicide	3,681	1.7	12.0
Nephritis, nephrotic syndrome and nephrosis	2,654	1.2	8.0
Chronic liver diseases and cirrhosis	2,030	0.9	6.4
Neurotic disorders, personality disorders and other nonpsychotic mental disorders	1,163	0.5	3.5
HIV infection	626	0.3	2.0

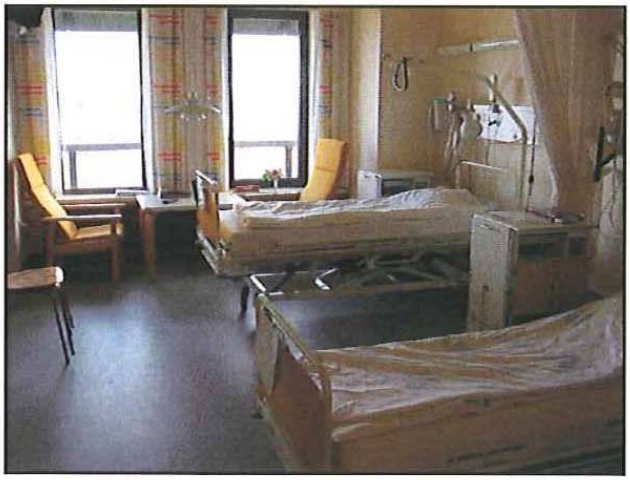


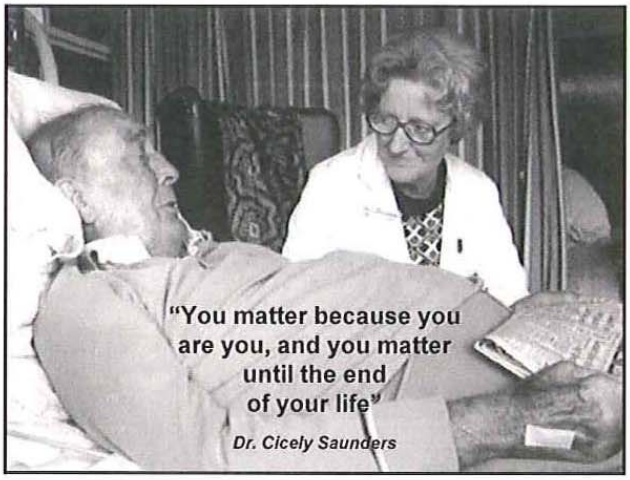



"And thus it seems a conspiracy of silence has descended . . . We all pretend toward our neighbor that the possibility of his death could never happen."
Albert Schweitzer


Prior to Antibiotics
Slide compliments of Dr. Frank Ferris Oct 2005
Health Status
Sudden, Unexpected
infections
accidents
adults lived into their 60s
Death
Time


1940s – 1980s
Slide compliments of Dr. Frank Ferris Oct 2005
Health Status
Prolonged Dying
predictable decline
Decline
Death
Time

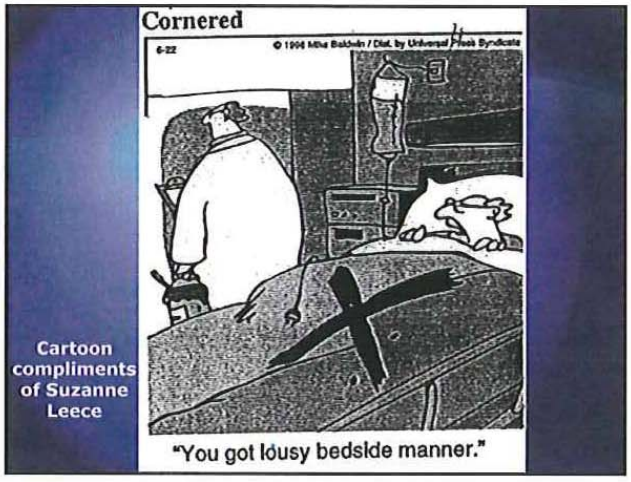




Traditional Model

Curative	Palliative		Death
	Active	Terminal	

Earliest Model of Palliative Care developed
Dame Cicely Saunders – 1960's –1970's



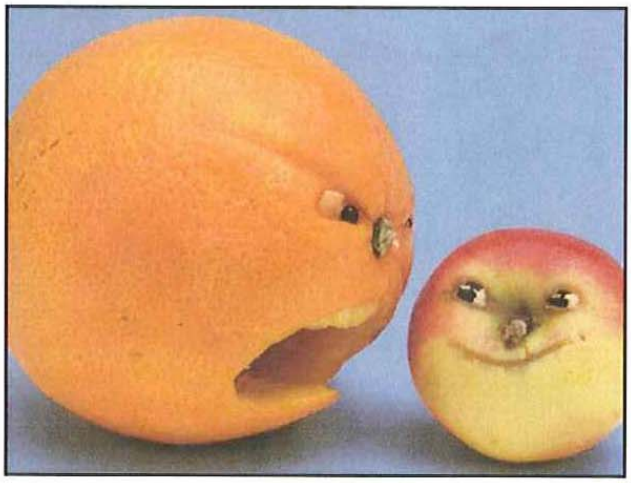
- "Is he palliative?"
- "He doesn't need that… He's not palliative yet!"
- "…to palliative."
- "…our palliative patients"
- "He's *really* palliative."

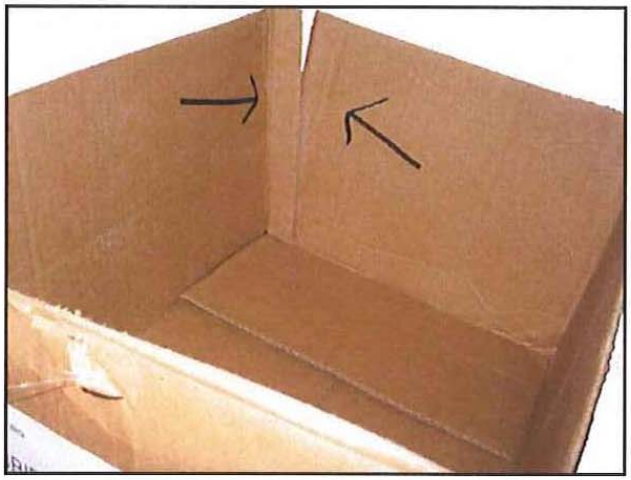
What???

The Meaning of "Palliate"

"It should be noted that these can be found simultaneously among health care workers in any one setting. That is, there is a lot of potential for confusion when people try to implement palliative care but each has a different interpretation."

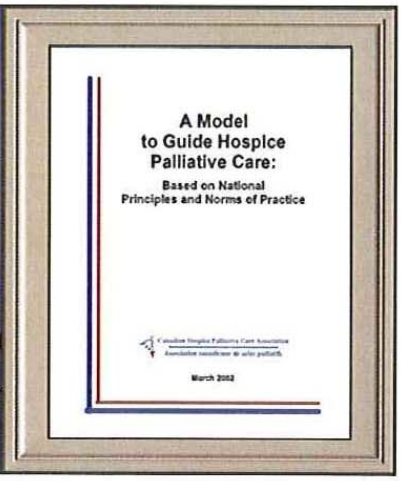
Medical Care for the Dying, Victoria Hospice Society

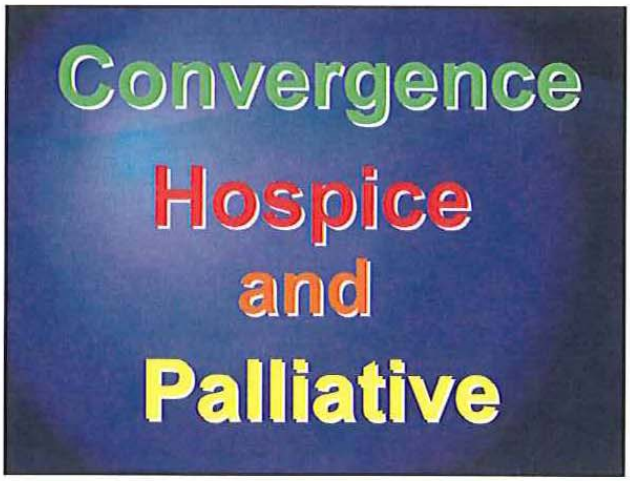


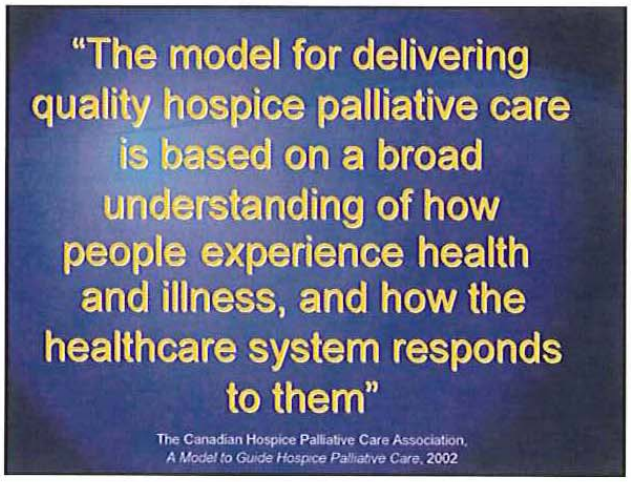


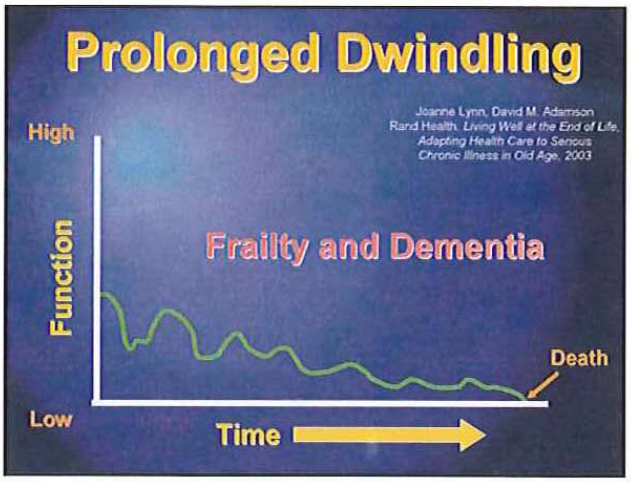
"...a consensus-building process led... to... a clear vision for hospice palliative care that everyone could use. The... model represents more than 10 years of collaboration... and is based on the nationally accepted principles and norms of practice."

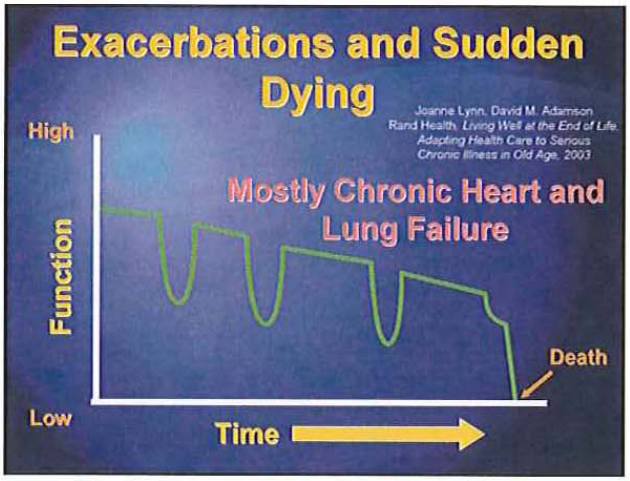
www.chpca.net

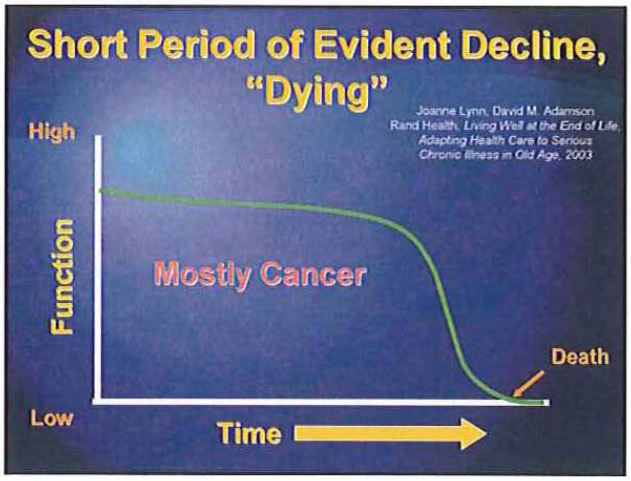


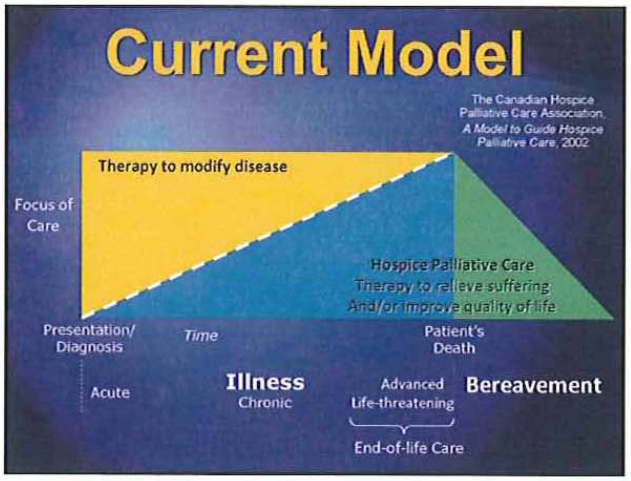

Convergence
Hospice
and
Palliative

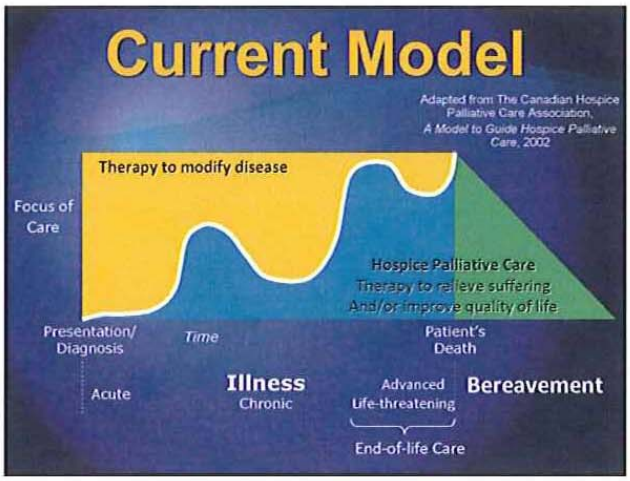

"The model for delivering quality hospice palliative care is based on a broad understanding of how people experience health and illness, and how the healthcare system responds to them"
The Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002

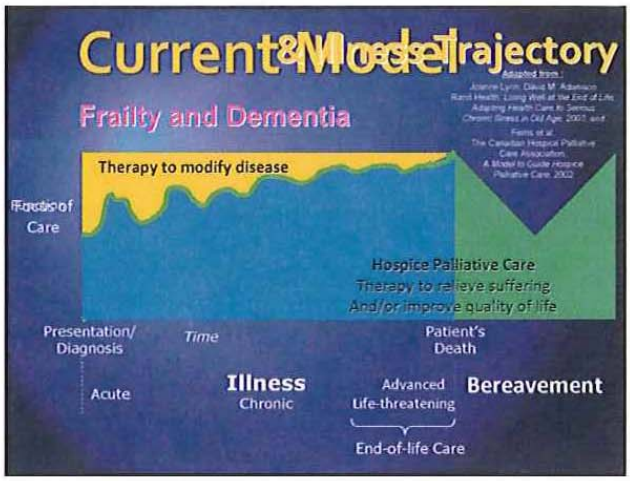

Prolonged Dwindling
Joanne Lynn, David M. Adamson Rand Health. Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age, 2003
High
Function
Low
Frailty and Dementia
Death
Time

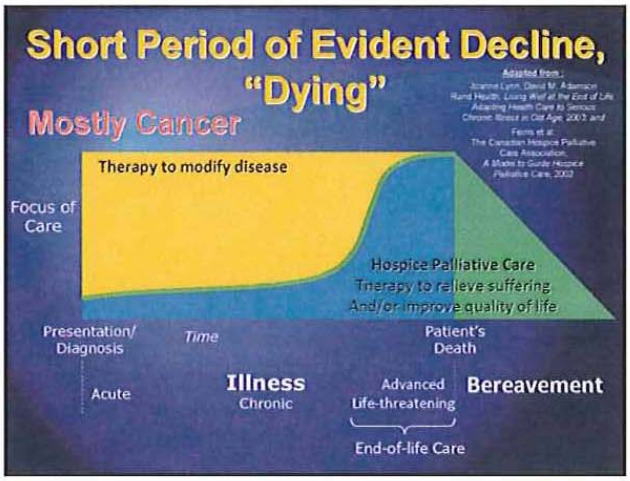

Exacerbations and Sudden Dying
Joanne Lynn, David M. Adamson Rand Health. Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age, 2003
High
Function
Low
Mostly Chronic Heart and Lung Failure
Death
Time


Short Period of Evident Decline, "Dying"
Joanne Lynn, David M. Adamson Rand Health. Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age, 2003
High
Function
Low
Mostly Cancer
Death
Time


Current Model
The Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002
Therapy to modify disease
Focus of Care
Hospice Palliative Care
Therapy to relieve suffering
And/or improve quality of life
Presentation/ Diagnosis
Time
Patient's Death
Acute
Illness
Chronic
Advanced Life-threatening
Bereavement
End-of-life Care


Current Model
Adapted from The Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002
Therapy to modify disease
Focus of Care
Hospice Palliative Care
Therapy to relieve suffering
And/or improve quality of life
Presentation/ Diagnosis
Time
Patient's Death
Acute
Illness
Chronic
Advanced Life-threatening
Bereavement
End-of-life Care


Current Model & Illness Trajectory
Frailty and Dementia
Therapy to modify disease
Focus of Care
Hospice Palliative Care
Therapy to relieve suffering
And/or improve quality of life
Presentation/ Diagnosis
Time
Patient's Death
Acute
Illness
Chronic
Advanced Life-threatening
Bereavement
End-of-life Care


Short Period of Evident Decline, "Dying"
Mostly Cancer
Therapy to modify disease
Focus of Care
Hospice Palliative Care
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Presentation/ Diagnosis
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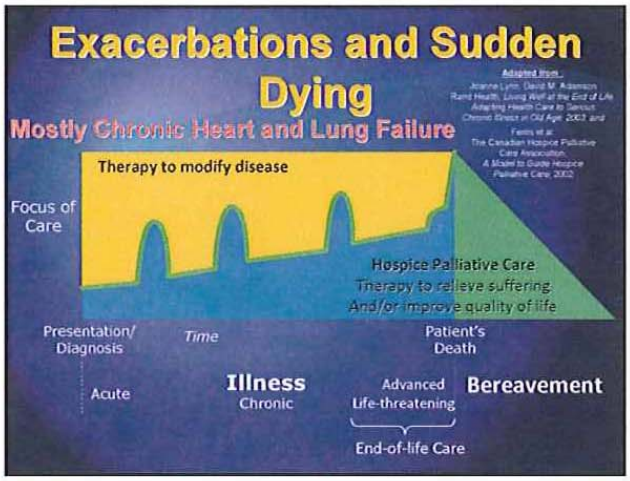
Exacerbations and Sudden Dying
Mostly Chronic Heart and Lung Failure
Therapy to modify disease
Focus of Care
Hospice Palliative Care
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Presentation/ Diagnosis
Time
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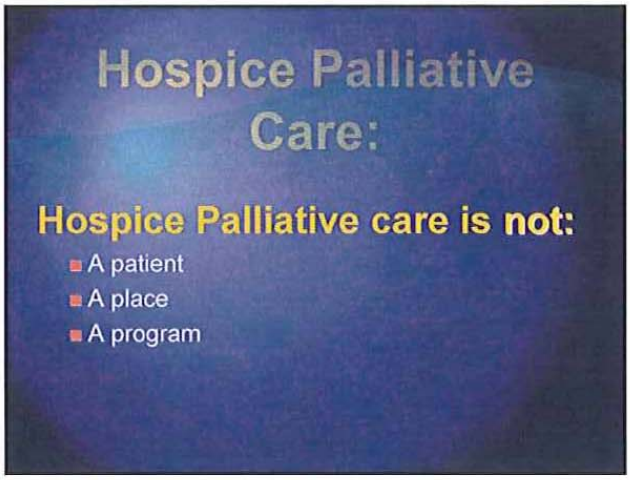
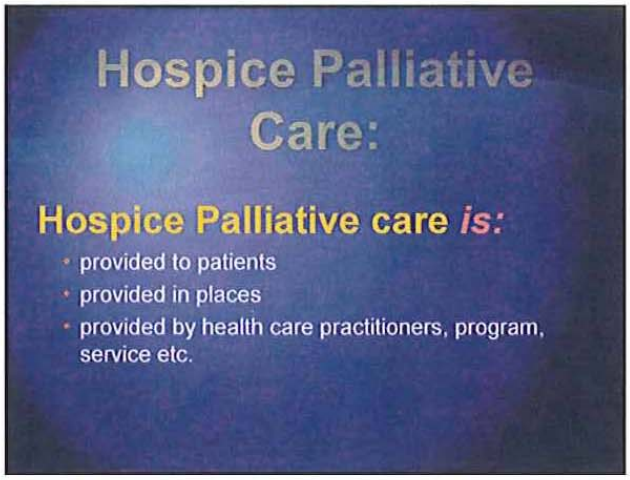
End-of-life Care


Hospice Palliative Care:
Hospice Palliative care is not:
A patient
A place
A program


Hospice Palliative Care:
Hospice Palliative care is:
provided to patients
provided in places
provided by health care practitioners, program, service etc.

Hospice Palliative Care: Definition

- **Hospice Palliative Care** aims to relieve suffering and improve the quality of living **and** dying.

The Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002

Hospice Palliative Care: Definition

- **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, at any time that they have unmet expectations and/or needs, and are prepared to accept care.

The Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002

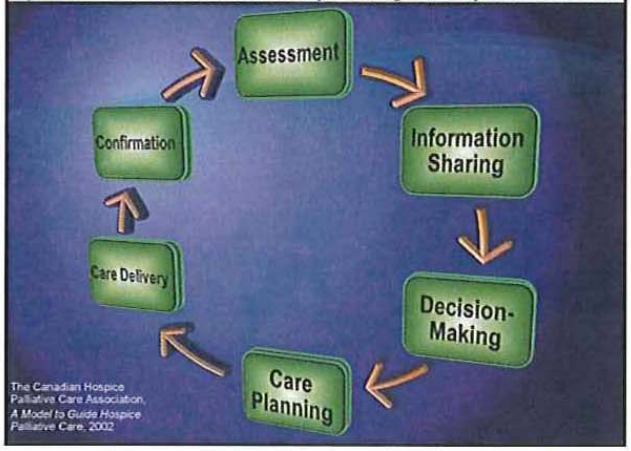
Domains of Issues

PATIENT AND FAMILY Characteristics

- Demographics (e.g., age, gender, race, contact information)
- Culture (e.g., ethnicity, language, cuisine)
- Personal values, beliefs, practices, strengths
- Developmental state, education, literacy
- Disabilities

The Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care*, 2002

Figure #10: Essential and Basic Steps During a Therapeutic Encounter



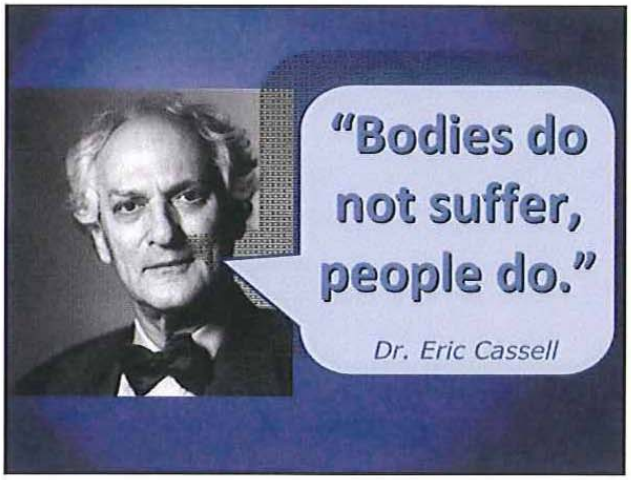
The Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care*, 2002

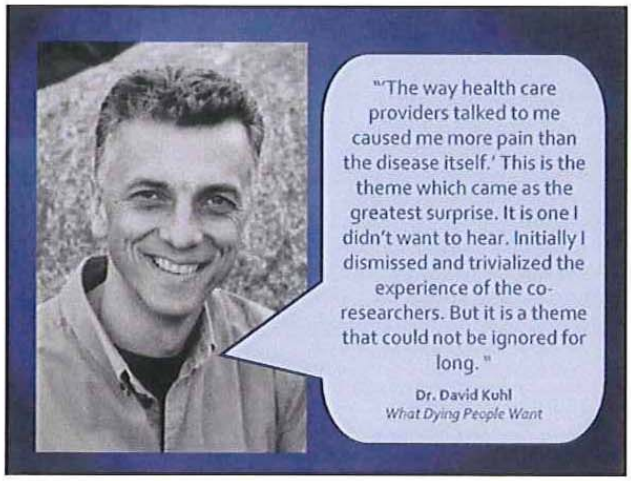
The Square of Care: A Conceptual Framework

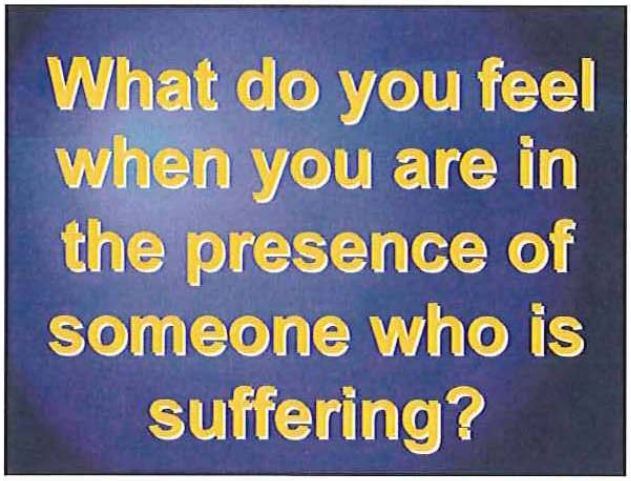
		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

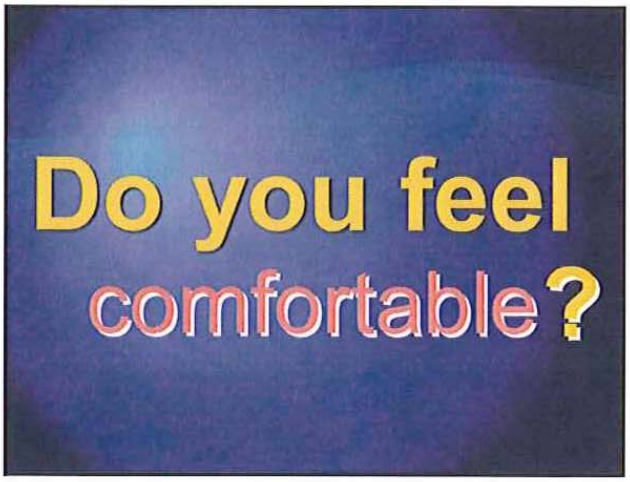
Patient and Family Care

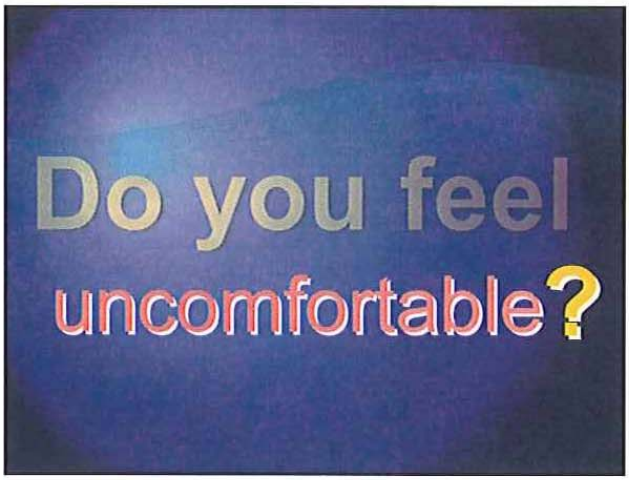
Hospice Palliative Care is what we do as health care providers in response to the needs of people!!


"Bodies do not suffer, people do."
Dr. Eric Cassell

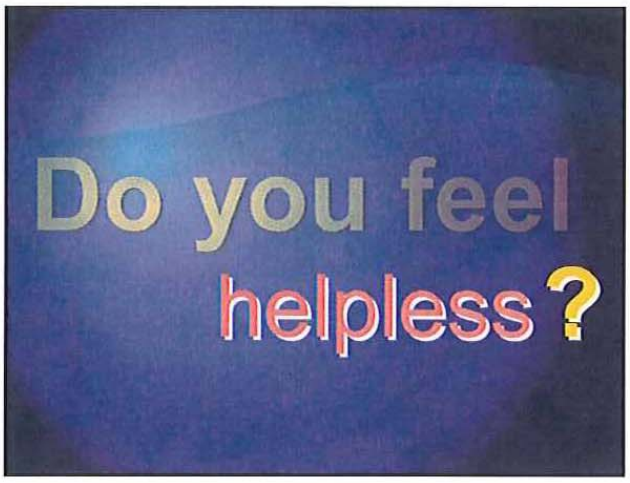

"The way health care providers talked to me caused me more pain than the disease itself.' This is the theme which came as the greatest surprise. It is one I didn't want to hear. Initially I dismissed and trivialized the experience of the co-researchers. But it is a theme that could not be ignored for long."
Dr. David Kuhl
What Dying People Want

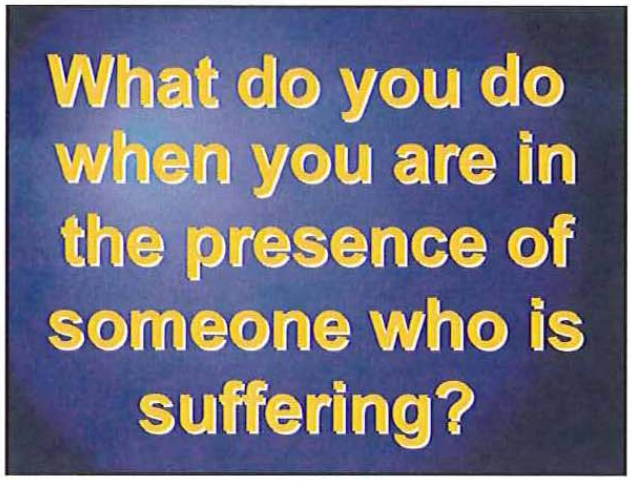

What do you feel when you are in the presence of someone who is suffering?


Do you feel comfortable?

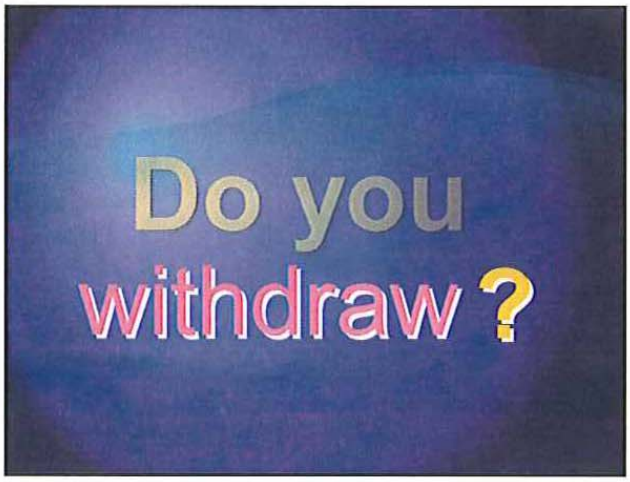

Do you feel uncomfortable?

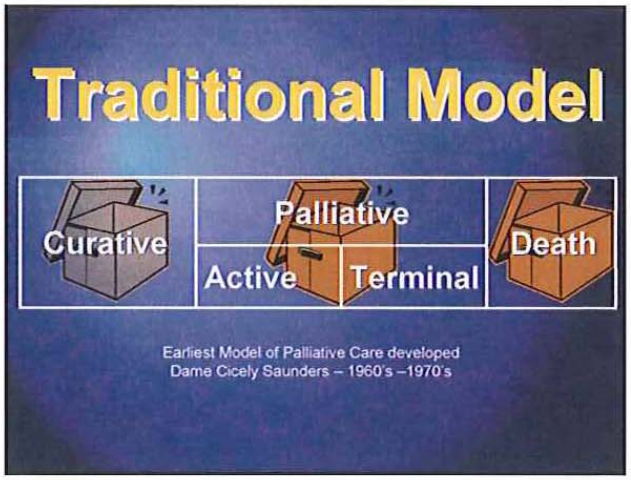
Do you feel helpful?

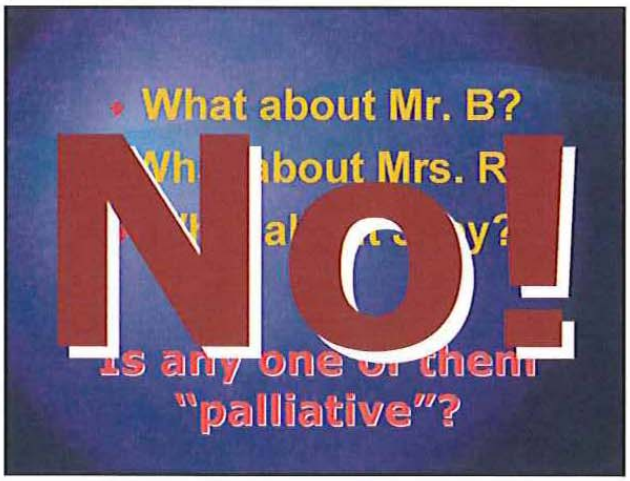

Do you feel
helpless?

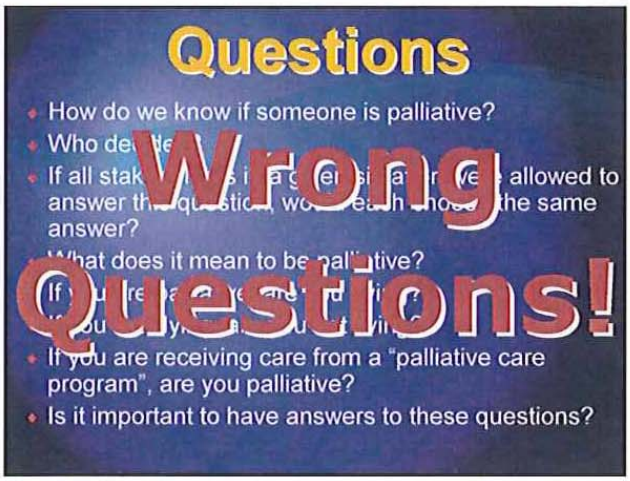

What do you do when you are in the presence of someone who is suffering?

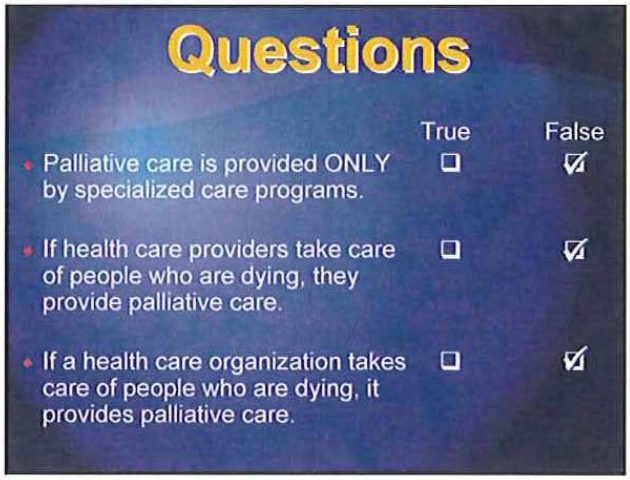
Do you
engage?

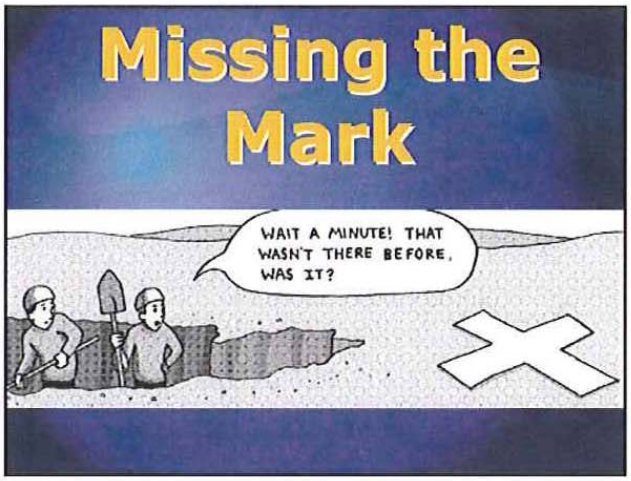

Do you
withdraw?

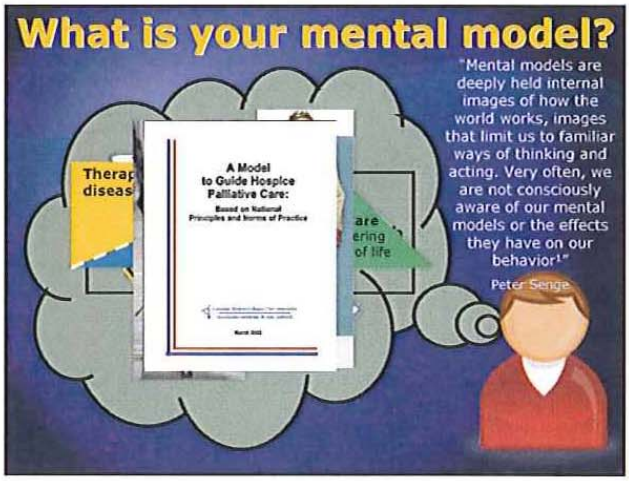

Traditional Model
Curative
Palliative
Active
Terminal
Death
Earliest Model of Palliative Care developed
Dame Cicely Saunders – 1960's –1970's


What about Mr. B?
about Mrs. R
NO!
"palliative"?

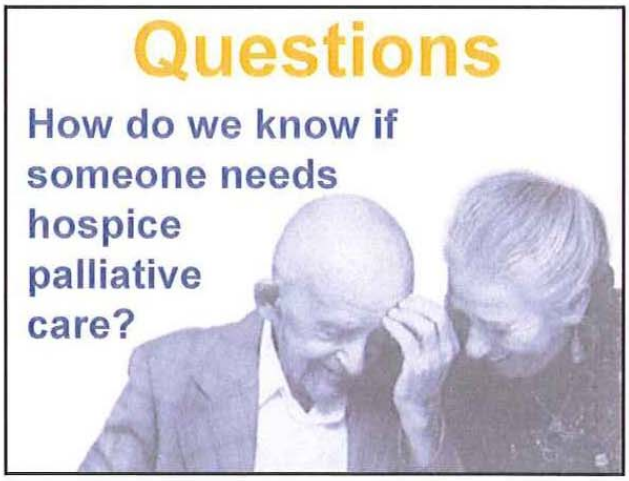

Questions
How do we know if someone is palliative?
Who de
If all stak
allowed to answer th
the same answer?
What does it mean to be pall
tive?
If you are receiving care from a "palliative care program", are you palliative?
Is it important to have answers to these questions?
Wrong Questions!

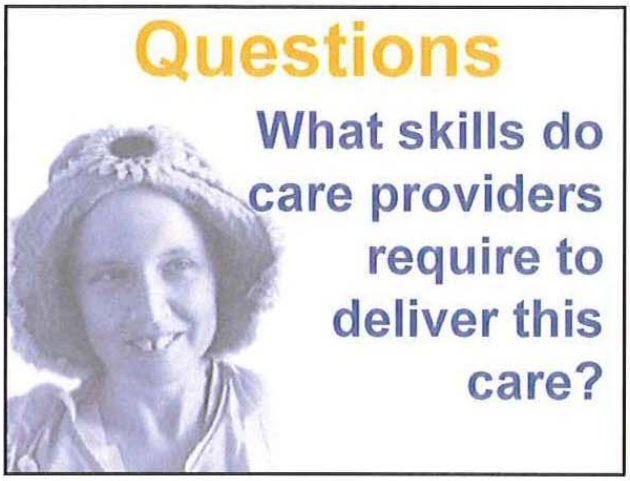

Questions
True
False
Palliative care is provided ONLY by specialized care programs.
If health care providers take care of people who are dying, they provide palliative care.
If a health care organization takes care of people who are dying, it provides palliative care.

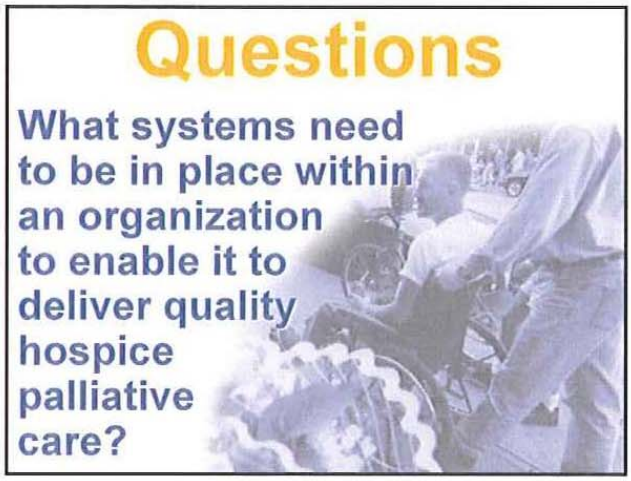

Missing the Mark
WAIT A MINUTE! THAT WASN'T THERE BEFORE, WAS IT?

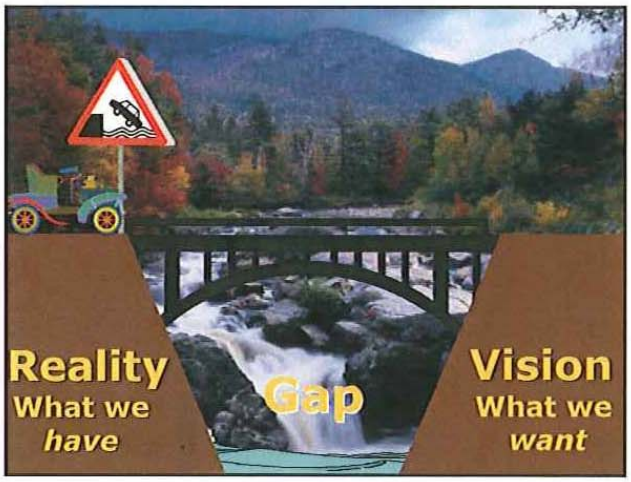

What is your mental model?
"Mental models are deeply held internal images of how the world works, images that limit us to familiar ways of thinking and acting. Very often, we are not consciously aware of our mental models or the effects they have on our behavior!"
Peter Senge
A Model to Guide Hospice Palliative Care:

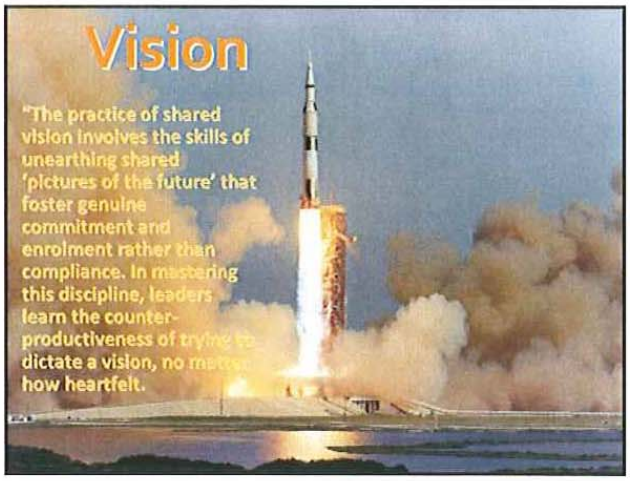
Think outside the box.
FOREST LAWN
MEMORIAL GARDENS & MEMORIAL CHAPEL
Pre-Plan Today

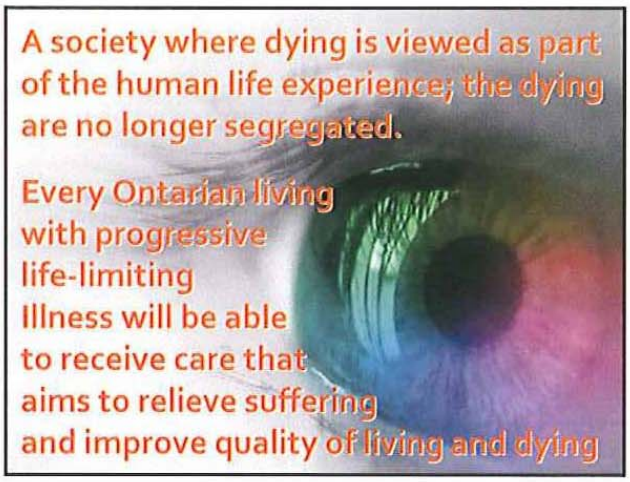

Questions
How do we know if someone needs hospice palliative care?

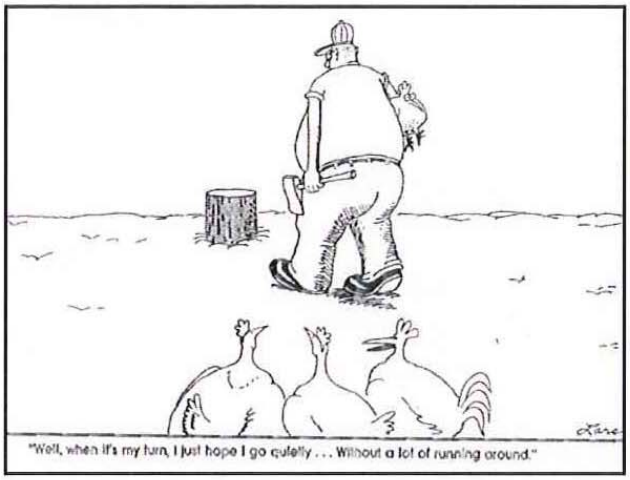

Questions
What skills do care providers require to deliver this care?


Questions
What systems need to be in place within an organization to enable it to deliver quality hospice palliative care?


Reality
What we have
Gap
Vision
What we want

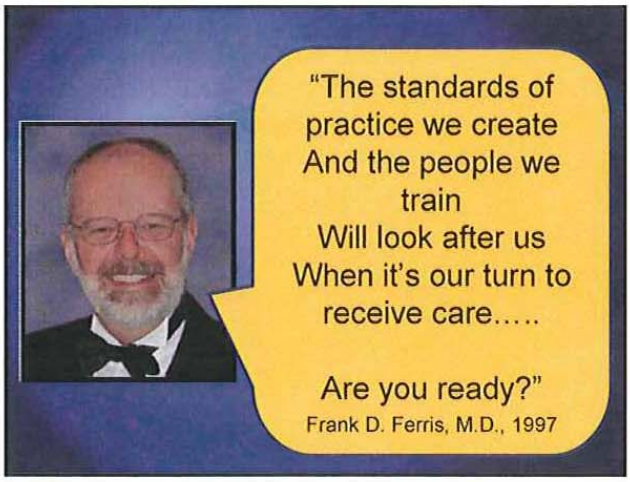

Vision
"The practice of shared vision involves the skills of unearthing shared 'pictures of the future' that foster genuine commitment and enrolment rather than compliance. In mastering this discipline, leaders learn the counter-productiveness of trying to dictate a vision, no matter how heartfelt.

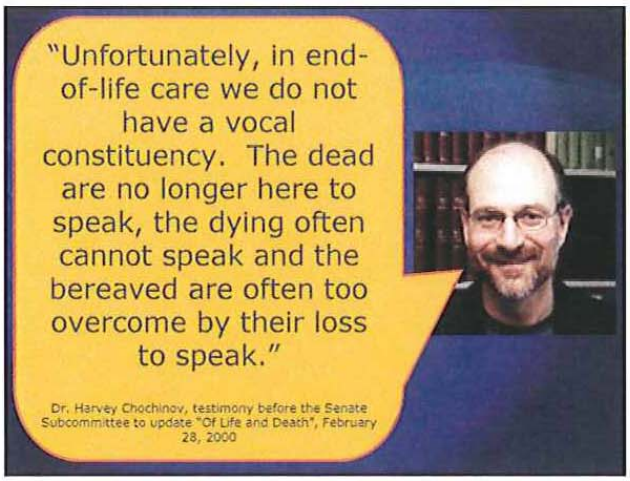

A society where dying is viewed as part of the human life experience; the dying are no longer segregated.
Every Ontarian living with progressive life-limiting Illness will be able to receive care that aims to relieve suffering and improve quality of living and dying



Take Home Messages

- People aren't palliative… care is!!!
- Recognize that there are far more people who need HPC than are currently receiving it.
- Every person living with progressive life-limiting illness should automatically care that aims to relieve suffering and improve quality of living and dying
- HPC is challenging work. Health care organizations need to ensure that their health care provider staff are equipped to provide it.
- Develop systems that are consistent across the continuum of care so that people experience the system working for them





Regional Models of Care for Palliative Cancer Care: Recommendations for the Organization and Delivery of Palliative Cancer Care in Ontario

Dr. Deborah Dudgeon, MD FRCPC
Provincial Program Head, Palliative Care

Hospice Palliative Care Strategy Development Workshop
June 23, 2009

cancer care ontario | action cancer ontario

Scope of the Report

- Regional cancer programs and inpatient hospitals delivering palliative cancer care treatment
- Organization and structure of palliative cancer care programs in Ontario
- Types of providers and their roles
- Education of providers
- Service type/complexity
- Service volumes
- Quality improvement

Methods

- Environmental scan
- Interdisciplinary working group
- Assessed current system
- Estimated demand based on benchmarks
- Identified gaps
- Consulted with the provincial End-of-Life Care Network

Goals of the Recommendations

- To create sustainable, accessible, quality care and improve patient outcomes
- To provide a comprehensive regional and provincial framework for the delivery of palliative cancer care treatment

Underlying Principles

- Patient centred care: optimizes outcomes for patients that are patient focused and are based on the patient's needs as opposed to prognosis,
- Optimal care: optimizes systems and access to services within available resources to provide the best care for the patient that is high quality and safe,
- Interprofessional and intraprofessional collaboration
- Coordination and continuity of care: consistency and continuity of care exist across all care settings.

Key Elements

- Common screening, assessment tools and guides to practice
- Performance data linked to quality indicators
- Education, training and health human resource planning
- Palliative care bed allocation

Recommendations

Recommendation 1: Each region should have three levels of palliative cancer care available: Primary, Secondary and Tertiary.

Primary Level

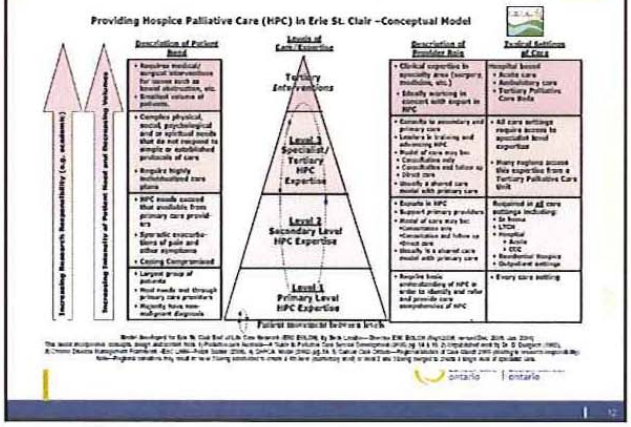
- Available in every care setting
- Includes interprofessional primary care providers with a basic understanding of palliative care
  - Able to identify, refer and provide the core competencies of palliative care
  - Able to address physical, emotional, social, cultural and spiritual needs with dignity and compassion
  - Provide clinical management and care coordination including assessment, triage and referral using a palliative approach for patients with uncomplicated needs
  - Have access to specialized services and links with secondary and/or tertiary palliative care providers for purposes of referral consultation

Secondary Level

- Required in all care settings e.g., in home, LTC, hospital, residential hospice and outpatient setting
- Includes interprofessional health care providers with basic training and significant experience in managing pain and other symptoms and providing psychosocial oncology care
  - Provides consultation, support, information and mentorship to primary care providers
  - Able to identify patients requiring specialist level palliative care and refer them appropriately
  - Provides palliative care for patients and families whose needs exceed the capability of primary care providers (e.g., sporadic exacerbations of pain and other symptoms)

Tertiary Level

- Required in settings such as: regional cancer centres, academic medical centres, a tertiary hospice palliative care unit with palliative care beds
- Includes experts in palliative care that are available to consult secondary experts and primary providers on difficult to manage cases, to educate and train secondary experts, conduct research and develop advocacy strategies
- Provides a level of service for patients who require specialized, frequent and skilled assessments and interventions over a short period of time and/or require diagnostic tests, complex treatments or invasive procedures
- Includes tertiary interventions such as surgery and acute medical interventions



Recommendation 2: Each region should have a mix of services that are patient focused, based on the patient's needs, as opposed to prognosis, and optimizes outcomes for patients.

Recommendation 3: All regional cancer programs should offer a tertiary level of expertise to maximize access to specialist palliative care services throughout the cancer centre, hospital and the region.

Recommendation 4: Common screening, assessment tools and guides to practice should be implemented in all levels of care in each region (e.g., ESAS, Palliative Performance Scale, Collaborative Care Plans and Symptom Management Guides to Practice)

Recommendation 5: Standardized education, training and health human resource planning should be implemented

Recommendation 6: The Regional Palliative Care Program should continue to work with the End-of-Life Care Networks to establish formal linkages amongst palliative care providers in different settings of care.

Recommendation 7: Each Regional Cancer Program should address interprofessional and intraprofessional collaboration within the integrated cancer program and regional cancer program, as collaborative practice is essential for the effective delivery of palliative care in any care setting and between settings of care.

Recommendation 8: A mixture of structure, process, and outcome indicators should be established for palliative care services to identify if symptoms are improving, whether services are accessible and whether there is equitable distribution of services across the province.

Recommendation 9: An appropriate number of designated palliative care beds within the acute care and non-acute care sector including complex continuing care, residential hospice and LTC should be established based on current benchmarks and projected need

Next Steps

- Consult with CCO Regional Vice Presidents and regional cancer program administrators to develop strategies to implement the recommendations within the cancer programs
- Develop a health human resource plan based on current bench marks and projected need
- External consultation with additional stakeholders

Hospice Palliative Care Integrated System Design Framework

Provincial Palliative Care Think Tank
June 23rd, 2009

Presenters : Andrea Martin and Julie Darnay
Co-Chairs of the Provincial EOL Care Network

On Behalf of the
System Design Working Group, PEOLC, lead by Beth Lambie ESC

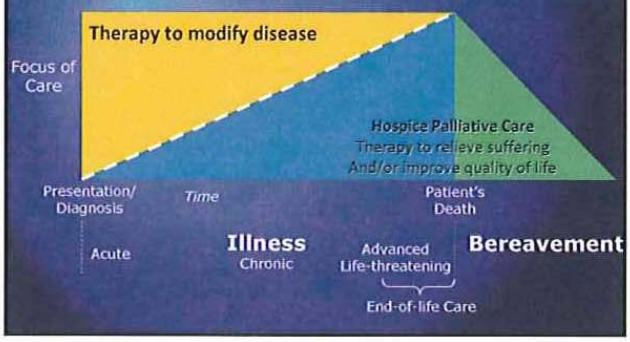
Acknowledgement

- Erie St. Clair End-of-Life Care Network members and its Director, Beth Lambie lead the development of the System Design Framework
- Provincial input was obtained from members of the Provincial End-of-Life Care Network & Hospice Palliative Care System Experts
- Knowledge transfer expertise (E. Lusk) provided through the SHRTN/PEOLCN partnership
- Chris Sherwood, Palliative Care Consultant, HNHB Hospice Palliative Care Network for his contribution to the development of this presentation

Definition of HPC

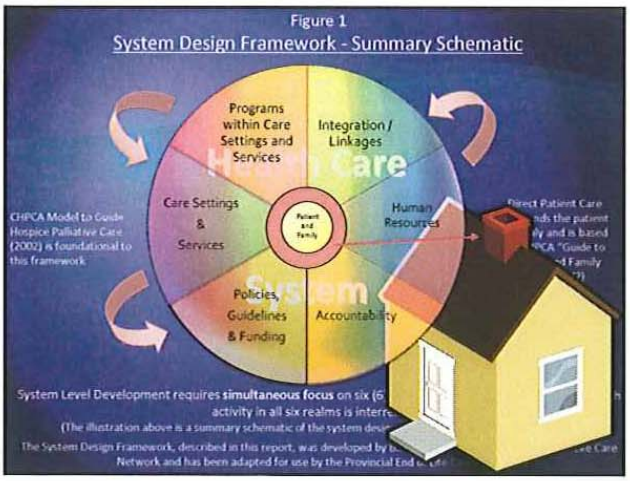
Care that aims to relieve suffering and improve the quality of living and dying.

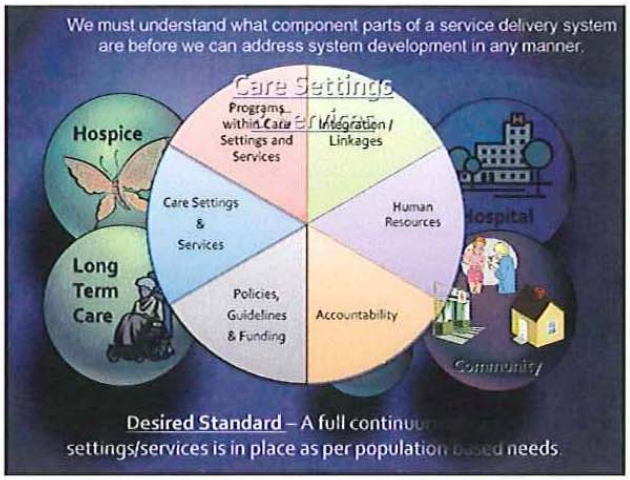
CHPCA Model to Guide Hospice Palliative Care, 2002



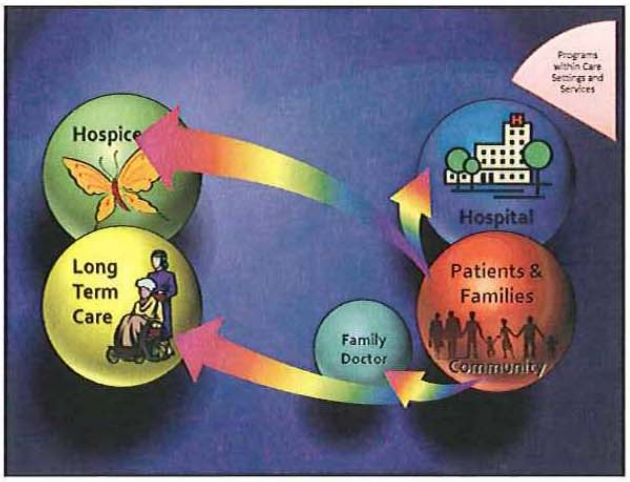
The Square of Care: A Conceptual Framework

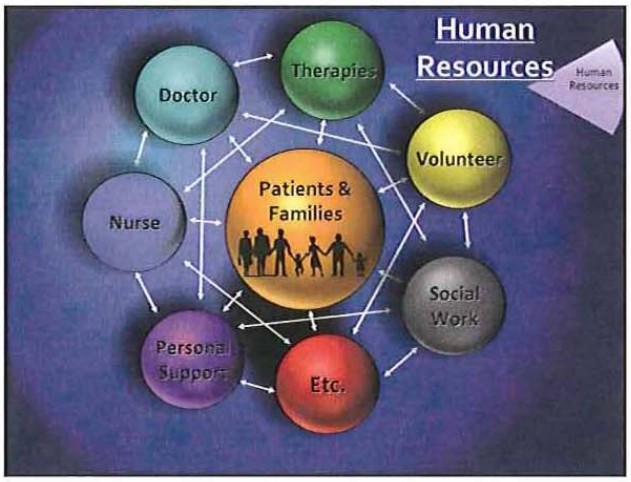
		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical			Patient and Family Care			
	End of life/ Death Management						
	Loss, Grief						



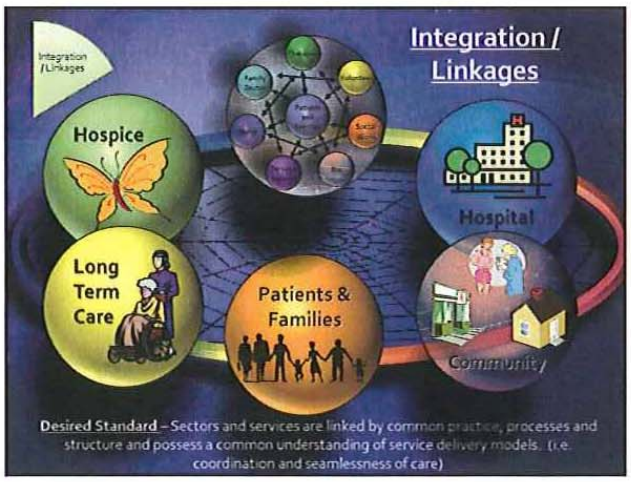

We must understand what component parts of a service delivery system are before we can address system development in any manner.
Care Settings
Programs within Care Settings and Services
Integration / Linkages
Care Settings & Services
Human Resources
Policies, Guidelines & Funding
Accountability
Hospice
Long Term Care
Hospital
Community
Desired Standard – A full continuu
settings/services is in place as per population based needs.

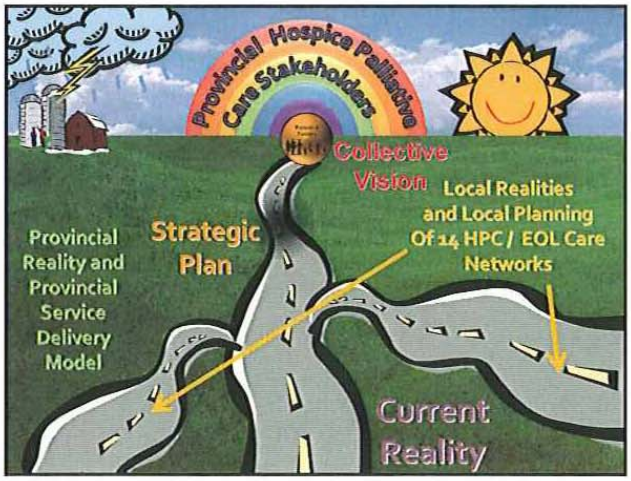
Programs within Care Settings and Services
Hospice
Long Term Care
Hospital
Patients & Families
Family Doctor
Community
Desired Standard – in each care setting where patients die there is a clearly defined HPC program developed. All HPC services articulate a clear mandate and service specific criteria. (i.e. 24/7 availability)

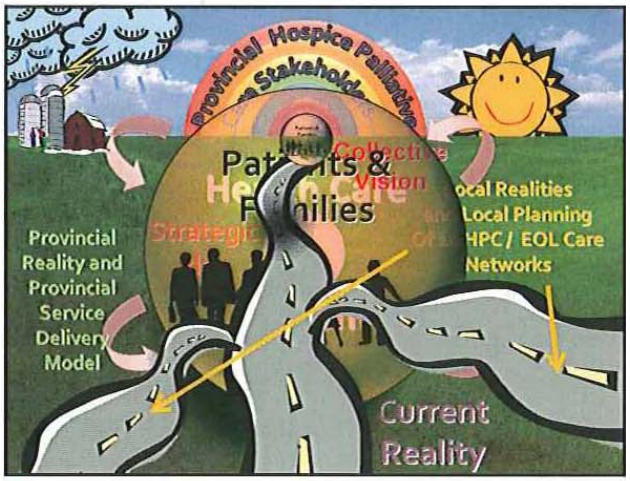

Programs within Care Settings and Services
Hospice
Long Term Care
Hospital
Patients & Families
Family Doctor
Community


Human Resources
Human Resources
Doctor
Therapies
Volunteer
Patients & Families
Nurse
Social Work
Personal Support
Etc.

Human Resources
Human Resources
Hospice
Long Term Care
Hospital
Family Doctor
Community
Desired Standard – adequate number of trained inter-professionals are available as per population based needs assessment


Integration / Linkages
Integration / Linkages
Hospice
Long Term Care
Hospital
Patients & Families
Community
Desired Standard – Sectors and services are linked by common practice, processes and structure and possess a common understanding of service delivery models. (i.e. coordination and seamlessness of care)





Current Status Review

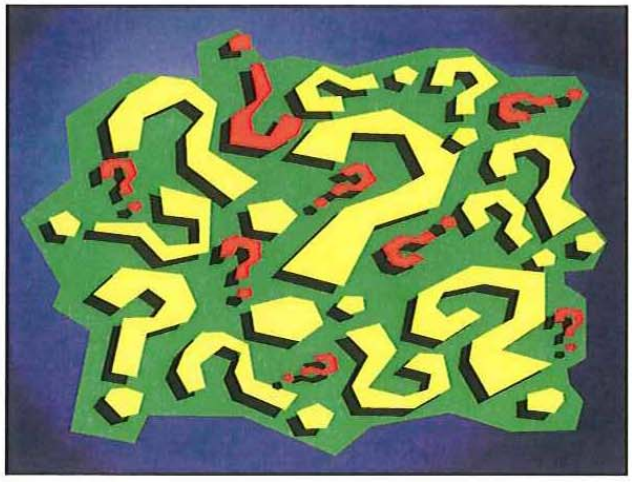
- 14 HPC Networks aligned to each LHIN area and a PEOLC Network infrastructure
- HPC Community of Practice established 2007 involves broad HPC organizational leadership
- Preliminary HPC System Design Framework including population based planning
- Preliminary Inventory and review of HPC system in Ontario
- Preliminary Provincial Gap Analysis
- Preliminary LHIN-wide Gap Analysis underway

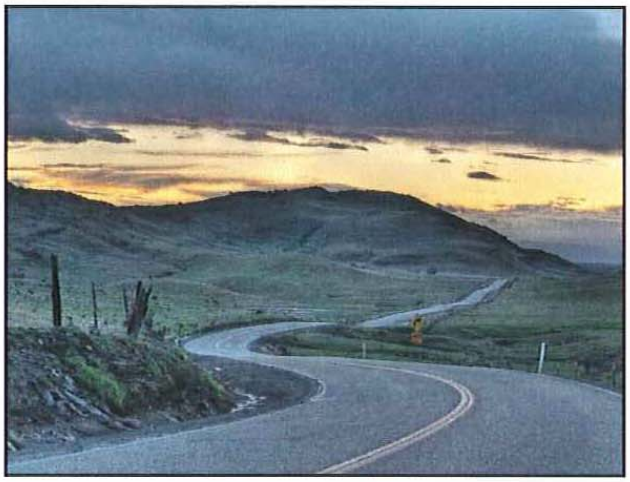
Our Vision

A fully functioning integrated service delivery model throughout Ontario

Our Desired Outcome for Today

Provincial and local agreement on, and participation from, all stakeholders in the development of a gold standard HPC Service Delivery Model for Ontario





Ontario's End-of-Life Homecare Patients: How They Use Homecare, Hospitals & Emergency Rooms

RESEARCH SUMMARY March 2009

Written by Hsien Seow, PhD
Cancer Care Ontario Research Chair in Health Services Research, Department of Oncology, McMaster University

Homecare has become a major provider of end-of-life healthcare services for patients in Ontario in the hopes to shift care from acute settings[1]; however little is known about how end-of-life patient use homecare and acute care services over time. This study describes the trajectories of end-of-life nursing and personal support service use from homecare admission to death and how patient's use acute care services in late life, particularly hospitalizations, emergency room visits, and death in hospitals.

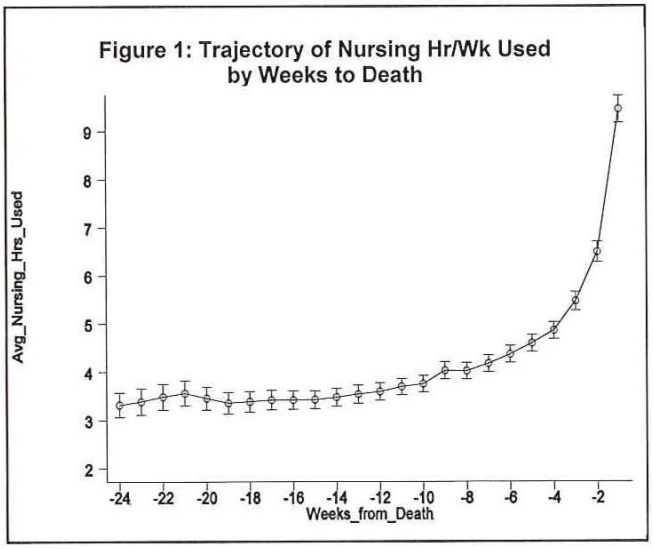
The Ontario Homecare Database was used to identify end-of-life homecare patients admitted from April 1, 2005 to December 31, 2006 and who died before March 31, 2007. These patients were linked to other administrative databases, such as the Discharge Abstract Database, National Ambulatory Care Reporting System, and the Registered Persons Database. To compare patients equally, dates of death were assigned as time zero, aligned together, and examined backwards by weeks to initial homecare admission.

How End-of-Life Patients Use Homecare Services from Homecare Admission to Death

11,867 decedents were identified, 84% had a cancer diagnosis, and about one-third were admitted to homecare 1 month or less before death. The average nursing and personal support hr/wk used by patients were 3.1 hr/wk and 3.3 hr/wk respectively. 7% of patients used no nursing services after homecare admission, while 40% used no personal support services.

There was a sharp increase in the nursing hr/wk used by patients in the last 4 weeks of life. (Figure 1) Personal support hr/wk used follows a similar trajectory. Among individuals using any services, the ratio of nursing and personal support hr/wk increased by 2% each week closer to death and by an additional 20% and 11% respectively for each of the last 4 weeks of life compared to hr/wk used 6 months before death.

Figure 1: Trajectory of Nursing Hr/Wk Used by Weeks to Death



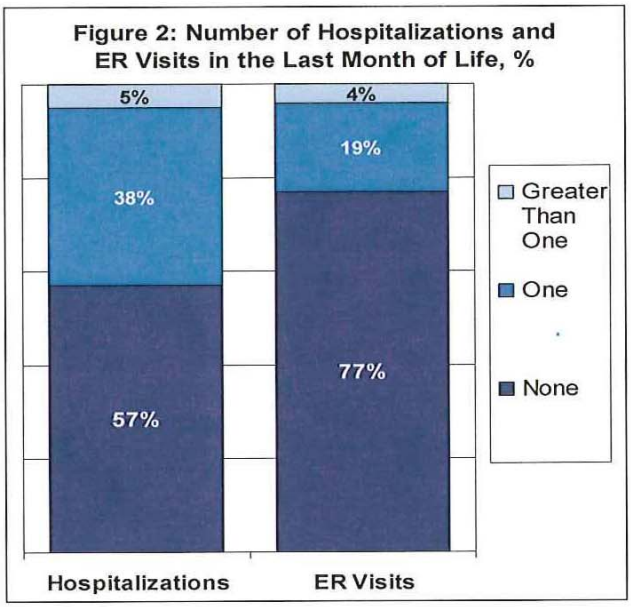
Factors Affecting the Use of Homecare Services

Noncancer patients used 24% more nursing and 20% more personal support hr/wk than cancer patients. Patients older than 80 used 20% less nursing and 16% less personal support than patients aged 18-49. Females used 17% more personal support hr/wk than males. Patients living in rural areas used 20% less nursing and 7% less personal support hr/wk than those living in non-rural areas.

How End-of-Life Patients Use Acute Care Services

The majority of end-of-life homecare patients did not have a hospitalization (57%) or ER visit (77%) in the last month of life; and only about 5% of patients had greater than 1 hospitalization or ER visit. (Figure 2) However, of those who had at least one hospitalization in the last month, one-third spent more than 14 days in the hospital in that last month. Therefore, preventing any unnecessary ER visits and hospital admissions in the last month of life could avoid lengthy hospital stays for patients.

Figure 2: Number of Hospitalizations and ER Visits in the Last Month of Life, %



Indeed, end-of-life homecare patients used fewer acute care services than other studies of cancer end-of-life populations. Among all end-of-life homecare patients:

- 38% died in a hospital, compared to 53-56% in cancer decedents in Ontario[2,3]
- 16% had an ER visit in the last 2 weeks of life, compared to 28% in cancer decedents in Ontario[4]
- 32% had a hospitalization in the last 2 weeks of life

Therefore, end-of-life homecare patients are less likely to have a hospital death, and have fewer ER visits and hospitalizations in the month before death, than cancer decedents. This may be due to the homecare services supporting the patient and family in the home thus preventing the need for acute care services in the weeks before death.

More End-of-Life Homecare Services are Associated with Fewer Emergency Room and Hospital Services

RESEARCH SUMMARY March 2009

Written by Hsien Seow, PhD
Cancer Care Ontario Research Chair in Health Services Research, Department of Oncology, McMaster University

Effective end-of-life homecare, that improves quality and shifts care from acute settings, requires care providers to know which services to give patients, how much, and when. This research investigates whether patients' use of end-of-life homecare services, specifically the average nursing and personal support hours/week (hr/wk) used, are associated with the odds of using acute care services in late life. Specifically, the acute care outcomes examined were:

- having a hospitalization in the last 2 weeks of life;
- having an ER visit in the last 2 weeks of life; and
- dying in the hospital.

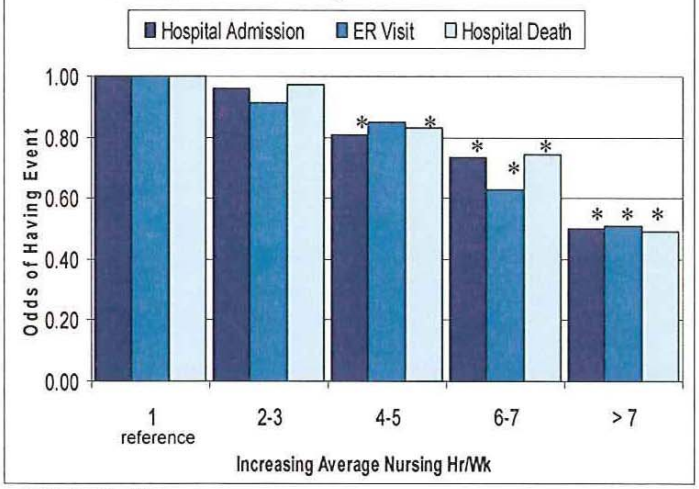
The cohort included end-of-life patients in Ontario who were admitted to homecare between April 1, 2005 and December 31, 2006, and who died before April 1, 2007 from the Ontario Homecare Database. Exposures of interest included the average nursing and personal support hr/wk used from 12 until 3 weeks before death. Average hr/wk of homecare services used were categorized into groups: 1 hr/wk (reference), 2-3 hr/wk, 4-5 hr/wk, 6-7 hr/wk, and >7 hr/wk. Patients were excluded if they were admitted to homecare for 2 weeks or less before death.

More Nursing Hours Matters

Patients using more than an average of 3 nursing hr/wk were associated with a significant decrease in the odds of having a hospitalization, ER visit, or hospital death, controlling for other covariates.† Moreover, the odds of having any of the three acute care outcomes decreases in a compelling dose-response manner. (Figure 3) Thus compared to the reference group of patients using 1 nursing hr/wk, patients using more nursing hr/wk had a reduction in their odds of having each of the three acute care outcomes by the following ratios:

- 4-5 nursing hr/wk had a 20% reduction in odds;
- 6-7 nursing hr/wk had a 25-35% reduction in odds; and
- > 7 nursing hr/wk had a 50% reduction in odds.

Figure 3: Association Between Average Nursing Hr/Wk and the Odds of Having an Acute Care Outcome



* significant <0.05

Only 7% of all end-of-life homecare patients used more than 7 nursing hr/wk, using an average of 16 nursing hr/wk and 9 nursing visits/wk.

More Personal Support Hours Matters

Similarly, patients receiving more than an average of more than 7 personal support hr/wk were also associated with a significant decrease in the odds of having a hospitalization (decrease by 35%) or ER visit (decrease by 27%) in the last 2 weeks of life, and having a hospital death (decrease by 29%), controlling for other covariates.† Only 13% of all end-of-life homecare patients used more than 7 personal support hr/wk, using an average of 17 personal support hr/wk and 8 personal support visits/wk.

Implications

These results show that those using >7 hr/wk of end-of-life nursing or personal support services are strongly associated with using fewer acute care services in late life—a 50% reduction in the odds of having any of the three outcomes (hospitalizations, ER visits, or hospital death). Moreover, the incremental dose-response nature of the association suggests that the increased nursing hours are linked with the decreased acute care outcomes. Why? The integrated nursing and personal support services provided by the Community Care Access Centers, may anticipate some patient needs in the home (e.g. pain), thereby managing symptoms well and avoiding the potential need for an ER visit or hospitalization.

These results can support case managers to justify increasing homecare services for specific patients. It should also encourage policymakers to continue supporting end-of-life homecare services and providers, particularly as the healthcare system strives to reduce the burden on hospitals and control healthcare costs. However, further research is needed to determine if a causal relationship exists between increased homecare services used and reduced acute care service use, particularly accounting for patient preferences.

†Covariates controlled for in the analysis included: sex, age, cancer diagnosis, comorbidity, income, rurality, average hospital length of stay/week, average nursing hours used/week, average personal support hours used/week, time from referral to death (weeks), and Community Care Access Center region.

Acknowledgements

This study was funded by the Canadian Institute of Health Research's Doctoral Research Award--Institute of Aging and supported by the Institute of Clinical Evaluative Sciences.

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Hsien Seow, PhD, graduated from Johns Hopkins School of Public Health from the Department of Health Policy and Management, specializing in health services research, palliative care, and gerontology. This research summary are the results from his dissertation. His research involves improving the quality of palliative care.

NW EOLC

We are here on earth to do good to others. What the others are here for, I don't know.

W. H. Auden

NW EOLC Niagara West End-of-Life Care Model

Enhancing Family Physician Capacity to Deliver Quality Palliative Home care:
The Niagara West End of Life, Shared-Care Model

Project Investigators:
Principals: Dr. Denise Marshall and Dr Doris Howell
Co-Principals: Dr. A. Taniguchi, Dr. J. Kaczorowski, Dr. K. Brazil, Dr. M. Howard.

Funding: *MOHLTC, Primary Health Care Transition Fund Project*

NW EOLC Why Community Care?

- Most Canadians with advanced progressive illness prefer to receive end-of-life Care at home
- Most prefer to die there IF adequate supports is available to minimize suffering and burden on family caregivers
- Patients suffer with transitions and long for continuity of care (Heyland et al)
- The astounding work of Donna Wilson et al (2009) on the rapidly changing location of death of Canadians (one decade-77% to 60%)- home and LTC- default or chosen place of death

NW EOLC Why a Shared Care model?

- Primary caregivers are seldom able to address the multiple domains of care that occur at end of life
- Primary caregivers repeatedly express the desire to be able to provide such care if given adequate support
- Interprofessional, collaborative practice now known to be key to sustainability , efficiency and effectiveness of our healthcare system
- Primary Health Care Reform

NW EOLC Health Canada Report
Canadian Best Practice Integrated End of life care Model or Approach

- 4 Key components
  - Universality
  - Care coordination
  - Ready access to a broad range of basic and advanced EOL services
  - Assurance of EOLCare regardless of care settting
    - Wilson et al

NW EOLC What do we mean by Shared Care?

- *Primary care providers* in a team partnership of care with *expert clinicians* who *together share the care* of the patient in an *integrated and seamless way*
  - Primary care *gatekeepers*
  - Primary care *capacity is enhanced* and the pattern of practice is *sustainable* for the primary care providers (provider satisfaction)
  - Expert clinicians are *collaborative consultants*
  - Care is negotiated patient by patient
  - To the patient, care is *seamless* (patient satisfaction)

Canadian Shared Care models

- Obstetrical care=family doctors and midwives + Obstetric specialists
- Mental Health= primary care doctors, nurses and social workers + psychiatrists, psychiatric nurses and mental health counselling specialists
- Chronic Disease management (ie diabetes) = FHT nurses and doctors + Diabetic clinic specialists

Shared Care model in Palliative Care

- Are not new.....but they arent widespread either...
- UK Gold Standards framework (across the UK)
- Pan Canadian Gold Standards/Romanow
- Individual programs and services currently exist
- Shared care is a concept and based on a spectrum (Peirera et al)
- Overarching tenets and components, with locally driven customization

Components of Shared care models Primary care...secondary care interface

- Defined population
- Patient identification
- Standardized assessment and process of care (mutually agreed upon)
- Education from specialist to primary care
- 24/7 access to specialist support
- Primary care does the "ABCs"...
- Specialists assess, reassess and do the "DEFGs..."
- Crosses care settings
- System navigation

Canadian/Ontario Background

- Family physicians:
  - view palliative care as an inherent and important part of their role (Lehman & Daneault, 2006: Marshall, Howell, et al, 2007)
  - potential to provide effective palliative home care given adequate knowledge, skills, confidence and timely access to specialist advice (Fainsinger, et al, 2001; Higginson, 1999).
  - family doctors and specialists often fail to develop the collaborative working relationships that would protect patient-doctor relationship and strengthen the role of the family physician (Kasperski, et al, 2006).
- Shared care between specialists and primary care physicians in mental health, maternity care, and chronic diseases have shown improvement in timely access and improved health outcomes (Rocker, 2006).

Purpose and Specific Aims

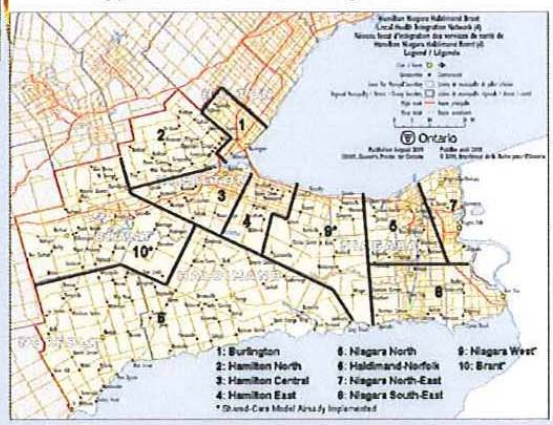
- Purpose: To improve quality of EOL care through implementation of a shared care model that integrated family physician care with specialist interdisciplinary palliative care.
- Specific Aims:
  - To build capacity of family physicians to provide quality palliative care 24/7 through academic detailing, role modeling and shared care.
  - Improve access to quality palliative care early in the EOL trajectory through best practice screening in GP offices .
  - Evaluate impact of model on patient/family outcomes; primary cre provider outcomes; and health system outcomes.

Niagara West project and model

- 3 municipalities population 80,000, 3 major towns, one 60 bed hospital
- Settings of care
  - Home, retirement lodge, adult group home
  - Flow to/from acute care; to LTC
- 3 Family Practice Groups (21 GP's).
- Inception cohort of all palliative patients in year who met inclusion criteria:
  - Would you be surprised if this patient died in the next 12 months? If answer is no.
    - Does the patient have symptom and/or support needs? If answer is yes.

3 municipalities-Grimsby, Lincoln, West Lincoln

Appendix B: HNHB LHIN Region Divisions



Primary Care Interventions and Integrations

- Family HealthTeam practices
- 'Case finding' best practice established
- Advanced Practice Nurse as key point of contact
- 'Point of care' education- using EIP model, academic detailing, Small group, case-based
- Palliative care practice lead-self selected
- Layered on-call- 1st call, 2nd call
- Shared care visits, shared care model, cross care settings with consistency

Integrated Care Model

PALLIATIVE ENHANCED/INTEGRATED PRIMARY CARE TEAM

APN Navigator/Palliative Medicine Consult/Shared 24/7 Call/ Psychosocial and Bereavement Counseling/Designated CCAC Manager/ Enhanced Services (24 Nursing/Drugs/Equipment)

ASSESSMENT
EOL Domains
Outcome-Based (ESAS, PPS, CAM, Patient Distress, Family Distress)
ACCESS
Best Practice: Early Identification of Palliative/Population-Based Screening Across Sectors/Rostering

EVALUATION OF PATIENT/FAMILY EXPERIENCE

CARE COORDINATED CONTINUOUS
Follows Patient Across Care Sectors
Integrated Care & Team Planning (Right Provider)
Explicit Resource Allocation: Respite Need Tool, Bereavement Risk

EDUCATION/DECISION SUPPORT
Practice-Based Education to Support GP Adoption of Best Practices (Academic Detailing)
Decision Support: "Just in Time"

Patient and Provider Outcomes

- Provider
  - Sustainable care
  - Increased capacity and confidence
  - "who to call for what"
  - Help in times of need
- Patient and Family
  - Satisfaction with care
  - Decrease symptom burden
  - Caregiver support
- Health Care system
  - Cost effective
  - Decreased hospital utilization

Concordance with Place of Death Preference (n=54)

	Home Death	Hospital Death	Total, n (%)
POD Preference			
Home (50)	32	18	50 (93)
Hospital (3)	0	3	3 (6)
Other (1)	0	1	1 (1)
TOTAL, n (%)	32 (59)	22 (41)	54 (100)

64% achieved their preference for place of death; 54% (32/60) of cohort of patients who died, died at home

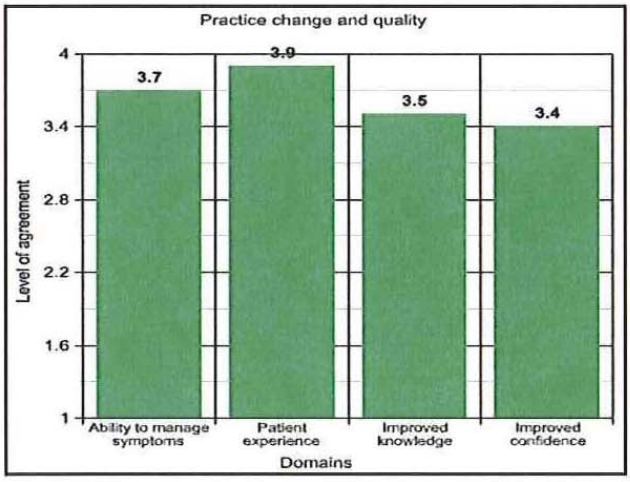
Pearson Chi-Square 6.28, p=.043**

Costs Vary by Patient Need and Less than Hospital Day

	Case 1	Case 2	Case 3	Case 4	Case 5
LOS	65	125	163	16	83
Home Care Days	57	125	159	15	49
Hospital Days	8	0	4	1	34
Total cost per direct home care day.	$316.25	$215.17	$254.83	$406.13	$195.36
MOHLTC Acute care per diem rate	$674				

Primary Care Outcomes

- Family physician uptake -100%
- Non physician practice leads emerged from each FHT
- 3/4 MD leads continuing with role
- Education became practice-lead
- Improvements made in non- pain symptoms, and patient communication and confidence in providing care
- High acceptability of the APN
- Increases perception of ability to manage and feel capable to take on care (nurse and MD)



Provider Outcomes-Physician and nurse focus groups

- Most valued components;
  - Access to the team and oncall support
- Impact on role and practice
  - Confidence in decision making
  - Better anticipation of patient needs
- Care coordination
  - Comprehensiveness, quality of communication, nurse/md trust and respect
- Impact on Care Quality
  - Enabling home death, averting crisis, reduced fears of suffering

Summary….

- A shared-care , population based model such as this that integrates specialty PC supports with primary care can ;
  - be efficient, effective and sustainable care
  - Increase capacity to achieve preference for place of care and death
  - Enhance the capacity of the Family Physician to provide geographically based Palliative care
  - Underscore the vital role of Palliative care Advance Practice Nurse as " patient navigator"

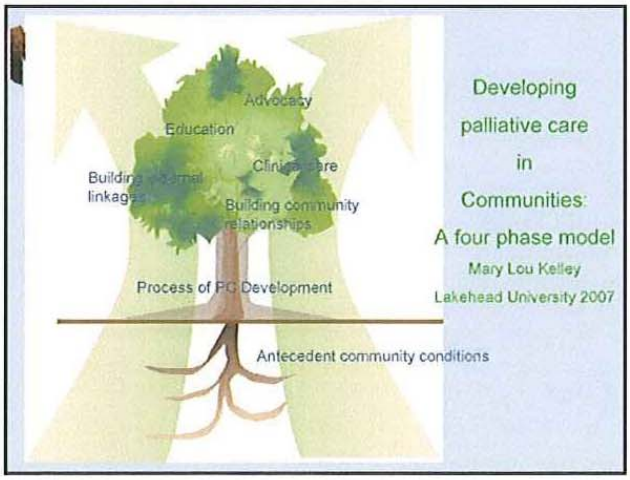
Shared Care Palliative Care models in Ontario- Consensus ??

- PHCTF -3 projects- Consensus at Humber 2007
  - Experts to consult with- MD, nurse, and counselor
  - 24/7 support from consult team
  - APN nurse navigator
  - " Education " to family doctors

April 2009 OPCA/HAO conference

Over 50 secondary level care providers/managers – input re Shared Care;

- 24/7 experts- single most important need in the community
- Provincial initiative/ province wide approach
- Fam doctor and Palliative Care MD engagement especially with advent of FHT
- MD champions
- Local flexibility and implementation
- Non disease specific care
- Firm connections with hospital programs –inpt and outpatient to ensure non-duplicative care close to home



Rural Palliative Care- a Comprehensive Review Robinson et al 2009

- Clinical issues
  - Emotionally challenging but high degree of commitment
  - Blurred distinction between private and professional life
  - Social and geographic isolation
  - Interprofessional team "gold standard" non existent
  - Generalists trying to maintain knowledge and skills
  - ***Inadequate role preparation since undergraduate education***
  - Specialists as asset vs undermine local skills?
  - Lack of resources and support
  - No 24/7 access to support or care
  - Medications after hours

Growing Shared Care teams

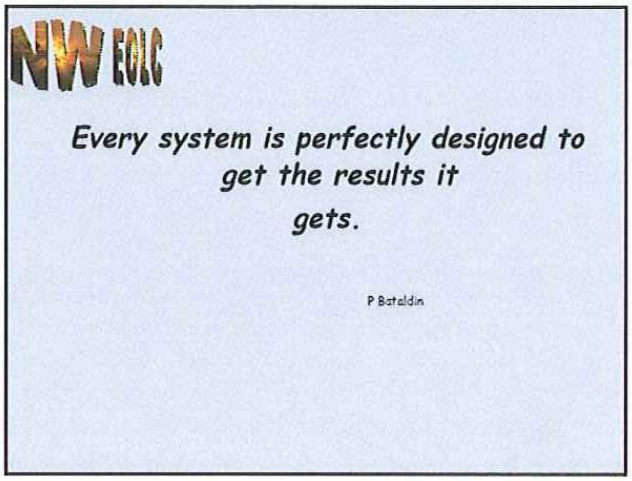
- Expected Outcomes
  - Impact on Alternative Level of Care (ALC),
  - Emergency Room (ER)
- Growing Physician Capacity via Engagement
  - Education in all the ways that work
  - Mentorship, locally customized peer consultation
  - "putting the expert out of work"
- Building Community Capacity – the Kelley Model (J of PC, August 2007)
- Patient and caregiver outcomes
  - Greater achievement of requested place of death
  - Fewer patient transitions in care

- Provincial Direction
  - To date four Network proposals have been approved within the Aging at Home Strategy across the province for community based teams, including:
- Erie St. Clair
- Wellington Waterloo
- Central
- HNHB

Distinctions within the models, but similar values, components and outcome performance measures

Summary for small group discussion- Shared Care

- Shared care palliative care models seem to be an important component of primary care engagement and sustainable community care
- Careproviders and consumers in Ontario support them
- They need to be organically grown and locally customized and clear on what "shared care" really means at the local level
- Further research is unfolding
- Shared care fits with the overall spectrum of care and need to connect with institutional programs


NW EOLC
Every system is perfectly designed to get the results it gets.
P Bataldin

Who is the Puzzle Maker?

Patient and Caregiver Perspectives on Navigating Health Services in Ontario

Cathy Fooks
President and CEO
The Change Foundation
June 23, 2009

Why a Focus on Patient and Caregivers' Views?

- A high performing health system understands, measures and responds to patient experience.
- Quality improvement frameworks incorporate the patient experience and views directly into improvement methodologies.
- Ontario has created a relatively new governance structure (LHINs) to plan and integrate care at local level at the same time as regionalizing priority programs like cancer. Case management functions for community care (home and LTC) under different organization (CCAC). Physician services remain independent.
- What is the patient experience related to how well integrated care is in Ontario?

Research on Patient Perspective

Three separate projects: (not specific to cancer)

1) Literature review on patient and families views on navigating the system

   - systematic review at University of Calgary
   - limited to empirical studies of expectations and experiences of integrated health care since 1997
   - 53 studies were included, 12 of which were Canadian

Research on Patient Perspective

2) General population survey about information flow and communication across transition points

   - 1015 Ontarians aged 18 and over at the end of April 2008
   - asked about information flow and communication; provider access to information; coordination of care; whether the health system values their time

Research on Patient Perspective

3) Ten focus groups with regular users of the health care system (minimum of six interactions in last 12 months with different providers) and caregivers

   - divided between patients and caregivers
   - caregivers had to participate in appointments

What Did We Find?

In general:

- Patients have reasonable expectations
- Strongly support their health care providers and professionals
- Understand the government's concern about ever increasing resources directed at health care

BUT:

- They see where things break down and can identify clearly where "things don't make sense"

Four Common Themes

1) Navigating the System – is anybody joining the dots?

2) Dealing with Repetition, Redundancy and Delay – could it be a bit more logical?

3) Worrying about Communication – is anybody listening?

4) Getting Lost in the Transition – who is the puzzle maker?

HEALTH CARE DESERVES OUR FINEST THOUGHT

System Navigation

- 54% of people surveyed reported they were not confident that there was a single, lead person in charge of coordinating their health care services (S)
- Patients and families report that as they move across services, they are "left to make their own way through the continuum without the skills, support or confidence to do so" - this was particularly true for parents with special needs children and families dealing with chronic, debilitating illness (LR)

HEALTH CARE DESERVES OUR FINEST THOUGHT

System Navigation

- Patients report that they understand they must shoulder some responsibility for their care but are looking for a partnership (FG)
- Patients receiving care in clinics featuring multi disciplinary teams reported higher levels of satisfaction and less difficulty navigating services (LR and FG)

HEALTH CARE DESERVES OUR FINEST THOUGHT

Tanya from Kingston

"The difficulty was the coordination of care once she got home from hospital...There just doesn't seem to be a good flow of information between specialists. And so it's a bit difficult to navigate. I thought it would be helpful to have someone sort of helping us with that."

HEALTH CARE DESERVES OUR FINEST THOUGHT

Repetition, Redundancy, Delay

- 41% of those surveyed reported they do not feel the health care system values their time (not seen at time of appointment, allowed only one issue to be discussed at each appointment, short notice appointment during work hours) (S)
- Patients report:
  - having to convey the same information repeatedly
  - being sent for duplicate tests (first results were not available or too much time had passed between test date and appointment)

HEALTH CARE DESERVES OUR FINEST THOUGHT

Repetition, Redundancy, Delay

Patients report:

- appointments or procedures being cancelled after patient arrived onsite (FG)
- rebooking an appointment because provider did not have adequate information at the time of the appointment (LR and FG)

HEALTH CARE DESERVES OUR FINEST THOUGHT

Keith in Toronto

"With my Dad, every time I've gone, and he's been to various places and I've been there, we have the big file. Now if I wasn't educated and he wasn't organized...

Every time you have to fill in the forms again."

HEALTH CARE DESERVES OUR FINEST THOUGHT

Communication

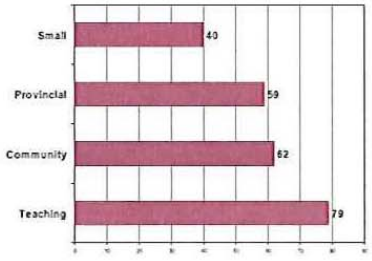
- Most common area of concern from all three sources

1) Information at point of services
   - 41% of those surveyed reported they did not think their health care practitioner had access to all information, tests and records related to their health (S)
   - Misplaced records (LR)
   - Incomplete information sent (LR)
   - Patients deliver their own test results (FG)

HEALTH CARE DESERVES OUR FINEST THOUGHT

IT – Hospitals Using Clinical Information Technology, Hospital Group Average

Hospital Report, Acute Care, 2007



HEALTH CARE DESERVES OUR FINEST THOUGHT

Use the Following Electronic Aids, FP/GPs,Ontario

Source: National Physician Survey, 2007

% Indicating they have:

Electronic billing	66.1%
Electronic patient scheduling	54.1%
Electronic health records	28.2%
Electronic reminder for pt care	20.1%
Electronic interface to external pharm	4.9%
Electronic interface to lab/diag imag	26.8%
Electronic interface to share pt info	18.9%
Electronic warning for adverse prescribing and/or drug interactions	19.3%

HEALTH CARE DESERVES OUR FINEST THOUGHT

Communication

2) Clarity About Next Steps in Treatment
   - 30% of people surveyed reported that they sometimes received instruction about symptoms to watch for.
   - 35% reported they occasionally, seldom or never received such instructions (S)

   - 27% of people reported they sometimes received instructions about where to seek further care if needed.
   30% reported they occasionally, seldom or never received such instructions (S)

HEALTH CARE DESERVES OUR FINEST THOUGHT

Communication

3) Communication Between Health Care Providers
   - perceptions of coordination are directly linked to perceptions of the extent of communication between providers (LR)

   - numerous instances of a provider not knowing a patient had been seen elsewhere, not having results of the episode elsewhere (FG)

HEALTH CARE DESERVES OUR FINEST THOUGHT

Transition Points

- Emphasis in both the literature review and the focus groups that the problems (navigation, repetition and communication) are acute at points of transition
- Relates to other work we are doing

1) Flo Collaboratives – hospital-CCAC patient flow
2) Transitions project with OACCAC – experience of patients with discharge planning and community placement

HEALTH CARE DESERVES OUR FINEST THOUGHT

Joy in Kingston

"People are leaving the hospital and then they're kind of on their own. When they're out there's home care, but only for so long and then…it's unloaded deeply on families. Honestly, if you don't have daughters or sons close by, you are on your own."

HEALTH CARE DESERVES OUR FINEST THOUGHT

Carmen in Toronto

"They asked my father 'Is there someone at home who could take care of you? And he said, 'Yes, my wife.' But my mother is blind, she has mobility issues. I said, 'He cannot come home under these circumstances.' So they told me I was the primary caregiver."

HEALTH CARE DESERVES OUR FINEST THOUGHT

Transitions Project with South East CCAC and Quinte Health Care (Trenton Memorial Site)

"I want accurate information that I can understand at the right time and place, including viable options, so my family and I can make the right decisions for us."

"I want to feel confident that people care and to be treated with respect."

"I don't want to make a decision out of fear, inadequate care of surprises."

HEALTH CARE DESERVES OUR FINEST THOUGHT

Transitions Project Diagnostic

- Too many steps in process – each with potential delay (53)
- Too many forms (36)
- Too many staff roles involved in process from hospital and CCAC (5)
- Five separate data entry points into client information system (generating 9 forms in and of itself)
- Confusion for patient and family as to who they should call and when decisions needed to be made

HEALTH CARE DESERVES OUR FINEST THOUGHT

Transitions Project Outcome

- Change in local process
- Focused preplanning done by CCAC case manager in the hospital
- Reduction of forms and steps
- Clear information for patients and families with one designated support person (sometimes the CCAC and sometimes the hospital – decided jointly).
- Phase Two just wrapping up in Toronto.

HEALTH CARE DESERVES OUR FINEST THOUGHT

Solutions?

Research and public agree:

- Speed up EHR implementation
- Designate navigators or care coordinators across continuum
- Increase use of multidisciplinary teams
- Better support for caregivers
- Better connect primary care practitioners to rest of system
- Undertake QI process mapping at transitions
- Coordinate/integrate care maps across providers

HEALTH CARE DESERVES OUR FINEST THOUGHT

What Next for Ontario?

- Improve local communication?
- Develop regional networks and collaborative governance?
- Supportive provincial policy, regulation and funding?
- Focus on measurement of integration from a patient perspective?

HEALTH CARE DESERVES OUR FINEST THOUGHT

Personal Plea

- Palliative Care in 2015:
  - Understands the patient experience from the perspectives of the patient and their family
  - Is integrated across providers – primary care, hospital, home, hospice
  - Has a coordinated information management platform that provides real time information to facilitate care decisions and communication
  - Is resourced appropriately and with flexibility to support the wishes of patients and their families

HEALTH CARE DESERVES OUR FINEST THOUGHT

THE CHANGE FOUNDATION

HEALTH CARE DESERVES OUR FINEST THOUGHT www.changefoundation.com

Appendix D:

Participants List

Table 1	Table 2
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1. Dr Marissa Slaven (Regional CA Program) 2. Janet Noble (CCAC) 3. Kate Reed (LHIN) 4. Dr Edward Fitzgibbon (Palliative Care /EOL Network) 5. Katherine Smith (Nursing) 6. Marta Krywonis (HPC/EOL Chairs & Directors) 7. Dr Andrew Knight (Prov. Palliative Care Lead) 8. Brendon Lalonde, CCO 9. Beth Ellis (HPC/EOL Chairs & Directors)	1. Raquel Shaw Moxam (CCO) 2. Dr Rick Irvin (Regional CA Program) 3. Roberta Lee (LHIN) 4. Dr. Russell Goldman (Palliative Care /EOL Network) 5. Dr Peter Spadafora (Palliative Care /EOL Network) 6. Cathy Kitley (Nursing) 7. Cate Root (HPC/EOL Chairs & Directors) 8. Sheila Bauer (HPC/EOL Chairs& Directors) 9. Dr Anne Smith (RVP) 10. Kathryn Ramsay (CCAC)
Table 3	**Table 4**
Facilitator: Ms. Esther Green (CCO)	Facilitator: Ms. Andrea Martin (HPC/EOL Chairs & Directors)
1. Prabhjot Minhas (CCO) 2. Mark Berry (Regional CA Program) 3. Glenda Owens (CCAC) 4. Monique Rocheleau (LHIN) 5. Dr AJ Kirshen (Palliative Care /EOL Network) 6. Dr. Michael Mills (Palliative Care /EOL Network) 7. Beryl Cable-Williams (Nursing) 8. Wilma Sletmoen (HPC/EOL Chairs & Directors) 9. Dr Geoff Davis(Regional Pall Care Lead) 10. Dr Louis Balogh (RVP)	1. Dr Carol Sawka (CCO) 2. Eveline Rosen (CCAC) 3. Anne Leesio (LHIN) 4. Dr Sarah Etheridge (Palliative Care /EOL Network) 5. Dr Donna Spanner (Palliative Care /EOL Network) 6. Deborah Gravelle (Nursing) 7. Vivian Papaiz (HPC/EOL Chairs & Directors) 8. Dr Linda Rabeneck (RVP) 9. Susan Niro (CCAC) 10. Dr Edward Fitzgibbon (Regional CA Program)
Table 5	**Table 6**
Facilitator: Mr. Chris Sherwood (CPAC/Community)	Facilitator: Dr. Hsien Seow (Palliative Care /EOL Network)
1. Dr Craig Earle (CCO) 2. Kathy Condie (CCAC) 3. Toni Lemon (LHIN) 4. Dr Lesia Wynnychuk (Palliative Care /EOL Network) 5. Dr Hilli Huff (Palliative Care/EOL Network) 6. Kim Rovers (Nursing) 7. Margaret George (HPC/EOL Chairs & Directors) 8. Dr Sharon Russell (Regional Palliative Care Lead) 9. Dr Lee Donohue (RPCL)	1. Dr Lisa Barbera (CCO) 2. Heather Brien (CCAC) 3. Susan VanderBent (CPAC/Community) 4. Kathy Coulson (Nursing) 5. Paul Cavanagh (HPC/EOL Chairs & Directors) 6. Dr Ingrid Harle (Regional Palliative Care Lead) 7. Donald Fenn (Media) 8. Lynn Huizer (LHIN) 9. Dr James (Jim)Gall (Palliative Care /EOL Network)

Table 7	Table 8
Facilitator: Ms. Lisa Droppo (OACCAC)	Facilitator: Ms. Georgina White (OACCAC)
1. Ms Susan King (CCO) 2. John Crean (CPAC/Community) 3. Jacob Mksyartinian (MOHLTC) 4. Dr Doris Howell (Nursing) 5. Brent Charette (HPC/EOL Chairs & Directors) 6. Dr Robert Sauls (Regional Palliative Care Lead) 7. Dr Cheryl Levitt (RPCL) 8. Dilys Haughton (CCAC) 9. Dr Vincent Maida (Palliative Care /EOL Network)	1. Christine Nuernberger (CCAC) 2. Barbara Busing (CCAC) 3. Jennifer Mossop (Media) 4. Sandy White (Nursing) 5. Barbara Pidcock (HPC/EOL Chairs & Directors) 6. Dr Glen Maddison (Regional Palliative Care Lead) 7. Jane Hatton-Bauer (Regional CA Program) 8. Cynthia Martineau (LHIN)
Table 9	**Table 10**
Facilitator: Dr. Denise Marshall (Palliative Care /EOL Network)	Facilitator: Ms. Julie Darnay (HPC/EOL Chairs & Directors)
1. Gale Turnbull (Regional CA Program) 2. Margaret Mottershead (OACCAC) 3. Mieka Busman (LHIN) 4. Bill O'Neill (CPAC/Community) 5. Lynn Kachuik (Nursing) 6. Maureen Riedler (HPC/EOL Chairs & Directors) 7. Dr Donna Ward (Regional Palliative Care Lead) 8. Joanne Billing (CCAC) 9. Dr Anne Woods (Palliative Care /EOL Network)	1. Frankie Vitone (CCAC) 2. Kelly Gillis (LHIN) 3. Dr Mary Anne Huggins (Palliative Care /EOL Network) 4. Dr Arthur Dick (Palliative Care /EOL Network) 5. Dr Sanjeev Goel (OCFP) 6. Dr Mary Lou Kelley (HPC/EOL Chairs & Directors) 7. Cathy Joy(HPC/EOL Chairs & Directors) 8. Dr Camilla Zimmermann (Regional Palliative Care Lead)
Table 11	**Table 12**
Facilitator: Dr. Amna Husain (Palliative Care /EOL Network)	Facilitator: Dr. Deb Dudgeon (CCO)
1. Donna Ladouceur (CCAC) 2. Mark Edmonds (LHIN) 3. Dr Deb Harold (Palliative Care /EOL Network) 4. Dr Stephen Wetmore (OCFP) 5. Beth Lambie (HPC/EOL Chairs & Directors) 6. Dr Nancy Merrow (Regional Palliative Care Lead) 7. Dr Samantha Winemaker (Palliative Care /EOL Network) 8. Susan Graham (CCAC) 9. Julie Johnston (HPC/EOL Chairs & Directors)	1. Kim Voelker (CCAC) 2. Teresa Martins (LHIN) 3. Dr Allison Williams (Palliative Care /EOL Network) 4. Greg Ujiye (CPAC/Community) 5. Janet Doering (Integrated Client Care Project/CCAC) 6. Theresa Greer (HPC/EOL Chairs & Directors) 7. Dr Larry Librach (Palliative Care /EOL Network) 8. Saul Melamed (MOHLTC)

Not assigned to tables

1. Jan Kasperski
2. Elaine Kachala
3. Tazim Virani
4. Cathy Fooks

Appendix E:

Breakout Session #1

Summary:

- Need common understanding of HPC
- Define the HPC Care Team and build appropriate supports
    - Development of trust and working relationships – inter and intra-professional collaboration
    - Defined competencies, scopes of practice
    - Communication systems that work – need electronic record/databases
    - Key role to support – Advanced Practice Nurse working in partnership with Physicians and others (navigation, coordination, collaboration) – must be accountable to the team no matter where the funding is coming from or where the pt is located
- Priority should be provided to primary health care – FHT, CHC, Primary Physicians
    - Unnecessary visits to Cancer Centres – now time to go back to family physician
    - Billing codes – GPOs negate family physician billings
- Integrate primary, secondary, tertiary care settings – require infrastructure and system supports to promote collaboration
- Essential components of HPC
    - Provides all the services in the square in all settings and all diagnostics
    - Performance measurement, accountability, reporting to support comparative analysis
    - Human resource plan with regional considerations
    - Resource the system properly (HHR, IT, physical space, tools, etc)
    - Population based registry (e.g. like diabetes registry)
    - Definitions – need to be translated/adopted
    - Navigation competencies
    - Forms for transitions
- Market the solutions (define system and its components) to LHINs, clients, public – using same language (e.g. Wait times)
- Communication of improvements - provincially – a coordinated effort to inform patients/caregivers/professionals (there is varied levels of knowledge of initiatives at the table)
- Use quality indicators to drive change (address gaps e.g. Volunteer hours; data collection systems)
- Identify and develop a mandatory provincial framework across the continuum of care (driver), utilizing all 14 EOL/HPC networks (implementers using community development, grassroots approach) - (address system issues e.g. RFP process for home care providers)
    - Integrated system – equitable access
- Define and share accountability for primary care – ONE BIG STEP – change the dynamics
- Need for a structure such as a Hospice Palliative Care Ontario (HPCO) that reports or is an agency of MOHLTC
- Need a HHR strategy that incentizes people to specialize in HPC; caring for seniors, chronic disease
- Agree on population based needs ratios (e.g. staffing levels) – rural strategy/considerations separately

- Tools, processes and systems needed:
    - Need for linkage between positions – family physician and cancer; common – when patient comes out of cancer system
    - Develop a mechanism to link “orphaned” patients to a family health team
    - Gain consensus on a common database – patient health information – determine how that should standardize admission criteria to access palliative care services

  - Family physician accountability – sign a service accountability agreement, including compensation
  - Family Health Teams need direction from MOHLTC or give/let LHINs provide direction to FHT
  - Strategy for more mentoring and training of specialty palliative care nursing and/or integrate palliative care into nursing education
  - Electronic health record – interface with CCAC, hospitals, primary health care, clinical connection. Access to technology in peoples home
  - More use of technology (e.g. telemedicine) for teaching, assessment in home, etc.
  - Continuity of information across settings and providers e.g. e-records, etc
  - Provide infrastructure and support for home and community care includes physicians, SW, dieticians, etc. Broad interdisciplinary care.
  - Navigator is key
  - LTC home sector increase palliative care, expertise, knowledge
  - Communication – common referral forms, ESAS, PPS, algorithms, IT, e-Health
  - Develop plan for engagement of primary care practitioners – advocate for home visits with F (MDs, RNs)
  - Formal teams (including psych/social support)
  - After hours accountability
  - Patient advocate, navigation
  - Increase public awareness (empowerment) – culture shift
- Develop plan for: 24/7 care
  - Anticipate needs – kit for meds, death at home
  - Single point of access
  - Develop on-call system
  - Registration – shared information
  - Develop common record (electronic)
- "The local networks will define the gap between the local reality and the provincial vision and implement local strategic plans to achieve the model at primary, secondary and tertiary levels and across all care settings. This would include using the CHPCA model and Square of Care to define functions and roles."
- Address system issues
  - Review CCAC RFP contract, to see how to improve communication
  - RFPs for palliative care (nursing, SW, PSW), standards consistent across province
  - System compartmentalized
- Palliative/EOL integrated system – at each LHIN
  - Provincial strategy
  - System level navigation and strategic direction
  - Patient/individual level navigation – use lay navigators, virtual navigator (IT system), professional navigator
  - Funding tied to patient rather than organization
  - Overcome legislative barriers (# of hours per patient, funding for hospices)
  - Inter-disciplinary collaborative practice – IPE, standards for education

Appendix F:

Breakout Session #2

Top Three Priorities Discussed by Breakout Sessions

Priority #1	Priority #2	Priority #3
Need one unified voice that works with and reports to Ministry, LHIN; clear reporting structure	Need HPC quality indicators, specifically include ALC, ER, Wait times, care at home etc. to speak the same language and get them adopted/mandated	Identify key components of a regional service model, which is consistent across the province
Resurrect HPC Coalition (HPCO)		
Accountability; a regional primary care program; have funding similar to CCO – regional cancer program	Centre of Excellence/identify/expertise – responsibility to LHIN/provincial accountability	Communication – transparent, shared records
Develop a group that speaks to the Ministry (EOL Network, CCO, OACCAC, PPCA HAO, Academic, P Medicine programs, patients, Secretariat of LHINs ("Provincial Palliative/EOL Care Coalition") • Policy – separate contracts for primary care; E-HHL, 24/7, on-call, funding for APNs/NPs	Communication – common referral forms, ESAS, PPS, algorithms, IT, e-Health	Develop plan for engagement of primary care practitioners – advocate for home visits with F (MDs, RNs)
Common health record – electronic board, pt owned (life goals on record)	24/7 access to on-call physicians coverage to nurse (networks scope the problem)	Clinical navigator/communicator
Electronic health record – interface with CCAC, hospitals, primary health care, clinical connection. Access to technology in peoples home	Palliative care – cluster team - Porter model – RFPs for palliative care only or alternate care model – full, integrated care	Population based funding model (inventory, recommendations, resources (human) and operational $. Capacity and funding)
Palliative/EOL integrated system – at each LHIN • Provincial established benchmarks (define indicators, measures, public reporting, system indicators) • System level navigation and strategic direction • Provincial strategy • Funding tied to patient	Regional level navigation (LHIN)	Patient/individual level navigation – use lay navigators, virtual navigator (IT system), professional navigator

Priority #1	Priority #2	Priority #3
rather than organization • Overcome legislative barriers (# of hours per patient, funding for hospices)		
"The executive of the PEOLCN will engage the 14 LHINs to identify an approach to provide provincial leadership and the development of an accountability framework to support local implementation of the service delivery model"	"The local networks will define the gap between the local reality and the provincial vision and implement local strategic plans to achieve the model at primary, secondary and tertiary levels and across all care settings. This would include using the CHPCA model and Square of Care to define functions and roles."	
Standardize the local network and provincial EOL network with provincial accountability (changing the existing to have more authority) • Mirror Regional Infection Control Network	Develop a universal access system for palliative care services – ownership required; LHIN has the responsibility; many patients do not have family physicians	Engagement of Family Health Teams and other primary care providers leading to formal accountability – a new system to incorporate; on-calls; provide end of life care
Create a provincial structure (e.g. HPCO)	Develop a palliative care strategy that includes a policy and performance accountability framework/infrastructure – Ministry to coordinate with key stakeholder involvement/leadership (including patients and families)	Identify the minimum practice standards and resource needs (e.g. UK, Manitoba, HNHB), quantify the gaps and advocate to fill the gaps (include HR – multidisciplinary team, IT, education)

Appendix G:

Evaluation and Comments

Evaluation Summary

Improving the Quality of Hospice Palliative Care (HPC) – A Strategy *Development Workshop*
Tuesday June 23, 2009 ♦Metropolitan Hotel ♦Toronto

Total Evaluations Received: 53

Family Physicians	32%
Type of Practice	
Full Time	26%
Part Time	6%
Office	2%
Hospital	8%
Both	11%
Urban	11%
Suburban	11%
Rural	6%

Consultant Physician	LHIN	CCAC	Nursing	Other
36% †	11%	9%	13%	25%‡

COMMENTS:
† Palliative Medicine, Focused Palliative Care, Family Practice Palliative Care Consultation, Medical Director: Hospice Renfrew, Geriatric/Internal/Palliative Medicine

‡PEDLCN, CWPCN + Hospice, End of Life Care Network, Communications - Government Relations, Mississauga Halton Palliative Care Network Chair, Admin: Cancer, PPSMC, Researcher at McMaster, Palliative Care Consultation Network, Cancer Care, Co-Chair of the Central HPCN (background specialty is LTC)

1 – strongly disagree	2 – disagree	3 – neutral	4 – agree	5 – strongly agree

The Program					
	Average	Highest	Lowest	Median	Mode
The program was relevant to family medicine.	3.90	5	1	4	4
The program was relevant to your area of specialty	4.60	5	2	5	5
The program met the stated objectives.	3.60	5	1	4	4
The program met my expectations.	3.62	5	1	4	4
The program met my learning objectives.	3.72	5	1	4	4
I was able to interact with other participants.	4.30	5	1	5	5
The program was credible and non-biased.	4.10	5	1	4	4
The program was well organized.	4.21	5	1	4	4
There was adequate time.	3.65	5	1	4	4

What advice do you have on moving forward that was not adequately discussed?

- None - Conversation at end of day was important because it addressed the need to identify and invite people/individuals and associations who were not here and are key to move forward
- Need more primary care involvement at all levels
- Need to refine the model to move forward with it

- Ensure that all relevant stakeholders are part of the coalition
- In hindsight - facilitator or chairs should have provided greater descriptions of objectives/trajectory of the day's activities as they related to action items process by which today's ideas/plan reach the government
- Governance of coalition, in particular, representation of steering committee
- Linking to local End of Life/Palliative care networks, and how to engage the networks to move this forward
- Need to change the current system and move it provincially back to the LHINs
- Role of the End of Life Networks needs to be reviewed, possibly strengthened/broadened/held to account
- Too much info, not enough general discussion time
- We needed to have those end discussion about how this would go forward
- Action Plan, statement to MOH - who were the MOH representatives who will be responsible for moving this mandate forward?
- Engagement of broad base of primary care/medical/radiation oncology support
- Time participation in action groups
- We need to be more directive, we complain that "people" don't understand Palliative care, we need to set a model and stick with it
- Development of Primary Palliative/Hospice care teams - what are the next steps?
- We do need a steering committee/coalition with appropriate stakeholder representation to move the required changes forward. We need action for change!
- Impact on current providers of the implementation, and the ability to actually provide the care has not been considered
- No considerations about personal support for the providers to prevent burnout was not included
- More than one day was required; 1) too many presentations, 2) not enough time for open discussion, 3)needed more clarity on what would be required for development of action plan at the end of the day
- I think it would be helpful to have an intentional discussion to identify what level of detail should be determined provincially vs. locally
- How to make it happen; action outcomes, do not let it drop!
- Clear action plans articulated with performance accountability
- Need to have a champion at the LHIN level to move the agenda forward for the LHIN and province
- Still fuzzy on current structure, leadership, and how today's work is linked to reform
- Decide on a model: How that should happen
- Prioritize action items
- Less speakers - more focused on outcomes, less background material
- Opportunity to have open discussion earlier
- Keep talking to each other and resist name calling or slamming other sectors
- Need to; integrate common language, consider common assessment, tools, and adequate funding for sustainability
- How we influence provincial agenda regarding HPC
- I thought we were going to endorse the recommendations in the CCO document (which was excellent)
- Action Team 5 is the priority for moving forward

What information, experts, or other resources would you suggest that may be valuable for one or more of the Action Teams?

- More primary care participation
- Need data for ER visits; why and who is doing primary care and who is not and why not?
- Ministry of Health representatives LHIN (representatives) - tripartite committee? OPCA/OHA

- I would be willing to participate in an Accountability Team or defining Programs and Services
- Administrative support and financial/in-kind support for meetings
- Practicing family physician - comprehensive care
- Hospice groups, and psycho/social worker
- I don't understand why OHPCA, HAD, CCO, CCAC, and LHINs need us to do their work. Where are the recommendations for best practice? Why aren't we bringing forward a model? Feels like Square 1
- LTC rep
- HAO
- Let the "action" happen at a more local level in PCN's, don't duplicate the actions done at that level, and create an overarching coalition with "teeth" that can mandate
- HAO-PCAO-Ministry
- Oncologists need to be actively involved
- This is the beginning and if you try to involve everyone at this point it can be onerous - a small initial action group is key (SWAT team)
- Current admin structure for HPC, key documents
- An invited list that could go to each network/LHIN and ask for a representative from each of the 6 groups?
- Information: electronic records, experts: LHIN/MOHLTC representatives with commitments
- Have some one from the MOH and LTC as part of a day like this - where is Palliative care in the whole
- MOH, wait times people, experts in ALC/ER
- Systems design documents
- I support moving toward on Action 5, who is accountable for Palliative care in the Province? Need formal authority, budget, etc

Do you feel more informed about the Hospice Palliative Care System in Ontario, including the evidence and best practices, as a result of this session?

66% **Yes** 25% **No**

Do you feel that your ideas will influence the development of an integrated quality hospice palliative care system in Ontario?

75% **Yes** 11% **No**

Do you feel that this workshop was organized to achieve its goal of moving forward with action steps to achieve an integrated, quality hospice palliative care system in Ontario?

72% **Yes** 17% **No**

Describe two particularly strong features of this program.

- Organization, background reading, and level of participation
- Wonderful participation of stakeholders across the spectrum
- Good info and group discussion
- Bringing stakeholders together, excellent discussion of important issues
- Coming to a consensus that the work of this group could lead to a provincial framework
- Brought together an unprecedented coalition of stakeholders
- Co-chairs did an excellent job motivating and launching the discussions in the morning - I would have liked to see them involved in setting a context for the afternoon's activities
- Varied collection of Health Care Providers

- Presentation of Evidence
- Excellent facilitators and table discussion
- The participants, Cathy Fooks
- Reports from the research and current practice models was very informative
- Meeting of the minds, good discussion at small group
- Broad invitee list
- Coalition
- Good ideas at the table
- Participation with other people from other parts of the province with different needs, excellent "table facilitation", combining disparate ideas into consensus
- Liked hearing the overviews of how we got here - CCO, initiatives, EOL Case Strategy, Aging at Home, Projects networking across province
- Statistical data
- Inclusiveness - but could've been better more directive, and passion for the issue
- Development of action items, self-decided action team involvement
- Lots of time for interaction
- Narrowing down focus of concern, objectives not clearly defined
- Presentations
- Good cross-sectional representation, and good small group interactions
- Identification of need for a coalition, seeds of change
- System level accountability, and funding model
- Good mix of lectures and group work, opinions of others at the table
- Regional Models of Care - CCO, Shared Care Models
- Sharing of information, and opportunity to hear from many experts in the field as well as discussions at the table
- Round table discussion on moving forward on integration of palliative care into primary care into primary care, Dr Deborah Dugeon's talk on regional models of care: recommendations for organization and deliveries of palliative care
- The educators, Esther Green, and Denise Marshall presenting with enthusiasm
- Level of collaboration was high, best practice information and context setting was very helpful
- Collaboration across groups represented
- Right people at the table - good presentations
- Excellent presentations by some, break out sessions excellent
- Good family medicine involvement
- Will be followed with action planning, and right players at the table
- Representation from a wide variety of services, specialties, programs, etc
- Great speakers but missing link between speakers and ultimate goal
- Well organized with good prep materials, and seating well thought out
- New ideas for services and the amount of physician engagement
- Good use of evidence and data, use of experts as facilitators
- Overall commitment to the enhancement of palliative care inclusive
- Overview of system design, and developing a common vision for HPC
- Mix of people at tables, provocative thinking towards solution
- We did get together and this does represent an important step forward…well done
- The materials sent for pre-needs assessment, the discussion - whether you agreed or disagreed, it stimulated your thinking

Describe two areas of weakness in this program that you would like to see changed.

- In hindsight, it might have articulated what it was hoping to achieve and what it wanted from participants
- Already said - need to ensure right people - experienced, committed, representative, able to represent are at table - hospitals, OPCA, universities
- I would have liked to hear more about Australia & Fraser Valley
- I would like some answers on population based resources
- We need to know if primary care sector wants this
- Do not act on a model, and did not have specific action steps
- Perhaps we needed less didactic presentations at the beginning?
- The introductory sessions were too numerous - could have excluded several
- Professional facilitators needed to be more carefully scripted or co-facilitated by planning group member
- Audience was looking for a consensus statement - this was not achieved!
- More time in small groups, introductions too long at beginning of meeting
- I was expecting a review of the documents and discussions regarding the model in these documents…perhaps this is the next step?
- Need to forward action items back to participants
- If the objectives were articulated, I missed them
- Too many plenaries crammed together
- There are dissenters - I hope they felt heard
- Fatigue factor
- Too much background info in the morning session which should be given as "reading material"
- Session needs to be more directive
- It may be useful to have primary care providers in the same region, sit down and discuss how palliative care could look like
- A lot of uncertainties as to how to proceed - perhaps needed more discussion?
- Classified nurses as a nurse - no location or area of practice identified on table allocation
- Facilitation process didn't set out expectations or clearly define hoped for outcomes, not enough group discussion
- Not clear from the outset what the objectives were, first several speakers covered material that was too basic
- Too much information in morning, most of what people already knew
- Our table was very good at including the community sector, nursing, hospice, and such
- Spending 3 hours presenting at this audience/very disappointing. Too PC! Abrogates adult education principles. You presented as if we knew nothing. You had no respect for the prior knowledge of the audience and wasted my time.
- Not enough open discussion, need clear objective of what you wanted to accomplish by the end of the day
- Clarity of next steps was challenging, emphasis on a set number of action committees may have limited thinking regarding priorities going forward
- Lack of time for discussions and to validate discussions
- Slides were at times too 'childish' and no new material in some slides
- Poor Virani facilitation
- More time for group/open forum discussion, move more quickly to action planning
- Development of action steps from individual tables not well represented in action teams
- Better clarity on mission of the day

- Tying it together at the end: the vision became muted. Perhaps the minister of health or someone to co-host to let us hear these efforts are supported
- Ought to read 3 priorities from all tables to the whole group…not done up front with facilitators. Would have been useful to hear other priorities to see if there is consensus. More clarity as to next steps. How data will be used.
- Not clear process outlined, too many speakers
- Overview of the palliative system may have been valuable to help present discussion before we moved into Action Plan, clarity about the intended goal of the day.
- Did not engage tables regarding their belief of directions in afternoon thus no buy in to future action plans
- What's next?
- Defining the process forward, seemed ambiguous at the end, need high level structure, accountability
- Very poorly done in terms of agreeing on a governance structure. There was no discussion of the documents we received - what will happen to them because there are several things there that I believe could be improved. If it was clearly stated how they are simply initial thoughts, great. However, because there was nothing explicitly stated about what will happen to the documents, I am left unclear and cannot sign off on them.

General comments and suggestions?

- I am interested in questions 3 and 4
- The 6 Action Team seem very similar and not really action items
- I think this meeting provided the first necessary steps towards consensus
- The workshop lost some momentum in the afternoon - synthesis of group's discussion needed to be presented, before moving on to asking audience to choose action teams. A description of the process of the action teams (i.e. at formative stage declare that tasks, time commitment, resources needed, all need to be worked out.
- Important and necessary meeting; crucial to push forward with Action at Governmental launch to ensure today's ideas come to fruitation
- Thank you for an interesting and thought-provoking day
- Ask for a report from each HPC EOL Network do they have the right memberships? Are they doing anything to move integration forward?
- Need to reach consensus about the model
- We can remain hopeful that this will be a beginning
- Feels like we will finally move forward! ++ Possibilities!
- need more Family Physician attendance
- CCO should NOT be the main driver in this process
- Very good day - it will be important to imagine a top-down provincial strategy with a bottom-up approach at the local/regional level
- Need to clarify comment from page 14 - "generalized registered nurse" RNs and RPNs under general class of registration both have palliative care competencies
- Leadership and formation of a coalition of PC organization important to move forward
- There is a tremendous need to move forward and a lot of energy now
- Presentation by consumer's family very good
- Planned Outcome should have been explicit and maintained throughout
- Excellent day! I was impressed with the commitment in the room and level of physician leadership and engagement
- There were action plans developed in the individual tables - I'm afraid these will be lost

- Suggest steering committee pull together major themes, consolidate and send out summary paper and plan including request for expressed interest
- Good work Steering Committee
- Ambitious agenda and afternoon was long
- Need to look high level - who is leading who and what are we accountable to? It is so diffused that we have to first identify! How do we expect to have MOH hear us when we have no common strong voice programs, services etc? This has been discussed for years but with no strength or teeth behind it.
- I would like to see standardization of education for nurses and physicians
- Where were the MOH people?? Jacob didn't participate
- The discussion may have been frustrating for some participants but it needed to happen

Topics you would like to see addressed in the future.

- What are the academic issues associated with system design, implementation that might be addressed by academic palliative care programs or other bodies?
- Implementation of primary, secondary, and tertiary levels will need support for 24/7 on call = $$
- I think we also lost opportunity by not using this forum for agreement on the foundational documents we circulated. Overall, the meeting was a success and this will be measured by the actions we take next
- Continue a 2nd session of what next steps are being taken
- Who owns HPC?
- How to get FPs involved?
- Methods to promote transitioning of patients from active care to palliative care
- Palliative care for primary care providers
- A firm plan of how the implementation of a model will take place in a LHIN and provincial level.
- Good opportunity to move forward
- Palliative care standards, sharing across the province of actual practice models