

**Pallium Project & Canadian Hospice Palliative Care Association (CHPCA)
Putting Progress Into Action (PPIA)
Provincial Hospice Palliative Care (HPC) Service Development Introduction Workshop
New Brunswick, September 13, 2005**

Record of Small Group Exercise Report Back

(source – small group flip chart/oral report back)

Background/Context

The baseline process The Pallium Project uses to support local/regional hospice palliative care service development is a one-day provincial workshop entitled Putting Progress into Action (PPIA). It is based on the Canadian Hospice Palliative Care Association (CHPCA)'s, *Model to Guide Hospice Palliative Care Based on National Principles and Norms* (i.e., CHPCA Model).

PPIA is designed as a starting point to protect time, focus attention/energy and facilitate dialogue at the local health authority-level, so local system leaders and hospice palliative care champions can move forward together to strengthen, streamline and improve the quality and sustainability of hospice palliative care services as part of a commitment to primary health care renewal.

In addition to briefings for local communication of hospice palliative care policy and quality/best practice directions and developments at the national-level (e.g., accreditation changes), time is protected for local health service leaders within the province to commence a dialogue about potential opportunities to advance HPC locally/regionally.

This document is a record of the Small Group Work report backs to the plenary for the small group work conducted during the Putting Progress into Action workshop on September 13, 2005, as outlined in the day agenda presented in Appendix A. The information presented in this document is intended as a participant reminder of the report for the day. The reader who was not present during the workshop is urged to use this document with caution due to the exclusion of specific context around the report back comments. Participants during the day represented a cross-section of health region front-line leaders, program staff and community-based hospice staff.

Errors, omissions and clarifying comments can be sent by registered participants to Michael Aherne at michael.aherne@pallium.ca.

Question #1 – Challenges in providing hospice palliative care services in New Brunswick

A) What is “hard” (i.e., difficult) in providing “good care” for patients and families living with life-limiting illness?

Group A

- Inconsistent services in level of expertise of the providers
- Unrealistic expectations from families (e.g., how much time RNs can spend onsite versus their professional role in assessment and management of other resources) (*facilitator note: A point was tabled during the plenary debrief that some of this issue could be immediately addressed by RNs educating family about roles, responsibilities and resources during home visits*)
- Divergence (gap) in family expectations and reality of the service that is provided – lack of public knowledge about the service

- Service differences between urban and rural populations
- Transportation/access
- Timely access and availability to equipment, beds, wheel chairs and other equipment required to support patients and families in the community during various points in their illness
- Pay scale issues and continual loss of home care workers
- Timely access to home support services and hospice palliative care to facilitate d/c
(facilitator note: unable to interpret group's notation d/c)
- Timely referral to Extramural Program
- Care providers – symptom management; assistance with communication; how to go about providing psycho-social assistance

Group B

- Having access to home care services/not enough education, time (certainly in rural areas)
- Problems with networking, communicating to docs or having them communicating with us
- Physicians perceptions about dying (dilemma)
- Lack of professional resources (related to different regions)
- Patients and families perception and conflicts arising with care choices to be made (i.e., code/no code).

Group C

- Difficulty in establishing “fair” comprehensive criteria
- Ideology/communication about HPC
- Providing “team” management (i.e., “every one on the same page” from administration to caregivers)
- Respect for individual expertise
- Lack of resources
- Collaboration in coordinating care
- Emotional preparation and support/timely discussion and support
- Cultural/societal barriers
- Misperception about palliative care
- Inequality of service/care for the working poor

Group D

- Communication with all parties (e.g., oncologist) using standardized assessment tools
- Initiation of “palliative care”
- Access to a full range of palliative care services
- Care for out-of-province patients

B) Who has a role to help change it?

Group A

- John from the Government (i.e., policy framework) (*facilitator note: reference to John Serkiz who was the representative from the New Brunswick, Department of Health*)
- Communication experts
- All professionals and their associations
- Physicians
- Health care providers have a role as patient advocate
- Administrators [in RHA (Regional Health Authorities) and LTC (Long Term Care)]

Group B

- We all have a role in changing it
- More community volunteers/participation
- John and the others from the Government 😊 (*facilitator note: reference to John Serkiz who was the representative from the New Brunswick, Department of Health. Happy face added by the Working Group #B*).
- The media, cultural groups, etc.

Group C

- Governments – Federal and provincial
- Local communities and community leaders
- Regional Health Authorities
- Physicians/nurses/multi-disciplinary teams
- Faith leaders
- Everyone – clients, patients, families
- US! – and with good communication

Group D

- Communication tools have to be adopted at all levels (whole team)
- Initiation of care – family doctors, oncologists, nurses(?), extra-mural nurses(?) (*facilitator note: small group added question mark after nurses, citing traditional inter-professional issues and health delivery system cultural issues about accountability lines for initiating care and “permission” for leadership in planning and initiating care*)
- Equal access – Provincial forums and Department of Health & Wellness; Regional Health Authorities

C) What are the early priority steps?

Group A

- Appropriate resources (i.e, right staff in right place at right time with right skills)
- Coordination of planning provincially
- Increased awareness
- Involvement of appropriate stakeholders including involving patients/families in the discussion/planning
- Quality assessment tools (indicators/data)
- Training – home makers/professionals

Group B

- Public awareness
- Education
- Communication at the early stages (i.e., the patient, family, doctors and “the team”)
- Developing a standard model of care
- There has to be an understanding within the family (i.e., the client, the family and advanced directives)
- Sufficient financial resources for home care providers (i.e., salary money)

Group C

- Identification of needs
- Education and communication at all levels (earlier priorities in this order – government, professionals, community)
- Commitment
- Policy implementation (i.e., see CHPCA Norms)
- Accreditation
- Provincial integrated hospice/palliative care service delivery model
- Inequality of care (for the working poor)

Group D

- Education/lobbying
 - Public (media, etc.)
 - Government leaders and politicians
 - Regional Health Authorities (RHAs)
- Funded program development (e.g., palliative home care)
- Development of a full range of resources

Question #2a – Who and what is in place?

Group A – What is already in place that could be built upon?

- Extramural program
- DVA
- Volunteers
- Long-term care
- Family caregivers
- Palliative care units (RHAs) with designated beds and improved cooperation between primary and tertiary-levels
- Philosophy – What are patients’ needs and where and how they can be best met?
- Hospice palliative care consultative service – initial and follow-up consultative response
- Insurance plan
- Access to palliative care therapy
- Increased proliferation of alternative therapies

Group B – What is already in place that could be built upon?

- Provincial extra-mural program
- Forums for dialogue (e.g., Pallium Project)
- Partnerships with provincial mental health/family and social services
- Hospital/residential care nurses
- Palliative hospital units
- Hospice (e.g., Hospice Shediac and others)
- Clergy/pastoral care
- Oncology team
- Hospital social workers

Group C – What is already in place that could be built upon?

- Existing service links
 - Hospital units, Hospice, Nursing homes, Home care workers, Extra mural program
- Public awareness
- Resource outlets (e.g., Red Cross)
- Employment Insurance (*facilitator note: reference is to the EI administered Compassionate Leave program*)
- Widespread interest
- Federal/provincial awareness, interest, mandate

Group D – What is already in place that could be built upon?

- Chaplains & clergy and pastoral care workers
- Palliative care beds (i.e., some “Palliative Care units”)
- Extramural palliative care
- Bereavement programs (Grief share memorial services)
- Hospice/volunteer programs
- Palliative care teams and rounds

Question 2b - What and who is untapped?

Group A

- New Brunswick Hospice Palliative Care Association (NBHPCA) and Canadian Hospice Palliative Care Association (CHPCA)
- Telehealth capacity
- Alternative therapies
- Insurance plans
- Homemakers/home support workers
- Volunteers
- Seniors federation
- Lobbyists (informed)
- Extended family
- Faith communities
- University/education partners
- Appropriate use of the Internet (i.e., reputable sites)
- Networking
- Support services in RHAs (e.g., purchasing)

Group B

- Extended family
- Natural caregivers (e.g., neighbors)
- Needs for standardized seamless, integrated, comprehensive model of service
- Community involvement (e.g., fundraising)
- Common language and understanding in palliative care (i.e., clarity)

Group C

- The community (they will give for the “right reason”)
- Community teams/service organizations
- Technology – not fully utilized for patient care education
- Families
- Internet learning/help/opportunities

Group D

- Hospice/volunteers
- Spiritual care
- Legacy work
- Long term care – palliative care
- Community centres or service clubs
- Musicians/artists/pet therapy/massage/others
- Social work

Question #3 – Who are the “hidden helpers” in moving HPC forward at the community-level in New Brunswick?; Are they welcome?

Group A

Facilitator note: This group considered the potential “hidden helpers” to be the same as those identified in Question 2b. The following response is the flip chart points to a question the group posed (i.e., how to mobilize) and are they welcome?

Are they welcome?

- Yes!

Group B

- Physicians’ support staff (i.e., secretaries/nurses/clerks)
- Clergy
- Professionals (not necessarily referred)
- Students/teachers (school, university, community colleges)
- Members of the Legislative Assembly (MLAs)/politicians
- Hospital support staff (e.g., house keeping, lab workers)
- Community members (word of mouth/fund raising)
- People that have had chronic illness

Are they welcome?

- All aboard! – If patient is willing, we need to mobilize – will require awareness, education, patient advocacy, communication!

Group C

- Everyone!
- Volunteers
- Faith leaders
- Leaders of opinion
- Raising funds in the local community from local business owners
- Service organizations

Group D

Facilitator note: This group considered the potential “hidden helpers” to be the same as those identified in Question 2b. The following response is the flip chart points to a question the group posed (i.e., how to mobilize) and are they welcome?

- These potential helpers are not always welcomed!
- Leadership with vision is required to mobilize/include them
- They need to be involved in the education process
- We need to be prepared to open up the medical model
- It requires unified funding.

Appendix A

AGENDA, SEPTEMBER 13, 2005, FREDERICTON		
Time	Activity	Facilitator / Speaker
0830-0840	Welcome & Introduction to Pallium Atlantic	Sandy Johnson, Hospice Saint-John & Sussex
0840-0900	New Brunswick Context and Developments	Dr. Chris O'Brien, Physician Leader, Hospice Palliative Care
0900-0920	Primary Health Care & Hospice Palliative Care	Michael Aherne, Pallium Project
0920-0945	Accreditation & Other Quality Initiatives	Laurie Anne O'Brien, Co-Chair, National Working Group on Quality Care & Best Practices, Canadian Strategy on Palliative & End-of-Life Care
0945-1015	Cross Canada Check-up (National Developments)	Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Assn.
1015-1030	Morning Break	
1030-1200	CHPCA Square of Care & Organization	Sharon Baxter
1200-1240	Networking Lunch	
1240-1315	Challenges in HPC Services	Working Groups (Michael Aherne and Provincial Co-chairs)
1315-1400	Building on Regional / Provincial Strengths	Working Groups
1400-1420	Afternoon Break	
1420-1515	How will we know how we are doing?	Working Groups
1515-1600	Action planning discussion of "Doing the Doable"	Working Groups
1600-1615	Concluding Comments	