

**Prince Edward Island (PEI) Provincial
Hospice Palliative Care (HPC) System Transition Planning Workshop
Dutch Inn, Cornwall, PEI
January 10, 2006**

Record of Group Notes/Bullet Points from Flips Charts of Group Work

Question # 1

Do patients and families feel “the system” is there for them when experiencing serious and life-limiting illness? ELABORATE!

GROUP 1:

- Lack during evenings, nights and weekends response
- People feel not enough support from the system regarding drugs and equipment
- No GAP provision for young adults that are ill in parents' home and no financial support
- A lot of people missed in compassionate care benefit (i.e. unemployed, friend is primary caregiver, etc.)
- Late referrals – support and care comes too late – could have benefited much earlier – others too early for service resources so more timely referrals
- Not enough support and training to both primary caregivers and team or professional care providers
- Stigma still attached to word “palliative”

GROUP 2:

- Course for RNs: National Course
- Struggle
- Couldn't get patient from nursing home to palliative care unit
- 24/7 coverage problem for patients/families and having to go to emergency
- Quality of care excellent
- Difficult accessing palliative care unit
- Medications larger gap
- Ambulance service not paid for issue for patients
- Gap between home and palliative care unit – “Residential Hospice care would be ideal!”
- Patients not aware of services to make demands
- Not enough capacity
- Lack of using resources; lack of resources
- Pain and symptom management problem
- Patients afraid not to support hospital, nurses, etc. by making suggestions for improvement

GROUP 3:

- System is not there for medication and supply cost and health care professionals
- Families do not know what could be available
- Misconception about services available
- No standard delivery care of over the community
- Some people's journeys are very smooth and well supported
- System needs to have better lines of communications with various partners
- Need for education regarding term philosophy palliative care
- Team work has improved care, less duplication
- Will work over and above and beyond to make it happen -- burnout

GROUP 4:

- Yes, but:
- Some find out it's not what they thought it was, but generally they feel it is there for them
- Community not sure what the system is and how to access it
- Complex unless guided the right way. Restructuring makes it even more difficult
- Physician access. Some clients don't have doc (key player) – resource physician not enough – if not available, access to service is difficult
- Need full time dedicated (not an add on) to palliative care resources
- Wonderful program but need resources
- Human as well as medications and 24/7 service
- Home death hard to organize with present resources
- Gaps in system
- Draining (ongoing)
- Do not provide 24 hour services
- Funding for education
- Communication/coordination
- Public education (palliative) – system needs to educate

GROUP 5:

- What is the system, broad or palliative care?
- No
- Number of individuals/families not accessing the service
- Misconception of what service is or lack of knowledge
- Limits to the service, cost of care, volume of care, human support
- Acceptance of diagnosis
- Availability of services
- Movement within services (road blocks)

Question #2 - What are the key considerations for system transition to support those dying an expected death?

- A) Progressive chronic illness**
- B) Towards end-stage (6 months or less)**

GROUP 1:

A) Progressive Chronic Illness

- Resources needed in education of illness itself (i.e. ALS, COPD, AIDS, etc.) for families and clients. Education through access to family support groups, directory of services that can be accessed easily (i.e. Cancer Society Service Directory which will be in telephone book).
- Respite
- Resources for coordination of services (i.e. volunteer services to clients and families for long term illness)
- Resources for financial burden again of meds, care, supplies
- Resources for psychosocial and spiritual support early on

B) Towards end-stage

- 24 hour care
- Resources in care, meds, respite
- Palliative care services with direction and coordination

GROUP 2:

A) Progressive Chronic Illness

- Medications/supplies needed for both
- Staff
- Could roles be developed (i.e. nursing homes could provide IV)
- Resource teams: used more as resource
- Better/more transparent access to system
- Education around palliative
- Palliative care unit: increase access for all of PEI
- Physician education around integrated program

B) Towards end-stage

- 24/7 care is essential for home
- Easier access to palliative care bed at end stage
- Prearranged admission – not through emergency
- More support for family/caregiver in end stage
- Exhaustion/fear/cost of medications
- Resources/plans to deal with complications that arise
- Bereavement after care goal
- A visit one month later
- One year phone contact
- Going through hospice

GROUP 3:

- Identify other groups of patients deserving of palliative care
- Improve symptom management support (pain, respite, emotional, financial)
- Referral process is used to optimal level through increased awareness
- Supports set up earlier to avoid crises at end stage
- If identified earlier coverage may begin earlier
- Communications between various team players
- Broadening vision of palliative care
- Educate general public on issues surrounding palliative care

GROUP 4:

A) Progressive Chronic Illness

- Progressive chronic illness challenges determine when someone qualifies for the services
 - What would we change!
 - Access to medication, supplies, oxygen
 - Care coordination, OT, physio, funeral, social worker
 - Expand tele-home care provincially for chronic illness
 - Resources for 24/7
 - One number to access what they need
 - Care coordination, case management, GOOD assessment
 - At what point does the client join/access palliative care program?
 - Initial assessment (SAST?), prior directive, will, what are they thinking? Pamphlets to clients, psychosocial, may lead to other things
 - Availability/access to respite care? Under 60 years.
 - Doing assessment, you share your own services but also other community services.
- Community development.

- Standard care plans for chronic diseases.
- ? End stage standing orders.

B) Towards end-stage

- A lot of “A” applies...
- Client/family have a good understanding knowledge of his prognosis of his care
- Education and communication
- Care coordination of cases
- 24/7 support critical or at least access to
- Ongoing assessment
- A number to call 912
- Good support system in the home
- What are the wishes of the client/family, so they want to die at home? Are we able to support that?
- If 24/7 not planned acute care is the place where they may go
- Education to clients/family, other supports may be out there, rural hospitals
- Rural communities no private care to (?)
- Cities only go so far with supports (i.e. meals on wheels)
- Primary health care principals: equality of health services to all islanders
- Identify core services
- Palliative care essential services

GROUP 5:

- 24/7 access to support
- Education regarding policy for care of deceased – health care directive
- Medication costs – all means tested – cover all meds – revamp all programs (med)
- Education of community (public ed and awareness EOS) regarding palliative care – both end of life and chronic illness
- Education of staff and caregivers regarding what is and what available
- Bereavement care

Question #3 - Part A - Three priorities in the next year to improve HPC that require low/modest investment

Part B - Three priorities in the next three years to improve capacity of system to provide better care for those with life-threatening and life-limiting illness

GROUP 1:

A) In the next year...

- Centralized system provincial coordinator
- Education for front line workers to continue, HSW, SW, LPN, Nursing from all settings and resources to make it happen, staff replacement and continued education for resource teams
- Good bereavement care

B) In the next 3 years....

- Cost of medications and supplies covered for those who cannot afford
- More resources put into home care
- University level courses for all health care providers in palliative end of life support and bereavement care

GROUP 2:

A) In the next year...

- Provincial coordinator
- Recognition of palliative care as a core/essential service (government and public education)
- Physician resource positions need to be filled/ (?) increased

B) In the next 3 years...

- Medication supplied for home usage
- Increased resources (Nursing, psychosocial, respite)
- Implementation of palliative care as a core service
- 24/7 coverage (i.e. NS Cancer Care's Patient Navigator)

GROUP 3:

A) In the next year...

- Develop position for provincial coordinator for palliative care
- Develop policies
- Integrate teams
- Keep statistics
- Report to government
- Political advocate
- Coordinate education for resource team
- Program to cover supplies needed at home, dosage, feeding, catheters
- More education for team resource members
- Educating public through talking with groups WI, Christian Counsel
- Develop contact person with list of speakers available
- Education in high schools regarding end of life issues
- Early referrals

B) In the next 3 years...

- Lobby government to cover medication cost under provincial pharmacy
- Enlist media's support to cover palliative care issues
- Develop provincial collaboration of all partners enlisted – hospice, professional associations, volunteer groups, national association groups, National Collaboration End of Life

GROUP 4:

A) In the next year...

- Provincial coordinator
- Long term lobby provincial-federal for money
- Utilize experts from our regions (resource persons)
- Inservices and education days (to promote palliative care)
- Island group take active role in hospice palliative care (networking and model practices)
- Communicate/collaborate with other areas
- Be accountable for (money)

B) In the next 3 years...

- Form a coalition with other provincial groups across the island regarding palliative care
- Hospice, ALS, Lung, AIDS, Heart and Stroke
- Full time resources – dedicated to palliative care – i.e. rural pharmacy
- Palliative care as a stand alone program with own budget manager
- barriers between PCU, CCU, HC, acute

GROUP 5:

A) In the next year...

- Early referral
- Educate caregivers including physicians to recognize and value the importance of palliative care and how it can enhance the quality of remaining life
- Educating caregivers (professional and informal) to what palliative care is – disseminate regularly
- Standardize forms (common assessment) and share information – palliative care chart to stay with patient
- Improve transition to long term care
- Communication improved
- Meet regularly provincially
- Share problem solving approaches/examples.

B) In the next 3 years....

- Coordinated program
- Provincial Director and coordinator – want input to selection
- Funding for continued education for palliative care teams and service providers
- Medication and supplies funded
- Funding for human resources to support patients and families

Appendix - Group Assignments

Group 1 Members

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Group 2 Members

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Group 5 Members

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