

**British Columbia**  
**Putting Progress into Action Workshop**  
**Small group Discussions**  
**June 28, 2004**

**Patient/Family Care**

*Gaps*

Spiritual Care  
Psychological Support  
Recognition of Advance directives/patient choices, end of life planning, understanding age of consent  
Standardized protocols/assessments  
Integrated assessment tools across hospital/community continuum  
Communication/Information sharing-between teams, poor exchange of info among health care providers  
Lack of working together  
No hospice beds  
Lack of volunteers in several communities  
Minimal grief and bereavement support  
Lack of professionals to lead bereavement care in several areas  
Cultural awareness, respect for ethnic diversities  
Assessment of non-verbal population  
Need to spread knowledge and commitment to quality dying beyond cancer care to frail seniors, chronic disease  
Narrow disease focus of hospice palliative care (lack of services in heart, renal etc)  
Broaden view of palliative care to early stages  
Lack of protocols for non-cancer patients  
Support for caregivers  
Hospice palliative care is still medically driven  
Human resources (CNS in community, social workers in communities)  
Family physician involvement  
Disease management –untimely and/or inadequate access to specialist and internist for diagnosis and treatment  
Conflict between specialist (is pediatrician) and general practitioner who provides palliative care  
Pediatric issues- specific training required, impact on family and school, need for community program for neonatal population, lack of pediatric assessment scales

*Strengths*

Volunteer training in some communities  
Emerging resources (hospice units, palliative care beds)

Pediatric Hospice (only one in Canada)  
Willingness to share amongst areas  
Coordinated plan  
Network available for communication between members  
Strong grief and bereavement support in some communities  
Pediatric bereavement (Griefworks) that has begun some education in palliative care  
Family support  
Great communication at front line  
Families becoming more involved  
Support of community  
Developed client user friendly hospice palliative care pamphlets  
Pain and symptom management manual  
Equipment in each rural site  
Palliative Care drug program  
Client in home chart  
Palliative Care teams, Palliative Care Coordinators  
Excellent care for dying and bereaved  
Strong group of clinicians advocating for improving patient and family care  
Palliative Care Coordinating group in Vancouver  
Many experts  
Palliative response teams  
Integrated teams (volunteers, MD's, RN's, SW, Pharmacy)  
Great caring nurses and doctors

## **Education**

### *Strengths*

Wide supply of educational material  
Some excellent written material (guidelines, information for families, books)  
National Curriculum for PPC  
Strong regional focus and support for hospice palliative care education  
Educational modules for volunteers and professionals  
Excellent educational material at the basic level  
Model in place for on-line education for volunteers across the provinces through griefworks  
Excellent Resource material  
Increasing awareness and skills of quality care  
Bi-annual end of life issues conference  
Learning Centre Concept  
Educational opportunities  
Victoria Hospice Education Courses  
Expanded medical school in Victoria and Prince George  
Pediatric palliative care course planned for 2005  
Some Courses and material in BC  
Commitment to use of internet, on-line learning approach

Standardized HP P and P manuals, including pain and symptom management, traveling chart, etc across health authorities Palliative resource material for health workers

### *Gaps*

Lack of standard education and accreditation for volunteers  
Cultural needs not adequately addresses  
Misconception of palliative care by public  
Physician education (not following protocols)  
Financial support for education  
Standard curriculum  
Interdisciplinary education by all service providers (acute, community, pediatric)  
Lack of effective health board education  
Educate staff education and orientation updates as staff changes  
No formal education programs (academic and non-academic)  
Education resources across health authority  
Decrease teaching resources in rural sites  
Lack of educational workshops  
Acute Care staff poor understanding of hospice palliative care  
Non-consistent education through acute care, residential, and community  
Need for Skill cased education for all team members and dollars to support  
Limited palliative care knowledge  
Misconception of palliative care by other health professionals  
Medically driven focus  
Lack of common curriculum for training of providers  
Few resources to practically educate professionals so they are adept at the psycho-social  
Poor continuity in education programs  
Accessible education  
Difficult to attend as no relief staff  
Financial support to attend conferences for rural nurses  
Physicians do not inform patients of community services for hospice palliative care

### **Management/Administration**

#### *Strengths*

Devoted beds in communities where acute care beds were closed- supports care at home  
Standard pain and symptom management guidelines and protocols  
Planning team regionally  
Efforts towards exploring palliative care  
All rural sites have community advisory planning committee  
Two free standing hospices that provide patient and family care  
Drug program  
New dollars for hospice beds and consult teams  
New Management structure ( 1 manager across residential services, acute care and community care)

Pockets of leadership and expertise  
Capacity building through hospice societies (financial resources, human resources, focus, expertise)  
Strategic plan developed  
Support and shared work across all sites  
Norms of practice  
Region-wide multi-disciplinary working groups  
Standard care plans  
Many excellent leaders  
Pediatric oncology developing a palliative care approach  
Getting Pallium workshop in fall  
Volunteer network established  
Dedicated staff  
National and International Networks are emerging  
National granting agencies acknowledging children  
Strength of teams where they exist  
Coming together as a group to discuss future options (Pallium project)  
Strong Hospice Palliative association  
A dedicated interdisciplinary team  
Foundational hospice palliative care values and principles  
Long term team members – dedication and commitment  
Good relationship with hospice volunteers  
Good working clinical advisory committee (back bone of palliative care program)  
Great working relationship with hospice team work  
Integrated steering committee  
Caring and committed staff  
First pediatric palliative care fellow  
Commitment of Board to move forward  
Great community management support for palliative care program  
Symptom management programs in the lower mainland  
Project support (funding provided)  
Excellent collaboration between tertiary and community health care providers leading to high at home death rates in some parts of the region  
Core group of committed front line providers

### *Gaps*

Lack of regional consistency/coordination  
No coordinated strategy across region  
No coordinated pediatric palliative care across the organization and PHSA  
No dedicated palliative care coordinator  
Government strategy for P.E.O.L.  
Each region requires coordinator or manager  
Palliative Care beds in acute and residential facilities used as medical transitional beds – not available when needed  
Mega planning but lack of implementation

Need formalized communication plan for service providers and clients and families

Silos

Lack of trust between organizations

Acute not part of hospice palliative care planning

Lack of understanding of hospice palliative care at High Level (decision-makers, funders)

Cultural Awareness and sensitivity versus risk management

Lack of outcome evaluation

Organizational planning

No dedicated funds except for coordinator

Limited resources and communication with experts in spiritual care

Inconsistent funding throughout health authorities

Hospice palliative care not recognized as core service in funding decisions

No communication strategies, marketing strategies

Resources do not match push to community care

Review is sporadic dependent on time

Need dollars for physician champions and support

Lack of funding for individuals with expertise or advanced practice skills to provide care

Home equipment and supplies

Increase workload

Sustainable funding

No regional framework for delivery of palliative care services (fragmented, duplication, inconsistencies)

Lack of appropriate environment for LTC palliative AIDS patients usually IV drug users

Lack of beds

Lack of community resources

Lack of resources in rural areas (no home care nursing)

No dedicated resources or limited

Geographical challenges with diverse, small populations-limited resources

Funded volunteer coordinators

Lack of funding for home support in last days of life

Lack of equitable, sustainable funding for hospice not-for-profit organizations

Ongoing support for some programs

No clear leadership structure or decision structure

No obvious accountability or organizational structure for the region

No regional process

Organizational structure does not support ;link between planning and operations

Lack of high level vision and commitment

Governance not formalized

Data collection

Information systems

Databases

Central registry

Lack of integrated electronic record for community and acute palliative

Communication with other health care teams

Need for better communication, collaboration, and integration between health authorities and hospice societies

Need aboriginal palliative care planning  
No local plan  
No strategic plan implemented  
Hospice societies not “real” partners in care  
Strategic plan leading to action  
Lack of disease management and supports within coastal rural areas  
Common assessment tools not being consistently applied  
No policy procedure manual  
No standards practice or care  
Quality management and review  
No clear indicators for outcome design  
No attention to outcomes and evaluation of care  
Unclear designation of palliative care  
Physician remuneration model for hospice palliative care  
Critical skill and capacity gap such as advanced skill at the community level  
Minimal content and practice experts  
Pharmacist not available in each acute care setting  
No Social Work support at any level or site  
Very little Mental Health support  
Physician and acute care do not attend multi-disciplinary meetings, no time  
Burn out in hospice organizations  
Still barriers between volunteers and professionals  
Right people in the right place with the right skill  
Fee schedule for physicians  
Focus usually on cancer –need to focus on other non cancer diseases  
Need to formalize integrated palliative care programs including teams, local resources and communication  
No palliative physician for palliative unit  
Tendency of health authorities to professionalize end of life care

## **Research**

### *Strengths*

Protocols for pain and symptom management  
Many individuals interested in research  
Pediatric palliative care Research 101 accepted by CIHR

### *Gaps*

Dedicated research funding  
Support for clinical research  
Time for research or participation  
Need to consider research projects at Home support Aide level to ultimately ensure improve quality

No regional collaboration in research  
No system to collect common data  
Lack of quality assurance, quality indicators and programs

## **Advocacy**

### *Strengths*

Media attention  
Volunteer Board members knowledgeable in palliative care  
Strong local hospice societies  
Interested individuals, potential volunteers, participants  
Numerous local hospice palliative care champions in various communities  
Donors to Hospice palliative care  
Public is ready for discussion  
Representation at many discussion tables  
This collaboration across the provinces to achieve consistency- Western Canada Rocks!  
Spirit of Hospice – such as sharing info

### *Gaps*

Need public education  
People's expectations vs health care capabilities  
Awareness of Hospice Palliative Care principles and values, chronic disease, and other end stage illnesses  
Hospice care or end of life care- ongoing debate  
No champion at senior leadership levels  
Lack of understanding of pediatric oncology and palliative care  
Hospice palliative care for young adults (18-25 years)  
Cost of advocacy – most effective means is most costly  
Health care providers do not necessarily have skills in advocacy  
What is most effective way of advocacy?  
Need for increased communication  
Right hand does not know what the left hand is doing – communication

### ***How do we reach the decision-makers?***

Not discussed

### ***What kind of supports can Pallium Provide?***

Educational Tools  
Data re approaches to fund both palliative care physicians and family physicians  
Build Communication and Advocacy Skills  
Data collection strategies

Critical mass of individuals trained  
Local education