DISCUSSION PAPER ON A PROVINCIAL STRATEGY FOR END-OF-LIFE CARE IN BRITISH COLUMBIA

October 2002



Ministry of Health Services

Responding to this Discussion Paper

This paper has been prepared to encourage a dialogue on end-of-life care in British Columbia. Readers are encouraged to send in their comments and feedback.

You may send a written submission about this discussion paper to:

Home and Community Care Branch Ministry of Health Services 1515 Blanshard Street Victoria B.C. V8W 3C8

Alternatively, submissions may be forwarded electronically to:

HLTH.EndOfLifeCare@gems2.gov.bc.ca

Table of Contents

RESPONDING TO THIS DISCUSSION PAPER	I
TABLE OF CONTENTSII	I
1. INTRODUCTION1	
2. BACKGROUND AND CONTEXT1	
2.1 WHY A PROVINCIAL STRATEGY IS NEEDED	
3. THE BEGINNINGS OF A PROVINCIAL STRATEGY9)
3.1 Vision for End-of-Life Care in B.C)
4. POSSIBLE STRATEGIES FOR ACTION	;
4.1 DEVELOP AND ADOPT A PROVINCIAL SERVICE FRAMEWORK FOR END-OF-LIFE CARE	5
5. CONCLUSION	;
REFERENCES	,

1. Introduction

All British Columbians have at least one thing in common – every one of us, one day, will die. And when we do, our hope is that we will have a pain-free and peaceful death. For British Columbians who are dying today, and their families, this hope for comfort is immediate – and their need for compassionate, competent, respectful care at the end of life is urgent.

The purpose of this paper is to encourage discussion about how quality end-of-life care should look in British Columbia.

2. Background and Context

Through its New Era document and service plans, the British Columbia government has committed to expanded home care and palliative care services for chronically and terminally ill patients. These services provide supportive home environments as an alternative to hospital care. Also, the government has committed to providing patients living at home, in palliative care, or in long term care with the same drug benefits they would receive if they were in hospital, and to providing better home support and home care services.

The British Columbia Select Standing Committee on Health noted in its December 2000 report to the Legislative Assembly of British Columbia that it is necessary to meet the needs of the chronically ill, dying, mentally ill, and elderly outside hospital and institutional settings – in their homes, in the community and in alternate institutions.

Defining end-of-life care

"End-of-life care" is the term used for the range of clinical and support services appropriate for dying patients and their families. It is the total care of people who are dying. It is active comfort care.

The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying patients and their families.

2.1 Why a Provincial Strategy is Needed

In 2000, there were 27,273 deaths in British Columbia, 90 per cent of whom died of a disease such as advanced heart disease, cancer, or chronic lung disease. Only 10 per cent of all deaths each year are unexpected.

The majority of people die in hospital. This occurs despite the fact that a 1997 Angus Reid survey reported that nearly 90 per cent of Canadians feel it is important for dying

people to be at home, and despite the fact that an acute care hospital bed is the most expensive resource in our health care system.

Reliance on hospitals as the place for dying is part of a national trend over the past century. This 'medicalization' of death took dying and death from the home to the professional environment of the hospital.

Despite high use of hospitals, many British Columbians are dying without appropriate care and support. Of all persons who died in hospital in British Columbia during 2000, estimates are only 5 to 10 per cent received palliative care as part of their care in hospital. No formal standards for end-of-life care or hospice palliative care service delivery have been established in British Columbia.

End-of-life care could be a key part of good medical care, and end-of-life care services could be provided as part of regular health services. At the same time that British Columbia is working on a provincial strategy for end-of-life care, the Secretariat for Palliative Care at Health Canada is developing a national strategy. Many British Columbia health care providers are involved in that effort and many of the recommendations in this paper are similar to those at the national level.

2.2 Key Factors and Challenges

2.2.1 Rise in demand for end-of-life care

End-of-life care will become more important as British Columbia's population grows and ages. In 2001, the population of British Columbia was just over four million people. In 2026, it is projected to be well over five and a half million. Seniors will account for 41 per cent of this increase in population.

The end of life, once commonly following brief and severe illness, now usually results from long-term illness and a long process of disability and decline prior to death. This includes cancer, heart diseases and lung diseases. With the increasing age of British Columbia's population, there is more dementia and related illnesses. Our health care system is not identifying people with these illnesses as patients who can benefit from hospice palliative care services. Often, this lack of referral is due to the uncertain course of illness with these diseases and to the unpredictability of death.

2.2.2 Inappropriate settings for end-of-life care

As noted earlier, the majority of deaths in British Columbia take place in a hospital. While this is appropriate for many patients who need acute and intensive care services, it is unlikely that all patients who currently die in hospital need the resources of an acute care hospital for end-of-life care.

Acute hospital care

The hospital setting is sometimes seen by patients and their family caregivers as the best place to receive care, particularly for families who become increasingly burdened with care-giving at home. In other instances, hospital care is preferred for reasons such as a cultural view that a death in the home will bring bad luck to the others in the home. In some situations, care in hospital is the best place to provide the clinical and medical care

needed by the patient to manage their pain and symptoms. Often however, patients and their families just don't think they have a choice.

Whether the hospital is preferred by the patient or family, or assumed as the best place to die, recent research has found that hospital care is viewed as least ideal in the opinion of patients and families.

The creation of palliative care units and palliative care consultation programs in acute care hospitals has improved the control of pain and other symptoms in terminally ill patients. Unfortunately, in British Columbia, designated palliative care teams exist only in urban centres such as Vancouver/ Lower Mainland, Greater Victoria, and Kelowna. Smaller centres often have physicians who are consulted by colleagues because of their interest in palliative care, but no team of professionals is available.

> Alternatives to acute hospital care

Research suggests that patients and their families who need end-of-life care are best supported by a system that offers a variety of options. A well developed system would include home care, free-standing hospices, residential care facilities, acute care in hospital for episodic care, and care in hospital inpatient palliative care units or from tertiary palliative care services, when specialist hospice palliative care services are needed.

Edmonton's experience suggests that providing alternatives to hospital care can be costeffective. When Edmonton established a Regional Palliative Care Program in 1995, the proportion of cancer deaths in acute care fell from 86 per cent to 49 per cent by the second year of the program, and 17,000 hospital days were shifted from acute care to the home and other care facilities, a saving of about 50 Alberta hospital beds.

In British Columbia, people who might prefer care in a hospice or at home often find it unavailable because only five publicly funded hospices exist in the province and many communities lack adequate and appropriate community palliative care services to support patients and their family caregivers at home.

The decision to provide care at home often depends on caregivers' ability and willingness to provide care, and on the degree of support, information, and education they receive. Care at home can also be financially difficult if family caregivers must take time off work. Evidence from Edmonton, Kelowna and Victoria shows that where a dedicated team, such as a palliative response team is part of a community palliative program, home deaths increase, admissions to hospital and the number of emergency visits for palliative patients decrease, and average days per stay for the palliative program patients decrease.

Hospice facilities can provide an alternative for people who cannot be cared for at home but do not require care in hospital. A hospice is a place outside the regular hospital environment where quality palliative care is provided. As our population ages and more people live alone or far away from family, it will be difficult to support all people at home, so more hospices may be needed.

Possible ways to provide hospice facilities in British Columbia include contracting for the service, hospice beds at residential care facilities, or hospice beds in a hospital. Many

Hospice Societies in British Columbia are interested in partnerships with health authorities to develop hospices. Communities want to develop hospices according to their own culture, tradition, demographics, and geography.

Currently, there are no standards in Canada for the human resources, design or standards of care under which hospice facilities should operate.

2.2.3 Need for co-ordinated end-of-life care services

Service development for end-of-life care in British Columbia has not been coordinated by an overall plan. Pockets of clinical excellence in hospice palliative care have developed across the province. These programs are well used by patients who have access to them, but there are gaps in access and in the quality of care.

Communication between hospital and community based programs is essential to integrated, well-coordinated services, but this does not happen consistently.

Many communities do not have interdisciplinary teams that focus on end-of-life care. There may be little coordination among professional disciplines and care of patients can be fragmented.

Except for the Fraser Health Authority, no regional integrated palliative care programs exist in British Columbia. Regional service delivery is fragmented, there is no central coordination of care, and no clear accountability for standards. Community-based palliative care services are underdeveloped in British Columbia. Home care nursing is available in most communities, but usually only during weekdays, with evening, night and weekend service available only in a few large urban communities. Similarly, home support services are only available during weekdays in many parts of British Columbia.

Access to specialized services such as hospice palliative care consultation/ support teams, community palliative response teams, and coordinated care using dedicated local hospice palliative care coordinators is not well developed. Specialist consultation for primary care physicians, nurses and pharmacists is available by phone, but access for patients and their families is lacking.

A major challenge for family physicians that provide end-of-life care as part of their family practice is finding the time to spend with patients. Some physicians spend large amounts of time on issues that take them away from their patients – phone calls trying to pull together resources, travelling to the local hospital after hours to find catheters, drugs, and other urgently-needed supplies, or searching for information on symptom management.

Most physicians who provide end-of-life care are paid a set fee that doesn't take into account the time it takes to provide quality care. Payment models should recognize the workload and time involved in providing quality end-of-life care.

2.2.4 Meeting the needs of distinct populations

End-of-life care needs tend to be similar for most patients, although some groups require different service delivery that fits unique needs. Different social and ethnic groups sometimes need particular attention. Aboriginal people, especially those living on reserve, have trouble getting access to quality end-of-life care. Aboriginal people and

other ethnically diverse groups have different expectations, rituals, and desires around dying and death. The needs of special populations such as persons with HIV/AIDS, street people, and people in jail can also be different from 'average' needs.

Dying children have additional needs and, current care is not always able to meet their needs and those of their families. Children need specialized services, and specialized caregivers in addition to the support of their families. This is a challenge because specialized palliative pediatric services are provided at a provincial level (by Children and Women's Health Centre and Canuck Place). In addition, not all communities have pediatricians, so care is sometimes delivered through a family physician who may not have expertise in pediatrics or palliative care.

The challenges of providing effective home palliative care are greatest in rural areas. Compared to urban areas, rural areas tend to have fewer specialist doctors and less access to health care resources. Long travel times to provide care are added to the already high time demands on palliative patients. Generally, fewer formal services are available in rural areas, so families provide more of the care and support. This often means family members and health care providers work more closely together and there is a need for different ways to provide family caregiver support.

2.2.5 Lack of integration in end-of-life care

The experiences of serious illness, dying, care-giving, grieving, and death cannot be completely understood by looking at the medical side of the issues. These events are personal, but also part of their communities. Every community responds to its members who are living through these difficult experiences in ways that both reflect and shape community life. Community service and social service organizations, non-profit, church and school organizations are supporting patients and families, but that role needs to be recognized, expanded and integrated with the health care system.

British Columbia has an active hospice community development movement, and support services such as volunteer visitors, pastoral care, psychosocial counselling, grief and bereavement support provided through non-profit voluntary hospice societies. Many of these non-profit societies have small budgets, and must spend much of their staff time fundraising.

For many years, the BC Hospice Palliative Care Association has provided leadership for the many community hospice groups throughout British Columbia. In 2000/2001, more than 7,000 British Columbia hospice volunteers provided over 450,000 hours of service to individuals and families facing death. There is no formal partnership between the professional system and community hospice societies.

Currently, hospice societies are the main way that people get information about end-oflife care. Community volunteers are essential in providing information and support to patients and their families, and to complementing the care provided by professional health care providers.

2.2.6 Education for Health Care Professionals

There is not enough training in end-of-life care in undergraduate and graduate health care provider programs as well as a lack of education for practicing health care providers. There is no strategy for ongoing continuing education.

> Coursework

In British Columbia, physician undergraduate education includes a total of 16.5 hours of teaching on end-of-life care, representing only 0.8 per cent of formal classroom hours. Medical students can take elective courses in palliative care in their final year, but are not required to do so. Starting in July 2002, UBC School of Medicine began a new 'Year of Added Competency' – a fellowship year in palliative care.

The UBC undergraduate nursing program includes a fourth year course in palliative care, but this is an elective. Nurses can choose to do work experience in palliative care during their undergraduate degree. There are other nursing schools throughout the province with varying programs, but none include mandatory palliative care experiences.

The UBC Faculty of Pharmacy offers no lectures in palliative care and no specific courses in the undergraduate program. Some graduates will do a residency that could involve spending time on a palliative care unit or with a palliative care physician.

The Faculty of Social Work offers an optional inter-professional course in HIV/AIDS in fourth year that has content on palliative care, but the mandatory program does not contain any palliative care education. The Master of Social Work program has one course that touches on palliative care issues.

2.2.7 Clinical and program standards

Clinical practice guidelines are important in any area of health care. In end-of-life care, such guidelines are especially important as there is no 'second chance' to do things correctly.

Clinical practice guidelines encourage caregivers to apply consistent and effective ways of intervening in a clinical situation. Such guidelines for end-of-life care are non-existent in British Columbia and Canada.

The Canadian Hospice Palliative Care Association has recently released its *Norms of Practice* in palliative care that should help in creating program standards and guidelines for clinical practice.

2.2.8 Research

There are few Canadian researchers, let alone British Columbia researchers, whose time is committed to investigating end of life issues. There is limited information, both at the provincial and health authority level supporting health service planning in end-of-life care. There is little research into clinical issues, such as the effectiveness of specific medical and non-medical procedures, ways to measure how appropriate and cost-effective health care services may be, or analysis of demographic, geographic, cultural and other factors that might affect the experience.

2.2.9 Public awareness of care options

The health care system can be difficult to use, even for health care professionals who work in it. There is no basic "road map" of information for patients and families entering the health care system. In addition, people who are diagnosed with a life-limiting illness are often in shock emotionally or in physical difficulty and cannot actively search for information.

Information resources are not generally available that describe hospice palliative care services, the options available for care and support of the patient and the family caregiver, or how to get access to such services. Patients and their families often suffer needlessly because they are unaware that pain and symptoms can be managed effectively and do not know what options are available to help them during this difficult time.

Many patients agree to treatment they do not want because they are unaware of their treatment options and that it is their right to choose or refuse treatment. The reality is that modern medical technology can save lives, but it can also prolong the dying process. Talking with our loved ones about our wishes and their wishes for what a good death would be is an important part of life.

Capable adults who are suffering from an illness have a well-established moral and legal right to say 'no' to any form of medical treatment, including life-prolonging medical treatment. Family members who must make medical decisions for an incapable person also have the right to refuse any form of medical treatment on their behalf, so long as they are acting in a way that is consistent with the known wishes or best interests of their loved ones.

The presence of advance directives makes a difference in medical decision-making, as physicians and other health care providers are much more likely to respect the patient's wishes for care and treatment, if they know what they are.

Several communication tools have been developed in British Columbia to provide opportunities for people to express their wishes about care and treatment, including Do Not Resuscitate (DNR) policies and forms, No CPR (cardiopulmonary resuscitation) forms, and Degree of Intervention (DI) policies and forms. The Joint Protocol for the Management of Planned Home Deaths, released in 1996, clarified the processes, procedures, roles and responsibilities, and communication involved in a planned home death.

A review of advance care planning and decision-making about treatment goals and goals of care at the end of life is needed. A 'Best Practices' approach to advance care planning and decision making is needed to clarify roles, processes, and legal concerns, and to make it clear for patients, their families or substitute decision makers, health care

providers, and the public about what to expect when the time comes and decisions must be made.

3. THE BEGINNINGS OF A PROVINCIAL STRATEGY

3.1 Vision for End-of-Life Care in B.C.

Our vision for end-of-life care in British Columbia is one where health care providers, health authorities, communities, and voluntary agencies work closely together and create an effective end-of-life care system through coordinated, joint planning.

Under this vision, end-of-life care becomes a regular part of health services and the best possible use is made of limited resources to make sure quality services are available for British Columbians who need competent, compassionate and respectful care at the end of life. Patients and families have choices, and a range of options is available to support death with dignity and comfort in the setting that best meets patients' and family caregivers' needs.

Scope for End-of-Life Care

End-of-life care services include care in all settings, including hospitals, residential care facilities, hospices, homes, and other locations where persons may need care such as in prison or on the street.

Improvements should be made in access and quality of care for all people facing end-oflife, regardless of their age or circumstances.

3.2 Framework and Guiding Principles for a Quality System

This discussion paper proposes that a provincial strategy be guided by the overall principle that any British Columbian who needs end-of-life care can have access to quality end-of-life care services. This overall principle is supported by four guiding principles: patient and family-centred care, quality, community involvement, and affordability.

I. Patient and family centred care

A quality end-of-life care system is based on what patients and their families need and want. Patients' and families' preferences are known and respected. Clinicians, planners, policy makers, and the broader community use this information to plan for and provide quality end-of-life care services.

II. Quality

Patients and families should have access to appropriate and timely services regardless of where they live in British Columbia. Principles of quality include:

People should be able to expect and receive good end-of-life care – that is free from avoidable distress and suffering for patients, families and caregivers, consistent with patients' and families' wishes, and with clinical, cultural and ethical standards.

- Care for those approaching death is an important part of health care. Good end-oflife care depends on strong people skills, medical knowledge, and technical skill, and is based on scientific evidence, values, and personal and professional experience.
- The health care community has special responsibility for educating itself and others about the identification, management, and discussion of the last phase of advanced illness.
- More and better research is needed to increase our understanding of the clinical, cultural, organizational, and other practices or views that can improve care for those approaching death.

III. Community involvement

The voluntary sector and the broader community are involved in working with others to plan and develop end-of-life care services, and contribute unique views to a 'whole community' approach to improving the end-of-life experience. The broader community helps to create appropriate information and education about end-of-life care, and supports spreading information through the community.

IV. Affordability

The health care system has many demands on its resources. Redesign of existing services can improve patient and family care. Costs can be kept down by providing the necessary end-of-life care through the most appropriate service provider, and in moving resources to develop primary care services, care at home, consultation support and alternatives to hospital care.

3.3 Core Elements for a Quality End-of-Life Care System

To develop a quality end-of-life care system, it is important to define the core elements that make up an effective system.

3.3.1 Essential end-of-life services

Patients and their families would have access to appropriate and timely services, regardless of where the person lives in British Columbia. Services would be developed to meet the needs of British Columbians who live in rural and remote communities. Essential services that would be available to those who need them include:

- pain and symptom management;
- practical support of patients and family at home, including respite for family caregivers;
- advance care planning and decision support;
- psychosocial support;
- bereavement support;
- community supports such as a physician, home care nurse and home support available 24 hours/day seven days a week; and,

consultation support to the primary health care providers available 24 hours a day seven days a week.

3.3.2 Information resources

Patients would have access to information at the right time, in the right way, and in the right amount. Information would be available when patients and families ask for it and in ways they can use and understand. Information resources might include:

- family caregiver manuals;
- brochures, leaflets, booklets and videos;
- web sites; and,
- > translations of information into their language.

3.3.3 Range of care options

Patients would have a range of options for where to receive care, including home care, hospice, residential care in a facility, acute care in a hospital for short term care, and care in a hospital inpatient palliative unit or from specialized hospice palliative care services when it is needed.

3.3.4 Coordination and integration of care

Coordination of care would occur across all settings where patients receive care. Regional integrated service delivery systems would be developed that involve a network of agencies and service disciplines that work together.

The regional program would be a patient and family focussed program that makes it easy to get access to all levels of palliative care and to move between levels, with full support being provided by the family physicians and others.

Clinical and administrative tools would be available to support quality practice. A common clinical record and a common database are two important components of the clinical information systems.

The voluntary sector and the broader community would be involved and work together on regional integrated service delivery, and contribute unique views to a 'whole community' approach to improving the end of life experience for all members of the community.

3.3.5 Clinical tools and standards

Clinical tools such as clinical practice guidelines, assessment instruments, and protocols to guide decision-making on end of life issues would be available to support medical practice.

3.3.6 Education of health care providers

Health care providers would be knowledgeable and competent to provide end-of-life care, and sufficient numbers of specialist practitioners with expertise in symptom management

and hospice palliative care would be available to provide needed consultation services and to be involved in teaching.

Consistent, comprehensive and standardized education would be available to train new health care professionals in end-of-life care and to meet the continuing education needs of practicing health care providers.

3.3.7 Evaluation and research

Performance measures, care outcomes, and quality indicators would be available to measure how well end-of-life care services are being provided. Health professionals would do research in coordination with palliative care researchers in order to continually improve practice.

3.3.8 Accountability

Quality indicators, performance indicators, and measurement mechanisms would be available to measure and monitor effective and efficient delivery of end-of-life care services.

4. Possible Strategies for Action

This section proposes six possible concrete strategies for action that can be pursued by the Ministry of Health Services, health authorities and community partners to address key challenges and accelerate development of appropriate end-of-life care services in British Columbia.

4.1 Develop and adopt a provincial service framework for end-of-life care

Hospice palliative care services and settings should be developed in a planned and comprehensive way and within a provincial framework that sets out measurable service standards for end-of-life care. The Ministry of Health Services should establish a provincial service framework for end-of-life care and work with health authorities to identify effective ways of monitoring service development and service delivery to make sure standards are met. Elements that could be covered include:

- defining essential hospice palliative care services;
- defining levels of hospice palliative care;
- > creating standards for hospital palliative care units and residential hospices;
- setting standards for specialist palliative care consultation services and access to these services;
- integrating pediatric programs such as Canuck Place, Nursing Support services, and the At Home Program;
- > setting standards for regional delivery of end-of-life care services;
- defining reporting requirements to ensure accurate information on utilization and costs with improved reliability; and,
- accountability mechanisms, including appropriate outcome measures and performance indicators.

4.2 Develop an appropriate range of options and alternative care settings

All health authorities should take active steps to address and develop end-of-life care services. Expansion of options and alternative care settings could:

- > Build on existing capacity and the successful implementation of existing models.
- Focus on introducing options for care for clients whose needs don't require hospital resources.
- Eliminate policy barriers to alternate approaches, in particular for residential care hospice beds and the difficulties in providing narcotics to patients dying at home.
- Work with the Ministry of Children and Family Development (MCFD) to ensure pediatric needs are addressed.
- Support family physicians' involvement in end-of-life care, including innovative models for paying family physicians who take on end-of-life care. Where a community lacks primary care physicians to provide end-of-life care, innovative solutions should be considered, such as nurse practitioners with expertise in end of life and the development of lists of physicians willing to take patients.
- Work with Aboriginal and other cultural groups to develop approaches responsive to their needs.

- Explore formal partnerships with hospice societies and other non-profit organizations through mechanisms such as service agreements or contracted arrangements.
- Reorganize aspects of care provided in the hospital setting to better meet the needs of patients and their families.
- Establish regional integrated hospice palliative or end-of-life care programs as a defined organizational and administrative program.

4.3 Expand home and community palliative services

Home and community palliative care services should provide the type and level of service needed by patients and their families. Development of options such as symptom management clinics, palliative day programs and respite across health care sectors should be given priority. Key actions might include:

- Review and update of policies on the provision of home and community palliative services to ensure that no barriers exist to new service options, or to the allocation of adequate and appropriate service levels.
- Expansion of home care nursing and home support availability over the 24 hour period, seven days a week, for those critical times when family caregivers need the greatest support.
- Review of the Palliative Care Benefits Program, to ensure coverage of a full range of supplies and equipment that are needed in alternate settings.
- Integration of MCFD Nursing Support Services, and the At Home Program to ensure maximum coverage and avoid overlap.
- The Ministry of Health Services could explore with the federal Secretariat for Palliative Care the possibility of a joint pilot project on paid leave and job protection for British Columbians who take time off work to care for a family member who is dying.

4.4 Foster an informed and involved public

British Columbians need to be more aware of treatment options and choices, what services are available for end-of-life care, and how and when to get access to these services. Efforts should be directed to this information gap and to developing information resources. Key actions might include:

- Collaboration with the federal Secretariat on Palliative Care, Health Canada and other organizations on public awareness and education.
- Participation with the federal government and national, provincial and community partners to define information needs and identify existing effective information resources.
- Development of a provincial best practices approach to advance care planning, including clarification of roles, processes, and legal concerns, and possibly the development of a tool for admitting physicians to elicit goals of care from the patient and preferences for intervention.

4.5 Develop an education strategy to improve professional training

An education strategy is needed to standardize the teaching that is given to health care providers in British Columbia. End-of-life care should occupy a much larger part of education for professionals and should be a core subject that is testable and requires competency in order to begin to practice. An education strategy should address:

- Issues of communication between professional and patient, in particular involving the patient in decision-making, and care needs of loved ones.
- The continuing education needs of currently practicing health care professionals, to ensure basic competencies for all health care providers.
- Innovative ways to encourage practitioners to view end-of-life care as a mainstream part of health care that requires skills, knowledge and attitude as the basis for quality practice.

The education strategy for health care professionals in palliative care must also include self-care. The education strategy must explore the professional's views about their own mortality and give palliative care teams the ability to design formal and informal means of supporting each other in their work.

4.6 Address data and information needs

Consistent collection of data and analysis of information about palliative care/ end-of-life care services, and the care received by patients and their families, would support evidence-based decision-making, service development, and system accountability. Key actions might include:

- Consistent coding of palliative patients across the settings of care, to ensure timely tracking of information for future service planning.
- Participation with the National Action Plan Surveillance initiative that has begun to define a set of performance indicators for palliative care.

5. Conclusion

British Columbians expect to receive quality care at the end of life. This discussion paper is the first step toward creating a collaborative, cost-effective, quality end-of-life care system in British Columbia.

This work will take coordinated and sustained effort by the Ministry of Health Services, health authorities, partners in the voluntary sector, and various other groups and organizations that make up the broader community.

This paper identifies issues, challenges and barriers that must be faced. Feedback will assist us in determining how these obstacles can be overcome.

Notes

¹ Characteristics are adapted from the World Health Organization (WHO), *Cancer Pain Relief and Palliative Care*. Technical Report Series No. 804, 10990.

² Recommendations from the B.C. Select Standing Committee on Health Report released December 10, 2001.

³ Characteristics are adapted ffrom the World Health Organization (WHO), *Cancer Pain Relief and Palliative Care*. Technical Report Series No. 804, 10990.

⁴ Senate of Canada. Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology, to update "Of Life and Death". Final Report, *Quality End-of-Life-Care : The Right of Every Canadian*, June 2000.

⁵ B.C. Vital Statistics Agency.

⁶ Social and Health Care Trends Influencing Palliative Care and the Location of Death in Twentieth-Century Canada. Final Report to the National Health and Research Development Program (NHRDP award # 6609-2096-96), 1998.

⁷ Ministry of Health Services, Information and Analysis.

⁸ See glossary for definitions of palliative care, and hospice palliative care.

⁹ Selected Vital Statistics and Health Status Indicators, Annual Report 2000, Table 22, twelve leading causes of death by gender, British Columbia 2000.

¹⁰ Submission by the Canadian Institute of Actuaries to the Senate Standing Committee on Social Affairs, Science and Technology, *Health Care in Canada: the Impact of Population Aging*, March 21, 2001.

¹¹ Do not resuscitate (DNR) orders are a communication mechanism for recording patients' expressed wishes and preference for treatment and care at the end of life.

¹² Hospital Report 2001, Complex Continuing Care. Produced by the Hospital Report Research Collaborative, University of Toronto, Toronto, Ontario. A joint initiative of the Ontario Hospital Association and the Government of Ontario. December 2001

¹³ Vancouver/Richmond Health Board, 2000.

¹⁴ A Rural Palliative Care Model: The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island. A Federal Health Transition Fund Project Report. March 2001. ISBN 0-88871-673-7.

¹⁵ The Health Care (Consent) and Care Facilities Admission Act

¹⁶ The Representation Agreement Act and The Health Care (Consent) and Care Facilities Admission Act.

¹⁷ Ministry of Health and Ministry Responsible for Seniors, *The Joint Protocol for the Management of Planned Homes Deaths*, 1986

References

- <u>A Health Care Provider's Guide to Consent to Health Care</u>. Developed by the Ministry of Health and Ministry Responsible for Seniors and the Public Guardian and Trustee of British Columbia. February, 2000.
- <u>A Rural Palliative Care Model: The Development and Evaluation of an Integrated</u> <u>Palliative Care Program in Nova Scotia and Prince Edward Island.</u> A Federal Health Transition Fund Project Report. March 2001. ISBN 0-88871-673-7.

Bennett, M., Corcoran, G. (1994) "The impact on community palliative care of a hospital palliative care team." Palliative medicine, 8: 237-44.

Bruera, E., Neumann, C.M., Gagnon, B., Grenneis, C., Quan, H., & Janson, J. (2000).
"The impact of a regional palliative care program on the cost of palliative care delivery." <u>Journal of palliative medicine</u>, 3(2), 181-186.

- Byock, I., Norris, K., Curtis, R., & Patrick, D.L. (2001). "Improving end-of-life experience and care in the community: A conceptual framework." <u>Journal of pain and</u> <u>symptom management, (22)(3), 759-771.</u>
- Byock, I., (1993). "Consciously Walking the fine line: Thoughts on a Hospice Response to Assisted Suicide and Euthanasia." Journal of Palliative Care, 9 (3), 25-28.
- Canadian Strategy for Cancer Control. (2002). <u>Canadian strategy for cancer control:</u> <u>priorities for action.</u> Ottawa: Canadian Strategy for Cancer Control.
- Canadian Hospice Palliative Care Association (CHPCA). (2002) <u>Norms of Practice for</u> <u>Hospice Palliative Care. Developed by the Revisions Workgroup, CHPCA</u> <u>Standards Committee</u> Ottawa: Canadian Hospice Palliative Care Association.
- Capital Health Region. Palliative Care Core Service Steering Committee. (2001, November). <u>Building capacity ensuring quality.</u> Victoria: Capital Health Region.
- Cassel, C.K., & Foley, K.M. (1999). Principles for care of patients at the end of life: An emerging consensus among the specialties of medicine. New York: Milbank Memorial Fund.
- Chochinov, H.M., Tataryn, D., Clinch, J.J., & Dudgeon, D. (1999). "Will to live in the terminally ill." <u>Lancet, 354</u>(9181): 816-9. Abstract retrieved January 15, 2002 from the World Wide Web: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=A bstract&list_uids=10485723.
- Chochinov, H. M. (2001). "The Senate report on end-of-life care: The ball is in our court." <u>Canadian Medical Association Journal, 164(6)</u>, 794-795.
- Client Service Standards for the Volunteer Hospice Visiting Service 1999.
- Department of Health and Children; Ireland. 2001. Report of the National Advisory Committee on Palliative Care.
- DeStoutz, N.D., Glaus, A., Supportive and palliative care of cancer patients at the Kanton hospital, St Gallen, Switzerland. <u>Support Care Cancer</u>. 1995; 12:221-226.
- Downing, M. *Palliative Care: Innovations, Solutions, Best Practices.* Presentation at the Health Association of B.C., Continuing Care Conference, February 19, 2002.
- Ellershaw, J.E., Peat, S.J., Boys, L.C., Assessing the effectiveness of a hospital palliative care team. <u>Palliative Medicine</u>. 1995; 9: 145-52.
- Fainsinger, R., Fassbender, K., Vigano, A., Hatcher, J., Brenneis, C., Brown, P. Braun, T., Neumann, C., & Jacobs, P. (2001). Economic <u>evaluation of two regional</u> <u>palliative care programs for terminally ill patients.</u> Edmonton: Alberta Heritage Foundation for Medical Research.

- Ferris, F.D., Balfour, H.M., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., & West, P.J. (2001). 2001 <u>proposed norms of practice for hospice palliative</u> <u>care.</u> Ottawa: Canadian Hospice Palliative Care Association.
- Field M, Cassel C. Eds. 1997. Approaching Death: Improving Care at the End of Life. Institute of Medicine. National Academy Press, Washington D.C.
- Fins, J.J., Miller, F.G., Acres, C.A., Bachetta, M.D., Huzzard, L.L., Rapkin, B.D., End-oflife decision-making in the hospital: current practice and future prospects. <u>Journal</u> <u>of Pain and Symptom Management. 1999; 17(1): 6-15.</u>
- Fisher, R., Ross, M.M., & MacLean, M.J. (2000). A guide to end-of-life care for seniors. Ottawa: Health Canada.
- Fox, E., Landrum-McNiff, K., Zhong, Z., Dawson, N.V., Wu, A.W., Lynn, J. (1999). Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. SUPPORT investigators. Study to Understand Prognoses and Preferejnces for Outcomes and Risks of Treatments. JAMA. Nov.3; 282(17): 1638-45.
- Gallagher, R. Using a trade show format to educate the public about death and survey public knowledge and needs about issues surrounding death and dying. <u>Journal of</u> <u>Pain and Symptom Management 2001</u>; 21(1):52-8.
- Grey Nuns Community Hospital. Regional Palliative Care Program. (2000). Regional <u>palliative care program annual report, April 1, 1999 – March 31, 2000.</u> Edmonton: Grey Nuns Community Hospital.
- Hardwick, J., with N. Hentoff, D. Callahan, F.Cohn and J. Lynn, L.R. Churchill, 1995. <u>Is</u> <u>there a duty to die?</u>, Routledge, New York.
- Hearn, J., Higginson, I.J., Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. <u>Palliative Medicine</u> 1998; 12: 317-32.
- Health Association of British Columbia (HAB.C.). Issues Backgrounder: Palliative Care. June 12, 2001.
- Hospice Association of Ontario 1999. *Client Service Standards for the Volunteer Hospice Visiting Service*. Author.
- Kats N et al. 1996. National Conjoint Committee on Mental Health Care Shared Mental Health Care in Canada - Position Paper. Canadian Psychiatric Association and College of Family Physicians of Canada.
- Macey, N. (2001, November 9). <u>Brief to the Select Standing Committee on Health.</u> Delta Hospice Society/Delta Hospice Foundation.
- MacLean, M.J., Kelley, M.L., Arthur, M., & Stones, M. (1999). Palliative <u>care in rural</u> <u>Canada.</u> Ottawa: AgeWise, Inc.

- McGrail, K., Green, B., Barer, M.L., Evans, R.G., Hertzman, C., & Normand, C. (2000). "Age, costs of acute and long-term care, and proximity to death: Evidence for 1987-88 and 1994-95 in British Columbia. <u>Ageing 29</u>(3), 249-253.
- Middlewood, S., Gardner, G., Gardner, A., Dying in hospital: medical failure or natural outcome? <u>Journal of Pain and Symptom Management</u>. 2001; 22 (6): 1035-1041.
- Molloy, D.W., Guyatt, G.H., Russo, R., Goeree, R., O'Brien, B.J., Bedard, M., Willan, A., Watson, J., Patterson, C., Harrison, C., Standish, T., Strang, D., Darzins, P.J., Smith, S., & Dubois, S. (2000). "Systematic implementation of an advance directive program in nursing homes: A randomized control trial." <u>Journal of the</u> <u>American Medical Association 283</u>(11), 1437-1444.
- Morrison, R.S., Siu, A.L. (2000). Survical in end-stage dementia following acute illness. JAMA. Jul.5, 284 (1):47-52.
- Protocol for the Management of Planned Home Deaths. British Columbia Ministry of Health and Ministry Responsible for Seniors, 1996.
- Quill TE. Initiating End-of-life Discussions with Seriously III Patients: Addressing the "Elephant in the Room". JAMA 2000; 284(19): 2502-2507.
- Schneiderman, L.J., Jecker, N.S., 1995. Wrong Medicine: Doctors, Patients, and Futile <u>Treatment</u>. The John Hopkins University Press, Baltimore.
- Silveira, M.J., DiPiero, A., Gerrity, M.S., & Feudtner, C. (2000). "Patients' knowledge of options at the end of life: Ignorance in the face of death." <u>Journal of the American</u> <u>Medical Association, 284</u>(19), 2483-2488.
- Simon Fraser Health Region. Palliative Care Strategic Planning Group. (2001). Regional palliative care: A proposal. New Westminster: Simon Fraser Health Region.
- Simon Fraser Health Region Continuing Care Services. (2001). Planning for Hospice in SFHR.
- Singer, P.A., Martin, D.K., & Kelner, M. (1999). "Quality end-of-life care." <u>Journal of the</u> <u>American Medical Association, 281(</u>2), 163-168.
- Social and health care trends influencing palliative care and the location of death in twentieth-century Canada: Final report to the National Health and Research Development Program (NHRDP award #6609-2096-96), 1998. Ottawa: Health Canada.
- South Fraser Health Region. Hospice Palliative Care Advisory Committee. (2001), Hospice palliative care program. Surrey: South Fraser Health Region.
- Stajduhar, K.I. (2002). The idealization of dying at home: The social context of homebased palliative caregiving. Final report summary. Victoria: Capital Health Region.

- Standing Senate Committee on Social Affairs, Science & Technology. (2000). "Quality end-of-life care: The right of every Canadian." Retrieved January 11, 2002 from the World Wide Web: <u>http://www.parl.gc.ca/36/2/parlbus/commbus/senate/come/upda-e/rep-e/repfinjun00-e.htm</u>.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., & Tulsky, J.A. (2000). "Factors considered important at the end of life by patients, family, physicians, and other care providers." <u>Journal of the American Medical</u> <u>Association, 284</u>(19), 2476-2482.
- Submission by the Canadian Institute of Actuaries to the Senate Standing Committee on Social Affairs, Science and Technology, *Health Care in Canada: the Impact of Population Aging*, March 21, 2001.

The New Zealand Palliative Care Strategy. (2001). Wellington: Ministry of Health.

Vachon, M. Burnout and Symptoms of Stress in Staff Working in Palliative Care. In H.Chochinov (Ed.) Handbook of Psychiatry in Palliative Medicine. New York: Oxford University Press 2000.

- Vancouver/Richmond Health Board. (November 2000, March printing). Living well, dying well: Regional palliative care planning project report. Vancouver: Vancouver/Richmond Health Board.
- Waddell, C., Clarnette, RM, Oldham, L., Advance directives affecting medical treatment choices. Journal of Palliative Care, 13(2): 5-8, 199.
- World Health Organization (WHO). Cancer Pain Relief and Palliative Care. Technical Report Series No, 804. 1990.