Proceedings
of the

Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming

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Appendices:

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Introduction

Health Canada sponsored the Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming in Ottawa on March 23-24, 1997. This document provides an account of the proceedings of the symposium.

The proceedings are divided into three main sections. Part I presents summaries of recent research projects and papers. Part II highlights some of the initiatives in palliative care in several provinces. Part III reports on discussions held among symposium participants about future planning in palliative care related to programming, services, education, training, information requirements and the role of governments. The symposium agenda, lists of participants and selected papers are included in the document as appendices.

Overview and Purpose of the Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming

Louise Plouffe (Research Manager, Division of Aging and Seniors, Health Canada)

This symposium evolved from the work of an interbranch committee on continuing care within Health Canada. The committee examined issues in continuing care and looked at what Health Canada can do to support the development of continuing care in the provinces and territories. Palliative care was identified by the committee as one of the priority areas within continuing care.

The objectives of the symposium are:

- to assess the current situation with respect to palliative care in continuing care, and more specifically in community-based and home-based care; and
- to identify common issues and areas of potential collaboration for future development of palliative care services.

The symposium will consist of keynote speakers, panel presentations and brief descriptions of palliative care initiatives in several provinces. As well, there will be discussion groups to discuss, in greater depth, issues related to services and programs, and to training and education.

Part I—Presentation Summaries: Recent Research Projects and Papers

A Snapshot View of Palliative Care across Canada

Susan Fletcher (Acting Director General, Population Health Directorate, Health Canada)

I want to extend my appreciation for your enthusiastic response to this symposium on palliative care trends and issues. Quite obviously, the need to provide sensitive and high quality care in the community to people at the end of life strikes a responsive chord among the experts, representatives of non-governmental organizations and federal and provincial officials assembled here today. I realize as well that this opportunity to assess together the current situation with respect to community-based palliative care and identify common issues and needs has been made possible by your work. All provinces and territories have generously contributed the information required to develop a fairly complete picture of palliative care programs in Canada today[*].This picture—which I will shortly draw in broad brush strokes—will serve as the starting point for discussion. I hope too, that it will be a canvas for future collaborative efforts among government and non-government stakeholders.

This symposium represents a necessary step in responding to the growing need to integrate palliative care as an essential element in the continuum of health care. The aging of the population, the increasing proportion of deaths due to chronic illnesses, notably cancer, the heated debates about ethical questions surrounding death—all these phenomena have contributed to increase the importance of quality care at the end of life.

In 1995, the Special Senate Committee on Euthanasia and Assisted Suicide recommended that all jurisdictions make developing palliative care services a priority in health care reform. As we shift health care delivery from hospital to the community, we must give sufficient place to palliative care in the community. Cost-effectiveness is a relevant, but secondary reason for doing this. More important is the need to give dying people the choice of maintaining their quality of life to the very end in the environment where they are most comfortable, and that is usually at home.

Both Minister Dingwall and his predecessor, Minister Marleau, have made end-of-life care a priority for Health Canada in response to the recommendations of the Senate Committee.

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[*] Health Canada Working Group on Continuing Care. *Overview of Provincial and Territorial Palliative Care Services*, March 1997.

The priority given by the Ministers to palliative care has been acknowledged through the initiatives of Health Canada. For example, Health Canada gave financial support to the Canadian Palliative Care Association as well as its predecessor, the Palliative Care Foundation. In 1981, the Department developed the first guidelines on palliative care in Canada. These guidelines were revised in 1989 to reflect the increase in palliative care at home and to strengthen the notion of interdisciplinary care. Health Canada also financed a variety of projects to create educational resources related to AIDS, cancer and palliative care for seniors as well as to support scientific research and professional conferences**.**

Minister Dingwall put palliative care on the agenda of the meeting of Ministers responsible for seniors in June, 1996. Ministers responsible for seniors agreed that a meeting of government officials and other stakeholders with palliative care responsibilities should be organized to address issues surrounding palliative care for seniors. Indeed, while many Canadians do die prematurely, most deaths occur in later life.

The survey of palliative care programs to which many of you have contributed points to encouraging trends across the country*. Palliative care programs are now well-established in hospitals across the country. All provinces and territories are working to integrate palliative care services as part of the expanding range of community-based health care services and to ensure that these services are an essential part of an increasingly regionalised delivery system. For instance, Quebec has integrated palliative care into the network of services offered by the Centres laces de services communautaires, or CLSCs. Saskatchewan has developed guidelines for developing an integrated palliative care service in regional districts governed by district health boards.

There are indications that palliative care programs are benefiting from increases in provincial funding allocated for community-based health care. As well, in some provinces, such as Ontario and British Columbia, palliative care services have benefited from special provincial funding programs directed towards innovations, demonstrations, or collaborative initiatives in community care.

The importance of providing education and training in palliative care is increasingly recognized. Several provinces have developed educational initiatives which draw upon expertise available in urban centres to provide training and to reach out to all regions. Manitoba has implemented the Terminal Care Education Project in which multidisciplinary teams from various regions receive training at the St. Boniface Hospital Palliative Care Unit, after which they return home to train other service providers. There are examples as well of educational outreach initiatives in Newfoundland, British Columbia, Nova Scotia and Ontario. Palliative care education responds to the unique geographical and cultural needs of diverse, or of remote communities. In Newfoundland, remote communities are served through teleconferences, phone-in consultations using a 1-800 number and through in-service training during site visits by a palliative care consultant. The Northwest Territories have developed culturally sensitive training programs which take into account traditional native views about dying, and First Nations staff receive training without having to leave the communities they live in and serve.

Finally, there is an emerging commitment on the part of governments to strengthen palliative care services. To illustrate, Alberta has developed a "Policy Framework for Palliative Care" and Ontario has established a "Palliative Care Strategy". In Nova Scotia,

a proposal to establish palliative care as a provincial program is under review. New palliative initiatives, or proposals to complement existing services are being considered in other jurisdictions, such as New Brunswick.

These are all positive signs. Nevertheless, it is also evident that community-based palliative care faces the same challenges across the country as home care generally. The extent to which palliative care services are available through home care programs varies from one province or territory to the next. Even within one province or territory, the availability of community-based palliative care can vary greatly from one region to another, for a variety of reasons. Eligibility criteria for palliative care services, the range of services available and the extent of public coverage for services also vary greatly across the country. These issues go beyond palliative care to become part of the larger challenge to modernize our national health care system. But the right of all Canadians, regardless of place of residence, to be assured of the best care possible when they face death, is a compelling reason to resolve these long-standing disparities.

In conclusion, I expect that this symposium will give greater impetus to the positive trends that are occurring and will lead us a step further in resolving difficult issues. I think all of us can anticipate to leave tomorrow with:

- a better understanding of the status of palliative care services across the country
- plenty of information and ideas regarding innovative programs and models of service delivery for palliative care in the community
- and finally, some common agreement on priority needs relative to education, resources and programs for service providers and to the information that is needed to plan and evaluate palliative care programs.

I wish you a successful and stimulating meeting.

Ethical and Legal Issues

The Ethical and Legal Dimensions of End-of-Life Treatment Decisions: What we can learn from the treatment of persons living with Aids.

Jocelyne Saint-Arnaud (Professor, Faculty of Nursing Science, University of Montreal)

This presentation is part of a much larger study concerning the ethical-legal aspects of end-of-life treatment decisions arising from a review of the literature of the past ten years in France, Great Britain, the United States of America, the Netherlands and Canada. A summary of the presentation and her paper is provided here. The complete presentation is found in Appendix E. The complete research paper is available from Health Systems and Policy Division, Policy and Consultation Branch, Health Canada. 10th Floor, Brooke Claxton Building, Ottawa, ON, K1A 0K9. Telephone: (613) 941-1806. Facsimile: (613) 941-9093.

The work presented by Jocelyne Saint-Arnaud is part of a wider field of inquiry concerning the ethical and legal aspects of end-of-life care.[2]The text is based on a review of the literature related to ethical problems relevant to the decision making process surrounding end of life care in France, Great Britain, the United States, the Netherlands and Canada. The text is also based on the experiences of people living with HIV/AIDS, since the experiences related by such groups makes it possible to explore the ethical and legal issues that arise from the decision making process related to end of life treatment.

The author believes that most of the legal issues related to end-of- life care can be grouped in two distinct themes: the consent or refusal of treatment and the request for euthanasia and assisted suicide. Furthermore, the author states that the source of legal and ethical problems related to end of life care and euthanasia requests can be attributed to the absence of training directed towards health care workers concerning law, and ethical conduct as well as communication difficulties existing between the patient and the care team.

In countries where acts of euthanasia or assisted suicide are institutionally accepted, the reasons evoked for such requests are loss of dignity, pain, the eventuality of indecent death, and the dependance on others. Generally, requests for euthanasia are greater than requests for assisted suicide, and patients choose to die when the care team has estimated their life expectancy to a month. The author also mentions that euthanasia and assisted suicide are usually part of a longer process towards death and that requests are not granted without further discussions on the subject.

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[2] By *end of life care*, the author refers to the following definition:≪ care aimed at relieving pain and providing comfort to allow the patient to enjoy the highest quality of life possible at the end of life. ≫

In countries where such practices are not institutionally accepted, numerous problems related to euthanasia and assisted suicide arise since physicians and other professionals are not trained to intervene effectively in order to relieve pain symptoms. The author therefore opts for a communicational approach that will allow rational decision making. This particular approach is possible, according to Ms. Saint-Arnaud, by clarifying the care team’s personal values regarding life and death, by assuring that the patient’s request to die is not motivated by a depressive state and by assuring that proper and up to date information is disclosed to the patient concerning his or her disease and the treatments available. The communicational approach promotes open communication between patients and care givers.

Generic versus Specific Palliative Care Services: Caring for All Canadians

Linda Kristjanson (Associate Professor, Faculty of Nursing, University of Manitoba)

The following is a summary of the highlights presented by Linda Kristjanson from a report she prepared for the Health Care and Issues Division, Systems for Health Directorate, Health Canada entitled *Generic versus Specific Palliative Care Services.* The executive summary from the report is found in Appendix F. The complete report, released in March 1997, is available from Health Systems and Policy Division, Policy and Consultation Branch, Health Canada. 10th Floor, Brooke Claxton Building, Ottawa, ON, K1A 0K9. Telephone: (613) 941-1806. Facsimile: (613) 941-9093.

Approximately 270 articles were reviewed and critiqued in the report. A synthesis of key issues, integrative comments and recommendations is provided. A mixed model of palliative care services is proposed. In her presentation, Linda Kristjanson emphasized the major trends and concerns that she saw emerging from the literature and some of the challenges that need to be addressed. A number of recommendations are presented.

Evolving Definitions of Palliative Care

Over the years, there have been many definitions of palliative care. They have similar core elements but contain subtle nuances that have implications for health care planners. The early definitions of palliative care talked about it in terms of "to cloak" or "to cover." and "to ameliorate symptoms of distress" and focused primarily on the end of life after curative efforts had been exhausted.

More recently, the view of palliative care by the World Health Organization, by the Canadian Palliative Care Association and by the document produced by Health and Welfare Canada in 1989 was that we are looking more at a continuum of palliation that might begin at the onset of an illness and might occur in conjunction with active treatment from time to time.

The definition that seems to be most current and most inclusive and that was used to guide this review is the one put forward in the Canadian Palliative Care Association's Standards Working Document.[***]

We seem to be at a place of definition incongruence. Despite the brisk evolution of thinking about whom palliative care should be directed at and what it includes, the primary model still in the minds of the public and most health care practitioners is an outdated one.

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[*] Canadian Palliative Care Association. (1995). *Palliative Care: Towards a consensus in standardized principles of practice*. First phase working document. Ottawa: CPCA.

This is the view that when all else fails, palliative care might be offered. What is important about the preponderance of this inaccurate definition is that this may discourage people from transferring people to palliative care services and may also discourage inclusion of palliative care services during phases of active treatment.

The literature review resulted in three major themes: the description of palliative care services and the essential components of those services; the needs of different populations and the challenges associated with the provision of care.

Palliative Care Delivery Services

There are a number of documented delivery services: home care services, day hospices, free-standing hospices and palliative care provided in tertiary care hospitals. There are seven components across these settings and in differing blends and amounts that seem to be essential. They are:

Symptom Management

There is a growing body of literature on how to assess and manage pain, nausea, dyspnea and delirium. A value and emphasis on quality of life underpins this symptom management work.

Psychological Care

Knowledgeable psychological care is important. It has been estimated, for example, that between 25% and 45% of individuals facing a terminal illness are experiencing some form of clinical depression. The concern is that many of these individuals are under-treated.

Spiritual Care

There is less written about spiritual care but the literature indicates that many individuals dealing with life-threatening illnesses discuss how important spiritual issues are and do not necessarily discuss them as end-of-life concerns. These concerns may appear early in the illness trajectory. Spiritual issues may be of concern to a wide range of individuals, not only those affiliated with a religious organization or belief system.

Family as Unit of Care

The family as the unit of care came through consistently in the literature. Evaluations of palliative care programs showed benefits to families, such as decreased anxiety. Family members were also described in terms of the variability in who they are and what they can provide.

Role of Volunteers

Less has been written about volunteers. Studies revealed that many palliative care programs rely heavily on volunteers. Volunteers should be viewed as an unpaid workforce that needs to be screened, trained, monitored and evaluated.

Team Approach

The team approach is central to any palliative care service. Team members bring both generic and specific knowledge and skills to the situation. The team should be broadened to include individuals such as volunteer coordinators, those who have alternative therapy training and elders in the community.

Bereavement Support

There is considerable writing in this area, including the identification of risk factors that indicate who should receive attention. Those at risk include young widows and widowers, individuals with dependent children, those in poor health prior to the illness, those with a history of alcohol use and those whose family member did not "die on time."

The Needs of Different Populations

Five groups were focused on in this review: multicultural populations, persons living with AIDS, children, those with advanced renal disease and patients and families living in rural and remote areas.

Multicultural Populations

The need for knowledge about Canada’s multicultural population is especially important for those with a terminal diagnosis. The cultural response to death and dying can take on increasing importance once biomedical interventions have failed to cure. There is evidence that a family’s social and cultural background may influence how to relate to health care providers, whether they get care at all and the caregiving roles they are comfortable assuming. The overall conclusion in looking at this literature is that health care providers cannot provide sensitive care to those of different cultural groups unless there is a better understanding of what death and dying means in those groups. There is very little training and research in these areas.

There is very little information in the literature on the perspectives of First Nations Peoples in the context of palliative care. The little knowledge that does exist about cancer in the First Nations Peoples, for example, is very fragmented and limited. There is a lack of comprehensive national data. Some provincial data point to the fact that there may be increasing palliative care needs among the First Nations Peoples. There is research suggesting that attention must be given to learning about how the death and dying experiences of First Nations Peoples might be more sensitively addressed with respect for cultural and spiritual beliefs and practices.

Persons Living with AIDS (PLWAs)

Individuals living with AIDS are less likely than many other patients to receive care within the traditional palliative care model. Differences in age distribution, family composition, course of the disease, care goals, types of symptoms and socio-economic factors are potential barriers to palliative care by this population. The emphasis in traditional palliative care programs on "death with dignity" may be in conflict with patients' efforts to fight their illness and maintain a positive approach and hope for survival.

It is also predicted that the fastest growing group of persons infected with HIV in the 1990s will be heterosexual women. Fourteen per cent of Canadian women with AIDS were infected through injection drug use. Women using drugs are likely to have limited support networks, be estranged from their families, may be caring for children and may not be accessing health care. The challenge for palliative care teams is to determine how to provide pain relief to groups who are used to drug habits. Children pose a special challenge to palliative care, as parents and siblings may also be experiencing the syndrome. HIV dementia is a common manifestation in infected children and requires an inordinate amount of energy and care.

Children

There are two approaches to look at: children as patients and children as family members. There is little literature is this area. The growth of palliative care for adults has not been paralleled in pediatrics.

1. Children as Patients

Children most frequently receive care in pediatric settings. The transition of care from an acute care approach to a palliative care approach is difficult in a pediatric context. Health care professionals may be reluctant to "give up" on treatment-oriented care. Pain assessment and pain management for pediatric populations are reported to be a problem. Pain assessment tools are lacking and the many misconceptions we have about pain management for adults hold just as true for children e.g, fears of addiction. The psychological and spiritual needs of children may also be neglected because there is a need to want to protect children and a lack of understanding that children really do understand a lot about what is happening to them. It appears that the ideal location for children to receive care is in the home but that the care needs to be provided with the support of palliative care consultation teams and resources for the family.

2. Children as Family Members

Children who are family members of individuals with terminal illnesses are also neglected. They talk about being sheltered from the illness, report feeling isolated, often turning to peers for support. A few studies document the developmental delays and behaviourial problems that can occur for children who are experiencing the terminal illness of a parent. As well, there are anecdotal reports of support groups for children that seem to report some good benefits in terms of helping them to discuss the illness, allay fears that they may have been responsible for the illness and helping them to cope in the bereavement period.

Patients with End-Stage Renal Disease

These people may be well served on palliative care units. The decision to stop life-saving treatment such as dialysis and move to palliative care must be made based on the patient's informed consent, sensitive inclusion of family members and meticulous communication between the renal care team and the palliative care team.

Palliative Care Needs of Individuals in Rural/Remote Regions

These people have particular needs as well. Often health care providers are challenged because they must serve as generalists. They may often receive the blame if the family thinks there was a delay in diagnosis and the specialist in the city was able to diagnose it. There can be difficulties later trying to reconnect with the rural physician for provision of palliative care.

Challenges Associated with Provision of Palliative Care

A number of challenges emerged from the literature: palliative care service delivery limits, cost-benefit issues, "lane change" problems, education and training problems, integrity and survival of palliative care programs and requirements for research related to palliative care.

Palliative Care Service Delivery Limits

The conclusion reached is that it is necessary to provide a continuum of care. Home seems to be a very good setting for many people and much good symptom management and emotional support can be provided if resources are in place. The question, "Should palliative care services by generic or specialized?" over-simplifies the issue. We need a mix and combination of services.

Cost-Benefit Issues

The literature is quite extensive. Four conclusions emerged:

1. care becomes increasingly expensive as one moves a patient further outside of their home setting
2. some treatments offered to dying patients may be of little benefit, while expending considerable cost
3. patients who have more financial resources are more likely to be cared for at home and are more likely to die at home, and
4. costs of providing care incurred by family members may be substantial and should not remain “invisible” in estimates of cost-benefit evaluations of care.

“Lane Change” Problems

There may be difficulty moving from an acute care to a palliative care model if people are reluctant to “let go” of individuals for fear that it represents failure. Two approaches would assist in the lane change: 1. make greater use of family physicians and 2. reexamine our consultative approach to palliative care and not keep it locked into a physician referral method only. There is evidence that nurses are more likely to refer to palliative care than oncologists and in some models families and patients can refer directly without a specialist having to be involved. This makes care much more accessible.

Education and Training Problems

It is necessary to look at the public context within which this whole discussion is occurring. When we are in a society that says “cancer can be beaten”, we are communicating a very strong message that there is one approach to dealing with terminal illness and that is to courageously fight this thing. This is an important message to think about in terms of health professional and public education.

There have been some advances in terms of health professional education but much more work has to be done. A number of recommendations are offered specific to health professional education. One is that we need to identify palliative care as a medical specialty. Parallel recommendations are offered in nursing.

Recommendations are offered related to rural and remote training. Three mechanisms need to be established in each province or territory to ensure palliative care competence of health teams in rural and remote communities: 1. delivery of baseline palliative care training programs for rural and remote health teams, 2. establishment of a 24-hour consultation line for rural and remote health team members who require advice and 3. development of an expert palliative care mobile team that can go out and provide support and consultation to these individuals. Volunteer training needs to be addressed.

Integrity and Survival of Palliative Care Programs

The intensity of palliative care cannot be underestimated in terms of the emotional work involved. This must be acknowledged in terms of infrastructure support and funding support so that resources are there to help these individuals. At present, people in many programs feel that their program is under assault and feel uncertain about whether their programs will be stable.

***Requirements for Research related to Palliative Care*.**

To address the complex needs of individuals who might benefit from palliative care, it is necessary to develop a cadre of palliative care researchers who can generate this science and to develop a concerted research initiative.

Palliative Care Needs and Seniors

Margaret Ross (School of Nursing, Faculty of Health Sciences, University of Ottawa)

The needs of older adults who are dying have not been systematically addressed according to Margaret Ross. In presenting her paper, Margaret began with the story of Leonard and his family and of their struggle to receive palliative care. The presentation proceeded with a discussion of the inevitability of death, the heightened awareness of finitude and the symbolic meaning of death in later life. It continued with a discussion of medical aspects of dying, and dying both at home and in long-term care institutions. The presentation concluded with a plea for the universal application of the philosophy and principles of palliative care, and in particular, to those who are both old and dying.

The full text of the paper and references are presented in Appendix G.

Education for Palliative Care in the Community

A. Community-Based Palliative Care Project

Linda Lysne (Executive Director, Canadian Palliative Care Association) and Sharon Sholzberg-Gray (Co-Executive Director, Canadian Association for Community Care)

Preamble

Linda described the 15-month joint project in community-based palliative care for seniors that has been funded by the New Horizons Program and which is in the final stages. A National Steering Committee comprised of representatives from the palliative care community, long-term care sector and seniors guided the project. The project managers are Dawn Walker, Co-Executive Director of the Canadian Association for Community Care (CACC) and Linda Lysne.

Sharon Sholzberg-Gray spoke about the development of the proposal, as well as about its significance in terms of the philosophy of sharing, and organizational partnerships.

The project has been carried out in two phases: 1) the identification of the gaps and barriers in existing services to seniors, and 2) the development of resources to address those gaps and barriers.

First Phase

1. ***A national survey process*** was carried out, which involved questionnaires directed towards seniors and family members, non-professional caregivers and program administrators. The surveys were distributed through palliative care programs and a CACC mailing list of seniors interested in receiving health-related information. The survey provided information about the most used services as well as the most needed services. Those responses have been incorporated into the public awareness video now nearing completion. It is interesting to note the areas in which there is consensus and the areas in which there was a discrepancy between the responses from the three groups.

The most used services were as follows:

Seniors/Family	Caregivers	Administrators
access to services	coordination of services	coordination of services
coordination of services	support for the family	support for the family
support for the family	managing symptoms	managing symptoms

The most needed services were ranked as follows:

Seniors/Family	**Caregivers**	**Administrators**
info re: who does what	info re: who does what	info re: who does what
care for the caregiver	care for the caregiver	care for the caregiver
what to ask the doctor	grief counseling	bereavement support

2. ***A comprehensive literature review*** was carried out. Patients strongly identified the need for relief of pain and other symptoms, as well as their need for clear information about what palliative care is, who does what and who pays for what. Caregivers noted their occupational stress and educational/ training needs, as well as their need for support. Issues with implications for care provided by families, other caregivers and service providers include the potential for increasingly complex care, communication difficulties and caregiving resources.

Obstacles to effective palliative care in the home and other community settings were identified as factors relating to the patient (uncontrolled pain, confusion), family caregivers (dissension, burnout, illness) and the caregiving situation (inadequate home support services, inadequate financial resources). Factors which were found to support effective care include the provision of effective pain and symptom control, information and adequate support services.

3. ***Focus Group Meetings*** were held in eight Canadian cities, to which representatives from palliative care groups, long-term care facilities, seniors groups and other community organizations were invited. The discussions were fascinating—different in each case—and yielded the following information about training materials already in use and areas which need to be addressed more fully in a national training package:

- Some organizations have been able to develop training materials for their staff, others have not. Even though there are a number of fine resources in existence, they are not universally available. Some programs feel unable to share resources they have developed or the cost of those resources may be prohibitive for a small organization. These comments supported the development of a national training resource package.
- Representatives from long-term care facilities highlighted the growing need for palliative care education for their staff, as residents now remain in their facilities until death, rather than being transferred to acute care hospitals. Support workers spoke strongly of their need to be recognized and supported as caregivers.
- Training should include information about complementary therapies, total body substance precautions and care which is culturally sensitive.
- There is a need for organizational policies and procedures to be consistent with the principles of palliative care. The most frequently cited example was that of Do Not Resuscitate (DNR) orders.

- There is a need for training of support workers to be incorporated into the workday rather than outside regular working hours, which creates a financial burden (child care, transportation) as well as a stress burden in terms of extra time.
- In response to requests, a separate review of francophone materials was carried out and will be included as an appendix in the training package.

The information gleaned from the surveys, literature review, focus groups and review of available educational materials reinforced the development of a national training resource, the second phase of the project.

Second Phase

The second phase of the project included development of a video to be used to heighten awareness of palliative care, with specific reference to people's concerns, fears and questions about end-of-life issues. A poster and public service announcement will be developed from the video which is titled, "Facing the Fears, Making the Journey."

At the same time, following a review of available educational resources, work commenced on creation of a national training resource package for support workers.
Consistent with recommendations from the focus group participants and the national steering committee's own review process, two resources were selected to form the basis of the training package (with, of course, permission from the owners of the materials).

The materials are:

Palliative Care for Home Support Workers Course Information from the Victoria Hospice Society.

Palliative Care: Visiting Homemaker Training Program by Senior Care of Toronto.

The CPCA working document, *Palliative Care: Towards a Consensus in Standardized Principles and Practice* was used as an additional resource.

The manual is designed as a series of modules, which can be taught as stand alone sessions (approximately 45 minutes in length) or combined. Some modules are designed for a longer presentation.

The project coordinators hope to do a small pilot project with this resource package (e.g., in three home care settings and long-term care facilities) in the next few months, incorporating an evaluation into the process (pre-test, immediate post-test and four-month follow-up post- test).

An adjunct to this project has been the development of an "Information Sheet" on the palliative care needs of seniors and appropriate approaches to palliative care, which addresses their most common questions and concerns, as well as provides basic information about palliative care services available to them. A draft of this information sheet has been prepared in both official languages and has been distributed at this meeting. Linda requested that participants forward their comments to the CPCA National Office no later than Friday, April 4. The Information Sheet will also be provided to Ministers Responsible for Seniors later this year.

Linda referred to the five recommendations related to palliative care included in the *Report of the Special Senate Committee on Euthanasia and Assisted Suicide* (June 1995), which remain relevant today. They are:

1. that governments make palliative care programs a top priority in the restructuring of the health care system.
2. that development and implementation of national guidelines and standards be continued.
3. that training of health care professionals in all aspects of palliative care be increased.
4. that there be an integrated approach to palliative care. The delivery of care, whether in the home, in hospices or institutions, with the support of volunteers, must be coordinated to maximize effectiveness. The provision of respite services is an essential component.
5. that research into palliative care, especially pain control and symptom relief, be expanded and improved.

To date, there has been only limited progress related to these recommendations. In October 1995, CPCA published a working document, *Palliative Care: Towards a Consensus in Standardized Principles of Practice*. The standards process has been supported by Health Canada. The next phase, that of consensus building and implementation, is beginning with continuing support from Health Canada.

During the past year, CPCA has worked in partnership with CACC on this project, with Volunteer Canada on national screening workshops for palliative care programs, and on palliative care education in HIV/AIDS through funding from the AIDS Care, Support and Treatment Program. In 1997, workshops will be held in conjunction with provincial palliative care associations and with various AIDS meetings across the country to address attitudes, knowledge and skills in the area of palliative care for persons with HIV disease.

While each of these initiatives is important and brings needed resources to the field, CPCA and CACC believe Health Canada should adopt a **national** approach to palliative care to include the following:

1. development of a palliative care strategy to implement the recommendations of the Special Senate Committee.
2. creation of a national palliative care council which would identify priorities and coordinate activities on an ongoing basis (with representation from various levels of

government, palliative care associations (CPCA, CSPCP), professional associations (CMA, CNA, CCFP, RCPS) and charitable associations (CCS, CAS) involved in the provision of palliative care.

The development and implementation of a national palliative care strategy and the creation of a coordinating council are essential if every Canadian is to have access to palliative care in his or her own community and if every health professional is able to provide that care.

B. Comprehensive Guide for the Care of Persons with HIV Disease: Module 4: Palliative Care Module

John Flannery (Executive Director, Casey House Hospice)

John Flannery presented this paper of behalf of the authors (John Flannery, Patricia Balogh, Dr. Frank Ferris and Deborah Randall-Wood). The paper begins with a discussion of the history of palliative care in Canada and the factors that influenced its development. It then reviews the evolution, issues and barriers and key principles related to HIV/AIDS palliative care. One national initiative, *A Comprehensive Guide for the Care of Persons with HIV Disease: Module 4: Palliative Care*, is described. Future actions are identified. The paper concludes with a message from a person living with HIV.

The full text of the paper is presented in Appendix H.

Part II—Vignettes and Panel Presentations: Provincial Initiatives

A more detailed discussion of provincial initiatives in palliative care may be found in the working paper, *Overview of Provincial and Territorial Palliative Care Services*. It was prepared for this symposium in March 1997 by the Health Canada Working Group on Continuing Care in consultation with provincial and territorial government officials and others involved in palliative care services. It is available from Health Systems and Policy Division, Policy and Consultation Branch, Health Canada. 10th Floor, Brooke Claxton Building, Ottawa, ON, K1A 0K9. Telephone: (613) 941-1806. Facsimile: (613) 941-9093.

Palliative Care: A Policy Framework (Alberta)

Vivien Lai (Health Policy Division, Policy Development Branch, Alberta Health)

This presentation addressed the development and implementation of the palliative care policy in Alberta. The palliative care policy framework was released in 1993. The policy was developed by consulting with care providers and professionals who worked in different sectors. Two themes emerged: 1) palliative care must be developed in a continuum of services and not in a particular service and 2) a palliative care philosophy must be acquired by all health care providers, not only those working in palliative care units.

Several principles are outlined in the policy framework. One important principle is preference for people to be cared for in the home. The goal is that the program should support people who choose to die at home in the community. Funding priorities should be given to home care to provide coordinated service.

There should be palliative care units in long-term care facilities for those who choose to die there. Some have been established. There should also be consultative teams to provide expertise in palliative care to the facilities.

In hospitals there should be palliative care units and service teams. One important role for hospitals, particularly teaching hospitals, is to provide education to home care staff and staff in long-term care facilities. Voluntary and community organizations are also very important partners in delivery of palliative care services.

How was the palliative care policy implemented? The draft policy framework was released in 1991 and finalized in 1993. The home care regulations were amended to allow the home care program to cover the costs of palliative care services to palliative care clients, including costs greater than the $3,000 per month limit for home care. In 1991, $4.6 million was allotted to a pilot project called Hospital and Facility Partnership

Program. Many of the pilot projects funded under the Hospital and Facility Partnership Program are palliative care projects. Most Home Care Programs in Alberta received funding to implement this program.

In 1994, regionalized health services began. All regional health authorities are expected to provide palliative care as a part of core health services. Edmonton started their service in 1995, Calgary in 1996, and this year a number of rural services are beginning.

Update on Palliative Care (Ontario)

Anna Burwash (Project Manager, Program Design Unit, Policy Branch, Long-term Care Division, Ministry of Health)

In the philosophy underlying palliative care initiatives in Ontario, palliative care services are seen a part of a continuum of care, not as a separate service stream or a separate program. What is wanted is a mix of service providers who have the expertise in palliative care. Some will spend all or most of their time providing palliative care service. An increasing number of other service providers will have the expertise to provide palliative care but will serve clients who have a broad range of needs in any given year.

Palliative care education initiatives have assisted in increasing the capacity of family physicians, community-based health and social service providers, staff in long-term care facilities and volunteers in community hospice organizations to provide services in the community.

The staff of Home Care Programs and Placement Coordination Services are coming together to form Community Care Access Centres (CCACs). Some are already operating. A CCAC is a single point of access for a broad range of long-term care services, including palliative care. A person can contact the CCAC directly or have another person make the contact on his or her behalf. Staff in CCACs will be able to refer clients to a number of services that terminally ill people and their support networks of family, partners and friends may require. Similarly, other service providers in the community such as community hospice organizations, disease-specific support organizations, individual health and social service providers can refer people to CCACs.

Palliative care initiatives were announced in Ontario over four years ago. District Health Councils are beginning to recommend that additional funding be allocated to two of these initiatives: the pain and symptom management teams and volunteer hospice organizations. In making recommendations about allocation of health care funding, the District Health Councils are recognizing that increasing numbers of people wish to receive palliative care services at home and that increased support is required in the community to meet the needs of people who are terminally ill.

Provision of Palliative Supplies without Charge to Home-Based Clients

(Saskatchewan)

Roger Carriere (Director of Program Support, Community Care Branch, Saskatchewan Health)

In the delivery of health care services in Saskatchewan, the emphasis is placed on caring for people at home. The next alternative usually is in a special care home or health centre, followed by a hospital. Guidelines for developing an integrated palliative care service in Saskatchewan are presented later in these proceedings. Presented here is a description of a unique palliative care initiative whereby the province provides palliative supplies without charge to home-based clients.

The provincial drug plan provides drugs without charge to people at home who are designated as palliative by their physician. Until recently, supplies necessary for palliative care were not covered by a provincial plan when palliative care was provided at home or in special care homes. This arrangement served as a disincentive for some people to leave hospital.

A Policy Directive was issued requesting district health boards to provide without charge to individuals receiving palliative care at their own homes (effective July 1, 1994) and at special care homes (effective July 1, 1995):

- required dietary supplements/meal replacements, and
- all required basic supplies.

Basic supplies include:

- dressing supplies (other than those currently available without charge to cancer patients);
- hypodermoclysis equipment;
- computerized ambulatory drug delivery (CADD) pump equipment, including pain cassettes, and other approved pain control delivery technologies;
- intravenous (IV) equipment, including the minibag IV solutions, tubing, cathlons, heparin locks and caps, syringes and needles; and
- urinary catheter equipment, including catheter bags, connectors and catheter trays.

Within the same time frame, the co-payment for the use of oxygen was eliminated, and blood gas and oximetry criteria for oxygen coverage was waived. In addition, district health boards were requested to provide incontinence briefs without charge to individuals receiving palliative care at their own homes effective April 1, 1995.

To be eligible for benefits related to palliative supplies, individuals must be designated as palliative through the assessment and case management process established by the district health board.

Some outstanding issues remain in terms of access to palliative care services. There is some inconsistency in charges across service sites for individuals designated as palliative. As well, it may be difficult for some district health boards to determine when to initiate the policy regarding supplies.

There is general agreement, however, that this policy regarding palliative supplies is a simple but well received initiative for encouraging palliative care at home and in other settings.

Provincial Palliative Care Steering Committee (Manitoba)

Marion Saydak (Consultant, Program Development Branch, Manitoba Health)

The largest group of people accessing palliative care services in Manitoba are those with cancer. Most deaths occur in acute care hospitals and long-term care facilities.

A goal of the Manitoba direction is to promote a coordinated approach, reduce duplication and ensure effective and efficient resource allocation. Palliative care is provided in a number of arenas--acute care, chronic care, personal care homes and community settings. Manitoba Health funds direct care costs for in-patient services and provides services in the community through the Home Care Program in all community health regions. Palliative care was designated as a core category of service for the newly formed regional health authorities.

Palliative Care Program Steering Committee

This committee was established in 1996. Membership includes representation from facilities, government, NGOs and community. Recommendations are currently under review.

The Terminal Care Education Project

This project was initiated by the Manitoba Home Care Program in response to province wide requests from professionals and family caregivers for information and educational forums on how to care for terminally ill people at home.

Regional expert teams were established to facilitate workshops through regions using modular videotapes and a workbook developed by St. Boniface General Hospital Palliative Care Unit staff. Workshops are directed to professional staff in home care, hospitals, personal care homes, physicians and pharmacists. The teams are also available to provide first line consultation regarding symptom control to the health care professionals in the region. Workbooks and information for health care professionals and informational packages for lay caregivers are also available.

Overview of Provincial Palliative Care Initiatives (Newfoundland)

Eleanor Gardner (Director, Continuing Care, Department of Health)

In 1991, it was recognized that there was a growing demand for a variety of programs, including palliative care, in settings other than acute care hospitals. A response was needed on the part of the government to address these increasing demands as well as correct some of problems of the past such as duplication of services, lack of coordination of services and lack of a reliable information data base.

In 1992, the government released a document outlining a provincial reform process which involved a change from an illness to a wellness model. One of the problems in implementing reforms is that 87% of communities have populations of less than 1,000 people. Therefore, it is difficult to plan programs. In terms of planning palliative care programs for seniors, there are only 56,000 seniors out of a total population of around 500,000. It is hard to plan a highly specialized program for seniors because of the small percentage of seniors who live in towns with small populations.

The government divided the provinces into regions. Each region has two health authorities, one for institutions and the other for the community. Having a separate authority for the community was seen as a way of strengthening the wellness approach. In time, the two authorities may merge.

In each region, there is a community health board with five areas of responsibility: health promotion, health protection, mental health, continuing care and drug dependency. Within continuing care are home care, assessment and placement, home and school support, palliative care, emergency response, rehabilitation and respite services. There is now a single entry model for continuing care services. All referrals come in to one site at each community health board. There, an intake coordinator completes a provincial assessment tool which includes palliative care. As a result of the single entry model, the information data base is improving.

Comprehensive Palliative Care Committee (Newfoundland)

Laurie Anne O’Brien (Palliative Care Program Manager, Consultative Services, Health Care Corporation of St. John’s)

The St. John’s Region Comprehensive Palliative Care Committee (CPCC) came together, through the initiative of Dr. Margaret Scott, out of concern for palliative care clients and to look at coordination for palliative clients across all sectors.

The CPCC is intersectorial and transdisciplinary (committee membership transcrosses multiple professions, sites and agencies with the patient/client/family as the centre of care).

The mandate of the CPCC was to:

- review existing programs and services for palliative care in the St. John's region. The clients will be seriously ill and dying patients with particular emphasis on the home setting.
- identify gaps and challenges in the current provision of palliative care in the region.
- develop a comprehensive palliative care system that improves identified challenges, and that is flexible, available and allows freedom of movement from one care context to another.
- devise an implementation process for this palliative care system.
- assist the Cancer Foundation, Health Care Corporation of St. John's (HCCSJ), Community Health-St. John's Region and other groups in implementing a palliative care system across the continuum of care.
- evaluate the effectiveness of the palliative care system after its implementation and recommend changes when necessary.

Update:

The CPCC has:

- approved a mandate and terms of reference for the CPCC working group and circulation of that document.
- reviewed 11 existing mandates from groups involved with providing palliative care at different levels.
- identified challenges in the current provision of care.
- written the preamble, accessibility and criteria for admission drawing heavily on the 1988 Report of the Community Palliative Care Working Group.
- examined the referral process and identified the need for two streams: routine and crisis.
- examined and modified a "Palliative Care Passport" (based on the Edmonton Model) for patient use to enhance information and communication. This passport will be used on a pilot basis at the Cancer Centre.
- documented the number of calls regarding palliative care by keeping a log of telephone calls and interventions from a variety of settings. This research will help decide about the need for a special 24-hour crisis line and give some idea of the volume of calls.
- listed tentative recommendations

In the middle of carrying out these activities, the HCCSJ was formed. Palliative care was identified as one of the unique programs that should be within the Corporation. From October 1996 to February 1997, the CPCC became the Focus Group for "Phase 2" of program development for palliative care for the St. John's Health Care Corporation with several new members being added.

Some of the major recommendations of the committee were:

- liaison with the provincial palliative care program (which has been done)
- a telephone help line
- that the CPCC be the external advisory committee for the Palliative Care Program of the HCCSJ
- that a database system be developed
- standardization (e.g., assessment tools, standards of care).

Overview of Palliative Care (Nova Scotia)

Susan MacDonald-Wilson (Provincial Director of Home Care, Home Care Nova Scotia, Department of Health)

There are a few successful palliative care programs based in hospitals providing in-patient care and outreach services in Nova Scotia (such as Halifax), although they are in a limited number of hospitals. In some communities there have been volunteer-based initiatives established, but these are few. The availability of palliative care services in Nova Scotia is spotty at best. This is being recognized by the health care community in general and the Nova Scotia Department of Health, specifically. There is a need for an over-arching strategy and policy for the development of palliative care services across sectors. Initial work to that end is under way.

Nova Scotia is in the midst of regionalization. Services are being devolved to four Regional Health Boards. All hospitals, except the tertiary care facilities, have been designated to those regional boards. On April 1, 1997, public health, drug dependency and mental health will be devolved to the boards. Within the next year or two, long-term care and home care will also be devolved to the regional boards.

Home care started much later in Nova Scotia than in the rest of Canada. A provincial program began in 1988, although it was quite restrictive. This program narrowly targeted individuals and did not meet the needs of the province, particularly when Nova Scotia began to move through the health reform process. In 1994, the province undertook the building of a comprehensive home care system, 20 years after the first home care program started in Manitoba.

Home Care Nova Scotia: A Plan for Implementation was published in 1994. In 1995, Home Care Nova Scotia was officially started. This program had substantial differences in policies, structure and governance than the previous home care program in Nova Scotia. The new program is being developed in a step-wise methodical manner over time. The changes in the program were accompanied by dramatic increases in funding, with increases of over 100% in the first year, and corresponding increases in the number of clients. The growth in the home care budget and the number of clients has continued since the first year of operation.

As part of the step-wise evolution of Home Care Nova Scotia, two categories were started in 1995: Chronic Home Care and Home Hospital Care. Chronic Home Care provides similar services as the old program, however age and financial limitations were removed. The Home Hospital Care category provides for early discharge from hospital or hospital diversion. The payment policies in Home Hospital Care are similar to hospitals, i.e., the client does not have to pay for services, acute care medications and supplies. In the Chronic Home Care category, clients may have to pay a fee for home support services.

A Palliative Home Care category is planned in the future. Just recently, the Minister announced another substantial increase in funding for home care. Over the course of this year (1997/98), there will be significant policy development and planning in Palliative Home Care with the view, in the fourth quarter, to piloting some initiatives in one or two areas of the province. The real challenge is not just one of timing; the challenge is also to complement and not duplicate already existing services in acute care, long-term care and home care, while at the same time, over the next few years, insuring that there is equitable access across the province. Such access is currently not available.

Palliative Care Initiatives (British Columbia)

Laurianne Jodouin (Program Manager, Policy, Planning and Standards Branch, Acute and Continuing Care Programs Division, Ministry of Health and Ministry Responsible for Seniors)

Laurianne described one of the pioneer hospice programs in British Columbia—Hospice Victoria. It has been a unique model that other communities in the province are looking to for leadership.

In 1980, the Ministry of Health initiated Victoria Hospice as the first of two pilot projects. The second was Vancouver Hospice. It was initiated to develop a model of care for the dying and to assess its value in the community. A Steering Committee with representatives from the Ministry of Health, the Royal Jubilee Hospital in Victoria and the Capital Regional District appointed a core team to design and set up the project. The pilot phase was completed in 1982 and evaluated by the Ministry of Health. The evaluation showed tremendous community support, effective bed utilization and cost-effectiveness. Hospice Victoria was designated as an ongoing essential part of the health care system.

The hospice had its beginning in grass roots movements in the Victoria community among which was the Victoria Association for the Care of the Dying. This organization was formed to provide a volunteer program of support for the care of the dying. It amalgamated as the volunteer component of Victoria Hospice in 1983, at which time the Victoria Hospice Society was created to operate the organization.

This model has beds located in the Greater Victoria Hospitals Service Society. Victoria Hospice Society operates a community-based regional palliative care program throughout the Capital Regional District. Its offices are located at the Royal Jubilee Hospital where the main acute care hospice unit of seven beds is operated. The budget is 70% government funded and 30% community funded. Its operating budget at the moment is approximately $1.5 million. Government funding accounts for $1.2 million. The remainder comes from the fundraising activities of the Victoria Hospice Society. The public profile of the Hospice Victoria is high.

The program is for anyone suffering from a progressive chronic illness where life expectancy is limited. Referrals are mainly from physicians, home care and hospital nurses but may be made by anyone including the patient or family member. Case management is provided by home care nursing. The range of services provided by professionals and volunteers is available to both patient and family members 24 hours a day. Bereavement follow-up is available for one year after the death of a patient.

In 1987, funding was made available under the Hospital Partnership Program to start the Palliative Care Response Team, a team of physicians and nurses available 24 hours on-call for home visits. This has been one of the major strengths of Hospice Victoria and has filled major needs in terms of access, continuity and the continuum of care.

Education has been an essential component of Hospice Victoria from the beginning. The Society's staff have developed comprehensive educational materials, particularly for professional services. *Hospice Resource Manual: Medical Care of the Dying* was published in 1990 and is available for sale from Hospice Victoria. It is used as the foundation of a two-week education program for physicians at Hospice Victoria. It was also used to develop a nursing continuing education program at the University of Victoria. As a part of this continuing education program, nurses spend time at Hospice Victoria to learn about pain control and symptom management.

Hospice Victoria is highly regarded in the province and with regionalization, it is looking to its future in a regionalized system.

Panel: Palliation in the Continuum of Care: A Diversity of Approaches

Sandra Tingley (New Brunswick)
Terry Kauffman (Quebec) unable to present*
Roger Carriere (Saskatchewan)
Laurianne Jodouin (British Columbia)
Louise Plouffe (Moderator)

This session involved presentations from provincial representatives about palliative care services in New Brunswick, Saskatchewan and British Columbia. What follows are excerpts from those presentations. For further information about provincial and territorial palliative care services, the reader is referred to the document, *Overview of Provincial and Territorial Palliative Care Services* (March 1997), prepared for this symposium. Because of time constraints, group discussion planned in this section of the agenda took place in conjunction with the final plenary session.

New Brunswick

Sandra Tingley (Director, Extra-Mural Program, Health and Community Services, Hospital Services, New Brunswick)

Palliative Care in the Extra-Mural Program (EMP)

History

One of the primary objectives of the Extra-Mural Hospital (EMH), when it was established in 1981, was the provision of palliative care services. Palliative care has always been a high priority and a very visible part of the program. As the EMH opened new service delivery units, one unit began as a palliative care service only for a number of years. It was eventually expanded to provide the full range of home care services. During the years that it was only palliative care, staff became very skilled at, and assisted in, educating staff from other units on palliative care.

Statistics

On any given day, the EMP has approximately 4,000 clients on its caseload of which 5-10% are palliative clients. The number of deaths in the home per year was approximately 700 in 1994/95, an increase of 200 over 1993/94. In 1995/96 an average of 83 bereavement visits were carried out per month.

Services

Palliative care is provided to people of all ages who have a New Brunswick medicare number and who have been referred to the EMP by a physician. Palliative care services are provided in homes and substitutes for homes. EMP also looks after some components of palliation in nursing homes, such as oxygen and IV therapy. They offer a variety palliative care services: symptom management, emotional support, counseling, education, direct care, coordination of services, equipment and support. Any or all members of the interdisciplinary team may be involved. They offer homemaker support especially in the terminal phase and bereavement follow-up.

If clients have insurance, they use it for drugs. If there is no insurance or if the drug is not covered, the EMP provides a drug card. In really high cost cases, the EMP sometimes augments the cost of over-the-counter laxatives for clients who are having side effects from the drugs. Supplies such as dressings, IV solutions, dietary supplements (e.g., Ensure) are provided by the EMP. Some but not all clients may have supplies such as incontinence pads provided by the EMP. Sick room supplies are obtained from the Red Cross or the Canadian Rehabilitation Council for the Disabled.

Policies and Procedures

The EMP has policies and procedures related to death in the home. Topics covered include: death in home expected, death in the home unexpected/unexplained, death in home within 24 hours of admission, registration of death, organ donation, burial permits and Do Not Resuscitate (DNR) orders.

Education

There is a major emphasis in the organization on training. There are resources in each unit. The former Medical Director was also the Director of a Palliative Care Unit which was helpful to the development of the program and staff education. Foundation monies support traveling workshops and major conferences.

Tracking

Many statistics are gathered within the organization but are not integrated with any other system.

Issues in Palliative Care

The following issues were identified regarding palliative care in New Brunswick:

- better education is needed in training professionals, especially physicians, on proper palliative techniques, especially pain management.
- the public needs to know that they do not have to endure insufferable pain and that most pain can be controlled. They need to demand appropriate care and pain management for themselves or their loved ones.
- legislation should not hamper access to appropriate drugs for clients needing narcotics for pain.
- there is a desperate need for enhanced respite resources if clients are to remain at home to die. Often when a client is admitted back to hospital, it is due to burnout in the family which could probably have been prevented with adequate respite.
- it is critical, for palliative care in the home to be successful, that there is 24-hour accessibility of a professional.
- when looking at what is possible to do in the home now, we must not get caught up in our enthusiasm. Just because it “can” be done does not mean it “should” be done.
- there can be much satisfaction for clients and families in providing palliative services in the home environment.
- there are also many costs—physical, emotional and financial burdens on caregivers. This can result in more “patients” for the system if they become unwell from the stress.
- we must be careful how much burden we shift to families. Community care does not necessarily mean care **by** the community.
- in **high cost** case plans, it is not always cheaper to manage someone in the home and so there is the struggle that comes in making decisions that pit “quality of life” issues against “utilization of resources” issues.
- the bottom line is that, although the move is to providing palliative care services in the community, it is not necessarily for everyone.

Saskatchewan

Roger Carriere (Director of Program Support, Community Care Branch, Saskatchewan Health)

This discussion centered on the development of provincial guidelines for delivering palliative care services at the district health board level. These guidelines are described in more detail in the document *Guidelines for Developing an Integrated Palliative Care Service* published by Saskatchewan Health in April 1994.

The Development of Palliative Care

There were a number of drivers that led up to the Guidelines Document. In 1984-86, prior to district health board formation, there was a pilot project at Saskatoon Home Care. That program looked at providing palliative care in home-based settings whenever possible. The program which was interdisciplinary in approach, was viewed as successful by consumers and home care staff. It raised a number of issues such as physicians' willingness to make home visits, assignment of tasks to homemakers, the role of volunteers, whether the person doing the assessment should also be the one providing care, staff time for debriefing and associated costs, philosophical issues such as providing "enriched" services to those who are dying versus sometimes the lower level of support provided to those with long-term illnesses.

Through the late 1980s, the provincial government said that all home care programs should have a palliative care component. Implementation was delayed.

In 1992, there was an official start to the Health Renewal process. The focus was on service that is: client-centred, community-based and outcomes-oriented. The palliative care program fit very well with this philosophy. In 1993, district health boards were formed with the authority to provide all health services. This facilitated the coordination of services in palliative care.

There is a very active provincial palliative care association. There was very serious commitment at the Ministerial and senior bureaucratic level for the development of palliative care in the province.

The Guidelines Document

The purpose of the document was to help district health boards develop a district palliative care program that was integrated and community-based. It was developed in collaboration with the provincial palliative care association, care providers and individuals from the University of Saskatchewan.

The document outlines the principles on which a palliative care program should be based. These are:

- The terminally ill individual and family control the decisions that determine care.
- Palliative care is provided through a coordinated service for assessment, planning and provision of care.
- Palliative care is based on an assessment of the individual's abilities and available family and community resources.
- Service plans preserve and promote the autonomy and functional independence of the individual and family. This is accomplished by recognizing the rights of the terminally ill individual to be heard, to be told the facts, to share in care decisions and to maintain control of one's life.

- The palliative care service addresses the physical, psychosocial and spiritual needs of the terminally ill individual and family.
- An interdisciplinary team of health service caregivers provide a range of commonly required health services, services specific to their own disciplines, and as well with appropriate training and when appropriate, some services associated with other disciplines.
- Skilled medical, nursing and therapist care are available to provide effective pain and symptom control.
- The community of caregivers who provide physical, psychosocial and spiritual support is preserved and promoted.
- Home-based services are the preferred options whenever they provide service appropriate to meet the needs of the individual and family.
- Institutional services are appropriate only when the needs of the individual cannot be addressed by the family and available community services.
- An integrated palliative care service provides bereavement follow-up and support for families and care providers.
- An integrated palliative care service provides educational opportunities for care providers and the public.
- Palliative care services are to be evaluated so that quality care is ensured.

The following outcome expectations were identified for an integrated palliative care service. These include:

1. Palliative care service assists the terminally ill person to live and die in comfort and dignity.
2. Palliative care service is centred on the terminally ill individual and reflects the autonomy and functional independence of the individual and family.
3. Palliative care service preserves and promotes community caregivers and volunteer services to provide support for the terminally ill individual and family.
4. Palliative care education is provided for terminally ill individuals, volunteers, care providers, families and the community.
5. Palliative care service provides for a coordinated system for assessment, care planning and service provision.
6. Palliative care services are provided in an environment appropriate to the needs of the individual and family. Continuity of service is provided should the person move between care settings.
7. Palliative care services address the need for bereavement care to promote wellness in the family.
8. The palliative care services address the physical, psychosocial and spiritual needs of the terminally ill individual and family.
9. Skilled medical, nursing and therapist care are available to provide effective pain and symptom control.

10. Palliative care service provides for legal/financial counseling as needed by the terminally ill individual and family.
11. Palliative care service provides cost effective and efficient care to the terminally ill individual and family.

In home-based service, there has been a general increase in clients and units of service (one hour of care or a meal). Some of this increase may be due to an increased awareness of palliative care. As well, the home care budget has been increased so people are able to provide more care in the home.

The future

District health boards are in various stages of development. Most have programs up and running. However, not many programs have been thoroughly evaluated.

Among the issues for future consideration are: inconsistency in charges across service sites, physician involvement and services in rural areas.

British Columbia

Laurianne Jodouin (Program Manager, Policy,Planning and Standards Branch, Acute and Continuing Care Programs Division, Ministry of Health and Ministry Responsible for Seniors)

In British Columbia, palliative care is viewed as an integral component of the health care services available to residents of the province. In 1994, palliative care was designated as a "core" service. This designation means that palliative care services are required to be provided in each region of the province.

Features of British Columbia’s Approach to Palliative Care

Three features regarding the province’s approach to palliative care were identified.

1. Use of the Existing System

   British Columbia has relied on the existing system as the framework for development of palliative care services and as the mechanism for delivery of these services. A primary reason behind this approach was an assumption that palliative care services be developed at no additional cost to the system. It also meant a reliance on what were seen as the strengths of the existing system: primary care physicians who worked front line with their patients and their families, the hospital system where specialist and specialty services were readily available and a network of provincial health units where community nursing and home support services were already well developed.

2. Mix of Hospital/Specialized Residential/Community-Based

   The Ministry of Health has not been prescriptive with regards to an appropriate mix of services. As a result, the mix is different in each community. Further, the mix in each community evolved based on who the champions were in that community.

   Models emerging are consistent with the provincial approach of using generic existing services complemented by specialized services. Models emerging demonstrate consensus as to the essential components of palliative care. These include: physician consultation, pain and symptom control, interdisciplinary team, counseling, volunteer support, bereavement programs and spiritual care.

   Specialized services are specific programs that offer combinations of treatment, consultation and professional education services. They may be hospital- or community-based. These specialized programs served as focal points for development of expertise in palliative care and development of new service approaches.

   Not-for-profit hospice societies have been a strong element in BC. Programs offered through these societies include volunteer visiting, social and emotional support, grief recovery and bereavement follow-up.

3. Use of an Evolutionary Process to the Development of New Approaches and Funding Mechanisms.

<u>Issues/Trends</u>

The following issues and trends have been identified:

- palliative care as “core service”
- home-based care
  - more people are choosing home as their preferred choice of location
  - barriers include: availability of support: physician, nursing, home support, cost of medications, 24-hour nursing, burden becomes too much for family, availability of respite services, availability of supplies (e.g., incontinence products, skin care, bathroom aids), management at the time of death.
- support for families
  - respite services
  - training in pain and symptom control
  - counseling
- volunteers
  - paid* coordinators for volunteer recruitment, coordination, training and ongoing support, program management. (* This was a frequent funding request of Closer to Home proposals).

Community-Based Palliative Care in a Regionalized Health System

In BC, the regionalization process began under the New Directions program. It involves the development of Regional Health Boards, Community Health Councils and Community Health Service Societies that would assume governance responsibility for health care services in their region and that would receive authority for the allocation for resources within their region.

Delegation of authority to regional and local health authorities is progressing rapidly. Transfer of responsibility to Regional Health Boards is scheduled to occur on April 1, 1997. To date, BC has 11 Regional Health Boards, 34 Community Health Councils and 7 Community Health Service Societies. Transfer of responsibility to Community Health Councils and Community Health Service Societies is scheduled to be completed by October, 1997.

Some of the opportunities under a regionalized system:

- move to a patient-centered delivery system will mean eliminating barriers to care in the home and greater emphasis on support services (respite, 24-hour nursing and volunteers)
- integration of services across the continuum
    - possibility to develop a common philosophy, definitions
    - important to view the palliative care program as a regional system. There needs to be: better linkages to other parts of the system (e.g., hospital, community-based services, voluntary), data linkages, comprehensive and coordinated service approach, efficient delivery, components supporting each other, flexibility to shift resources where needed (e.g., shift nurses in home), emphasis on financing gaps in the system, detailed cost and impact analysis, priority setting, evidence-based decision making.
- collaborative planning
    - can develop a system that works for the community (urban, rural)
    - all stakeholders at the table determine needs together
    - new mechanisms for collaborative planning—Advisory Committees/Regional Councils
    - new mechanisms for sustained development of palliative care services.

Conclusion

The Royal Commission of Health Care and Costs, in its 1991 report, told of communities' request for palliative care. Commissioners felt that such requests reflected a deep concern that the last days of someone's life be as fulfilling and pain-free as possible. They further commented that while British Columbians can be proud of the programs which are in place, more can be done to provide palliative care.

The findings of the Commission has set the tone for the next phase of development for palliative care services in British Columbia. Commissioners recommended that palliative care should be:

- an option for people of all ages who are dying from any disease
- provided wherever and whenever the dying person chooses
- home-based, whenever possible.

Given the strong tradition of advocacy for palliative care in the province of British Columbia, and the strong foundation of services which has been built across the continuum of care, there is a strong basis to believe that British Columbia will meet the challenge ahead in community-based programming for palliative care.

Part III—Discussion Topics for the Future

Discussion #1: Tradeoffs and Balance in Provincial Programming: The Place of Special Needs, Legal and Ethical Considerations in the Development of Provincial Programs and Services

Louise Plouffe, Sue Morrison, Nena Nera (Facilitators)

1. Where does palliative care fit in the spectrum of home- and community-based services? Is it (or can it be) a stand-alone program? How is it connected to other services?

Home- and community-based care encompass a wide variety of services for maintenance, prevention, etc. Palliative care is an area where there is a need for a number of services. The main issue is how to advance palliative care within the continuum of services.

The following arguments were put forth for having palliative care a stand-alone program:

- palliative care is a different service with a distinct philosophy and set of goals. Therefore, care should also be distinct.
- starting a palliative care program as a separate program allows it to have focused development as a program, helps it to be taken out into the community and allows issues such as definition to be discussed among stakeholders. Integration can occur later.
- it will not get lost among competing services.
- palliative care programs often begin through grass roots initiatives to meet local and regional needs.
- administratively, palliative care and home care may be integrated but from a service perspective, they should be kept separate.
- some suggest that from a funding point of view, a separate program is easier to manage.

Reasons suggested for having palliative care integrated with other programs included the following:

- creating a stand-alone program could create overlaps and duplication of services and disrupt continuity of care. Many components of palliative care are the same as for other kinds of supportive care. We cannot afford to create parallel systems.
- it is more efficient to use palliative care teams in a general program.
- stand-alone programs are not viable in areas of low population density. In remote areas, it is often difficult to provide general home care service let alone specialized palliative care services.

- when the philosophy of care incorporates “death as part of living” as in CLSCs, it is considered best to deal with palliative care from a general approach, otherwise, people may be changing categories of care as often as their condition changes.

There was also discussion about having all care providers trained in palliative care versus specialized palliative care teams. Specialized teams or specialized consultants may be required in some circumstances, e.g., to meet complex care needs of children. Specialized consultation can be accessed through 24-hour telephone lines. In some jurisdictions, specialization occurs only in terms of case management.

Some providers have found that it is preferable to have all staff knowledgeable about palliative care. The Victorian Order of Nurses (VON) palliative care program evolved from a specialist to generalist program. Generalists with a broad knowledge base were more effective at providing service at an early stage in the disease process.

2. What factors have shaped existing community- and home-based palliative care programs/services? What emerging issues and trends will play roles in the future evolution of these programs/services?

Several issues have determined and will determine where palliative care services are provided. In general, people prefer care in the home with access to support services. However, no one setting is appropriate for everyone. The types of needs and the availability of resources influence where people will receive palliative care. It is sometimes preferable for patients to receive palliative care in hospitals.

Cost and funding issues

The Canada Health Act is viewed as a barrier to home- and community-based palliative care because care (other than physician care) outside of hospitals is non-insured. Charges for drugs and services outside the hospital can be incentives for individuals and families to use hospital services and for the public sector to discharge people home (even if the overall costs of home care may be greater). There was general support for the recommendation of the National Forum on Health that community-based services and prescription drugs be included as insured services. Some provinces, such as New Brunswick, cover home care as an insured service.

There is also an assumption “out there” that it is cheaper to provide palliative care at home. This is generally untested although there have been reports of studies is particular regions that have found this to be the case. Good quality palliative care at home is not cheap. The assumption that it is cheaper than hospital-based palliative care frequently rests on the assumption that family and friends will provide care at no cost. The direct and indirect costs to family and friends are not factored into the equation. This is cost shifting rather than cost saving. Family and friends are not always available nor able to provide care. In these circumstances, the ability to receive palliative care at home may be decided by the ability to pay for support services. It appears that private insurers are requiring more detailed information to assess clients' needs and determine what will be covered.

Substitutes for home that are closer to home are needed such as nursing homes and day hospices. The scope of partnerships needs to be widened. Non-traditional partnerships could be formed by linking up public sector programs with suppliers and the corporate sector. More creative planning is required.

Definition of palliative care and designation as a palliative care client

There are often many operational tangles related to the designation of who is eligible for palliative care and when. As well, common definitions of what services and components are needed for palliative care may create barriers to good care. For example, programs need to be flexible to allow for several episodes of heavy care with lighter care in between. People need to understand what services can be provided at home and what the limits are. For some individuals and families, institutional care may be better. It should also be recognized that a person may have the support necessary to die at home without the services of a formal palliative care program.

Continuity of care

Although community/home care has done a better job of meeting a whole range of client needs than hospitals which tend to compartmentalize programs, patients often experience little or no continuity and integration (e.g., between hospital and home). Regionalization of service delivery may help to ensure that planning is done in a holistic way across sectors. However, "turf" wars and rigidity related to issues such as funding and labour may make continuity difficult to achieve.

Health care provider issues

Interdisciplinary practice should be promoted. Better communication among professionals is needed. The model of collaborative practice developed by CNA and CMA should be investigated by those working in palliative care. As well, collaboration could be enhanced by interdisciplinary programs for professionals during their basic education. In palliative care, much of the care is provided by home support workers and paraprofessionals who may not be considered part of the interdisciplinary team. These workers need adequate pay and support. The contribution of volunteers must also be recognized.

With the move to self-managed care, employer-employee relationships and unionization have become issues. As well, in the move to home care and privatization of services, concern is being expressed regarding workers' rights (e.g., lower wage scales).

Physician support

The lack of physician support has been identified as a barrier to the delivery of palliative care services at home. It was suggested that, with medical backup in the home, 80% of persons receiving palliative care could die at home. Suggestions for increasing physician support include: increasing the level of physician awareness of palliative care programs, providing specialist support to primary care physicians, increasing the amount of consultation with physicians when programs are being set up; changing physician billing structures to include adequate reimbursement for home visits and interdisciplinary communication; having salaried physicians with training in palliative care.

Family support

Families need access to 24-hour on-call services, respite care, counseling, bereavement support.

3. Within palliative care, is there a place for even more specialized programs and services (e.g., for specific disease entities, age groups, living situations, etc.)?

Both general and more specialized palliative care programs are needed. The needs, costs and goals are different in terms of organization, structure and issues. Specialized services are needed especially in the early stages of program development.

There is a need for specialized programs for people with AIDS in communities with a large number of clients.

Several palliative care programs have identified the populations they are able to serve in the information they provide for the Canadian Palliative Care Association's directory of palliative care services.

4. To what extent should we incorporate legal/ethical considerations in the determination of the elements of palliative care services?

Palliative care needs to look more closely at the issue of advance directives. Advance directives need to be discussed as part of general health system considerations so that they are not labeled as a palliative care initiative alone.

The CPCA has a province by province directory on the status of advance directives. Each province approaches advance directives differently. Many people are not aware of advance directives and are not informed that completing an advance directive is an option for them. More public and professional education about advance directives is needed. For example, educating physicians about stages of treatment may be useful.

One U.S. study indicated that the number of palliative care patients with advance directives was 15%. Seventy per cent of people asked if they wanted treatment said no. The study concluded that $55 billion could be saved if advance directives were used by 50% of palliative care patients. Through the use of advance directives, it may be found that many people would not chose expensive options. The amount of money spent on futile treatments is significant and unnecessary. The question of futility needs further study. Decisions regarding advance directives are still at the individual level. A meta-analysis of the literature regarding the use of advance directives at various levels is needed.

Discussion #2: Provincial/Territorial Training and Education in Palliative Care: Identification of Issues and Needs

Louise Plouffe, Sue Morrison, Nena Nera (Facilitators)

1. What are the greatest needs regarding resources for training and education for palliative care?

There is some good training being done in palliative care but overall there is a lack of training.

Training and education are needed for all health care workers who provide palliative care but need to be targeted specifically to:

- physicians in rural areas
- workers transferring from hospital to community sectors
- volunteers
- those working in the homes of people with HIV/AIDS.

Recommendations regarding training and education:

- educational needs could be explored considering level of response, i.e., first response level is person needing care, then primary informal caregiver, then primary formal caregiver, then specialist, etc.
- basic as well as continuing education in palliative care is required (e.g., two-year specialty program in medicine)
- mentorship programs for physicians should continue to be developed
- an infrastructure for funding in education is needed
- in addition to formal education, alternate educational methods need consideration (e.g., conferences from CPCA and hospice associations, teleconference for in-service, telemedicine).

Recommendations regarding training and educational resources:

- a listing of palliative care resources should be published in a variety of public publications
- there should be encouragement for sharing resources
- program content concerning spiritual and cultural issues and emphasizing the importance of confidentiality are needed.

Some suggested resources are:

- list of palliative care education programs in Canada prepared by Nova Scotia
- CPCA web site which is being developed
- designated specialists for consultation
- specialists in palliative care who travel to other sites to provide palliative care education
- *The Aid for Palliative Care*, a resource developed for physicians at the University of Alberta School of Medicine.

2. To what extent are paid home care workers trained for palliative care? Should all home care workers receive some palliative care training, or should there be a degree of specialization for palliative care?

Paid home care workers need more training. Currently, there is great variation in training. For example, palliative care content may be part of core training programs in community colleges for homemakers. Others receive little formal training.

Many home care workers want training but the opportunity is not provided during work hours nor is there remuneration for attending training sessions. As well, the rate of staff rotation may be a disincentive for accessing appropriate training. The different entry levels of home care workers make providing training a problem. Some have little education; others may be highly educated health providers displaced from other positions. This lack of consistency in educational preparation can also cause problems in terms of employee and employer expectations. For example, nurses working as unregulated home care workers may be expected to perform as nurses without the formal responsibility and at much lower wages. Self-paced learning packages and educational videos may be useful training methods for this group of home care workers.

3. What is the role of informal caregivers and volunteers, and what training and education do they have access to and need for?

There was little discussion of the role of informal caregivers and volunteers. It was pointed out that informal caregivers need to be informed about the extent of services available for home care and the possible need to pay for additional services. This will assist the individual and family decide whether care at home is a realistic option.

Families need training in areas such as pain management. Volunteer training should be carried out by paid staff using standardized materials (curriculum and training guide).

Public education in areas such as pain control and how to access the system is the most effective lever to effect change. Public service announcements and posters during Palliative Care Week developed by the Canadian Palliative Care Association will assist with public education. The first thrust of public education should be on changing people’s attitudes toward dying at home. Then it is necessary to ensure that the financial incentives are in place to allow this to happen. In Australia, for example, informal care providers receive a “carer’s allowance”.

4. How much uniformity in training resources and programs is there/should there be? Would a greater degree of information sharing/networking/standardization be desirable, or does the diversity of approaches to palliative care programming dictate a diversity of approaches to education and training as well?

In general, there was little specific discussion about these questions. It was suggested that there should be more uniformity is terms of standard core curriculums. The CMA, for example, is encouraging a standard core curriculum.

There should also be standards for education. A more general discussion of standards for palliative care took place. The issue of having best practice guidelines was raised. The draft standards of CPCA could be used to form basic guidelines. Some facilities have used these as part of preparation for accreditation. Standards need regular monitoring. It was pointed out that rural areas would have difficulty meeting provincial standards. The Canadian Home Care Association is working with the Canadian Council on Health Services Accreditation on home care standards.

A national initiative on palliative care by Ministers Responsible for Seniors and Ministers of Health is needed. As well, palliative care should be put on the agenda of the Federal/Provincial/Territorial Advisory Committee on Health Human Resources.

Presentation and Discussion: Information Requirements: Approaches for the Future

Sue Morrison (Senior Advisor, Health System and Policy Division, Health Canada) and Frank Fedyk (Acting Director, Health System and Policy Division, Health Canada)

The Report of the Working Group on Continuing Care identified three types of issues to be addressed:

- system and provider issues
- population and target groups
- tax and transfer issues.

The Working Group also identified the three key components of federal continuing care strategy:

- address needs of population groups whose needs are not currently adequately addressed
- support caregivers
- support movement to health determinants/a community-based care model.

There are a variety of health system impacts related to the cost of care at the end of life. For example, according to the OECD, care in the last year of life represents about 20% of all care costs. Focus on care at the end of life can have a significant impact on the effectiveness and efficiency of the system. Although there is no Canadian data on cost of care at the end of life, it is likely that a large amount of money is spent on people near death.

Several impacts of care on population health have been identified. These include:

- the direct impact on health/quality of life of the dying person
- system-mediated impacts on family and caregivers (e.g., stress, coping capacity)
- observed quality of care contributes to the population’s security/insecurity and sense of control about one’s own death in the future.

The Health Canada Working Group on End-of-Life Care adopted the following Frame of Reference:

- consider the Senate Committee recommendations in the context of Health Canada’s roles, responsibilities and priorities
- identify work done or under way
- identify gaps and possible approaches
- implement measures within the existing mandate and means of subgroup members
- identify components of an approach to address remaining needs.

The major identified gaps and needs are:

- need for information systems and population-based data
- need to compare, evaluate and assess models of care
- need to address the issue of focus and scope of palliative care
- need for outcome measures
- education gaps
- lack of researchers
- need for professional guidelines and public education.

There have been several examples of recent and ongoing Health Canada activities related to palliative care:

- support to the Canadian Palliative Care Association for the development of the working document on Standards (through the AIDS initiative)
- guidelines regarding care and treatment of breast cancer in the areas of pain management and follow-up (through the Breast Cancer initiative)
- funding of research and publications on AIDS care and treatment
- pilot project/feasibility study on a national palliative care surveillance system (Cancer Bureau)
- National Working Group on AIDS Palliative Care: education, training and awareness work
- Communication Skills in Breast Cancer
- Palliative care was a priority in the 1996 National Health Research and Development Program.

Reasons for action on end-of-life care at the present time include:

- the aging of the population
- the growing importance of chronic diseases as a cause of death as well as the cost of care at the end of life
- the shift to home-based and community-based care
- the evidence of a significant degree of unmet need (e.g., from the Special Senate Committee)
- ministerial affirmations of the importance of palliative care and home care
- the findings and recommendations of the National Forum on Health
- the level of public concern.

Several priorities and possible actions have been identified including:

- information sharing (e.g., program information, outcomes and impacts of reforms)
- more standardization of definitions, terminology, data elements and outcome measures
- further development of program guidelines and standards
- collaborative development of education resources and training programs

- evaluative studies to assess systems, determine “best practice” models, evaluate different models of delivering services to dying patients
- a national surveillance system for palliative care
- research support, such as Centres of Excellence.

Health Canada cannot do all of this alone. Partnerships with the provinces, territories and NGOs are very important.

Summary of Group Discussion

The discussion centered on the priorities and possible actions identified above.

The question was asked: “Is there a need for a **national surveillance system** and, if so, are provincial systems functioning in a way to allow link up?” One participant indicated that she would be concerned about a national surveillance system for palliative care that was separate from a surveillance system related to the whole health system. If people are coded as palliative care in a single entry system, we may not know how they move through the system. It was suggested that carrying out evaluative studies should be a priority. A national surveillance system could be the infrastructure on which evaluation studies could be built.

A number of participants stressed the necessity to move toward **standardized definitions.** Standardized definitions, terminology, etc. would facilitate comparisons between provinces, information sharing about programs and outcomes, development of a national data set for palliative care.

It was suggested that **support for caregivers** be added to the priorities. This action ties in with other identified priorities such as the development of education resources and training packages. Informal and formal caregivers are impacted by such developments. In evaluative studies, it would be important to examine how training impacts on caregivers.

Several participants identified another priority action: **the development of a mechanism to facilitate ongoing federal/provincial/territorial dialogue about palliative care issues**. Among the reasons put forth to support the importance of developing such a mechanism were the following:

- collaboration on priority issues in palliative care is essential. Most issues are beyond the mandate of any one jurisdiction. It is important to learn from each other and not to duplicate efforts.
- there has been an absence of a formal process for collaboration about continuing care and palliative care at the federal/provincial/territorial level at a time when these sectors are emerging as an important part of the health care system. For example, there has been no forum to discuss the impact on the continuing care sector of financial constraints in the health care system.

- in the absence of a formal mechanism for collaboration, informal strategies have been developed (e.g., teleconference for home care directors). Although helpful, these informal mechanisms do not substitute for the formal collaborative processes that were available in the past.
- a mechanism for federal/provincial/territorial collaboration would facilitate futuristic thinking concerning palliative care policies and strategies. At the provincial and territorial level the focus is, of necessity, on planning and paying for services.

Given the current ministerial interest in continuing care and palliative care, it is important to seize the opportunity to advocate for the development of a formal mechanism for federal, provincial and territorial dialogue and collaboration.

Plenary Discussion: The Future of Community- and Home-Based Palliative Care in Canada: What can Governments do to Advance the Markers?

Louise Plouffe (Chair)
Frank Fedyk and Sue Morrison (Facilitators)

Frank Fedyk set the stage for the final plenary discussion. What is needed is for all levels of government to have a common idea of the issues, challenges and opportunities in community-based and home-based palliative care and then to propose solutions and recommendations.

In summary, the issues concerning community- and home-based palliative care in Canada include those related to:

- programs, services and benefits (e.g., agreed-upon common definitions and standards)
- education and training
- the care recipient and care provider (e.g., recognition of the role of formal and informal caregivers and multidisciplinary teams)
- public awareness and education (e.g., the Fact Sheet on Palliative Care for Seniors)
- ethical and legal dimensions
- research and knowledge generation (e.g., a coordinated national approach to research, Centres of Excellence Program, a national surveillance system).

We need to identify the challenges and opportunities related to each of these issues and, for each challenge or opportunity, identify some solutions and recommendations. We need to ask:

- what needs to be done?
- what should be done first?
- who should be responsible?
- what is the time frame for action?

What can governments do to move the markers? Who should governments be working with on these issues?

Summary of Group Discussion

A **federal/provincial/territorial forum** for discussion of palliative care issues is urgently needed. Such a forum would facilitate needed philosophical and public policy debate and should have as its goal the generation of a minimum national policy or set of standards for palliative care.

Members of a F/P/T forum on palliative care could help prepare for the future by:

- debating philosophical and policy issues related to palliative care. For example, do we have adequate resources to deliver home- and community-based palliative care? Can we as a country afford to provide 24-hour nursing care to enable everyone who wishes to die at home to do so? Is this realistic? How does quality of life measure up against efficient use of resources?
- identifying how the federal and provincial and territorial governments can work collaboratively on financial issues such as portability of palliative care services, out-of-pocket expenses for drugs, 24-hour nursing care
- developing a research agenda in palliative care
- proposing mechanisms to increase both public and professional awareness of palliative care issues.

A F/P/T forum on palliative care should not be structured as such forums were in the past with the federal government leading and the provinces and territories following. Rather, it should be an equal partnership in which the federal government provides the tissue to connect the provinces together. In this way, we can collectively come to our own national agreements and develop good public policy and implementation strategies not only for palliative care but for continuing care as well.

In the words of one participant, “We have identified the issues...why not just get on with it.”

Frank Fedyk closed the symposium by delineating some of Health Canada’s **next steps** related to palliative care. Health Canada will:

- prepare and distribute the Symposium Proceedings
- move forward with its action plan related to end-of-life care and palliative care
- ensure that palliative care is included on the agenda of the Federal/Provincial Territorial Officials Meeting on Seniors Issues
- ensure that palliative care is included on the agenda of the meetings of the Ministers of Health and Ministers responsible for Seniors.

Appendices

Appendix A: Symposium Agenda

INVITATIONAL SYMPOSIUM ON PALLIATIVE CARE: PROVINCIAL AND TERRITORIAL TRENDS AND ISSUES IN COMMUNITY-BASED PROGRAMMING

Radisson Hotel, 100 Kent Street, Ottawa - Salon 2 (lower lobby)
March 23-24, 1997

Agenda

Day 1, Morning:

8:30 - 9:00	Registration, Coffee and muffins
9:00 - 9:15	Overview and Purpose of the Symposium - Louise Plouffe, Master of Ceremonies
9:15 - 9:30	Opening remarks: “A Snapshot View of Palliative Care Across Canada" - Susan Fletcher
9:30 - 10:15	Presentations: “Ethical and Legal Issues” - Jocelyne Saint-Arnaud "Generic versus Specific Needs in Palliative Care: Caring for All Canadians” - Linda Kristjanson
10:15 - 10:30	Break
10:30 - 10:50	Presentation: Palliative Care Needs and Seniors - Margaret Ross
10:50 - 11:10	"Vignettes" - Brief presentations of some provincial initiatives: Alberta - *Palliative Care: A Policy Framework* - Vivien Lai Ontario - *Update on Palliative Care* - Anna Burwash Saskatchewan - *Provision of Palliative Supplies Without Charge to Home-Based Clients* - Roger Carriere

11:10 - 12:00 Break-out into discussion groups:
Tradeoffs and balance in provincial programming: The place of special needs, legal and ethical considerations in the development of provincial programs and services.

12:00 - 1:15 Lunch

Day 1, Afternoon:

1:15 - 2:30 Education for Palliative Care in the Community Presentations:

"Community Based Palliative Care Project" (A project carried out jointly by the Canadian Palliative Care Association and the Canadian Association for Community Care, funded by New Horizons: Partners in Aging)
- Linda Lysne and Sharon Sholzberg-Gray

"A Comprehensive Guide for the Care of Persons with HIV: Palliative Care Module" (Funded by the AIDS Care, Treatment and Support Unit under the National AIDS Contribution Program of Health Canada) - John Flannery

2:30 - 3:00 "Vignettes" - Brief presentations of some provincial initiatives:

Manitoba - *Provincial Palliative Care Steering Committee*
- Marion Saydak

Newfoundland - *Overview of Provincial Palliative Care Initiatives* - Eleanor Gardner
- *Comprehensive Palliative Care Committee*
- Laurie Anne O'Brien

Nova Scotia - Susan MacDonald-Wilson
British Columbia - Laurianne Joduoin

3:00 - 3:15 Break

3:15 - 4:00 Break-out into discussion groups:
Provincial/Territorial Training and Education for Palliative Care: Identification of Issues and Needs.

4:00 - 6:00 Video session: screening of videos developed for palliative care education needs.

Day 2, Morning:

8:30 - 9:00	Coffee and juice
9:00 - 9:10	Introduction to the day
9:10 -10:00	Presentation and Discussion: Information Requirements: Approaches for the Future - Frank Fedyk and Sue Morrison
10:00 -10:15	Break
10:15 -11:30	Panel: Louise Plouffe, Moderator Palliation in the Continuum of Care: A Diversity of Approaches New Brunswick - Sandra Tingley Quebec - Terry Kauffman Saskatchewan - Roger Carriere British Columbia - Laurianne Jodouin
11:30 - 12:25	Plenary Discussion: The Future of Community- and Home-Based Palliative Care in Canada: What can governments do to advance the markers? Chair: Louse Plouffe Discussion Facilitators: Frank Fedyk and Sue Morrison
12:25 - 12:30	Closing Remarks

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Appendix D: Videos Developed for Palliative Care Education Needs

1. “Palliative care in the home: Breaking Down the barriers” from the Manitoba Terminal Care Education Project (Duration: 38 minutes)*

2. “Journey” from the B.C. Hospice Palliative Care Association (Duration: 16 minutes)**

3. “When does palliative care begin?” from the Manitoba Terminal Care Education Project (Duration: 18 minutes)*

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Appendix E: The Ethical and Legal Dimensions of End-of-Life Treatment Decisions: What we can learn from the treatment of persons living with Aids

(Text of presentation)

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Today's presentation is part of a broader study of the ethical and legal aspects of end-of-life treatment decisions. Based on a survey of the literature of the last ten years in France, Great Britain, the United States, the Netherlands and Canada, it focusses on the ethical problems that arise in decision making in the context of end-of-life treatment. Of necessity, such decisions have a palliative goal, in the sense that the illnesses involved are irreversible and terminal. End-of-life care and treatment will therefore be aimed at pain relief and comfort measures (Scanlon, 1989) so as to maximize the patient's well-being at this time.

Our interest here is in the experience of patients with AIDS, because we feel that their particular experience provides a good example of the ethical and legal issues that arise when someone is dying, no matter where the experience takes place or who is involved.

All the legal issues concerning end-of-life treatment revolve around two major themes: consent to or refusal of treatment on the one hand, and requests for euthanasia or assisted suicide on the other. Ethical issues are more varied. They concern the release of information regarding diagnoses and prognoses and the concomitant conditions, treatment decisions, respect for the patient's autonomy, conflicts between members of the health care team and conflicts between the health care team and patients or their relatives with respect to values propounded, requests to hasten death, withdrawing or withholding of life-sustaining treatment, and the moral distress of those involved. The source of all these problems is two-fold: the various parties involved have not received adequate training regarding legislation and ethical benchmarks by which these problems can be effectively managed and, even more fundamental, the patient and the health care team have trouble establishing good communication, i.e. communication leading to consensual decisions regarding end-of-life treatment that supports the palliative goals mentioned earlier.

In this paper, I will use the case of patients with AIDS to illustrate the ethical and legal problems involved in end-of-life treatment decisions. With these patients, the problems are often further complicated by their relative youth, the etiology, and the taboos surrounding illness and death. These circumstances bring out problems that are less obviously present in other groups of patients but that insidiously undermine the palliative goals pursued. First of all, certain data with respect to requests for euthanasia in this group will be analyzed with this situation in mind. Then, communication problems reported in the literature with respect to requests for euthanasia and assisted suicide will be extended to include communication problems related to any decision to provide, or not to provide, treatment. Finally, guidelines to improve the decision-making process in the solution of ethical and legal problems concerning end-of-life treatment will be presented.

I - Requests for euthanasia and assisted suicide

The most important legal issue in the treatment of persons with AIDS is, in our view, concerned with these groups' more frequent requests for euthanasia and assisted suicide (Werth, 1995; Battin, 1995; Mazuk et al, 1988, cited by Werth). The legal context for such requests is different for the Netherlands, where the practice is established and legally tolerated under certain conditions.

In the context of the Netherlands, requests for euthanasia are more numerous than requests for assisted suicide, and it is interesting to note that authors like Bindels, et al (1996) use the terms like "extreme form of palliation" to describe acts of euthanasia carried out on persons with AIDS. Those who chose this manner of hastening their death did so when physicians estimated they had only about one month to live (van den Hoek, 1996; and Bindels et al, 1996). Of those diagnosed with AIDS between 1985 and 1992, all of whom died before January 1995, 22% according to Bindels et al (1996) and 26% in Amsterdam according to Laane (1995) opted for euthanasia or assisted suicide. It is those who survive the longest after diagnosis that chose this manner of death. This would indicate greater suffering and more of an opportunity to discuss this option with friends and physicians (Bindels et al, 1996). It is important to note that one author mentions that requests for euthanasia made at the end of life when physical suffering begins, without discussions or earlier exchanges of view, are not granted (van den Boom, 1995), which would eliminate as candidates for euthanasia those who died soon after being diagnosed. It must also be understood that not all requests were granted and that many patients who initially opted for euthanasia changed their minds. Since half the requests resulted in euthanasia (van den Boom, 1995), it can be concluded that 44% of persons with AIDS in the Netherlands had seriously considered euthanasia and requested it. According to van den Boom (1995), 48.1% of persons with AIDS had discussed euthanasia with their partners in the initial stages of the illness. The reasons given are loss of dignity, pain, an unworthy death and dependence on others (Laane, 1995). By turning to euthanasia, people want to prevent unbearable suffering and a degrading existence (van den Boom, 1995).

Persons with AIDS in the Netherlands resort to euthanasia more often than to suicide, as does the general population for that matter. Those with suicidal ideation are more often found among those who die by refusing treatment or by increasing pain relief medication. These groups have trouble accepting their HIV/AIDS status (van den Boom, 1995)

In countries where euthanasia and/or assisted suicide are not institutionally accepted, the context is very different. These actions are therefore not performed openly, although an American author (Battin, 1994) is of the opinion that assisted suicide is readily available to persons in the terminal phases of acquired immunodeficiency syndrome, and a Canadian author (Voigt, 1995) says that family physicians who treat seropositive individuals receive more requests for euthanasia than most other physicians. Canadian authors (Voigt, 1995; and Kuhl, 1994) write freely about how to manage requests for assisted suicide and euthanasia, and several authors such as Tindall et al (1993) think that it is legitimate for persons in the terminal phases of illness to think about hastening their death, and that there is such a thing as rational suicide.

A 1995 study in Great Britain by Green found that 28% of HIV-positive individuals (33% if interview data are included) had considered asking for assistance to hasten death, but only 3% of them had asked for their seronegative controls to be monitored. These results are comparable to the results of a study done of the relatives and friends of those dying of any other illness, excluding sudden deaths (Searle and Addington-Hall, 1994).

HIV-positive individuals form opinions about the progress of the illness and about death from the experience of their friends (Green, 1995). And according to Green (1995), family members are more inclined to want death hastened, while a study of family members in the Netherlands indicates that the majority of survivors would have liked the action postponed (van den Boom, 1995). In that country, there was a study of the grief experienced by survivors. Twenty percent suffered clinical depression and 29% of partners suffered depressive episodes, although no relationship could be found between the manner of death and complicated grief. In fact, it seems that when the euthanasia process is complicated, grief is also complicated. In van den Boom’s study (1995), grief was complicated in six out of 12 cases, for the following reasons:

- the patient died the moment the injection was given;
- the patient was conscious for a period of 4 to 6 hours after the injection;
- the physician asked the relative to administer the medication;
- relatives had to decide when euthanasia would be performed;
- two partners became psychotic, one of them because he could not stand the thought that his friend was in possession of medication which he could use to end his life at any moment (van den Boom, 1995).

In all these cases, complications could have been anticipated if physicians had taken a clear stand on euthanasia or assisted suicide from the outset, and if they had a better knowledge of the dosages required to bring about death within the desired timeframe (van den Boom, 1995). This is a very technical consideration. However, in this, as in the simple case of failure to relieve pain, which is mentioned as one reason, if not the main reason for resorting to euthanasia, physicians have not received the training they need to intervene effectively. This is even more true in the case of HIV-infected children, a particularly vulnerable group (Rushton et al, 1993). Nothing is done to relieve their suffering and they often have no one to come to their defense. The other issue of the need for health care providers to examine their own values about death and the kinds of intervention they find acceptable brings us directly to an examination of the decision-making process as it relates to end-of life treatment.

Kuhl (1994) found that euthanasia and assisted suicide were not the most important issue raised by the patients in his study of persons living with AIDS, because requests apparently came only from patients whose pain was not relieved. It is our view that the crux of the matter lies in the quality of communication between the various people concerned.

II - The decision-making process in the choice of end-of-life treatment.

Numerous authors (Rushton, Hogue et al, 1993; Rusin, 1992; Scanlon, 1989) favour the use of advance directives (living wills and powers of attorney) by the patient. However, even in the United States, where caregivers are required by law to inform patients of the existence of these opportunities, barely 20% of patients drew up such a document (Rusin, 1992) and the provisions contained in them were not always applicable or applied. Good communication concerning end-of-life treatment is therefore necessary. Unfortunately, a number of obstacles stand in the way, particularly concerning clarification of the values of the various people involved.

Contrary to the situation with oncology, a psychological approach has been favoured in the case of patients with AIDS (Kuhl, 1994). The reason undoubtedly lies in the social prejudices surrounding this illness and in the fact that the majority of persons afflicted are relatively young homosexuals (90% are between 20 and 49 years of age, Werth, 1995) who have not always come to terms with their sexual orientation when they find out they are HIV positive. Some patients experience guilt, remorse or regret, preferring that their illness and sexual orientation be kept from their families. When euthanasia is first considered, the patient's dominant emotion is fear: fear of death, fear of pain, fear of becoming a burden, fear of losing control. These fears and guilt feelings are shared by friends and relatives alike. For an understanding of how families feel on learning of this diagnosis, when they were unaware their sons were homosexual, read Stewart (1994, pp. 332-333). Some parents blame themselves or are blamed by others. Emotional reactions in these circumstances lead to rifts or dramatic changes of attitude.

How can a professional caregiver help the patient and his relatives confront any fears, distress and emotions they may have at the news of a fatal diagnosis if they have not themselves clarified their own values about death and terminal illness? It is therefore vital that those working with patients with illness for which there is no treatment give thought to their own values and reflect on the extent to which they are prepared to become involved in all issues of treatment related to withdrawing or withholding of treatment that will result in death, as well as the issues of euthanasia and assisted suicide. It must be possible to discuss these matters openly and without discrimination, particularly on grounds of sexual orientation. The clarification of each individual's values therefore appears to be the first stage in a decision-making process that is not a once-in-a-lifetime event but that must take place at all the important stages in the progress of the illness (Baudouin and Parizeau, 1987). Allowing patients to examine their hopes and fears makes the process of dying easier for the patient and for the physician (Kuhl, 1994, p. 38) and, I would add, for the other caregivers and for relatives taking part in the process.

It is often a crisis that gets patients talking about various choices of treatment or non-treatment, or about euthanasia. In the treatment of HIV or AIDS, as in the treatment of other terminal or chronic illnesses, however, periods of crisis are too charged emotionally for patients to look at things rationally (Voigt, 1995). It is important that the patient be able to play an active role in the decision-making process. Physicians must be especially vigilant for signs of depression that are more deep-seated than the wish to die and distinguish them from symptoms of illnesses such as dementia and from the side-effects of medication. If clinical depression is present, it is reasonable to prescribe the use of anti-depressants and, if necessary, hospitalization. The patient must know that all his requests to hasten death will be considered subsequently. Such a guarantee helps the patient through the crisis (Voigt, 1995).

A patient expects to be given clear and reliable information about his illness, his diagnosis and prognosis, and possible treatment. Any mistaken notions he may have about his illness (Voigt, 1995) must be corrected, and the most recent data regarding the results of the various treatments available must be provided. New medications offer more hope than before. The patient will have to have the best information possible and be made aware of the iatrogenic risks of treatment and the possibility of premature death (Battin, 1994) when deciding to undergo experimental treatment. The physician can help the patient make a more rational choice, or increase his chances of making a poor choice by withholding relevant information (Battin, 1994). This author deplores the lack of an accessible guide describing the stages of the illness, the likelihood of certain pathologies occurring, in addition to the severity of effects, the kinds of pain involved and their likelihood (Batting, 1994). Patients want objective data on which to base their decisions. An author like Cole (1993) calls for guidelines for an approach to communications.

The physician also needs to find out from the patient who to contact in an emergency, whether there is social support, whether the patient has made a living will or has assigned power of attorney, whether he is prepared to discuss the possibility of withdrawing or withholding of or any other matter, including euthanasia and assisted suicide. The patient must know that all options can be discussed. One author (Voigt, 1995) suggests that the physician take the initiative in addressing the worst-case scenarios, by asking the following questions: What do you fear most about your illness? Do you think you will die alone? Do you want to die alone? Do you think you will die in pain? The physician must be aware of the patient's expectations regarding the moment of death. He must encourage the patient to discuss various options with his support group. Patients, who see themselves as a burden to others, will often be reassured to hear about the help available and could change their mind about their request of euthanasia.

Battin (1995) suggests questions that patients can ask themselves to clarify where they stand on various options. These are as follows:

1. Do I want to exercise active control over my own death?
2. Do I want to take a chance on an experimental treatment?
3. Should I hang on or not?
4. What importance do I attach to the well-being and interests of others?

Each individual must answer these questions in light of his or her own values and this process may contribute to communication with the various health care providers.

These recommendations for productive exchanges with respect to end-of-life treatment were proposed specifically for patients with AIDS . Furthermore, in certain cases, they were proposed to ensure that, where assisted suicide is an option, the related decisions are as rational as possible (Battin, 1994). It is clear, however, that these decision-making guides have relevance for other terminal illnesses and for any decision regarding interventions to hasten or slow down the process of dying.

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The full text of the research paper is available from Health Systems and Policy Division, Policy and Consultation Branch, Health Canada. 10th Floor, Brooke Claxton Building, Ottawa, ON, K1A 0K9. Telephone: (613) 941-1806. Facsimile: (613) 941-9093.

Appendix F: Generic Versus Specific Palliative Care Services

Executive Summary

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This paper examines the spectrum of palliative care services, needs of different populations that might be served by palliative care, and challenges health care planners must address before implementing an integrated palliative care model. A review and critique of relevant literature related to palliative care is presented along with a synthesis of key issues, integrative comments, and recommendations.

An analysis of the literature revealed that, despite substantial developments in palliative care knowledge over the past twenty years, there are many individuals, families, and communities who are under-served by palliative care. To date, most palliative care has been directed towards individuals living with cancer in the end-stages of their illness. Evaluations indicate that these individuals and their families benefit from the expert symptom management, psychosocial support, respite, and spiritual care provided. However, persons living with AIDS (PLWAs), children with life-threatening and long-term illnesses, and those with degenerative illnesses do not receive the full benefits of current palliative care knowledge. As well, those living in rural or remote areas may have limited access to palliative care.

The literature also documented different needs of various groups. For example, needs of family members vary according to the ages, composition, and resources of the family. Families with young children, elderly family members and those with limited incomes have more limited resources and greater needs. To date, the palliative care needs of those from different cultural groups are not well described in the literature.

Palliative care education is needed for health professionals, patients, family members, and the public. Despite the existence of exceptional palliative care services in many locations in Canada, they are fragmented and not well integrated into the larger health care system. Cost-analyses studies suggest that palliative care provided in the patient's home is more cost-effective than institutional care. However, adequate home care resources must be provided to ensure that patients receive appropriate care and family members obtain the support they require. Currently, palliative care resources comprise a small fraction of the overall health care expenditures. Many individuals receive palliative care late in their illness trajectory and a large number who do not have a terminal illness, but who might benefit from the knowledge of palliative care teams, never receive palliative care.

A mixed model of palliative care, structured as a continuum of care weighted toward home care is proposed. Development of this model would require vigorous home supports, trained family physicians who are affiliated with the home nursing service, "home substitutes" for those without family caregivers, day hospices, long-term hospice settings (e.g. nursing homes) and intensive specialized palliative care units in tertiary care teaching hospitals. The model would include a centralized consultative service and a mobile palliative care team to provide consultation to rural/remote communities. Some individuals would continue to be cared for in settings where they have received the majority of their care (e.g. paediatric settings, medical units), supported by palliative care consultation teams. The paper further recommends that in communities with large numbers of PLWAs, specialized palliative care units be established for these individuals to provide more specific and sensitive palliative care directed toward the unique needs and care objectives of this group.

The complete report, released in March 1997, is available from Health Systems and Policy Division, Policy and Consultation Branch, Health Canada. 10th Floor, Brooke Claxton Building, Ottawa, ON, K1A 0K9. Telephone: (613) 941-1806. Facsimile: (613) 941-9093.

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Canada's aging population is a major phenomena that will continue well into the next century. The seniors of today and tomorrow are more numerous and constitute a larger proportion of the population than any previous generation. While the needs of individuals who are dying and their families have come under increasing scrutiny during the past decade, issues related to the needs of older adults who are dying have not been systematically addressed. Despite the demographic changes that have resulted in death and dying being increasingly associated with old age, the conceptualization of palliative care in later life is not well developed. All too often the philosophy and principles of palliative care are not invoked in the care of those who are both old and dying. This paper begins with Leonard's story. It then proceeds with a discussion of the inevitability of death, the heightened awareness of finitude and the symbolic meaning of death in later life. It continues with a discussion of medical aspects of dying and dying both at home and in long term care institutions. The paper concludes with a plea for the universal application of the philosophy and principles of palliative care, and in particular, to those who are both old and dying.

Leonard's Story

Leonard lived into his eighty-ninth year independently in his own home with four elderly friends and a younger caretaking couple. He drove his own car and fished in the Cascepedia River throughout the summer of his last year. The next winter, he spent six weeks in an acute care hospital. During the last of those weeks, it became evident to his sister and extended family who lived at a distance that he was dying. He had lived with emphysema for many years. They went to visit. Upon their arrival, Leonard was in a private room close to the nurses' station. He was in bed with his head elevated, his respirations were 58 a minute, his mouth was open as he attempted to breathe, his eyes had a wild look, and he was obviously in very bad shape. Nevertheless, he recognized his sister and nieces, asked about their trip and tried to chat about the family. During the next hour, a nurse came into the room and gave him his inhalation therapy, which provided absolutely no relief. The family spoke with the nurse who agreed that he was in agony and dying and who promised that she would get the physician to provide for his relief. The next day, however, no relief had been forthcoming. The sister then spoke with the physician who told her that her brother had a respiratory condition that was very difficult to treat and that he should be moved to a hospital 200 miles away for a bronchoscopy. He would not acknowledge that Leonard was dying nor that he required sedation for reasons of comfort. Rather he said that he suffered from anxiety. Neither Leonard nor his family felt that such a trip would be in his best interests. Indeed they acknowledged the futility of such a plan. He also wanted to die in the community where he had spent his entire life. During further discussions, the nurses admitted that they felt helpless as the physician, who was in control, felt that Leonard would become addicted to pain relief medication. That afternoon his niece, who was a nurse and had a Ph.D., announced in desperation to the physician that she was a doctor and wanted her uncle to have some morphine to ease his breathing and discomfort. This resulted in an order for atavan, which shortly after administration, was successful in reducing Leonard's respiration to 24 a minute and giving him the relief he needed to visit with his family, be the sociable person that he had always been, and talk about what he needed to talk about. It turned out that this had been a "stat" or "once only" order and again that evening Leonard was in agony with respirations approaching 60 a minute. The niece again demanded sedation, this time on a four hourly basis as needed, a request she later found out was not forthcoming. Rather, the medication was ordered on a once only basis because the physician believed that the nurses would be too liberal in their interpretation of a "prn" or "as necessary" order for medication. The third day of the visit continued with requests for sedation. Finally, on the fourth day of the visit, when it became obvious that no on-going relief would be provided at this hospital, Leonard and his sister agreed to the transfer. The family was able to get a final dose of the medication that had provided so much relief for Leonard's trip and the family said their good byes. Shortly after their arrival home, they received a call from the physician at the new hospital reporting on the sad condition in which Leonard had arrived. She asked what the family wished for his care, acknowledging that Leonard was dying and the futility of a bronchoscopy. The family made a plea that he be kept comfortable. The physician agreed with the appropriateness of that request and acknowledged that she would be able to do so. Leonard died two days later.

The Inevitability of Death

Death, and in particular, death in later life is inevitable. In spite of the fact that those over 75 years of age are the fastest growing segment of the population, there is a paucity of information about the experience of dying in old age or about the care of those who are both old and dying. In 1908, George Simmel wrote: "We are, from birth on, beings that will die. We are this, of course, in different ways. The manner in which we conceive this nature of ours and its final effect, and in which we react to this conception, varies greatly. So does the way in which this element of our existence is interwoven with its other elements." It is noted (Marshall, 1986) that Simmel recognized the inevitability of death as a fact of life and distinguished between the fact of death and its definition in the consciousness of individuals. In addition, Simmel stressed that the ways in which people deal with death affect other aspects of social life. I would add that other aspects of social life, in particular, palliative care, affect the ways in which people deal with death and dying.

Awareness of Finitude

Seniors have a heightened recognition that their remaining time on earth is limited and that death is drawing near. Marshall (1986) suggests that this heightened awareness of finitude results in the initiation of processes that help to reduce anxiety and make older persons more accepting of death. The first of these processes is "**legitimation of biography**". By this, he means that when older people become aware that their time is limited, they see themselves in a metaphorical sense as in the last chapters of their autobiography. In addition, they want these last chapters to make sense. He concludes that legitimation of biography is marked by changes in time perspective, a withdrawal from orientation to the future, a focussing on the past and a heightened preoccupation with identity. The second process Marshall refers to is "**legitimation of death**". Older people who realize they are in the last chapters of their lives not only want their lives to be good stories, they want them to have good endings. They want to be useful and to be able to make others happy. They don't want to be a burden. They want to maintain their independence and sense of mastery and control. They do not all think that death comes too soon. The vast majority of older persons reach a point where death and their own dying makes more sense than continuing to live forever. The last part of Marshall's metaphor is "**authorship**". Elderly people want to be the authors of their stories. They want their stories to have meaning and to have good endings. They want to be in charge of their life as a whole, including its ending. The application of the principles of palliative care, which offer awareness, truth-telling, pain relief and social and spiritual support may do a great deal to increase the likelihood that elderly persons will have good endings and be in control during the final phases of their lives.

Symbolic Meaning of Death

Death may have a symbolic meaning in later life that is particularly significant for some older persons. Barbara Myeroff (1978) chronicled the special poignancy and melancholy of Eastern European Jews who face death knowing than when it comes, the last living witness to their vanished culture will be gone. Other anthropologists have documented similarly painful situations in later life (Amoss, 1981; Cool, 1981).The health and social consequences of advancing age, increasing dependency and the process of dying result in a change in roles and responsibilities between older persons and their families that may or may not be problematic. Whereas in younger life, parents were the primary caregivers of their children, in later life, children assume a greater role in the care of their parents. Diminishing resources and sense of control also have a particular meaning in later life. There are also suggestions that elderly patients have a different social status from patients with cancer. Whereas cancer patients have a clearly defined right of entry into the sick role, elderly persons may be seen to have an uncertain, ill-defined and at times stigmatized role (Seale, 1989). One writer referred to an "underclass" of dying persons resulting from the concentration of palliative care resources on those with cancer (Harris, 1990). Some elderly people fit within this category. Older people who are dying in hospitals and long term care facilities may be marginalized and seen primarily in terms of practical problems.

Elderly patients in hospitals are referred to as bed-blockers, transition patients and persons who are waiting placement. Residents of long term care facilities may be viewed as unworthy or at least of low priority with respect to the allocation of resources, including those of a palliative care nature.

Medical Aspects of Dying

Medical aspects of dying for elderly persons include a multiplicity of diseases, including cancer. Indeed, the majority of new cancers are found in persons over the age of 60, and given the changing demographics of our society, an increase in both new cancers and in recurrent and secondary cancers in old age is predicted (Deachman, 1995). Elderly persons, however, also die from congestive heart failure, chronic obstructive airway disease, and multiple sclerosis. In addition, they die from Alzheimer's disease. The multiplicity of diseases found in older people makes the diagnosis of dying problematic and frequently one of exclusion (Blackburn, 1989; Charlton, 1992; Ley, 1989). Multiple symptoms, which are frequently complicated by advanced age and multiple diseases, further complicate the process of diagnosis. The recognition that older persons are dying may not happen until all attempts at treatment have proven unsuccessful. Indeed, the acknowledgement that an older person is dying may not happen at all. In addition, the illness trajectory of an elderly person may be slow and punctuated by a series of acute events prior to the onset of death. Little is known about symptoms in later life or the best ways to provide for their relief. Although studies show that age is not itself an obstacle for the use of safe and effective analgesics (Rapin, 1989), the use of narcotics and other drugs for symptom control may be viewed as problematic. Shortness of breath may also be a problem for some seniors and agitation may go unrecognized and unsolved. Suffering and dependency may be prolonged. Consequently, elderly persons may require palliative care for an extended period of time (Ley, 1989). Issues related to when and where palliative care should be initiated, although problematic, should be addressed. The acute medical model, heavily reliant on technology and an emphasis on cure frequently does not meet the needs of elderly persons who are dying.

Dying at Home

Many elderly people want to, and do die at home. Sankar (1993) tells us, however, that our current image of dying at home is informed by romantic notions of the past, when it was thought, that families took better care of their elderly relatives when compared with the care they receive today. In these images, dying elders are in their own bed, surrounded by devoted and caring family members. A more contemporary image of dying at home, she argues, would include the equivalent of establishing an intensive care unit, sometimes accompanied by sophisticated medical technology, in one's home and placing the family on 24 hour call. This image may be particularly relevant in our changing health care environment.

The provision of palliative care at home can be arduous. Elderly persons are living longer and are sicker than they have ever been. Dramatic improvements in medical and nursing science mean by the time they die, their bodies are severely compromised and very weak and debilitated. They are also very frail. Families are often not prepared for the level and intensity of the care they are required to provide. This may be particularly so for elderly spouses whose social and material resources and indeed their own health may be declining. Fatigue and feelings of burden and stress may be problematic. A recent study revealed that elderly wives were worn out from caring for husbands who were highly dependent in activities of daily living and required a high level of intensive care as a result of physical and cognitive impairments (Ross, Rosenthal and Dawson, forthcoming). These wives had been essentially housebound for years. Their own physical and emotional health was in decline, few received any home support services, and they had reached a point where they could no longer continue to manage. Many of their husbands died shortly after admission to hospital.

Little is known of bereavement in later life. Although it has been reported that death of an old person does not cause as much difficult grief as the death of a younger person (Bromberg and Higginson, 1996), the death of an elderly spouse or companion of many years can be devastating. Bereavement is very painful and elderly survivors may have to face the loss of their loved one with no children close at hand and a diminishing social network. Palliative care must become an integral part of the care of seniors who are dying at home.

Dying in Long Term Care Institutions

Many old people die in long term care institutions. There is evidence that residents of long term care facilities face death as a common problem and develop ways to make sense of death and to accept the deaths of others with equanimity and anticipate their own in the same way (Hochschild, 1973; Marshall, 1975). Advance directives are increasingly providing direction for care related decision-making. Nevertheless, many long term care facilities seem to marginalize death and operate with a policy of "closed awareness", keeping those who are dying and those who are caring for them in ignorance of the poor prognosis. Residents of long term care facilities are more likely to experience chronic and long term conditions than those living on their own or in relatives' homes. They will more likely die of respiratory disease, strokes and Alzheimer's disease. Despite the fact that the prognosis of persons with Alzheimer's disease is poor, aggressive medical treatment is not indicated and they have significant health problems associated with their underlying conditions, only a small proportion of persons who receive palliative care have a primary diagnosis of Alzheimer's disease (Hanrahan and Luchins, 1995). It may be that because their survival time is uncertain, they do not fit the usual criteria for palliative care services. Residents of long term care facilities are also more likely to have greater restriction of their activities of daily living and a lower capacity to do things unassisted than those living elsewhere (Burry and Holme, 1990; Cartwright, 1991). Higher levels of mental confusion, greater loss of continence, more constipation and greater difficulty in seeing and hearing are also reported. Little is known about their pain (Ross and Crook, 1995). Communication may be particularly problematic. Visitors may be few. Whereas at one time, elderly residents were transferred for acute care during the final days of their lives, this is, and will increasingly be, no longer the case. Palliative care must become an integral part of the care of elderly residents of long term care facilities.

Formal Care Providers

If the needs of elderly persons who are dying and their families remain largely unrecognized, so do the needs of staff. Trained and untrained personnel, many of whom work on a part time basis may recognize the inadequacies of their care without being able to discuss or improve it. This in itself is problematic. Mary Vachon (1987) showed that the key stressors in the care of people who are dying lie in workplace problems that may be partially alleviated by improvements in workplace conditions. Another more recent study identified the challenges experienced by nurses who provided care to elderly persons who were dying in their own homes (Ross and McDonald, 1994). These nurses reported contradictions between the quality of care they wished to provide and that which they were able to provide. This was particularly so with respect to affective dimensions of care, including spending time with clients, listening and reminiscing with them and providing comfort and support. Preliminary analysis of data from a long term care study in Ottawa-Carleton (Ross, Carswell & Dalziel, 1997) suggests that stress management is the greatest area of need for health care providers in long term care facilities. This is followed by a need for assistance with managing pain and discomfort, providing emotional support to residents and working more effectively with families and each other. These are all aspects of palliative care.

Conclusion

In conclusion, it is crucial that the philosophy and principles of palliative care be extended to the care of elderly persons in all settings where they spend the final phases of their lives. There must be no more stories like Leonard's. Seniors must be empowered to be the authors of their lives to the end and provided with the assistance required to make the last chapters of their autobiographies meaningful and their endings good. Health care workers must recognize and acknowledge when older people are dying, collaborate trustfully and respectfully with each other, and achieve optimal symptom control and quality of life. Elderly spouses and family members must be recognized and supported. There must be an end to the marginalization and abandonment of elderly persons, and in particular those who are dying, in our health care settings. Strategies must be developed to ensure that they do not die alone, but rather in the company of another, and in peace and comfort. Formal health care workers must be empowered, through supportive work environments and continuing education, to provide the care of a palliative nature required by older adults who are dying. Evidence-based practice must become the norm. This paper is a plea for the universal application of the philosophy and principles of palliative care to all age groups, and in particular, to seniors.

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Appendix H:

A Comprehensive Guide for the Care of Persons with HIV Disease: Module 4: Palliative Care

This paper was prepared by John Flannery, Patricia Balogh, Dr. Frank Ferris and Deborah Randall-Wood and delivered by John Flannery.

History of Palliative Care in Canada

In Canada, over the last 25 years, there has been growing interest in and commitment to the needs of the terminally ill and their families and loved ones. Although hospitals for the chronically ill have existed for decades, the principles and practices of modern palliative care only began to develop in the early 1970s, driven by pioneers in several Canadian centres.

The emergence of palliative care as an area of expertise and the rise of the hospice movement occurred in response to advancing medical technology in the treatment of cancer. It became obvious that the curative approach to the management of cancer was not adequately addressing the symptom management and psycho-social needs of people succumbing to their illness. Palliative care developed largely in response to inadequacies in established health care practices. It emphasized compassionate comfort and quality of life until death when disease was no longer responsive to traditional treatments. The philosophy of palliative care was interdisciplinary in nature as it focused on emotional, physical and spiritual care for the individual, family and loved ones and extended into the bereavement period.

Although early palliative care initiatives in Canada were hospital-based, palliative care services have developed in a number of innovative home-based and community programs.

History of Palliative Care: Influencing Factors

The advancement of palliative care services has been influenced by a number of factors including:

- a growing recognition among health care providers that death is part of the continuum of health care and must be integrated into mainstream service delivery models
- advances in symptom and pain management
- the influence of key clinical experts on program development, resource allocation and education and research in health sciences
- societal influences on personal decision-making and attitudes towards the end of life

- the establishment of the Canadian Palliative Care Association which has articulated standards of palliative care including the philosophy and principles of palliative care and,
- the HIV/AIDS epidemic.

In spite of the evolution of palliative care, there is a paucity of services across the country. Although there is both an economic and ethical imperative to provide this care within the health care continuum, most Canadians do not currently have access to palliative care services. As the next century approaches, palliative care in Canada is challenged by diminishing health care resources and growing demographic pressures due to an aging population, an increased incidence of terminal cancers and the HIV/AIDS epidemic. Further development of palliative care services will be impacted by the needs and expectations of those infected and affected by HIV/AIDS.

HIV/AIDS Palliative Care: Evolution

Since HIV/AIDS first appeared in Canada, the disease has challenged health care and social services, bringing with it socio-economic, medical and ethical dilemmas. While there is no cure for HIV/AIDS, advances in technology and health awareness have improved the survival rate of people diagnosed with HIV/AIDS. As a result, individuals are living longer and experiencing more complex clinical, social and mental health problems.

The reality has shifted HIV/AIDS from an acute illness to a chronic yet progressive and ultimately terminal disease characterized by intermittent acute episodes. The changes in the disease trajectory in the last decade have had a significant impact on the provision of HIV/AIDS palliative care.

Due to the disease manifestations and the unpredictable progression of HIV/AIDS, the transition between curative care and palliative care is not easily marked. The multiple and simultaneous manifestations of HIV/AIDS are frequently treatable. Programs offering HIV/AIDS palliative care are, therefore, required to provide aggressive treatments which necessitate complex care planning and expert clinical management.

Within HIV/AIDS care and treatment, it is recognized that quality of life for people infected and affected by HIV/AIDS is enhanced through early and ongoing attention to psychological and physical symptoms. HIV/AIDS palliative care is not viewed as a care approach in the final stage of illness but is an integral aspect of care which begins early and becomes increasingly important as the disease progresses.

The evolution of HIV/AIDS palliative care expertise in Canada has been influenced by a number of salient factors including:

- the natural history of HIV/AIDS which necessitates a balance between diagnosis/treatment and interventions directed solely at comfort care

- the inability of traditional palliative care services to meet the needs of those infected and affected by HIV/AIDS
- new treatment options for People Living with HIV and AIDS (PHAs) which have increasingly shifted treatment from in-patient settings to either ambulatory or community care
- the stigmatization and social isolation which accompany HIV/AIDS disease
- the psycho-social impact of HIV/AIDS which compounds the complexity of palliative care
- strong community activism by people infected and affected by HIV/AIDS for a client-focused approach to HIV/AIDS palliative care
- community based services and volunteer care teams, in many cases, support HIV/AIDS palliative care services
- the intensity of collective grief and bereavement imposed on communities by the HIV/AIDS epidemic.

As a result of these and other factors, it is understood that living with and dying of HIV/AIDS is qualitatively different than other life-threatening illnesses.

The experience of HIV/AIDS palliative care is not homogenous. Across Canada, a variety of integrated and dedicated service models at primary, secondary and tertiary levels of care have emerged. Although notable programs, which are recognized for their HIV/AIDS palliative care expertise, do exist, many people living with HIV/AIDS do not receive palliative care. Access to HIV/AIDS palliative care varies significantly throughout Canada and is influenced by demographic, geographic, economic and societal factors.

In spite of advancements in HIV/AIDS palliative care, the needs of emerging populations such as women, children, substance users and aboriginal people require further development. These unmet needs are expected to place additional demands on programs and services which are already strained. HIV/AIDS palliative care has pushed the limits of traditional palliative care practices.

The future development of HIV/AIDS palliative care will be challenged by growing demands and shrinking health care resources.

HIV/AIDS Palliative Care: Issues and Barriers

In 1985, the Parliamentary Standing Committee on National Health and Welfare undertook a study of the major concerns and problems surrounding the issue of HIV/AIDS in Canada. Based on testimony from leading experts in the field of HIV/AIDS care, the Committee published the *Report on AIDS in Canada* in May 1986. This report contained 23 recommendations for national action on AIDS including the development of integrated palliative care for PHAs.

The subsequent Report of the Expert Working Group on Integrated Palliative Care for Persons with AIDS to Health and Welfare Canada (at the time) entitled *Caring Together*, published in 1989, articulated issues related to HIV/AIDS palliative care. The recommendations and conclusions of that research initiative addressed multiple factors which impacted care delivery, education, support for caregivers, policy development and economic issues.

Caring Together defined HIV/AIDS as a disease with three dimensions: biological, social and societal. The report stated that all three components must be addressed in future health care strategies to ensure the access to required services for people infected and affected by HIV/AIDS from diagnosis to death.

In 1996, Health Canada initiated the development of a discussion paper on HIV/AIDS palliative care in Canada. To achieve this, focus group consultations were held to identify issues and barriers in palliative care service delivery for people living with HIV/AIDS. As a result, a number of recommendations in four key areas: policy development, care delivery, education and evaluation and research were identified.

Underlying these recommendations are a number of key principles that emerged from the national focus groups.

HIV/AIDS Palliative Care: Key Principles

The key principles of HIV/AIDS palliative care are that:

- palliative care services must be an integral component of the continuum of health and social service care for PHAs
- palliative care for PHAs must be available in all communities. This can be accomplished through integration with existing palliative care programs or, through dedicated HIV/AIDS services
- the principles of portability, accessibility, universality, equality and adequacy espoused in the Canada Health Act must guide the development of HIV/AIDS palliative care services
- advocacy by consumers and caregivers must continue to occur to ensure the policy development and the enrichment of HIVAIDS palliative care services
- quality of life, as defined by PHAs, must be a guiding principle when planning, implementing and evaluating palliative care services
- people infected and affected by HIV/AIDS must be involved in the development, delivery and evaluation of palliative care services
- PHAs should be able to access palliative care in their place of choice
- health, social and economic barriers impacting palliative care services are interrelated and must be addressed through inter-governmental co-operation, and finally
- collaboration and cooperation amongst service providers at all levels is necessary to enhance the quality and cost-effectiveness of palliative care services.

National Initiatives

Despite the real and perceived barriers in palliative care service delivery for PHAs, there have been numerous initiatives and much progress in addressing these barriers since the onset of the HIV epidemic. For the balance of this presentation, I would like to highlight one such initiative. This initiative is Module 4: Palliative Care which is one of a series of modules which make up the *Comprehensive Guide for the Care of Persons with HIV Disease*.

Overview of Module 4:

In December of 1993, Dr. Gerry Bally, representing the AIDS Care Treatment and Support Program of Health Canada, approached Mount Sinai Hospital and Casey House Hospice to develop a palliative care resource that would become a component of the *Comprehensive Guide for the Care of Persons with HIV Disease*. Recognizing the extensive nature of such a project, a survey of existing palliative care resources in HIV/AIDS was undertaken and additional partners were identified to collaborate in the development of the palliative care module. The survey of existing resources only served to identify the need for just such a palliative care resource as we found no similar references in Canada, the USA, Europe or Australia.

Participating Organizations

Our search for additional partners proved to be fruitful as 9 organizations, and 5 additional institutions joined with us to prepare our proposal. A national working group composed of representatives from the participating organizations and institutions was formed to advise the project co-chairs and participate in the overall development of the module. Through the dedicated work of 29 lead expert authors, 43 resource people who supported the writers, 26 internal reviewers and more than 60 people who participated in focus test groups in Montreal, Toronto and Vancouver, the module took shape through 4 major drafts to produce the palliative care module. Of key importance, was the participation of people living with HIV/AIDS in the development of Module 4.

It was the needs and issues identified by PHAs that assisted the national working group in structuring the various sections and content of the module.

Module 4: Main Sections

The module is structured within four main sections. I would like to briefly highlight each of these sections.

Section 1: HIV/AIDS and Palliative Care

The first section relates to HIV/AIDS palliative care. HIV/AIDS has challenged palliative care. The complex dynamics of the disease process, the treatments, the social circumstances including stigmatization have brought new dimensions to the provision of palliative care. Section one highlights some of the complex issues that provide challenges that arise within the context of HIV/AIDS.

Section 2: Caring for the Living

The second major section of the module focuses on Caring for the Living. By addressing issues related to quality of life, ethics, symptom management, activities of daily living, psycho-social support and spirituality, within a holistic perspective, caregivers will find information that will help to plan for and address the expectations and needs of those who live with HIV/AIDS.

Section 3: Caring for the Dying and the Bereaved

Section three explores issues related to caring for the dying and the bereaved. Care providers inexperienced in caring for a person who is dying may experience discomfort as a person approaches death. Practical approaches to care during the last hours of living are highlighted and considerations related to funerals, memorial services and rituals are explored. Finally, this section deals with the critical issues of grief, loss and bereavement. Just as AIDS has challenged us to rethink much about providing palliative care, so too has the disease impacted our understanding of grief. This section reviews issues pertinent to AIDS grief along with interventions for working with multiple loss and supporting community initiatives related to grief. The challenge of AIDS grief is to understand what is normal in such an abnormal situation.

Section 4: Care for the Caregiver

The fourth section of the module addresses issues important to us, the caregivers, to support those who live with HIV/AIDS. Whether you are interested in the unique organizational and personal challenges arising in the provision of palliative care, the work related stresses that are unique to caring for persons living with HIV/AIDS, you will find related information and many useful resources in this section.

The development of such a resource requires tremendous commitment and I would like to commend the following individuals. Dr. Gerry Bally from the AIDS Care Treatment and Support Program for his leadership in developing the vision for a Comprehensive Guide for Persons Living with HIV Disease, Dr. Frank Ferris, co-chair of this project whose incredible talent and relentless energy provided the foundation for this project and Helen McNeal who oversaw the development of the project, kept us all to our deadlines and whom without, the palliative care module would never have been.

The Future: CPCA

But the challenge of such a resource is to ensure that it is useful in promoting improved clinical care for those living with HIV/AIDS. Since the publication of Module 4, in 1995, the Canadian Palliative Care Association and the AIDS Care Treatment and Support Program have worked together to develop an action plan to address the barriers and issues that persons living with HIV/AIDS experience in accessing palliative care services. With Module 4 as a foundation, CPCA is working with a national steering committee to educate health care professionals in HIV/AIDS and palliative care as well as increase awareness in the general public with respect to HIV/AIDS and palliative care. These important initiatives are crucial and I would like to commend the AIDS Care Treatment and Support Program and the Canadian Palliative Care Association for moving these initiatives forward. These actions are only possible as a result of our federal government's commitment to HIV/AIDS through the National AIDS Strategy. Special recognition must be given to Dr. Ina Cummings and Linda Lysne from CPCA as well as Nena Nera and Bob Shearer from the AIDS Care Treatment and Support Program of Health Canada.

I would like to conclude with the following passage written by Wayne Moore, a person living with HIV:

> *The great tragedy of the AIDS epidemic lies in our unwillingness - individually or collectively - to face death. Instead, we have chosen to look for someone or something to blame, thereby diminishing the meaning of our deaths.*
>
> *Through our stories, you can help us find answers in our search for meaning. Help us work together to alleviate our suffering, without excessive drugs making us unaware of our environment. Stories will help us deal with multiple losses in our lives, which incite fear that we will be the one left behind, with no one to care when those close to us have all died or walked away. In our isolation and fear, we need to be assured that services will be available to care for us when our time comes. Our stories must be stated loudly - on behalf of those who died slowly, bit by bit, consciously accepting their inevitable dependence - assuring those who loved and wanted to care for them that such dying is not undignified. Recognize and support us through our deliberations around ending our lives at the moment of our choice, rather than facing the possibility of unbearable pain and suffering.*
>
> *Through our stories, hear our concerns for our families, partners and friends. Help our parents - caught in their own web of aging, community and generation - to understand our grief and their own. Bridging disparate realities eases our isolation, enabling those around us to help us live safely in whatever place we choose to call home.*

Listen closely to our stories and you will understand our desire for empowerment, for control over who we are and how we live our lives. In turn, you will help us be proud of who and what we are.