

## **A COLLABORATIVE INTEGRATED HOSPICE PALLIATIVE CARE PROGRAM FOR YUKON**

[Presented here as released August 17, 2006 to The Pallium Project from Jan Horton, PHCTF Coordinator, Yukon Territorial Government]

### **Background**

In 2002, a Palliative Care Working Group recommended options to the Minister of Health and Social Services to improve the availability, access and integration of palliative care services to the territory. One recommendation identified the need for a Hospice Palliative Care (HPC) Program Development Coordinator for a two-year term to facilitate the development, redeployment and integration of existing palliative care services. Yukon Health and Social Services and Pallium, a project consortium that works to build capacity in palliative care nationally, cost-shared support for this Coordinator position from November 2004 to December 2005, with funding obtained from Health Canada through the Primary Health Care Transition Fund.

The Palliative Care Working Group became the Hospice Palliative Care Advisory Committee (HPCAC) to the initiative. Members included representatives from the Department of Health and Social Services, Whitehorse General Hospital, and Hospice Yukon Society, as well as health professionals, with the Coordinator acting in an *ex-officio* capacity. The Advisory Committee was asked to make recommendations on:

- sustainable and transitional changes to the way HPC services are provided throughout the territory;
- improving access to coordinated, consistent, quality palliative care throughout the Yukon;
- improving coordination and communication among patients, caregivers and palliative care professionals; and
- improving and maintaining public and professional skills and knowledge of palliative care.

In undertaking this work, the Coordinator reviewed literature and surveyed programs in other jurisdictions to learn of best practices in palliative care, and conducted an HPC needs assessment in the Yukon. Based on this work, the Advisory Committee developed a list of recommendations for improving HPC service in the Yukon.

This document outlines the vision, mission statement, values, guiding principles and model of care developed by the committee on the basis of their research. It provides a summary of the findings of the Yukon needs assessment and identifies the elements recommended to strengthen Yukon palliative care services.

This work has helped build the foundation for future changes in HPC. The recommendations were sent to the Department of Health and Social Services. Subsequent action will require policy and funding support obtained through regular Government of Yukon approval processes.

## **Vision**

A collaborative integrated model of HPC in Yukon will provide Yukon residents with access to HPC services and supports that are:

- Accessible – Yukoners, no matter where they live in the territory, will have access to HPC service in a timely manner.
- Client-centered/family-focused – the person and his or her family are treated as a unit of care.
- High Quality – standards of practice are based on national norms and specific standards of professional conduct for each discipline, and are sensitive to the realities of professional practice environments in the territory. Safe, effective, ethical HPC activities are collaborative, based on current national understanding of norms and effective practices, ensure confidentiality, protect privacy, reduce risk of discrimination, and are accountable.

## **Mission Statement**

The Collaborative Integrated Yukon Hospice Palliative Care Program will strive to help Yukon residents to die with dignity, as free of pain and distress as reasonably possible, surrounded by their loved ones, in a setting of their choice.

## **Values Framework and Guiding Principles**

The Yukon Hospice Palliative Care Program supports the following values:

- Each person is an autonomous and unique individual.
- Life and the natural process of death both provide opportunities for personal growth.
- A person's and his or her family's suffering, fears, expectations, needs, and hopes must be addressed.
- Care is provided when the person and/or family are ready to receive it.
- Care is guided by quality of life as defined by the dying person.
- Caregivers enter into a therapeutic relationship with people and their families with dignity and integrity.
- Communities become stronger when people work together in response to suffering.

Program policies and services will reflect these values in day-to-day practice.

*p.19, A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, 2002.*

## **YUKON HOSPICE PALLIATIVE CARE NEEDS ASSESSMENT**

The Advisory Committee and the Coordinator reviewed and identified formal care providers, volunteers, and family/friend caregivers who should be included in a needs assessment about HPC.

Two sets of questions were developed. One solicited people's values and service needs, in order to direct program service and model development. The second one gathered information from formal care providers related to educational needs, in order to guide the development of a Yukon education strategy.

## **Community Consultation Overview**

The Coordinator visited all communities with a health centre (nursing station) to meet with staff from Health and Social Services, local First Nation Health and Social Program staff, First Nation elders, family and friend caregivers, and any interested members of the public. A copy of the needs assessment questions was sent out prior to the community visit. Local people in each community advertised the meeting. Some people who were unable to attend the meetings completed the needs assessment and returned it via e-mail. All meetings allowed time for general comments and questions along with focussed discussions related to each of the questions.

## **Feedback on Hospice Palliative Care Program Needs**

During the consultation, health practitioners and family caregivers consistently identified needs in the areas of:

- 1) Access
- 2) Coordination
- 3) Support
- 4) Education

### **Access**

Formal care providers and family/friend caregivers need to be able to call an identified number to link into whatever HPC service they need. Some family members and formal caregivers noted that the community members should be able to access the number when they are ready, as opposed to being told what they need to do to support someone who is dying in their community.

### **Coordination**

Coordination of community supports – for the person and the person’s family -- is essential to helping the family care for the person at home. Systematic coordination of communication and service between the various formal care providers also needs to occur to prevent duplication of service and support quality care.

### **Support**

Community nurses, family physicians, home care nurses, and social workers in Yukon communities need ready access to clinical support including by telephone or videoconference. Interviewees suggested that having an identified HPC team assist with complex assessments, discharge planning, teaching and community follow-up would help them provide quality care in the communities.

Another area of need mentioned by people in several communities is enhanced local support for volunteers and family/friend caregivers. Therefore, planned support for family/friend caregivers and trained volunteers needs to be part of the hospice palliative service offered in the communities. This will support healthy grieving and sustain the capacity for caregiving in the community. Individuals whose health has suffered from providing care for a family member or friend in their community stated that they would have great difficulty stepping forward to be a caregiver again unless they knew there would be planned support for them as the caregiver.

## Education

Questions developed for the educational needs assessment for formal care providers were derived from competencies noted in The Pallium Project's Primary Palliative Care Professional DACUM chart, from the Canadian Hospice Palliative Care Association's (CHPCA) *A Model to Guide Hospice Palliative Care*, and from the Hospice Palliative Care Advisory Committee.

Education needs related to the new Government of Yukon legislation regarding competency assessments, substitute decision-making and advance care directives were identified during the course of the community interviews.

Responses from health care and social services professionals confirmed the need for a comprehensive review of all issues related to HPC. A particular area of concern for many professionals was dealing with complex family needs.

Family and friend caregivers said that they need to know both the general information e.g. "how to move someone in bed without hurting them or ourselves" and specific care needs related to that person's condition.

Unique differences in the smaller communities outside of Whitehorse need to be considered when planning education. For example, in some communities there are those who would be pleased to be trained hospice palliative volunteers for the community. In other communities, however, potential caregivers would only want to take care of somebody they know and would only access training/education at that time.

Another complicating issue with some First Nation communities is long established cultural protocols about receiving care from individuals based on their clan status. It became clear during the needs assessment that some Elders would likely refuse assistance from various people in the community, depending on their particular clan status.

Finally, a major barrier to volunteerism in HPC is the impact of un/underemployment in small Northern communities. The cost of gasoline, for example, is a common barrier when traveling to offer informal respite to community members. Similarly, potential caregivers living a subsistence lifestyle cannot devote time to caregiving when "the system" doesn't necessarily support filling their basic needs to harvest food, get wood for heat, etc.

Both health professionals and members of the public in rural/remote areas suggested using videoconferencing as an effective medium for education and supportive debriefing sessions.

## **Model of Care**

In summary, feedback from health practitioners and members of the public during the needs assessment supports a model of care that includes:

- a specific contact number for HPC service;
- support for primary practitioners providing care at end of life; and
- an identified HPC clinical resource team, when needed, that would support practitioners in providing end-of-life care as part of their general practice.

To best use current and future HPC resources within this model, coordination is essential. To this end, the stakeholders will need to agree upon a system of coordination and communication that ensures efficient and effective provision of care.

## **Recommendations for Key Components of a Collaborative Integrated Yukon Hospice Palliative Care Program**

In order to successfully develop a collaborative integrated Yukon Hospice Palliative Care Program, HPC will require funding support within the Yukon health care system. The key components of this program recommended by the Advisory Committee are:

### **A Hospice Palliative Care Coordinator to:**

- coordinate program development, an education strategy, and evaluation activities for the program;
- coordinate and support implementation of HPC service with major care providers;
- ensure coordination and integration of care services; and
- establish and maintain best practice guidelines for HPC in Yukon, consistent with national standards.

### **A Central Access Number for Hospice Palliative Care Service to:**

- facilitate ease of access to HPC services, as an integral step towards coordination of services; and
- provide for a timely and supportive response.

### **A Multidisciplinary Hospice Palliative Care Resource Team to:**

- provide consultation and education support to primary health care providers;
- include a physician, nurse, social worker, pharmacist, occupational therapist, physiotherapist, volunteer coordinator and others, as needed (e.g. pastoral care, speech language pathologist, dietician, professional counselling);
- enhance HPC service in a variety of settings e.g. hospital, long-term care, community;
- promote palliative care as a unique and specific service based on best practices in the field;
- provide multidisciplinary assessment of individual and family abilities and needs using standardized assessment tools;
- include a volunteer coordinator who will be part of the team and will be responsible for the ongoing recruitment, training and coordination of volunteers; and
- support coordination of bereavement services.

### **A Public Awareness and Education Strategy to Focus on the Specific Learning Needs of:**

- the Hospice Palliative Care resource team;
- primary health care providers;
- volunteers; and
- public and family/friend care providers.

These recommendations are intended to help improve the quality of hospice palliative care services in the Yukon. One of the major principles of hospice palliative care is helping the person to live as fully as possible while he or she is dying. Providing collaborative integrated hospice palliative care services will ensure that Yukoners can do so.

In a society that fears death, it is important to demystify the process of dying, to help us understand that it is part of living. A person's right to die with dignity, as free of pain and distress as possible, surrounded by loved ones is without a doubt the sign of a society that values its citizens.