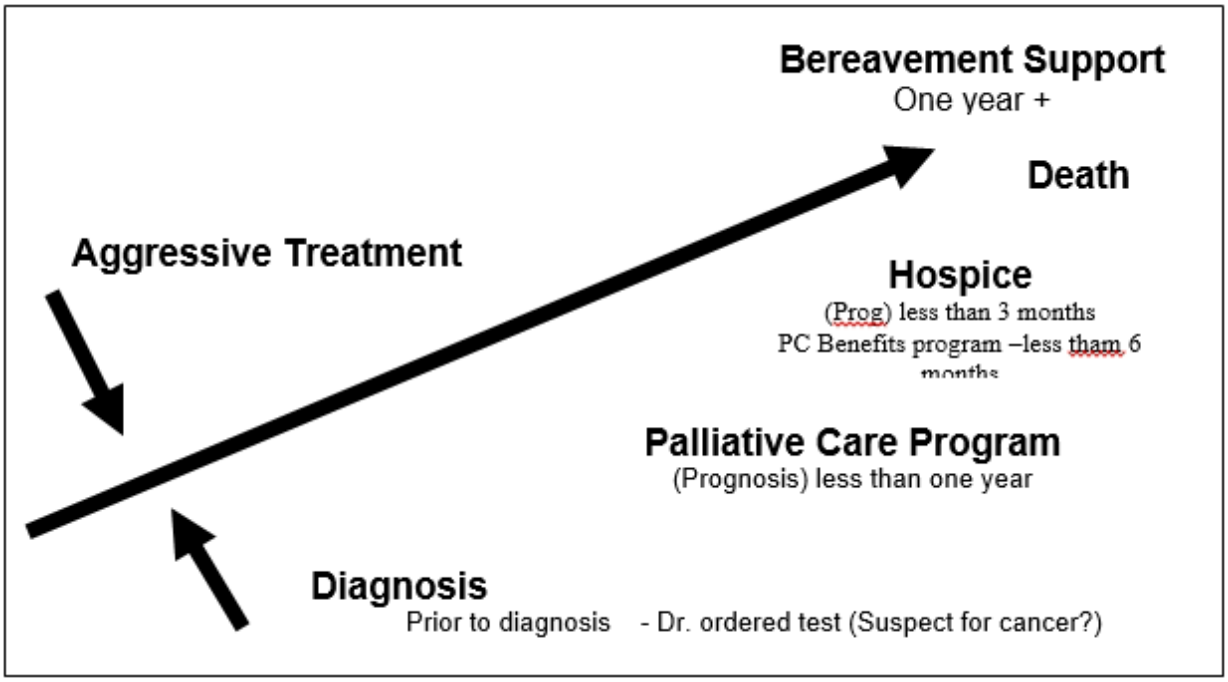
Hospice Palliative Care Model



GUIDING PRINCIPLES FOR HOSPICE PALLIATIVE CARE

The following principles guide all aspects of hospice palliative care:

GP1. Patient / Family Focused. As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

GP2. High Quality. All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection/documentation guidelines that are based on validated measurement tools.

GP3. Safe and Effective. All hospice palliative care activities are conducted in a manner that:

- is collaborative

- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition complies with laws, regulations and
policies in effect within the jurisdiction, host and hospice palliative care organizations.

GP4. Accessible. All patients and families have equal access to hospice palliative care services:

- wherever they live
- at home, or within a reasonable distance from their home
- in a timely manner.

GP5. Adequately Resourced. The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

GP6. Collaborative. Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

GP7. Knowledge-Based. Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

GP8. Advocacy-Based. Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

GP9. Research-Based. The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

Courtesy Prince George Hospice Society

THE PALLIATIVE CARE TEAM: AN EXAMPLE

Commentary

A team is a group of individuals with a common purpose working together. Each individual has particular expertise and training. Their work is a collaborative effort in which members share information and work together to develop goals and future actions.

The palliative care team is made up of a diverse group of health professionals and volunteers. Although the team members may vary according to the individual needs, the individual and their family remain constant, key members of the team.

Team Members

The Patient (guest) and Family

The patient and family are integral members of the palliative care team. The information about their life experiences and response to illness is central in developing a care plan. Only the patient can identify which problem is of greatest importance at the moment. Therefore, the patient and family are well informed and encouraged to participate in decision making.

Physician

The physician plays a central role in the multidisciplinary palliative care team. Relief of physical symptoms must be the foundation on which all other aspects of palliative care rest. For example, all else is secondary when uncontrolled pain and physical symptoms are present.

Nurse

The nurse is the team member who will most frequently see the patient and family. This close contact gives the nurse a unique opportunity to get to know the person and to observe what brings comfort and relief. It is the nurse's primary responsibility to help the patient cope with effects of the advancing disease. This includes physical as well as emotional aspects of care.

Social Worker

The goal of social work is to help the patient and family deal with the personal and social problems of illness, disability and impending death. A social work assessment can include the following:

- The patient's and family's understanding of diagnosis, prognosis
- Present expectations
- The strengths and resources available to the family
- The problems precipitated by the illness
- The past experiences of loss and how they were handled
- Particular cultural and social factors that are unique to the patient and family
- Expectations and plans for the future

Pastoral Care

The role of pastoral care is one of listening, facilitating past recollection, dealing with regrets, giving thanks for what has brought love and meaning, and growing in readiness

for what lies ahead. The presence of pastoral care provides a focus and a stimulus for the airing of questions of meaning that are present for patients and their families. Sometimes there will be guilt for past events, a sense of meaninglessness, and a sense of life as unjust and unfair. Faith that previously seemed secure may be questioned.

Physiotherapist
The goal of the palliative care physiotherapist is to help plan activities aimed at maximizing the patient's diminishing resources, rather than attempting to improve function. This role sets very different goals to those encountered in rehabilitative physiotherapy and calls for much more time spent listening to the patient and providing emotional support.

Occupational Therapist
The occupational therapist assesses the functions in which the patient needs assistance and those that can be done independently. Self-care needs are basic to a person's sense of integrity. Adapting household routines and providing adaptive self-help equipment for bathing and dressing can change a life of dependence for patients at home to one of productive living.

Dietitian
The dietitian seeks to provide frequent small attractive portions of food according to the taste preference of the patient. Quality of life rather than nutrition becomes the goal.

Pharmacist
The pharmacist's knowledge of pharmacology allows them to be a resource to physicians less familiar with certain medications. They can advise on potential drug interactions, anticipate side effects and suggest the best formulations.

Volunteers
Volunteers in the palliative care team assist the medical and paramedical team in providing the optimum quality of life for the patient and family. Palliative care volunteers may be used in several capacities, including direct services to patients and families. Roles that volunteers can fulfill are companionship, shopping, homemaking, respite care and support and care for children.

Courtesy Prince George Hospice Society

OMEGA

There is no need to be afraid of death. It is not the end of the physical body that should worry us. Rather, our concern must be to LIVE while we're alive to release our inner selves from the spiritual death that comes with living behind a façade designed to

conform to external definitions of who and what we are. Every individual human being born on this earth has the capacity to become a unique and special person unlike any who has ever existed before or will ever exist again. But to the extent that we become captives of culturally defined role expectations and behaviours–stereotypes, not ourselves–we block our capacity for self-actualization. We interfere with our becoming all that we can be.

Death is the key to the door of life, it is through accepting the finiteness of our individual existences that we are enabled to find the strength and courage to reject those intrinsic roles and expecting stereotyped role.

It is the denial of death that is partially responsible for people living empty lives; for when you live as if you'll **live forever**, it becomes too **easy to postpone** the things you know that you must do. You live your life in **preparation for tomorrow** or in **remembrance of yesterday,** and meanwhile, **each today is lost. In contrast, when you fully understand that each day you awaken could be the last you have, you take the time THAT DAY to grow, to become more of who you really are, to reach out to other human beings.**

There is an urgency that each of you, no matter how many days or weeks or months or years you have to live, commit yourself to growth. We are living in a time of uncertainty, anxiety, fear and despair. It is essential that you become aware of the light, power, and strength within each of you, and that you learn to use those and others' growth. The world is in desperate need of human beings whose own level of growth is sufficient to learn to live and work with others cooperatively and lovingly, to care for others–not for what those others can do for you or for what they think of you, but rather in terms of what you can do for them. If you send forth love to others, you will receive in return the reflection of that love; because of your loving behaviour, you will grow, and you will shine a light that will brighten the darkness of the time we live in–whether it is in a sickroom of a dying patient, or the corner of a ghetto street in Harlem, or in your own home.

Humankind will survive only through the commitment and involvement of individuals in their own and others' growth and development as human beings.

Dr. Elisabeth Kubler-Ross
Death: The Final Stage of Growth, 1975