



Module 1 BACKGROUND

*Those who have the strength and the love
to sit with a dying patient
in the silence that goes beyond words
will know that this moment
is neither frightening nor painful,
but a peaceful cessation of the functioning of the body.
Watching a peaceful death of a human being
reminds us of a falling star;
one of the million lights in a vast sky
that flares up for a brief moment
only to disappear into the endless night forever.*

Elisabeth Kubler-Ross



Learning Outcomes

By the end of Module One, the volunteers will have

1. An overview of Hospice Palliative Care;
2. An overview of the training they will receive;
3. An introduction to the Cycle of Care model
4. Be able to identify the members of the hospice palliative care team and their roles.
5. An introduction to the concept that death is a part of life's journey.
6. An understanding of their role with respect to safety.
7. An introduction to complementary therapies.

Guiding Principles of Hospice Palliative Care

The following principles guide all aspects of hospice palliative care:

1. Patient/Family Focused
2. High Quality
3. Safe and Effective
4. Accessible
5. Adequately Resourced
6. Collaborative
7. Knowledge-Based
8. Advocacy-Based
9. Research-Based

From: A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

A History of Hospice Palliative Care

International Hospice

Although the hospice movement claims its origins in the 11th Century work of the Sovereign Order of S. John of Jerusalem during the Crusades, the modern hospice movement has its roots in nineteenth century France, Ireland and the USA. Some milestones include:

1843: a home for the dying was opened in Paris by L'Association des Dames du Calvaire leading to the foundation of six other establishments for the care of the dying between 1874, in Paris and 1899, in New York.

1879: the Irish Sisters of Charity opened Our Lady's Hospice for the Dying in Dublin followed by others in Australia, England and Scotland, all of which still exist today and are run by the Order as modern palliative-care units.

1900: the Dominican Sisters of Hawthorne established St Rose's Hospice in Lower Manhattan and then another in New York, followed by others in Philadelphia, Fall River, Atlanta, St Paul and Cleveland.

Although not connected with each other, the principals of these organizations shared a concern for the care of the dying, and in particular the dying poor. Although they were not places that offered sophisticated medical or nursing care, these early facilities created some of the pre-conditions for the development of modern hospices which gathered momentum after the Second World War.



The Twentieth Century

By the mid-twentieth century some important changes were occurring in western medicine and healthcare. Specialization was advancing rapidly; new treatments were proliferating; and there was an increasing emphasis on cure and rehabilitation. At the same time death in the hospital rather than at home

was becoming the norm; and the dying patient or ‘hopeless case’ was often viewed as a failure of medical practice.

Concerns about the improving care at the end of life began to surface more widely in the 1950’s. In the UK, attention focused on the medical “neglect” of the dying; whereas in the United States a reaction to the medicalization of death began to take root. A new view of dying began to emerge which helped refine ideas about the dying process and explore the extent to which patients should and did know about their terminal condition. An active rather than a passive approach to the care of the dying was promoted. Within this, there emerged a determination to find new and imaginative ways to continue caring up to the end of life – and beyond it, in the care of the bereaved.

Dame Cicely Saunders founded St. Christopher’s Hospice, in South London, in 1967, and it quickly became a source of inspiration to others. As the first “modern” hospice, it sought to combine three key principles: excellent clinical care, education, and research. It therefore differed significantly from those homes for the dying which had preceded it and sought to establish itself as a centre of excellence in a new field of care. Its success was phenomenal and it soon became the stimulus for an expansive phase of hospice development, not only in Britain, but also around the world.

From the outset, ideas developed at St Christopher’s were applied differently in other settings. Within a decade it was accepted that the principles of hospice care could be practised in many settings: in specialist in-patient units, but also in home-care and day-care services. Hospital units and support teams were established that brought the new thinking about dying in the heartland of acute medicine.

The work of Elizabeth Kübler-Ross in challenging the medical profession to change its view of dying patients brought about great change and advanced many important concepts such as living wills, home health care, and helping patients to die with dignity and respect.

Her bestselling first book, *On Death and Dying*, 1969, made her an internationally-renowned author. Even today, her trail-blazing book is required reading in most major medical, nursing, and psychology programs. A 1969 *Life Magazine* article outlining her work gave further mainstream credibility and awareness to this new way of dealing with dying patients, although her conclusions were quite revolutionary at the time.

The “five psychological stages of dying” (denial, anger, bargaining, depression and finally acceptance) outlined in her book became accepted as common knowledge throughout the world.

“She was always very proud that her work helped to bring the hospice movement in the mainstream in the United States.”



The Canadian Scene

In Canada, hospice palliative care has developed to meet local needs largely as a result of the rapid expansion of cancer treatment programs in the 1970's whereby treatment was defined as either curative or palliative.

The hospice palliative care movement began in 1974 with the creation of palliative care units in a hospital setting at Winnipeg's St. Boniface General Hospital and at the Royal Victoria Hospital in Montreal. Subsequently, hospice palliative care programs developed as divisions of larger organizations or agencies. Volunteer-based hospice societies and organizations began to develop soon after.

Just as it is difficult to think of the modern hospice movement without reference to Dame Cicely Saunders, so it is impossible to think of the Canadian hospice movement with mention of Dr. Balfour Mount. Dr. Mount, a physician who has survived two personal bouts with cancer, took his end-of-life care training with Dame Saunders in England before becoming the founding director of the Royal Victoria Hospice Palliative Care service in 1974. In fact, he created the use of the term "palliative care" in searching for an appropriate bilingual term after discovering that the word "hospice" in French was used to describe nursing homes in France. He was the Founding Director of the Palliative Care Division of the Department of Oncology at McGill and was later named to that university's Eric M. Flanders Chair in Palliative Medicine. He is the author of 130 publications and has participated in the production of 19 teaching films and audiotapes on Oncology and Palliative Care.

In the mid 1980's health care systems began using terms such as acute, chronic, geriatric, or palliative to define a category of patient. These new terms mandated specialized needs. Hospice palliative care became quickly and widely accepted as a societal movement reforming health care delivery to balance, what the Canadian Hospice Palliative Care Association refers to as, "high tech" acute care with "high touch" palliative care.



Future Development

Within the professional lifetime of the founders of the modern hospice movement, a remarkable proliferation has occurred. At the same time, the definition of hospice and palliative care has come into sharper focus.

Recognition of the speciality of palliative medicine first occurred in the UK, in 1987, and was seen by some as a turning point in hospice history. It was part of a wider shift away from 'terminal' and 'hospice' care towards the concept of palliative care.

As hospice and palliative care continues to evolve, the hope remains that the benefits of a model of care previously available to just a few people at the end of life will, in time, be extended to all who need it – regardless of diagnosis, stage of disease, social situation or means.

In 2001 the Canadian Palliative Care Association changed its name to the Canadian Hospice Palliative Care Association concluding that “due to the fluidity of the English language, “hospice care” and “palliative care” are no longer recognized as separated entities. The term that is now widely accepted in Canada is “hospice palliative care”.

Local Hospice History

Insert your local hospice history here.



Hospice Volunteer Training

Introduction

The role of the hospice volunteer is very rewarding but also very demanding. Hospice volunteers provide a wide range of supportive services for patients and families including:

Direct patient care, such as assisting with feeding, turning, transferring from bed to wheelchair or commode, changing bedding and clothing, and other activities of daily living.

Respite care, which entails staying with the patient, thus freeing the family members to rest or to attend to other matters.

Companionship, which may include reading to the patient, listening to their concerns, or simply providing a silent presence.

Chores, that may include light housekeeping, errands, preparing snacks, etc.

In order to prepare the volunteer, we will provide them with all the training and support they require. At no time will a volunteer be asked to do anything that they are not prepared and willing to do.

Training can consist of group learning led by qualified facilitators, experiential learning based on practical experiences, reading suggested materials, mentoring support, and self-reflection possibly supported by journaling.

The volunteer is expected to attend all training sessions relevant to her/his role and/or to make the necessary arrangements to complete the required training in a reasonable span of time.

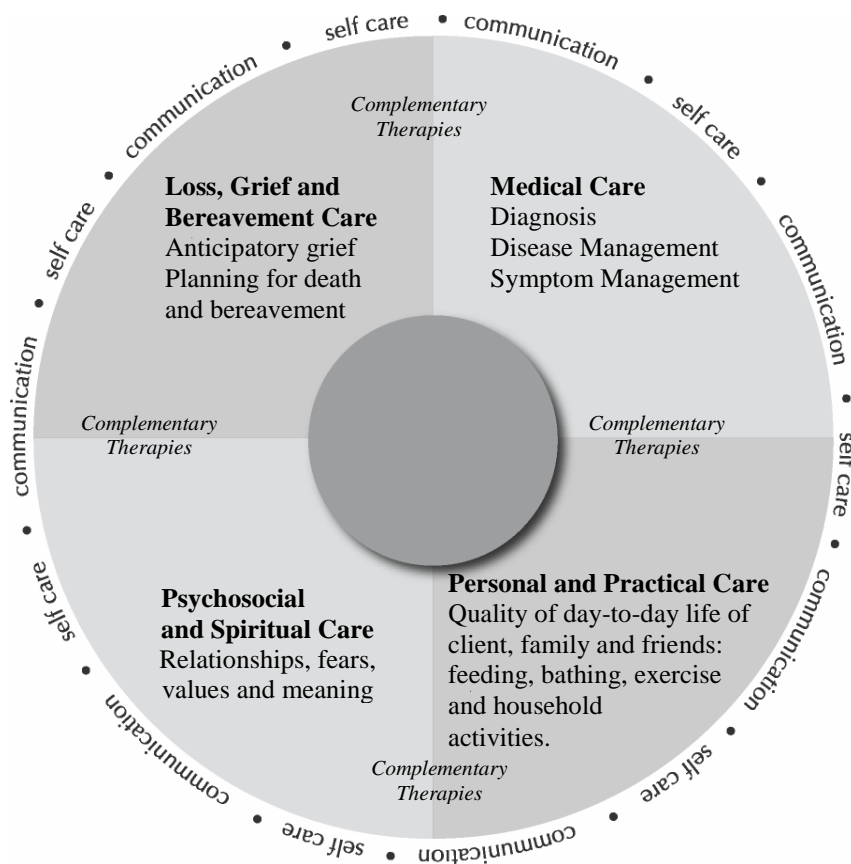
If at any time the volunteer feels that s/he need additional training or support, or require clarification of any material presented or discussed, that additional help or guidance should be readily available. The intention is to make the volunteer feel as comfortable and supported as possible.

Terminology

Some hospice palliative care programs have a preference for the use of the term client or patient. While patient tends to be the preferred term in the medical sense, most hospice organizations expressed a strong preference for the word client. Client is the term we have tended to use in this document and for the sake of simplicity of language we have tended not to use client/patient. Similarly, where the word family is used, it is also meant to include loved one(s), friend(s), and others who might be involved.



The Cycle of Care Model ~ A Framework For Learning



The Cycle of Care model used in the Training Guide is based upon a similar model described in CHPCA's 2004 discussion paper on the role of informal caregivers¹. It has been adapted here to help describe the various roles of the hospice volunteer in a range of settings.

The model is presented in a circle to reflect the interconnectedness of each aspect of the hospice palliative care journey and the natural back and forth flow between quadrants. Recognizing this fluidity, this manual begins in the top right hand quadrant with Medical Care, as it is usually the entry point for hospice/palliative care. The circle is completed by loss, brief and bereavement. As indicated earlier, trainers may present the modules in any order they wish, one or more at a time. The repetitive themes of self-care and communication encircle the full range of experience. The volunteer is placed in the centre of the Cycle of Care diagram with the various settings in which he/she may work. The model helps to illustrate the roles of the volunteer in each stage of the client's and family's progression through the hospice palliative care journey.

¹ *Voice in Health Policy; The Role of Informal Caregivers in Hospice Palliative and End-of-Life care in Canada: A Discussion of Legal, Ethical and Moral Challenges; CHPCA, April 2004.*



The Cycle of Care Model cont'd

The repetitive themes of self-care and communication encircle the full range of experience. The volunteer is placed in the center of the Cycle of Care diagram with the various settings in which he/she may work. The model helps to illustrate the roles of the volunteer in each stage of the client's and family's progression through the hospice palliative care journey.

Medical Care

Medical care is a significant factor in the lives of most hospice clients and their families. It is appropriate that the hospice volunteer have some understanding of the most common elements of this care component.

Historically, medical care, including disease management, pain and symptom management and side effects of medication, has been the exclusive purview of professionals. In most hospice settings, this continues to be true.

A significant increase in hospice care in the home, however, has led to the delegation of some medical care tasks (e.g. administering medications) to informal caregivers. It is inevitable that the hospice volunteer will occasionally find her/himself being asked to support the informal caregiver in these tasks. Volunteer training must address these issues in an appropriate and comprehensive way.

Personal and Practical Care

This element of care may be of primary importance to the hospice volunteer who is likely to be involved in some aspects of practical or personal care regardless of the setting. These essential elements greatly affect the quality of day-to-day life and may include bathing, feeding, exercise, household chores, diversionary activities such as reading and other activities of a personal nature. The policies of individual hospice organizations may prohibit volunteers from carrying out some or all of these activities. These limitations should be thoroughly addressed in the training.

Psychosocial and Spiritual Care

This very special aspect of care is frequently the principal focus of the hospice volunteer whose professional counterparts may be more involved with the physiological dimensions of care. The psychosocial factors refer to the client's relationships with family members and others and to the emotional dimensions dealing with values, fears and meaning. Spiritual care refers to the spiritual dimension which may include the client's faith and religious beliefs.

Volunteers are not meant to be counsellors. However, a good grounding in what the dying client might be experiencing will help prepare the volunteer to listen compassionately to whatever the client may choose to share.

Loss, Grief and Bereavement Care

Although the sense of loss associated with death affects different people in different ways, nearly everyone involved is affected to some degree. By being aware of the dynamics of the grief and loss process, hospice volunteers play an important role in helping the people they serve.



Bereavement Care: Bereavement is a period of sadness and/or loneliness following the loss of a family member or friend/loved one. This period of time may be extended up to a year or even more. Some hospice organizations offer bereavement care as a separate end of life care.

Others provide some additional training to hospice volunteers who may offer bereavement care in addition to the other elements of hospice care.

Communication and Self-Care

Communication and self-care are included around the outside of the circle to indicate their connections to all four aspects of hospice palliative care. Both the communication and self-care modules are equally important components of hospice volunteer training. These are areas that volunteers must constantly tend to in order to be trusted and effective supports to their clients and families.

In addition to personal requirements, both communication and self-care are presented in relation to their HPC team, their clients and their hospice organization's team.

Though you may choose to hold training sessions specifically in these areas, it is highly recommended that you also incorporate communications and self-care into each of the other modules.

Communication: Training and practice in communication will support volunteers to understand the dynamics of communication in a variety of settings and to respond effectively, whether it be through active listening, sitting quietly with a client, or providing feedback to a staff member.

Self-Care: While the work of the hospice volunteer is very rewarding, it can also be highly emotional and, at times, very stressful. It is important that strategies be available to deal with stress and prevent burnout. Self-care options for volunteers will vary with each hospice organization, depending upon training and proximity to resources. Volunteers should have access to both group and individual self-care options that work well for them.

Hospice Palliative Care Settings

The setting in which a volunteer may work are listed in the centre of the circle as that is where the clients and families are. A client may remain in one setting throughout the volunteer's involvement with them or the client may move from setting to setting. It is important for a volunteer to understand the differences in how hospice palliative care is delivered in each setting and to know how each setting will affect their responsibilities.

Creating Safe Spaces

Hospice work involves clients who are vulnerable, isolated and often elderly. We continuously seek to identify ways that we can protect everyone's well-being. We define well-being as a person's emotional, mental, spiritual and physical health. Therefore, it is the responsibility of the hospice organization to identify safety issues and to reduce potential risks in order to protect volunteers, staff and clients.

Regardless of the hospice setting, creating a safe place is a management responsibility – part of general risk management. Volunteers have a contributory role to play in ensuring that



Creating safe spaces cont'd

everyone's well-being is protected, including their own. Training should clarify the nature of some of these risks and the volunteer's role in addressing them.

The Hospice Palliative Care Team and the Role of the Volunteer

The interdisciplinary HPC Team should include the client and family, nurses, physicians, other health professionals, para-professionals and volunteers.

Volunteers are respected and important members of this team. In addition to extensive hospice palliative care training, their range of life experiences contributes rich and diverse perspectives. Their gifts of time and compassion are essential to the team's holistic approach. It is most helpful if all members of the HPB team are aware of and, if possible, able to participate in relevant aspects of the volunteer's training. This strengthens the team and provides all members with a shared understanding of the depth of knowledge and experience that volunteers offer.

Members of the hospice palliative care team may include, but are not limited to (in alphabetical order):

Chaplains, clients, dieticians, family members, nurses, pharmacists, physicians, psychologists, social workers, speech pathologists, integrative therapists, occupational therapists, physiotherapists, recreational therapists, volunteers.

Registered Complementary Therapies

Increasing numbers of people have been supplementing their health care needs with complementary therapies. Complementary therapies have been used to promote health and treat clients with a variety of ailments. Types of complementary therapies used in hospice palliative care have included massage, reflexology, healing touch, therapeutic touch, Reiki, art and music therapy, aromatherapy, and hypnotherapy.

Working in palliative and supportive care is complex and challenging. Therapists need to be well qualified and experienced in the therapy (ies) they practise and they must be able to adapt their practice for use with people at different stages of illness. It is also helpful if therapists have undertaken some professional development training in adapting complementary therapy to working in a palliative hospice care setting, and/or have some experience in this area.



Training

Orientation and Basic Training

1. Provide an overview of the history and guiding principals of Hospice Palliative Care. Include a history of your own local hospice organization.
2. Provide an overview of BCHPCA Standards
3. Provide an overview of the training the volunteers will receive, including the various ways the training will be delivered; e.g., workshops, lectures, field trips, etc.
4. Introduce volunteers to the Cycle of Care Model and each of its components.
5. Describe the Hospice Palliative Care Team, particularly as it relates to your organization.
6. Outline their role with respect to safety for both themselves and their client.
7. Provide an overview of complementary therapies that may be available to clients.



RESOURCES

Module 1 BACKGROUND

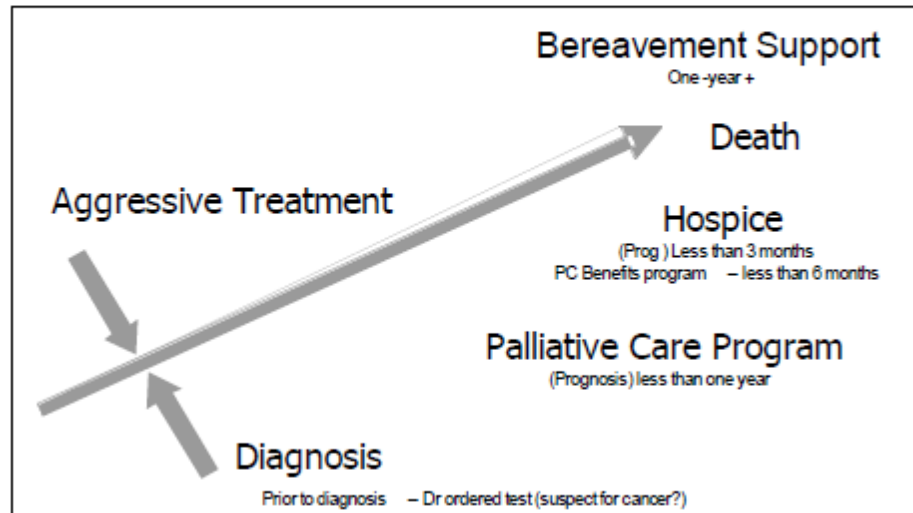


RESOURCES

- ❖ **Hospice Palliative Care Model: an Example**
- ❖ **Guiding Principles for Hospice Palliative Care**
- ❖ **The Palliative Care Team: an Example**
- ❖ **Palliative Care Team and Other Resources: a Model**
- ❖ **What is a Hospice Volunteer Visitor?**
- ❖ **Expectations of Volunteers: an Example**
- ❖ **Training Practices of Some Hospice Organizations**
- ❖ **Responsibilities of Training Participants and Facilitators**
- ❖ **My Profile**
- ❖ **Session Evaluation Form Sample**
- ❖ **“You Are Not Alone” brochure**
- ❖ **10 myths about Palliative Care**
- ❖ **Advance Care Planning**



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.

A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

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

Courtesy Prince George Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

THE PALLIATIVE CARE TEAM: AN EXAMPLE cont'd

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.

Dietician

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

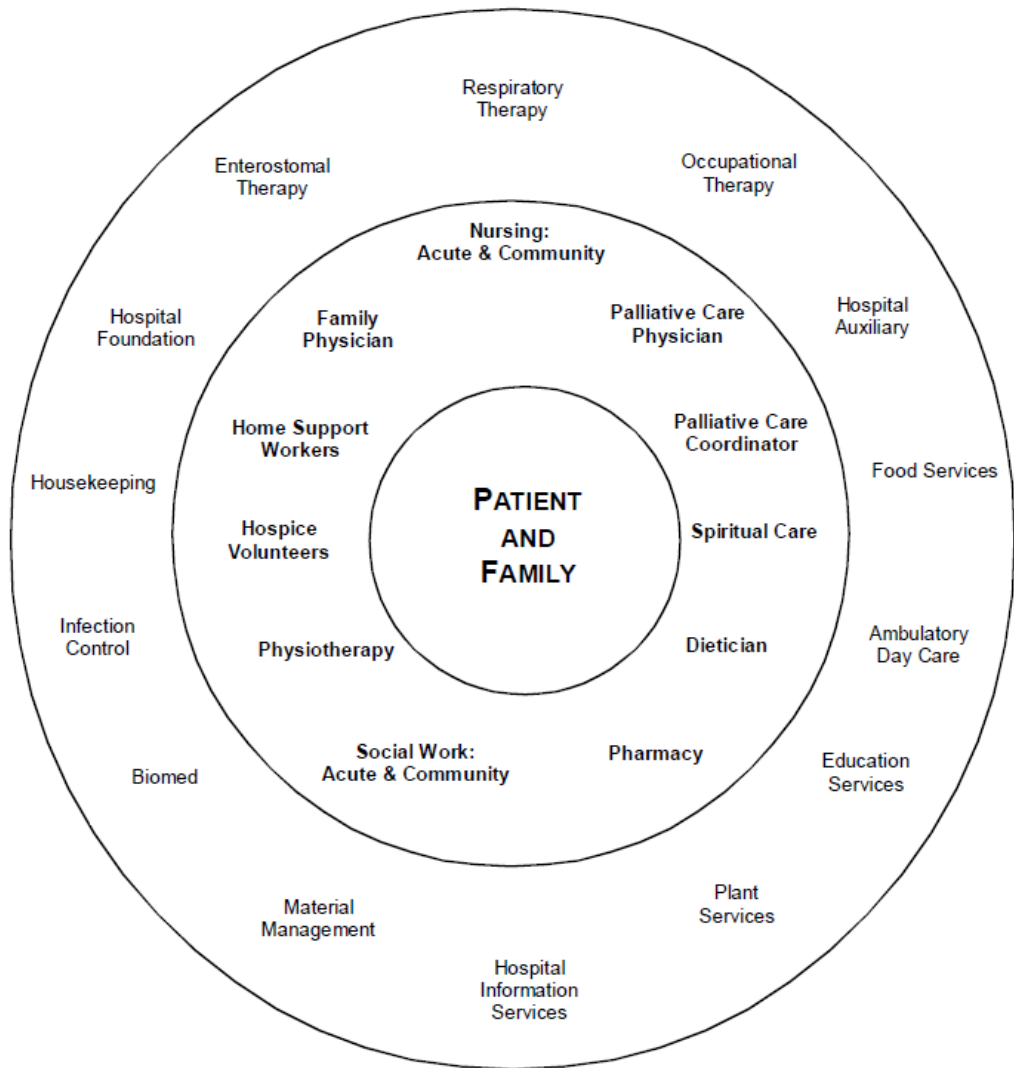
Volunteers in the palliative care team assist the medical and paramedical team in providing the optimum quality of life for the patient and family. Palliative care volunteers may be used in several capacities, including direct services to patients and families. Roles that volunteers can fulfill are companionship,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

Courtesy Prince George Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

Mission Palliative Care Team And Other Resources



Courtesy Mission Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

WHAT IS A HOSPICE VOLUNTEER VISITOR?

A Hospice Volunteer Visitor:

- is a specially selected and trained individual who has the maturity and experience to be a caring listener to a terminally ill person or family member;
-
- does not, under any circumstances, replace nursing care, home support, community health workers, or any other professional service required;
-
- does represent a caring community, absent friends and family;
-
- brings to a stressful situation, a “new face” and a “fresh” but understanding approach;
-
- listens without judging or interpreting; responding if necessary to the feelings expressed and if possible facilitating the resolution of those feelings;
-
- is able to be supportive without “rescuing” or giving advice;
-
- in quiet times, simply shares in silence;
-
- respects the need for confidentiality at all times;
-
- is provided with a support system and ongoing education.

Categories of Hospice Volunteer Visitors

1. One-to-one, Client and/or Family Volunteer:

Volunteer visitors who request and are assessed as appropriate are assigned to a client and/or family according to the individual Volunteer’s personal skills and experience. The same Volunteer remains with the client/family whether the client is at home, in hospital or in facility.

2. Bereavement Support Volunteer:

Bereavement clients enter the program in one of two ways: either as a survivor of a palliative client who was in the program, or as what is known as a “community” bereaved client. In the first instance, when a Volunteer has been assigned to the palliative client, the volunteer will continue supporting the bereaved after the death occurs. In the second instance, a volunteer will be assigned strictly for bereavement support.

3. Clerical, Promotional, Fundraising Volunteer:

In cases where a volunteer does not wish one-to-one contact, related office duties and promotional work can be arranged.

WHAT MAY BE EXPECTED OF A HOSPICE PALLIATIVE CARE VOLUNTEER AN EXAMPLE

Welcome to the Prince George Hospice Society Team

Our expectations of you:

- You treat your responsibilities the same as if it were a paid job ... as soon as you are aware that you are unable to do a shift or complete an agreed upon task, you are expected to phone in and let the coordinator know.
- You treat all members of the Hospice team with respect and dignity
- You treat all guests and clients of Hospice with respect and dignity
- You maintain confidentiality of all staff, guests and clients of Hospice
- You represent Hospice in a favorable light.

What you can expect from other members of the Hospice team:

- You are treated with respect and dignity.
- You are valued for your contribution.
- You are never pushed to take on more than you are comfortably able or willing to do.
- You are supported in taking care of yourself.
- You are given opportunities to try out new jobs if you so desire provided you have the appropriate training and possess the personal skills necessary for that job.
- You have the ability to withdraw from duties and either take a break or switch to other types of duties without penalization or harassment.
- You are offered the chance to take further training as those opportunities arise.

Courtesy Prince George Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

TRAINING PRACTICES OF SOME HOSPICE ORGANIZATIONS

• VICTORIA HOSPICE TRAINING 1

- 12 sessions (3 hours each) \$20.00 for materials
- Wed & Thurs 6:00 – 9:00pm for 6 weeks

• NANAIMO TRAINING

- Monday – 9:00am – 4:00pm
- Monday & Wednesday: seven three-hour sessions
- Monday – 9:00am – 4:00pm
- (\$125 - \$75 refund after 100 hours) Fee waived if a challenge.

• GRAND FORKS TRAINING

- Three full days 8:30am – 4:00pm (once/week for 3 weeks)
- \$40 includes lunch, coffee breaks & manual
- Monthly in-service for all volunteers 10 months/year

• YUKON TRAINING

- Weekend training: Friday evening and all day Saturday & Sunday
- Plus self-directed learning & a listening practicum
- Mentorship group meets three times
- \$75 includes binder “Book of Mourning” & 1st year membership

• POWELL RIVER TRAINING

- 2½ hour sessions for nine weeks (one session is a funeral home visit)
- Six-hour session R/T communication
- Use a variety of presenters
- \$40 (no charge for VCA employees)

• DELTA HOSPICE TRAINING

- Initial orientation session for all applicants
- Two 2½ hour sessions/week (daytime or evening) for five weeks
- \$65

• VERNON HOSPICE TRAINING

- 30 hours over four weeks (8 evening sessions & 2 Saturdays)
- Different modules presented by different facilitators
- \$50 includes manual & membership

• SAANICH PENINSULA PALLIATIVE CARE TRAINING

- Twelve 2½ hour sessions
- No charge for in-house volunteers (\$25 for others)

RESPONSIBILITIES OF TRAINING PARTICIPANTS AND FACILITATORS

It is the responsibility of participants and facilitators to show mutual respect in the following ways:

Participants:

- Attend all sessions unless excused due to illness or emergency (notify the office)
- Arrive on time for all sessions with required training materials
- Complete all assignments on time
- Honour the confidentiality of information shared during the group process
- Allow others equal time for mutual learning and sharing
- Practice good listening skills by having only one person speaking at a time
-

Facilitators:

- Provide a safe environment for all participants
- Encourage, but do not force, active participation
- Keep the group focused on the learning objectives
- Begin and end sessions on time
- Be available to participants for debriefing after and between sessions

Courtesy Pacific Rim Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background

My Profile

Name: _____

Date of Birth: _____

<i>What do I expect to get out of volunteering?</i>	<i>What gifts, talents, interests do I have to share?</i>
<i>What do I hope to learn more about and what skills might I develop while I'm here?</i>	<i>Please list things that you know you don't like to do or would not like to be asked to do.</i>

Courtesy Pacific Rim Hospice Society

RESOURCES: BCHPCA Facilitator's Guide

Module 1: Background



Palliative care is still widely misunderstood by many Canadians. Here are 10 common myths we often encounter.

10 MYTHS ABOUT PALLIATIVE CARE

MYTH 1: Palliative care hastens death.

FACT: Palliative care does not hasten death. It provides comfort and the best quality of life from diagnosis of an advanced illness until end of life.



MYTH 2: Palliative care is only for people dying of cancer.

FACT: Palliative care can benefit patients and their families from the time of diagnosis of any illness that may shorten life.



MYTH 3: People in palliative care who stop eating die of starvation.

FACT: People with advanced illnesses don't experience hunger or thirst as healthy people do. People who stop eating die of their illness, not starvation.



MYTH 4: Palliative care is only provided in a hospital.

FACT: Palliative care can be provided wherever the patient lives – home, long-term care facility, hospice or hospital.



MYTH 5: We need to protect children from being exposed to death and dying.

FACT: Allowing children to talk about death and dying can help them develop healthy attitudes that can benefit them as adults. Like adults, children also need time to say goodbye to people who are important to them.



MYTH 6: Pain is a part of dying.

FACT: Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be alleviated.



MYTH 7: Taking pain medications in palliative care leads to addiction.

FACT: Keeping people comfortable often requires increased doses of pain medication. This is a result of tolerance to medication as the body adjusts, not addiction.



MYTH 8: Morphine is administered to hasten death.

FACT: Appropriate doses of morphine keep patients comfortable but do not hasten death.



MYTH 9: Palliative care means my doctor has given up and there is no hope for me.

FACT: Palliative care ensures the best quality of life for those who have been diagnosed with an advanced illness. Hope becomes less about cure and more about living life as fully as possible.



MYTH 10: I've let my family member down because he/she didn't die at home.

FACT: Sometimes the needs of the patient exceed what can be provided at home despite best efforts. Ensuring that the best care is delivered, regardless of setting, is not a failure.



Aussi disponible en français.

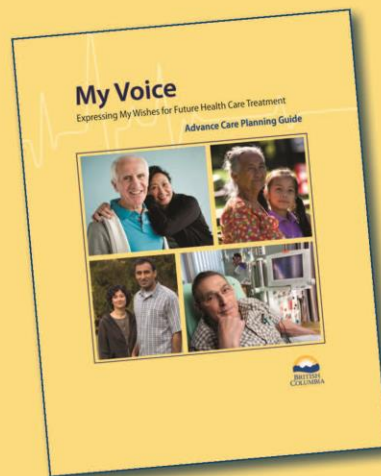
What to do with your advance care plan

Keep it at home in an easily found location - e.g. placed in a folder and attached to the fridge with a magnet.

Be sure to give a copy to your close family, health care provider, your Representative (if you named one) and any others close to you.

What if you change your mind?

Circumstances change. Even your beliefs, values and wishes can change. As long as you are capable of making your own decisions, you can cancel or change any part of your advance care plan.



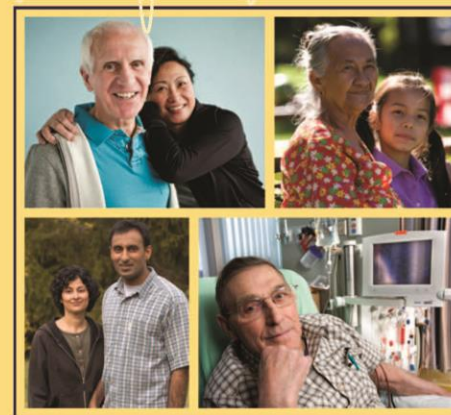
Download the provincial advance care planning guide and workbook at:
www.gov.bc.ca/advancecare

For more information on advance care planning, call HealthLink BC at 8-1-1.



Advance Care Planning

Expressing your wishes and instructions for future health care treatment



By planning ahead, you have a voice in your future health care decisions and will be sure your wishes are respected.

Every capable adult should think about making an advance care plan.



What is advance care planning

Advance care planning begins by thinking about your beliefs, values and wishes regarding future health care treatment. It is about having conversations with your close family, friends and health care provider(s) so that they know the health care treatment you would agree to, or refuse, if you become incapable of expressing your own decisions.

By planning ahead you:

- make your wishes and instructions for your future health care known;
- provide your health care team with information to guide them in your care; and
- ease the burden of your loved ones at a difficult time.

Why you should plan now

You never know when a serious accident or illness may result in you being incapable of making your own personal and health care treatment decisions.

It is never too early to start advance care planning. When the people you trust know what is important to you, it will be easier for them to make decisions on your behalf.

How to start advance care planning

Tell someone close to you, or your health care provider, that you want to talk about your future health care. Have as many conversations as you need. Use the provincial guide and workbook, *My Voice: Expressing My Wishes for Future Health Care* to guide you and write down your options.

When you write down your wishes and instructions for future health care, you are making an advance care plan. A basic advance plan consists of the following:

- Conversations with close family or friends, and your health care provider(s).
- A written record of your beliefs, values and wishes for future health care treatment.
- The names and contact information of the people who qualify to be on your temporary substitute decision maker (TSDM) list.

When a TSDM is needed, one person is chosen from this list in the order below (the order is set by B.C. law):

1. Your spouse (married, common-law, same sex)
2. Your son or daughter (age 19 or over, any birth order)
3. Your parent (either, includes adoptive)
4. Your brother or sister (any birth order)
5. A grandparent
6. A grandchild (any birth order)
7. Anyone else related to you by birth or adoption
8. Your close friend
9. A person immediately related by marriage

Advance care plan options

Your advance care plan can also include:

- A Representation Agreement (RA) where you write your instructions and name someone to make your health and personal care decisions if you become incapable. There are two types: A Section 9 or 'enhanced' RA (allows decisions to refuse life-support), and a Section 7 or 'standard' RA for individuals with lower levels of capability (does not allow decisions to refuse life-support).
- An Advance Directive with your instructions for health and personal care that are given to your health care provider, which he/she must follow directly when it speaks to the care you need at the time.
- Appointing someone to make decisions about your financial affairs, business and property in an Enduring Power of Attorney, which would take effect only when you become incapable.



SESSION EVALUATION FORM

Name: _____ (optional)

Session: _____ Date: _____

1. Were your expectations met: ☐ YES ☐ NO

Comments:

2. What part of the workshop was the MOST helpful?

3. What information can you use immediately?

4. Are there any topics on which you would like further information?

5. Suggestions for improvement:

Thank you for your feedback.

You are not
alone.

You are now confronting a
life-threatening illness.

This is a difficult and perhaps
frightening time, but you
should know that you are not
alone. There is a net of caring
to support you: compassionate,
experienced people who can
ease your pain and help in any
way that is important to you.

Living Lessons®

*About quality of life for
the last stages of life.*

Every life must come to an end, yet it requires great courage to know that the end may be imminent, and to face it. No one should have to be alone at this time in their lives. No one should be in pain. Everyone should live the end of their lives with dignity.

This is not about dying: it is about living well to the end of your life. Hospice palliative health care professionals and volunteers can help. Your family doctor will help you to find access to this net of caring.

You are not alone.

YOU DESERVE

- to be a full partner in your own care,
- to live free of pain,
- to have your decisions and choices respected and followed,
- to be treated with openness and honesty, without deception or half-truths,
- to receive quality medical and nursing care, even though its goals may have changed from cure to comfort,
- to be cared for by compassionate, sensitive, and knowledgeable people who will attempt to understand your needs and try to meet them, and
- to live and die in peace and with dignity.

YOUR QUESTIONS

YOU MAY WANT TO KNOW...

What is hospice palliative care?

Hospice palliative care supports people living with life-threatening illnesses. It provides care for patients' every need, and for those of their loved ones, whether medical, psychological, social, spiritual or practical. Physicians, nurses, physio- and occupational therapist, volunteers and counsellors work together with friends and family to ease a difficult life passage. Care can be provided at home, in hospitals, in nursing homes or in free-standing hospices.

Hospice palliative care considers that dying is an important part of living, and that it is essential to manage pain and other symptoms effectively so that those facing death, and their loved ones, can devote their energies not to fighting physical discomfort, but to embracing the time they have left together.

Hospice palliative services vary from place to place in Canada, but they usually include these elements:

- expert medical care to ease pain and other symptoms;
- planning with loved ones for a team approach to care;
- emotional support for patients and their loved ones;
- spiritual support for people of all faiths and beliefs;
- support for at-home care with, for example, help with medication, dressing changes, bathing, and other health services;
- help with home-making, driving, and physical support;
- telephone counselling in crisis situations;
- respite care to give caregivers a break;
- sympathetic listeners who are not afraid to talk about dying; and
- ongoing bereavement support after the death of a loved one.

*What will I experience with regard to...
...the management of my care?*

You deserve to be a full partner in the management of your own care, and you deserve to have your needs and desires respected by all your caregivers, from your family physician, your nurses and therapists, to your family and friends.

Begin a dialogue with your caregivers so that they are always aware of your concerns and wishes, and it will be easier for you to be honest and open as these change.

...my prognosis?

You are a full partner in the team that is caring for you at this stage of your life. You deserve, therefore, to be told as much about your condition and its likely progression as you want to know at any one time. Be honest and open about what – and how much detail – you want to know. Your loved ones can help, too, by attending physician and care meetings and taking notes.

...my feelings?

People experience this transition in an entirely personal and individual way.

You may feel shock, numbness, disbelief, panic, helplessness, or hopelessness.

You may feel angry or frightened, anxious or guilty, or terribly sad.

You may feel all of these things, your mind zigzagging between emotions like lightning bolts, or none of them.

It is all normal. There are no ways that you 'should' behave or emotions that you 'should' feel, but there are people on the hospice palliative care team who can help you understand and cope with the power of your own feelings.

...pain and other symptoms?

Hospice palliative care understands pain in two ways: It can be both physical pain and 'soul' pain, anguish that is in a person's head and heart. Physical pain and symptoms can be eased with the careful use of medication, a process in which health care teams, patients and their families work together to find the best pain and symptom relief. Hospice palliative care teams include compassionate counsellors who can help patients and their loved ones work through soul pain.

...my death?

Experienced members of the hospice palliative care team can answer your questions about death itself. They aren't afraid to talk about it, and can respond gently but straightforwardly to anything you want to know.

...I don't want to be alone at this time in my life. Where can I find hospice palliative care in my area?

The hospice palliative care team works to ensure that you and your loved ones are supported in whatever ways you need. Hospice palliative care is offered in different ways in communities across Canada. Your doctor, hospital discharge planner or local home care organizer can give you a referral. You can also call the Living Lessons® Help Line at: 1-877-203-INFO, or look on our website for "Groups that can help" at www.living-lessons.org, or visit the Canadian Hospice Palliative Care Association's website at: chpca.net



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

10 TIPS FOR CAREGIVERS

“Living Lessons® – A Guide for Caregivers”, developed by the Canadian Hospice Palliative Care Association and The GlaxoSmithKline Foundation, recommends the following tips for Canadians caring for someone with end-of-life illness. The tips will help caregivers achieve open, honest communication among their loved ones, their doctors and themselves.

1. As caregiver, you are your loved one’s primary advocate on the healthcare team.
2. If you decide to provide care at home, find a doctor who will visit you there.
3. Schedule a triple appointment instead of a single one: the average doctor’s appointment is seven minutes, which may not be enough time to ask and get the answers to all your questions.
4. When making a doctor’s appointment, explain why you need to see the doctor and what you hope to get from the appointment.
5. Make a list of questions you want to ask and identify their priority. Give a copy of this list to your doctor.
6. Arrange for friends or volunteers to attend a doctor’s appointment with the patient if you or other family members cannot. Ask them to prepare questions.
7. As caregiver, you should act as a second pair of ears during the appointments. Take notes so that you can refer to them later.
8. Keep a logbook or journal of all care and treatment. Include in it details of the administration of drugs, appointments, names and numbers of the healthcare team and so on.
9. Remember that as caregiver you may notice changes and symptoms that other members of the healthcare team do not. Communicate these to other members of the team.
10. After appointments, ask for a report or a diagnostic summary if you feel it would be helpful.