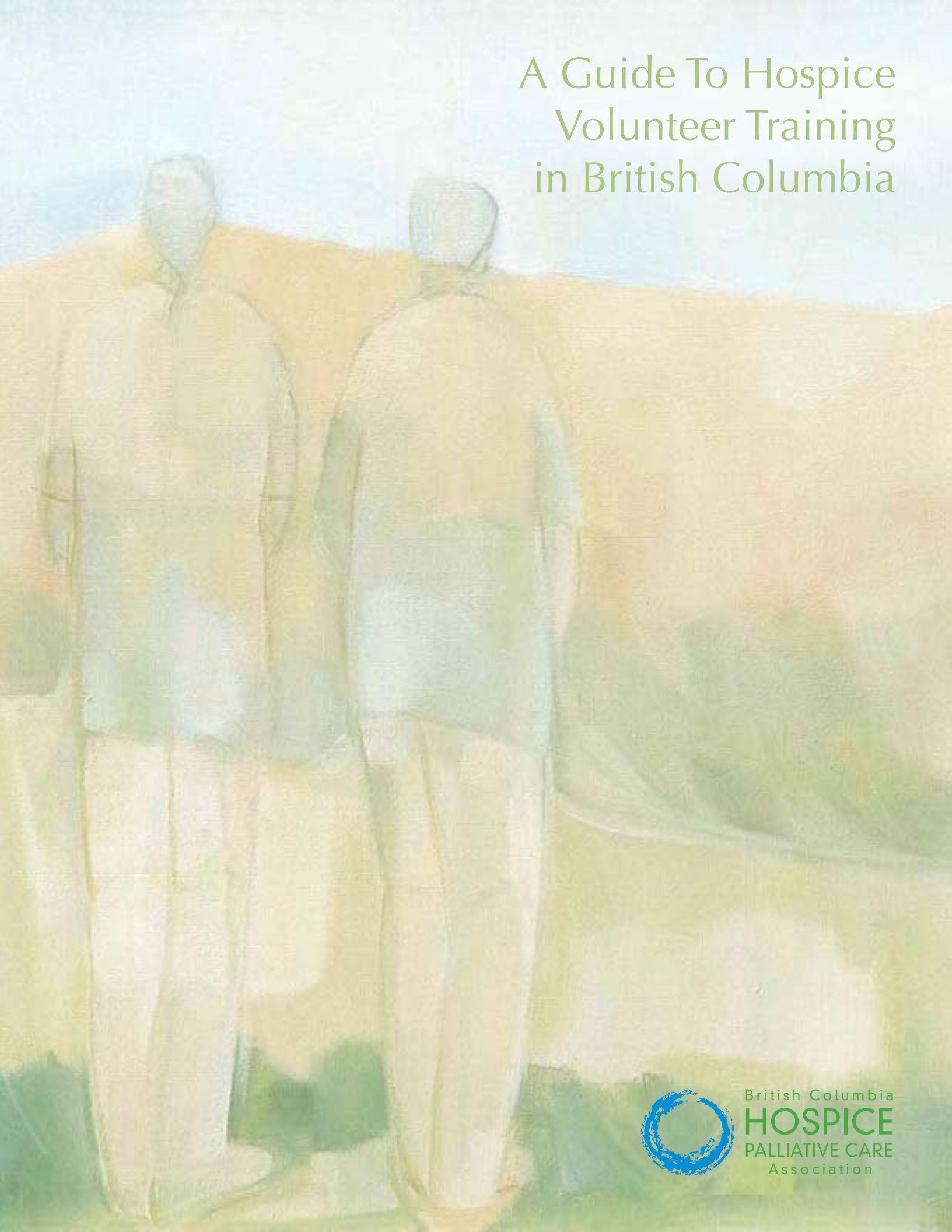
A Guide To Hospice Volunteer Training in British Columbia



British Columbia
HOSPICE
PALLIATIVE CARE
Association

A Guide To Hospice Volunteer Training in British Columbia

2008

British Columbia Hospice Palliative Care Association

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The BCHPCA Steering Committee:
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BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION

The aims of BCHPCA include:

- Encouraging the study and promotion of Hospice and Palliative Care in British Columbia, through advocacy, public awareness and support of new and developing programs;
- Providing education resources for the establishment and maintenance of institutions and organizations devoted to providing Hospice Palliative Care;
- Promoting recognized standards of Hospice Palliative Care;
- Providing a network of communication and shared resources for all those concerned with the care of the dying in British Columbia.

Mission Statement

British Columbia Hospice Palliative Care Association (BCHPCA) is an umbrella organization whose purpose is to ensure the quality of life for all British Columbians affected by life-limiting illness, death, and bereavement. BCHPCA serves its members in British Columbia and the Yukon by:

- Building and supporting the capacity of the hospice and palliative care community, and;
- Providing strategic leadership for, and advocating at all levels as the collective voice of, hospice and palliative care in BC.

In fulfilling this mission, BCHPCA is guided by these Core Values:

Excellence	Our professionalism, expertise and creativity ensure our best at what we do.
Collaboration	We work in partnership and teamwork in a spirit of cooperation and involvement.
Accountability	We are accountable, committed and responsive to our members and stakeholders.
Integrity	We are clear and respectful and uphold the highest ethical standards.
Diversity	We honour and respect diversity.

A MESSAGE FROM THE PRESIDENT

This Facilitator's Guide for Hospice Volunteer Training is the result of a collaborative effort of many people. It was guided by the leadership of the BC Hospice Palliative Care Association but was really made possible only by the caring insight and active involvement of people from hospice organizations throughout BC. We are grateful for the contributions made by all of the participating hospice palliative care stakeholders involved in this project.

Based on the newly crafted Hospice Volunteer Standards, this volume is intended as a guide to those who are responsible for designing and delivering hospice volunteer training in BC. It became apparent through the course of this project that BC hospice organizations conduct some of the best hospice volunteer training in the country. This initiative is not an attempt to challenge or take anything away from the high quality training that is already being provided. It is intended to provide a more level knowledge threshold for all hospice organizations in the province in an attempt to ensure that a minimum level of training is either met or exceeded.

BCHPCA is committed to ensuring quality hospice care in BC by providing strategic leadership in the field and by supporting the capacity of the hospice palliative care community in the province. The introduction of this facilitator's guide for hospice volunteer training is a definitive step forward in this endeavour. Consistent with its values, aims and purposes, BCHPCA is proud to lead the province into a new era of hospice palliative care by enhancing the hospice volunteer component of that care. The introduction of this guide, together with a shared set of standards, will help shape the delivery of hospice care into the future and create a new benchmark of performance and credibility.

This training guide will advance the association's work by supporting our core values of:

Excellence: This guide will affirm our professionalism, expertise and creativity, helping us achieve the best at what we do.

Collaboration: We have developed this guide in a spirit of partnership and teamwork with cooperation and broad based involvement of our membership and colleagues in hospice palliative care.

Accountability: This guide will help demonstrate that we are accountable, committed and responsive to our members, stakeholders and the people we serve.

Integrity: This guide helps to illustrate that we are respectful of the people we serve, that we honour the hospice palliative care network and that we uphold the highest ethical and practice standards as expressed in this new level of support for hospice volunteer training.

Diversity: This guide and the training it will support reflect the reality that while we hold ourselves accountable to the highest possible level, we recognise and celebrate the wide-ranging diversity and varying levels of capacity within our membership and the broader hospice palliative care community.

A MESSAGE FROM THE PRESIDENT cont'd

BC has long been a leader in Canada's hospice palliative care movement. We were one of the first provincial associations ever to be established and, in fact, came into being some seven years before the first national association was formed. We continue to be leaders in the country. Of the one hundred and fifty-eight Canadian charities registered under the hospice banner, sixty-five of them are in British Columbia. The BCHPCA is proud to list most of them as members of this association and is equally proud to offer this guide for use in training all hospice volunteers in the province.

This guide has been developed with the full cooperation and generous input from hospice organizations throughout the province. More than one hundred individuals participated in focus groups held in every region of the province. A province-wide survey drew additional input from hospice palliative care stakeholders in nearly every community. In addition, a wide range of hospice organizations provided us with samples of their training guides and other resources so that we might build upon the good work already being done. The declared support for the introduction of a provincial training guide for volunteer hospice care was overwhelming. This document is our initial response to that overwhelming support.

It is our intention that this draft will spark discussion and debate around those fundamental elements of hospice volunteer training that are most important to us all. We encourage that discussion and welcome your further input into the refinement of this training tool.

Please join with us in celebrating the value of the ongoing and important work of hospice volunteers throughout British Columbia.

Thank you to all of you who have made this guide a reality.

President

BCHPCA

THE CASE FOR A COMMON FACILITATOR'S GUIDE

For the past twenty years, the BC Hospice Palliative Care Association (BCHPCA) has been committed to supporting hospice palliative care in British Columbia. Now with a membership of more than 400 spanning the province of BC and the Yukon, the Association consists of hospice organizations and individuals involved in, or supportive of, hospice palliative care services in this province.

Since the inception of the contemporary hospice movement nearly thirty years ago, hospice services have been provided by dedicated volunteers with varying degrees of preparation for their important role. Historically, volunteer orientation and training have been offered by hospice organizations throughout BC. This training has been developed independently by each organization and has varied widely across the province in terms of both breadth and depth. For example, some hospice volunteers in this province receive thirty-five hours of training, some just five. These variations are largely attributable to significant differences in capacity amongst these hospice organizations. This common guide, a facilitator's guide, is intended in part, to address these differences in capacity.

There is a strong case for some degree of standardization in hospice volunteer training. In fact, efforts have been made in other jurisdictions with varying degrees of success.

In 2002 the Canadian Hospice Palliative Care Association concluded a decade-long period of collaboration to produce A Model to Guide Hospice Palliative Care, based on the national Principles and Norms of Practice[12]. Although the initiative to develop this model reflected the intention to provide "a more standardized approach to hospice palliative care", the document offered a set of "norms" rather than "standards". In fact, the pursuit of national standards is still ongoing some twenty years after work started in this area.

The Hospice Association of Ontario (HAO) has produced provincial standards for Volunteer Hospice Visiting Service and for Residential Hospice Service. The HAO has also developed a common curriculum for Visiting Volunteer Training.

BCHPCA has been an ardent supporter of national standards and we will continue to support the efforts to achieve them. In the interim, however, it is important that we express our commitment to quality volunteer hospice care in a variety of ways. The preparation of this training support document is but one expression of that commitment to quality care. Our membership has told us that this document is badly needed and will be most welcomed. Non-member hospice organizations in BC have echoed that sentiment. We are proud to be able to respond by making this facilitator's guide available.

We welcome your active review of this facilitator's guide and we anticipate your valuable input into its ongoing refinement and improvement.

---

1 A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice; Canadian Hospice Palliative Care Association, 2002.

USING THIS FACILITATOR'S GUIDE

This Facilitator's Guide is provided as a template for client-based hospice volunteer training in BC and the Yukon[1]. The content reflects the BCHPCA Standards for Volunteer Hospice Care. It is structured in a balanced way, however, providing enough guidance to help ensure that the basic requirements are covered while allowing ample flexibility to accommodate the wide range of hospice organizations and training facilitators that will be using it. You know your organization best. You know the peculiarities of your hospice organizations and the training needs of the volunteers you employ. The guide is adaptive to fit your needs and requirements.

The guide reflects the Cycle of Care model described in Module One. It follows a logical sequence reflective of the hospice experience beginning with medical care and concluding with loss, grief and bereavement. The repetitive themes of self-care and communication encircle the full range of experience.

Beginning with an orientation that includes background information, the guide follows the Cycle of Care sequence within seven modules. While it is recommended that they be covered in numerical sequence, the modules are adaptable enough that you may change the order without serious consequence. Each module includes learning outcomes and content guidelines, together with suggestions for experiential learning, handouts and reference material.

The binder format allows for the inclusion of your own teaching materials and resources. Tabbed dividers within each module are provided for this purpose.

Experiential Learning

Experiential learning can include practical exercises and case studies based on practical experience from the field. You should strive for a range of learning activities to accommodate different learning styles and interests.

Practicums and Job Shadowing

Practical hands-on training and observation of experienced volunteers can follow, and greatly enhance, the more theoretical learning that takes place during delivery of the seven-module package.

Mentoring

Mentoring, the association of an experienced volunteer with a newly trained volunteer, is a means of providing an enhanced level of training to the novice while providing the veteran with occasion to reaffirm and refresh earlier learnings.

We hope that you find this guide to be a useful enhancement to the important and valuable task of training hospice volunteers. Your feedback would be welcome and helpful in our ongoing refinement of this tool.

[1.] Wherever BC is referenced it is assumed to include the Yukon.

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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 St. 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.

International Hospice cont'd

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 improving care at the end of life began to surface more widely in the 1950s. 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 into 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 Twentieth Century cont'd

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 into 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 without 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 Hospital 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 separate 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.

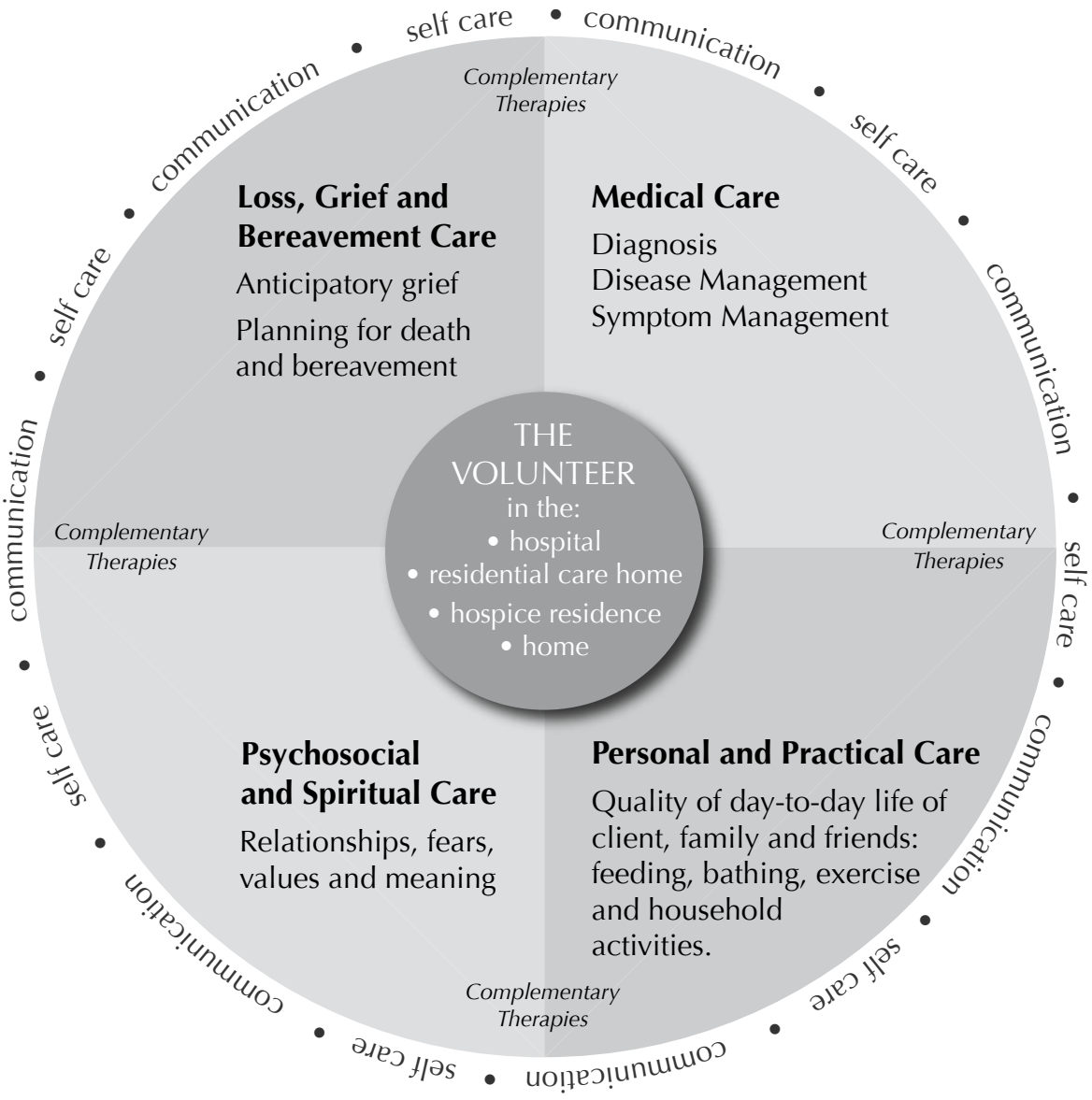
The volunteer is expected to attend all training sessions relevant to her/his role and/or to make the necessary arrangements to complete the required training in a reasonable span of time.

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 this Training Guide is based upon a similar model described in CHPCA's 2004 discussion paper on the role of informal caregivers[1]. 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, grief and bereavement. As indicated earlier, trainers may present the modules in any order they wish, one or more at a time.

[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 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.

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 activieis such as reading and other activities of a personal nature. The policies of individual hospice organizations may prohibit volunteers fom 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 service using specially trained volunteers who may or may not be involved in providing 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 connection 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 settings 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 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 contribute 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 HPC team are aware of and, if possible, able to participate in relevant aspects of the volunteers' 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.

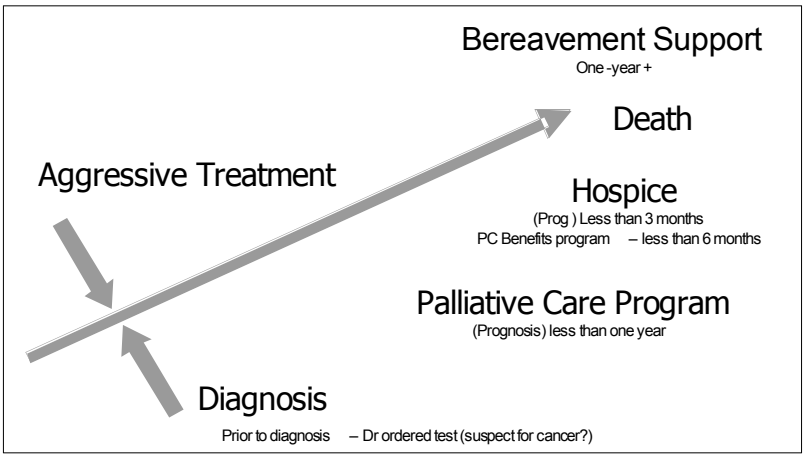
RESOURCES

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**

Hospice Palliative Care Model



Courtesy Crossroads Hospice Society

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.

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

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

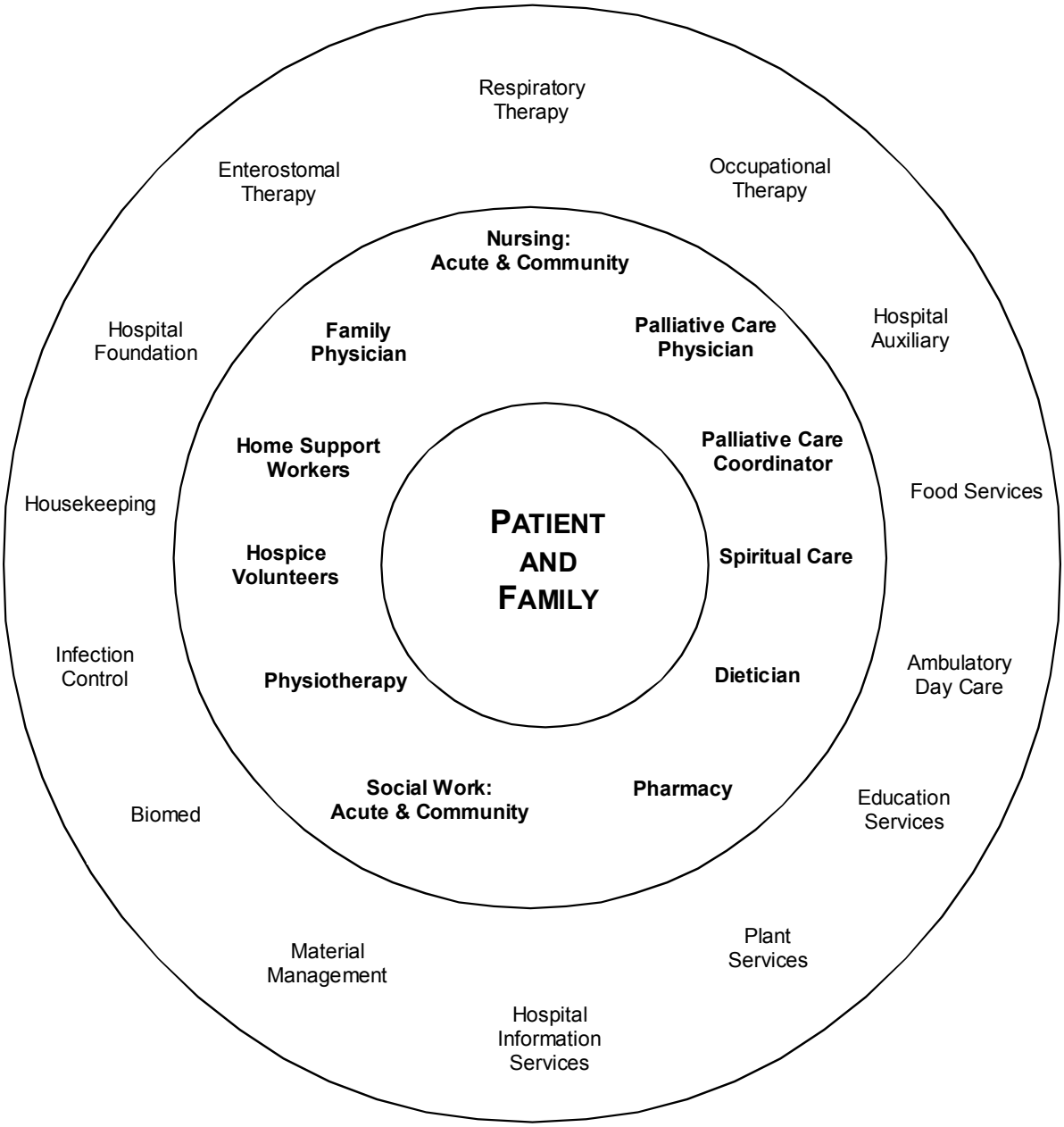
The pharmacist's knowledge of pharmacology allows them to be a resource to physicians less familiar with certain medications. They can advise on potential drug interactions, anticipate side effects and suggest the best formulations.

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

Mission Palliative Care Team
And Other Resources



Courtesy Mission Hospice Society

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 favourable 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

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

My Profile

Name: _____ Date of Birth: _____

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

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.

Living Lessons®
About quality of life for the last stages of life.

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.

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 terribley 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**

The GlaxoSmithKline Foundation

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.

The GlaxoSmithKline Foundation

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Module 2
MEDICAL CARE

At the end of life
when restoring health is no longer possible
Healing becomes more
than just the relief
of pain, suffering, and emotional distress.
During this challenging time
Healing manifests on the purest level--
an extension of the soul
a reflection of the spirit.

Real Healing is
an authentic expression of caring and love,
an aide in accepting a life drawing near,
helping a person discover a calming peace
and a place of serenity on the journey leading to transition.

Kirsti A. Dyer MD, MS. from *Healing: A Gift of Self*

Learning Outcomes

Upon completion of the Medical Care module, volunteers will:

1. Have a general understanding of the medical care component.
2. Understand and respect the limits of their role in relation to medical care.
3. Have the competence and capacity to carry out their responsibilities.
4. Be familiar with community resources and systems of service delivery.

Definition of Medical Care

Medical care is the primary responsibility of professional members of the hospice palliative care team – those who assess, diagnose and manage the client's disease (doctors, nurses, technicians, pharmacists, etc.). Symptom management and pain control are also the responsibility of the medical team. It is helpful for volunteers to be familiar with the composition and roles of the medical team for their own sake and for the benefit of the clients they serve.

Medical Care and The Role of Hospice Volunteer in Different Settings

Setting	Medical Care	Volunteer Role
Hospital	• More medical treatments are available on site.	In all settings the volunteers will have no responsibilities for medical care of their clients. Their role may be to: • Be supportive and respectful of the medical team. • Be familiar with the policies and procedures in each setting that relate to volunteers. • Know when to call for assistance. • Record observations that may assist professional staff (and volunteers) coming on duty *(communication book). • Be prepared to listen while the client talks about her condition without offering medical information or advice. • Be able to direct the client's/family's questions to the right person. • **Hand the client a medication that has been prepared by the family member or nurse, (usually only when a family member is not available). • ** Assist in the moving or turning of a client in the home setting.
Hospice Residence	• Primarily nursing care with visits from doctors. • Pain and symptom management.	
Residential Care Home	• Primarily nursing care with visits from doctors. • Pain and symptom management.	
Home	• Home care nurse will administer medication, change dressings, communicate to medical staff on behalf of client. • Home support workers or community service workers may provide some medical care, under supervision. • Doctor may visit occasionally.	

* Many hospice societies and/or health authorities have developed a "communication book" to support clients and their families on their journey. In binder format, it may provide sections for: recording the names and contact information of the client's support team, including the volunteer; an appointment calendar; a chart for recording medication details; information and helpful advice; and a daily journal for recording questions, events, thoughts, feelings and messages to and from family, friends and support team members.

** As regulations related to medication assistance and lifting and moving a client will vary from region to region and setting to setting, hospice organizations must ensure volunteers are informed and respect the regulations relating to their work setting. These regulations may change over time and volunteers must be kept informed.

Training

Orientation and Basic Training

1. Provide a general overview of what medical care involves. Include information on how medical care is managed in each of the settings in which your volunteers will be working.
2. Provide a tour of each setting in which the volunteer will be working and introduce volunteers to medical members of the hospice palliative care team, if possible.
3. Promote an environment of collegiality where volunteers feel comfortable asking questions.
4. Introduce volunteers to new staff who may be working during the volunteers' shifts.
5. Ensure that volunteers understand and respect the policies and regulations in each setting they will be working, around feeding and moving/turning a client.
6. As regulations vary significantly from region to region and setting to setting, new volunteers who have worked in other regions must be oriented to their new situation.
7. Incorporate a mentoring or "job shadowing" component to allow volunteers to learn on the job from an experienced volunteer.
8. Review universal precautions, including proper handwashing procedures.
9. Provide an orientation to the Palliative Performance Scale (PPSv2). See "Resources".

Ongoing Training

1. If and when appropriate, provide opportunities for volunteers to sit in on medical components of hospice palliative care team meetings, information and debriefing sessions, etc.
2. In keeping with your organization's policies, provide opportunities for volunteers to participate in training sessions on specific procedures if you think the knowledge will enhance the volunteers' abilities to support their clients – whether or not they are permitted to carry out the procedure (i.e. feeding, moving, etc.).
3. Include a segment on emergency preparedness.
4. Provide facts about pain management including the use of non-medical approaches.
5. Include a segment on non-cancer illnesses.

RESOURCES

Module 2
MEDICAL CARE

RESOURCES

- **About Pain**
- **Pain Management**
- **Palliative Performance Scale from Victoria Hospice**
- **Physical Process of Dying: Adapted from Victoria Hospice**
- **The Dying Process ~ Final Hours**

ABOUT PAIN

What is Pain?

Pain: "An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." (*International Association for the Study of Pain*).

Pain: "Whatever the person experiencing it says it is, existing whenever he says it does." (McCaffery, 1999) "The mainstay of pain assessment is the patient's self-report" (Jacox, Carr, Payne et al, 1994, p.3).

Pain is a major symptom in those who are terminally ill.

Terms people use to describe their pain:
Hurt – Ache – Uncomfortable – Tingling – Burning – Shooting – Cramping – Pins and needles – Dull – Sharp – Stabbing

The experience and expression of pain is determined by personal and cultural values, gender, and age.

- Stoicism vs. verbal and emotional expression: Some cultures value silent suffering, while others expect intense verbal and emotional response to pain.
- Women tend to be more communicative about their experience of pain than men
- Older persons may have grown up with the idea that pain is something to be expected as one ages, or with the belief that pain is something shameful or not to be "complained" about ("Mind over Matter")

The presence of pain is not necessarily demonstrated in the sufferer's behaviour. A person may report severe pain, yet have a calm facial appearance, may be talking and laughing with friends, or may be asleep (and only reports the pain on awakening). We should never disbelieve a person's report of pain, or a family member's insistence that the person is in pain, when the person cannot self-report.

Many people report less pain than they are actually having. There are several reasons for this. Often people fear that an increase in pain means the disease is worsening, or that feeling pain is to be expected when one has an illness and must be tolerated. Some people believe that pain is either punishment for past sins or a way to attain salvation in the after life. Fear of addiction to pain medication or fear that using a strong painkiller now will prevent good pain relief in the future when the pain gets worse may result in people not reporting the pain they are experiencing.

Every patient should be encouraged to speak openly and honestly to the nurse and the doctor about the physical pain they are having, and to take their pain medicines as prescribed. Poorly controlled pain and uncontrolled pain increase suffering and diminish quality of life. At the same time it is important to respect the person's right to choose to not report pain or not take pain medication. For some people, physical suffering is meaningful. The important thing is to ensure that patients and families know the facts about pain and pain management, in order that they can make informed decisions.

ABOUT PAIN cont'd

Cancer Pain

There are several different types of pain associated with cancer. Knowing what kind of pain a person is experiencing and where the pain is located helps the doctor determine how best to treat it, including the choice of pain medication. It is important to assess pain intensity and the level of distress it is causing the sufferer and whether the treatments are effective in relieving the pain.

Since pain is subjective it is necessary to ask the person experiencing it to describe the pain, and to rate its intensity using some kind of scale. There are ways to assess pain in people who are unable to communicate, but usually these scales are useful in only a general way and often their accurate interpretation depends on how well the observer knows the sufferer.

***Acute Pain*:**

- starts suddenly and is usually relieved within days, but may last a few weeks
- may be related to surgery or radiation treatments; sometimes is the result of tumour growth (such as pain that occurs with bowel obstruction)
- usually is the result of tissue damage and inflammation is often present
- may or may not be obvious to an observer, and the patient may or may not appear anxious

Chronic Pain:

- pain that has been present for longer than 3 to 6 months, and that persists beyond the expected course of an illness or injury
- associated with a chronic disease process, such as arthritis or cancer
- may lead to depression
- often not obvious to an observer

***The longer pain persists, the more intense it becomes.

Nociceptive Pain: caused by tissue damage; can be acute or chronic.

Neuropathic Pain: caused by injury to nerves or to the central nervous system (following a stroke, for example); can be acute or chronic.

Mixed Pain: has both nociceptive and neuropathic features.

Total Pain

A person is made up of body, mind, and spirit and spends his or her whole life (usually) in relationship with other people. Therefore, when an illness such as cancer strikes, it affects more than just the individual and more than just the physical body. Cecily Saunders coined the term "Total Pain" to capture the all-encompassing nature of the pain experienced by those with a terminal illness.

Psychological, emotional, social, financial, and spiritual pain contribute to the experience of physical pain (See Total Pain graphic). Physical pain can be made worse when other sources of pain are not addressed. This is another reason that an interdisciplinary team is so important.

ABOUT PAIN cont'd

Pain Management

I. Use of Medications

It is important to understand the source of the pain in order to treat it effectively, but it is equally important to have some way of determining how severe the pain is and whether or not the treatment is effective in controlling the pain. The best way of doing this is to use a scale, such as 0 = No Pain ---→ 10 = Worst Pain Imaginable, and ask the person to say where on that scale they would rate their pain. Pain intensity should be assessed before and after giving the person some form of treatment for the pain. Sometimes a person is willing to have *some* pain, but the goal of comfort should be negotiated between the patient and the doctor or nurse. Usually the comfort goals are:

1. First, to be comfortable during the night and to get a good sleep.
2. Next, to be comfortable during the day while at rest.
3. Finally, to be comfortable during the day when one is moving around and doing the things that are important to the person.

Mild, Moderate, and Severe Pain

The World Health Organization developed a simple model to guide health professionals in choosing the most appropriate pain medication for the severity of pain being experienced. (See WHO Analgesic Step Ladder) There are two basic types of pain medicine: non-opioid (for mild pain) and opioid (for moderate and severe pain). Opioids are drugs such as codeine and morphine.

Mild Pain

- Acetaminophen (Tylenol)
- Anti-inflammatory drug, such as ibuprofen
- Tylenol #3 (codeine) or MOS (morphine syrup)

Moderate

- Codeine
- Morphine
- Hydromorphone (Dilaudid)
- Fentanyl patch

Moderately Severe and Severe Pain

- Morphine
- Hydromorphone (Dilaudid)
- Fentanyl patch
- Methadone*

*Methadone is a very effective drug for people with severe pain, especially when the pain is both from the cancer and from nerve injury. If a person is taking methadone it does NOT mean that he or she is a recovering addict.

ABOUT PAIN cont'd

Pain Management cont'd

Myths about Morphine (and other opioids)

1. **MYTH: "You need to save strong pain medication for when the pain gets worse."**
    a. FACT: Treating pain early can prevent worse pain and loss of function.
    b. FACT: There is no limit to the amount of opioid that a person can take.

2. **MYTH: "Taking strong pain medication will cause a person to become addicted."**
    a. FACT: Less than 0.1% of patients taking opioids for pain control become addicted.
    b. FACT: Addiction is a compulsive desire to take a drug such as morphine in order to experience the "high". People with pain take the drug in order to relieve the pain.

Side Effects of Opioids

1. Constipation – This always accompanies the taking of opioids, and can be prevented or treated by the regular use of a laxative. Stool softeners alone are rarely effective in preventing constipation.
2. Nausea, with or without vomiting – This is commonly seen when people first start taking an opioid, and can be prevented or treated by several kinds of medication. Nausea can also be caused by constipation.
3. Drowsiness, decreased mental alertness – This side effect usually decreases or disappears within a few days, but will re-occur whenever the drug dose is increased; this is also a natural occurrence as people come closer to death.
4. Itchiness, especially an itchy nose.
5. Difficulty with urination – This sometimes occurs in elderly people who are taking opioids.
6. Respiratory depression – This is rarely a problem when a person has been taking an opioid for some time.

II. Other Ways of Managing Pain

1. Surgery
2. Radiation
3. Chemotherapy
4. Nerve blocks
5. Acupuncture
6. Massage, positioning
7. Heat/Cold

ABOUT PAIN cont'd

Other ways of managing pain cont'd

Remembering the concept of Total Pain, there are a number of other important ways to control pain. Hospice volunteers are able to provide some or all of the following helpful interventions:

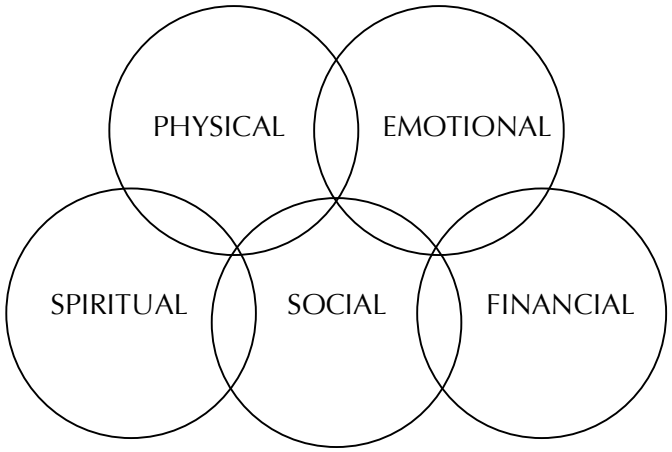
- Listening, companionship
- Use of Imagery
- Relaxation techniques
- Therapeutic touch, Healing touch
- Distraction (games, music, watching TV or movies, outings, arts and crafts, creation of a legacy)
- *If the person requests*: reading of scriptures, singing of hymns, prayer.

Counselling for the person and family members, assistance with putting affairs in order, and making final arrangements are other services that the interdisciplinary team can offer, and that will have an impact on Total Pain.

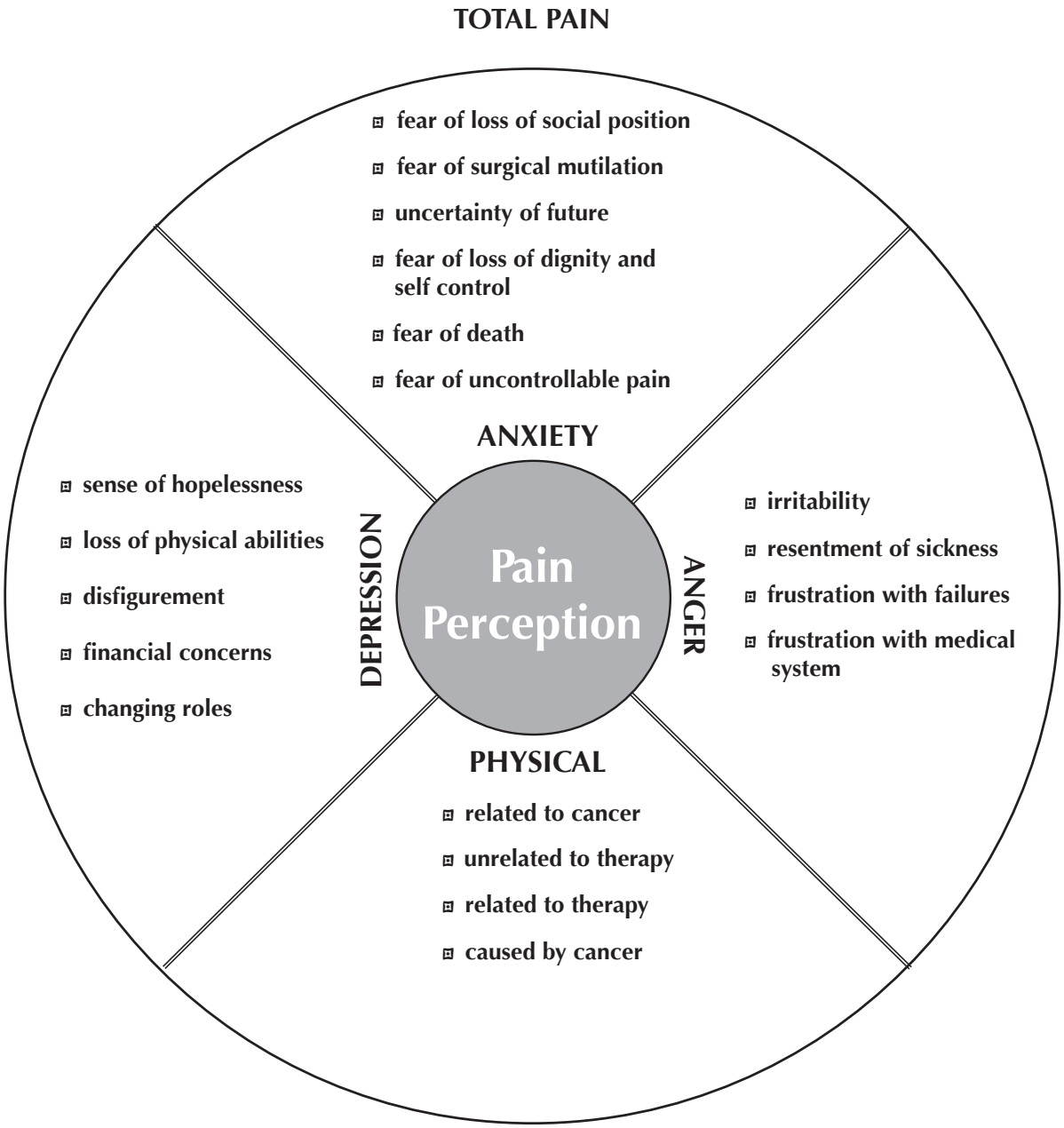
Total Pain Concept

The dying person's perception of and response to pain has emotional, social, spiritual and psychological components. All components are interrelated and can increase sensation of pain.

THE MULTIFACETED COMPONENTS OF PAIN



Source: Multifaceted Components of Pain, Amenta and Bohnet, 1986


TOTAL PAIN
fear of loss of social position
fear of surgical mutilation
uncertainty of future
fear of loss of dignity and self control
fear of death
fear of uncontrollable pain
ANXIETY
sense of hopelessness
loss of physical abilities
disfigurement
financial concerns
changing roles
DEPRESSION
Pain Perception
ANGER
irritability
resentment of sickness
frustration with failures
frustration with medical system
PHYSICAL
related to cancer
unrelated to therapy
related to therapy
caused by cancer

PAIN MANAGEMENT

Physical pain cannot be treated in isolation from other causes of suffering - for example anxiety, grief, spiritual concerns. Addressing these issues together with pain management strategies reduces the need for strong analgesics.

Pain is what the person says it is; not what anyone else thinks it should be.

Pain can be controlled in most situations. Unless it is their choice, there is no excuse for anyone's attention to be focused on their discomfort.

The degree of pain does not relate to the extent of the illness. Some people with advanced disease may have no pain, while someone with the same tissue damage may experience severe pain.

In terminal illness, several different types of pain usually occur together and require different therapies simultaneously. For example: pain from invasion of a tumor into surrounding tissue, pain from swelling, hypersensitivity in the hands and feet from chemo and muscle aches from weakness and inactivity.

Pain Management Strategies

Encourage people to utilize the pain relief methods they believe in, regardless of whether you believe them to be helpful or not.

- ✓ Attention to issues beyond the physical pain (fear, stress, anxiety)
- ✓ Rest and relaxation (maybe through music, visualization, listening to stories etc)
- ✓ Application of heat or cold
- ✓ Imagery
- ✓ Alternative therapies (healing touch, massage, biofeedback, acupuncture, acupressure, crystals, herbal remedies, etc)
- ✓ Analgesics
- ✓ Surgery

Analgesics:

- o Over-the-counters such as Tylenol, Ibuprofen, ASA
- o Combinations such as Tylenol or ASA with codeine – prescription
- o Coanalgesics treat something other than pain but also alter the experience of pain.
- o Narcotics or Opioids such as Morphine, Demerol, Diladid

Morphine

Side effects include constipation, sedation, nausea and possibly vomiting and sometimes hallucinations, muscle jerking, itching, sweating, difficulty urinating. Many of these can be prevented or managed through the use of another medication and some may actually clear up after the first few days.

PAIN MANAGEMENT cont'd

Common Myths About Narcotic Use

Myth:
Giving morphine or other opioids on a regular basis will turn the person into an addict.

Fact:
Opioids are highly addictive drugs. However, when used to manage physical pain under the care of a physician, it is possible to take the medication without becoming addicted. Keeping a steady low dose of pain killer in the body reduces the roller coaster ride of a large dose being introduced, waiting for it to wear off, introducing another large dose and then waiting again. When used in a medical setting with a continuous administration, addiction is well below the rate within the general population.

Myth:
If you use morphine now, it won't work later when your pain is worse.

Fact:
Morphine and other opioids are given in doses appropriate for the level of pain at the time. As pain increases, the amount of the drug may also need to be increased or the drug changed. The increased dosage is reflective of the increase in pain, not in the decrease of effectiveness of the drug.

Myth:
Narcotics can only be given for so long.

Fact:
Morphine and other narcotics are usually given in the last few days or weeks of life. However, there are some cases where the pain level is very high long before the end of life (months or even years). When prescribed, administered and taken appropriately, these drugs can be effective for several years.

PALLIATIVE PERFORMANCE SCALE (PPSv2)

PPS LEVEL	AMBULATION	ACTIVITY & EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduce	Unable normal job/work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally bed bound	Unable to do any activity Extensive dis34ase	Total care	Normal or reduced	Full or drowsy +/- confusion
20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10	Totally bed bound	Unable to any activity Extensive disease	Total care	Mouth care only	Drowsy or Coma +/- confusion
0%	Death				

Courtesy Victoria Hospice Society

Victoria Hospice
SOCIETY

INSTRUCTIONS FOR USE OF PPS

PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient, which is then assigned as the PPS% score.

1. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.
    i. Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.
    ii. Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although, this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.
    iii. Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
2. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
3. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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INSTRUCTIONS FOR USE OF PPS cont'd

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items 'mainly sit/lie,' 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs. need to lie down.

'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on his or her own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease

'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 13 holes to 9 holes, or just a par 3. or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (e.g. trying to walk the halls).

INSTRUCTIONS FOR USE OF PPS cont'd

Definition of Terms for PPS cont'd

3. Self-Care

'Occasional assistance' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'Considerable assistance' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat or his or her own accord.

'Mainly assistance' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'Total care' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with 'normal intake' referring to the person's usual eating habits while healthy. 'Reduced' means any reduction from that and is highly variable according to the unique individual circumstances 'Minimal' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. 'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. 'Drowsiness' implies fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. 'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24-hour period. ©

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The *Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J Pail* Care 9(4): *26-32J. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with* appropriate *recognition. Available in electronic Word format [b]y email request to judy.martellcaphealth.org*

Correspondence should be sent to Medical Director, Victoria Hosice Society, 1900 Fort St, Victoria. BC, V8R 1J8. Canada

Nanaimo Community Hospice Society Volunteer Training Program
DEATH & DYING

THE PHYSICAL PROCESS OF DYING

The Palliative Performance Scale (adapted from Hospice Victoria)

The Palliative Performance Scale developed by Hospice Victoria is a new tool for measurement of physical status in palliative care. As a result of having this tool, one can more readily profile the general physical condition of a patient and plan the supports and services they may need.

Critical Levels on the P.P.S.

P.P.S. of 60 - 70%

A person is still at the stage when diversion is important (e.g. outings, massage, music, humour, movies/videos, visiting).

P.P.S. of 50%

This is a level of great transition. Reality of the disease process sets in. Spiritual shifts occur; hope is refocused; fear of dying an issue: good time to establish relationships. There is a need to feel safe, have feelings validated, review their life, and balance energy use. Family may be overwhelmed with needed care. Patient and family need information.

P.P.S. of 40%

Similar issues, Family also needs continued support

P.P.S. of 30%

Another level of transition. Due to further physical changes independence becomes a big issue. Feels closed in, is less talkative, with little future prospects. There is a fear of death and a need for information. Both patient and family may accept the inevitability of death on one level but don't wish to let go.

P.P.S. of 20%

At 20% the body doesn't process water. Food and drink is not desired: Sleep most of the time: Encourage families to feed the spirit rather than the body; stay with the patient and remember with him/her. Empower the family with information. Patient may arouse if it is important enough to do so (e.g. visit of loved one). May communicate in a symbolic way, which can have a positive affect on family (e.g. grandmother is packing to go on a trip).

THE PYSICAL PROCESS OF DYING cont'd

Palliative Performance Scale (PPS) and Psychosocial Care

Psychosocial care of dying patients and their families includes emotional, spiritual, and practical support and counseling through the process of dying, death and bereavement. It is generally thought of as a key component of palliative care. However, delivery of this service is often inconsistent and not always based on a thorough assessment of patient and/or family issues, needs and wishes. This may result in psychosocial care that is uneven, based on problems rather than on an integrated approach of caring.

The counseling team at Victoria Hospice is always looking for ways to improve the consistency, coordination and quality of the psychosocial care provided to patients and families. To enhance communication with one another and our many medical teams we began to include the Palliative Performance Scale (PPS) both in the completion and discussion of psychosocial assessments.
In using the PPS, we have become increasingly aware of the timing and relationship between physiological and psychosocial issues; that changes in mobility and functioning are closely tied to spiritual, social and emotional struggles. This information further cements our understanding of and commitment to ensuring holistic care. Identifying critical transitions allows us to use our limited counseling resources more efficiently and effectively.

The tool also provides another avenue for communicating with medical team-mates about changing psychosocial care needs and draws staff attention to expected or predictable patient and family issues and concerns – the process of dying and grief becomes normalized.
This section presents the key transition points that occur along the continuum of a terminal illness from 50% PPS through to death and is summarized in Table 17.5 below. It looks at basic physical changes, emotional, spiritual and communication issues for the patient and family, as well as psychosocial interventions. These include planning for care, teaching, mediation and counseling.

PPS	Person	Physical	Emotional	Intake	Communication
50%	Patient	Symptomatic, decreased energy	Need to engage, spiritual questions	Decrease in appetite, interest	Difference in coping arise
	Family	Poor self-care	Overwhelmed, feeling helpless		
30%	Patient	More dependence, key body changes	Worn out, closure/endings important	Small amounts	Often impeded
	Family	Fatigued	Strengths & struggles intensify, lots of questions		
10%	Patient	Unresponsive, systems shutdown	Possible agitation, refocusing	Mouth care only	Hearing & touch decline
	Family	'Auto-pilot,' exhausted	Focusing on death, relief & sadness/anger		
0%	Patient Family	Dead	Varying needs, reactions		

Table 17.5

Courtesy Nanaimo Community Hospice Society

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 50%

A. The Patient

1. Symptoms and Responses

At a PPS of 50%, the disease re-declares itself, often with metastatic spread to bones, lungs or other tissues. As a result, the patient experiences an increase in symptoms and body changes. A decreasing energy level results in the curtailment of normal activities meaning reduced mobility, walking with aids or assistance, and less stamina for chores or outings. Patients usually are aware of a loss of appetite and interest in food, unless they are on dexamethasone, which increases appetite.

When the reality of disease sets in, a patient finds that earth-shattering psychosocial changes and shifts are triggered. The prospect of cure is unlikely. Along with a loss of control and autonomy come shifts in family roles and responsibilities. This is a time of overwhelming and mixed emotions; panic, confusion, fear, resignation, helplessness, hopelessness.

Patients face fears of suffering and dying. Spiritual questions arise about the meaning of life and meaning of death. There is a shift in hopes, drams and expectations. Patients have a need to continue engaging with life in a meaningful way through activities that have particular value for them, such as, pursuing alternative healing methods, holding on to hope, or maintaining social contacts and relationships.

At this time, the difficulties that arise tend to be based on pre-existing family style and patterns. Between patient and family there will be differences in grieving process, and issues around dealing with illness or expected death can surface.

2. What Helps

Planning: Involvement in planning for care, family future, and other issues can help patients maintain areas of control. Decision making about palliative care and symptom management often occurs at this point, PPS 50%.

Teaching: Information about supports and resources available [medical, emotional, spiritual, practical], in the time ahead, is helpful at this time.

Counselling: Building a solid, safe relationship is important now, as is information and support to address feelings of being overwhelmed. Offer available resources; ensure beliefs and understanding arc accurate; consult with appropriate team members.

Begin to explore what lies ahead. Determine what is predictable and known, and what cannot yet be known; explore fears of dying, of pain and of suffering. Exploration and validation of feelings and emotions can help to give reassurance and normalize their experience. Life review and reminiscence offer meaning and perspective to present circumstances.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 50% cont'd

B. The Family

1. Responses

When the patient is at PPS 50%, the family often are unable to recognize the physical impact on themselves of providing care to the patient. They may be unable to pace themselves, feeling totally responsible, wanting to maintain control, and unaware of the demands of ongoing care. These factors often lead to poor self-care, especially through poor sleep, nutrition, and lack of exercise.

Similarly to the patient, when reality of the disease sets in, major psychosocial changes and shifts are also triggered within the family. As the prospect of cure is recognized as unlikely, shifts in family roles and responsibilities take on new significance.

This is a time of overwhelming, often mixed emotions. Families may be needing information and/or a prognosis but afraid of the answers, feeling unsure and insecure. Despite having fears of the future, they are starting to plan for it. As the focus on the patient's needs and situation increases, less importance is placed on family members' own feelings and concerns. They put their own needs on hold, in part to protect the patient.

The impact of the disease may become more apparent to the children in a family, prompting questions, fears, and changes in behaviour.

2. What Helps

Planning: This is when family need to be talking to the professional caregiving team; to get information about the disease process, to plan for help with care, to coordinate resources. Family conferences are an excellent way to get everyone involved directly discussing concerns, needs and plans.

Teaching: There is a lot of new information to be absorbed during this time; information about resources and care options that are available in the community, the workings of the various systems family must deal with, and self care issues and approaches.

The adults may need information about children's understanding of illness and their developmental needs; modelling of appropriate attitudes and language may help. Direct support may be appropriate.

Counselling: A number of areas need to be addressed with family. Intense feelings of being overwhelmed by changes in disease and condition may need to be explored and supported. Fear of not knowing what lies ahead and loss of control need to be discussed. The family's ways of dealing with this new reality [denial, avoidance, hope, acceptance] need to be acknowledged. The impact on the family and its functioning brought about by changes, needs to be addressed in terms of the dynamics of the family in the present situation.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30%

A. The Patient

This is a time when changes become more predictable, more apparent and closer together. Often the time frame, of remaining life and approaching death becomes clearer. Symptoms, such as pain, continue to change, requiring adjustments or increases, and possibly, admission to hospital or palliative unit for effective management.

The patient's body may begin to look noticeably wasted, unless medications cause increased appetite or fluid retention. Activity levels decrease dramatically. The patient is totally bed bound and doesn't get dressed, although they may get up to the commode or lounge chair.

They are increasingly dependent on others for care such as feeding, drinking and re-positioning. Energy continues to decrease and there is little desire or ability for socializing, except with immediate family or friends.

As the disease progresses and its impact continues to be felt, the patient may experience waves of helplessness and hopelessness. The ability to adjust to the dramatic changes now, the loss of independence and control, will depend on how well the patient was able to accept and move through the psychosocial shifts that occurred at PPS of 50% and 40%.

Concerns about dependency and being a burden to others often arise with the recognition of increasing care needs. The patient can feel emotionally worn out, tired or drained and often experiences increased periods of drowsiness, sleepiness and confusion. They may begin to think about letting go - of life, of the fight, of worries.

Along with this, unresolved concerns can become an emotional burden and there may be a sense of urgency to bring closure to these issues. This is the time when a shift from fearing death to an acceptance of death often occurs for the patient.

At this PPS level, intake will be significantly reduced to small amounts of soft or liquid foods, such as food supplements or a few spoonfuls of soup, ice cream, and yogurt.

The patient's conversations are often impeded by sleepiness, wandering attention, and lack of focus or energy. Also, the patient may find it hard to discuss their fears or feelings with family due to the family's usual communication style and boundaries.

At this time, the patient and family may find themselves in very different places along the acceptance-denial continuum, making communication difficult between them. This is affected by the patient and family having different opinions, concerns or feelings about care, different hopes or expectations, and different information. The patient is often more familiar with the reality of their disease and its progression than is the family.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

A. The Patient (cont'd)

2. What Helps

Planning: It is helpful to the patient that attention is given to addressing family support during and after death. Concerns often include reviewing practical matters, such as will, power of attorney, and funeral/memorial planning, especially if these matters have not already been attended to. This is a time to re-evaluate plans for care and death: the patient will choose their level of participation in this process. Discussion about family visiting or attendance during the time that remains is important.

Teaching: The patient will appreciate helpful hints on adjusting their life style to suit changed abilities and energy levels. Times spent conversing with the patient or addressing issues will need to be managed according to the energy levels of the patient. This is a time to introduce and provide opportunities for the patient to experience the benefits of touch therapies, guided imagery, and relaxation.

Information about individual differences, in terms of coping, grieving, and processing one's experience, and information about family systems, in terms of communication and the roles of children, can ease tensions for the patient in relation to the family.

Counselling: The patient may wish to explore the meaning of life and death through expressing their thoughts and feelings about death, dying and spirituality. This can include exploration of religious concerns or beliefs with a spiritual counsellor or leader. As fears and concerns are explored, appropriate reassurance can be provided about the dying process. emotional and physical suffering, and separation. Assistance can be given to facilitate some kind of closure for unfinished business, whether that is resolution, letting go, or acceptance of the situation that causes distress.

Offer times for the identification, acknowledgement, and expression of the losses experienced through the progression of the disease.

Mediation: The patient may appreciate help to address differences with or within the family.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

B. The Family

1. Responses

The family continue to be fatigued and weary through responding to the various demands of the situation. Family will be dealing with a dilemma – how to start separating emotionally from the patient, while wanting to be physically present and needing to be more involved in care. They are also attending to current and ongoing family needs and making necessary arrangements for the approaching death and the future thereafter.

As stress increases, different coping styles, personalities, life experiences influence family relationships and dynamics, often quite dramatically.

Children, similarly to other family members, adjust according to life experience, developmental level, available support and information, and their ongoing involvement with the patient.

At this time, family may struggle when patient begins the process of letting go as they perceive this as giving up or giving in. Family caregivers may reach the end of their tether, physically or emotionally, becoming overwhelmed by the demands of care and no longer able to manage. Requests for admission into a care facility or for increased home supports are common at this level.

Family may want a prognosis or time frame now as they shift from long-term hopes to wanting the patient to live until a particular day or event, or until the arrival of certain family members. Concerns are often expressed about how to handle out-of-town family who may need time to adjust and integrate the changes.

When the patient is at PPS 30%, pre-existing family strengths and stresses are intensified or heightened as they cope with the situation. Their ability to support and work together and their individual personalities and coping styles will be apparent.

2. What Helps

Planning: As the care needs of the patient increase, it is important to help the family to liaise with Home Care Nursing, Long Term Care, and/or the palliative team for ongoing care. Plans for unit admission or increase in home supports should be discussed in terms that are realistic considering the wishes and abilities of both the patient and family. Offer information that allows family to make decisions, which require a specific timing, i.e., planning events or family visits.

Teaching: It is helpful to model and support care for the patient and the family that includes therapeutic touch, gentle massage, and relaxation techniques.

Information about symbolic communication, reduced consciousness, or patient withdrawal, can help to prepare family for the changes ahead.

Counselling: At this juncture, it is imperative that channels of communication are kept open to ensure that information is shared and questions are addressed. Ensure that questions about the disease, prognosis, medications are asked and that answers are understandable. Family will need support around the issues of out-of-town family, symbolic language and prognosis. There may be specific fears or incorrect assumptions about starvation and dehydration as the patient becomes unable to eat and drink so that reassurance about reduced intake must be provided. Be open to attend to any further concerns and issues that may arise at this time.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

B. The Family

Counselling cont'd

Talking about family self-care, that is individual and mutual self-care, is critical for their physical and emotional health, now and after the death. Help parents and other family members to understand children's needs and behaviours, at this time. Families find it helpful and positive to explore hopes and dreams in the context of the current situation. Reframing the tasks that they are facing, like letting go and making adjustments, help family to gain new perspectives on their experience and the situation.

Mediating: Family may need and want help to deal with misunderstandings and issues that arise.

Psychosocial Care at PPS 10%

A. The Patient

1. Symptoms and Responses

Over the decline from PPS 30% to PPS 10%, the impact of the disease on the mind becomes increasingly noticeable. Both the mind and body are weakened due to the toxic effects of the disease. Increased drowsiness and sleep due to the burden of the disease are part of the weakness and withdrawal experienced by the patient. These drastic physical changes will have required adapting care through changes in medication routes, use of catheters, and increased personal care.

When the patient is at a PPS of 10%, they are usually unresponsive, in a state of continuous sleep or coma, and do not wake when touched or spoken to. There are increasing signs that different body systems are shutting down: the pulse becomes irregular and weak; breathing patterns are increasingly irregular and shallow; breath sounds moist; the skin is cool to touch and pale bluish grey in colour or even mottled looking. There is limited or no output 24-48 hours prior to death.

If the patient displays occasional unexpected agitation, which is not directed at anything observable, consider whether it may be expressions of thoughts and feelings, or completion of some necessary internal work. The patient, at this point, may be focusing on the journey ahead of them, that is, the transition of leaving the body.

At this time, only mouth care is provided.

Levels of consciousness or mental functioning can vary so that patients may be alert until moment of death, move between levels of consciousness, or become increasingly drowsy. There may have been moments of alertness in which the patient roused to say a few words or communicate using symbolic language. Such efforts to communicate may be increasingly difficult to understand. Pre-death restlessness is common and is sometimes interpreted as confusion or poor symptom management.

Although either verbal or non-verbal communication is rare when a patient reaches a PPS of 10%, the patient does maintain their connection with the people around them through the sense of hearing.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 10% cont'd

A. The Patient cont'd

2. What Helps

Counselling: What is helpful to the patient at PPS of 1 0% is to respond to whatever seems to be offered in the moment. Approaches such as therapeutic touch, Reiki, guided imagery and gentle massage allows the patient to receive support in a non-demanding way. Be present and comfortable, and speak quietly.

Acknowledge and validate any metaphorical communications by listening and trying to understand their meaning, rather than dismissing them. Family often are able to interpret these communications from their intimate knowledge of the patient.

B. The Family

1. Responses

The family may be operating on "auto-pilot," as they are exhausted physically and emotionally. They experience increasing difficulties with sleep, relaxation and taking time away as they may prefer to be continually by the patient's bedside. There is an increased risk of injury or broader health consequences for family caregivers at this time due to physical stressors and general self-neglect. Some families arrange a rotation of family visiting to allow for some rest. Often family members experience loss or increase of appetite, causing a disruption of usual eating patterns.

Families will have struggled with a number of emotional conflicts as this time approached.

Their awareness that death will be soon conflicts with not being ready to let go. They may be wanting the death to occur, yet holding on; wanting suffering to be over, yet not wanting the person to die. They may be feeling angry or relieved about the death, yet guilty about wanting the death to come soon.

There may be a range of feelings about the death, from letting go, to holding on, to withdrawal. An increased awareness of the impending losses and life without the patient is common. If the dying process has lingered on, family may feel extremely weary and empty. Feelings of abandonment may occur at being excluded by patient's withdrawal. Some family may have feelings of fear and anxiety about being present at time of death. As death approaches, family who are aligned with what is happening may experience a profound sense of peacefulness. At the time of death, feelings of relief are common, accompanied by feelings of sadness and loss.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 10% cont'd

The Family cont'd

2. What Helps

Planning: This is the time to plan for death: gathering family, discussing what to expect, and reviewing what to do when death occurs. In preparation for death, plan what needs to be done, including a review of funeral planning, keeping both patient wishes and family needs in mind.

Teaching: Model respectful behaviours by speaking directly to the patient to acknowledge their presence and addressing them by name.

Providing information on the dying process is very important. Family need to know about physical changes that indicate death is approaching, about communication with the patient and among themselves, and about choices concerning what they want to do at the time of death.

Counseling: It is helpful to listen to and normalize feelings of loss, abandonment, and fear. Offer opportunities for family to talk about present thoughts, concerns and feelings. This time can be an opportunity for life review and reminiscence, for humour as well as sadness.

Ensure children are included in ways that are comfortable for them and that their questions are answered, their presence is encouraged, and that they have space where play is permitted.

Acknowledge the family's grief: provide support and information about what is normal at this time. Part of this will be to address the fears or concerns there may be about being present at the time of death. It is helpful at this time to acknowledge and validate differences amongst family members as each person has their own particular grief process, readiness for death, and their own feelings about their person dying. If necessary, address emotional conflicts: give information and opportunities for expression.

Mediating: This is a time to check out any unfinished business family members may have with the patient or with each other that is affecting their ability to be present and peaceful.

THE PYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 0% Time of Death

The Family

1. Responses

The family may have varying needs at this time. For example, they may wish to stay close to the person who died and have private time with them. Time to say goodbye may include prayers or rituals, preparation of the body, reminiscing and spending family time. It is common for family to repeatedly check the body and review the time of death. Sometimes family will not want to be in the presence of the body but will want time for these same closure activities.

2. What Helps

It is helpful to provide opportunities for family to acknowledge their particular needs at this time. As mentioned above, these may include time with the deceased, preparing the body, rituals, prayers, and saying goodbye. Opportunities for family to come together and support one another in a comfortable way will be appreciated. Privacy, respect, unlimited time, and easy access to the deceased are aspects that need to be considered.

This is a time to review information about the steps to be taken in completing funeral arrangements. Provide information about the grieving process and normalize what the family members are experiencing. It will be helpful to let family know how to access bereavement services. Both grief handouts and discussion are helpful sources of information. Written information is appreciated as it can be referred to later, in a less stressful moment.

THE DYING PROCESS ~ FINAL HOURS

The physical and mental changes that you will be seeing may seem frightening and distressing. The guest may experience a variety of changes. Each person's death is different. Changes may occur quickly or slowly, may appear and then disappear only to reappear again. People die when they are ready.

Many feelings expressed in the last few days are part of the grieving process, both for the dying person who mourns for her/himself and the family who grieve the loss. Although sadness is common, many people who believe in eternal life are happy to see God or those who have died before them. For them, death is comforting and reassuring.

In general, people die as they have lived. If a person if cheerful and copes well, then s/he will probably approach the end of life in the same way.

Usually within the last 3-6 days of someone's life, the person is less hungry and their body can longer process food. The person will eat very little, or have a total lack of interest in food. The body is shutting down and no longer requires nutrition. Fluid intake continues, but usually not to the point of death. The person becomes unable to swallow and mouth care is needed at this point. Due to the lack of fluid intake, urine output decreases and becomes more concentrated. Bloating, water retention and swelling can also occur.

Changes in strength and awareness are other signs of death. The person may drop things or experience twitching and jerking of their hands and legs. The jerking and twitching will be most noticeable to caregivers and family, more so than to the person who is dying. Weakness increases. The person may shift in their experience of reality. They may talk to someone who is not present, or relate that they have seen someone who is dead. They may talk of a bright light. They may appear unaware of who is with them. The person can also appear confused, repeating sentences that do not seem to make sense. Some people become restless, pull at their bed linens and/or try to get up. This is known as 'pre-death restlessness'.

The person will start sleeping longer and sometimes have trouble waking or responding. The person may have a fixed stare and can become non-verbal.

Changes in breathing are common. There can be a period of 6 – 12 hours where they have very rapid breathing. Breathing can become irregular and shallow. Sometimes there are periods when breathing can stop for 30 seconds or so and then start again. Moist breath that bubbles or gurgles is common as mucous collects in the throat and lungs. This is called the 'death rattle'. This noise is often troubling to family and friends, less so to the dying person.

All senses start to fail and hearing is the last to go. Always assume the dying person is alert and can hear everything you say.

THE DYING PROCESS ~ FINAL HOURS cont'd

The dying person's circulation will slow and the body temperature will drop. The skin may become cool and clammy.

Most people die by slipping into a coma before the moment of death.

Active Dying can take hours or days. Even when many of the signs are present, it is not always possible to predict when death will occur. These ups and downs can be emotionally and physically draining on the family and caregivers.

Summary of Signs of Death

- Sleeps longer, sometimes having difficulty waking. Eventually slips into coma
- Reduced intake of fluid and food
- Appears confused, does not recognize familiar people or surroundings
- Weakness becomes profound, difficulty responding verbally, difficulty swallowing or forgetting to swallow
- May have a fixed stare
- Breathing becomes irregular and shallow
- Periods when breathing stops and starts
- Breathing is moist, may develop a rattle, may gasp for air
- Pulse becomes irregular, weak, then absent
- Hands and feet become cool
- Skin color may be pale, bluish or mottled
- Urine output will decrease or even be absent for 24-48 hours
- May lose bladder control
- Bowel movements may be absent, or uncontrolled oozing of soft or liquid stool

Family Response

During the last few days, family members may wish to stay with their loved one 24 hours a day. Sometimes they may need to tell the dying person it is okay to die.

After the death, family members may show signs of relief, exhaustion, and sadness. Reactions are varied and individual.

Encourage the family to spend time with the deceased. There is no rush to act at this point. The doctor will need to be called to verify the death and the funeral home will need to be called to come and pick up the body, but it does not have to be done immediately.

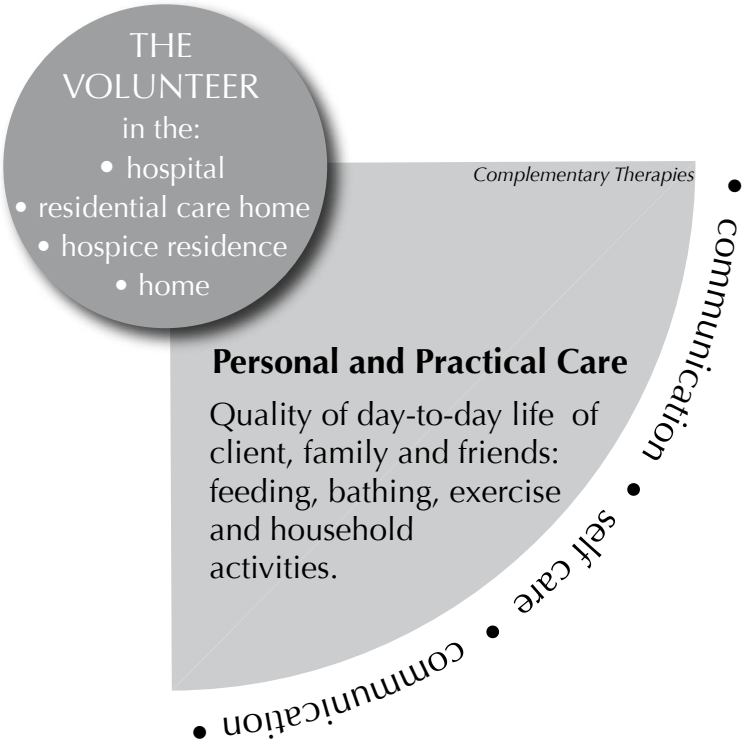
Module 3

PERSONAL & PRACTICAL CARE

This is the most fulfilling work I have ever performed. The opportunity to serve the patients and their families during this period in their life is a blessing.

Mike South, Hospice Volunteer

British Columbia HOSPICE PALLIATIVE CARE Association



Learning Outcomes

Upon completion of the Personal and Practical Care Module, the volunteers will:

1. Be aware of and respect the policies of their individual organizations regarding personal and practical care.
2. Understand what is involved in the personal and practical care of their clients.
3. Know the team members who are most involved in the personal and practical care of their clients.
4. Understand the changes in care throughout their client's journey.
5. Understand and have the competence and capacity to carry out their responsibilities.
6. Recognize and respect their own limits in providing personal and practical care to their clients.

Definition of Personal and Practical Care

Attention to personal and practical care helps maintain the quality of the client's day-to-day life during a stressful and consuming time. Focusing on physical comfort, personal care supports the client's medical care and provides reassurance to both the client and family.

Assistance with everyday practicalities can help to reduce stress felt by both the client and family when chores and errands are left undone. Hospice Volunteers play a key role in supporting the personal and practical care of the clients and families they serve.

Personal and Practical Care and the Role of the Hospice Volunteer in Different Settings

Setting	Personal & Practical Care	Volunteer Role
Hospital Hospice Residence Residential Care Home	• Bathing, comfort, meals, hydration, primarily carried out by staff and/or family members. • Primarily nursing care with visits from doctors • Pain and symptom management • Comfort: turning, feeding	• Will vary in all three settings. • In some settings, where permitted, the volunteer may be able help feed, hydrate or bathe the client. They may provide other comfort measures such as massage or applying warm blankets. • May run errands or do chores for client and family. • If policies permit, may assist in transfers, repositioning and feeding.
Home	• Bathing, comfort, cooking, housework and other household chores, errands, dog walking, etc.	• Support client and family/friends by assisting with such things as errands, household chores, cooking, dog walking and grooming, gardening etc. • If policies permit, may assist in transfers, repositioning and feeding.

Training

Orientation and Basic Training

1. Provide an overview of personal and practical care, including a description of how this care is managed throughout the client's journey in each of the settings where the volunteers will be working.
2. Ensure the volunteers are provided with the necessary policies and procedures on personal and practical care including feeding, hydrating, bathing and chores, etc.
3. Ensure that volunteers understand and respect their own personal limitations, particularly physical limitations when such things as heavy chores are involved.
4. Incorporate a practicum or "job shadowing" component to allow volunteers to learn on the job from an experienced volunteer.
5. Pair new volunteers with experienced volunteers as "mentors" to support the volunteer and provide opportunities for experienced volunteers to be supportive and refresh their knowledge.

Ongoing/Advanced Training

1. Provide any updates to volunteers on policies and procedures around practical and personal care.
2. Provide periodic workshops/training to enhance volunteers' competence and confidence.
3. Encourage and support volunteers to take part in workshops relating to personal and practical care even if they are outside their limits of responsibility. The information will help them better understand the care being provided to their clients and may also be of personal value.

RESOURCES

Module 3

PERSONAL AND PRACTICAL CARE

RESOURCES

- **Caregiver's Role**
- **Do's & Don'ts of a Helping Relationship**
- **Maslow's Hierarchy of Needs**
- **Phone Support Guidelines**
- **Guidelines for Patient Visits**
- **Vigils: Volunteer Job Description**
- **Health and Safety Tips**
- **The Volunteer & Client Relationship**

CAREGIVER'S ROLE

- Listen without judging.
- Maintain confidentiality.
- Be honest and sincere.
- Be available and reliable.
- Be knowledgeable of resources.
- Provide encouragement and support.
- Recognize limitations – yours and others.
- Communicate with team members.
- Follow the family agenda – not yours.
- Expect repetition and go with it.
- Be flexible and go with changing needs.
- Be informed - but not the teacher.
- See where you fit in – you most likely will not be the primary support person.
- Stick to reality – promise only what you can deliver.
- Do not equate talking and activity with support. Doing and speaking may not be helpful.
- Be aware that you can't be everything to everybody.
- Sit on your urge to do something.
- Be OKAY with SILENCE.

DO'S AND DON'TS OF A HELPING RELATIONSHIP

DO

- take your time
- listen with your whole self
- maintain the "volunteer" role
- build trust
- encourage independence as limitations permit
- reach out
- be respectful and non-judgmental
- be genuine, open, honest, and sensitive
- be dependable and consistent
- have a cheerful approach
- encourage person to initiate subjects they wish to discuss
- use open-ended questions
- err on the side of caution and a slow pace
- maintain confidentiality
- respect person's right to (physically and in emotional) privacy
- know and admit your strengths and weaknesses

DO'S AND DON'TS OF A HELPING RELATIONSHIP (cont)

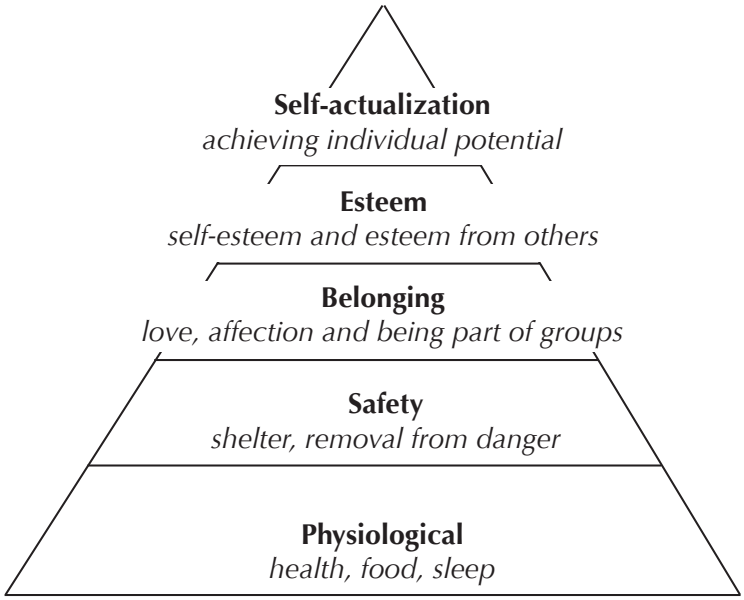
DON'T

- get into telling role
- use "you should"
- give advice
- focus on self enhancement (the "savior" role)
- over praise.
- intrude
- probe
- appear busy, distracted
- follow your own agenda
- talk down to person
- stay too long
- monopolize the conversation
- gossip
- direct premature discussion of action plans
- patronize or placate - "that's all right now"
- rely on the use of clichés
- change the subject
- ignore the problems raised by the person
- use closed, irrelevant or inappropriate questions
- use inappropriate warmth or sympathy
- use inappropriate, irrelevant or premature self-disclosure

MASLOW'S HIERARCHY

The hierarchical effect

A key aspect of the model is the hierarchical nature of the needs. The lower the needs in the hierarchy, the more fundamental they are and the more a person will tend to abandon the higher needs in order to pay attention to sufficiently meeting the lower needs. For example, when we are ill, we care little for what others think about us: all we want is to get better.



The five needs

- Physiological needs are to do with the maintenance of the human body. If we are unwell, then little else matters until we recover.
- Safety needs are about putting a roof over our heads and keeping us from harm. If we are rich, strong and powerful, or have good friends, we can make ourselves safe.
- Belonging needs introduce our tribal nature. If we are helpful and kind to others they will want us as friends.
- Esteem needs are for a higher position within a group. If people respect us, we have greater power.
- Self-actualization needs are to 'become what we are capable of becoming', which would our greatest achievement.

Three more needs

These are the needs that are most commonly discussed and used. In fact Maslow later added three more needs by splitting two of the above five needs.

Between esteem and self-actualization needs was added:

- Need to know and understand, which explains the cognitive need of the academic.
- The need for aesthetic beauty, which is the emotional need of the artist.

Self-actualization was divided into:

- Self-actualization, which is realizing one's own potential, as above.
- Transcendence, which is helping others to achieve their potential.

Credit: www.changingminds.org

PHONE SUPPORT GUIDELINES

Prior to the first call:

When the office receives notice of a recent death that requires follow up, the Director of Client Care sends a sympathy card and information letter to the appropriate person. The letter outlines the bereavement services that we offer and informs the person to expect a phone call from a Hospice volunteer within 2 – 3 weeks.

Usually, it's the Grief Support Coordinator who makes the first phone call in order to establish contact with the person, find out how the person is doing, and assess need. Should the coordinator feel that it is important to keep in contact with the client, she asks the client if it's okay if someone from Hospice phones again in a couple of weeks.

When making the call:

The first call is the hardest for both the volunteer and the bereaved client, but it becomes easier over time:

Always identify yourself, give the purpose for the call, and ask if the timing of the call is appropriate. For example:

> "Hello Mrs. Hanson, my name is Mary Peters and I'm a grief support volunteer with Cowichan Valley Hospice. I'm calling to ask how you are getting along. Is this a good time for you or would you prefer that I call at another time?"

Listen carefully to what the person says and how he or she is saying it. If the client cries, don't hang up. Allow time for the person to regain composure and be sensitive as to whether or not they wish the conversation to continue.

Ask how the client prefers to be addressed, i.e. by their first name or their surname. If you don't already know it, ask the name of the deceased and don't be afraid to refer to the deceased by name during the conversation.

Sorts of questions to ask during the first one or two calls:

- How are you sleeping, eating, feeling physically?
- Are you concerned about yourself or any other family member?
- How are you managing the practical issues—estate, daily routine, returning to work (if appropriate)?
- Are you getting the support you want?
- Do you have people you can talk to about the person who died?
- Would you like other Hospice services: 1:1, Thursday afternoon drop-in, on-going phone support? Mention the resources in the office: pamphlets, library books, etc.

Something to remember in the early days following the death or funeral

Client may feel some relief and euphoria that things went as well as they could, that family managed well, and that care was good. These feelings often sustain family members for a while before reality sets in and other feelings arise.

Courtesy Victoria Hospice and Grace Hospital, Manitoba

PHONE SUPPORT GUIDELINES cont'd

The early days following the death or funeral cont'd

Some indicators of difficulty in the early days:

- Keeping busy all the time, no time for grief, "just get on with life."
- Can't cry or won't allow themselves to cry.
- Continuing shock, which prevents necessary functioning.
- Use of alcohol or drugs for coping; previous mental illness.

Sorts of questions to ask in subsequent calls:

- How are you looking after yourself? Any changes in your own health?
- Do you have opportunities to talk about your memories, your emotions, and your worries with family or friends?
- How are you managing the ups and downs, the good days and the bad days?
- How different has life been since the person died? How are you coping with these changes?
- Have any other losses or major changes happened since the death?
- Are you concerned about yourself or any other family member?
- What expectations do you have about managing over the coming weeks and months?
- How are you planning to deal with upcoming events e.g. Christmas, Easter, Thanksgiving, birthdays, anniversaries etc? How are you feeling about these times?

Indicators of difficulty later on:

- Being overwhelmed by emotions.
- Stuck with a certain aspect of what happened.
- Going round and round without being able to resolve an issue.
- Feeling abandoned by usual support systems.
- Inability to return to most normal routines.
- Flashback images of the death.

NOTE: Statements like, "I feel like I'm going crazy."; or "I feel depressed."; or "What's the point of getting up in the morning?" are normal, **but such statements need to be checked out further.**

At the anniversary of the bereavement, it's best to call a few days before the date and ask the following sort of questions:

- With the anniversary coming up, what plans do you have for that day?
- Who will you share it with you?
- Are you having thoughts and memories of this time last year? How has that been?
- Over the last months and weeks, how do you think you've been managing?

Courtesy Victoria Hospice and Grace Hospital, Manitoba

PHONE SUPPORT GUIDELINES cont'd

Indicators of difficulty around the anniversary of the death:

- Feeling no change from earlier days of grief.
- More bad days than good days.
- Fears of facing the future or inability to see a positive future.
- Guilt or resistance about going on with life

NOTE: It's normal to feel worse close to the anniversary date, so it's important to check the extent and duration of difficult feelings and thoughts.

Risk Factors or Indicators of Difficult Grief

Make a note if clients express any of the following concerns and report all concerns to the Grief Support Coordinator or the Director of Client Care:

- Difficult relationships with family members or with the person who died.
- Lack of perceived support.
- Difficult circumstances surrounding the death such as a sudden, violent, or suicide death, or if drugs/ alcohol use/abuse were involved
- Multiple losses; concurrent deaths, or past unresolved losses.
- Mental or physical health problems or disabilities.
- Emotional or spiritual crises.
- Major changes in life circumstances.

Points to Remember

- Listen and accept where the client is at today.
- Provide information and normalize the grief process.
- Suggest other appropriate Hospice grief support services as appropriate.
- Do **not** just stop phoning the client because you think they are doing fine. The second year after a death is often worse than the first.
- Tell the client if you plan to go away and ask if they would like someone else to phone while you're away.
- Consult coordinator/Director of Client Care before finishing with a phone client.

Home phone number

It's a matter of personal choice whether you give a client your home phone number. Usually it's best to avoid sharing your home number until you have developed a rapport with the client.

GUIDELINES FOR PATIENT VISITS

- Program coordinator will introduce you to your patient.
- Match the patient's mood, a smile is important but don't overdo cheerfulness.
- Actively listen to the patient, tune into what is being said and not said.
- Avoid jumping to conclusions. If in doubt, ask the person to verify feelings.
- Be aware of the patient's environment. Take note of setting including things such as books on a bedside table, a certain tape playing, pictures of family, an afghan on the bed etc. These items might be the place to start a conversation and build a connection.
- Respond in language the patient can understand, use common vocabulary.
- Summarize what you heard the person say to ensure accurate communication. "What I heard you say is …" or "Are you saying …" or "To recap …" or "As I understand it our agreement is …" This lets the person know that you heard and understood what s/he said. It is important to summarize whenever an action or decision has been agreed to.
- Use the person's name in conversation.
- Watch for signs of fatigue. Try to leave before the person becomes overtired, or, give permission for her/him to rest and sleep in your presence. A patient who tires easily or fades in and out will often appreciate having a person there for the moments they are awake.
- Learn to recognize the person's non-verbal messages such as body posture, eye contact, voice tone and volume, position of hands and arms, etc.
- Remember that the family has many concerns. They may want a break while you sit with their loved one, however, they may want to talk about concerns of their own. Balance your support to both the patient and the family.
- Relay patient concerns to the nurse. You can relay simple messages to family such as a desire to be moved or have a particular food. You make no judgments on how the family handles the request nor on the validity of the request. You take every precaution to not become a go-between in the family, get caught up in disagreements, or take sides. If you have any concerns regarding patient care from the family, the nurse or anyone else … contact the program coordinator immediately. Do not intervene on your own.
- Do not accept money or gifts form patients. Donations may be made to the Prince George Hospice Society.
- Do not get involved with money, marital, legal or family structural issues. Refer to the social worker, the nursing staff, or other appropriate professional. If unsure of where to refer to, contact the program coordinator for direction.
- Maintain confidentiality at all times.
- **Do not administer medication at any time.** A family member, physician or nurse should be giving medication. If the family is going to take a break and leave you alone with a patient, make sure all medication has been brought up to date before they leave. You should never administer any medication. Ever.

GUIDELINES FOR PATIENT VISITS cont'd

- You do not move a patient or take any lead role in patient care. You may assist a family member or home care nurse with moving, washing, feeding a patient. But it MUST ALWAYS been done under the supervision and direction of the family member or other professional and only as you are comfortable and physically able to do. Never take on a task that may push your own physical abilities or could possibly cause you any harm.
- Wear your hospice name tag to every visit.

When Visiting a Patient in the Hospital

- If visiting someone in the hospital, do not assist the nurse in moving a patient, there are enough professional people to take care of patient needs.
- Check in with the nurse on duty, let them know who you are and why you are there, ask if there is anything you need to know about before entering the patient's room.
- Obtain permission from the nursing staff before offering any food or drinks to the patient.
- If doctor's, nurses or other hospital staff are with the patient when you arrive, wait a few minutes to see if they will be leaving. If it appears they will be awhile, or the patient is going for some tests etc. then you must call back later. Ask a nurse at the desk what a good time might be to come back.
- If hospital staff come in to see the patient while you are there visiting, ask if you can/should wait or if you should come back at another time.
- If the patient does not want a visitor at that time, ask if you can come back at another time.
- Before leaving the hospital, report any concerns or issues that may have come up during your visit to the nursing staff.

Things to Do When Visiting

- Share music, books, reading with the person
- Discuss topics of interest to the person
- Allow the opportunity for a life review
- Sit in silence – be a witness
- Listen to concerns, fears, stories of the person and the family
- Share information to allay fears
- Refer to appropriate agencies and professionals
- Pick up items, library books, medications, etc if requested
- Be a friendly ear and support

VIGILS

VOLUNTEER JOB DESCRIPTION SAMPLE

ORGANIZATION: Cowichan Valley Hospice Society

QUALIFICATIONS: must have completed 30 hours of initial Hospice training

OBJECTIVES: to provide support to a dying person and his/her family or caregivers, in accordance with the principles of the Society, in a hospital, care home, or private residential setting.

VIGIL VOLUNTEERS ARE EXPECTED TO:

- adhere to strict rules of confidentiality
- know you may be asked to sit with someone at a **moment's notice**
- be aware that evening hours may be needed
- be comfortable with the final stages of dying
- respect differing personal, cultural and religious beliefs, and lifestyles
- be aware that some family members may wish to stay, and will welcome a calming presence and an excellent listener
- be sensitive to family needs for privacy – you are there to support not to take over
- in this time of great sensitivity be aware, and respectful, of family dynamics
- be respectful of staff and other caregivers
- seek input from a supervisor regarding any problems or concerns that may arise during the performance of one's duty
- attend scheduled meetings and training sessions
- prepare a self-care kit - books to read, refreshments etc., to take to vigils
- balance care of others with care of self

DUTIES:

1. sit with a person who is in the final stages of dying
2. discuss with staff what personal care they wish you to provide
3. provide support and comfort to patient when necessary
4. determine if, and when, family members wish to be notified of patient's status
5. notify staff of changes in patient's status
6. provide support and comfort to family members/caregivers, and staff, when indicated
7. normalize the dying process for family/caregivers, when needed
8. provide after death information, upon request
9. inform caregiver/family of other Hospice services available following a death
10. provide information on other community resources that may be helpful to caregiver/family, upon request

Courtesy Cowichan Valley Hospice Society

VIGILS cont'd

HOW DO VIGILS HAPPEN?

1. How do vigils happen?

Call to Hospice office or coordinator from CDH, Lodge, Cairnsmore or home nursing. All information on the client, address, floor, room # and some details of the family available, who is requesting it, etc are taken down to be passed on to the volunteers responding to the vigil.

2. How do we respond?

The coordinator starts by making calls to volunteers to find someone available to go immediately, and continues to make calls to line up a schedule for the rest of the period of time needed. Often volunteers who have been scheduled will have to be cancelled as the client has passed on.

3. What's expected from the volunteer?

When volunteer arrives you would head straight to the room given to you. Enter quietly and slowly. If they are alone approach the client, even if they are not conscious, and let them know you are there by quietly telling them your name and that you are from Hospice and have come to sit with them.

If family is with them again introducing yourself, they are most likely expecting you. If family comes in while you are sitting, introduce yourself and ask them if they would like to have some time alone with their loved one. They may not, and indicate they would like to sit and talk with you or may tell you that they will take it from there. We always take our cue graciously from the family and nursing staff. Do not be afraid to ask them if they would like you to leave the room, etc. Depending on what they are going to do, like clean and turn the patient, you will become familiar with the routine in time.

If the client is still with us at the end of your shift a new volunteer will have arrived to take over. Give them any information that is necessary. If the client is conscious and can converse, has shared personal information, this is NOT shared. Only information concerning the care level that we are doing, swabbing the mouth, holding a hand, reading or playing music. Most often you are just sitting and this is where bringing a book or craft is a good idea. They know you are there and that is a comfort.

4. When the client has passed

If you are alone with the client at this time, call the staff and let them know that you think the client has passed. If you notice while sitting there that there has been a sudden change in the breathing etc, call the nurse. From there, usually more than one staff member will come into the room and check for vital signs. Stand back from the bed and let them do their job. If the client has passed they will indicate this to you, and at that time quietly leave.

If you are with the family in the room – sometimes when death is coming and you have called the nurse they will ask you to leave the room. If the family indicates that they would like you there or if the nurse does not say leave then again, stand back and be quietly available for the family, etc until the time comes for you to leave. Leave a brochure or let them know that we will be available for them at a later time if they should need us. You will find that every vigil is different. Trust your instincts.

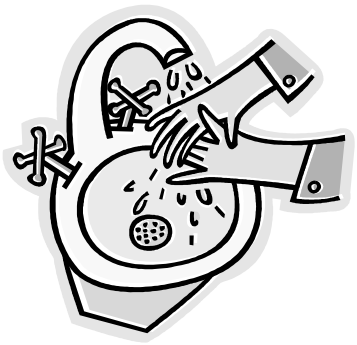
Note: If the client passes during your shift, be sure to phone the coordinator to let them know that the next volunteer is **not** needed.

Courtesy Cowichan Valley Hospice Society

VANCOUVER ISLAND health authority

HEALTH AND SAFETY TIPS

Stay Healthy and Use Antibiotics Wisely



The Vancouver Island Health Authority offers tips to stay healthy through cold and flu season – and cautions residents to use antibiotics wisely to prevent bacteria from becoming resistant to antibiotics.

Stay Healthy

Did you know that 80% of common infections are spread by hands?
Handwashing is the best way to stop the spread of infections.

Proper hand washing technique includes:

1. Fifteen seconds of vigorous rubbing of hands together until soapy lather appears.
2. Scrub between the fingers, under the fingernails, around the tops and palms of the hands.
3. Rinse under warm running water.
4. Dry the hands with a clean, disposable towel, and turn off the faucet using a towel as a barrier.

Always wash your hands:

- Before meals
- After blowing your nose or wiping your child's nose
- Before breastfeeding
- After changing diapers
- After using the toilet or helping your child use the toilet
- After playing with toys shared with other children

Use Antibiotics Wisely

Using antibiotics when they are not needed can lead to antibiotic resistance. Although both bacteria and viruses cause respiratory tract infections, antibiotics only work against bacteria.

Viral:

- Infections include: colds, flu, croup, laryngitis, chest colds (bronchitis) and most sore throats.
- Viral infections are more contagious (if more than one family member has the same illness, odds are it is a viral infection).
- Be patient if you have cold symptoms, cough or a sore throat. Most viral illnesses take 4-5 days before getting better and up to 3-weeks for full recovery.

Bacterial:

- Cause infections such as pneumonia and strep throat.
- Are less common and do not spread from one person to another as readily.
- Use regular soap. Antibacterial soap is not recommended because it promotes bacterial resistance.

THE VOLUNTEER AND CLIENT RELATIONSHIP

The volunteer does not carry the primary responsibility for medical care or psychosocial support. Instead, he/she complements the other team members. Freed from these responsibilities she is really at the disposal of the client, and can allow the client to choose how she can best serve him - to share, to listen, to accept without judging. The volunteer will be able to give of her time and of herself, without expecting in return, and often not knowing the fruits of the gift. As Kahlil Gibran wrote:

> "There are those who give and know not pain in giving
> nor do they seek joy, nor give with mindfulness of virtue;
> They give as in yonder valley the myrtle breathes
> its fragrance into space.
> Through the hands of such as these Gods speaks, and
> from behind their eyes He smiles upon the earth."

In giving of themselves however, the volunteer must recognize their own limits. They are there as helpers and if they get too involved they are no longer able to be objective and helpful. Volunteers must learn to follow the narrow line between empathetic sharing and personal over-identification. In finding this balance, volunteers are helped by the presence of other team members.

SUPPORT FOR THE VOLUNTEER

It is sometimes assumed that because volunteers may work only one period a week, they are not stressed. It is true that they usually bring a freshness and vitality that may be more difficult to sustain in full-time staff, but they do need support and encouragement. This comes in a variety of ways:

- peer support from other volunteers. It is essential that volunteers working together be communicative and cooperative.
- informal interactions between volunteers and nurses.
- the availability of the coordinator for ready advice and counsel.
- staff meetings in which they can see how their effects are playing an important part in the total effort.
- meetings between new volunteers and experienced ones to share reactions, problems and insights
- social events organized for the whole team.

Courtesy Prince George Hospice

Module 4

PSYCHOSOCIAL & SPIRITUAL CARE

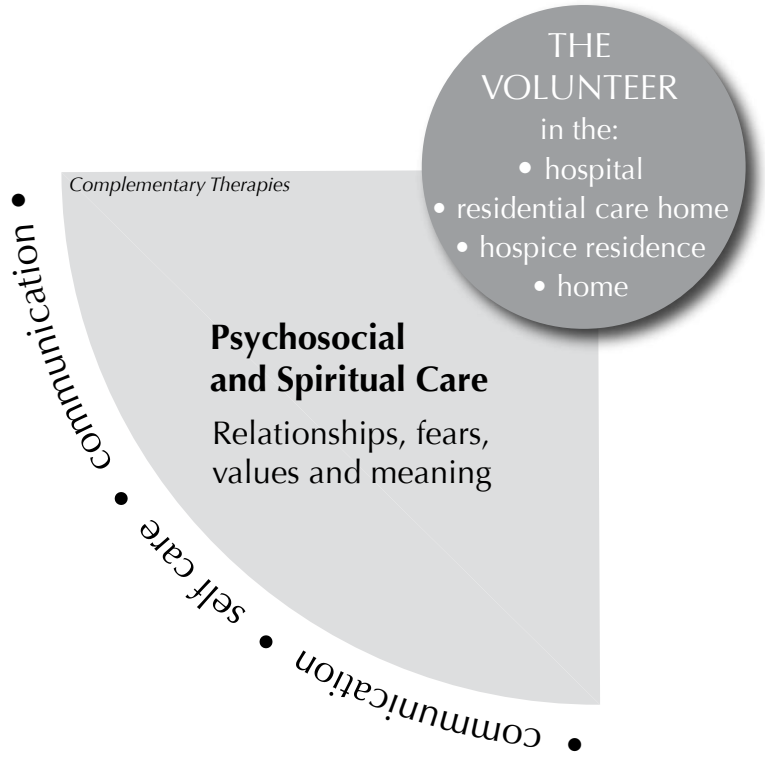
The Way of the Heart

"Let us not underestimate how hard it is to be compassionate. Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely and broken. But this is not our spontaneous response to suffering.

What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant (caregivers), we want to earn our bread by making a real contribution.

This means first and foremost doing something to show that our presence makes a difference. And so we ignore our greatest gift, which is our ability to enter into solidarity with those who suffer."

Henri Nouwen



Though interconnected, there are distinctions between psychosocial, and spiritual care that warrant separate attention. To facilitate training, this module has been divided into two sections with spiritual care presented on its own. This provides the option to integrate the two sections or refer to them individually.

A. Psychosocial Care

Learning Outcomes

Upon completion of the Psychosocial Care Module, the volunteers will:

1. Understand what is involved in the psychosocial care of their clients.
2. Understand and respect how their clients may respond emotionally and socially to their illness.
3. Understand and respect how their client's family and friends may respond emotionally and socially.
4. Acknowledge and respect their own psychosocial preferences and needs.
5. Recognize and respect the limitations and healthy boundaries around psychosocial care of their client and family.

Definition of Psychosocial Care

Psychosocial care tends to the emotional well being of the client and family and honours and supports their relationships with those close to them and those involved in their care. Psychosocial care enriches the quality of a client's day-to-day life.

Hospice volunteers play a key role in the psychosocial care of their clients and families. It can be the most challenging and rewarding aspect of their work. Above all, volunteers will need to listen and communicate well and be comfortable and confident in their ability to be present for, and responsive to, the clients and families they support.

The volunteer's training in loss, grief and bereavement (Modules Five and Six) will be integral to Psychosocial Care. In other words, volunteers will be attentive to and comfortale with the client, family or friend as they express their feelings of grief, loss and/or lonliness.

Psychosocial Care and the Role of the Hospice Volunteer in Different Settings

Setting	Psychosocial Care	Volunteer Role
Hospital Hospice Residence Residential Care Home	• Staff in all three settings may be skilled in integrating compassionate psychosocial care with medical, personal and practical care. • Staff may be time-limited in their ability to provide this care. • This care may also be provided by social workers and counsellors.	Volunteer involvement may include: • Being with the client and/or family either in silence or sharing activities. • Providing information on support options outside these settings when asked. • Knowing who to approach within these settings to obtain information or have questions answered.
Home	Professional care providers may be involved with the psychosocial care of patients in the home, although their time may be limited.	While personal and practical care are being tended to, the presence of the volunteer in the home is reassuring and supportive and includes: • Providing respite to family members. • Visiting with the client and/or family members. • Sharing activities with client and/or family. • When appropriate, sharing knowledge of supports and resources or finding out about resources when asked.

Training

Orientation and Basic Training

1. Provide an overview of psychosocial care, including a description of how this care is managed in each stage of the journey and in each of the settings where your volunteers will be working.
2. Provide an overview of psychosocial care in relation to:
   - family dynamics
   - children
   - teens
   - cultural diversity
3. Provide an opportunity for volunteers to explore their own feelings around illness, loss and grief.
4. Ensure that volunteers understand and respect their own personal limitations and boundaries.
5. Integrate with the module on loss, grief and bereavement.
6. Incorporate a practicum or "job shadowing" component to allow volunteers to learn on the job, in all settings, from an experienced volunteer.

Ongoing Training

1. Provide additional workshops or sessions on psychosocial care:
   - in different cultures
   - on family dynamics
   - of children and teens (both as clients and family members)
   - of people with disabilities, dimentia, etc.
   - of marginalized people (poverty, homelessness, addictions)
   - in relation to sexuality and intimacy
   - and non-cancer illnesses such as AIDS (Aquired Immune Deficiency Syndrome), HepC (Hepatitis C), cardiovascular disease, diabetes, renal failure, etc.
2. Provide ongoing opportunities for volunteers to explore their own needs and limitations around psychosocial care of their clients and families.
3. Strengthen their communication skills.

B. Spiritual Care

Learning Outcomes

In relation to spiritual care, the volunteer will:

1. Understand what is involved in the spiritual care of their clients.
2. Understand and respect their clients' needs and preferences around spiritual care.
3. Understand and respect the needs of their client's family and friends around spiritual care.
4. Respond appropriately to the spiritual needs of their clients and family.
5. Recognize and respect their limitations and boundaries in relation to spiritual care.
6. Be aware of and understand other resources available.

What is Spiritual Care?

Spirituality encompasses our view of life and the purpose and meaning we bring to it. For some, spirituality relates to a specific set of beliefs, values or practices. The spiritual care needs of each client will be determined by their uniquely individual perspective. At the end of life, a person's spiritual perspective may change. Spirituality involves faith and possibly religion.

Spiritual Care and the Role of the Hospice Volunteer in Different Settings

Setting	Spiritual Care	Volunteer Role
Hospital Hospice Residence Residential Care Home Home	Spiritual care may be provided by spiritual leaders or supports of the clients' own choosing, including their faith community, family and friends.	Volunteers may contribute to spiritual care by: • Sitting quietly with their client, listening to music, reading spiritual/ inspirational material, when asked. • Being present when the client wishes to talk. • Participating in spiritual practice with the client if invited and if comfortable doing so. • Exploring with the client and/or the family what is important to them. • Providing support to the client and family, when asked, with preparations for funeral or memorial services. • Supporting young children and teens in expressing their feelings. • Providing information on spiritual supports when asked. • Knowing who to approach to obtain information or have questions answered.

Training

Orientation and Basic Training

1. Provide an overview of spiritual care, including a description of how this care is managed in each of the settings where the volunteers will be working.
2. Provide an overview of spiritual care in relation to:
   - The different ways that clients respond spiritually to illness, death and grief.
   - How families, including children, may respond spiritually.
   - How different religions approach illness, grief, death and bereavement.
3. Provide an opportunity for volunteers to explore their own spirituality around illness, grief and loss.
4. Explore a range of ways that volunteers may support the spiritual needs of clients and families.
5. Ensure that volunteers understand and respect their own personal limitations.
6. Integrate this module with the module on loss, grief and bereavement.
7. Incorporate a practicum or "job shadowing" component to allow volunteers to learn on the job, in all settings, from an experienced volunteer.

Ongoing Training

1. Enrich the volunteers' basic training, with workshops or sessions on spirituality:
   - in different cultures
   - of young children and teens (both as client and family member).
2. Invite a range of leaders from different religions to speak to the volunteers about their beliefs and rituals around illness, grief, death and bereavement.
3. Support the volunteers to continue exploration of their own needs and limitations around spiritual care of their clients and families.
4. Support volunteers to strengthen their communication skills, particularly around listening, silence, being present and body language.
5. Provide a range of resources or, sources for resources, on spirituality of loss, grief and bereavement.

RESOURCES

Module 4

PSYCHOSOCIAL AND SPIRITUAL CARE

RESOURCES

- **The Needs of the Dying**
- **Fears About Death and Dying**
- **Practice Scenarios ~ Palliative Support**
- **Practicing Cultural Competence: Skills For Care Providers**
- **Strategies for Working With Families From Different Backgrounds**
- **Religion & Spirituality**
- **Kubler-Ross' Stages of Grief Reaction and Spiritual Struggle**
- **From Christian Roots to Secular Service**

THE NEEDS OF THE DYING

- *The need to be treated as a living human being.*
- *The need to maintain a sense of hopefulness, however changing its focus may be.*
- *The need to be cared for by those who can maintain a sense of hopefulness, however changing this may be.*
- *The need to express feelings and emotions about death in one's own way.*
- *The need to participate in decisions concerning one's care.*
- *The need to be cared for by compassionate, sensitive, knowledgeable people.*
- *The need to expect continuing medical care, even though the goals may change from "cure" to "comfort" goals.*
- *The need to have all questions answered honestly and fully.*
- *The need to seek spirituality.*
- *The need to be free of physical pain.*
- *The need to express feelings and emotions about pain in one's own way.*
- *The need of children to participate in death.*
- *The need to understand the process of death.*
- *The need to die in peace and dignity.*
- *The need not to die alone.*
- *The need to know that the sanctity of the body will be respected after death.*

Reprinted with permission from
"The Needs of the Dying" by David Kessler
Harper Collins Publishers (1997)
www.DavidKessler.org

FEARS ABOUT DEATH AND DYING

Volunteer contact with terminally ill people

The most valuable thing you have to offer someone else is YOU. Being consciously aware of and able to exhibit helpful behavior makes the contact stronger, but what the person you visited remembers most clearly is you, not what you did or said.

When we look at our fears about death and dying, we realize two things:

1. A death that might be fearful and unwelcome to one person is desired by another; e.g. someone may fear to die suddenly without the chance to say good-bye to family and friends. Another may fear the awareness of impending death and wish to die suddenly.

2. The specific deaths that people fear are varied. But there are common themes. These include fear of being:
    - a burden,
    - in pain,
    - helpless and out of control,
    - pitied,
    - treated as weak or less than human or,
    - abandoned.

No one can take away another person's fears. Sharing our fears with another may be a relief, so the volunteer can assist by listening. We must be sure, however, not to contribute to the client's fears. For example, if the volunteer does not notify the client that he/she cannot keep an appointment the client may feel abandoned by the volunteer and/or a burden to the volunteer.

The three most common fears of a Palliative Client are:

- uncontrollable pain;
- dying alone; and
- having their life viewed without meaning.

(Excerpt from material prepared by Victoria Association for the Care of the Dying)

PRACTICE SCENARIOS ~ PALLIATIVE SUPPORT

A. I've never been away from Joe for more than a couple of days. And I always left meals already prepared in the fridge and freezer when I did go away. I did all the grocery shopping and I'm the one who balances the cheque book. The neighbors and the kids have been keeping him feed and the house in groceries since I've been sick, but they can't do that forever. I guess he's going to have to learn how to do those things now.

1. What are possible feelings of the speaker?

2. What are possible concerns or content behind what has been said?

3. What is one response that would reflect content?

4. What is one response that would check assumptions?

5. What is one response that would clarify feelings?

B. Just before my dad died he talked about seeing a light and people he knew. Some say there is life after death. I never believed all that hooey. I think he was just hallucinating, maybe brought on by wishful thinking or a fear of there being nothing after you die. What do you think?

1. What is one response that would reflect what has been said and then effectively put the question back to the speaker to answer?

2. Do you think the speaker has any concerns or fears? If so, what do you think they might be?

3. What do you think the motivation is for asking for your thoughts on the issue?

4. How can you respond without being evasive or disrespectful?

PRACTICING CULTURAL COMPETENCE
SKILLS FOR CARE PROVIDERS

1. Self Awareness
2. Cultural Knowledge
3. Individual Focus and Attention
4. Don't Assume!
5. Ask questions – be interested
6. Be respectful – what customs and traditions are important?
7. Encourage the practice of traditions
8. Involve the family
9. Use an interpreter
10. Ask about and negotiate the treatment/care plan
11. Listen carefully
12. Consider non-verbal communication as Dr. Bowman states "*emotional control is not always indifference and emotional expression not always hysteria*"
13. Maintain Adaptability and Flexibility

Sources: *Bowman: Dr. K. "Cross cultural Considerations" presentation to Fraser Health Nov. 2004*
Victoria Hospice Society et al TRANSITIONS…2003, Health Profession Press

STRATEGIES FOR WORKING WITH FAMILIES FROM DIFFERENT BACKGROUNDS

1. Watch friends and family members. Pay attention to their actions, ways of communicating, etc.

2. Reserve judgment. Do not measure people by your standards.

3. Take note of the environment. If you're not sure about the significance of something, ask.

4. For a culture that is completely foreign to you … seek out some resources that you could use to familiarize yourself with customs/beliefs. Books, videos, multicultural society, etc.

5. Talk to other volunteers and nurses who have been with Hospice a long time. Draw on their experience.

6. Never assume that all immigrants, First Nations, particular religious groups, etc. have the same experience and customs. Check out what you think you know.

7. Remain aware of compounding issues.

8. Become familiar with resources to which you can refer the family should they have difficulty. Your hospice organization will have access to the community services directory.

9. If in doubt, ask!

Courtesy Prince George Hospice Society

RELIGION AND SPIRITUALITY

Although the two are not mutually exclusive, it is good to get a sense of the differences between religion and spirituality. The following chart was prepared by Art Anderson for the Chilliwack Hospice Volunteers and Awareness Group.

Religion	Spirituality
Concerns the customs, doctrines, creeds, rituals, writings, and traditions of a particular faith tradition.	Concerns an individual's or community's engagement in the work of developing and maintaining a sense of communion with the holy, the transcendent, the beyond.
Frequently is institutionalized, in a more or less hierarchical fashion, involving designated "holy persons" who have distinctly defined roles within the institution, while the majority of the faithful see themselves as participants, followers, or even spectators within the life and program of the institution.	May be institutionalized (as in a monastic order, or a Quaker meeting), but may also be experienced as a relatively solitary journey, with more of a "heart" connection to a fairly small community of mutual support and accountability.
Tends to be a matter of the head.	Tends to be a matter of the heart.
Often centered around regular communal worship and certain sacred writings.	Often centered around symbolic ritual and personal and communal experiences of spiritual engagement with the holy, while still honoring the importance of sacred writings.
Tends to focus on what is right.	Tends to focus on what is real.
Valuable in sustaining a faith tradition over many generations.	More concerned with depth of spiritual experience and the real outcomes of that experience in the lives of individuals and communities of the present.
May be inward looking and self-serving, or outward looking and self-giving.	May be inward looking and self-serving, or outward looking and self-giving.

Courtesy Mission Hospice Society

KUBLER-ROSS' STAGES OF GRIEF REACTION AND SPIRITUAL STRUGGLE

We can look at Kubler Ross' stages of grief reactions as another way to try to understand some dimensions of spiritual struggle and growth. These stages are:

1. *Denial:* The individual refuses to believe that the loss is happening. Serves as a buffer in helping the client mobilize defenses to cope with the situation.
2. *Anger:* The individual resists the loss. Anger is often directed at family and health care providers.
3. *Bargaining:* The individual attempts to postpone the reality of the loss. Serves as a plea for an extension of life or the chance to "make everything right".
4. *Depression:* The individual realizes the full impact of the loss. Serves as the preparation for the impending loss by working through the struggle of separation.
5. *Acceptance:* The individual comes to terms with the loss. Serves as a form of detachment exemplified by a void of emotion or Interest in worldly activities.

From: *Shelley Yeager, "Lecture Notes on Loss, Grief, Death and Dying: See* www4.allencol.edu/~sey0/loss1a.html

Not everyone experiences all these stages. People experience the different stages in their own way and order, often jumping from one "stage" to another and back and forth rather than in a smooth forward journey from "1." to "5."

When people are working through these reactions to loss, there is often a great deal of spiritual suffering. It is important that we don't try and take the suffering away by trying to impose our own spiritual solutions onto their spiritual struggles.

Each person needs to come to terms with their own losses in their own way. We're there to walk with them in that journey, not to tell them what to think, feel or believe.

FROM CHRISTIAN ROOTS TO SECULAR SERVICE

It is important to acknowledge where and how hospice and palliative care began, and it was indeed the Christian churches that pioneered this invaluable work.

It is equally important to acknowledge the changing world we live in and to keep up with the times.

- It is paramount that every individual feels welcome and comfortable at hospice.
- Each and every person has their own religious, spiritual, agnostic or atheist beliefs.
- We make no judgment on the validity of anyone's beliefs
- We acknowledge the right of each individual to exercise their beliefs and to be free of discrimination or harassment based on those beliefs.
- We acknowledge the right of each individual to question their own beliefs and go through their own questions without judgment or influence toward a particular belief.
- The Hospice Society will make every effort to accommodate the spiritual needs of each guest.
- One member of the Palliative Care Team is a chaplain or priest who acts as a spiritual advisor. Any guest is welcome to speak with this person or to any other spiritual advisor of their choosing.

Volunteers are NOT here to give spiritual advice, share their own spiritual beliefs or influence a guest who is questioning their own faith. **This work is left to those who are appropriately trained.**

Courtesy Prince George Hospice Society

Module 5

LOSS GRIEF & BEREAVEMENT CARE

Healing becomes...
A cheerful smile
An open ear
A gentle touch
A warm embrace
Taking the time to listen, to be,
and share a part of yourself.

The greatest gift one can give
may be the ability
to walk with a person
provide them with grace,
strength and courage
on their path to transition
...and then let go.

Kirsti A. Dyer MD, MS. from *Healing: A Gift of Self*

British Columbia HOSPICE PALLIATIVE CARE Association

Learning Outcomes

Upon completion of this Module, the volunteers will:

1. Be familiar with the basic concepts of loss, grief and bereavement.
2. Understand the wide range of emotions associated with loss.
3. Understand the personal nature of the grief process.
4. Be aware of the particular challenges of loss, grief and bereavement with respect to children.
5. Be aware of and respect religious and cultural influences on loss, grief and bereavement.
6. Recognize and respect their own loss, grief and bereavement experiences.
7. Understand their limitations in providing bereavement care and know when to recommend other resources.

What is Loss and Grief?

Grief is a normal and individualistic response to loss or anticipated loss. The grieving process, while highly complex, helps us adapt to the changes accompanying that loss. The sense of loss associated with death can be very profound and impactful. While we may generalize about the trends and patterns in the grieving process, each person's experience is unique.

The role of the volunteer is first to understand the grief and loss process and then to provide compassionate support to those who are experiencing it.

What is Bereavement?

Once a loved one has died, the bereavement process begins and is a uniquely individual experience for all those involved. Within the same family, members may respond to death differently. Bereavement is an important time of transition, encompassing many responses including the wide range of emotions identified with grief and the ways that we choose to live our lives following significant change. While respecting the individual experience, knowing about potential reactions and patterns of behaviour may be helpful.

With the death of the client, the role of the volunteer moves to family and friends during their period of bereavement. Some volunteers may prefer to work just in the area of palliative care, while others are drawn more to supporting the client and family during bereavement.

Training

Orientation and Basic Training

1. Provide an overview of loss, grief and bereavement including exposure to the process of grief and the healing nature of the grieving process.
2. Provide an overview of the common responses to loss including physical, emotional, social, mental (cognitive) and spiritual responses.
3. Provide the volunteers with a list of common clichés to avoid.
4. Help the volunteers better understand the concept of anticipatory grief.
5. Present the particular challenges associated with children's grief.
6. Provide the volunteers with an opportunity to share their own experiences with grief and loss.
7. Ensure that volunteers understand and respect their own personal limitations, particularly emotional limitations, when dealing with others experiencing grief and loss.
8. Provide opportunities for volunteers to gain knowledge of a variety of mourning rituals that may include:
   - a visit to a funeral home.
   - inviting representatives from different religions and cultures to talk to volunteers.
9. Invite experts in different areas of grief and bereavement to lead workshops or speak to volunteers.
10. Include the presentation of videos on bereavement to a group of volunteers followed by discussion.
11. Provide opportunities for volunteers to practice, through role plays, the experience of supporting individuals and families in bereavement.

Ongoing Training

Ongoing training in the more specialized aspects of loss, grief and bereavement may:

1. Address complicated grief associated with sudden or traumatic death, suicide and/or multiple deaths.
2. Include sessions on suicide risk, evaluation tools and protocols.
3. Continue to enrich the volunteers' learning with workshops, discussion sessions and guest speakers, such as those described in orientation and basic training.
4. Continue to provide opportunities for volunteers to become increasingly comfortable and enhance their skills through exercises such as role-play.
5. Include facilitator training for volunteers interested in working with bereavement groups.

RESOURCES

Module 5
LOSS, GRIEF AND BEREAVEMENT CARE

RESOURCES

- **Death and Dying Simulation**
- **The Dying Process ~ Final Hours**
- **Selected Theories on Grieving**
- **Grief Reactions**
- **What is Normal or Healthy Grief**
- **20 Helpful Suggestions & Handy Tools**
- **Grieving ~ What is Helpful and What is Not**
- **Tips to Help With Grieving**
- **The Parable of the Twins**

DEATH AND DYING: A SIMULATION EXPERIENCE

Purpose: to help individuals reach a conscious awareness of their thoughts, feelings attitudes, and values associated with loss through death and dying.

Objectives: At the completion of the simulation, each participant will be able to:

1) Personalize issues of loss through dying and death.

2) Identify own thoughts, feeling and attitudes about loss through dying or death.

3) Clarify own values about loss through dying or death.

4) Enable further private self-encounters about loss through dying and death.

Equipment: One packet of twelve slips of paper and a pen or pencil for each participant. Overhead transparency of questions (optional).

Procedure and Instruction: Distribute the packets of paper and give the following instructions:

On each of the slips of paper, write one of the following twelve items:

a) Three people who are very dear to you,

b) Three things you own that you regard as very special,

c) Three activities in which you enjoy participating, and

d) Three of your personality attributes of which you are proud.

Arrange the slips of paper in front of you so that you can see all of them.

Now get into a comfortable position and take a deep, relaxing breath.

Please listen without comment and follow the instructions I give you while I describe some happenings, some situations and some people.

(Scenarios should be read carefully, with an effort to awaken the senses)

1) You are at your doctor's office – Picture the office, what colour is the carpet, the walls? What seat are you sitting on –is it hard or soft. What are the smells you associate with your doctor's office – is there an antiseptic smell there? What can you hear? Are there phones ringing? Nurses talking? How are you feeling? Are you apprehensive? Impatient? Distracted? Picture yourself sitting beside your doctor's desk. What sort of look is on you doctor's face? Is it a serious expression? He or she is about to give you life changing news. How are you feeling? Your doctor tells you that you have a terminal illness.

   <u>You have thirty seconds to select and tear up three of your slips of paper.</u>

DEATH AND DYING: A SIMULATION EXPERIENCE cont'd

2) Picture yourself driving home from your doctor's office. How are you coping with the news you just received? Are you even paying attention to the scenery going by, the other traffic? What can you hear? What are you thinking? Imagine parking the car at home and walking to your door. See yourself putting the key in the door. Who is there? Who do you want to be there? What do you say? What do you want to hear?

   Tear up another three slips of paper.

3) Two months later – you are aware that your symptoms are worsening and you are feeling weaker. Where are you? Has it been an emotional roller coaster or have things been a steady progression? Who has supported you? Has it been hard to share the news of your illness with friends? How are you feeling? What is your lifestyle? What do you continue to do? What can't you do?

   Tear up another two slips of paper.

4) Four months later – you are undeniably ill. The pain has increased considerably. What other symptoms do you have? Where are you? Who stays with you? Are you feeling anxious? Scared? Lonesome? Sad? Angry? Who visits you? Who are the people around you?

   Tear up another two slips of paper.

5) Six months have passed, and you find that even the smallest activity of daily living takes most of your energy. How do you feel about yourself? How do you feel about having to depend on others to provide your basic needs? Where are you? Who is with you? How do you feel about knowing the end is closer, and you have to say good bye to your loved ones?

   Turn over the last two slips of paper on the table in front of you. I will take one from you at random. (*Go to each participant and take one slip of a paper.*)

6) Please look at the last slip you have left.

   Tear up your last slip of paper. You are dead.

DEATH AND DYING: A SIMULATION EXPERIENCE cont'd

Discussion of Experience

Give participants 15-20 seconds to react and follow the last instruction. Say something reassuring, such as:

Thanks for your involvement; Everyone's reaction to this simulation is different; This can be painful for you, depending upon your experience with death and dying; I appreciate the thoughtfulness and effort you have put into this experience; You have done well, and now are ready for the next part.

In small groups of three or four people, with one person acting as recorder, initiate a discussion of some or all of the following questions.

What issues arose for you with each scenario? Fears? Concerns?

What were the easiest items to give up? The most difficult?

When did this experience stop being just a game?

What emotional reactions did you have with each scenario? (Watch for denial, anger, disbelief, depression, resignation, sadness, acceptance, avoidance, relief, comfort…)

What did you think, feel, and/or experience when I took a slip of paper from you at random? Did I take the "right" one?

Did you anticipate or expect the content of the last scenario?

What were your thoughts, feelings, and/or reactions to the tearing up of the last slip of paper?

THE DYING PROCESS ~ FINAL HOURS

The physical and mental changes that you will be seeing may seem frightening and distressing. The guest may experience a variety of changes. Each person's death is different. Changes may occur quickly or slowly, may appear and then disappear only to reappear again. People die when they are ready.

Many feelings expressed in the last few days are part of the grieving process, both for the dying person who mourns for her/himself and the family who grieve the loss. Although sadness is common, many people who believe in eternal life are happy to see God or those who have died before them. For them, death is comforting and reassuring.

In general, people die as they have lived. If a person if cheerful and copes well, then s/he will probably approach the end of life in the same way.

Usually within the last 3-6 days of someone's life, the person is less hungry and their body can longer process food. The person will eat very little, or have a total lack of interest in food. The body is shutting down and no longer requires nutrition. Fluid intake continues, but usually not to the point of death. The person becomes unable to swallow and mouth care is needed at this point. Due to the lack of fluid intake, urine output decreases and becomes more concentrated. Bloating, water retention and swelling can also occur.

Changes in strength and awareness are other signs of death. The person may drop things or experience twitching and jerking of their hands and legs. The jerking and twitching will be most noticeable to caregivers and family, more so than to the person who is dying. Weakness increases. The person may shift in their experience of reality. They may talk to someone who is not present, or relate that they have seen someone who is dead. They may talk of a bright light. They may appear unaware of who is with them. The person can also appear confused, repeating sentences that do not seem to make sense. Some people become restless, pull at their bed linens and/or try to get up. This is known as 'pre-death restlessness'.

The person will start sleeping longer and sometimes have trouble waking or responding. The person may have a fixed stare and can become non-verbal.

Changes in breathing are common. There can be a period of 6 – 12 hours where they have very rapid breathing. Breathing can become irregular and shallow. Sometimes there are periods when breathing can stop for 30 seconds or so and then start again. Moist breath that bubbles or gurgles is common as mucous collects in the throat and lungs. This is called the 'death rattle'. This noise is often troubling to family and friends, less so to the dying person.

All senses start to fail and hearing is the last to go. Always assume the dying person is alert and can hear everything you say.

The dying person's circulation will slow and the body temperature will drop. The skin may become cool and clammy.

Most people die by slipping into a coma before the moment of death.

Active Dying can take hours or days. Even when many of the signs are present, it is not always possible to predict when death will occur. These ups and downs can be emotionally and physically draining on the family and caregivers.

Courtesy Prince George Hospice Society

THE DYING PROCESS ~ FINAL HOURS cont'd

Summary of Signs of Death

- Sleeps longer, sometimes having difficulty waking. Eventually slips into coma
- Reduced intake of fluid and food
- Appears confused, does not recognize familiar people or surroundings
- Weakness becomes profound, difficulty responding verbally, difficulty swallowing or forgetting to swallow
- May have a fixed stare
- Breathing becomes irregular and shallow
- Periods when breathing stops and starts
- Breathing is moist, may develop a rattle, may gasp for air
- Pulse becomes irregular, weak, then absent
- Hands and feet become cool
- Skin color may be pale, bluish or mottled
- Urine output will decrease or even be absent for 24-48 hours
- May lose bladder control
- Bowel movements may be absent, or uncontrolled oozing of soft or liquid stool

Family Response

During the last few days, family members may wish to stay with their loved one 24 hours a day. Sometimes they may need to tell the dying person it is okay to die.

After the death, family members may show signs of relief, exhaustion, and sadness. Reactions are varied and individual.

Encourage the family to spend time with the deceased. There is no rush to act at this point. The doctor will need to be called to verify the death and the funeral home will need to be called to come and pick up the body, but it does not have to be done immediately.

SELECTED THEORIES ON GRIEVING

There are many theories on the process of grief; however, we all go through similar phases, thoughts and feelings. Each loss is different and unique – you may not experience all the phases for each loss, nor will you go through them in the same order or for the same length of time. No two deaths are the same and no two relationships are the same. Grief around the deaths of friends or loved ones can be similar, but it is different each and every time.

Freud: (1917) Theory of Grief, Mourning and Melancholia

Kubler-Ross (1969) Theory of stages – for the dying **(DABDA)**

DENIAL (Disbelief)	"No, not me, It can't be true."
ANGER	"Why me?"
BARGAINING	"Yes, me ... but."
DEPRESSION	"Yes, me."
ACCEPTANCE	"It's okay"

Bowlby/Parkes (1970?) The Four Phases of Grief

Phase 1: Numbness - when faced with a loss, the person often feels stunned or numb. Varying degrees of denial or disbelief of the loss are usually present.

Phase 2: Yearning and Searching - the person has a strong urge to find, recover, and reunite with the loved one. Disbelief, tension, tearfulness, and the tendency to want to keep a clear visual memory of the deceased may be apparent.

Phase 3: Disorganization and Despair - the person gives up searching for the deceased. There is depression, a lack of hope for the future and a loss of purpose in life.

Phases 4: Reorganization - the person reduces the attachment with the deceased loved one and starts to establish new ties to others. There is a gradual return of interests and optimism for the future

Worden (1982) The 4 Tasks of Grief

1. To accept the reality of the loss
2. To work through to pain of grief
3. To adjust to an environment in the which the deceased is missing
4. To move the focus of emotional energy from the deceased to the living

Rando (1984) The 6 R Processes

1. **Recognize** the loss
2. **React** to the separation of the loss - both the primary and resulting secondary losses.
3. **Recollect** and re-experience the deceased and the relationship including the negative aspects of the relationship.
4. **Relinquish** attachments to the deceased and the old assumptive world.
5. **Readjust** to move adaptively into the 'new world' without forgetting the deceased.
6. **Re-invest** the 'freed up' energy in a new life or identity**.**

GRIEF REACTIONS

Grief can show itself in many different ways. One may experience one or more of the following symptoms…or none of them. This list is not meant to be a complete one.

Physical Reactions

- Tightness in throat
- Dry mouth
- Tightness in chest
- Breathlessness/ shortness of breath, frequent sighing
- Irregular heartbeat
- Hollowness in stomach
- Diarrhea/constipation
- Muscle weakness
- Lack of energy/fatigue
- Sexual disturbances
- Numbness
- Over sensitivity to noise
- Dizziness
- Sweating
- Rash
- Crying
- Sleep disturbances
- Appetite changes

Cognitive Reactions

- Confusion
- Lack of concentration
- Feeling of going crazy of losing one's mind
- Lack of control
- Numbness
- Detached, feeling of unreality
- Forgetfulness
- Denial, disbelief
- Constant thoughts of the person who has died
- Meaning of life

Emotional Reactions

- Sadness
- Guilt and regret
- Emptiness
- Anxiety
- Panic
- Fear
- Relief, release
- Anger
- Depression
- Loneliness
- Withdrawn
- Explosive

Spiritual Reactions

- Doubt faith/blaming God
- Question spiritual or religious beliefs
- Lack of meaning or direction
- Wanting to die/to join the person who has died
- Find solace in religion
- Examine values and meaning of life

Social Reactions

- Withdraw from social situations
- Refuse invitations
- No energy to initiate social contact
- Feeling of isolation, loneliness

Source: Theresa Rando, *Grief Dying and Death* Lexington 1984

Courtesy Mission Hospice Society

WHAT IS NORMAL OR HEALTHY GRIEF

Grief can show itself in many ways – here are some examples:

1. Physical reactions: tightness or lump in throat or chest, shortness of breath, tendency to sigh, hollowness/emptiness/discomfort/pain in the abdomen, aching arms, dry mouth, over sensitivity to noise, a sense of depersonalization, muscle weakness, loss of coordination, lack of energy, loss of sleep or appetite, over sleeping or eating, shaking, tremor, inability to concentrate, feeling heavy or weighted down.
2. Emotional reactions: feelings of loneliness, anger, guilt, fear, depression, isolation, sadness, yearning, inability to feel good or happy, feeling disorganized or confused, crying.
3. Psychological and social reactions: a desire to withdraw from others, a desire to talk about your relationship with the deceased, a desire to tell stories about the deceased, feeling like the person is in the room, having dreams of the person, hearing the person's voice or thinking you see them, not wanting to burden others, difficulty with interpersonal relationships, avoiding people places and things that are reminders of the deceased.
4. Spiritual reactions: Losing or decreasing faith/religious connections, searching for answers to and meaning in life, searching for meaning in death or for what happens after death, increasing faith/religious connections, reviewing your own priorities goals and beliefs, abandoning spiritual practices, taking up new spiritual practices.

What gets in the way of healthy grieving?

Getting stuck in one phase or feeling. Not wanting to appear weak. Believing in the myth that you should be able to just get over it. Societal attitudes. Well meaning others who say unhelpful things. Not letting yourself cry. Not acknowledging certain thoughts or feelings. Not allowing yourself to go through the process. Trying to be tough or strong for others and thereby denying your own needs. Drug and alcohol misuse. Unresolved past grief.

Unresolved past grief – deaths, moves, divorces, cultural losses, etc.

Courtesy Prince George Hospice

20 HELPFUL SUGGESTIONS AND HANDY TOOLS

1. **Normalize the grief**
   - assure bereaved they are not going crazy
   - provide information on the grieving process

2. **Allow the bereaved to tell their stories**
   - encourage them to talk about the loved one's life and death, and their relationship with the deceased

3. **Allow exploration of their feelings**
   - some of the feelings that may surface are sorrow/sadness, isolation, loneliness, regret, guilt, anger, fear, relief
   - suggest some ways to vent anger safely

4. **Teach relaxation, meditation, breathing techniques, and/or visualization techniques**
   - helps to boost the immune system
   - gives a time-out from the pain of grieving
   - aids sleep

5. **Suggest listening to music**
   - match music to mood
   - use as a relaxation aid

6. **Help grievers to devise rituals**
   - to recognize different aspects of grief

7. **Encourage creativity**
   - to open up new possibilities

8. **Suggest writing**
   - clustering, journaling, writing letters, writing stories, composing poetry

9. **Suggest drawing analogs as alternative to writing**
   - this activity uses the right side of the brain instead of the analytical left
   - it makes inner thought visible

10. **Suggest making a memory book of loved one's life**
    - arrange photographs & other elements into some order so they tell a story

11. **Suggest making a collage**
    - use cutouts from magazines to represent loved one's life, the griever's life, or the relationship between the griever and lost loved one

Courtesy Cowichan Valley Hospice Society

20 HELPFUL SUGGESTIONS AND HANDY TOOLS cont'd

12. Suggest recording dreams
- dreams often contain symbols significant to the grieving process
- do not interpret the dreams
- allow dreamer to draw own conclusions as to meaning of the dreams.

13. Encourage self care
- regular routines of sleeping, exercising, and eating a balanced diet
- importance of taking time off/of, treating oneself

14. Suggest respites from the grief
- actively think about something else for a while
- put aside some time each day to grieve

15. Suggest planning ahead for special days that might be difficult
- birthdays, anniversaries, holidays

16. Encourage talking with a close friend
- this not only helps to unload but gives the friend a specific role to play

17. Encourage enlisting others' help
- often friends and relatives don't know how to help
- get the bereaved to be specific about what helps and what doesn't help

18. Suggest writing important things down
- bereaved are often forgetful
- it helps to keep track on paper

19. Assist bereaved in finding professional help if required
- grief therapist
- financial advisor
- spiritual advisor

20. Listen, accept, and assure
- listen to what the griever has to say
- accept where the griever is at
- assure the griever that the pain will ease

Courtesy Cowichan Valley Hospice Society

GRIEVING - WHAT IS HELPFUL AND WHAT IS NOT

GRIEVING: WHAT IS HELPFUL

- Being able to talk about the person or share memories.
- Taking time for self.
- Enjoying nature.
- Getting physical exercise – walking.
- Public acknowledgement of the loss.
- Rituals to honour deceased.
- Personal belief system or faith.
- Hugs without words.
- Sensitivity to when a hug is not OK.
- Being encouraging to share memories.
- Sharing good times.
- Laughter & humour.
- A simple "I'm sorry" or "I can't imagine what you are going through".
- Tears/emotions – going with feelings.
- Helpful funeral directors.
- Meditation.
- Survival techniques such as sleeping pills (in the short term).
- Someone to take charge & provide practical help.
- Talking to deceased in private.
- Friends providing/encouraging opportunity for outings.
- Pets.
- Sunshine/music.
- Hospice support or other support group.
- Purposeful activity.
- Being "listened to" with sincerity, with respect.
- Not being judged or interrupted.
- Screaming in the car or into a pillow.
- Access to helpful information (books).
- Friends bringing prepared foods or being willing to do practical things such as cooking, shopping, laundry, baby sitting, cutting the grass.
- Follow up after a while when all busyness has died down.
- Personal note or letter with or without card at the time and later on.
- Taking it one day at a time or even one hour at a time.
- Singing.
- Grief counselling.
- Having to go on with life (e.g. see to children, work).
- Being given permission to grieve in your own way.
- Celebrating the life of the loved one in a creative way e.g. song, poem, art.
- Receiving an appropriate gift in memory of the deceased.
- Making a charitable donation.
- Being allowed to express self for as long or as often as needed.
- People remembering a year of two down the road.
- Making a memory board of pictures
- Trying to remember the person as they were normally and not just in the last few hours or days.
- Hearing people share memories at the service.
- A friend just being there.
- Wearing deceased's clothing.
- Being gifted a tree or plant in. remembrance.
- Special place to honour memories in the home.
- Making a remembrance book.
- Keeping a journal.
- Distraction for a while.
- Being gentle with self.
- Taking naps.
- Permission to cry.

Courtesy Nanaimo Hospice Society

GRIEVING: WHAT IS NOT HELPFUL

- Predictions of another death ("you better watch Grandpa or he'll be next").
- Suggestions that it is time to "get on with your life" or "you should be over it by now".
- Trying to meet other's expectations.
- False reassurance ("I know how you feel").
- People who avoid talking about the loss or who avoid talking to you.
- Not talking about the person who died, or how they died.
- Re: loss of child "well, at least you have other children / can have more children".
- Being forced to or not being allowed to view the body.
- Well meant advice like "Eat, you'll feel better" or too much advice or unwanted advice.
- Not caring for self.
- Lack of support (physical and emotional)
- Not being able to say goodbye to the person who died.
- Insensitive phrases (You're lucky - you have all those good memories, It was probably for the best, count your blessings, She's in a better place, She lived a good life, She was old, It was only a dog, at least it was quick, there is a purpose to this, You'll get over it, Time heals, It was their time anyway, He'll remarry, It was God's will, Snap out of it, It's OK, You're strong).
- Medication that dulls the senses but not the emotional pain.
- People tiptoeing around you.
- Visitors – overstaying their welcome (too exhausted to entertain).
- The memories of the time of suffering before death.
- Quarrelling amongst family members over possessions.
- Disposing of deceased's clothing or possessions without permission ("we thought it would be easier if we just got rid of them for you").
- Others being embarrassed by tears.
- Insensitive questions/attitudes/platitudes.
- Incorrect assumptions about the death.
- Others pushing religious beliefs.
- Making decisions too soon.
- Being told how you **should** feel.
- Being told not to cry.
- No funeral or ritual, or not having any input, or being unable to attend.
- Personal loss stories of the comforter which invalidate pain of griever.
- Not being given space or time to grieve in private.
- Competitive stories to minimize your loss.
- Not acknowledging your own need to grieve.
- Uncomfortable silence.
- Platitudes / clichés.
- Others nitpicking about details.
- As a child, being told "he is sleeping".
- Losing social contacts because now you are single and not a couple.
- People not visiting because it would "upset them too much" or "because I want to remember them the way they were".

TIPS TO HELP WITH GRIEVING

1. Cry, scream, yell – express your feelings as they come up
2. Talk to someone who will just listen. Tell stories. Share memories
3. Get regular sleep – go to bed at the same time each night even if you're not tired then get up at the same time each day (get up again if after 30 –45 minutes you still can't sleep – do an activity and then try again)
4. Do some physical activity each day
5. Take naps if you need them
6. Eat frequent healthy small meals and snacks – keep feeding your body
7. Drink water, juice, tea – keep yourself hydrated
8. Try a relaxation exercise
9. Listen to uplifting music
10. Go for a walk or run
11. Sit with nature - by the river or in a quiet park - breathe in some fresh air
12. Follow spiritual practices (sweat, church, prayer, song, etc.)
13. Write in a journal
14. Write a letter to the person who died, then bury it, burn it or put it away
15. Write a story, poem, song for the person
16. Let yourself have fun - Let yourself laugh
17. Don't judge yourself or your grieving process
18. Ask for help from friends and supporters
19. If you get stuck in a stage, or the feelings seem out of proportion, seek counseling
20. **Be gentle with yourself and acknowledge that healing is going to take time**

THE PARABLE OF THE TWINS

Once Upon a time, twin boys were conceived in the same womb. Weeks passed, and the twins developed. As their awareness grew, they laughed for joy: "Isn't it great that we were conceived? Isn't it great to be alive?"

Together the twins explored their world. When they found their mother's cord that gave them life, they sang for joy. "How great is our mother's love, that she shares her own life with us!"

As weeks stretched into months, the twins noticed how much each was changing. "What does this it mean?" asked the one. "It means that our stay in this world is drawing to an end," said the other. "But I don't want to go," said the other one. "I want to stay here always." "We have no choice," said the other. *"But maybe there is life after birth!"* "But how can there be?" responded the one. "We will shed our life cord, and how is life possible without it?" "Besides, we have seen evidence that others were here before us, and none of them have returned to tell us that there is life after birth. No, this is the end."

And so the one fell into deep despair, saying, "If conception ends in birth, what is the purpose of life in the womb? It's meaningless! Maybe there is no mother after all?" " But there has to be," protested the other. "How else did we get here? How do we remain alive?"

"Have you ever seen our mother?" said the one. "Maybe she lives only in our minds. Maybe we made her up, because the idea made us feel good?"

And so the last days in the womb were filled with deep questioning and fear. Finally, the moment of birth arrived.

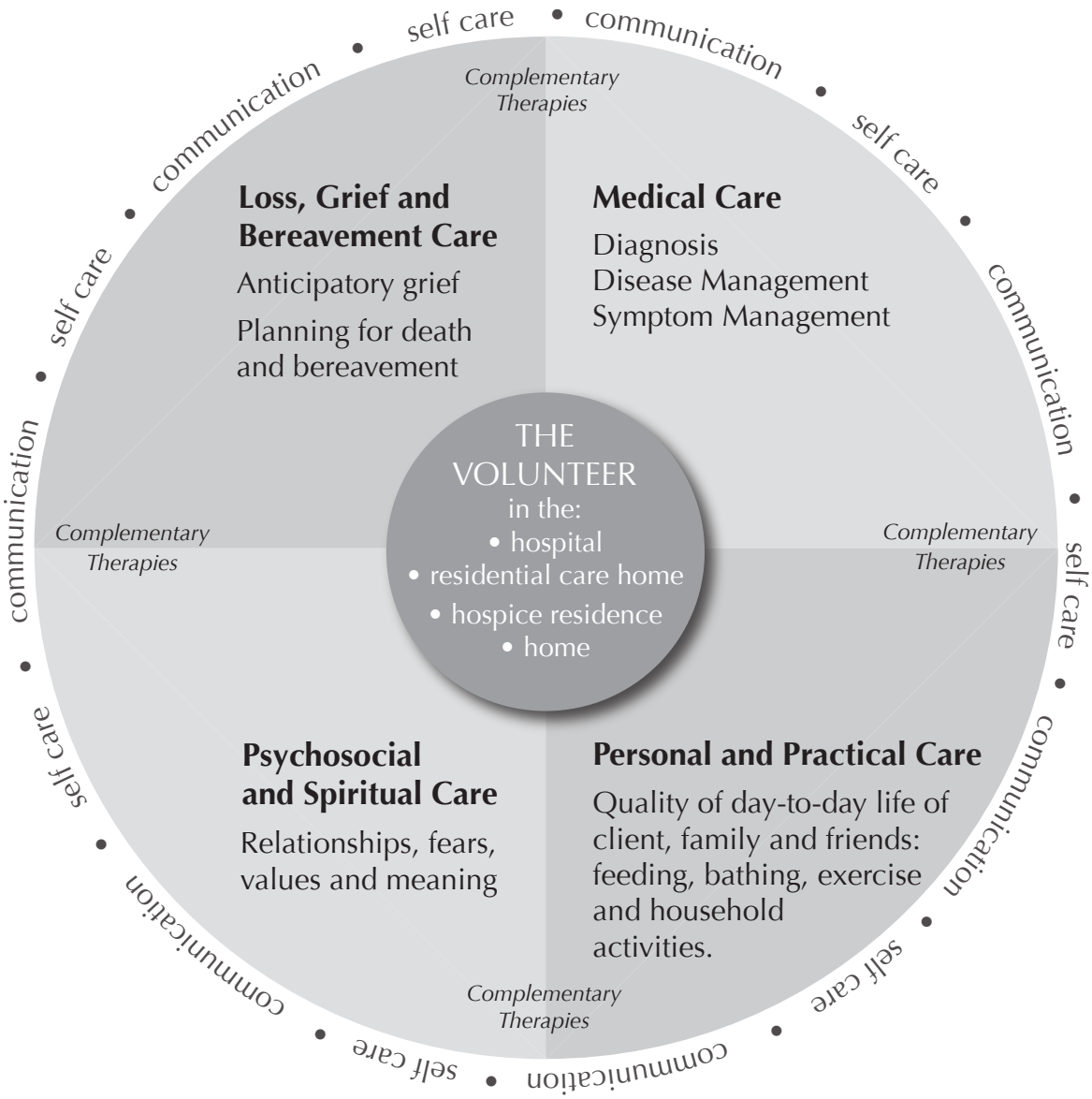
When the twins had passed from their world, they opened their eyes and cried for joy. For what they saw exceeded their fondest dreams.

Anonymous

Module 6
COMMUNICATION

The best way to find things out is not to ask questions at all. If you fire off a question, it is like firing off a gun – BANG it goes, and everything takes flight and runs for shelter. But if you sit quite still and pretend not to be looking, all the little facts will come and peck around your feet, situations will venture forth from thickets, and intentions will creep out and sun themselves on a stone; and if you are very patient, you will see and understand a great deal more than a person with a gun does.

Elspeth Huxley, The Flame Trees of Thika



Learning Outcomes

Upon completion of this module the volunteers will:

1. Understand the primary importance of listening in their role as hospice volunteer.
2. Understand the importance of and be comfortable just "being with" their client.
3. Understand the various ways that clients and their families react to illness, loss, grief and bereavement.
4. Understand cultural differences in communication.
5. Be aware of factors such as pain, loss of speech and confusion that may affect the client's ability to communicate.
6. Understand the continuing need to improve their communciation skill.

The Importance of Communication

Being an effective communicator is a primary role of hospice volunteers. It is integral to all aspects of their work and to all relationships. A client will be most at ease with a volunteer who is present, calm and attentive; one who is comfortable with silence; is aware of their own and the client's body language and is able to just listen.

NOTE: Though this module is presented at the end of the binder, you may choose to integrate parts or all of it at any time with other modules, particularly the Psychosocial and Grief, Loss and Bereavement Modules.

Training

Orientation and Basic Training

1. **Effective Communication**
2. **Factors and/or barriers affecting communication**
3. **Communicating with clients and families**
   - How clients and family may react to illness, grief, loss and bereavement.
   - How to respond to client and family reactions.
   - How family dynamics and cultural differences influence communication.
4. **Communicating with hospice team members**

   It will be important for volunteers to be familiar with:
   - the organization's staff members, their responsibilities and roles in relation to volunteers;
   - the organization's policies and procedures relating to volunteers;
   - the opportunities that exist through team meetings, education sessions and social gatherings for volunteers and staff to connect.
5. **Communication with other hospice palliative care team members in the hospital, hospice residence and residential care home**

   To ensure the volunteer is a valued and participating member of the hospice palliative care team, it would be helpful to have guiding principles in place that spell out how the team members will work together, including:
   - confidentiality;
   - how volunteers request and receive information, assistance and advice;
   - the limits of the volunteer's role (e.g. attending rounds as a silent observer, access to information, privacy, etc.);
   - ensuring that volunteers are familiar with protocols for reporting to and communicating with all staff they encounter including:

     -signing in;

     -procedures for communicating observations; (communication book, debriefing with staff, etc.)

     -what constitutes an emergency.

Orientation and Basic Training cont'd

6. Communication with client, family and care staff in the home:

To ensure the hospice volunteer continues to be welcome in the client's home and contributes to the quality of every day life of client and family, it will be important to include training on how to conduct oneself in a private residence.

Though volunteers may play a more significant role than a guest, they must remember that they are not family members or immediate friends and will need to know how to maintain appropriate boundaries. They should know for example to refrain from:

- joining family conversations unless invited;
- being drawn into family conflicts.

Ongoing Training

1. Provide opportunities for volunteers to practice and enhance their communication skills using role plays and exercises.
2. Encourage volunteers to attend workshops and courses on communication, such as those offered by the Justice Institute of British Columbia (www.jibc.bc.ca) or your local community college.
3. Offer workshops that focus on cultural context in communication.

Training Methods

1. Provide an overview of the above topics with handouts for reference.
2. Include experiential exercises, including role plays, that allow volunteers to practice their communication skills in many different situations and in different roles. This can even be done informally in pairs or threes when they get a chance.
3. Invite experts to speak to volunteers or conduct workshops on various aspects of communication.
4. Show videos that demonstrate various aspects of communication.
5. In a multicultural community, have guest speakers from the various cultures speak to the volunteers about how individuals and families in their cultures communicate, particularly around illness, grief, loss and bereavement.
6. Provide volunteers with guidelines for communication in each of the settings where they work. Information could include directions to each of the settings, sign and reporting protocols, floor plan of the facilities and volunteer related policies and procedures.

RESOURCES

Module 6
COMMUNICATION

RESOURCES

- **Being There**
- **Questions to Ask Yourself**
- **Communication Exercise**
- **Effective Listening Skills**
- **Going Empty**
- **The Way of Council Practice**
- **Ten Commandments for Good Listening**
- **Listening Checklist**
- **Phone Support Guidelines**
- **Risk Factors or Indicators of Difficult Grief**

BEING THERE

Palliative care makes the promise that the client and the family will be cared for spiritually, intellectually, emotionally and physically. No person could possibly do that, and of course no one person does.

The promise is impossible if one person or discipline presumes to provide it; next to impossible if specialists, however talented and well intentioned, work in isolation from one another; but possible if caregivers work as a well-trained and coordinated team.

People are not created as separate 'pieces' – a change in our physical well-being affects us totally. With the pronouncement of a terminal diagnosis, feelings flood our thoughts and spirits. The very foundation of our being is shaken and we look for, and need, more than medical science can offer. What is required is the willingness of the members of the health care team to be present with people in their fear and uncertainty – without the answers.

How then can each of us help? We begin with who we are. Our life experience of loves and losses, our history, our interests are all available to help us really connect with clients - and they need us to connect.

In this work, it simply comes down sooner or later, to how comfortable we are with ourselves, with others and with the whole idea of dying, because often working with the dying involves more "being" than "doing".

Generally it is the "doing" that we are more comfortable with but the client's need at this time, more than ever, is for someone who can be counted on to be there for them. Availability is probably the single most reassuring and helpful attribute in a person who is working with the dying. The highest praise any caregiver can hear may be: *"You were there when I needed you"*.

EMPATHY

The power of entering into the experience of
or understanding emotion outside ourselves.

The ability to identify with a person and so
understand his or her feelings.

The ability to communicate this understanding.

QUESTIONS TO ASK YOURSELF

Listen for Content

1. Are you sure you are hearing the speaker's situation correctly and completely?
2. What assumptions might you have made about the speaker?

Listen for Feelings

1. Are you sure that you are hearing the speaker's feeling correctly and completely?
2. What clues were you hearing to suggest what the speaker was feeling?

Responding to Feelings

1. Did you reflect specific feelings? What did you miss?
2. Did you link content to feelings?

Open-Ended Questions

1. Were you able to use both reflections and open-ended questions?
2. Was some of your question specific?

Voice

1. Was your voice warm, caring?
2. Was your voice genuine? Ask for feedback.

Respect for Speaker

1. Did you focus on the speaker's issues rather than other people's issues, or your own problems or perspectives on those issues?
2. Were you able to suspend judgements… both positive and negative?

Silence

1. Did it feel comfortable for you as the listener? Did you rush to fill in the silences?
2. Check with the speaker to see if the responses came too soon or too slowly.

COMMUNICATION EXERCISE

NOTE: It is important to remember that hospice volunteers are not "counsellors". There will be times when a social worker, a chaplain or other professional would be the most appropriate person for the client to talk to. In these cases it would be appropriate to say (after validating their feelings and a few moments of conversation) "Sounds like this is a very important issue for you. I'm feeling that the social worker/chaplain might be better qualified to help. Would it be OK with you if I ask her to come and talk with you?" Sometimes the client will refuse – they may have built up enough of a rapport that they are more comfortable talking to you. Remember your listening skills - you are not there to "fix"- you are there to offer support.

Most important, always try to validate feelings and invite the person to share more.
The following are some of the many possible responses in these scenarios.

1. **"The weather is so depressing. It rains all the time."**

   Feelings: Sadness, loss, discouraged, despairing, boredom, upset, lonely, hopelessness, low, frustrated, depressed.

   Responses:

   "Sounds like you are feeling pretty blue (or grey) today"

   "Could it be you are feeling a bit like the weather?"

   "Hard to feel sunny without the sun?"

2. **It is near Christmas time and a woman says "This is such a hard time of year for me this year."**

   Feelings: grief, lonely, abandoned, sad, lost, anxiety, stressed, nostalgic. This may be a grieving person. If a palliative client they might also fear being a burden, or scared it will be their last Christmas.

   Responses:

   "What's happened this year that makes it so difficult?"

   "Christmas can be a hard time, especially if you have lost someone you love"

   "Sounds as if you are feeling different this year. Has something happened to change your feelings?"

3. **"I should have been a better husband/wife. I let him/her down many times."**

   Feelings: guilt, fear of loss, regret, failure, self doubt, disappointment, sadness, despair, inadequacy, anxiety, anger, hopelessness, lonely, grief over lost opportunities.

   Responses:

   "Sounds like you have a lot of regrets."

   "Sounds like you have been reflecting on your relationship."

   "Sounds like you've given this a lot of thought – how do you feel you let him/her down?"

   "What do you wish you had done differently?"

Courtesy Nanaimo Hospice Society

COMMUNICATION EXERCISE cont'd

4. "That doctor…he never gets in here when he says he will."

Feelings: fear of abandonment, anger, frustration, insignificance, rejection, lack of control, afraid, resentment, worthless, impatient, anxious, disrespected

Responses:

"It must seem like an eternity waiting for doctors sometimes."

"Pretty frustrating eh?"

"Do you feel like you're always waiting for something these days?"

5. "I'm dying. I don't want to die…."

Feelings: anger, fear, regret, anxiety, defeat, sadness, sorrow, anguish, questioning, helplessness, defiance, self pity, denial, disbelief, concern for loved ones, panic, loss of control.

Responses:

Silence and a comforting touch.

"I can't begin to imagine how you are feeling?"

"Sounds like there are still things you want to do."

"This must be so hard for you."

6. A 35-year-old woman has been in the Palliative Care unit for 3 weeks and you have conversed with her a little each week. She says, **"I feel dreadful today."**

Feelings: pain, sorrow (suffering), discouraged, helpless, fear, fatigue, foreboding, weary.

Responses:

"What's going on for you today?"

"Sounds like you are feeling discouraged – what's happening today that makes you feel dreadful?"

7. An elderly woman has just found out she has cancer of the stomach and it is too advanced for treatment. She says, **"There must be something that can be done. I'm not ready to go yet."**

Feelings*:* fear, denial, feeling of incompletion, shock, feisty, loss of control, frustration, disbelief, wanting hope, cheated, anger, panic, bewilderment

***Responses*:**

"It must be so hard to hear that sort of news?"

"Sounds like you still have things you want to do."

"Sounds like you have had quite a shock."

"Must be hard to believe this is really happening to you?"

Courtesy Nanaimo Hospice Society

COMMUNICATION EXERCISE cont'd

8. A young woman has breast cancer, which has metastasized, and she knows she is dying. She says, **"I wonder if my husband will find somebody else soon."**

***Feelings*:** grief, fear of being forgotten, sadness, insecurity, lonely, concerned, jealous, love, betrayal

Responses:

"Is that something that you fear?"

"Are you worried that that's what will happen?"

"Are you thinking he might forget you once you are gone?"

"Is that a distressing thought or a comforting one?"

EFFECTIVE LISTENING SKILLS

Some people think that "listening" is the same as "hearing". It's not! Listening must be learned. You must actively participate in a conversation and comprehend the ideas behind the words in order to really listen and understand. To listen actively, pay attention to both what the speaker says and what the speaker does.

Show The Speaker That You Are Interested

Tone of Voice: Be aware of the tone of your voice when you respond to the speaker. A monotone communicates boredom. Even with moderate tones, you also show boredom when combined with certain tones in the voice. Change the level (modulation) of your voice to show interest when you are responding.

Expression: Look the speaker in the eye – it shows that you are paying attention to what is being said and lets the other person know that you are friendly and receptive.

Gestures: Gestures indicate that you like the speaker. In fact, a lack of gestures can indicate unfriendliness. Open palms and large open gestures with the hands show that you like people.

Posture: Leaning toward the speaker shows interest. It doesn't need to be overdone, but a movement of the upper half of the body towards the speaker says that you are really interested in what's being said. If you fold your arms or back away, you show that you aren't interested in what the speaker is saying.

Ask: Get the full story by asking questions. Don't assume that you know what is going to be said. Listen so you will be able to ask relevant questions to get even more information.

Create A Safe, Peaceful Atmosphere

Sit across from, and on the same level with, the person. Be sure you are not seated at a higher level, looking down at them.

Shut the door and let the person know that you are there to listen.

Note bad eyesight or hearing problems and situate yourself so as to decrease the impact of either of these challenges.

Above all, **DO NOT JUDGE.** Do not try to convince the person of what YOU believe. A person must find their own solutions; they must recognise their own problems and experience them for themselves. We are there to provide an environment that is safe and understanding from the heart. Be open and non-judgemental. Only then will the person feel safe**.**

GOING EMPTY

The term *going empty* means to leave your agenda, your issues (your "stuff") outside when you are going to visit the dying person. This does not mean that you never say anything personal, but it does mean that you are there primarily to listen to and support the dying person. *They* set the agenda. Their needs determine the content of the visit. As aware as we are of this, it can still be a challenge, especially after a difficult or busy day. Here are some suggestions, which might help you to "empty" yourself before a visit.

1. If the dying person lives within walking distance, walking could provide you with some quiet time and to rid yourself of the day's stuff.
2. Listening to some special music can help to quiet your mind.
3. A relaxing bath can work wonders to leave stresses behind.
4. Visualize that as you enter the dying person's room you are leaving your own worries and cares outside the door.
5. Make sure that you are getting enough sleep and that you are meeting the needs in all four areas of your life – mental, physical, spiritual and emotional. **SELF-CARE** is so important in the helping field.
6. Set boundaries and respect them. Do not over extend yourself. When we overdo, it speaks more of our needs than the dying person's needs.
7. If you are extremely upset or emotional, you would probably be wise to postpone the visit.
8. Take time to reflect on the previous visit. Some visitors find journaling helps them to express their thoughts and feelings.
9. Take a few deep breaths before the visit.
10. Talk to the Creator, or whoever your Higher Power is.

Other suggestions: (fill in your own ideas).

BROWN BAG YOUR STUFF AND LEAVE IT AT THE DOOR

Courtesy Mission Hospice Society

THE WAY OF COUNCIL PRACTICE

Council is a practice where we, as listeners, develop a quality of listening that elicits wisdom from the one who is speaking. To be in Council with someone means to bear witness to his or her story, to his or her suffering.

To be in Council, we listen with a kind of deep devotion to the speaker, not judging, practicing absolute tolerance and non-prejudice, as though we, ourselves, are listening from within the speaker.

Often, Council begins in silence, giving a chance for each person to drop down to the truth in his or her own heart.

Council honours the wisdom of the circle. Groups of First Nations Elders sit in a circle in a position of wisdom. Council allowed the Quakers practice in devout listening and speaking spontaneously from their hearts. There is even mention of Council in Homer's Iliad.

You can be in Council with one person or one thousand people. Council is a practice where each person can speak clearly and listen deeply. In Council, each sits so that he or she can see the others. In Council, a shift is made from busyness to intimacy and truth. In Council, connection is made with the spirit of place and the sacredness of space.

A Native American teacher suggests that a lighted candle, (or a flower, a rock, or some other chosen symbol) be placed in the center of the space. This symbol represents the Children's Fire. The Children's Fire is the fire of our own innocent heart. As devout listeners, we do not speak across the children's fire. The Children's Fire is there to remind us of who we really are: the spirit part of our experience.

A talking piece (a stone, talking stick, family heirloom, or another object of choice) helps to keep each person in Council on track. Whoever has the talking piece has the others' undivided attention and devout listening, as each practices the "The Four Intentions of Circle".

Adapted from audiotape by Joan Halifax *Being with Dying*

TEN COMMANDMENTS FOR GOOD LISTENING

1. ***STOP TALKING*:** You cannot listen if you are talking. As Polonius says in *Hamlet*, "Give every man thine ear, but few thy voice".

2. ***PUT THE SPEAKER AT EASE:*** Help them feel that they are free to talk. This is often called a "permissive environment".

3. ***SHOW THE SPEAKER THAT YOU WANT TO LISTEN*:** Look and act interested. Do not read your mail while they talk. Listen to understand rather than to reply.

4. ***REMOVE DISTRACTIONS*:** Don't doodle, tap or shuffle papers. It will be quieter if you shut the door.

5. ***EMPATHIZE WITH THE SPEAKER:*** Try to put yourself in their place so that you can see their point of view.

6. ***BE PATIENT*:** Allow plenty of time. Do not interrupt. Don't start for the door or walk away.

7. ***HOLD YOUR TEMPER*:** An angry person gets the wrong meaning from words.

8. ***GO EASY ON ARGUMENT AND CRITICISM*:** Argument and criticism puts people on the defensive. They may clam up or get angry. When you argue, even when you win, you lose.

9. ***ASK OPEN-ENDED QUESTIONS*:** This encourages people and shows them that you are listening.

10. ***STOP TALKING*:** This is the first and the last commandment, because all the others depend on it. You just can't do a good job of listening while you are talking.

We were given two ears, but only one tongue,
a gentle hint that we should listen more than we talk.

Courtesy Mission Hospice Society

LISTENING CHECKLIST

- ☐ Am I facing the speaker and making eye contact?
- ☐ Am I aware of body language?
- ☐ Do I know my bias and prejudices so that they do not unduly filter out certain messages?
- ☐ Have I established a comfortable distance?
- ☐ Am I relaxed and do I look interested?
- ☐ Do I try not to over-respond to emotionally charged words?
- ☐ Do I understand that in order to hear I need to stop talking?
- ☐ Do I consider the person involved as well as the situation?
- ☐ Have I shut out my own thoughts and distractions?
- ☐ Do I wait before responding (don't finish his/her sentence)?
- ☐ Can I tell when there is a hostile, emotionally charged atmosphere?
- ☐ Do I listen to content and acknowledge it?
- ☐ If I am having trouble being understood, do I understand that the burden is on me to try to understand the other person?
- ☐ Do I listen for what is not being said?
- ☐ Do I listen to feeling and validate them?
- ☐ Do I understand that being a good listener does not mean I must believe what I am hearing or subscribe to the values of the speaker?
- ☐ Do I talk about myself only <u>after</u> I have really listened?
- ☐ If I were a good listener, would I listen to myself?
- ☐ Do I understand that there will be silence and am I comfortable with it?

PHONE SUPPORT GUIDELINES

Prior to the first call:

When the office receives notice of a recent death that requires follow up, the Director of Client Care sends a sympathy card and information letter to the appropriate person. The letter outlines the bereavement services that we offer and informs the person to expect a phone call from a Hospice volunteer within 2 – 3 weeks.

Usually, it's the Grief Support Coordinator who makes the first phone call in order to establish contact with the person, find out how the person is doing, and assess need. Should the coordinator feel that it is important to keep in contact with the client, she asks the client if it's okay if someone from Hospice phones again in a couple of weeks.

When making the call:

The first call is the hardest for both the volunteer and the bereaved client, but it becomes easier over time:

Always identify yourself, give the purpose for the call, and ask if the timing of the call is appropriate. For example:

> "Hello Mrs. Hanson, my name is Mary Peters and I'm a grief support volunteer with Cowichan Valley Hospice. I'm calling to ask how you are getting along. Is this a good time for you or would you prefer that I call at another time?"

Listen carefully to what the person says and how he or she is saying it. If the client cries, don't hang up. Allow time for the person to regain composure and be sensitive as to whether or not they wish the conversation to continue.

Ask how the client prefers to be addressed, i.e. by their first name or their surname. If you don't already know it, ask the name of the deceased and don't be afraid to refer to the deceased by name during the conversation.

Sorts of questions to ask during the first one or two calls:

- How are you sleeping, eating, feeling physically?
- Are you concerned about yourself or any other family member?
- How are you managing the practical issues—estate, daily routine, returning to work (if appropriate)?
- Are you getting the support you want?
- Do you have people you can talk to about the person who died?
- Would you like other Hospice services: 1:1, Thursday afternoon drop-in, on-going phone support? Mention the resources in the office: pamphlets, library books, etc.

Something to remember in the early days following the death or funeral

Client may feel some relief and euphoria that things went as well as they could, that family managed well, and that care was good. These feelings often sustain family members for a while before reality sets in and other feelings arise.

Courtesy Victoria Hospice and Grace Hospital, Manitoba

PHONE SUPPORT GUIDELINES cont'd

The early days following the death or funeral cont'd

Some indicators of difficulty in the early days:

- Keeping busy all the time, no time for grief, "just get on with life."
- Can't cry or won't allow themselves to cry.
- Continuing shock, which prevents necessary functioning.
- Use of alcohol or drugs for coping; previous mental illness.

Sorts of questions to ask in subsequent calls:

- How are you looking after yourself? Any changes in your own health?
- Do you have opportunities to talk about your memories, your emotions, and your worries with family or friends?
- How are you managing the ups and downs, the good days and the bad days?
- How different has life been since the person died? How are you coping with these changes?
- Have any other losses or major changes happened since the death?
- Are you concerned about yourself or any other family member?
- What expectations do you have about managing over the coming weeks and months?
- How are you planning to deal with upcoming events e.g. Christmas, Easter, Thanksgiving, birthdays, anniversaries etc? How are you feeling about these times?

Indicators of difficulty later on:

- Being overwhelmed by emotions.
- Stuck with a certain aspect of what happened.
- Going round and round without being able to resolve an issue.
- Feeling abandoned by usual support systems.
- Inability to return to most normal routines.
- Flashback images of the death.

NOTE: Statements like, "I feel like I'm going crazy."; or "I feel depressed."; or "What's the point of getting up in the morning?" are normal, **but such statements need to be checked out further.**

At the anniversary of the bereavement, it's best to call a few days before the date and ask the following sort of questions:

- With the anniversary coming up, what plans do you have for that day?
- Who will you share it with you?
- Are you having thoughts and memories of this time last year? How has that been?
- Over the last months and weeks, how do you think you've been managing?

PHONE SUPPORT GUIDELINES cont'd

Indicators of difficulty around the anniversary of the death:

- Feeling no change from earlier days of grief.
- More bad days than good days.
- Fears of facing the future or inability to see a positive future.
- Guilt or resistance about going on with life

NOTE: It's normal to feel worse close to the anniversary date, so it's important to check the extent and duration of difficult feelings and thoughts.

Risk Factors or Indicators of Difficult Grief

Make a note if clients express any of the following concerns and report all concerns to the Grief Support Coordinator or the Director of Client Care:

- Difficult relationships with family members or with the person who died.
- Lack of perceived support.
- Difficult circumstances surrounding the death such as a sudden, violent, or suicide death, or if drugs/ alcohol use/abuse were involved
- Multiple losses; concurrent deaths, or past unresolved losses.
- Mental or physical health problems or disabilities.
- Emotional or spiritual crises.
- Major changes in life circumstances.

Points to Remember

- Listen and accept where the client is at today.
- Provide information and normalize the grief process.
- Suggest other appropriate Hospice grief support services as appropriate.
- Do **not** just stop phoning the client because you think they are doing fine. The second year after a death is often worse than the first.
- Tell the client if you plan to go away and ask if they would like someone else to phone while you're away.
- Consult coordinator/Director of Client Care before finishing with a phone client.

Home phone number

It's a matter of personal choice whether you give a client your home phone number. Usually it's best to avoid sharing your home number until you have developed a rapport with the client.

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Other Considerations

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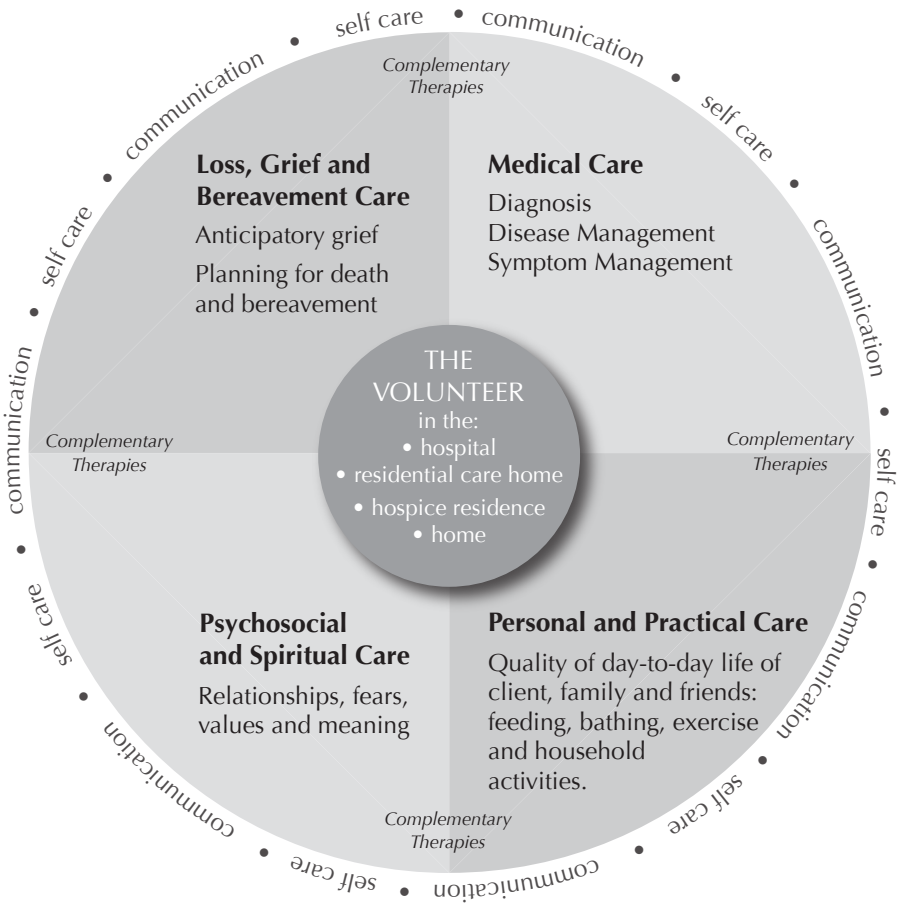
Module 7
SELF CARE

You mustn't be frightened
if a sadness
rises in front of you,
larger than any you have ever seen;
if an anxiety,
like light and cloud-shadows,
moves over your hands and over
everything you do.
You must realize that something is
happening to you,
that life has not forgotten you,
that it holds you in its hand
and will not let you fall.

Rainer Maria Rilke



Learning Outcomes

Upon completion of the Self-Care Module, volunteers will:

1. Recognize the importance of self-awareness and a support network to keep their life in balance.
2. Understand the need for personal boundaries – both theirs and their client's/family's – and will be able to effectively create and respect those boundaries.
3. Recognize and respect their own limitations and needs around self-care when working with a client and family.
4. Understand and respect the need to give themselves some time to process the loss of a client before beginning with another client.
5. Know what self-care options are available to them and which ones best suit their needs and preferences.
6. Be comfortable asking questions of and requesting support from hospice staff and volunteers and from other members of the hospice palliative care team.
7. Be comfortable and effective in supporting fellow volunteers and be able to express if they are not comfortable.
8. When appropriate, be comfortable and effective in sharing self-care options with clients and family members.

What is Self-Care?

Self-care includes the measures taken by hospice volunteers to ensure that they are able to remain present, appropriate and effective in supporting their clients and families. Self-care can help volunteers avoid burn out and compassion fatigue.

All hospice volunteers need to give themselves time to step back, to rest, to reflect, to seek support and/or to acquire new skills. This may be challenging, particularly for new volunteers who have little experience with self-care.

NOTE: As with the Communication module, you may choose to incorporate Self-Care into other modules or present it on its own, early in your training cycle.

Training

Orientation and Basic Training

1. Describe self-care, the importance of self-care and provide examples.
2. Provide opportunities for volunteers to learn experientially:
    - How to deal with loss, grief and bereavement in their own lives.
    - How to recognize and anticipate that they need self-care.
      - provide examples specific to the hospice volunteer experience.
    - How to recognize and respect their own limitations as hospice volunteers.
    - About boundaries
      - what they are
      - how to respect their own boundaries
      - recognize, acknowledge and respect the client's and family's boundaries
    - How to transition from their personal life to beginning a shift as a hospice volunteer and back to their personal life.

Ongoing Training

1. Continue to build self-care into any upgrading or advanced training.
2. Encourage those volunteers who are interested to take training/workshops in self-care and support them in sharing their experience/skills with other volunteers.

Training Methods

Provide opportunities for volunteers to share and experience different forms of self-care:

1. **Individually**
   - You may wish to invite practitioners and experts in the field to offer sessions or workshops.
   - Volunteers may also share their own skills and experiences.

2. **With others**
   Build in ongoing opportunities for and encourage participation in:
   - formal and informal debriefing sessions
   - networking, within and beyond your volunteer group
   - mentoring
   - counselling
   - sharing experiences of self-care with each other

3. **As a hospice organization**
   Ensure the following are supported:
   - evaluation (including self-evaluation)
   - volunteer recognition
   - celebrations
   - creating a supportive environment of dialogue, questioning and constructive feedback.
   - providing resources in your library and/or a list of resources volunteers may request from the public library, obtain on line or purchase.

A THANK YOU TO VOLUNTEERS

Volunteers offer wonderful gifts to British Columbians requiring end-of-life care and support. In addition, the volunteers discover opportunities for self-growth and education through their generous giving to others.

The opportunity to make a difference for humanity by offering caring support is a rich and rewarding endeavor.

We trust that this "Guide To Hospice Volunteer Training in British Columbia" will assist you in your preparation as a hospice palliative volunteer. Thank you for your generosity and caring.

RESOURCES

Module 7
SELF-CARE

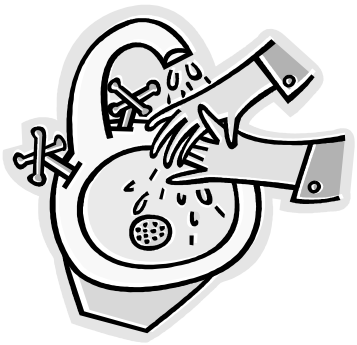
RESOURCES

- **Health and Safety Tips**
- **My Feelings List**
- **Keeping a Grief Journal**
- **A Significant Loss in My Life Exercise**
- **Self Care Manifesto**

VANCOUVER ISLAND health authority

HEALTH AND SAFETY TIPS

Stay Healthy and Use Antibiotics Wisely



The Vancouver Island Health Authority offers tips to stay healthy through cold and flu season – and cautions residents to use antibiotics wisely to prevent bacteria from becoming resistant to antibiotics.

Stay Healthy

Did you know that 80% of common infections are spread by hands?
Handwashing is the best way to stop the spread of infections.

Proper hand washing technique includes:

1. Fifteen seconds of vigorous rubbing of hands together until soapy lather appears.
2. Scrub between the fingers, under the fingernails, around the tops and palms of the hands.
3. Rinse under warm running water.
4. Dry the hands with a clean, disposable towel, and turn off the faucet using a towel as a barrier.

Always wash your hands:

- Before meals
- After blowing your nose or wiping your child's nose
- Before breastfeeding
- After changing diapers
- After using the toilet or helping your child use the toilet
- After playing with toys shared with other children

Use Antibiotics Wisely

Using antibiotics when they are not needed can lead to antibiotic resistance. Although both bacteria and viruses cause respiratory tract infections, antibiotics only work against bacteria.

Viral:

- Infections include: colds, flu, croup, laryngitis, chest colds (bronchitis) and most sore throats.
- Viral infections are more contagious (if more than one family member has the same illness, odds are it is a viral infection).
- Be patient if you have cold symptoms, cough or a sore throat. Most viral illnesses take 4-5 days before getting better and up to 3-weeks for full recovery.

Bacterial:

- Cause infections such as pneumonia and strep throat.
- Are less common and do not spread from one person to another as readily.
- Use regular soap. Antibacterial soap is not recommended because it promotes bacterial resistance.

MY FEELINGS LIST

Glad	Sad	Mad	Scared
Calm	Ashamed	Aggravated	Afraid
Caring	Blue	Angry	Anxious
Cheerful	Bored	Annoyed	Apprehensive
Comfortable	Depressed	Bitchy	Cautious
Confident	Devastated	Bitter	Concerned
Ecstatic	Disappointed	Disapproving	Confused
Encouraged	Discouraged	Disgusted	Distrustful
Excited	Down (in the dumps)	Enraged	Fearful
Fortunate	Embarrassed	Exasperated	Freaked out
Fulfilled	Exhausted	Frustrated	Frightened
Glad	Gloomy	Furious	Haunted
Happy	Guilty	Growly	Horrified
Joyful	Helpless	Grumpy	Insecure
Loving	Hopeless	Hateful	Nervous
Mischievous	Hurt	Irritated	Panicky
Passionate	Lonely	Mad	Restless
Pleased	Regretful	Offended	Scared
Overjoyed	Rueful	Pissed off	Shocked
Relieved	Sad	Resentful	Shy
Satisfied	Tired	Snarly	Terrified
Thrilled	Unhappy	Ticked off	Uncertain
Vibrant			
Vivacious			

Miscellaneous: Jealous, Tense, Bewildered, Surprised, Weird, Disconnected, Envious

Please add any others you can think of.

Courtesy Prince George Hospice Society

KEEPING A GRIEF JOURNAL

Get yourself a stenographer's notebook, a diary, a lined journal, or some other notebook. Nothing else goes in this book … it is a record of your journey through grief. Keeping a journal such as this, allows you to look back and see the change and progress you have made, when weeks and months down the road you get hit with the thought that nothing is getting better and that this pain will never end.

It is a tool to remind you what has been helpful to you already, when you get a day where you can't think of what to do next. In the beginning, this journal may seem like it is just highlighting your pain and does not bring much comfort. The comfort and importance you find in the journal will become evident with time. The journal will help you stay in charge of your grief rather than your grief taking control of you.

Leave a line or two between entries and be sure to record the time and date of each entry. The following are some suggested things to include in your journal:

- A significant event that happened today
- The person who was most important to me today
- Something I found helpful today
- Changes I observe happening to me
- My plans for tomorrow
- Notes to myself

The best time to write in this journal is in the evening at least an hour or so before bedtime. Often evenings are the hardest time. This is the time that loneliness and despair can sink in. By writing and focusing on the changes and the things that have been helpful, you can actually take charge of your grief.

Some people find that writing about their pain, their confusion, fears and frustration helps ease the intensity. If you want to include this type of writing divide your daily entry into two sections. The first section is where you write your feelings, thoughts and fears.

Do not worry about punctuation, spelling or grammar, just write. Get out all that you can; when you find yourself running out of things to write, stop.

The second section is more structured and includes the things suggested above. It focuses on events, people, progress and change, things that are helpful and what you are going to do next. It is important to follow this order. By doing the 'feeling' writing first and the 'thinking' writing second you will gain a better sense of control over your grief and be more grounded and in a better frame of mind for going to sleep.

A SIGNIFICANT LOSS IN MY LIFE EXERCISE

The "Talker":

Sit quietly and think of a significant loss in your life. It need not be the most traumatic one – it needs to be one you are comfortable talking about. If you have not experienced a death in your life, then think of another loss**. You are not to say anything - just get in touch with your feelings.**

The "Listener":

Maintain some eye contact**. If you must speak, you are allowed to say only, "I'm sorry for your loss."**

This will be maintained for a minute or two.

When the bells rings:

The "Talker" will talk for 10-15 minutes about this loss.

The "Listener" will practice creative (empathic) listening and open-ended questions (e.g. "tell me more").

LISTEN TO UNDERSTAND INSTEAD OF LISTENING TO REPLY.

Questions or comments will then automatically come if you need clarification or want to invite the "talker" to share more or want to let the "talker" know you have heard.

When the bells rings again, both of you stand up, take a few deep breaths to let go of the scenario and then switch roles and repeat the exercise. (This will be good practice for when you are with your clients – centering yourself and letting go after being with a client.)

Courtesy Nanaimo Hospice Society

A SELF CARE MANIFESTO

We who care for the bereaved and the dying have a wondrous opportunity to help others embrace and grow through grief and to lead fuller, more deeply-lived lives ourselves. But our work is draining – physically, emotionally and spiritually. We must first care for ourselves if we want to care well for others. This manifesto is intended to help you to practice good self-care.

1. ***I deserve to lead a joyful, whole life.*** No matter how much I love and value my work, my life is multifaceted. My family, my friends, my other interests and my spirituality also deserve my time and attention. I deserve my time and attention.
2. ***My work does not define me.*** I am a unique, worthy person outside my work life. While relationships can help me feel good about myself, they are not what is inside me. Sometimes I need to stop "doing" and instead focus on simply "being".
3. ***I am not the only one who can help the dying and bereaved***. When I feel indispensable, I tend to ignore my own needs. There are many talented caregivers in my community who can also help the dying and the bereaved
4. ***I must develop healthy eating, sleeping and exercise patterns.*** I am aware of the importance of these things for those I help, but I may neglect them myself. A well-balanced diet, adequate sleep and regular exercise allow me be the best I can be.
5. ***I must maintain boundaries in my helping relationships.*** As a death caregiver I cannot avoid getting emotionally involved with dying and bereaved people. Nor would I want to. Active empathy allows me to be a good companion to them. However, I must remember I am responsible ***to*** others, not ***for*** others.
6. ***I am not perfect and I must not expect myself to be.*** I wish my helping efforts were always successful. But even when I offer compassionate, "on-target" help, the recipient isn't always prepared to use it. When I do make mistakes, I should see them as an integral part of learning and growth, not as measurements of my self-worth.
7. ***I must practice effective time-management skills.*** I must set practical goals for how I spend my time. I must also remember Pareto's principle: twenty percent of what I do nets eighty percent of my results.
8. ***I must set limits and alleviate stresses I can do something about.*** I must work to achieve a clear sense of expectations and set realistic deadlines. I should enjoy what I do accomplish in helping others but shouldn't berate myself for what is beyond me.
9. ***I must listen to my inner voice***. As a caregiver to the dying and the bereaved, I will at times become grief overloaded. When my inner voice begins to whisper its fatigue, I must listen carefully and allow myself some grief downtime.
10. ***I should express the personal me in both my work and play.*** I shouldn't be afraid to demonstrate my unique talents and abilities. I must also make time each day to remind myself of what is important to me. If I only had three months to live, what would I do?
11. ***I am a spiritual being.*** I must spend alone time focusing on self-understanding and self-love. To be present to those I work with and to learn from those I companion, I must appreciate the beauty of life and living. I must renew my spirit.

Credit: Alan Wolfelt Courtesy Mission Hospice Society

APPENDICES

To die will be an awfully big adventure
J. M. Barrie

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- **Glossary**
- **Websites, Books and Videos of interest to Facilitators and Volunteers**
- **Standards for Volunteer Hospice Palliative Care in British Columbia (BCHPCA 2008)**

Glossary of Terms

Advance Care Planning:	The process of planning, in advance, for personal and financial care should one be unable to make decisions on their own behalf.
Activities of Daily Living (ADLs):	A term that refers to daily activities such as bathing, dressing, eating, toileting, transferring out of a bed or chair, and walking. Ability to do ADLs is one of the criteria used in assessing for residential and community-based care.
Alzheimer's Disease:	A progressive, neurological disease that affects brain functions including language, short-term memory, ability to reason, and the ability to care for oneself.
Anticipatory Grief:	A grief reaction that occurs in anticipation of an impending death. While this term is usually used in connection with spouses, other people and even the dying can experience anticipatory grief themselves. Anticipatory grief can be just as painful as the actual death of the person.
Aphasia:	Aphasia is a language difficulty. As a rule, people who have aphasia know what they want to say, but have trouble communicating their thoughts and ideas. Individuals with aphasia may have trouble speaking, understanding the speech of others, reading and writing.
Assisted Living:	Assisted living residences provide housing and a range of supportive services, including personalized assistance, for seniors and people with disabilities who can live independently but require regular unscheduled help with day-to-day activities.
BCHPCA:	The British Columbia Hospice Palliative Care Association. BCHPCA is an umbrella organization whose mission is to provide a leadership role for its member organizations and individuals to ensure quality of care for British Columbians faced with a life-threatening illness, death and bereavement.
Bereavement:	the period after a loss during which grief is experienced and mourning occurs.
Caregiver:	Any person who provides care for the physical and emotional needs of a family member or friend.

Glossary of Terms

Care Plan:	An individualized action plan that takes into account the client's unique needs and the goals of care.
CHPCA:	The Canadian Hospice Palliative Care Association is the national association which provides leadership in hospice palliative care in Canada offering leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.
Chronic Care:	The ongoing provision of medical, health, social, psychological and spiritual care services that enable people living with serious and long-lasting conditions to optimize their functional abilities and well-being.
Cognitive Impairment:	A deficiency in a person's short or long-term memory, orientation as to person, place and time, deductive or inductive reasoning or judgment. Cognitive impairment usually related to an illness or injury such as Alzheimer's disease, stroke, traumatic brain injury, Parkinson's disease, Lewy Body Dementia and others.
Compassion Fatigue:	A term that refers to a gradual lessening of compassion over time. Compassion fatigue may occur when, due to over-exposure to the experiences of people who are undergoing loss and grief, the volunteer develops a resistance to these experiences. As the impact of these messages lessens, their ability or willingness to respond empathically declines.
Dementia:	The medical term for a group of symptoms that describe a loss of intellectual ability, including loss of vocabulary, abstract thinking, judgment, memory, and physical coordination.
Delirium:	Is a reversible, acute condition where there are delusions, illusions, sleep disturbances, disorientation to time, place or person and memory impairment. Delirium is different from dementia in that it is a temporary state lasting a short time, whereas dementia is often permanent.
Depression:	A reversible psychological state characterized by an inability to concentrate, difficulty sleeping, feelings of hopelessness, fatigue, the "blues" and guilt.

Glossary of Terms

DNR:	A Do Not Resuscitate Order (DNR) is a legal document instructing medical professionals not to revive a patient in a condition, such as cardiac or pulmonary failure, who cannot be saved without invasive and continuous medical treatment. It is put in place only if there is no reasonable probability of recovery from the illness.
End-of-Life Care:	The term used for the range of clinical and support services appropriate for dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families.
Grief:	a multi-faceted response to loss. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social and philosophical dimensions. Common to human experience is the death of a loved one, whether it be of a friend, a family member, or other close companion. While the terms are often used interchangeably, bereavement often refers to the state of loss, and grief to the reaction to loss.
Home Care:	A range of supportive services in the home, from intensive medical support to assistance with activities of daily living to housekeeping. Home care can include nurses, social workers, occupational therapists, physical therapists and other rehabilitation services.
Hospice:	Hospice services involve palliative rather than curative treatments that aim to comfort the person who is dying and their family. It involves professional medical care, advanced pain and symptom relief, and emotional, spiritual and practical support based on the patient's wishes and family's needs. The term hospice is also often used to refer to a home-like place where people go in the last few weeks of life.
Long-Term Care Facility:	Often referred to as Complex Care or Extended Care Homes, provide a higher level of care and supervision than Assisted Living Residences. Designed for those who require ongoing 24-hour supervision, personal nursing care and/or treatment by skilled nursing staff.

Mourning:	in the simplest sense synonymous with grief over the death of someone. The word is also used to describe a cultural complex of behaviours in which the bereaved participate or are expected to participate. Customs vary between different cultures and evolve over time, though many core behaviors remain constant.
Occupational Therapist:	A rehabilitation professional who assists individuals to learn skills and techniques needed to perform activities of daily living.
Palliative Care:	The specialized care for people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term "palliative care" is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.
Patient-Controlled Analgesia (PCA):	Pain medication given through an IV, or epidural catheter. Patients control the dose of medication they take, depending on how much is needed to control the pain. PCA is usually used for chronic pain such as that due to cancer.
Physiotherapist:	A rehabilitation specialist who assists individuals in maximizing mobility and restoring strength and body movement.
Power of Attorney:	A power of attorney is a document that appoints a person, called an "attorney," to make financial and legal decisions for another. An enduring power of attorney allows the "attorney" to make the necessary financial and legal decisions for another in case of mental incapacity because of age, accident or illness.
Representation Agreement:	The Representation Agreement Act allows a person to appoint someone as their legal representative to handle financial, legal, personal care and health care decisions, if the appointee is unable to make them on their own. The document is called a representation agreement, and it creates a contract between the person and their representative. There are two types. One is a known as a Section 7 limited agreement – to cover straightforward, everyday decisions. The other is a Section 9 general agreement – to deal with complex legal, personal care and health care matters.

Residential Care Facility:	A residential care facility provides care and supervision for seven or more persons. Residential care homes provide care and supervision for 3-6 persons. Family homes that provide care for 1-2 persons do not require a community care facility licence.
Respite Care:	Services that provide a break, a temporary relief for caregivers. These can be delivered in the home or in a short-stay facility. Respite Care enables caregivers to achieve respite.
Retirement Home:	Is a place of residence where older adults can live independently, with minimal assistance. There are often recreational activities, common areas and other amenities.
Wellness:	A dimension of health that goes beyond the absence of illness, disease and/or disability. It includes social, emotional and spiritual aspects of health that are central to a person's quality of life.

WEBSITES, BOOKS AND VIDEOS OF INTEREST TO FACILITATORS AND VOLUNTEERS

WEBSITES

BC Hospice Palliative Care Association.	www.hospicebc.org
Canadian Hospice Palliative Care Association.	www.chpca.net
Hospice Net (USA).	www.hospicenet.org
National Hospice Palliative Care Organization (USA).	www.nhpco.org
International Association for Hospice & Palliative Care.	www.hospicecare.com
"Virtual Hospice." Interactive network	www.virtualhospice.ca
Griefworks BC. Support for children, teens and adults	www.griefworksbc.com
Vancouver Island Health Authority volunteer resources	www.viha.ca/volunteer_resources/

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24. How, Then, Shall We Live? Muller, Wayne. Bantam, 1996.

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DVD/VIDEO/AUDIO

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Order from: www.soundstrue.com

Death, A Love Story. Michelle LeBrun. Order from: www.docurama.com or www.newvideo.com.

Pioneers of Hospice: Changing the Face of Dying. Madison-Dean Initiative, 2002.
About Dame Cecily Saunders, Elizabeth Kubler Ross, Florence Wald and Balfour Mount.
Order on-line at www.pioneersofhospice.org or call 1-866-293-8200.

Journeys: An Educational Video Describing Hospice Palliative Care. British Columbia Hospice Palliative Care Association. Order form on-line at www.hospicebc.org.
Click on Helpful Resource under Hospice Palliative Care.

My Healing Journey: Seven Years With Cancer. Joseph Vismeg. National Film Board 1998.
Order on line at www.nfb.ca/boutique.

Fanlight Productions. Several videos on Death and Dying and Grief and Recovery.
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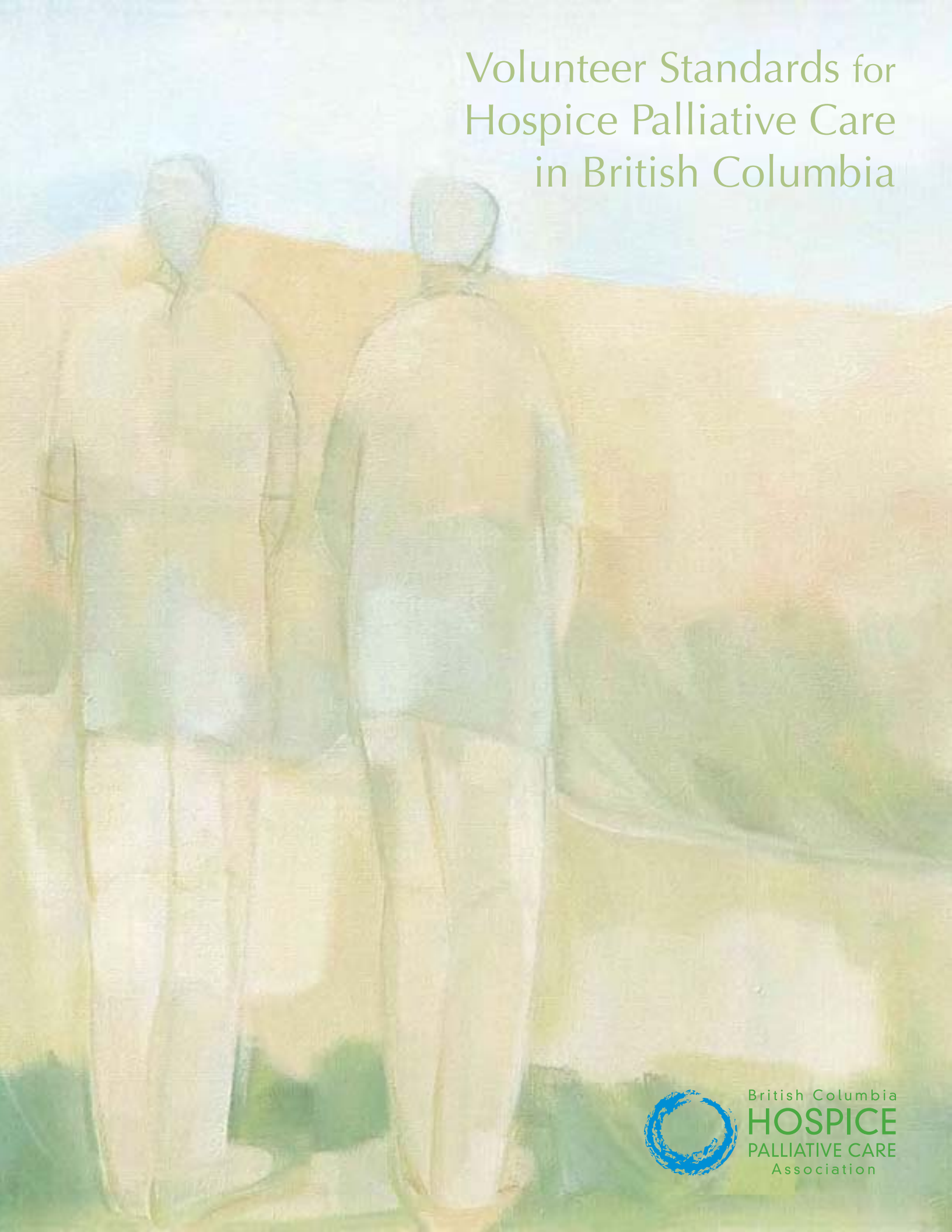
Volunteer Standards for Hospice Palliative Care in British Columbia



British Columbia
HOSPICE
PALLIATIVE CARE
Association

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and

The BCHPCA Steering Committee

Margaret (Meg) Milner, Regional Director – Interior
Sandra Castle, Regional Director – Fraser
Janice Waud Loper

A MESSAGE FROM THE PRESIDENT

The BC Hospice Palliative Care Association is committed to ensuring quality hospice care in BC and the Yukon[1] by providing strategic leadership in the field and by supporting the capacity of the hospice palliative care community in the province. The introduction of these Standards for Volunteer Hospice Palliative Care is a definitive step forward in this endeavour.

Consistent with its values, aims and purposes, BCHPCA is proud to lead the province into a new era of hospice palliative care. The introduction of a shared set of standards will guide the delivery of hospice palliative care into the future and create a new benchmark of performance and credibility. These standards will advance the Association's work by supporting our core values of:

Excellence: These standards will affirm our professionalism, expertise and creativity helping us achieve the best at what we do.

Collaboration: We have developed these standards in a spirit of partnership and teamwork with cooperation and involvement of our membership and colleagues.

Accountability: These standards will help demonstrate that we are accountable, committed and responsive to our members, stakeholders and the people we serve.

Integrity: These standards help to illustrate that we are respectful of the people we serve, that we honour the hospice palliative care network and that we uphold the highest ethical and practice standards.

Diversity: These standards reflect the reality that while we hold ourselves accountable to the highest possible level, we recognise and celebrate the wide-ranging diversity within our membership.

BC has long been a leader in Canada's hospice palliative care movement. We were one of the first provincial associations ever to be established and, in fact, came into being some seven years before the first national association was formed. We continue to be leaders in the country. Of the one hundred and fifty-eight Canadian charities registered under the hospice banner, sixty-five of them are in British Columbia. The BCHPCA is proud to list most of them as members of this Association.

The BCHPCA is a member of the Canadian Hospice Palliative Care Association (CHPCA) and endorses the *Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. This model provides a lexicon of commonly used terms and users of this document are referred to www.chpca.net for further information

A MESSAGE FROM THE PRESIDENT cont'd

These standards have been developed with the full cooperation and generous input from hospice organizations throughout the province. Nearly one hundred individuals participated in focus groups held in every region of the province. We are particularly grateful, however to the dedication and leadership of the BCHPCA Review Committee for overseeing the creation of this document. They are Regional Directors Meg Milner and Sandra Castle, and Janice Waud Loper.

A province-wide survey drew additional input from hospice palliative care stakeholders in nearly every community. The declared support for the introduction of provincial standards for volunteer hospice care was overwhelming. This document is our initial response to that overwhelming support.

Please join with us in celebrating the value of the ongoing and important work of hospice palliative care volunteers throughout British Columbia and the Yukon.

Thank you to all of you who have made this document a reality.

Sincerely,

BCHPCA President

[1.] Wherever BC is referenced it is assumed to include the Yukon.

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION (BCHPCA)

The aims of the BCHPCA include:

- Encouraging the study and promotion of Hospice Palliative Care in British Columbia, through advocacy, public awareness and support of new and developing programs;
- Providing education resources for the establishment and maintenance of institutions and organizations devoted to providing Hospice Palliative Care;
- Promoting recognized standards of Hospice Palliative Care, and;
- Providing a network of communication and shared resources for all those concerned with the care of the dying in British Columbia.

Mission Statement

The British Columbia Hospice Palliative Care Association (BCHPCA) is an umbrella organization whose purpose is to ensure quality of life for all British Columbians affected by life-limiting illness, death, and bereavement. BCHPCA serves its members in British Columbia and the Yukon by:

- Building and supporting the capacity of the hospice and palliative care community, and;
- Providing strategic leadership for, and advocating at all levels as the collective voice of, hospice and palliative care in BC.

In fulfilling this mission, BCHPCA is guided by these Core Values:

Excellence	Our professionalism, expertise and creativity ensure our best at what we do.
Collaboration	We work in partnership and teamwork in a spirit of cooperation and involvement.
Accountability	We are accountable, committed and responsive to our members and stakeholders.
Integrity	We are clear and respectful and uphold the highest ethical standards.
Diversity	We honour and respect diversity.

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Standard One: Competence

As a hospice palliative care volunteer, you feel safe, supported and competent in carrying out your responsibilities.

A. Training: The training you receive is current and comprehensive and supports you at your level of responsibility.

1. Trainers are competent in their ability to design and deliver volunteer training.
2. Your training has prepared you to offer and support a choice of care options for the people you serve.
3. The organization orients their trainers to the BCHPCA volunteer training manual and supports the integration of their own organization's training material into the BCHPCA modules.
4. The organization provides basic volunteer training that includes: a minimum of 30 hours similar to the format and content of the BCHPCA volunteer training manual; the integration of existing and new materials into the BCHPCA training modules.
5. The organization provides ongoing learning opportunities for volunteers. To refresh or advance their knowledge, volunteers are given opportunities to participate in seminars, workshops, courses, etc. throughout the year.
6. Mentorship is considered a valuable support to volunteers and recommended for hospice organizations.
7. Volunteers will have access to resources in a variety of forms including: literature, video, web-based information, etc. Volunteers are supported to participate in informal sessions that provide opportunities for networking, team building and learning.

B. Self-Care: In your work as a hospice palliative care volunteer you understand the importance of self-care and feel secure in the knowledge that personal support is available when you need it.The hospice organization prepares volunteers to support and assist clients and families who are dealing with illness, death and bereavement by:

1. Supporting volunteers to explore their own feelings and behaviour around illness, death and bereavement;
2. Having safeguards in place to support volunteers if a crisis should arise;
3. Making volunteers aware of counsellors, ministers, mentors and resources they may wish to access for support;
4. Providing time for volunteers to process their experiences with a client who has died before being assigned to a new client/family.

C. Ethics: You are confident that you are carrying out your responsibilities within the ethical guide lines of your organization and the setting in which you volunteer. Volunteers are oriented to and understand all ethical guidelines related to hospice palliative care including:

1. Confidentiality and privacy;
2. Boundaries to the relationship between volunteer and client/family;
3. Ethical guidelines specific to each of the settings in which they volunteer.

D. Acknowledgement, Recognition, Experience: You feel valued for the experience you bring and contribution you make to hospice palliative care in your community.

1. The hospice organization promotes the value of the volunteer component within the hospice palliative care team.
2. The organization values the experience and skills of its volunteers by encouraging and supporting them to:
   - be participating members of their hospice palliative care team;
   - share previous and new skills and experience;
   - share ideas for training and resource material.
3. The organization formally acknowledges volunteers, individually and collectively, for the contributions they make to hospice palliative care.

E. Supervision: The supervision you receive is adequate, reassuring and constructive.

1. Staff have the qualifications, experience and ongoing training to effectively supervise volunteers.
2. Volunteer coordinators, supervisors and facility staff encourage volunteers to ask questions and feedback is provided in a constructive way.
3. There is a formal mechanism in place for volunteers to express concerns about their supervision or issues related to their responsibilities.

F. Confirmation/Evaluation: You are reassured that you are volunteering for an organization that continually strives to remain current and improve in all areas of its organization. Formal and informal evaluation of the volunteer program is built into the organization's planning and includes:

1. Volunteer participation in evaluation of the volunteer program;
2. Evaluation of individual volunteers including self-evaluation;
3. Opportunities for palliative care team members to provide feedback to individual volunteers;
4. Supports for volunteers to participate, whenever possible, in evaluation of programs and procedures in the settings where they volunteer;
5. Mechanisms for clients and their families to participate in evaluation of hospice palliative care volunteer programs;
6. Welcoming informal feedback from clients and their families.

G. Governance: The hospice organization for which you volunteer is governed by a competent board of directors. The organization's board members are familiar with and support:

1. The organization's volunteer management plan that includes recruitment, training and support;
2. The hospice palliative care volunteer standards adopted by BCHPCA.

Standard Two: Accessibility

As a hospice palliative care volunteer you are confident that your organization has a reasonable community profile based on a reputable history of quality care.

A. Availability: Hospice services are readily available in the community and are adequately resourced with knowledgeable staff and trained volunteers.

1. Prospective clients and referring agents have reasonable access to accurate information about hospice services.
2. The hospice organization has systems in place to receive and process incoming inquiries and referrals in a timely manner.
3. A reasonable number of volunteers are available and ready for placement proportionate to service demands.
4. The hospice organization for which you volunteer allows you to encourage and support the clients you serve and to advocate on their behalf within the advocacy policy guidelines of the organization.

B. Public Awareness: The hospice organization maintains an ongoing public awareness campaign and keeps other agencies informed about its services and programs.

1. Reasonable resources are applied to an ongoing public awareness campaign including the use of brochures, service notices, public service announcements and other means of promotion.
2. Referral agencies and hospice palliative care partners are kept current on program and service developments.

C. Accommodation: Cultural minorities and marginalized individuals and groups in your community are reasonably accommodated. The hospice organization:

1. Provides for religious and cultural differences in its programs and services;
2. Ensures that volunteers are trained to be sensitive to religious and cultural differences, to those with disabilities and other special needs;
3. Makes provision for multi-lingual or interpretive services where numbers warrant.

Standard Three: Client/Family Perspective

As a hospice palliative care volunteer, you are confident in your ability to respect and respond to the concerns and needs of the clients and families you support.

A. Assessment: You are supported to be involved in and/or receive information about client needs. The hospice organization ensures that:

1. The role of the volunteer in client/family assessment is considered and included;
2. Volunteers receive appropriate information about the clients and/or families they are helping;
3. Volunteers are competent in their ability to participate and respond to the needs of the clients and/or family they are helping.

B. Boundaries: You understand the importance of being attentive to the clients' needs while respecting their individual preferences.

The hospice organization ensures that in their relationships with clients and families, volunteers:

1. Understand and respect the concept of boundaries;
2. Respect the client's and family's need for privacy;
3. Become comfortable just "being with" the client, knowing their role is not to "fix";
4. Are confident in their ability to support the client's family;
5. Have access to training and/or resources on how to support families dealing with illness, grief and loss.

C. Client/family participation: You are able to support full participation of the clients and their families in planning and decision-making around the client's needs.

The hospice organization prepares volunteers to be capable and comfortable in their capacity to:

1. Listen;
2. Hear and respond to feedback from the client and family;
3. Communicate client/family feedback to their supervisors and staff;
4. Acknowledge and support the caregiver's role;
5. Respond to cultural differences and the needs of those clients who are marginalized;
6. Support both children who face life-limiting illnesses and children who are dealing with illness, grief and loss;
7. Share information with client/family about programs, services and resources available to them within and beyond their community and, when required, advocate on their behalf within the advocacy policy guidelines of the hospice organization.

As a hospice palliative care volunteer you participate as a member of an inter-disciplinary team which is focused on meeting the overall care needs of the people you serve.

A. Teamwork: The hospice organization works collaboratively with other service providers to meet the comprehensive needs of the clients you serve.

1. The hospice palliative care team is developed to best meet the needs of client/family within the limitations of available resources including hospice volunteers.
2. The hospice organization is engaged early in the intake process to ensure the best allocation of resources.
3. A common intake process provides easy access for the people being served.

B. Access to Information: The organization with which you work is actively engaged as a member of the case management team and has adequate access to information on the clients to whom you are assigned.

1. While ensuring confidentiality and protection of private information, all members of the hospice palliative care team are provided with theinformation they need to fully meet the needs of those being served.
2. As a hospice palliative care volunteer you are familiar with the requirements for confidentiality and the protection of sensitive information.

C. Communication: Adequate lines of communication exist to allow for the sharing of appropriate information needed to meet the needs of the clients and their families/loved ones.

1. An individualized intake assessment is completed to include the client's personal, medical and service information and the individual's program plans.
2. The hospice organization will support the volunteer in having access to the information needed to provide care at an acceptable level.
3. As a hospice palliative care volunteer you have sufficient information to feel engaged and involved in supporting the people you serve and you have sufficient opportunity to share pertinent information to other members of the care team.

D. Joint Evaluation: The service partners have developed ways to evaluate the combined effects of the services they provide.

1. As a hospice palliative care volunteer you participate in the evaluation of the team's overall effectiveness in meeting the needs of the people you serve.
2. The people being served are given ample opportunity to have their questions answered and to give and receive information.
3. The people being served are provided with an opportunity to share their views on the services they have received or expected to receive.

Standard Five: Safeguards

As a hospice palliative care volunteer, you feel confident that the policies, procedures and practices in place provide you and the people you serve with a blanket of security and safety.

A. Screening: You and your volunteer colleagues have been thoroughly screened and selected based on clearly understood criteria that reflect the needs of the clients you serve.

1. Prospective volunteers are provided with comprehensive information about the organization and the nature and scope of volunteer responsibilities.
2. Answers to the questions of prospective volunteers are readily available.
3. A structured screening process is in place to ensure that volunteers are suited to the hospice environment and are appropriately placed.
4. A probationary period provides both the organization and the volunteer an opportunity to determine whether or not hospice palliative care is the right fit for the volunteer.
5. The recruitment, screening and selection process is positive and affirming for all concerned.

B. Confidentiality: Your personal information and that of your clients and their families is adequately protected by a written confidentiality policy that is easily shared and understood.

1. Confidential information is shared only on a need-to-know basis and even then information is released only with informed consent.
2. Confidential information is stored in a secure manner and is retained only for the required period of retention before being securely destroyed.

C. Scope: You fully understand the scope of your role as a hospice palliative care volunteer and are familiar with the limitations of your involvement.

1. As a hospice palliative care volunteer you have confidence that your training has prepared you for what you are required to do and has informed you about what you are not to do.
2. You know whom to contact if you are in doubt about how to respond to certain situations and any guidance you might require is reasonably available when you need it.
3. The lines of communication are clearly established between you and other members of the hospice palliative care team.
4. The hospice organization ensures that staff within all settings are made aware of the volunteers' roles and the limitations of their involvement.

D. Safety: Adequate measures are in place to provide for the physical and emotional safety for you and the people you serve in whichever setting you are engaged.

1. As a hospice palliative care volunteer you have ready access to supervision and support as required.
2. If a mentor program is in place, you have frequent contact with your mentor with whom you enjoy a positive and supportive relationship.
3. A report mechanism is in place for incidents of harassment or abuse.
4. You have ready access to written policies and procedures designed to protect the people you serve from physical and other hazards.

E. Risk Management: The organization for which you volunteer has adopted risk management policies and practices which protect you and the people you serve.

1. The hospice organization for which you volunteer has written policies and procedures in place to identify, prevent and reduce the incidents and impact of risk from a variety of sources.
2. You are made aware of those risks which are tolerable and those which must be either eliminated or assumed by another agency or organization.

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