



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Hospice Palliative Care Volunteers: A Training Program

2012

Hospice Palliative Care Volunteers: A Training Program

2012

Reproduction

Permission to reproduce and distribute this document for non - commercial educational purposes is granted when the attribution statement is displayed (as below). For any other uses, please contact the national office of the Canadian Hospice Palliative Care Association.

Attribution/Citation Statement

Training Manual for Hospice Palliative Care Volunteers. Ottawa, ON: Canadian Hospice Palliative Care Association, 2012.

© 2012 Canadian Hospice Palliative Care Association. All Rights Reserved.

Canadian Hospice Palliative Care Association

Annex D, Saint - Vincent Hospital, 60 Cambridge Street North
Ottawa, Ontario K1R 7A5

Tel: (613) 241 - 3663 or 1 - 800 - 668 - 2785; Fax: (613) 241 - 3986

Email: info@chpca.net Website: www.chpca.net

Acknowledgements

Production of this Training Manual for Hospice Palliative Care Volunteers has been made possible through a financial contribution from Rx&D: Canada's Research-based Pharmaceutical Companies and The Grand Priory in Canada of the Order of St Lazarus.

Project Advisory Committee

David Pike, Volunteer Issues Committee member and Agape Hospice, Hillcrest Nursing Home and Homecare Volunteer, Calgary, AB

Linda Callard, Volunteer Issues Committee member, Chair, Queens Advisor Chapter: HPCA of PEI, Mermaid, PE

Rick Firth, Volunteer Issues Committee member, Executive Director, Hospice Palliative Care Ontario, Toronto, ON

Stephen Claxton-Oldfield, Volunteer Issues Committee member, Associate Professor, Department of Psychology, Mount Allison University, Sackville, NB

Joan Williams, Volunteer Issues Committee member, Executive Director, Hospice Northwest, Thunder Bay, ON

Author

Jean Bacon, Consultant, Toronto, ON

Project Coordination

Sharon Baxter, Canadian Hospice Palliative Care Association, Ottawa, ON

Cheryl Spencer, Canadian Hospice Palliative Care Association, Ottawa, ON

TABLE OF CONTENTS

MODULE 1: INTRODUCTION TO HOSPICE PALLIATIVE CARE AND THE ROLE OF THE VOLUNTEER .	7
<i>Learning objectives:</i>	7
<i>Competencies:</i>	7
1. <i>The Philosophy and Goals of Hospice Palliative Care</i>	8
2. <i>Principles Guiding Hospice Palliative Care</i>	11
3. <i>The Hospice Palliative Care Team</i>	12
4. <i>The Role of the Volunteer on the Team</i>	16
5. <i>Who Makes a Good Hospice Palliative Care Volunteer?</i>	18
6. <i>Understanding the Boundaries or Limits of the Volunteer's Role</i>	19
7. <i>The Responsibilities of the Organization and the Volunteer</i>	21
8. <i>Information about (Name of Organization)</i>	22
MODULE 2: EFFECTIVE COMMUNICATION SKILLS	23
<i>Learning objectives:</i>	23
<i>Competencies:</i>	23
1. <i>What is Effective Communication?</i>	24
2. <i>Barriers to Communication</i>	25
3. <i>Active Listening and Empathy</i>	26
4. <i>When there's a Physical Barrier to Communication</i>	30
5. <i>Privacy and Confidentiality</i>	35
MODULE 3: FAMILY AND FAMILY DYNAMICS	37
<i>Learning objectives:</i>	37
<i>Competencies:</i>	37
1. <i>What is Family?</i>	38
2. <i>The Family's Role in Hospice Palliative Care</i>	38
3. <i>When Families Don't Work</i>	39
4. <i>The Volunteer's Role with the Family</i>	40
MODULE 4: EMOTIONAL/PSYCHOLOGICAL ISSUES AND SUPPORT	43
<i>Learning objectives:</i>	43
<i>Competencies:</i>	43
1. <i>What is a Good Death?</i>	44
2. <i>The Emotional/Psychological Needs of the Dying Person</i>	44
3. <i>The Volunteer's Role in Emotional Support</i>	48
4. <i>The Volunteer's Attitudes and Beliefs about Death and Dying</i>	49
5. <i>The Role of Culture and Spiritual Beliefs</i>	49
MODULE 5: SPIRITUAL ISSUES AND SUPPORT.....	52
<i>Learning objectives:</i>	52
<i>Competencies:</i>	52
1. <i>What is Spirituality?</i>	53
2. <i>Spirituality at End of Life</i>	53
3. <i>The Volunteer's Role in Spiritual Care</i>	54
MODULE 6: PHYSICAL ISSUES AND SUPPORT, INCLUDING PAIN AND SYMPTOM MANAGEMENT..	69
<i>Learning objectives:</i>	69
<i>Competencies:</i>	69
1. <i>What are the Physical Needs of People who are Dying?</i>	70
2. <i>Symptoms at End of Life</i>	71
3. <i>Managing Pain</i>	73
4. <i>Managing Other Symptoms</i>	75
5. <i>Signs that Someone is Nearing Death</i>	81
6. <i>The Importance of Infection Control</i>	85

MODULE 7: CARING FOR PEOPLE AT HOME OR IN A HOSPICE.....	87
<i>Learning objectives:</i>	87
<i>Competencies:</i>	87
1. <i>What's Different about Volunteering in Someone's Home or a Hospice?</i>	88
2. <i>The Importance of Food and the Impact of Loss of Appetite</i>	88
3. <i>Body Mechanics, Lifts and Transfers</i>	90
MODULE 8: GRIEF AND BEREAVEMENT	93
<i>Learning objectives:</i>	93
<i>Competencies:</i>	93
1. <i>What is Grief and Bereavement?</i>	94
2. <i>Stages in the Normal Grief Process</i>	97
3. <i>Promoting Health and Well-Being for People who are Grieving</i>	99
4. <i>What is Complicated Grief?</i>	100
5. <i>Helping Children Cope with Grief</i>	103
6. <i>Helping Older People Cope with Grief</i>	104
MODULE 9: SELF CARE	105
<i>Learning objectives:</i>	105
<i>Competencies:</i>	105
1. <i>What is Stress?</i>	106
2. <i>The Stresses of Being a Hospice Palliative Care Volunteer</i>	107
3. <i>Strategies to Manage Stress</i>	108
<i>The Volunteer Self-Care Kit</i>	110

Module I: Introduction to Hospice Palliative Care and The Role of the Volunteer

Learning objectives:

1. Understand the philosophy and goals of hospice palliative care
 2. Understand the role of the volunteer on the hospice palliative care team
 3. Understand the limits of the volunteer's role
 4. Understand how the organization where they are volunteering is structured
 5. Understand the relationship between hospice palliative care and other services
-

Competencies:

At the end of module one, volunteers will be able to:

- Define hospice, palliative and end-of-life care
- Describe the philosophy and goals of hospice palliative care
- Describe the interdisciplinary hospice palliative care team and the role of different members, including the role of the volunteer
- Recognize their rights and responsibilities as a volunteer
- Define the boundaries of the volunteer role
- Understand the structure of the organization where they are volunteering and its link to other services in the community.

1. The Philosophy and Goals of Hospice Palliative Care

What is Hospice Palliative Care?

Hospice palliative care aims to relieve suffering and improve the quality of living and dying by helping people with life-limiting and terminal illnesses live as comfortably and fully as possible.

Hospice palliative care recognizes dying as a normal part of living. The focus is on caring, not curing and on life, not death. The goal is to reduce symptoms and distress, and provide comfort and support.

Hospice palliative care neither hastens nor postpones death.

Hospice palliative care is for the person him or herself. It is also for family members and friends, helping them care for their loved one and for themselves during times of grief.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues as well as their expectations, needs, hopes and fears
- prepare for and manage the dying process
- cope with loss and grief during illness and bereavement.

Hospice palliative care uses a team approach to care and is only provided when the person and/or family is prepared to accept it.

While hospice palliative care is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life, individual organizations may use **“hospice”, “palliative,” or “end of life” care** – although end-of-life care usually focuses on the last few weeks or months of life while hospice palliative care focuses on the needs of anyone diagnosed with a life-limiting illness.

Hospice palliative care focuses on six aspects of care:

- Quality of life
- Pain and symptom control
- Comfort and support for the person and family
- Awareness of the psychological, social and spiritual sides of life
- Open communication between the person/family and the care team

What is the Difference between Hospice Palliative Care and Curative Care?

Curative care focuses on helping someone recover from an illness by providing active treatment.

Hospice palliative care focuses on providing comfort, reducing symptoms and distress, and providing opportunities for meaningful experiences, personal and spiritual growth, and self-actualization. Hospice palliative care takes a positive open approach to death and dying, and encourages discussions among the person, family and care team about death and dying, and their wishes for their care at end of life.

Hospice palliative care can be provided on its own or, in some cases, with curative care. For example, a patient may be receiving hospice palliative care for cancer while, at the same time, receiving curative care for a respiratory infection.

Where is Hospice Palliative Care Provided?

Hospice palliative care should be available in any setting where people die, including at home, in hospices, in hospital, in long-term and chronic care settings, in shelters and in prisons.

When Should Hospice Palliative Care be Provided?

The decision about when to start hospice palliative care is made by the person and family in consultation with the care team. Under many provincial health plans, people must have a diagnosis of having six or fewer months to live to be eligible for hospice palliative care services. In reality, it is difficult to make those estimates. In some cases, the health care system continues with curative care only for so long that the person doesn't have an opportunity to benefit from hospice palliative or end-of-life care. That is why there is a growing trend to provide both hospice palliative and curative care together, and to offer certain aspects of hospice

The History/Origins of "Hospice Palliative Care"

Dame Cecily Saunders, physician and founder of St. Christopher's House Hospice in London, England, is credited with launching the modern hospice movement. During the late 1960s and early 1970s, Dame Cecily pioneered an approach to caring for the dying that focused on symptom and pain control and not on curing the underlying terminal illness. As a medical teacher, she lectured health care providers at leading universities and their affiliated teaching hospitals in both North America and Europe.

In 1975, Balfour Mount coined the term "palliative care" when he brought the movement to Canada, so that one term would be acceptable in both English and French. Both hospice and palliative care movements have flourished in Canada and internationally. Palliative care programs developed primarily within larger healthcare institutions, while hospice care developed within the community

palliative care, such as advanced care planning and psychological and spiritual support, to anyone diagnosed with a life-limiting illness.

How do People Access Hospice Palliative Care?

People are usually referred to hospice palliative care by their physician or other care provider. They are then assessed to see if the service meets their needs and told about the options available to them.

2. Principles Guiding Hospice Palliative Care

Patient/Family Focused Care. The patient's and his/her caregivers' and family's needs and wishes guide decision-making and care planning. Their personal, cultural and religious values, beliefs and practices are respected. All aspects of care are sensitive to their preparedness to deal with the dying process. Care is guided by quality of life as defined by the person who is dying. Members of the care team enter into a therapeutic relationship with the patient and family based on dignity and integrity, and work with the strengths and limitations of the person and family. They act with compassion towards the person and family, and provide the care, information and support they need.

“Family” includes whoever the dying person considers family. Other terms used include: important ones, loved ones and family of choice.

Quality Care. All hospice palliative care activities are based on nationally accepted principles and norms of practice and standards of professional conduct. Members of the care team are trained and qualified to fulfill their roles. Policies and procedures are based on the best available evidence, and the care team receives ongoing education to ensure quality care.

Comprehensiveness and Coordination. The physical, psychosocial, spiritual and practical needs of the person and caregivers/family are assessed – initially and on an ongoing basis -- and strategies developed to meet those needs. Care is coordinated to minimize the burden on the person and his/her caregivers and family, and to make effective use of resources. Members of the care team share information to provide the best possible care.

Safe and Effective Care. All hospice palliative care activities are conducted in a way that is safe, collaborative, accountable and effective, and ensures confidentiality and privacy for the person and his/her caregivers and family.

Accessibility. All Canadians have equal access to timely hospice palliative care based on need.

Advocacy. The care team – including volunteers – advocates for the needs of the person and family and for high quality hospice palliative care in their communities.

Self Care. Members of the care team reflect on their practice and identify and apply strategies for self care.

3. The Hospice Palliative Care Team

Hospice palliative care is most effective when delivered by an interdisciplinary team. Members of the team:

- Work together to achieve common goals
- Are committed to the persons' and family's goals, and to other team members
- Share a set of values and beliefs about what they are doing and why
- Understand their roles, responsibilities and structures
- Know where they fit in the team and how their roles work with those of other team members
- Share relevant information
- Do the jobs and tasks they agreed to perform.¹

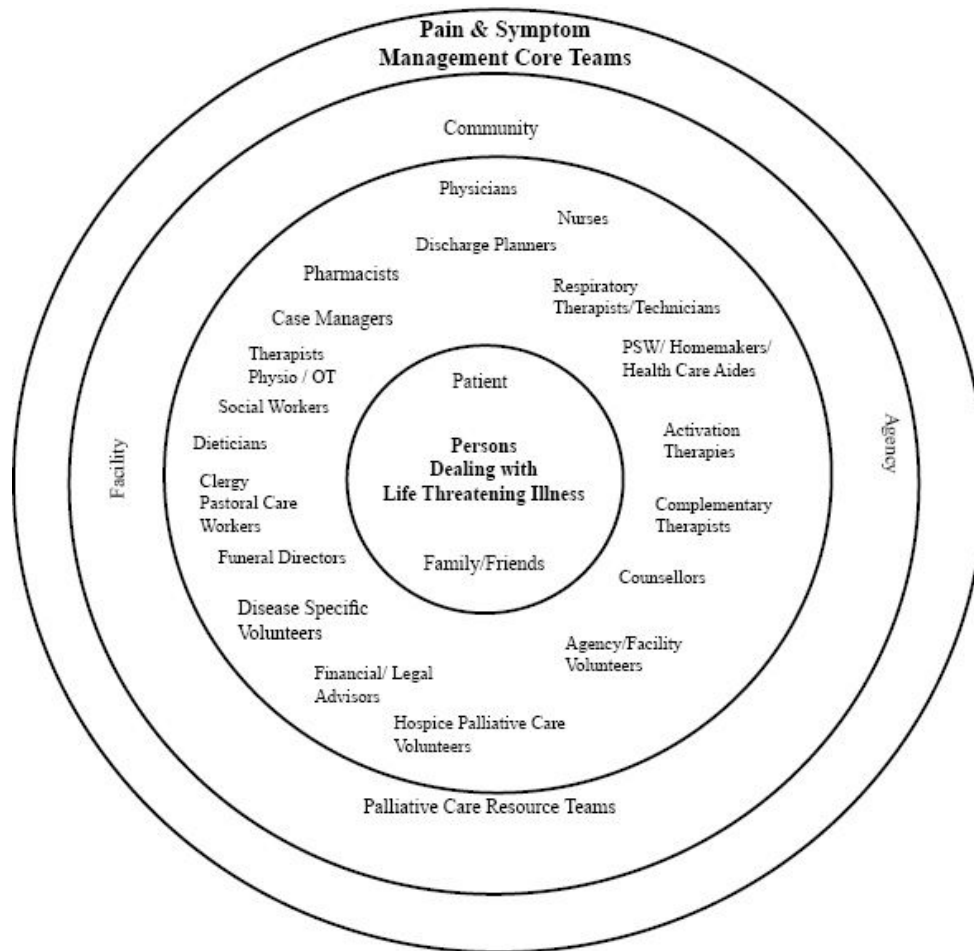
Roles and Responsibilities

Each person on the team provides care according to his or her different professional scope of practice and/or job description, and is expected to meet the standards set by his or her profession or discipline. Some roles can overlap, and each team may be different, depending on the person's and family's needs.

The following is a brief description of the roles of different team members². NOTE: all teams will not necessarily involve all these individuals and skills.

¹Gallasch P. (1996). Volunteer Training Manual. National Palliative Care Project (Australia).

² Based on: Core Concepts in Hospice Palliative Care, Module II – Self Awareness & Communication, Dr. Bob Kemp Hospice, Stoney Creek, ON, 2000



The Person who is Dying. The dying person is at the centre of the team, guiding and directing his or her care as much as possible.

Family Members. Family members are with the dying person at the centre of the team, helping to guide and direct care, and making decisions for the person if he/she is not able to do so.

Informal Caregivers. Family members – along with friends, neighbours, co-workers and members of the person’s faith community – are often informal caregivers. They play a key role on the person’s care team and they may also need care and support themselves to fulfill that role.

Case Manager. The Case Manager, in consultation with the person and family, develops a plan of care. He/she initiates services, orders supplies and equipment, and responds to changing client and caregiver conditions and needs.

Family Physician. The Family Physician coordinates the person’s medical care and offers a listening ear and compassionate response. The Family Physician is responsible for discussing advance directives with the person and family. At the time of death,

he/she attends to the certification of death, facilitates the transfer of the deceased and provides support to the bereaved family.

Nurse. The nurse works with the person and family to assess needs and establish goals related to coping, comfort and the effects of decreased mobility or weakness. The nurse plans, implements and evaluates nursing interventions and performs delegated medical acts such as those related to medications, wound care, catheters and suctioning. He/she also advocates for the dying person and fosters his/her autonomy.

Personal Support Worker. The Personal Support Worker assists with activities of daily living such as personal care (bathing and toileting) and observes and reports changes in physical symptoms and emotional responses of the person and family to the case manager, nurse and/or doctor. He/she may also provide some light housekeeping, laundry, shopping and respite services.

Volunteer. The volunteer provides companionship and emotional support as well as encouragement, comfort and practical assistance for the dying person and family members. (See next section, *The Role of the Volunteer on the Team* for more detail.)

Spiritual Advisor. The Spiritual Advisor assesses the person's and family's spiritual needs and supports their search for meaning and hope in changing circumstances. He/she provides opportunities for meaningful rituals, prayer and meditation, and may provide counseling. He/she assists clients and families with funerals and memorial services. If the person and family follow a particular faith, the Spiritual Advisor liaises with the faith leader (priest, rabbi, Imam) if directed to do so by the person and family.

Social Worker. The Social Worker assesses the psychosocial needs of the client and family. This includes exploring the emotional basis for intractable pain. He/she assists other team members with interactions with the person and family, and provides the person and family with individual, marital and family counseling if necessary. The Social Worker assists with practical matters: finances, wills, powers of attorney and funeral planning. The Social Worker also provides bereavement support.

Pain and Symptom Management Program Director. The Pain and Symptom Management Program Director provides telephone consultation support for team members and gives clients and families information about hospice palliative care and pain and symptom management. He/she advocates for clients in need of pain and symptom management and assists in developing local hospice palliative care and pain and symptom management expertise.

Palliative Care Physician. The Palliative Care Physician is a medical advisor or consultant to the other members of team. He/she has in-depth knowledge of all aspects of care of the dying and family, particularly pain and symptom control, client and family support, community resources and ethics. In most cases, the palliative care physician works with but does not replace the family physician.

Pharmacist. The Pharmacist prepares, dispenses and distributes medications and completes a medication assessment and pharmacy care plan.

Dietician. The Dietician assesses the dying person's nutritional status and develops a nutritional care plan that meets his or her changing needs.

Naturopathic Doctors.

Occupational Therapist. The Occupational Therapist helps the person maintain quality of life by enabling him/her to achieve his/her goals related to daily activity in self-care, productivity and leisure.

Physiotherapist. The Physiotherapist provides pain management, improves mobility, and helps with respiratory function and maintenance of skin integrity and wound management.

Respiratory Therapist. The Respiratory Therapist develops a plan to address difficulties with breathing and to optimize comfort. He/she is also responsible for educating clients and families and other team members regarding the operation, maintenance and precautions of equipment.

Speech-Language Pathologist. The Speech-Language Pathologist assesses the person's communication and swallowing needs and develops a plan to meet his or her changing needs.

Complementary and Alternative Medicine Therapist. Complementary and Alternative Medicine Therapists may be involved in helping the dying person to manage symptoms and providing services to caregivers. Alternate therapies may include: massage, aromatherapy, reflexology, Reiki pet therapy, music therapy and art therapy.

4. The Role of the Volunteer on the Team

Volunteers are members of the care team. They participate in team and case management meetings as required, communicate any concerns to other members of the team, and document information as required. The volunteer is in a unique position to connect with the person and family – to be seen as a peer and as more accessible than other members of the team. This means that people who are dying and their families may sometimes share information with a volunteer that they haven't shared with other members of the team, and the volunteer can help communicate their needs to the rest of the team. The main roles of the volunteer are:

Companionship and emotional support. Volunteers provide companionship and emotional support – talking and listening to the person and family, and just “being there” and sitting with the person. Volunteers allow the dying person to express their feelings (e.g. fear, anger, love, hope) and facilitate communication.

Comfort. Volunteers help to comfort the dying person by, for example, brushing their hair, massaging their feet and legs, and holding their hand.

Encouragement. Volunteers encourage the person to pursue their interests. They promote their health and well-being.

Practical assistance. Volunteers help with practical tasks, such as running errands or transporting the person to and from appointments.

Informational support. Volunteers act as a link or liaison between the person/family and the medical staff.

Respite care. Volunteers provide relief for the family or other caregivers, allowing them to take some time out. They also provide loss and grief support.

Spiritual/religious supports. If the person or family requests it, the volunteer can provide spiritual support by, for example, praying with the family or reading from sacred writings.

Grief and bereavement support. Volunteers help the person and particularly family members by providing support with grief and bereavement.

What Volunteer Services do Families Value Most?

- The opportunity to take a much needed break from the demands of caring for their loved one
- Emotional support
- The volunteer spending time with them
- The volunteer providing information

(Claxton-Oldfield et al, 2010)

Advocacy. Volunteers are advocates for hospice palliative care in their communities. Because they are knowledgeable about hospice palliative care, they can let people know that services are available. They can also encourage community action that supports hospice palliative care, such as public discussions or cafés on death, dying, grief and loss, education sessions about the benefits of hospice palliative care for people who are dying and their families, and more services for friends and families who are caring for someone who is dying.

Some programs have “professional service” volunteers: hairdressers, accountants, computer programmers and complementary therapists (e.g. massage, reflexology, Reiki, aromatherapy) who donate their services to the dying person or family. Some programs also recruit volunteers for administrative roles, such as working in the office, serving on the Board or helping with fundraising.

5. Who Makes a Good Hospice Palliative Care Volunteer?

Researchers have identified the characteristics of people who are good hospice palliative care volunteers (Claxton-Oldfield and Banzen, 2010). Effective volunteers are:

Good Listeners. They are comfortable with silence and they are active listeners and good communicators.

Empathetic. They feel compassion and concern for others.

Extroverted. They tend to be sociable, talkative, warm and friendly.

Agreeable. They are altruistic and trustworthy, and sympathetic to others.

Open and Nonjudgmental. They are cheerful and upbeat, nonjudgmental and flexible. They have a good sense of humour and are open to new experiences.

Culturally Sensitive. They understand the importance of culture in how people perceive and cope with dying. They are aware of cultural differences and respectful of each person's cultural beliefs and traditions.

Trustworthy. They are dependable and respect the person's and family's right to privacy and confidentiality.

They are calm in stressful situations, at ease – or at least comfortable – with death and dying, and able to cope with the demands of caring for the dying and supporting the bereaved.

The goal for most hospice palliative care programs is to have a range of volunteers – women and men, youth and older, different cultures – who are as diverse as the people at end of life and their families and who can relate well to them.

6. Understanding the Boundaries or Limits of the Volunteer's Role

In their role, volunteers often become very attached to the dying person and his/her family, who also come to rely on the volunteer.

Volunteers must walk a fine line between being a person's/family's friend and being a member of a care team that is accountable for their conduct, practice and quality of care. In the course of their work, volunteers may find themselves in situations that test the boundaries of their role. For example:

- What if the person or family offers the volunteer a gift or some money?
- What does the volunteer do when the person is uncomfortable and asks for more pain medication?
- What if the person tells the volunteer something about his or her health or care, and then asks the volunteer not to tell the family members or other members of the care team?

The hospice palliative care organization will have policies about what volunteers should and should not do. The following "dos" and "don'ts" were identified in surveys with hospice palliative care volunteers (Claxton-Oldfield et al, 2011). As you can see, in some cases the volunteer's boundaries are quite clear while others involve more judgment.

Do Not:

- Accept money from a patient or family
- Lend money to a patient or family
- Do the person's banking
- Agree to be a person's power of attorney
- Agree to witness a patient's will
- Share personal information about previous personal experiences with the deaths of other patients
- Discuss a patient's diagnosis or prognosis with other family members
- Discuss or talk about a patient or family with others in the community
- Provide medical care (e.g. give medications) to a patient who is uncomfortable
- Discuss assisted suicide with a patient
- Gossip about other members of the care team

- Preach, proselytize or attempt to save or convert a patient to the volunteer's particular religious beliefs
- Counsel or advise the person or family member
- Become romantically involved with anyone in the household.

Think Twice About:

- Buying a gift for a patient or family member
- Lending things to the person or family
- Sharing personal information about one's self that is unrelated to previous experiences with death and dying
- Giving a business card to a patient or family
- Inviting a patient or family to join in an activity or party outside the volunteer assignment
- Breaking down emotionally in front of a patient or family (It's okay to be human but the patient and family should not be comforting the volunteer.)
- Attending a patient's medical appointment
- Providing opinions or advice to a patient/family.

Be Aware of Any Possible Harm in:

- Sharing personal information about a previous personal experience with a loved one's death and dying
- Giving one's phone number to a patient or family member
- Staying with a patient/family for longer than the agreed time
- Accepting an invitation from a patient/family to a family activity/party
- Doing jobs around the patient's home
- Providing clothes, toys or meals to a patient/family
- Continuing to visit with a family after a patient's death.

When in doubt, check your organization's policies or ask your volunteer coordinator for advice.

7. The Responsibilities of the Organization and the Volunteer

Responsibilities and Expectations of the Organization

To support volunteers in their role, the organization will:

- Treat volunteers as valued members of the care team, and treat all volunteers fairly
- Have up-to-date volunteer policies and procedures
- Provide an orientation to the organization as well as initial and ongoing training
- Give volunteers meaningful assignments that make good use of their knowledge and skills
- Ensure volunteers have the information and support to fulfill their assignments
- Have a volunteer coordinator or someone else designated and available to answer questions or talk about issues
- Provide appropriate constructive supervision and feedback
- Recognize volunteers for their contribution
- Organize events to help volunteers deal with loss and take care of themselves (e.g. annual memorial service, retreats).

Responsibilities and Expectations of the Volunteer

To fulfill their roles, volunteers are expected to:

- Commit enough time
- Be dependable and flexible
- Participate in team meetings and work as part of a team
- Complete all required training and demonstrate they have achieved the desired competencies
- Be open to supervision and feedback
- Adhere to the organization's policies (e.g. confidentiality).

Rights of Volunteers

Volunteers are not paid staff. They are giving the hospice palliative care program the gift of their time and skills. Volunteers have the right to refuse assignments and should not feel guilty if, for some reason, they are not able to take on or complete an assignment.

8. Information about (Name of Organization)

Insert information about:

- the organization
- its structure
- where the volunteers fit in that structure
- all information the volunteer needs to know to function within the organization
- the organization's links with other services
- any other relevant information

Module 2: Effective Communication Skills

Learning objectives:

1. Understand the importance of communication, different means to communicate with patients, families and team members, and the barriers to communication
 2. Develop active listening skills
 3. Appreciate the value and uses of silence
 4. Reflect on own communication style and strategies to improve communication
 5. Understand the volunteer's responsibility to protect the patient's and family's confidentiality and privacy
-

Competencies:

At the end of module two, volunteers will be able to:

- Define the basic principles and purposes of communication in hospice palliative care
- Describe what enhances or interferes with communication
- Describe and practice different means of communicating with patients and families, including listening and empathy, silence and being present, and humour and laughter (when appropriate)
- Communicate effectively with other members of the care team
- Identify effective communication strategies to support clients and families, and to cope with difficult situations
- Describe and implement practices to ensure the patient's and family's confidentiality and privacy.

1. What is Effective Communication?

As a hospice palliative care volunteer, communication is central to your role. Being there to help individuals and families discuss their fears and share their feelings is one of the most precious gifts you can offer. Your conversations and shared moments have the potential to help patients and families:

- Feel less isolated
- Cope better with fears and concerns
- Find a sense of meaning.

When we talk, more than 80% of the “message” is in how we say it, not what we say.

You also have to be able to express yourself well to communicate with the person, the family and other members of the care team.

The word communication comes from the root "common". To communicate effectively, people must speak a "common" language of words and body language. They must be able to listen, and to know when to speak and when to be silent.

As a volunteer, your goal is to develop the skills, perspective and energy to accept 100% of the responsibility for communication: for understanding what the other person is saying to you and for ensuring the other person understands what you are saying. To do that, you do not have to be an expert on all the mysteries of life and death. You simply need to be honest, open and non-judgmental in your conversations and develop a sense of trust with the person, family and other members of the care team.

Be available and “present”
Give your undivided attention
Listen without interruption and with empathy

Think about the way you communicate. Are you comfortable being silent? Do you ask open-ended questions that encourage people to talk? Do you give people time to answer? Are you an active listener?

2. Barriers to Communication

There are five key barriers to communication in a hospice palliative care situation:

1. **Poor listening skills.** If people feel they are not being listened to, then there is no communication.
2. **Stress.** People often do not communicate well when they are in a crisis situation. If they are feeling ill or in pain, their attention may be focused inward and they may not hear what is said to them.
3. **Language and culture.** Culture affects the way individuals and families communicate. Words and gestures can mean different things to people from different cultures. For example, eye contact is an important part of Anglo-European cultures but in other cultures it can be disrespectful. Language can also be a barrier, particularly when people don't understand one another's language or have to speak through an interpreter who may not convey the full intent of what was said.
4. **Intense feelings.** When people are emotional, they are more likely to mishear or misunderstand, and less likely to speak clearly themselves.
5. **Lack of information and secrecy.** If information is being kept from some people, then communications can become confused.

Five Tips for Effective Communication

1. To get a conversation started, **ask open-ended questions** that cannot be answered by "yes" or "no". Give the client and/or family member some time to respond and listen actively. It may take time before the person decides to trust you or how much he or she wants to say.
2. **Be comfortable with pauses** in the conversation. Pauses may mean that the client is thinking about something sensitive or is tired. Let the silence last. Do not rush in to fill the void.
3. **Be yourself.** Don't try to be a social worker, counsellor or therapist. Encourage clients to share stories about their lives and don't be afraid to respond with humour. Laughter is "the best medicine" and an important way of coping with threats and fears.
4. **Try not to give advice.** Instead, reflect the person's own thoughts back to him or her. This can help the person look at the situation in a new way.
5. **When you don't know what to say or do, say or do nothing.** Being there and honestly saying you don't know the answer is more supportive than pat answers. However, if a patient or family members asks for information about services or resources and you don't know the answer, contact the hospice palliative care program.

3. Active Listening and Empathy

The first step in communication is listening to one another. Without listening there is little communication, and without communication there is little love. Each of us needs desperately to be listened to and to be loved by another who can listen to us and love us just as we are.³

Most people would say they are good communicators but, for many, that means being a good “talker”. In hospice palliative care, it’s important to know when to talk and when to listen. The main role of the volunteer is to be a “listener”.

Real or active listening is a difficult and demanding discipline that requires energy and concentration. It involves paying attention to the person's total message, both what’s said (the verbal messages) and what isn’t said (the non-verbal messages). Active listening is open and objective, and does not judge or evaluate. The listener must make an effort not to just hear what he or she wants to hear. Instead, he or she must focus on the other person's needs.

Here are some guidelines for active listening:

Clear your mind. To really focus on the person, you need to keep your own thoughts from wandering.

Be silent. Silence is more than staying quiet or not interrupting when someone is speaking. Before you start to talk, pause to allow the speaker to catch his/her breath or gather his/her thoughts. He/she may want to continue. This short break gives you time to form your response and helps you avoid the biggest barrier to listening: listening with your answer running. If you are making up a response before the person is finished, you miss the end of the message that often contains the main point. At the same time, use common sense. For example, pausing for several seconds when someone has asked for assistance with moving may be inappropriate.

Make eye contact. Try to be at eye level with the client. If your client is in bed or sitting down, do not stand over them while you talk. Make eye contact – it demonstrates interest and attention. Whether or not you look directly at the client

If we do not listen to the needs of others, how can we possibly know what those needs are? If we project our views on them, we are satisfying our own needs.

Not every person who is dying experiences peace and/or acceptance. However, your visits will go a long way to helping the person reach this goal if you are able to offer compassion, love and acceptance.

³Buckman R. (2001).Communication skills in palliative care: a practical guide. NeurolClin. Nov;19(4):989-1004.

depends on the client's comfort level. Cultural considerations come into play. In most cases, looking at the other person while he/she speaks demonstrates your attention and helps keep your mind from wandering. Sit beside a person at a 45-degree angle, if possible, to allow him or her to break eye contact with you if they wish. If appropriate, go for walks with the person who will stop and look at you when he or she wants to make eye contact.

Relax and be open. You can communicate openness with facial expressions and body positions. Uncross your arms. Sit comfortably and informally. Sit beside the person (sitting right in front of them may be intimidating) and remove any physical barriers, such as a pile of books. Watch your non-verbal responses. A look of boredom or disapproval on your face can keep the other person from finishing what he or she wants to say.

Be compassionate. Someone who is dying will experience a variety of emotions. Sometimes the person may be angry or frustrated and direct that anger toward the people around them. Try to respond with understanding and compassion. Keep in mind that the anger is not personal. It is part of the response to the illness. Encourage them to express their fears and concerns; this will help them know that you understand their thoughts and feelings and are willing to journey with them.

Listen without interruption. Let the person lead the conversation. If he or she wants to recount favorite stories - even if you've heard them several times before - listen with enthusiasm. Note key words or phrases as the person talks so you can respond when it's your turn.

Your presence, not your words, mean the most. There is no magic formula, no magic words. Just being present for that moment will go a long way to helping the person heal, if not physically, then at least emotionally.

Listen for more than the words. Observe the way the person talks - the inflection in the voice, his or her enthusiasm or lack of it. Watch facial expressions and be aware of body language. All of these are essential parts of the message and conversation.

Send acknowledgements. Let the speaker know you are still there and interested by nodding your head or saying things like "Uh uh" and "OK".

Use touch -- but only with permission. Communication through touch can be very effective. Holding a person's hand or giving a comforting pat on the arm can mean a great deal to someone fighting fear and loneliness. However you must ask permission first. It can be as simple as asking the person if you may hold his/her hand or "give them a hug". It is essential to obtain this "consent" from the client and/or family member before touching.

Eight Strategies for Learning to Listen

- 1) We cannot listen until we stop talking.
- 2) Be silent in an active way. Be open and active, receptive and alive. Keep your mind from wandering. Your body language and eye contact will reveal how attentive you are.
- 3) Be patient. Sometimes it takes time for someone to reveal him or her self to you. We often have to listen to people's more superficial concerns before we are allowed into the deeper levels of the human soul.
- 4) Talking about deep feelings requires privacy and time.
- 5) There are no quick and easy answers. Simply respond, reflect and express understanding and empathy.
- 6) Listening is a skill that can be learned, but it requires practice and it sometimes involves sharing ourselves.
- 7) We will only hear from others when they know that we can and will keep their confidence.
- 8) Whenever you find yourself arguing or interrupting, recognize that it is usually because the conversation has hit a sensitive spot. But arguing will shut down communication.

Don't be afraid of tears. Tears help heal, and bottling up one's emotions is unhealthy. When the person is crying, you don't have to say anything; you can just hold the person's hand.

Listen

When I ask you to listen to me and you start giving advice
you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you are
trampling on my feelings.

When I ask you to listen to me and you feel you have to do something to solve my problem, you
have failed me, strange as that may seem.

Listen! All I asked was that you listen.

Not talk or do - just hear me.

Advice is cheap. 50 cents will get you both Dear Abby and Bill Graham in the same newspaper.

And I can do for myself; I'm not helpless. Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself, you contribute to my fear
and weakness.

But, when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I
can quit trying to convince you and get about the business of understanding what's behind this
irrational feeling.

And when that's clear, the answers are obvious and I don't need advice.

Irrational feelings make sense when we understand what's behind them.

Perhaps that's why prayer works, sometimes, for some people, because God is mute, and He
doesn't give advice or try to fix things. He just listens and lets you work it out for yourself.

So, please listen and just hear me.

And if you want to talk, wait a minute for your turn,
and I'll listen to you.

Anonymous

4. When there's a Physical Barrier to Communication

Communicating with someone with a speech impairment

When talking with someone with a speech impairment:

- Speak normally. You don't need to raise your voice.
- Be patient.
- Ask the person to repeat him or herself. They will know their speech is hard to understand.
- Ask if they can say it a different way or give you a clue in other ways
- Ask if there is someone close by who can help interpret for you.

Communicating with someone in a coma⁴

Coma is a state of unconsciousness. Someone who is in a coma cannot be roused by touching, shaking or calling; however, that does not mean that the person cannot hear and understand your voice or feel your touch. Coma is not always permanent nor does it mean that death is near, even in the terminally ill. Some people will slip in and out of coma; some will suddenly just wake up. Whatever the cause or duration of the coma, you must keep trying to communicate with the person.

To do that, you have to become aware of both your own and the other person's inner feelings and perceptions. You need to look for tiny clues about how the person is feeling such as changes in breathing pattern, tiny facial changes, changes in rigidity of the person's body. Once you are sensitive to these clues you will be able to send and receive messages. Trust your "sixth sense" or intuition.

Speak normally. Tell the person what you see and feel. Encourage him or her to feel what he or she is feeling.

Use touch as a way of communicating. Placing your hand on the person's chest and breathing when he or she breathes will help you to tune into the person's inner world. (Tell them that you will be placing your hand on their chest before you do it.)

Remember that a coma is an inner experience. Do not try to make the person come out of it. The inner experience is part of dying and for most people it is a necessary experience.

Be relaxed and calm inside yourself. You do not have to communicate all the time. The person experiencing the coma has less awareness of the external environment.

⁴ KFL&A Palliative Care Education Project, as presented in Hospice Kingston Volunteer Training Manual, Hospice Kingston, Ontario.

Avoid saying anything negative. Continue to express words of love and encouragement.

Remember that the person in the coma can perceive your touch, tone of voice, and inner feelings.

Techniques that help communication and empathy:

Giving recognition	Good morning, Mr. Smith You've written some letters today. I notice you've chosen your favourite music for today.
Giving information	My name is.... I'm here because I'll be taking you to the...
Giving broad openings	How do you feel? Is there something you'd like to talk about? Where would you like to begin?
Accepting	I understand... I agree... I hadn't thought of that...
Using silence	Yes, Uh-huh, Hmmm, nodding.
Offering general leads	Go on and then? Tell me about it.
Placing the event in time or in sequence	What seemed to lead up to...? Was this before or after...? When did this happen...?
Making observations	Are you uncomfortable when you...? I notice you are biting your lips.
Encouraging description	Tell me when you begin to feel anxious. How would you describe your pain?
Restating	<i>Client:</i> I seem to hear the clock strike every hour at night. <i>Volunteer:</i> You have difficulty sleeping?
Note: When using restating, do not overdo the obvious. Only restate complex statements or those that seem to have an unspoken message behind them.	
Reflecting	<i>Client:</i> Do you think I should tell the doctor? <i>Volunteer:</i> Do you think you should?
Attempting to translate feelings	<i>Client:</i> I can't talk to you or to anyone. It's a waste of time. <i>Volunteer:</i> Do you feel no one understands? <i>Client:</i> I'm way out in the ocean. <i>Volunteer:</i> Do you mean you feel abandoned?
Seeking clarification	I'm not sure that I follow. What would you say is the main point of what you said?
Focusing	This point seems worth looking at more closely.

Encouraging a plan of action	Next time this family problem comes up, what might you do to handle it? What could you do to let your anger out harmlessly?
Offering self	I'll sit with you a while. I'm interested in making you comfortable. Perhaps you and I can discover what might reduce your anxiety.
Requesting an explanation	Why do you think that? Why do you feel this way? What made you do that?

Techniques that hinder communication and empathy:

Offering false reassurance	I wouldn't worry about... Everything will be all right. You're coming along fine.
Expressing judgement	That's good. I'm glad that you... That's bad. I'd rather you wouldn't...
Advising	I think you should... Why don't you...?
Disagreeing	I definitely disagree with... I don't believe that. <i>Client:</i> I'm nothing. <i>Volunteer:</i> Of course you're something. Everybody is somebody.
Defending	No one here would lie to you. But Mrs. B. is a very capable caregiver.
Making stereotypical comments	It's for your own good. Keep your chin up. Just listen to your doctor...he knows
Introducing an unrelated topic	<i>Client:</i> I'd like to die. <i>Volunteer:</i> Did you have any visitors today?
Using jargon	I hear you saying that ...
Sympathizing	Oh, you poor thing.
Story-telling	That reminds me of the time ...
Correcting	That's not how it happened.
Educating	This could turn into a positive experience for you if you just ...

What will I talk about?⁵

As a volunteer, you may be anxious about what you will talk about with the dying person, particularly when you first meet. Here are some tips to get the conversation started:

- Before your visit, review the information on the person's likes, dislikes and any sensitive topics that you should avoid.
- Remember to ask open-ended questions.
- Be prepared to share information about yourself and do not be afraid to describe your own feelings when appropriate.
- When you arrive, "take the temperature of the room" by asking family members how the person is and how he or she is coping.
- When greeting the person, introduce yourself -- something you may have to do several times with some clients.
- Be yourself.

Conversation Starters

Talk about the person's room or home – such as cards on display, plants, pictures, furnishings, views from windows, colour or style of décor, garden and/or surroundings.

Ask about the person and family – siblings, children, grandchildren, family achievements, education and reminiscences.

Ask about their life story – where they were born, their childhood home, pets, family life when they were young, special friends, historical events they lived through, hurdles and heartbreaks, and favourite occasions.

Discuss what's happening now or this week – the weather, current events, how their week was, family members' activities in the past week and any planned outings.

Explore social interests – hobbies, favourite pastimes, sports, travels, jobs, friends, movies and community involvement.

Talk about thoughts and feelings– their dreams, fears, hopes and expectations for themselves and their family members (psycho-spiritual issues).

⁵ Adapted from Hospice of Waterloo Region Volunteer Training Manual: The Art of Conversation

5. Privacy and Confidentiality

Being part of the care team and communicating with the person, family members and other care providers, you will learn very personal information. As a hospice palliative care volunteer, you have a responsibility to respect the person's and family's privacy and protect their confidentiality. You must not disclose what you have learned to anyone other than other members of the team. This rule applies to everyone on the team, and is key to creating an atmosphere of trust.

Respecting Privacy

To respect the person's and family's right to privacy, you do not disclose:

- who you are caring for
- the state of wellness of the ill person or family members
- anything that is said to you by the person and/or family members
- anything that you observe or overhear during your assignment
- how the person died
- how the family members grieve.

Keep confidential anything you:

- See
- Hear
- Read
- Observe with your five senses or
- Already know about the person and family members

Respecting privacy can be particularly difficult if you live in a small community where everyone knows everyone else. Neighbours and friends of the dying person and family may know that you are a volunteer and ask you questions. In those situations, you should always suggest that they talk directly to the family.

Protecting Confidentiality

Confidentiality means "entrusted with secrets". As a member of the care team, you may have access to other people's personal and health information. You are required to keep all that information confidential.

Breaching of confidentiality by a volunteer is a serious breach of ethics and may result in termination.

The only time it is acceptable to break confidentiality is when there is an unacceptable risk of harm to the individual or someone else, such as:

- a communicable disease that must be reported by law to the authorities (This is done by the nurse and/or physician.)

- a medical condition (e.g. mental illness) that may result in personal harm or harm to others
- reasonable suspicion of abuse.

Module 3:

Family and Family Dynamics

Learning objectives:

1. Understand the family as a system and the impact of family dynamics and culture.
2. Explore possible role changes in the family in response to illness and death.
3. Understand the volunteer's role in supporting and assisting family members.
4. Know resources for families in the community.

Competencies:

At the end of module three, volunteers will be able to:

- Describe how family dynamics and culture can affect the dying person's needs.
- Describe the family's role in caregiving as well as their need for care and support.
- Identify ways that volunteers can support and help family members in their role as caregivers.
- Describe the boundaries that the volunteer must maintain when supporting family members.

1. What is Family?

Family consists of people who are tied emotionally, spiritually, economically and socially to one another either by birth or by choice. Hospice palliative care defines family as anyone outside the interdisciplinary care team – relatives, friends, neighbours or others -- involved in caring for or supporting the dying person.

Each family is different. Its members form a complex system that function based on dynamics and family culture that will define:

- the roles of each member of the family – including gender roles
- who has authority and who makes decisions for the family and for the dying person
- how the family communicates with one another and with people outside the family, including the care team.

There are many types of families and many ways to run families. In some families, decision-making is shared; in others, one or two key people make decisions. Some families discuss issues openly and share information, while others do not. How families work may be influenced by culture. For example, in some families and cultures, the eldest son may make decisions for a dying parent.

2. The Family's Role in Hospice Palliative Care

In hospice palliative care, the family plays two roles. They provide care and support for the dying person and they also receive care and support from the care team.

Providing care and support

When a family has to provide care for a dying member and face the prospect of someone dying, the normal rhythm of the household changes. Roles may change dramatically and family interactions can be disrupted:

- Children become caregivers for parents.
- A spouse who never made decisions about family matters or household finances may suddenly be thrust into that role.
- The person who always provided emotional support for the rest of the family may now be the one who needs emotional support.
- Husbands and wives have to take on intimate care tasks – such as bathing, cleaning or feeding their spouse -- and the familiar relationship as a couple is put on hold.

To take on these new practical and emotional roles, family members must often learn new skills, and they may need professional support.

Receiving care and support

Families who are caring for someone who is dying need care and support to help them manage their own worries and concerns, such as:

- Is their loved one receiving the best nursing and medical care?
- Is it OK to leave the dying person alone?
- What will happen when he/she dies?
- How will I ever survive without my loved one?

It is during this time that family members will begin to feel the impending loss of their loved one. Sadness, depression, anxiety and guilt – can all come to the surface. This is known as *anticipatory grief*

– a period of grieving that starts before the person actually dies. This process is complicated by the fact that not all family members will experience the same emotions at the same time.

To help families cope, volunteers must be ready to respond to a variety of emotional responses – sorrow, anger, guilt, resentment -- while remaining supportive and non-judgmental.

In addition to their concern about the person who is dying, family members will experience a wide variety of emotional, social, economic and sometimes physical changes and difficulties. They will likely be very tired and worried, and face pressures trying to balance their other responsibilities (e.g. work, caring for other family members) with caring for the person who is dying. Some may begin to feel trapped in their role as a caregiver, and start to resent the situation and the person. These feelings – the impact of living with someone who is dying on the life and health of family members -- are often described as *caregiver burden*. A family's ability to cope with caregiver burden depends on many factors, including their coping skills and social support networks.

3. When Families Don't Work

The dramatic changes that can occur in family systems when someone is dying are not always smooth. Family members may take advantage of the turmoil to pursue longstanding issues. Cooperation among family caregivers can be strained and break down. Resentment, anger and frustration can all surface.

The dying person and/or family members may have a history of problems such as substance abuse, financial difficulties, mental illness or disability. If these problems surface, the care team can provide care and support.

4. The Volunteer's Role with the Family

Hospice palliative care volunteers often spend more time with family members than anyone else on the care team. Because they have such close contact, they often develop close relationships at a time when family members' energies, emotions and resolve are being sorely tested. Volunteers can be drawn into family situations as members grapple with changing roles, strong emotions and caregiver burden.

Working with families that look and act very differently from our own can be stressful for volunteers. Whenever you encounter problems or challenges with the family, talk to your supervisor.

To be able to provide support, it's very important for volunteers to understand the limits of their role:

- **Volunteers support, they don't fix.** Volunteers are not social workers or family counselors. It is NOT your role to provide family or marital counseling or to intervene in financial or legal matters. Your role is to demonstrate support and concern, while allowing the family members to cope in their own way.
- **Volunteers are not alone.** Other members of the team will be better able than the volunteer to help families that are not working. There are also resources in the community to help families that are coping with emotional issues as well as more serious issues such as substance use or domestic violence. You can help the family by calling another member of the team or giving the family information on community services – depending on the situation.

1. Helping Families Provide Care and Take on New Roles

Volunteers can help families in their caregiving by:

- Sharing their knowledge about comfort measures and about “tricks of the trade” the care team may have that will make the dying person more comfortable.
- Being alert to the changing care needs of the dying person and reporting these to the hospice supervisor.
- Bringing any concerns about a family caregiver's ability to continue to provide care to the hospice supervisor or care team members.
- Helping family members with unfamiliar tasks or referring them to community resources for help.
- Giving the family members and dying person time to be together as a family (e.g. help to prepare a “picnic” lunch/supper in the dying person's room, or an “evening at the cinema” – favourite video and popcorn - in the dying person's room).

2. Supporting Families

Hospice palliative care volunteers can support families by being aware of their needs, including the pressures they face in caring for someone who is dying:

- Take time to listen to family members and just “be there” for them
- Pay attention to family members’ feelings and changing moods
- Offer to keep the dying person company so that family members can take a break and look after themselves
- Remain non-judgmental
- Allow family members to express their frustration and anger.

3. Helping Families Manage Stress and Caregiver Burnout

Because volunteers spend so much time with family members, they are in a good position to recognize the signs of caregiver burnout and help families cope:

- Be aware of the caregivers’ stress level and how much of a burden they feel their caregiving role is becoming to them.
- Encourage caregivers to stay healthy and help them to achieve this in practical ways (e.g. by offering to stay with the dying person while they go for a walk or have a rest). Don’t just say it, create opportunities for the family member.
- Be aware of signs of caregiver burnout and help caregivers recognize the signs themselves.
- Help family members confront any negative feelings and find appropriate ways to deal with them such as seeking professional counseling and/or spiritual care.
- Tell the family about community resources that are available, such as services that can help with finances, counseling programs and caregiver support groups.
- If you are concerned about the health of the family member or the safety of dying person, talk to other members of the care team.

Signs of Caregiver Burnout

- Need for control
- Exhaustion
- Lack of patience
- Resentment towards the dying person
- Financial difficulties
- Substance abuse
- Excessively concerned or unconcerned
- Treats the dying person like a child (especially if he or she is a senior)
- Has minimal eye contact with the dying person, or care team members (remember not to confuse this with cultural deference)
- Blames the dying person.

4. Recognizing When Families have Serious Problems

Long-standing family problems, such as financial problems, substance use or domestic abuse, will not necessarily go away because a family member is dying. In fact, because of the pressure on a family, they may get worse. Family members who feel overwhelmed by their caregiving responsibilities or angry with the dying person for leaving them can also become abusive.

It is not up to volunteers to deal with these serious family problems; however, volunteers may be in a position to recognize signs of abuse and neglect, and help families get help.

It is sometimes hard to detect abuse or neglect. In particular, it can be hard to distinguish neglect from the effects of a life-limiting illness. It's important for volunteers to be sensitive to the situation in the dying person's home and to the family members' well-being. It's also important for volunteers to trust their instinct.

If you see any signs of abuse or neglect, talk to your supervisor. If the family is at all abusive towards the volunteer, the supervisor will remove the volunteer from the home.

5. Providing Support for Grief and Bereavement

The worries and emotions that families experience as the person is dying will not magically disappear when the person is gone. Family members will continue to struggle with grief and bereavement. That is why the care team begins to support the family during the person's illness and continues to provide support through the period of bereavement. For more information on supporting families through grief and bereavement, see Module 8.

Factors that contribute to abuse/neglect:

- Alcohol or substance abuse
- Financial hardship
- History of abusive family relationships
- Lack of communication/agreement among family caregivers and client about care
- Isolation and lack of social support
- Dependency on the caregiver
- Lack of caregiver recognition.

Signs of abuse/neglect:

- Unexplained injuries in various stages of healing or grip marks
- Delay in seeking treatment
- Dying person is withdrawn, passive or apathetic whenever the abusive family member is present
- Unexplained discrepancy between family income and dying person's standard of living
- Lack of attention to personal hygiene.

Module 4:

Emotional/Psychological Issues and Support

Learning objectives:

1. Understand the emotional needs, losses, fears and hopes of the dying person and the family
 2. Explore personal attitudes and feelings about death
 3. Develop the skills to provide support for the dying person and family as they cope with emotional issues
-

Competencies:

At the end of module four, volunteers will be able to:

- Describe the emotional/psychological issues and needs of someone who is dying and their family
- Describe how the palliative care team will provide emotional support during the dying process
- Describe the role and limits of the volunteer in providing emotional support
- Describe their own concept of “dying well” and how this may influence their work as a volunteer
- Demonstrate the ability to provide emotional support.

1. What is a Good Death?

Dying is a very intimate, personal experience.

Each person will have his or her own definition of “dying well” that will be affected by his or her personality, gender, culture, ethnicity, and spiritual beliefs.

However, most people believe that dying well includes:

- being pain free
- having a sense of choice and control over what happens in their lives (including who is present and shares the end) while gradually relinquishing the responsibility for their care to significant others
- maintaining their dignity and privacy
- having access to emotional and spiritual support
- resolving long-standing conflicts
- satisfying final wishes
- having time to say good-bye
- being able to leave when it is time to go and not have life prolonged.

“Death and dying bring out the best in some people and the worst in others. Most people muddle along, coping as best they can. As volunteers we can help with the latter.”

Gallasch, 1996

2. The Emotional/Psychological Needs of the Dying Person

Each person diagnosed with a life threatening or terminal illness will have a unique emotional reaction to impending death – and unique needs, losses, fears and hopes. To help someone who is dying, it’s important to understand his or her needs and concerns – and to remember that it’s not the volunteer’s role to “fix” the person, the family or the problems, but just to be there and listen.

Here are some common emotional needs of people who are dying – and steps the volunteer can take to provide emotional support.

A life-limiting illness is frightening. It affects relationships, lifestyles and the individual’s sense of who they are. If we are to offer support ... we need to understand the fear as well as the various illnesses and treatments.

Gallasch, 1996

A Dying Person's Emotions/Emotional Needs	The Support a Volunteer Can Provide
<p>Fear of pain: Fear of pain is the main concern of many people nearing end of life. Pain creates anxiety in the dying person and family members.</p>	<ul style="list-style-type: none"> • Reassure the person that he/she can be kept comfortable with medication, massage, cleanliness, exercise (when possible) and diet. • Remind the person to report any pain to the doctor, nurse or other caregivers, and not try to be brave about it. • Reassure the person and family that the final dying is usually painless. It's a common misperception that pain and dying are inseparable, but they rarely go together.
<p>Fear of death and other fears. Most people are afraid of death. People need opportunities to express their fears, anxieties and anger – although some people find it easier than others to talk about emotions. Some may want to talk about what it will be like and/or about their concept of an afterlife.</p>	<ul style="list-style-type: none"> • Listen and ask questions. • Be sensitive. Ensure that people who talk easily about their fears feel accepted. Be patient and wait for those who find it harder to express their feelings. • Avoid giving advice or forcing your views on the person. • Notice as much as possible about the person's cultural and spiritual beliefs, and how they've handled difficult situations in life before.
<p>Need for acceptance, understanding, love, nurturing and intimacy. People who are nearing end of life need to feel loved, nurtured and accepted. They need opportunities to connect with other people and share their thoughts and fears, and to feel understood.</p>	<ul style="list-style-type: none"> • Recognize that it is a privilege when someone shares his or her intimate stories with you. • Be deeply respectful of the person. See the other person as an equal.
<p>Loss of independence: A dying person gradually loses the ability to function and look after him or herself, and becomes much more dependent on others. Many people</p>	<ul style="list-style-type: none"> • Be aware of the person needing help with activities such as eating or drinking, and offer assistance in a way that respects the person's

<p>suffer more from the loss of function than they do pain, and find it difficult to let others do things for them – particularly intimate things, such as bathing or cleaning them.</p>	<p>dignity and reduces their feeling of dependence or being a burden on others.</p>
<p>Concern about physical appearance: Someone who is dying may feel repulsive, freaky, dirty or unclean. They may be mourning the loss of their physical appearance and feel unattractive or unlovable.</p>	<ul style="list-style-type: none"> • Touch can provide comfort and reassurance, and help reduce the feeling of isolation or being alone. • Ask permission to touch the person if and when appropriate. • Put an arm around them, hold their hand, give them a hug or wipe away their tears. Touch can often mean more than words.
<p>A need to connect with others or set things right. As people grow closer to death, they want to be able to express their love to the people closest to them and they often want to set things right – seek or offer forgiveness or deal with any regrets.</p>	<ul style="list-style-type: none"> • It is not necessary to engage in long conversations with someone who is dying. • Being present is often all people need to let them know they are not being abandoned.
<p>Loneliness and isolation. As people get closer to death, they may have fewer visitors and less contact with the health care providers they saw often when they were receiving curative treatment. They may fear being left alone or going to sleep in case they die alone. This fear can have a profound relationship to pain: many people report more intense pain when they are alone.</p>	<ul style="list-style-type: none"> • Avoid giving advice or false hopes, or trying to fix the person or his/her problems. • Think about the kind of support you like to receive when you face a crisis.
<p>Lost dreams. Some people experience sadness over failed expectations in their lives – the things they didn't get to do with their family or friends or in their careers.</p>	<ul style="list-style-type: none"> • Ask yourself: How did I feel? What did I want? What response did I most appreciate? What did I do? How did others best help me?
<p>Anticipatory grief. Some people actively grieve that they will no longer be alive - that life is ending earlier than they expected or wanted - that they are leaving family and friends with whom they have shared their lives. As they experience their own grief they may remember the many family and friends who have died before them – which can intensify their sense of grief and loss.</p>	

<p>Concern about the future of their loved ones. A dying person may be able to talk calmly about his or her own illness and impending death, but become very distressed when talking about his or her family. Who will take my place in looking after my family? People are often concerned for their future of their loved ones and the impact that their death will have.</p>	
<p>Concern about their wills or funeral. Some people may be concerned about making or changing their will – or ensuring that people they know are given something of theirs to remember them by. Some will want to be involved in their funeral planning.</p>	<ul style="list-style-type: none"> • Listen but do not give advice or try to solve any problems. • Put them in touch with the appropriate support people

3. The Volunteer's Role in Emotional Support

People who are dying and their families need:

- Empathy – the feeling that someone understands their experience.
- Permission – to express their thoughts or feelings, to be afraid or angry or withdrawn.
- Individuality – to be treated as a person, to be asked about their needs and to not have people make assumptions about how they feel.
- Advocacy – someone to speak on his or her behalf if necessary and advocate for their needs.
- Truth – an accurate diagnosis and facts about their care and prognosis.
- Time – to integrate their experience and have their questions answered.

To provide effective emotional support, the volunteer must:

- be in tune with his or her own feelings and emotions about death and dying
- give people the freedom to express what they need to express
- be sensitive to people with special needs, such as people who been in abusive relationships or who are estranged from their families
- acknowledge their sense of loss
- give people the time they need to come to terms with their fears and confusion.

When to Ask for Help?

In the process of being with and listening to someone who is dying, volunteers may learn that the person is dealing with emotional or other issues that are beyond their skills. For example, volunteers should consult with their supervisor if a dying person reveals:

- a history of domestic violence
- a history of substance abuse, including alcohol
- that he or she wants to die and is planning how to do it (i.e. suicide, euthanasia)
- signs of spiritual anger or distress (e.g. lashing out).

Volunteers are not social workers and are not authorized to offer therapy. Whenever volunteers feel uneasy with the family dynamic or the emotions the dying person is expressing, they should talk to their supervisor who can ensure the person and family receive professional help from other qualified team members.

4. The Volunteer's Attitudes and Beliefs about Death and Dying

What are your beliefs and attitudes towards death and dying? Do you see death as an ending or a new beginning? Is it sad or inevitable or both? Is it a tragedy or a fact of life?

Like the person who is dying, your attitude toward death and dying will depend on your beliefs and practices, your values and experiences. It's important to think about your own emotions about death, and how they may affect your reaction to the person's way of coping with the emotional issues of death and dying.

To help you understand how you feel and think about death, answer the questions on the next pages. Then discuss and reflect on your answers with your trainer and/or volunteer coordinator.

5. The Role of Culture and Spiritual Beliefs

The challenge for hospice palliative care volunteers is to provide support and not to direct or interfere with the choices made by the person or family. This can be particularly difficult if the dying person and/or family are in denial or there are some deeply held cultural beliefs that the volunteer doesn't know about or doesn't agree with. Many people – because of culture, social class or personality -- do not openly express emotions, may have taboos about death and dying, and do not subscribe to the accepted notions of "dying well". It is critical that the volunteer be open and non-judgmental, and understands something about the beliefs and practices of different cultures related to death and dying.

"Pop psychology" talk shows where people reveal the most intimate of details of their lives, and advice columns in newspapers all illustrate our society's value of "talking things through" and sharing experiences and emotions. However, this value is not universal.

For more information on different cultural and spiritual beliefs, see Module 5: Spiritual Issues and Support.

Personal feelings about death and emotional reactions⁶

Answer the following questions and identify the underlying emotion(s) using the list of possible emotions provided and adding any missing emotions. Indicate how you would express this emotion. For example: by crying, staring into space, becoming aggressive, or talking a lot.

I think that death is: _____

It makes me feel: _____

I would show this emotion by: _____

I think a corpse is: _____

Seeing one makes me feel: _____

I would show this emotion by: _____

I think cemeteries are: _____

They make me feel: _____

I would show this emotion by: _____

I think that mourning and grieving are: _____

They (mourning and grieving) make me feel: _____

I would show this emotion by: _____

Possible emotions: sadness, fear, pain, joy, nervousness, shock, anger, loneliness, discomfort, despair, elation, etc.

⁶ Based on "Personal feelings about Death", Core Concepts in Hospice Palliative Care, Module 1, p.6, Dr. Bob Kemp Hospice, Stoney Creek, Ontario, 2000.

Your History of Losses

To understand another's feelings following the loss of a loved one, volunteers should look at their own history of losses. This reflection on your own life can pay dividends later on in helping to make you more effective in your own work as a hospice volunteer.

- 1) The first death I can remember was the death of

- 2) I was age

- 3) The feelings I remember I had at the time were

- 4) The first funeral (wake or other ritual service) I have ever attended was for

- 5) I was age

- 6) The thing I most remember about that experience is

- 7) My most recent loss/death was (person, time, circumstances)

- 8) I coped with this death by

- 9) The most difficult death for me was the death of

- 10) It was difficult because

- 11) My primary style of coping with loss is

- 12) I know my own grief is resolved when

- 13) Reflecting on all of the above, I sense that for me palliative and hospice care volunteering will be

Module 5: Spiritual Issues and Support

Learning objectives:

1. Understand the spiritual needs of the dying person and the family
 2. Understand different spiritual concepts and practices
 3. Understand the role of the volunteer in providing spiritual support
 4. Develop the skills to provide spiritual support for the dying person and family
-

Competencies:

At the end of module five, volunteers will be able to:

- Describe the spiritual issues and needs of someone who is dying and their family
- Describe how the palliative care team will provide spiritual support
- Describe the role and limits of the volunteer in providing spiritual support
- Demonstrate the ability to provide spiritual support.

1. What is Spirituality?

Spirituality is a personal journey. It has been defined in many ways: as the “innate yearning, longing for harmony and wholeness”, “the strength to go on”, the “experience of striving for self-transcendence, to be in a relationship with the other” (author unknown), and “the energy within each person that looks for meaning and purpose in life”.

As you ought not to attempt to cure the eyes without the head, or the head without the body, so neither ought you to attempt to cure the body without the soul... for the part can never be well unless the whole is well... You must begin by curing the soul.

Plato

There is a difference between spirituality and religion. Religion is an organized system of beliefs, practices, rituals and symbols while spirituality is a personal quest for answers to questions about life and meaning. Not everyone will need religious care, but all need spiritual care. Spirituality is the whole life of the person lived in relationship with the transcendent (God). Spirituality can be expressed in many ways – formal and informal. Some people do not belong to a religion but still lead highly spiritual lives. Others live out and express their spirituality within an institutionalized religion.

2. Spirituality at End of Life

Spiritual care is an integral part of hospice palliative care. As people approach death, they reflect on the meaning of life. They tend to review their life, evaluate the choices they've made, and search for some kind of meaning in their illness (e.g. Why me? Why now?).

Most of us want our lives to be meaningful and useful: to have a sense that our lives counted for something. Some of the ways that people find meaning include:

- Belonging to a caring community – which can be a group of family and friends, including the hospice palliative care team – that nurtures all members
- Telling their stories – including stories of shame, pain and grief – so they can move from a sense of guilt or anger to forgiveness
- Healing old wounds – when stories are shared and accepted with love and in a non-judgmental way, it can be a great relief for a person and help heal long-held pain.
- Experiencing moments of transcendence or peak experiences – such as a beautiful sunset or a new insight – or feeling a sense of awe and wonder
- Feeling valued by others

- Developing one's higher self or soul – some people may have neglected this longing for a greater sense of wholeness because of fear, lack of understanding or a busy lifestyle but this desire may surface in a profound way as a person faces a life threatening illness.

3. The Volunteer's Role in Spiritual Care

Because volunteers have so much contact with the dying person and family, they are likely to see the person striving to find meaning in their situation and dealing with spiritual issues. Volunteers can provide spiritual support in many ways.

1. Recognizing a spiritual need

It can be difficult to recognize when someone has a spiritual need. Some people may have clear spiritual goals that they pursue through prayer, reading or being close to nature. Others may wrestle with their faith when they find they are dying.

People may ask questions about the future, such as how will I die, when will I die or what comes after death. It is possible that family members are reluctant to talk with them about death so they turn to the volunteer. It's important for volunteers to listen carefully to what the person is really asking. The questions may mean the person is frightened and seeking reassurance or just wanting someone to be present with them in their reality.

One sign of spiritual need or distress is greater anxiety, which may be expressed as anger against God, life, family members – even the volunteer. The volunteer can learn to recognize spiritual need by listening and being sensitive to small clues. For example, is the person generally content with what he or she has done in life? Is he generally more forgiving of others? Can she identify a purpose for her existence? Or does the person express a lot of bitterness, regret or anger? Those who are angry are more likely to need more spiritual support.

We are to be a calming presence and if those we are with want to talk they will. We can come with our own agenda believing that the other needs to talk about dying or what we consider spiritual matters. The reality is that some never will and it is their choice. This doesn't mean that we are not offering spiritual care.

Cassidy S. Sharing the Darkness, 2003

2. Providing spiritual support

Hospice palliative care volunteers can provide spiritual support by:

- building trust
- encouraging the person to talk about things they have done in their lives – things they feel proud of – so they can find meaning or value in their lives
- listening patiently and gently to people’s stories – how it was (past), how it is (present) and how it might be (future) -- and letting them tell their stories more than once if they need to
- treating the person with dignity and valuing them for who they are
- respecting the person’s and family’s belief systems and responding according to their belief system (rather than the volunteer’s belief system)
- sharing personal beliefs only when asked by the person or family member
- never, never proselytizing or trying to convert the dying person or family member
- providing whatever the person or family asks for in terms of spiritual support including contacting or not contacting their faith leader in the community
- being present even when people want to go into difficult places. Being comfortable in the silence and allowing the other to explore.

3. Understanding people’s spiritual beliefs

As a volunteer, you may be providing support for people from different faith communities. To fulfill your role, you have a responsibility to understand the dying person’s and family’s spiritual belief system, and to provide spiritual support that reflects their needs and beliefs. See page 58 for a

Journaling

Keeping a journal can be a good way for the dying person and/or family member to reflect on their experiences, frustrations and moments of joy – past, present and future. The volunteer can help by:

- suggesting themes to help them start writing, such as life-changing events, relationships, work and leisure
- offering to write for the person
- asking questions that will reveal greater detail
- being there to provide support.

Spirituality is about building mutual human relationships, and creating reflective spaces, rather than making assessments and delivering interventions. The volunteer should:

- accept the individual unconditionally
- allow the person to lead the conversation and define their need for spiritual care
- practice being able to sit with questions, not having the answers. understand that, as part of their spiritual journey, people may pose questions with few answers.
- recognize that spirituality includes all the person’s life experiences

description of different faiths and their traditions and practices related to death and dying.

If you are uncertain about the family's customs and rites – ask them.

4. Knowing when to ask for help

When providing spiritual support, volunteers may sometimes feel out of their depth. They may not know all the answers or know how to cope with the person's struggle.

Remember:

- Volunteers are not expected to have all the answers.
- It's enough to stay with the person in the conversation.
- If you feel overwhelmed, talk to your supervisor or the pastoral care worker on the team.

Religion	Philosophy/Beliefs	Practices Related to Death
Aboriginal	<ul style="list-style-type: none"> • Spirituality is a very personal thing. • Ceremonies and rituals are a manifestation of spirituality. Myth, ritual and ceremony are used at each stage of life to help adjust to a new spiritual transformation. • People believe in a Creator that provided laws to live by, which are internalized. In general these laws include: respect, honour, courage, kindness, sharing, acceptance and communication. • There is a strong belief in the unity of all things both animate and inanimate. • The concept of the circle of life, balance, harmony and relationship often expressed through the medicine wheel. • Many Aboriginal cultures have incorporated Christian beliefs into their spiritual lives. 	<ul style="list-style-type: none"> • Burial customs and traditions as well as mourning customs vary among cultural groups and from Aboriginal community to Aboriginal community. • It is important to seek guidance from the family members or elders in order to provide the most appropriate support.
Buddhism	<ul style="list-style-type: none"> • Human life is pervaded by suffering that can be mediated through “right living”. • People seek “truth” through middle way between extremes of asceticism and self-indulgence. • People emphasize meditation to relax mind and body to see life in true perspective. • “Right” living will enable people to attain nirvana. • There is belief in reincarnation of 	<ul style="list-style-type: none"> • Quietness and privacy for meditation is important. • Goal at death is for the mind to be calm, hopeful and as clear as possible. • There are no special rituals regarding body. • Cremation is common.

	the soul.	
Christianity (Catholic, Protestant, Eastern Orthodox)	<ul style="list-style-type: none"> • Grounded in teachings of Jesus Christ • World and everything that exists was created and depends on God. • Belief in afterlife and soul is integral to faith. 	<ul style="list-style-type: none"> • As death approaches, specific rites and observances may be required based on the person's denomination (e.g. Catholic, Protestant, Orthodox) • After death there is a two to three day visitation to home (funeral home) prior to funeral. • Funeral/memorial service to celebrate life of deceased and departure of soul to afterlife. • Burial or cremation occurs after funeral service.
Hinduism	<ul style="list-style-type: none"> • Wide variety of beliefs are held together by an attitude of mutual tolerance: all approaches to God are valid. • Goal is to break free of imperfect world and to reunite with Brahman (i.e. everything physical, spiritual and conceptual). • There is belief in reincarnation and transmigration of soul until reunited with Brahman. • People disapprove of killing of living things (vegetarian). 	<ul style="list-style-type: none"> • Married women wear a nuptial thread and red mark on the forehead; males may wear a sacred thread around the arm; dying patient wearing neck/arm thread may indicate a special blessing - none of these symbols should be removed. • Readings from Bhjagavad Gita comfort patient. • It is important that last thoughts or word be of God to ensure rebirth to higher form. • People prefer to die at home and as close to mother earth as possible. • It is important for family to wash body; eldest son arranges funeral. • Cremation is usual with ashes scattered on water (preferably the holy river Ganges). • Set pattern for mourning and final service two weeks after death.
Islam (Muslim)	<ul style="list-style-type: none"> • It is a complete way of life, based on teachings of the Prophet Mohammed and interpreted through the Koran. 	<ul style="list-style-type: none"> • Friday is holy day: cleansing ritual prior to prayer, and head must face towards Mecca • Reading from Koran will comfort the

	<ul style="list-style-type: none"> • There is a belief in God: all people are created, live, die and return to God by God's command. • Death is part of life and a rebirth into another world. • There is a belief in an afterlife. • Pork and intoxicating substances are prohibited. • Rituals are shaped by local culture. 	<p>dying person who is encouraged to recite verses.</p> <ul style="list-style-type: none"> • After death, a spouse or relative of the same sex washes the person's body. • Burial occurs soon after death; it is simple with no coffin. • There are three days of mourning except for the spouse who mourns for four months and ten days.
Judaism	<ul style="list-style-type: none"> • There is a belief that God has a covenant relationship with humans and salvation is achieved by obeying God's laws. • People believe they have been chosen to be examples to all. • The "Messiah" will come to bring world to perfection. • The faith is highly family focused. 	<ul style="list-style-type: none"> • As death approaches, readings and prayer provide comfort. • There are practices at death to <ul style="list-style-type: none"> • honour dignity of body • assist bereaved through process using laws of the whole mourning ritual • affirm basic belief that life and death are part of God's plan • Burial takes place 24 to 48 hours after death; body must not be left unattended from death until burial. • Family receives visitors and food gifts during seven day SHIVA. • There are 30 days of social withdrawal with one year official mourning. • There are specific services of remembrance after death and at unveiling of tombstone.
Sikhism	<ul style="list-style-type: none"> • There is a belief in one God for all humanity. • The faith has incorporated many Islamic and Hindu beliefs and preaches religious tolerance. • People observe dietary rules and other rituals and customs. 	<ul style="list-style-type: none"> • There are five traditional symbols which could cause distress if removed from dying person: <ul style="list-style-type: none"> • Kesh - long uncut hair of face and head • Kanga - hair comb (symbol of discipline) • Kara - steel bangle on wrist (strength and unity)

		<ul style="list-style-type: none">• Kirpan - sword, worn as broach (authority and justice)• Kachha - special shorts (spiritual freedom).• Family members may play a role in preparing the body.• Cremation with ashes scattered on water is common.• Mourning services last ten days and final service marks end of official mourning.
--	--	--

The Role of Prayer

Prayer may be important to some people and not to others so it's important for volunteers to take the lead from the dying person and family. If someone asks you to pray with him or her, ask "What would you like me to pray for?" People often find it helpful when prayers include their fears or concerns.

Here are examples of prayers from different faith traditions taken from the Oxford Book of Prayer (1989) that volunteers can use when someone asks for a prayer.

A Buddhist Litany for Peace

As we are together, praying for Peace, let us be truly with each other.

Silence

Let us pay attention to our breathing.

Silence

Let us be relaxed in our bodies and our minds.

Silence

Let us return to ourselves and become wholly ourselves. Let us maintain a half-smile on our faces.

Silence

Let us be aware of the source of being common to us all and to all living things.

Silence

Evoking the presence of the Great Compassion, let us fill our hearts with our own compassion -- towards ourselves and towards all living beings.

Silence

Let us pray that all living beings realize that they are all brothers and sisters, all nourished from the same source of life.

Silence

Let us pray that we ourselves cease to be the cause of suffering to each other.

Silence

Let us plead with ourselves to live in a way that will not deprive other living beings of air, water, food, shelter, or the chance to live.

Silence

With humility, with awareness of the existence of life, and of the sufferings that are going on around us, let us pray for the establishment of peace in our hearts and on earth.

Amen.

Sikh Prayer

I am thirsting for your love, my Beloved!

I shall make this body a lamp, and my tender heart shall be its wick;
I shall fill it with the scented oil of my young love and burn it night and
day at Your shrine, O Beloved!

For Your love I shall sacrifice all the wealth of my youth;
Your name shall be the crown for my head.

I am longing for You, O my Lord: for the season of the sowing has come;
but You are not beside me.

Clouds gather on my brows and my eyes shed heavy showers.
My parents gave me to You, I have become Yours for ever; who but You
can be my Lord?

This separation troubles my breast; make me Your own; make me perfect
like You, O Lord of Perfection!

Mirabai, 16th Century

A Jewish Prayer

Sometimes I feel lonely, and from the depths I cry unto Thee, and within me,
Thy voice answers me, and I know that Thou, Eternal Friend, art near me.

Sometimes the sense of failure seizes me, and I am disheartened.

Unto Thee do I raise mine eyes,
and the light of my heavenly Father shines upon me,
and bids me to persevere.

Sometimes my daily life oppresses me.

Unto Thee do I lift up my soul, and I realize that by doing my duty manfully and cheerfully

I am serving Thee, Divine Master,
and my task is revealed to me as something good and sacred.

Sometimes I am sad and sick at heart, but when I think of Thee,
Spirit of perfect righteousness and love, a wonderful joy comes to me,

for I know that Thou art guiding me.

O Lord God of Hosts, surely Thou wilt ever comfort me.

Blessed be Thy Name for ever and ever.

Amen.

A Hindu Prayer

You, O Lord, are the body's protector.

My body protect.

You, O Lord, are the giver of life.

Grant life to me.

From You, O Lord, comes brilliance of mind.

Illumine my mind.

Whatever is lacking to my being, O Lord,

Supply that to me.

O Lord of the home, best finder of riches

for our children are you.

Grant to us splendour and strength,

O Master of our home.

A bounteous bestower of plenty is the God

Who is Master of our herds.

Grant to us splendour and strength,

O Lord and Master.

Muslim Prayer (Islam)

O Thou that art as the soul in the body of the universe,
Thou art our soul, and art ever fleeing from us.
Thou breathest music into life's flute:
Life envies death, when death is for Thy sake.
Once more bring comfort to our sad hearts:
Once more dwell in our breasts:
Once more demand from us the sacrifice of name and fame.
Strengthen our weak love,
We are often complaining of destiny.
Thou art of great price and we have nought.
Hide not Thy fair face from the empty-handed.
Give us the sleepless eye and the passionate heart.

MohammudAqbal (1875-1938)

Secular Poem

In Blackwater Woods

By Mary Oliver

Look, the trees are turning their own bodies
into pillars of light,
are giving off the rich fragrance of cinnamon and fulfilment
The long tapers of cattails
are bursting and floating away over
the blue shoulders of the ponds,
and every pond, no matter what it's name is, is nameless now.
Every year everything I have ever learned
in my lifetime
Leads back to this: the fires, and the black river of loss
whose other side is salvation,
whose meaning none of us will ever know.
To live in this world you must be able to do three things:
to love what is mortal;
to hold it against your bones knowing your own life depends on it;
and, when the time comes to let it go
to let it go.

Module 6:

Physical Issues and Support, including Pain and Symptom Management

Learning objectives:

1. Understand the most common life-limiting illnesses, their treatments and side effects
 2. Understand the care needs of people with those illnesses
 3. Understand the volunteer's role in providing physical care and pain and symptom management, and how to provide that care
 4. Recognize when a person is experiencing pain and appropriate comfort measures
 5. Recognize the signs of death and care needs when the end is near
 6. Understand infection control policies and know which practices to use
-

Competencies:

At the end of module six, volunteers will be able to:

- Describe common illnesses and their treatments
- Describe their role in providing physical care, including any limits to that role
- Demonstrate that they can recognize pain and choose appropriate comfort measures based on the person's needs
- Describe the signs of death and describe the care volunteers provide at end of life
- Demonstrate the ability to choose and implement appropriate infection control practices

1. What are the Physical Needs of People who are Dying?

The physical needs of people who are dying will vary depending on their illness.

Common Illnesses

The most common life-limiting illnesses seen in palliative care are:

- cancer
- progressive neurological conditions, such as motor neurone disease (a progressive wasting and paralysis of the muscles), dementia including Alzheimer's disease, stroke or other cerebral vascular injury, and multiple sclerosis
- HIV/AIDS
- end stage organ failure, such as lung diseases, chronic obstructive pulmonary disease (COPD), progressive heart disease and renal failure.

The Stigma of a Life-Limiting Illness

In our society, people don't want to talk about life-limiting illnesses or death – largely because we fear dying. Some illnesses, particularly HIV/AIDS, are highly stigmatized which can lead to fear and discrimination. However, even though cancer is a more socially acceptable disease, people are often reluctant to let people know that they or a loved one has cancer. Volunteers can help fight fear, ignorance and stigma by being informed about different illnesses.

People's physical needs will be affected by the illness itself as well as by side effects of treatments for the illness, such as chemotherapy or radiation therapy for cancer. Although people who are in palliative care will likely not be receiving curative treatment, they may still be receiving chemotherapy, radiation therapy or other treatments to help relieve their symptoms, prolong their lives and make them as comfortable as possible. Some may also be participating in clinical trials or taking complementary or traditional medicines. It's important for volunteers to support the person and family by:

- remaining nonjudgmental about the choices that a person and/or family members may make about palliative treatments
- helping the person and/or family members to live as fully as possible
- being alert to the person's changing needs (physical, emotional and spiritual) and communicating these to the hospice supervisor.

2. Symptoms at End of Life

The table on the next page lists different illnesses and their symptoms. Although each illness will have some unique symptoms, almost all will cause the following symptoms:

- pain
- loss of appetite (anorexia)
- nausea and vomiting
- fatigue and exhaustion
- breathlessness (dyspnoea)
- constipation.

What is a symptom?

A symptom is any feeling a dying person has that makes them uncomfortable, restricts their activity or keeps them awake. Symptoms often make the person anxious because they don't know what they mean. Does it mean their disease is progressing?

Illness	Common Symptoms
AIDS (HIV disease)	Neuropathy (pain), dementia, confusion, depression, weight loss, weakness, renal failure and infections such as pneumonia because of the compromised immune system
Alzheimer's disease	Confusion, forgetfulness, dementia, depression, insomnia, hallucinations, seizures, anxiety, hostility, coma
ALS - Amyotrophic Lateral Sclerosis	Progressive loss of muscle function starting with limbs and eventually affecting swallowing, speech, and respiratory function; weakness, fatigue, depression
Cancers	Bladder -- Blood in the urine, pain on urination
	Bone - Intense pain, increased tendency to fracture, collapsed vertebrae
	Brain - Confusion, headache, lethargy, weakness or paralysis of arm or leg, nausea or vomiting, seizures, decreased level of alertness, possibly coma
	Breast - Swelling in the arm on the side of the mastectomy, tumours breaking through the skin
	Cervix, Uterus - Abnormal discharge, bleeding
	Colon - Nausea, vomiting, decreased appetite, diarrhea, constipation, fluid in the abdomen that creates blisters on the skin (ascites), possibly a colostomy
	Esophagus - Decreased ability to swallow, may have a feeding tube, difficulty speaking
	Kidney - Pain in lower back, blood in urine

	Liver - Profound weakness, loss of appetite, abdominal fullness, yellowing of the skin, confusion
	Lung - Shortness of breath, coughing of blood and sputum, fear
	Lymphoma - Night chills and sweats, low-grade fever, increased tendency to bleed, increased susceptibility to infection, weakness, back pain (this is the same for leukemia)
	Ovary - Nausea, vomiting, constipation, swelling of abdomen and ascites (see above)
	Pancreas - Pain, loss of appetite, yellowing of skin, foul smelling stools
	Prostate - Inability to urinate, bloody urine, late symptoms from places where the cancer has spread especially bone, lung, brain
	Skin - Late symptoms from the places where the cancer has spread (e.g. pelvis, brain)
	Testes - Late symptoms from the places where the cancer has spread (e.g. pelvis, lungs, liver, brain)
COPD -Chronic obstructive pulmonary disease	Blue colour to the skin, nail beds, shortness of breath, restlessness, anxiety, fatigue, reliance on oxygen and need to sleep sitting up
CHF - Congestive heart failure	Shortness of breath, swelling in feet and ankles, fatigue, anxiety, fluid in lungs (coughing), insomnia
Cirrhosis – Liver disease	Yellowing of the skin and the whites of the eyes, nausea, vomiting, build up of fluid in the abdomen with blisters forming on the skin (ascites), profound fatigue, weakness, confusion, somnolence, coma
Renal Failure	Decreased urine output, confusion, pain in the lower back, weakness and fatigue, may have blood in the urine.

People who have been treated for cancer may also experience the side effects of:

- chemotherapy including nausea and vomiting, fatigue and risk of infection, muscle weakness or tingling/loss of sensation, constipation, diarrhoea, mouth ulcers and hair loss (alopecia).
- radiation therapy including hair loss, vomiting, nausea and diarrhoea, dry mouth, increased risk of infection, tiredness and headache.

3. Managing Pain

Pain is one of the most common and feared symptoms for people at end of life. Hospice palliative care specializes in pain management. It may take time to find the right pain control measures for each person, but 98% of pain can be relieved. There are now a large variety of treatments for pain including:

- drugs like acetaminophen, codeine, morphine and other narcotics
- nerve blockers
- chemotherapy, radiation therapy and surgery.

The physician in consultation with other health professionals on the care team will decide on the most suitable combination of treatments. Treatments can be given in many forms, including liquid, tablets, injections, patches and lollipops.

Unfortunately, treatments that relieve pain can lead to other symptoms, such as nausea, fatigue and constipation, so it's important to find the right balance to give the person maximum pain relief and comfort while minimizing negative side effects. The success of a treatment is measured by the person's response and comfort, not by the amount of medication.

Pain is whatever the person says it is, and occurs whenever and wherever the person says it does.

Margo McCaffrey

Factors that Affect Pain and Pain Management

Many factors can affect pain and pain management:

- **Lack of knowledge about painkillers and their use.** People can receive inadequate doses of pain medications.
- **Attitudes towards pain treatments.** Many people – including many health care professionals -- worry that taking narcotics to manage pain will lead to an addiction. Many people are also not aware of the range of treatments available now for pain.
- **Lack of access to services.** Some people – because of language, geographic or barriers – may not have good access to hospice palliative care or strong emotional support.
- **Culture.** In some cultures, it is a weakness to acknowledge pain. In others, the understanding of pain may be different.
- **Self image.** For some people, the pain of their illness is increased by the emotional impact or affect on their self-image. For example, women with breast cancer may suffer more pain because of the importance of the breast to their sexual self-concept.
- **Personality.** People who have always coped with adversity often cope better with pain, while those who feel that everything bad always happens to them may feel more pain.

One of the chief fears about pain management is the possibility the person will become addicted to the narcotic used for pain. However, addiction WILL NOT OCCUR if the medication is taken at regular intervals to provide continuous relief from pain, in an amount just sufficient to keep the pain under control. When a dying person needs higher doses of pain medication over time, this is due to an increase in pain, not addiction. Addiction occurs when narcotics are abused, and taken in large doses in the absence of pain for the purpose of producing a “high”.

Pain feels worse when we're:

- fearful or anxious
- tired
- lonely or isolated
- angry
- stressed or depressed
- insecure
- sad
- bored

When we're in pain, the pain itself is often all we can think about. Our nerves, our senses and our intellect are united in a silent battle to cope. Pain destroys quality of life – in fact, when we're in pain it may feel as if we have no life.

- uncomfortable

It's easier to tolerate pain when we have:

- plenty of rest
- the sympathy and understanding of others
- laughter and support
- interesting discussions
- companionship
- distraction and involvement in any activity.

The Volunteer's Role in Pain Management

Volunteers play a unique role in pain management. They NEVER administer medications. Their role is to observe the person, to provide comfort measures – such as support and companionship – and to report any signs that the person is in pain to other members of the care team.

It is very common for people nearing end of life to not report symptoms to their caregivers -- in order to protect their family or not bother the health care professional. In many cases, the hospice palliative care volunteer may be the only one aware the person is in distress. The privileged role of volunteer as confidant is not undermined when the volunteer shares this information in order to assure the best quality of care.

Volunteers can also use their communication skills to help the dying person identify and express how they are feeling.

The hospice palliative care program should give volunteers a copy of its medication policy.

4. Managing Other Symptoms

Volunteers can also play a role in helping the dying person manage the following symptoms.

Breathing problems

Shortness of breath is a common breathing problem that can be very frightening for both the person and family. Use the following measures to help a person breathe:

- If people have difficulty breathing during an activity, stop the activity. Offer them a chance to “catch their breath” by encouraging them to gradually slow their breathing rate and remind them not to hold their breath if they are focusing on doing a particular task

- If the person is lying down, ask which position helps improve his or her breathing. Usually sitting works best and propping the person's arms on pillows will help to expand their chest.
- Breathe with the person – concentrate on slowing down the breathing by taking breaths “in through the nose, two, three and out through the mouth, two, three...”
- Suggest opening a window or bringing a fan into the room. Increasing the air supply in the room can decrease the sensation of breathlessness.

If the person is using oxygen:

- Remember: oxygen is a medication and so hospice medication policy applies. DO NOT attempt to adjust the airflow or refit the oxygen mask or prongs.
- Advise the family and the hospice supervisor if the person is still uncomfortable or experiencing breathing problems
- For safety reasons, make sure that no one smokes or lights candles while the oxygen is being used!

Vomiting

Certain foods, drugs, scents or internal pressure from blocked intestines may cause the person to feel nauseous. If the person vomits when you are with them, you can:

- Stay close and offer whatever assistance he/she may need.
- If possible support the person's head and wipe the face with a cool damp cloth during and after an episode of vomiting.
- Offer cool water so the person may rinse his/her mouth
- Remove soiled linens (ask for help if the bed needs changing) and bowls quickly, as the odour may prolong or induce vomiting.
- Wash your hands thoroughly with warm, soapy water.

Remember to follow standard infection control procedures when providing symptom care for a dying person. Always wear gloves when sponging a client who is feverish or cleaning up vomit or diarrhea. Wash your hands – with soap or hand sanitizer – before and after each contact with the person.

If you are one of the small percentage of people who vomit when they see, hear or smell vomit, ask for help from a family member and offer whatever help you can.

Fever or Chills

When a person is experiencing fevers or chills, you can help by:

- covering someone who is shivering with extra blankets
- sponging the person's face, neck, arms and legs with a warm damp cloth and placing a towel under his/her head and neck to absorb extra sweat.
- encouraging the person to drink as much as possible.

Diarrhea

Diarrhea is potentially very embarrassing for someone who is dying. Foul odours or accidental soiling can cause the person great distress. Diarrhea can come on very suddenly, so you may need to respond quickly:

- Make sure that you know where to find the client's usual toileting facility (bedpan or commode) even if you do not regularly assist with toileting.
- Remain calm and supportive. Watch your body language, especially your facial expressions.
- Use room deodorizers that do not add a scent to the air.

Constipation

Constipation is a medical condition that the health care professionals on the team will monitor and treat. Volunteers can help by encouraging the client to:

- go for short walks, if possible
- drink lots of fluids
- follow the nurse's or dietitian's dietary recommendations (e.g. eat whole grains, fruits, vegetables).

Headaches

The health care professionals on the team will monitor and treat any headaches. Volunteers can help by:

- encouraging the person to practice meditation or relaxation techniques
- keeping noise and distractions to a minimum.

Problems with Sleep

Many emotional, psychological and physical concerns may interfere with the client's ability to sleep. To help the person sleep, volunteers can:

- use their communication skills to listen and talk or spend quiet time with the client
- give back rubs, hand and foot rubs
- use relaxation techniques and mental imagery to promote relaxation

- offer a warm drink (nothing with caffeine, please).

If the person's insomnia or inability to sleep is caused by uncontrolled pain, the volunteer should report this to the hospice supervisor who can follow up with the health care professionals on the team.

Skin and Mouth Care

Health care professionals on the team will monitor and treat any skin breakdown or mouth sores.

Volunteers can support clients by:

- helping the nurse or family member reposition the person to relieve pressure
- encouraging the person to use lip balm or whatever has been prescribed for dry or cracked lips
- encouraging the person to use the relief measures for sore mouth that the nurse or doctor has suggested, such as sucking on ice chips or popsicles and drinking lots of fluids
- being alert to the person's changing needs
- being aware of the risk of choking – difficulty swallowing can turn into a swallowing dysfunction that can cause the person to choke. If that is the case, the volunteer should NOT offer drinks of water.

Fatigue

Many people who are dying suffer from constant fatigue. Some say tiredness is worse than pain or nausea. Unfortunately, treating fatigue is not as straightforward as treating some other symptoms. Volunteers can help by encouraging the person to:

- talk about his or her tiredness – understanding how it feels will help everyone
- conserve energy for the things that really matter
- plan to do things at the time of day when they are least tired. morning is best for most people.
- take short naps during the day.
- set short achievable goals
- try gentle exercises like sitting out of bed for meals or taking short walks

What Do People Need Near End of Life?

1. Good symptom control
2. Feeling of security
3. Not to feel they are a burden
4. To be needed
5. Expressions of affection
6. Clear explanations of the disease processes
7. Acceptance regardless of mood
8. The opportunity to be involved in decision-making.

- drink high calorie, high protein drinks. These fluids may also slow weight loss and help maintain muscle strength.

Comfort Measures

There are a number of things volunteers can do to help a dying person feel more comfortable.

1. Keep the room warm, free from drafts but ventilated.
2. Turn out lights that are not necessary. Keep room fairly well lighted during the day. See that lights are not glaring and shining in the person's eyes.
3. Avoid excessive noise. Radio or television should be audible, but not too loud.
4. Reduce odours. Never smoke or wear scented products.
5. Offer cool drinks at least every 2 hours.
6. Brush the person's teeth after each meal. Use a soft brush only. Commercial mouth washes should not be used as they contain alcohol.
7. Give backrubs with a lotion. Massage the person's heels and elbows with lotion as they can become very dry.
8. Help the person turn from side to side every 2 hours – if allowed by your organization. (NOTE: volunteers need special training to assist with turning and positioning.) Place 1 or 2 pillows under the head, 1 behind back and 1 between legs. Bend the legs.
9. Keep under sheets free from wrinkles. Make sure the top bedding isn't too tight over the feet.
10. Brush the person's hair several times during the day, especially if the person enjoys it.
11. Wash the person's face and hands as necessary. Put a cool cloth over the forehead, especially if the person's temperature is high. This is cooling and refreshing.
12. Cut, file and clean fingernails. Use a lotion to keep hands soft.
13. Soak the person's feet in a basin of warm water for 10 to 20 minutes. Dry well, especially between toes.
14. If possible, encourage the person to dress in his or her regular clothes and sit in a chair. If not, help the person put on a housecoat and slippers. Cover the knees with a blanket. Keep the person warm.
15. Assist the person with short walks if he or she is able to walk.

5. Signs that Someone is Nearing Death

When a person enters the final stage of the dying process, two different but inter-related dynamics are at work. Physically, the body begins the final process of shutting down. Emotionally and spiritually, the spirit of the dying person begins the process of release from the body and detachment from the physical, human environment.

While these symptoms may be disturbing to witness, they are normal natural events and the person is seldom in any real discomfort at this stage. The best way to respond to these signs is to provide comfort and support – such as extra blankets for warmth, clean bed linen and clothes, ice chips or moist cloths for dry lips and mouth, reassurance and love.

It is also important for the person to receive permission to say good-bye and die. A dying person will often hold on, even though it brings prolonged discomfort, to be sure those who are left behind will be alright. Assurance from loved ones that it is okay to let go when ready is one of the greatest

As death approaches, our final gift of love is to accept and affirm every aspect of the dying experience, no matter how strange or unfamiliar it may seem to us. Our role is not to belittle, explain, contradict or try to change anything. It is simply to be there and validate the dying person's journey, however it may present itself.

gifts we can give a dying person. Allowing the person to say their goodbyes also makes the final release easier, more loving and, at times, even joyous.

As death approaches, there will be some predictable changes in the person's appearance and behaviours. Although these often follow a pattern, physical decline is very individual. Signs of dying may last for hours or days. Some people may appear to be at "death's door" and then suddenly improve and become very responsive. It is very difficult to accurately predict "how much longer" a client has. Volunteers should be very careful not to speculate or make statements like "it shouldn't be long now".

Hearing is the last sense to go

The client's senses will start to fail, with eyesight usually the first and hearing the last to go. Family members may find comfort in knowing their loved one can still hear so encourage them to continue to speak to the person. Everyone should also be conscious of talking in front of the person as he or she is likely hearing what is being said.

Appetite is gone

Dying people are generally not hungry and may not eat at all during the final days. Similarly, they are not thirsty and do not drink. This will result in decreased urine output. However, there can also be incontinence or some bloating or fluid retention.

Dreaming and hallucinations

More and more time is spent sleeping. The difference between dreaming and wakefulness often blurs. The person may lose touch with reality and confuse their surroundings, the identities of family members and may have conversations (lucid or mumbling) with persons from the past and/or hear voices. Family members may find this distressing, especially if the person is also waving his/her arms or moving his/her legs. Reassure them that this is similar to sleepwalking and does not cause the person any discomfort.

Breathing changes

A dying person's breathing changes dramatically. It may be laboured and there may be unusually long pauses between breaths. Gasps are also common. The person's lips may be bluish and his/her skin cool to the touch. The fingernail and toenail beds may be blackened.

The "death rattle"

Perhaps the most distressing sign is the so-called "death rattle" that is the result of mucous collecting in the throat and lungs. A palliative care physician can treat "death rattle" to help reduce the stress on the family. The "death rattle" does not bother the person as it occurs very close to the actual death and the client is in a reduced state of consciousness.

At the time of death

At the time of death, there will be:

- no response to any stimulation such as shaking or calling the person's name

Signs that a Person is Nearing Death

- Sleeping longer/talking less
- Eating and drinking less
- Trouble swallowing or forgetting to swallow
- Becoming confused – not recognizing time of day or people – and needing more reassurance
- Becoming restless
- Breathing becoming irregular, shallow or "wet" sounding
- Making vocal sounds, often unconsciously
- Irregular heartbeat
- Not reacting to voice or touch
- Feeling less pain
- Eyes remain open even when the person is asleep
- Having vision-like experiences
- Becoming confused or disoriented about familiar things, such as time, place and the identity of family and friends
- Turning away from people or withdrawing.

- no breathing
- no heartbeat and no pulse.

The person's eyes will be fixed in one direction and the eyelids may be open or closed. The jaw may be relaxed and the mouth slightly open. There is commonly loss of bladder and bowel control because of loss of muscle tone.

Death in the First Person

Anonymous

I am a student nurse. I am dying. I write this to you who are or will become nurses, in the hope that by my sharing my feelings with you, you may some day be better able to help those who share my experience.

I am out of the hospital now - perhaps for a month, for six months, perhaps for a year...but no one likes to talk about such things. In fact, no one likes to talk about much at all. Nursing must be advancing, but I wish it would hurry. We're taught not to be overly cheery now, to omit the "everything's fine" routine, and we have done pretty well. But with the protective "fine, fine" gone, nurses are left with their own vulnerability and fear. The dying person is a symbol of what every human fears and what we each know, at least academically, that we too must some day face.

But for me, fear is today and dying is now. You slip in and out of my room, give me medications and check my blood pressure. Is it because I am a student nurse myself or just a human being that I sense your fright? And your fear enhances mine. Why are you afraid? I am the one who is dying!

I know you feel insecure, don't know what to say, don't know what to do. But please believe me, if you care you can't go wrong. Just admit that you care. That is really for what we search. We may ask for whys and wherefores, but we don't really expect answers. Don't run away...wait...all I want to know is that there will be someone to hold my hand when I need it. I am afraid. Death may get to be a routine to you, but it is new to me. You may not see me as unique, but I've never died before.

You whisper about my youth, but when one is dying, is he really so young anymore? I have lots I wish we could talk about. It really would not take much more of your time because you are in here quite a bit anyway.

If only we could be honest, both admit of our fears, touch one another. If you really care, would you lose so much of your valuable professionalism if you even cried with me? Just person to person? Then, it might not be so hard to die...in a hospital...with friends close by.

6. The Importance of Infection Control

Colds, flus and other infectious diseases spread easily from person to person and can pose a real risk to someone who is dying. The greatest risk is from contact with body fluids, such as blood, urine, feces and the droplets we expel when we cough or sneeze. To protect themselves as well as the dying person and family, volunteers are expected to know and use the following standard infection control precautions at all times.

- Make sure you have all your immunizations – including flu shots, hepatitis B shots and TB testing.
- Wash your hands -- using warm soapy water or an alcohol-based hand sanitizer and rubbing your hands -- before and after every contact with the person you are caring for (even if you never touch them). This is the most effective way to prevent the spread of infections.
- Wear latex gloves if you have any open sores, cuts or cracks on your fingers or hands when in contact with the dying person.
- Wear latex gloves if you have to handle anything that is damp – such as laundry, garbage or soiled clothing -- or if you have to clean up any of the dying person’s fluids or secretions (e.g. wiping a nose, helping to clean teeth, cleaning up spills on the floor). Dispose of the gloves immediately afterwards and wash your hands.
- Do not visit the person if you have a cold or flu. Contact your supervisor and look after yourself at home.
- Wear a mask if the person is coughing excessively. But let him/her know that you are taking this precaution for their protection as well as your own.
- Never, never handle needles. Follow your organization’s procedures.

What to do in case of accidental exposure

Should you accidentally:

- get stuck by a needle
- be cut or scratched by a razor blade or other sharp instrument that could be contaminated with body fluids
- have blood or other body fluids splashed in your eyes or mouth or onto broken skin

If it pricks, do not touch

For volunteers, just like Sleeping Beauty, “sharps” or needles are out of bounds. Volunteers are NOT allowed to “recap” or handle needles. If you come across an exposed needle in the person’s home and you are on your own, notify your supervisor or someone on the care team.

Remain calm:

- Immediately wash the affected area with soap and water or flush your eyes with cool water.
- Contact your supervisor to report what happened.
- Contact your family doctor to review your exposure and any additional steps you should take.

Module 7:

Caring for People at Home or in a Hospice

Learning objectives:

1. Understand the unique challenges of caring for a dying person at home or in a hospice
2. Understand the role of food in the life of a dying person and family, and how food affects the quality of hospice palliative care
3. Understand the causes of appetite loss as well as strategies to help people increase their food intake of food
4. Learn about body mechanics and practice lifts and transfers (if allowed/required by your organization)
5. Learn and practice other practical care skills, such as bed-making, positioning and toileting
6. Learn basic safety precautions

Competencies:

At the end of module seven, volunteers will be able to:

- Describe the role of a volunteer caring for someone at home or in a hospice and how it differs from the role of hospice palliative care volunteers in other settings
- Describe the role of food in people's lives
- Demonstrate the ability to implement strategies to help the dying person increase their food intake
- Demonstrate other practical skills that may be required when caring for someone at home or in a hospice
- Explain basic safety precautions in the home or hospice.

1. What's Different about Volunteering in Someone's Home or a Hospice?

The volunteer's role in hospice palliative care varies depending on the setting. In a hospital or long-term care home, there are more professional staff – nurses, aids and others – to provide care. At home or in a hospice, more of the care falls to family members and volunteers.

Volunteers who are caring for someone at home or in a hospice may be asked to help with feeding or lifting/positioning people. They may also be more directly involved in personal care tasks such as feeding the person, changing the bed, helping the person use a bedpan, or helping them get to the washroom. Many of these tasks – particularly the ones that involve physically moving the person – create more risk for the dying person and for the volunteer so it's important to learn the correct techniques.

2. The Importance of Food and the Impact of Loss of Appetite

What we eat and how we prepare our food are influenced by culture, tradition and choices. Food and eating are not only essential to survival; they are also central to many ceremonies and social events and are one way we express feelings of love, nurturing and community. Food is, in fact, the “staff of life”.

Most people who are dying develop aversions to certain foods and lose their appetite. Changes in appetite may be a side effect of medications, the disease process and even the dying process. Some changes are due to medically prescribed and monitored diets. In some cases, people simply decide not to eat.

Since food is so central to our concepts of health and well-being, it can be very disturbing to both the dying person and the family when normal appetites and eating patterns change. Sometimes families will feel the need to push food on the person to help build or maintain strength. Others will despair as they realize that loss of appetite signals “the end is near”. Volunteers who have a solid understanding of the pivotal role of food in the “human condition”, will be better equipped to support the dying person and family in coping with the challenges of eating.

Food and Nutrition Care

The health care professionals on the care team will develop a nutrition plan for the dying person that takes into account the foods the person likes as well as their culture. They will also provide tips on how to increase the energy and protein in the person's diet.

Keeping a team notebook is an effective way to record the person's fluid and food intake each day, as well as any concerns you may have about their nutrition.

Volunteers can help by:

- being sensitive to cultural and religious dietary requirements and how they may influence the feelings and actions of family members
- normalizing the eating experience and encouraging the person and family to follow the recommendations of the healthcare professionals
- encouraging the person to try small amounts of food and drink, or to eat small amounts more frequently
- cleaning the person's teeth and mouth before they eat to stimulate the taste buds
- supporting the person and family, and communicating their food-related needs to the care team
- helping the person participate in family ceremonies and rituals that they feel are important to their well-being
- using comfort measures they have learned, especially if the client has mouth sores, nausea and vomiting
- helping family members understand the person's decreased need for nutrition at the end of life.

When Families Make Decisions about Nutrition

During your volunteer assignments you may encounter family members who are distressed that the dying person is not eating and who think about or ask to have fluids and nutrition administered artificially through a feeding tube or an intravenous drip.

Although providing fluids and nutrition may keep the person from becoming dehydrated and confused or make them more comfortable, it is usually not beneficial in the end stages of life and will not change the eventual outcome. In fact, having a feeding tube or IV line will decrease the person's mobility and cause the skin to breakdown as well as other painful symptoms, such as vomiting, lung congestion, shortness of breath and swelling of limbs.

However, it is not the role of the volunteer to advise the person and/or family in making this type of decision. Volunteers can and should help by:

- supporting the person's and/or family's decision (no matter what it is)
- encouraging the person and/or family members to discuss their feelings of hope and loss.

3. Body Mechanics, Lifts and Transfers

In some jurisdictions, volunteers helping to care for people in their home or a hospice may be asked to help with repositioning people, getting them to the washroom or changing their beds. To fulfill that role, volunteers must know how to move people safely. If your organization requires volunteers to be able to help with lifts and transfers, your training program will include detailed instructions on body mechanics and the physics of how to safely reposition or assist a person.

But helping to shift and move people involves much more than physics. It also involves knowing enough about the person that you can help them without hurting them. Each person has unique needs. The health care professionals on the hospice palliative care team will tell you what you need to know about each person. The nurse's assessment of the person's pain will include a plan for managing pain during repositioning. For example, you may be asked to be sure that you only reposition a person after he or she has received pain medication and the medication has "kicked in" or you may be told that the person's right arm must be placed in specific position to reduce swelling. You will be shown how to take special care turning someone whose cancer has metastasized to the bone because pathological bone fractures can happen easily.

Before You Lift ...

Assess the Risks

The goal is to reposition or help the dying person without hurting them or yourself.

Before starting any lift or transfer, ask yourself the following questions:

- By assisting the client, am I at risk of hurting the client or myself?
- Have I been trained to safely complete this task?
- Is there someone else in the home who can assist with the task?

Remember:

- If you do not feel you can safely perform the task, ask for assistance or wait until someone arrives who can help.

- Check your posture – your back should be straight with its normal curves and your chin should be tucked in.
- Lift with the strong leg muscles – do not use your back.
- Shift don't lift – travel the shortest distance.
- Wear safe footwear, keep your feet shoulder width apart and the person's weight close to your body.
- Position equipment and engage the brakes.
- Lift first, then turn – do not twist your body.

Ask Your Supervisor

Before using what you have learned about lifts and transfers with a dying person, check with your supervisor. Make sure the supervisor wants you to do this type of task, and that you know what to do for the person you're helping.

What to do if the Person Falls

1. Remain calm
2. Do not attempt to stop a person from falling
3. Protect his/her head

Once the person is on the floor there is no hurry. Assess the situation. Has the person's condition changed? If not, take time to make the person comfortable and reassure them. Laugh, if you can. The person is safe on the floor (there is no danger of falls) so you can wait until help arrives.

Do not try to help the person up from the floor. This requires trained staff.

Tell family members what happened and reassure them the person is comfortable. The person may also want to reassure them directly.

Notify your supervisor and complete the required Incident Report.

If You Find the Person on the Floor

Say the person's name and ask if he or she is okay or if they have hurt themselves.

Do not try to help the person up from the floor. This requires trained staff.

Reassure the person and call for assistance. Call 911 only if it is a medical emergency.

Tell family members what happened and reassure them. The person may also want to reassure them directly.

Notify your supervisor and complete the required Incident Report.

Module 8: Grief and Bereavement

Learning objectives:

1. Understand grief as a normal part of life and how people cope with grief
 2. Understand the diversity and complexity of the grief experience
 3. Understand current grief and bereavement theory and practice
 4. Understand the role of the volunteer in support people who are grieving
 5. Be aware of grief and bereavement resources in the community
-

Competencies:

At the end of module eight, volunteers will be able to:

- Discuss examples of the human experience that may evoke a grief response
- Describe some of the losses that people might experience during the process of dying and how they may react and cope
- Describe some of the losses that families experience when someone is dying and how they may react and cope
- Identify personal, social and cultural factors that affect how people grieve
- Discuss what helps or hinders a grieving person
- Be able to identify complex grief and know when to link someone with other services

1. What is Grief and Bereavement?

Grief, mourning and bereavement part of the human response to death.

Grief is a natural response to any type of loss and a source of stress for anyone experiencing a loss. People need both physical and emotional energy to cope with the changes brought on by loss. In our society, grief is almost always seen in terms of “work” or “tasks” that must be accomplished in order to cope with the new situation created by loss. Although there are some common physical, emotional and behavioural signs of grief, each individual grieves each loss uniquely.

Anticipatory Grief is the grief someone experiences in anticipation of death. The dying person and family may experience this anticipated loss of life as well as all the opportunities that are lost when death will occur. During this period of anticipatory grief, the person and family will often deal with unfinished business and/or begin to mourn.

Mourning is a process that helps individuals cope with grief. It involves rituals – such as burial rites and memorial services -- that reflect cultural and social norms and practices. During this mourning period, a grieving person undertakes the “tasks of grief”.

Tasks of Grief generally include:

- acceptance of the reality of the loss
- the experience of emotional pain and suffering
- adjustment to living without the loved one
- letting go.

When someone moves on with their life, builds new relationships and settles into new patterns of living, it is generally accepted that they have completed these four tasks.

Physical, Emotional and Behavioural Signs of Grief

- Tightness in the throat
- Disturbed sleep patterns
- Loss of energy
- Changes in appetite
- Palpitations and/or chest pain
- Loss of sexual desire
- Numbness
- Sadness
- Anger
- Fear
- Guilt
- Disorientation
- Crying and sighing
- Restlessness
- Wanting to die
- Abusing alcohol or drugs

Bereavement is the state of suffering a loss. A bereaved person is someone who has experienced the recent loss of a loved one through death and who is going through the process of mourning.

Needs of People Who are Grieving

Everyone grieves differently and will have different needs. But most grieving people need and value:

- being alone and yet having company and being with others
- the opportunity to express their feelings without embarrassment – this often requires “permission” from those who are not bereaved
- the opportunity to tell and re-tell the stories of the life and death of the loved one
- information about what is normal (am I going crazy or is this normal to feel the way I do?)
- the gift of presence – just being there and being able to be counted upon
- permission to be self-absorbed and not feel guilty about it
- being able to laugh and not feel guilty about having fun
- permission to experience and express a roller coaster of feelings
- help with basic needs like grocery shopping, housekeeping and meal preparation.

We have all experienced loss in one way or another. All of us have mourned and grieved for some of those losses and we’ve done so in a way that reflects our background and outlook. Volunteers will witness grief in a variety of forms. You’ll see family and friends who “pull away” and distance themselves from a person they care for and you’ll see outpourings of emotion and hear tales of regret and sorrow. Loss and grief affects each of us differently.

Gallasch, 1996

Myths About Grief

Sometimes our ability to help people who are grieving is affected by common myths about grieving, including:

- Keeping busy is the best remedy for dealing with the death of a loved one.
- The less the subject of the death of a loved one is brought up, the easier it will be for the grieving person to adjust.
- Time heals.
- The person who openly expresses their feelings about the death of a loved one is better able to cope than the person who keeps to him/herself.
- Usually, three months after the death, family members will adjust and begin to seem normal again.

The role of the volunteer is to support the bereaved person -- not to try to “take away the pain”.

- The best thing to do is to forget about the dead person.
- If the loss is not the first, the person usually heals faster. They have been there and the second time is easier.
- Because of the duration of the illness, family members and friends should have an easier time coping: they expected the person to die.
- Personal belongings should be disposed of as soon as possible. This way there are no painful reminders around the home to upset family members.
- People who visit the gravesite are just living in the past and refusing to move on.
- It's best to protect young children from death and not express your emotions in front of them.
- Wait until the child is older and then explain to them what has happened to their loved one.
- Having many sympathetic people around tends to prolong grief.

Grief takes time – at least a year and a half -- and people grieve in different ways. They need support and understanding, and the chance to talk when they want to and to express their grief in their own way.

Grieving is a personal journey and people's needs will vary. Volunteers should never make assumptions about how people will handle grief or tell them what they should do. Volunteers can help by using their communication skills and just being themselves.

How Volunteers Can Help People Who are Grieving

- Be with the griever in their pain; don't shy away from it
- Affirm and reaffirm the griever's value as a person
- Allow the person to express anger, even towards you.
- Explain the process of grieving, and explain that the emotions they are experiencing are natural
- Reassure the grievers that they will survive and the pain will diminish, and encourage them to recognize the good that remains after the loss
- Help the person decide what to do with mementos/reminders
- Plan a schedule with the grievers and help them keep to it
- Help with the necessary decision-making, but don't make the griever's decisions
- Give comfort in ways that you would appreciate
- Bring "aliveness" to the person: plants, children, pets, people
- Plan for difficult events such as anniversaries and holidays
- Encourage the person to develop and maintain friendships and connections
- Watch for escape into addictive patterns and behaviours
- Recognize the griever's vulnerability and help prevent exploitation
- Recognize and reinforce each sign of returning strength
- Try to find ways in which the griever can give as well as receive
- Help the family deal with practical concerns such as bills and the funeral

2. Stages in the Normal Grief Process

Shock. Some people never go through a prolonged stage of shock and are able to express their emotions immediately. Others say they feel numb and no emotions or tears will come. Sometimes there is denial. Gradually the bereaved person becomes aware of what has happened and is able to cry or show emotion.

Emotional Release. Many people begin at this point. It is good to cry in grief, but some people may need permission to cry.

Pre-occupation with the Deceased. The bereaved person may try to think of other things but finds him/herself unable to shift her/his mind from thoughts about the deceased. This is normal.

Physical Distress. Symptoms such as tightness in the throat, shortness of breath or a hollow feeling in the stomach may come in waves lasting from 20 minutes to a full hour.

Hostile Reactions. People who are grieving often display a disconcerting loss of warmth in relationships and a tendency to respond with irritability and anger. This anger is often directed at the doctor, nurse or clergy, and these feelings can make the bereaved feel that he or she is going insane.

Guilt: There is always some sense of guilt in grief. The bereaved think of the many things that they felt they could have or should have done, but didn't. They accuse themselves of negligence. If there was any unresolved anger with the person who died, the bereaved person will feel guilty.

Depression: People may feel there is nothing to live for and that nothing seems worthwhile. They feel helpless/hopeless.

Withdrawal: People who are grieving often withdraw from social relationships and they sometimes find normal daily routines are disrupted.

Re-entering Relationships: Over time, the person readjusts to his/her new environment (without the person who has died) and forms new routines and relationships.

Resolution and Readjustment to Reality: The person gradually readjusts – although there will be times when grief reappears even when the person may have thought it was “all over”.

Helping People Manage the Stages of Grief

The role of the volunteer is to be there when the grieving person wants to talk. Volunteers will listen and may hear the same fears, emotions and stories over and over again. The repetition is part of integrating the past with the present, remembering and saying good-bye. As a volunteer, it's okay to show your emotions.

If you're at ease showing how you feel, it can make it easier for the person who is grieving.

- Help the person who is grieving:
 - express their pain and sorrow, and talk about their feelings of love, guilt and hostility
 - understand their emotional reactions
 - accept the pain of bereavement and find meaning in their suffering
 - talk about new ways of interacting with people and new modes of living
 - set short-term, realistic goals for themselves as they work through their grief process.
- Help with routine tasks if the person is having trouble concentrating on day-to-day things.
- Recognize when to keep silent. Don't try to fill empty spaces with words.
- Relax and keep your sense of humour and perspective. More than anything else, bereaved people need contact with these qualities. You may be the only one providing it.

When talking with the bereaved, respond with empathy. For example: "How can I be of help?" or "I wish I could take the pain away." Avoid clichés such as: "I know how you feel." or "You will marry again." or "You'll get over it." or "The person who died wouldn't want to see you cry."

3. Promoting Health and Well-Being for People who are Grieving

Volunteers should not give advice but they can point out things people who are grieving can do to protect their own health.

Physical health

- Exhaustion makes you susceptible to illness, so pay attention to nutrition, rest and exercise.
- Eat lightly, even if you have no appetite.
- Sleeplessness is common, so relax by reading, writing letters or a journal, knitting, and try to take naps in the day.
- Start small with exercise - take a walk, or garden - and gradually gain momentum.
- If you have symptoms of an illness or people are telling you to see a doctor, consult one - even if you feel it isn't necessary.
- Pamper yourself: sleep in, buy yourself something special.
- Feel free to cry as tears are healing and help to lift burdens.

Emotional health

- Accept or ask for help. People usually want to help, but are unsure what to do.
- Be aware that severe emotions are okay.
- Make it known when you don't want company.
- Try to find someone who has been through a similar experience: they understand.
- Don't feel that you have to put up a brave front.
- Numbness at first is normal.
- Seek new and different relationships if needed, but at your own pace. Avoid trying to replace the lost person quickly.
- Don't feel guilty about feeling happy.
- Take private time to get in touch with yourself and the changes in you.

Intellectual health

- Avoid hasty major life decisions within the first year. If this is necessary, seek advice from an impartial trusted source.

- Don't let others take control of your life.
- Don't idealize the dead person as this makes mourning difficult. Realize both their strengths and their weaknesses.
- Temporary lapses of memory are normal.
- Avoid losing yourself in work: you need relationships with family and friends.

Spiritual health

- Personal faith can be a source of comfort, but maintaining faith can also be difficult.
- Remember that it is okay to have a sense of humour.
- Let creativity come through in music, poetry and photography.
- Reaching out and helping others can be good therapy.
- Read, meditate and try to understand your faith.

4. What is Complicated Grief?

Complicated grief is the usual process of grief complicated by other issues. Many factors influence how an individual will grieve. Some people, in addition to grieving the loss of someone, will also be coping with:

- severe depression
- drug or alcohol dependency or both
- a history of mental illness
- developmental disabilities
- chronic health problems
- history of sexual or physical abuse
- suicidal history and/or plans
- multiple or other unresolved losses.

Signs of Complicated Grief

Some signs of grief are quite subtle, such as simply not eating or sleeping or being edgy or overreacting to small or minor annoyances. These may just be normal responses to grief or they may signal that the person has some underlying issues that are getting in the way of normal grieving.

Other signs are less subtle. Drinking too much can be a sign of complicated grief as can saying things like "I wish I could die". Statements like this should not be taken

lightly. It's best to talk to the person about it to see whether this statement is a suicide threat. One approach can be to ask the person how they would do this (i.e. die). If it appears that he/she has a plan, then get professional help, as soon as possible. If it is an emotional response to their pain and loss, then active listening and continued support should help. Volunteers should keep their supervisor and team aware of any signs of complicated grief.

Signs that People Need Professional Bereavement Support

People who are experiencing complicated grief need professional counseling and support. The following High Risk Bereavement Inventory is included in this manual, courtesy of Dr. Michele Chaban, Director of the Psychosocial-Spiritual Program, The Temmy Letner Centre for Palliative Care, Mount Sinai Hospital, Toronto, Ontario. This inventory, developed by Stephen Fleming, lists social, psychological, situational, physical and spiritual factors that may indicate the need for professional support for a bereaved person. Volunteers can use it as a guide when supporting bereaved people. Volunteers should be aware of the risk factors and contact their supervisor if they have any concerns about the person they are helping

Social Factors:

- perceived reduction in quantity and frequency of contact with old friends (i.e. becoming isolated)
- young, married childless spouse
- young children or adolescent dependent children
- anticipated loss of major social roles as a consequence of loss of dying person
- quality of marriage
- few activities, interests or hobbies
- poor contact and relationships with family members.

Psychological Factors:

- previous history of depressive or mental illness
- perceives environment as failing to meet needs and/or actively unhelpful (totally negative)
- past history of poor coping with major crises
- increasing consumption of sedatives, tranquilizers, alcohol or tobacco (watch for use of valium, sleep or "nerve" medication)
- increased intimacy with the dying person during terminal illness

- anticipatory grief (poses immediate post-death risk)
- complete denial of illness or its terminality (i.e. pretends it does not exist. Note: watch for cultural influence which mitigates denial).
- acknowledges any of the following feelings:
 - What will I do now?
 - I'm worried I might have a nervous breakdown.
 - It's not real.
 - I can't get myself to do things.
 - I feel empty.
 - I wouldn't care if I died tomorrow.
 - I don't want to live without him/her.
 - I can't stand being alone.
- presence of strong self-reproach, self-depreciating remarks and anger at self, particularly with respect to relationship with dying person
- made a pact with the ill person to take own life and has a plan how to do it
- inhibition of feelings, unable to acknowledge or talk about feelings of impending loss
- perception that dying person received "poor care"
- altered mental functioning, extreme difficulty in concentrating, remembering, making decisions
- severe depression.

Situational Factors:

- sudden unexpected death or short fatal illness (under two months)
- untimely death – premature or post mature, dying person does not die on schedule
- young bereaved (55 and under)
- ethnicity: not a cultured to prevailing attitudes toward bereavement and mourning (may not know what is expected or allowable for these in our culture)
- low socio-economic status
- multiple life crises, concurrent losses or problems:
 - loss of income
 - financial problems
 - job loss
 - divorce
 - difficulties with children
 - pregnancy

- marital conflict
- recent marriage
- recent loss of another close family member or friend.

Physical Factors:

- poor health before the illness of the dying person
- deterioration of health
- poor sleep patterns
- poor eating habits.

Spiritual Factors:

- perceived lack of help from faith, religion, church, God or clergy.

5. Helping Children Cope with Grief

Parenting styles and cultural norms will play a large part in how a family helps a child cope with grief. While many parents will be open and truthful about what is happening, others will feel strongly about protecting the child from grief. Even when volunteers disagree with the family’s approach, it is not appropriate for them to impose their values on the family. The volunteer’s role is to affirm the child’s feelings and support the adult family members.

Children understand death in different ways at different developmental stages. Children can be very aware of the disruption to their normal routines and lives but may not ask questions or reveal their knowledge. Adolescents may seek the volunteer out and want to talk about their feelings or ask for information. Always check with the parent before recommending any materials or resources.

Children should be allowed to share in grief and attend the funeral or wake but only if they want to. They might feel angry at being abandoned, scared of being alone, confused, or guilty that they might have caused the death. You can help by answering questions honestly, helping them express emotions, reassuring them that it is okay to feel the way they do, and being patient if they bring up the subject of death again and again.

Most hospice palliative care programs provide special training and screening for volunteers who work with children.

Listening is the oldest and perhaps most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to affect the most profound changes in the people around us.

Rachel Naomi Remen, 1996

6. Helping Older People Cope with Grief

It is easy to underestimate the effect of grief on older people because they are “used to it”. Older people may have developed ways of coping with grief but that doesn’t make grief easier for them. In fact, cumulative losses over a lifetime can lead to severe grief or “bereavement overload”.

With age, older people are already experiencing losses in their income, health, independence and status. The death of a spouse can be devastating for an older person because it can mean the loss of the last close relationship and source of physical affection. Although older people may be more realistic about death, they often have an intense fear of dying – in particular, dying alone. Older people may also be more reluctant to talk about how they feel or express their grief.

It may help to explore their “history of loss” by asking about the people they have lost, and how they came to terms with the loss. Older people need opportunities to describe their losses and find meaning in the losses and change. Talking about their experiences and acknowledging their pain and distress can prevent further depression. However, volunteers must walk a fine line between supporting an older person and encouraging self-pity. Genuine grief work lifts despair and bring relief.

Module 9: Self Care

Learning objectives:

1. Understand what stress is and how it affects health and well-being
 2. Understand the stresses a hospice palliative care volunteer may experience
 3. Learn strategies to manage stress
 4. Learn about the resources available to support volunteers and help them manage stress
-

Competencies:

At the end of module eight, volunteers will be able to:

- Define stress and describe how it can affect health and well-being
- Describe the stresses a hospice palliative care volunteer may experience and the impact of those stresses.
- Demonstrate the ability to use different strategies to manage stress
- Describe the resources available to support hospice palliative care volunteers and how to access those resources

1. What is Stress?

Stress is the body's way of responding to demands.

When people feel stressed by something, their bodies react by releasing chemicals into the blood.

These chemicals give people more energy and strength, which can be a good thing if the stress is caused by physical danger. But stress can be a bad thing when it is in response to an emotional situation or if the stress goes on for too long. Stress can affect both body and mind. People under large amounts of stress can become tired, sick and unable to concentrate or think clearly.⁷

Stress is the mind body reaction we experience in the face of an apparent threat to our well-being.

John Message, Cairnmillar Institute

People often experience stress when they find themselves in situations where they have little control.

The signs of stress include:

- muscle tension
- pounding heart
- sweating
- dry mouth
- increased breathing rate
- butterflies in the stomach
- cold hands and feet
- the urge to go to the bathroom.

If stress goes on for too long or becomes chronic, people may experience the following symptoms:

- fatigue
- apathy or depression
- being overly emotional
- loss of enjoyment and spontaneity
- excessive worrying, nervousness and anxiety
- loss of sex drive
- irritability or impatience

⁷ Mountain State Centers for Independent Living. Understanding and Dealing With Stress.

- inability to make decisions
- confusion or forgetfulness
- aggression
- racing thoughts and inability to “switch off”
- restlessness or feeling jumpy
- unrealistic expectations
- increasingly critical outlook or intolerance
- stomach pain, allergies, and/or urinary problems

As a hospice palliative care volunteer, you may see signs of stress in the families caring for people who are dying.

2. The Stresses of Being a Hospice Palliative Care Volunteer

Supporting a dying person and family can be stressful and exhausting. Volunteers come to care about the families they are helping but these relationships have a bitter-sweet quality to them because we know that there will be a final “good bye”. The connection will be short and intense, and it can be draining.

Many different factors can cause stress for the hospice palliative care volunteer, including:

- factors related to the dying person such as problems with symptom control, psychiatric or personality issues and anger or anxiety over dying
- trying to support a dysfunctional family
- workload
- lack of clarity about their role, lack of communication or conflict with other members of the team
- lack of resources or administrative problems in the program
- balancing the demands of their volunteer work with their other responsibilities (e.g. family, work, leisure)
- inadequate training for the role
- stresses in their own personal lives
- unrealistic expectations for themselves
- the challenge of just “being” with someone rather than “doing” for them.

3. Strategies to Manage Stress

Because being a hospice palliative care volunteer can be stressful, it's important to look after yourself and manage stress.

Reflection

Part of self-care is reflection. For some people, reflection comes easily. They keep a journal or have a friend with whom they can talk about their stress. For others, reflection seems like wasting time. As a hospice palliative care volunteer, reflection is essential. You will find yourself thinking about your own understanding of life and death and past losses. This kind of reflection will help you cope with your own personal reactions when someone you are helping dies.

If you never say NO, what is your YES worth?

A Support Network

Part of good self-care is having a support network: people with whom you can share at a deep level and who accept you unconditionally. The hospice palliative care team will be one network of support – as will other volunteers in your program. You can also get support from the families you are helping.

Having Fun

It's important to create time and opportunities for fun to recharge your soul, including:

- physical exercise
- mental exercise – artistic pursuits, reading, painting
- spiritual exercise – meditation, time alone for dreaming, gathering with like-minded people
- relaxation – listening to music, walking in nature, going to the movies, having a massage
- other things you like to do.

Relaxing into Being

To succeed in life, we are busy “doing” – getting degrees and promotions, rushing from task to task. However, when a person is nearing end of life, the doing is over and all that is left is simply “being”. Volunteers – along with other members of the hospice palliative care team – will be brought more

When are Boundaries Crossed?

If you say “yes” to any of the following, you may have crossed boundaries and should talk to your supervisor:

- You spend a lot of time thinking about the dying person and family.
- You want to take over some of their burdens.
- You are starting to think of the dying person as your responsibility.
- You are resentful of the dying person's expectations of you.
- You are spending either a great deal more or less time with the person than scheduled.
- You are spending significantly more time than allotted on a volunteer-related service.

and more to the place of just “being” with the person. This can be a difficult place to go, yet it is also an opportunity for the miracle of authentic human connection to occur.

Revisiting Boundaries

As a volunteer, it’s important to set boundaries with the person and family – to clearly define what your role is and what you can and cannot do. If you are not clear about your boundaries, you may find yourself becoming more involved than you want to be. If you allow your boundaries to get pushed too often, you will begin to feel overwhelmed and resentful, and your body will feel you’re not listening and do something to slow you down.

Personal boundaries imply that you are meeting your own needs before meeting the needs of others. This is not selfish: it is a way to stay healthy so that you have something to give to others.

Check that you are not trying to be indispensable – always coming to people’s rescue. That can lead to a loss of one’s self with all your time taken up with activities that you “should” do for others. If you feel you are stuck in over-doing, stop and rest. Play! Being aware of your own needs will help you stay out of the trap of excessive care giving.

The Volunteer Self-Care Kit

1. Be gentle with yourself. Remind yourself that you are human and not omnipotent. Responsibility for solving problems does not rest with you alone. Allow yourself to make mistakes and still feel okay as a person. You are bound to feel helpless at times – admit it without shame.
2. Ask for help when you need it – from your supervisor and/or other members of the team. Asking for help is a sign of wisdom, not failure.
3. Give timely support, encouragement and praise to other members of the team, and learn to accept support and praise in return.
4. Value the relationships you have. Say the things that are important to say and express the feelings that are important to share.
5. Get to know your own strengths and inner resources so you feel comfortable with yourself. Be aware of your feelings and how you experience them – then you will be able to allow others their feelings of anger, hurt and sadness without rushing in to comfort, challenge, change, defend or retaliate.
6. Learn to recognize the difference between complaining that relieves stress and complaining that reinforces stress.
6. Surround yourself with growing things, life, colour and creativity.
7. Let off steam emotionally and physically regularly.
8. Use your sense of humour frequently.
9. Change your routine often and your tasks when you can.
10. Practice saying “no” so that you can set limits when you need to.
11. Become familiar with your own signs of stress and develop ways to deal with them.
12. Take time to step back from what is happening to gain perspective. Be open to new learning, approaches and values.