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 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

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.

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

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 – mainly as free-standing volunteer programs. Over time, these programs gradually evolved from individual, grass roots efforts to a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with or dying from an illness.

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 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

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

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.

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 members[2]. NOTE: all teams will not necessarily involve all these individuals and skills.

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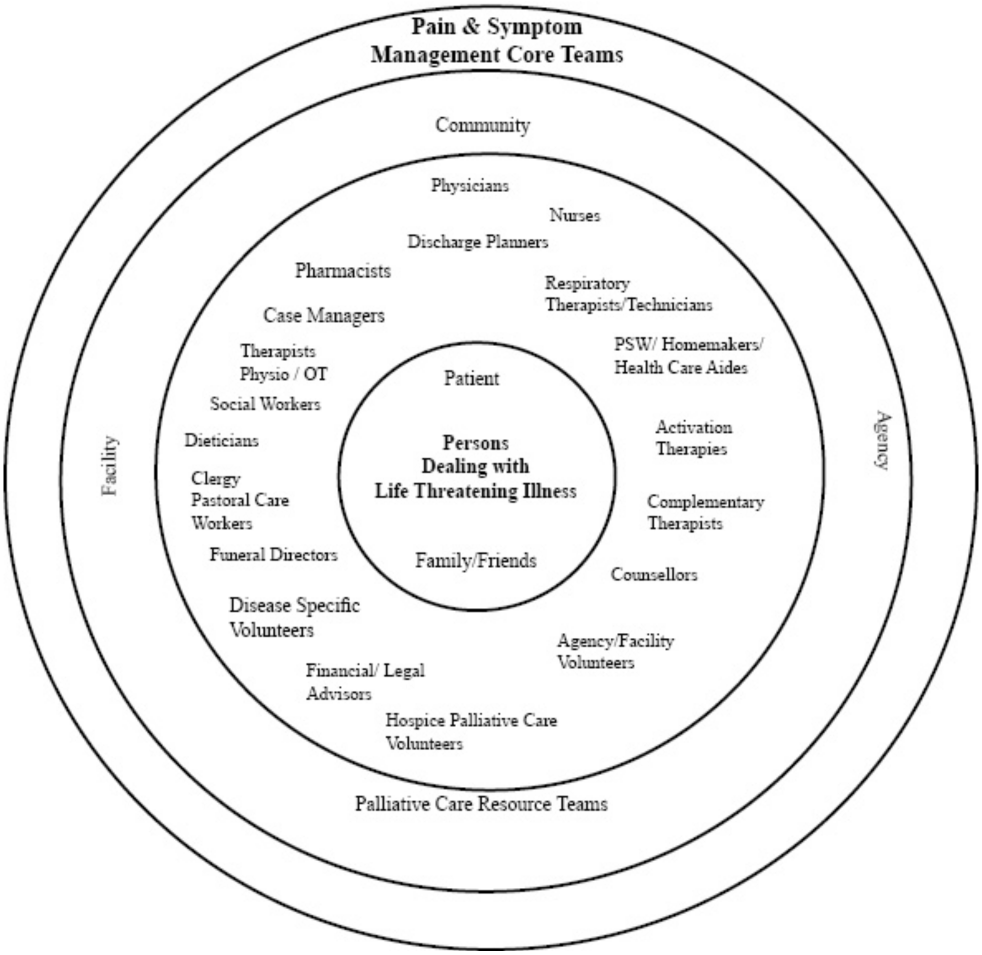
[1] Gallasch P. (1996). Volunteer Training Manual. National Palliative Care Project (Australia).

[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:

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)

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.

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 at 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).

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.

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).

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