HPCO
Hospice Palliative Care Ontario

Volunteer Training Handbook

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Acknowledgements

Enabling consistent, integrated and compassionate care is a shared goal of Hospice Palliative Care Ontario (HPCO) and its members. The training and support provided to hospice volunteers is an important aspect of ensuring high quality care. This training curriculum enables all hospice volunteer programs in Ontario, regardless of size or location, to achieve the same standard with respect to volunteer training.

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Background

Hospice services in Ontario are provided primarily in the homes of clients. Since the early 1990s, hospices have invested considerable time, expertise and energy into training their volunteers to meet the incredible variety of challenges posed by providing care in the home.

In 1991, Hospice Palliative Care of Ontario (formerly Hospice Association of Ontario) developed and published a training manual to assist its growing membership in preparing volunteers for hospice palliative care programs. At that time, the hospice programs in Ontario were in their infancy. A standardized training curriculum became an essential component in ensuring quality care by volunteers throughout the province.

The hospice system has grown substantially since 1991 and now HPCO member hospices have trained and supervised over 14,000 volunteers.

The original hospice volunteer training curriculum has been updated several times since 1991.

In 2016, the training content was updated by the Online Volunteer Training Working Group and HPCO provided access to an online learning system that was developed in collaboration with Saint Elizabeth. This system enables local hospice volunteer trainees to access the majority of HPCO Hospice Volunteer Training Curriculum online. The implementation of the online training system will support over 1,200 new volunteers annually.

HPCO's Hospice Volunteer Training curriculum is built on the expertise of our member hospices and meets the requirements of HPCO Standards.

Overview of HPCO's Hospice Volunteer Training Curriculum

HPCO's Hospice Volunteer Training consists of 15 required topics, listed in chart below.

HPCO Hospice Volunteer Training curriculum (2016)	Methods for delivering HPCO's Hospice Volunteer Training curriculum
Topic 1 - Introduction to Hospice Palliative Care Topic 2 - Role of the Volunteer and Understanding Professional Boundaries Topic 3 - Communication Skills Topic 4 - Pain and Symptom Management Topic 5 - Understanding the Dying Process Topic 6 – Spirituality Topic 7 - Grief and Bereavement Topic 8 - Care for the Caregiver Topic 9 – Family Topic 10 – Ethics Topic 11 - Psychosocial Issues and Impact of Illness Topic 12 - Cultural Considerations Topic 13 - Infection Prevention and Control	**May be taught in person or online**
Topic 14 - Body Mechanics, Assists and other skills* (offered in person with practice opportunity) • This a requirement for volunteers who visit in the community. • Must document completion of this module before training is deemed "complete". • See Visiting Hospice Services Standard D7.2 for more information. Topic 15 – Orientation to the Hospice policies, etc. • This a requirement for all volunteers. • Must document completion of this module before training is deemed "complete".	**Must be taught in person**

Completion of all the online modules does not mean that all required training has been received. Full training for hospice volunteers, as per HPCO standards, includes additional topics that are not currently available in the online learning system and must be delivered in person. Each hospice is responsible for ensuring completion of all training topics prior to assigning a volunteer to a direct service.

Methods for delivering HPCO's Hospice Volunteer Training Curriculum

This Handbook contains the content for all 15 topics that are essential components of the HPCO Hospice Volunteer Training Curriculum. It can be provided to volunteers, at the Hospice's cost, as a reference document regardless of the method(s) by which the volunteer is trained.

This document alone does not replace completion of the required training topics (listed on previous page), which can be offered either in-person or online. The Hospice determines which training method will be used for the various topics (except for **Topic 14 and Topic 15** which **must be completed in person**).

The Hospice is responsible for screening the volunteer prior to training, regardless of the training method.

In-person training sessions

- The Volunteer Coordinator may use the content located in Handbook, as well as the Facilitators/Best Practice Guide, to provide in-person training.
- The Volunteer Coordinator must take an active role in the continuous screening, supervision and support of each volunteer throughout the in-person training sessions.
- The Volunteer Coordinator must track each volunteer's progress throughout the training program.
- The volunteers can follow along and take notes using their personal copy of the Handbook provided to them by their local hospice.

Online training system

- When utilizing the online training system, in whole or part, HPCO's expectation is that the Hospice will register only volunteers that have been vetted (i.e. the Hospice is confident they will be accepted to volunteer once training is complete). Due to the cost involved, the **online training system is not to be used to determine suitability for the volunteer role**.
- The Volunteer Coordinator must take an active role in the continuous screening, supervision and support of each volunteer throughout the training program.
- The Volunteer Coordinator must track user progress throughout the training program.
- The volunteers can follow along and take notes using their personal copy of the Handbook provided by their local hospice.

The role of the Hospice

Each hospice provides a certificate of completion to its volunteer once it has ensured that the volunteer has completed all required training topics.

Chapter 1:
Introduction to Hospice Palliative Care

Objectives

- Identify the definition, values, philosophy, and principles of hospice palliative care
- Recognize the continuum of hospice palliative care and different models of care
- Develop an increased awareness of the common fears associated with death and dying
- Recognize the most common needs of the individual who is dying, as well as family members, friends and care providers
- Recognize the role of the volunteer and the importance of the interdisciplinary team

Sections in this Chapter

Section 1: Hospice Palliative care

What is Hospice Palliative Care?

Hospice Palliative Care is an approach to the way we care for individuals who have been diagnosed with a life-threatening illness or who are bereaved.
It aims to relieve suffering and improve the quality of living and dying for the person and their family.

Introduction

Hospice Palliative care is a philosophy of care that focuses on the physical, psychosocial, practical and spiritual needs of individuals living with a life-threatening or life-limited illness, those who are for them, and those who are bereaved.

- Aims to relieve suffering and improve the quality of living and dying
- Aims to treat all active issues, prevent new issues and occurring, and promote opportunities for meaningful experiences, personal and spiritual growth, and self-actualization

Strives to help the person and his or her family to address issues, expectations, needs, hopes, and fears; prepare for and manage self-determined life closure and the dying process; and cope with loss and grief during illness and bereavement. Is appropriate for any person and/or family living with or at risk of developing a life-threatening or life-limiting illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care

Is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.

May complement and enhance disease-modifying therapy or it may become the total focus of care. (Feris et al. 2002).

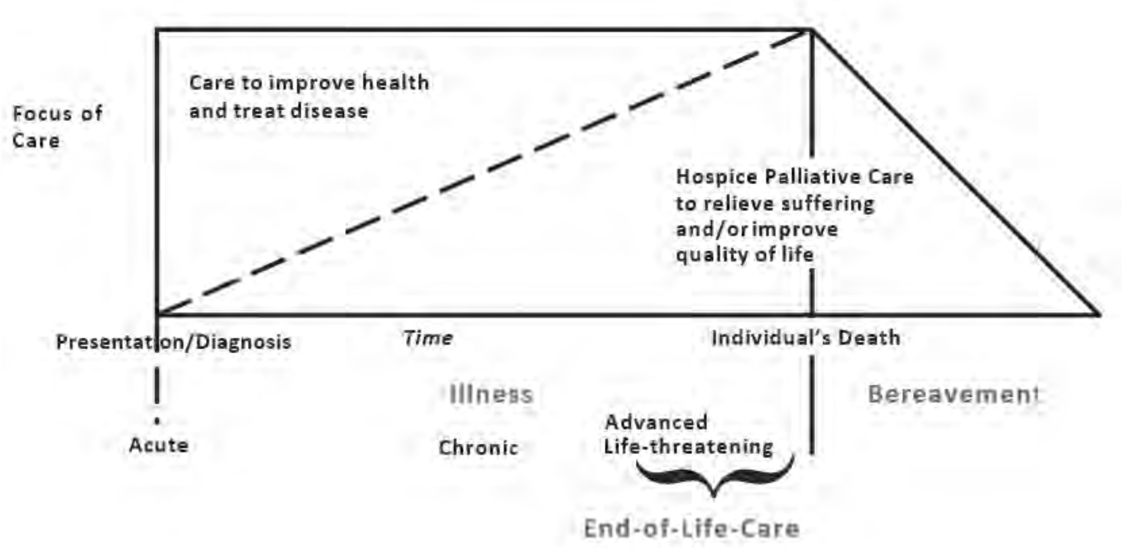
The Values of Hospice Care

- *Accountability* - To the individuals served, to stakeholders, to our donors, and our funders.
- *Achievement* - A standardized quality of palliative care across the province.
- *Compassion* - Individual choice and autonomy in the end-of-life journey.
- *Innovation* - Pain and symptom management, use of complementary therapies, interdisciplinary approach
- *Integration and Partnership* - All service providers work together in the provision of a holistic spectrum of care for the person and their family.
- *Interdisciplinary Approach* - The person and family are the centre of care and the team members contribute to a shared care model.
- *Social Inclusion* - Non-denominational, non-disease specific, includes all demographics of ages, cultures, sexual orientations, ethnicities and socioeconomic backgrounds.
- *Volunteerism* - Volunteers are involved in all aspects of hospice care.

Principles of Hospice Care

- Dignity, respect, and hope
- Quality of life – care is guided by quality of life as defined by the person who is dying.
- Holistic - Physical, psychosocial, spiritual and practical needs.
- Individual and family-centered - Care plan is driven by individual/family.
- Cultural humility - Personal, cultural and religious values, beliefs and practices are respected
- Informed choice - Information is provided to allow person-centered decisions.
- Pain and symptom management - Based on accepted principles, norms of practice, standards and the best available evidence
- Team approach and community partnership - Care is coordinated and the care team shares information to provide the best possible care.

Hospice Palliative Care Illness Trajectory



This diagram illustrates the palliative approach that the care team will take to the care of the individual and family. The hospice volunteer is a vital part of this care.

The holistic spectrum of supports offered are available at any stage of the person's trajectory of illness, from the time of diagnosis through to what is termed "end-of-life" care.

Hospice palliative care encompasses not only the individual with a life-threatening or life-limiting illness but also the family and/or any caregivers involved. The care does not end when the individual dies, but may continue with bereavement support services to the family and/or caregivers.

The hospice palliative care approach has been shown to increase quality of life for the individual living with a life-threatening or life-limiting illness as well as for family members and caregivers.

Section 2: History of Hospice Palliative Care

History of Hospice Palliative Care

The concept of hospice care has evolved since the date of the Romans and through the ages. The term “hospice” is derived from hostel or hotel, and was a rest home for those who were on a journey.

Dame Cicely Saunders started St Christopher’s Hospice after being inspired by a patient, David Tasma, who she met in 1948 when he was hospitalized with an inoperable cancer and she, a former nurse, was working as a medical social worker.

In 1974 Balfour Mount studied with Dr. Saunders at St. Christopher’s Hospice and brought the hospice approach to care back to the Royal Victoria Hospital (RVH) in Montreal. Mount felt the health care system would not support a structure outside the hospital so he opened a unit at the RVH within the funded health care system. Mount coined the term “palliative care” for this approach to care in Quebec as the term “hospice” in French had negative connotations.

The term palliative is from the Latin “pallium” meaning to cloak or cover. He called his unit a Palliative Care Unit. In Canada palliative care and hospice care developed separately, with palliative care being more medically-based, academic and in hospitals, with units and consultation services - while hospices in Ontario were community-based volunteer-driven charitable organizations.

The Canadian Hospice Palliative Care Association (CHPCA) eventually adopted the term “Hospice Palliative Care” to be more inclusive of hospices. Hospices in Ontario evolved to provide “hospice palliative care” with the addition of residential hospices and nursing and medical staff.

New Technologies, New Ways of Delivering Care

End of the 1980’s

- <u>New Era of Health care</u> - The end of the 1980s ushered in a new era for health care in Canada. Advances in technology meant that many services previously offered only in a hospital could be safely delivered in the home.
- <u>Growing Deficits</u> - At the same time, governments faced with growing deficits were reducing provincial health care budgets. By the end of the 1980s, hospitals began taking advantage of new technologies to help reduce costs and shorten costly days that patients spent in hospital.
- <u>New Demands on Home Care Programs</u> - As a result, individuals in Ontario were treated in an acute care setting (hospital) and then transferred home with ongoing home care support provided through the Community Care Access Centre (CCAC). New demands were put on home care programs, which now provided care for patients with chronic illnesses and long-term care needs with a view to delaying institutionalization of the frail elderly.
- <u>Emergence of Hospice Programs in Ontario</u> - This change in health care services provided the backdrop for the emergence of community-based hospice programs in Ontario, which reflects Canadians’ growing desire to remain and be cared for in their homes.

2001

- First Appointed Minister - In March 2001, the federal government appointed Senator Sharon Carstairs the first Minister with Special Responsibility for Palliative Care.
- Progress Report - The CHPCA was invited to present a progress report to the Romanow Commission looking into the future of health care in Canada. Quality end-of life care became recognized as the right of every Canadian.
- Ontario Partners - Ontario's volunteer-based hospices, many dedicated physicians, nurses and other health and spiritual care professionals are all partners in providing this holistic person-centred approach that embraces pain and symptom management, psychosocial and spiritual support, and family as well as bereavement needs.
- Ontario's Numbers Grow - Ontario's hospice volunteers are the largest direct service providers in the voluntary health care sector.

See Video: Dying for care*

This video illustrates how palliative care has evolved over the years. Despite its long history, the hospice palliative care approach is still relatively new to many professionals who have not received adequate education about it.

The focus of palliative care is not about dying: it's about living well with illness while receiving appropriate symptom management to improve quality of life and eventually death.

Discussion and care planning throughout the illness may help the person and family have more control over their situation.

Use the next page to take notes as you watch the video.

Reflecting on the messages in the video, and what you have learned so far, the following questions will help clarify your understanding of hospice palliative care. Use the space below to record your answers.

What is Hospice Palliative care?

Who is Hospice Palliative Care for?

Is Hospice Palliative Care just pain and symptom management?

When should Hospice Palliative Care begin for someone?

Practice Opportunity: Self Reflection

Take a moment to reflect on your personal experience of someone's journey through living and dying with a life-threatening or life-limiting illness. What were the positive aspects of the experience? What was not so positive? Was hospice palliative care available and offered?

Section 3: Models of Hospice Palliative Care

Models of Care

Hospice palliative care pioneers mobilized to meet their particular communities' needs. They created structures to sustain a variety of programs in an ongoing way.

Your community may have:

- Peer-support for clients and/or families
- Teams of trained volunteers and friends helping in the home
- Outreach teams composed of doctors, nurses, social workers, and other health care providers.

[1] Donald M. Berwick, MD, President and CEO, Institute for Healthcare Improvement

Continuum of Care Settings

Care can be delivered through an interdisciplinary approach in the following settings:

- Client's own house/apartment
- Seniors' residences
- Assisted living facilities
- Residential hospices
- Hospital palliative care units
- Long-term care facilities
- Community shelters.

Continuum of Care: Summary

Depending on the setting where care is provided, different terminology may be used to describe the person receiving care, including individual, patient, client and resident.

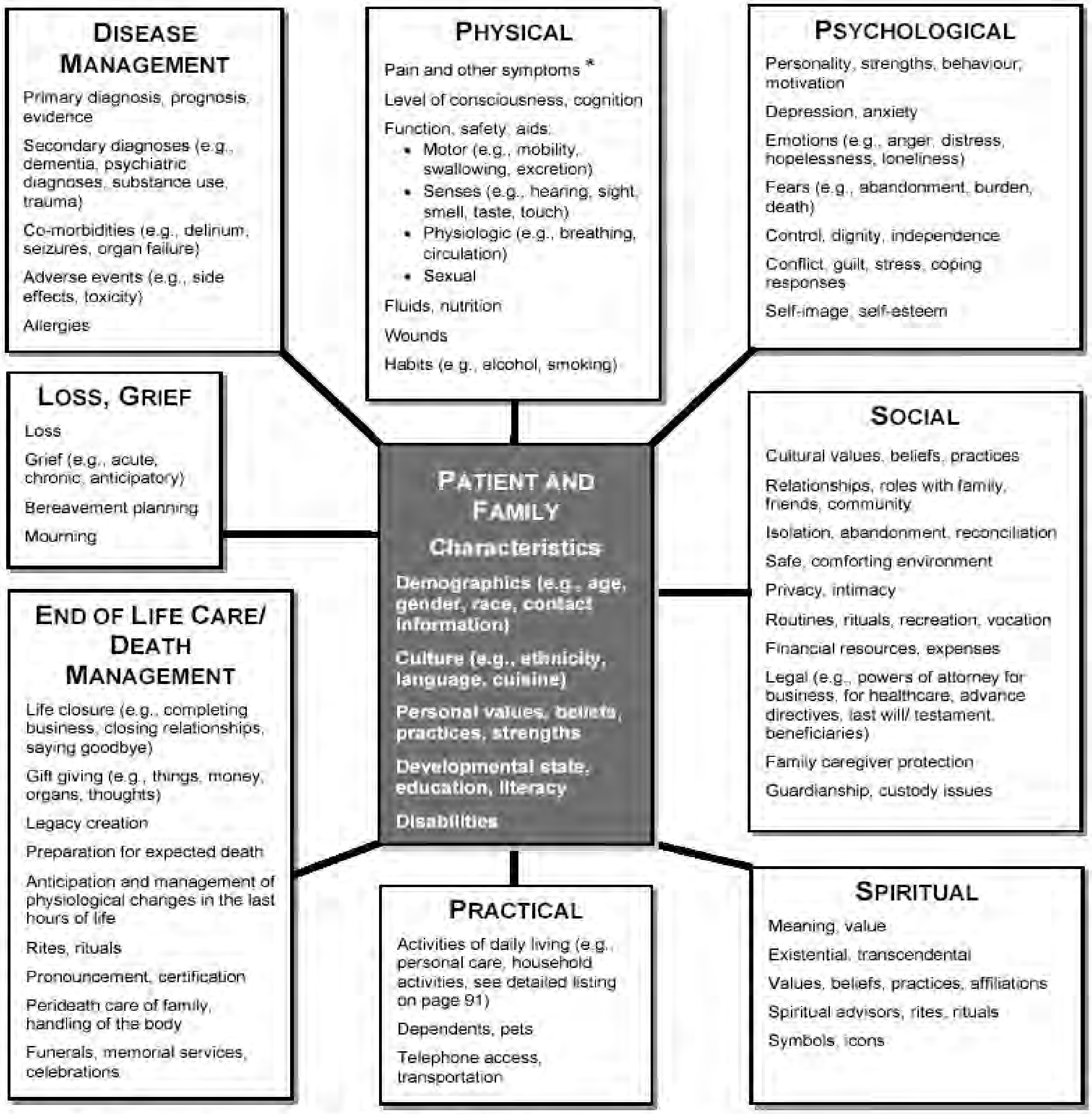
In this training program, we will refer to the person being cared for as the "client".

Section 4: Domains of Issues Associated with Illness & Bereavement

You will recall that the approach to hospice palliative care includes helping the client and family when particular issues arise. This chart outlines 8 domains or areas of issues that may arise for a client and family.

The domains address not only the physical aspects of the person's illness but also the client's and family's emotional, practical and spiritual needs.

Note that the client, family, and friends are viewed as one unit and are always at the centre of care.



DISEASE MANAGEMENT

Primary diagnosis, prognosis, evidence

Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)

Co-morbidities (e.g., delirium, seizures, organ failure)

Adverse events (e.g., side effects, toxicity)

Allergies

PHYSICAL

Pain and other symptoms *

Level of consciousness, cognition

Function, safety, aids:

- Motor (e.g., mobility, swallowing, excretion)
- Senses (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual

Fluids, nutrition

Wounds

Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL

Personality, strengths, behaviour, motivation

Depression, anxiety

Emotions (e.g., anger, distress, hopelessness, loneliness)

Fears (e.g., abandonment, burden, death)

Control, dignity, independence

Conflict, guilt, stress, coping responses

Self-image, self-esteem

LOSS, GRIEF

Loss

Grief (e.g., acute, chronic, anticipatory)

Bereavement planning

Mourning

PATIENT AND FAMILY

Characteristics

Demographics (e.g., age, gender, race, contact information)

Culture (e.g., ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL

Cultural values, beliefs, practices

Relationships, roles with family, friends, community

Isolation, abandonment, reconciliation

Safe, comforting environment

Privacy, intimacy

Routines, rituals, recreation, vocation

Financial resources, expenses

Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)

Family caregiver protection

Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT

Life closure (e.g., completing business, closing relationships, saying goodbye)

Gift giving (e.g., things, money, organs, thoughts)

Legacy creation

Preparation for expected death

Anticipation and management of physiological changes in the last hours of life

Rites, rituals

Pronouncement, certification

Perideath care of family, handling of the body

Funerals, memorial services, celebrations

PRACTICAL

Activities of daily living (e.g., personal care, household activities, see detailed listing on page 91)

Dependents, pets

Telephone access, transportation

SPIRITUAL

Meaning, value

Existential, transcendental

Values, beliefs, practices, affiliations

Spiritual advisors, rites, rituals

Symbols, icons

* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

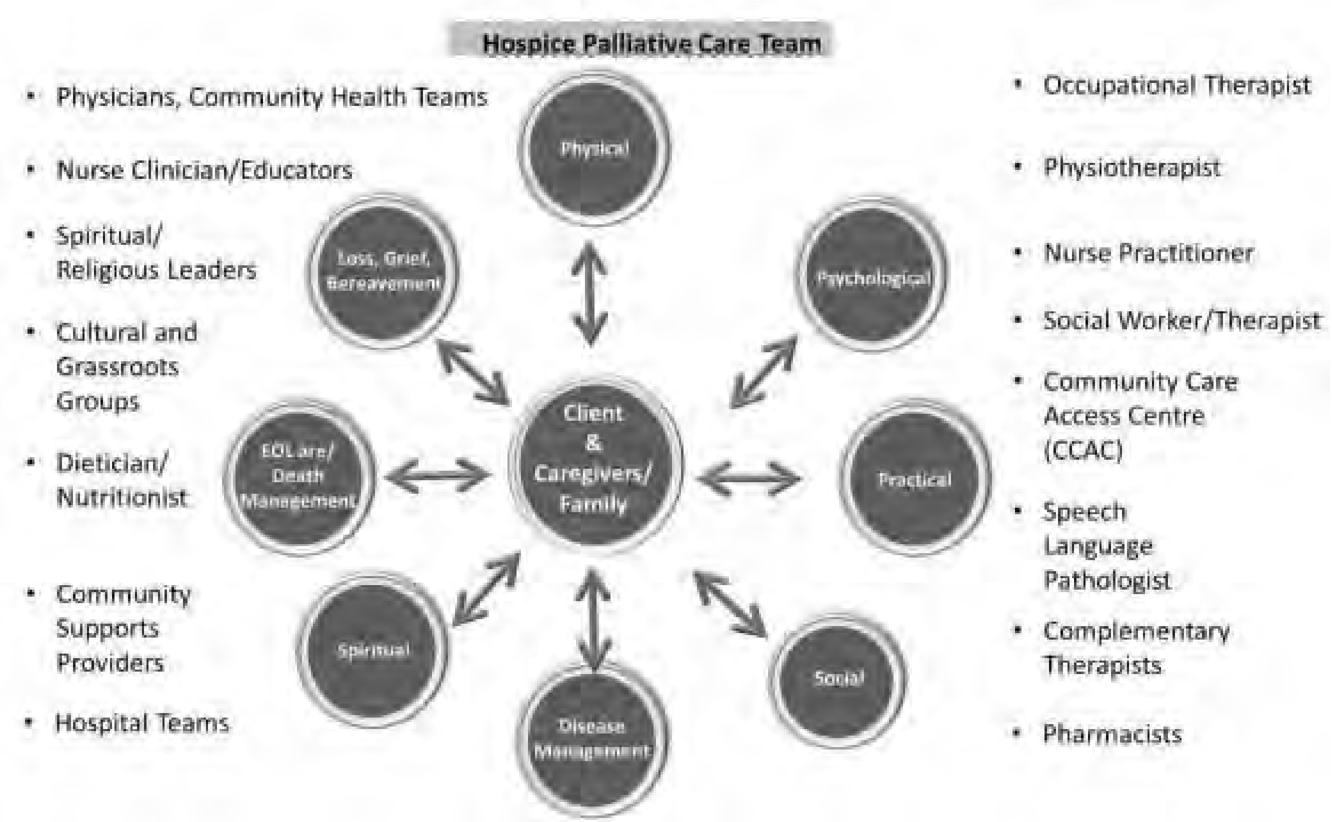
Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Section 5: Hospice Palliative Care Team

The Hospice Palliative Care team will provide care based on the:

- Client's values, beliefs and wishes
- Level of involvement and needs of family and friends
- Client's diagnosis and functional abilities
- Medical treatment plan
- Power of Attorney for Personal Care
- Rituals practiced - before and after death



Section 6: Needs of the Client, Family and Friends

See Video: Needs of the Client *

Use the space below to record notes.

Needs of the Client

Each client diagnosed with a life-threatening or life-limiting illness will have a unique reaction to and fears about illness and impending death.
However, it is possible to describe a cluster of fears and concerns that are fairly common to anyone in this situation.

To support someone who is dying, we need to understand some of these common fears and concerns, which include:

- How will I die?
- Will there be pain? Will it be controllable?
- Will I lose control over my body, my mind?
- I don't want to die alone.
- I don't want to be a burden.
- I'm afraid to die alone.
- What will happen to me when I die?
- What will happen to my loved ones after I'm gone?
- Is there an afterlife?
- I can't talk to my friends and family about my death.
- I feel that my life has no meaning.

The fear of pain and/or physical mutilation is often the primary concern for people facing the end of their life.

The presence of pain in life-threatening or life-limiting illness causes anxiety for both the client and family members.

The client may find comfort in having the following needs met at any stage of the illness:

- Adequate management of pain and other physical symptoms
- Emotional support
- Respect for my cultural beliefs and values
- Understanding of my unique spiritual needs
- Adequate information and support to make decisions about my treatment and care
- Access to and coordination of care among various service providers and agencies
- Management of my practical needs.

Needs of the Client's Family and Friends

The client's family and friends may have needs of their own which may include:

- Anticipatory Grief Support
- Spiritual Care
- Emotional Support
- Caregiver Support to Reduce Burnout
- Respite Care
- Information and Education on Disease Process and Symptoms
- Assistance with Practical Issues
- Bereavement Support

Practice Opportunity: Self Reflection

Imagine if you were diagnosed with a life-threatening or life-limiting illness. How would it impact your life? Use the space below to record your thoughts.

Section 7: Volunteers as Part of the Hospice Palliative Care Team

Introduction

Volunteers support clients and families in many ways, and are part of the team effort that is so essential to hospice palliative care. Volunteers complement the paid professionals on the team and play an important role in ensuring quality care for clients and families.

Optimum Hospice Care

Optimum hospice palliative care can only be achieved if there is time to:

- Listen
- Understand
- And provide care

Volunteers meet this need!

Volunteers can provide the kind of companionship that makes it easier for clients and family members to share information that can help professional members of the team gain a clearer insight into client and family needs.

Volunteers are in a Unique Position

As non-medical members of the care team, volunteers are in a unique position to act as an advocate for the client/family along with the rest the team.
Clients/families may share information with volunteers that they are unable to share with doctors, nurses, and/or other family members.

Volunteers can help the client/family to find non-threatening ways to communicate their needs to the rest of the team.

Vitality in Support

Volunteers do not usually see their client every day, so a certain freshness and vitality arrives with each volunteer visit.

This vitality can be a great support to the providers and family members who are often providing constant care to the dying client.

Volunteer Role

A volunteer is a non-paid person who:

- Is committed to the mission, vision, and values of the hospice palliative care organization for which they volunteer
- Meets the screening requirements of the agency
- Has completed the required training components as outline in the HPCO Visiting Volunteer Curriculum
- Understands and adheres to the agency’s policies and procedures as an important member of the interdisciplinary team
- Is accountable to an organization as outline by HPCO standards

Section 8: Confidentiality

See Video: The importance of Confidentiality*

Use the space below to record notes.

The Importance of Confidentiality

Definition

- Told in confidence; imparted in secret
- Of or showing trust in another; confiding
- Entrusted with private or secret matters a confidential agent

What you need to know about confidentiality

Volunteers are responsible for maintaining the confidentiality of all private or privileged information they receive while serving as a volunteer, whether this information involves a single staff member, volunteer, client, another person, or overall agency business. This includes:

- All information seen and/or heard – whether verbal, written, or computerized – must not be shared outside of the hospice palliative care team (i.e. your agency coordinator or designated individuals from the agency for which you volunteer, and others who are involved in the "circle of care").
- Confidential client information can only be shared outside the team when there is an unacceptable risk of harm to the individual or someone else.
- Volunteers must not use or disclose any confidential information following the termination or their contract/placement with their agency.
- Volunteers must acknowledge that their confidentiality agreement survives the termination of their volunteer relationship with the hospice.
- All clients, staff, and volunteers are governed in accordance with the Privacy Act (PHIPA- Personal Health Information Protection Act, 2004).
- Violating confidentiality is a serious breach of ethics and may result in disciplinary action up to and including dismissal of the hospice volunteer from the organization.
- In other words, confidentiality means to be: "entrusted with private information including what you: see, hear, read, observe, and already know about clients.

Chapter 2:
Volunteer Role & Understanding Professional Boundaries

Objectives

- Recognize the scope of your volunteer role
- Identify what professional boundaries are and their purpose
- Recognize the boundaries of your role and some strategies for maintaining them

Sections in this Chapter

1. The Role of the Volunteer
2. Understanding Boundaries
3. Key Boundaries in Volunteering

Section 1: The Role of the Volunteer

What are we here for?

We are here:

- To provide support and actively listen … not to work miracles
- To create a safe and sacred place for feelings to be expressed … not to make feelings go away
- To help people (re)discover their own strengths … not to rescue them
- To advocate for people's dignity … not to diminish their uniqueness
- To create an environment in which people can help themselves … not to take responsibility for them
- To support and normalize each person's personal process … not to impose our agenda on them
- To serve the needs of clients/families and the hospice … not our own needs
- To walk with people
- To learn

Volunteer Supports Provided

Depending on the hospice for which you are volunteering, your role may include providing some or all of the following supports:

- Companionship
- Emotional support
- Comfort
- Encouragement
- Practical assistance
- Respite care
- Spiritual support
- Grief and bereavement support
- Advocacy and assistance with finding information

'Doing' and 'Being'

Although the list of activities previously described are part of your role, it's most important to acknowledge the value of you just being present for the client and family. Your presence is often the greatest gift you can give. Being is:

- Holding a space
- Knowing that there is nothing to "fix"
- Listening and bearing witness
- Offering your presence and availability

Practice Opportunity: Self Reflection

See Video: Volunteer's Testimonial *

Use the space below to record notes.

Before Beginning Your Role

Before starting your volunteer role, the coordinator or lead volunteer at your hospice will discuss with you any specific expectations that the hospice has of you.
Your coordinator or lead volunteer should provide you with:

- A good understanding of how your hospice assigns clients and supervises volunteer with clients
- The lines of communication between the hospice and its volunteers and other members of the hospice palliative care team
- The hospice's expectations regarding reports, statistics, etc.
- The type of ongoing support, recognition and educational opportunities available to volunteers and
- How to raise issues and concerns and to whom

Reporting your client visits

Hospices require their volunteers to record and submit pertinent information about their volunteer activities.

Up-to-Date Records: This is important for a volunteer's own knowledge and to facilitate communication within the hospice palliative care team about how the client's illness is progressing

Reports for Funding Purposes: Reports may also be used for maintaining hospice funding.

Summary

A close bond may form between hospice volunteers and clients/families. Volunteers must walk a fine line between seeming like a "friend" and being a friendly presence in their life. Volunteers must remember that they are members of the interdisciplinary hospice palliative care team and are accountable for their conduct, practice and quality of care.

Boundaries are the dynamic (changing) lines between professional and therapeutic, nonprofessional and personal in the client/volunteer relationship

See Video: Testimonial Videos *

Use the space below to record notes.

Section 2: Understanding Boundaries

Introduction

Boundaries are understood, sometimes unspoken, physical and emotional limits of the relationship. They are that invisible "something" that is between you and others.
We say it's "something" because it's different in different situations with different people.

Boundaries are intangible. They define the limits and responsibility of the people in the relationship.

Boundaries are a framework that give clients/families and hospice team members a range of acceptable behaviours and activities.

What are Boundaries?

Boundaries depend upon you:

- Boundaries depend on who you are and what you're comfortable with in the role of a hospice palliative volunteer, which is influenced by your background, culture, upbringing, and demographics (i.e. age, gender).
- Boundaries also depend on the other person: who they are, what their background is, and their likes and dislikes

Boundaries Depend Upon the Relationship:

- Boundaries depend on whether you are a family member, a loved one, a friend, a professional or a volunteer in a supportive, compassionate role
- Boundaries Depend Upon the Situation:
- Boundaries depend on where interactions take place, the dynamics of the interactions, rule/policies of the organization you represent (i.e. even within an intimate relationship, boundaries can change depending on the circumstances of the interaction).

Practice Opportunity: Self Reflection

Take a moment and think about a role, in either your past work or volunteer activities where boundaries played an important part. Use the space below to record your thoughts.

Friends versus Volunteer: What's the Difference?

Friend	Volunteer
There's a history to the relationship. Mutual support is expected. You look to the future together. The relationship has some balance. Visit happens when you each want. You each decide how to behave. Gift giving often happens.	It's a new relationship. You are there to support the client/family. You know the relationship will end. There is a natural *imbalance* to the relationship. Visits happen according to an agreed upon schedule. Much of the interaction is governed by hospice policy. Gift giving/receiving is governed by hospice policy.

The Importance of Boundaries

“Boundaries do not mean that you lack empathy. This is preventative self-care and almost always results in better client care.”

What type of Boundaries are there?

- The types of boundaries that exists in your role as a volunteer include role boundaries and relationship boundaries
- Role boundaries are clearly defined by policies and procedures.
- Relationship boundaries are not always so clear, but are normally understood without even having to name them.

Why have Boundaries at all?

- To protect:
    - clients and families
    - the volunteer
    - the organization
- It’s important to have boundaries so that we respect the wishes of our clients and the space/situation our clients are going through (i.e. do no harm).
- It’s important to role-model healthy communication and professional relationships to clients and their families.
- There is less confusion when there are clearly explained rules.
- Boundaries also makes it easier for the volunteer by providing guidelines and a framework for their role.

Do Boundaries Prevent Caregiver Burnout?

- Yes, boundaries help to prevent caregiver burnout.
- Knowing what is reasonable and safe mean that you will not get into a position that makes you feel uncomfortable and then resentful and causes you eventually to stop volunteering.
- Our goal is to have volunteers who feel good about what they are doing for the clients and feel well supported by the hospice in their important work.
- It’s important to work in a similar way as your team members in order to ensure that we have a healthy communicating and functioning team.
- It’s important to always act ethically.

Why are boundaries important?

- Interpersonal work – boundaries are essential in “interpersonal work” or any type of interaction where you’re working with people. Some of the professions where interpersonal work boundaries are very important are teaching, health care, social work and therapy
- Position of power – volunteers and staff are positions of power and, as service providers, we have a responsibility to our clients to provide a safe and consistent service.

Five Steps towards healthy boundaries

Step 1: Define Them
Know your hospice's policies and procedures and abide by them. All hospices have policies and procedures that are available to their volunteers.

Step 2: Communicate Them
Be comfortable explaining the scope of your role, including limitations. Learn how to effectively say "no" in different ways.

See Video: The Pleasant No*
Use the space below to record notes.

See Video: The Conditional No*
Use the space below to record notes.

See Video: The Sleep-On-It No*
Use the space below to record notes.

See Video: The Alternative-Solution No*
Use the space below to record notes.

See Video: The Blame the Hospice No*
Use the space below to record notes.

Step 3: Self Reflection
Always ask yourself: "What are the implications for me and the hospice if I do this or say 'yes' to this action? What are the long-term implications?"

Step 4: Call and Ask
If in doubt don't make a commitment and call the hospice staff to discuss the situation.

Step 5: Self Care
The highest quality care begins with the highest quality you!

Assistance when boundaries are crossed

The volunteer role can be emotionally draining and cause stress. To stay healthy, a volunteer must practice regular self-care. Self-care may be different for each volunteer and this topic will be discussed more in the chapter on *Care for the Caregiver.*

Each hospice will have a staff person or someone else designated to answer your questions about boundaries and talk about any issues. Make sure you know who that person is and how to contact them.

Section 3: Key Boundaries in Volunteering

Introduction

Volunteers caring for clients and families come to know about very personal aspects of their lives.

Unless otherwise directed by the client and/or family, the volunteer must not disclose what they have learned to anyone other than the members of the hospice palliative care team. This includes the volunteer's own family members.

Whenever a volunteer has a concern about their client, the volunteer should bring these concerns to his or her coordinator.

Confidentiality applies not only to information about the client but also about their family, friends, and anyone else connected to the client.

- Privacy & Confidentiality
- Medication
- Gifts
- Physical Contact
- Respecting the client's space/environment
- Finance & Legal Matters
- Time Commitment
- Sharing of personal information

Privacy & Confidentiality

Right to Privacy

The right to privacy can create challenges for volunteers, particularly in small communities where everyone knows everyone else. Neighbours and friends of the client and family may know they you are a hospice volunteer and ask questions. In these cases, the volunteer must direct any inquires to the client and/or family.

Confidentiality

Volunteers are not permitted to take anyone along with them to a client's home or any other client setting unless that person has undergone the hospice volunteer screening process, signed a confidentiality agreement, and has been assigned to the client. This includes children and pets. It is a breach of confidentiality and privacy and potential grounds for dismissal.

Volunteers must not use or disclose confidential information following the termination of their contract/placement with the agency and must acknowledge that their confidentiality agreement survives the termination of their volunteer relationship with the hospice.

Address privacy

In situations where volunteers may be receiving a ride to/from their client visit, they must be dropped off/picked up in such a way that they client's exact address and/or location is not revealed

Respecting Privacy

Respecting the right to privacy means that you do not disclose:

- Who you are caring for or where they live
- The state of wellness of the ill person or family members
- Anything that is said to you by the client/family
- Anything that you observe or overhear during your assignment
- How the person died
- How the family members grieve

Limits to Confidentiality

Violating confidentiality is a serious breach of ethics and may result in the termination of a hospice volunteer.

- There are limits to confidentiality
- Confidentiality can be breached when there is an unacceptable risk of harm to the individual or someone else (e.g. a medical condition that may result in a personal harm to the client or others).

Summary

Confidentiality means "entrusted with secrets". Every volunteer is required to respect the confidentiality of the client and family members. Maintaining confidentiality is fundamental to providing high quality hospice palliative care.

Confidentiality:

- Meets the basic need for privacy
- Protects client/family from embarrassment or prejudice
- Creates an atmosphere of trust in which the client/family are more likely to share information vital to their care or support.

See Video: Conflict of Interest*

Use the space below to record notes.

Medication

Hospice Policy

Although hospices operate independently, their policies on the issue of medication will reflect the following:

- Volunteers are not permitted to prescribe, dispense, sell or compound a drug.
- Volunteers are not permitted to administer a substance by inhalation or injection (this includes assisting with oxygen).
- Volunteers are not permitted to put an instrument, hand or finger into an artificial opening in the body (this includes suctioning and tube feeding).

Adherence to Policy

Even when volunteers are members of a health care profession, when visiting an individual on behalf of a hospice, they are hospice volunteers and must follow the policies and procedures of their hospice during that visit.

Volunteer's Role

As volunteers, they must not handle, give or otherwise touch a client's medications.

Rationale

- If a client takes the wrong or too much medication, they may have a reaction or accidentally overdose and/or could become extremely ill or die. If a volunteer was involved in dispensing the medication, he or she may be liable for that action.
- The hospice palliative care team is responsible for identifying obstacles to good respite or caregiver relief (i.e. medication, nursing schedule) and determining how to meet the respite needs of the client and family.
- If the client needs assistance with medication during your visit, then someone else (i.e. a family member, nurse or personal support worker) will need to be there at the appropriate time to give that medication. The hospice palliative care team will help the family arrange this.
- Should an emergency arise when the volunteer is present, the volunteer must contact the hospice immediately.

Gifts

Close relationships may develop between volunteers and clients/families. It is important to understand the professional boundaries necessary when the subject of gifts may arise.

- As members of the hospice palliative care team, volunteers must not accept gifts. The volunteer must respectfully decline any offer of gifts and explain the hospice's gift policy.
- Should the client/family insist on giving a gift after the policy has been clearly explained to them, the volunteer may suggest that they make a donation to the hospice or a charity of their choice instead.
- Volunteers must always let the hospice know that they have been offered a gift, even if they have declined it. If a volunteer becomes aware of a bequest before or after the client's death, the volunteer must make the hospice aware immediately.
- Note: Some hospices will exercise flexibility with their gift policies by allowing volunteers to accept small tokens of appreciation. These might include consumable gifts, such as food and drink, or plants. Be sure you're aware of your hospice's gift policy and abide by it at all times.
- If you're uncertain whether a gift you've been offered is appropriate, ask your hospice for direction.

Rationale

- The giving and/or receiving of gifts changes the nature of the relationship between volunteers and clients/families and may cause the client/family to perceive the relationship as that of a friend.
- If the volunteer offers a gift, clients may feel they need to reciprocate by giving the volunteer a gift
- Although the volunteer may be acting out of genuine kindness, this action may actually make the client feel uncomfortable, particularly if they do not have the financial means to buy the volunteer something.
- Remember, the volunteer's greatest gift to the client is their presence.
- The hospice's credibility in the community may be affect if volunteers don't respect this boundary and accept gifts or bequests.
- Family members may expect to inherit certain items upon the death of the client and may become upset if/when they lean that an item has been given to a volunteer.

Physical Contact

Communication through touch can be very effective, however volunteers must always ask permission first.

- It is essential to obtain "consent" from the client/family before touching.
- It can be as simple as asking the client/family for permission to hold their hand or "give them a hug"
- It's also important for volunteers to be aware of their own comfort/discomfort with physical contact and to provide support within their own comfort level.

Respecting the Client's Space / Environment

When visiting a client, volunteers must always be respectful of their environment. For example:

- Returning any moved items back to where they were found
- Asking permission to adjust any sources of noise or distraction
- Dressing appropriately for providing close personal care
- Avoiding heavy scents like perfume or cologne
- Offering to remove outdoor shoes and bringing a pair of practical 'inside shoes' out of respect for their home
- Ensuring privacy in shared space when visiting someone who is in an institutional setting by moving to a more private location.

Finances and Legal Matters

As a general principle, volunteers are not permitted to handle the client's and/or family's finances.

Banking Transactions

- Under no circumstances are volunteers permitted to do any banking transactions or access the client's and/or family's PIN number information.
- Volunteers must not lend money to their clients/families.

Power of Attorney

- Volunteers must not act as the client's power of attorney or executor or agree to act in any legal capacity whatsoever.
- Volunteers may assist the client and/or family to gather resources and information that will help them make informed legal decisions.
- Volunteers must inform their coordinator whenever a situation such as this arises

Extenuating Circumstances

- On occasion, there may be extenuating circumstances where volunteers may be asked to handle small amounts of money for incidental purchases like bread or milk
- Depending on the policies of your hospice, this may or may not be permitted
- It is the volunteer's responsibility to be aware of the hospice's policies. If you are unsure, contact their supervisor and have the correct protocol explained.

Rationale

- Hospices reduce the risk of possible conflict of interest (real or perceived) or potential legal implications by prohibiting volunteers from handling the client's or family's finances, acting as their power of attorney and/or executor; and/or witnessing legal documents for clients and/or family members.
- ALWAYS contact your coordinator if you are unclear of your boundaries and/or in need of direction.

Time Commitment

The timing and length of volunteer visits are based on the client's/family's needs, and may vary from week to week. Some hospices may offer on-site programming, such as day programs, wellness programs and caregiver groups that have a set time commitment.

Calling Ahead

- Although volunteers are encouraged to establish a regular meeting time each week, it is still a good idea to call before the visit to ensure your visit is expected. It is important to be on time.
- When volunteers are unable to keep an appointment, they must contact the client/family and their coordinator to let them know that they won't be visiting at the agreed upon time.

Rescheduling

- If a volunteer's availability changes for any reason, it is important to contact the volunteer coordinator immediately, so that alternate arrangements can be made to support the client/family.

Short Breaks

- If you feel you need a break from volunteering at any time they are encouraged to discuss this with the volunteer coordinator.
- Taking a short break between clients or when personal commitments require it can allow you time for reflection and ensure that volunteers remain enthusiastic about their volunteer work.
- Volunteers must always keep open the lines of communication with the coordinator.

Rationale

- When volunteers can establish regular visiting times, the client/family and hospice palliative care team members know when volunteers will be with the client, which may make it easier to schedule other services.
- Clients often look forward to their volunteer visits, and families may also be relying upon volunteers to give them much needed caregiver relief.
- Volunteers are representatives of their hospice organization and, as members of the hospice palliative care team, must conduct themselves appropriately.
- The client/family and other members of the hospice palliative care team are counting on the volunteer to be reliable, professional, and committed to their service.

Sharing of personal information

As stated earlier, volunteers are not visiting clients/families as friends but as members of the hospice palliative care team. Volunteers must not share their personal contact information (i.e. phone, home address and/or email address) with the client/ family. If the client/family needs to get in touch with the volunteer they must contact the hospice.

Blocking your Phone Number

- Volunteers must block their phone number when calling clients/families.
- This can usually be done by entering *67 or #31# depending on the phone service provider. Volunteers should always confirm how to block calls on their phone before contacting clients/ families.
- Volunteers must not text clients/families from their personal cell phones as texting also identifies the volunteer's cell phone number.

Disclosing Personal Information

- Volunteers should also be mindful of how much personal information they share with their client/families about themselves or their own families.
- Volunteers must not disclose intimate details or give long descriptions of their personal experiences.

Self-Disclosure

- It may be tempting for volunteers to share personal information as a way of building rapport and strengthening their connection with clients/families. However, self-disclosure may not always be helpful for clients.
- Sometimes self-disclosure can be motivated by volunteers' own emotional needs.
- Often volunteers disclose personal information to clients/families because doing so helps the volunteers cope with their own challenges, such as issues in their relationships, career/school problems or concerns about their own or their loved ones' health.
- When volunteers share personal information, clients and family members may become concerned about the volunteer's well-being of their volunteer, and the focus switches from their needs to the volunteer's needs.
- As members of the hospice palliative care team, volunteers must always keep the focus of their visits on the client/family.

Rationale

- Many people feel that giving out a phone number, email address, last name or sharing other personal information is not a big deal. However, there is a deeper underlying meaning that comes from disclosing personal information to the client/family.
- They may perceive the volunteer as someone who is a good friend. Friends typically share their contact information so they can call anytime to chat or in case of an emergency. If the volunteer inadvertently shares information about challenges in their own life, this may add to the client/family's burden.
- The volunteer is visiting as a member of the hospice palliative care team and, as such, they are representing hospice in the role as a visiting volunteer and not as a friend.
- If asked for personal contact information volunteers must decline, tell the individual that they are unable to provide this information, and let them know that they can get in touch by contacting the hospice. This response establishes healthy boundaries and sets the tone for upcoming visits.
- It also makes the scope and limitations of the volunteer role very clear.

Short Breaks

If volunteers feel you need a break from volunteering to focus on or seek support for their own personal needs, they are encouraged to discuss this with their coordinator.

Taking a short break when personal needs or commitments require it, can allow time for reflection and ensures that volunteers are able to keep the client/family as the primary focus of their volunteer visits.

Volunteers must always keep open the lines of communication with their coordinator.

Chapter 3:
Communication Skills

Objectives

- Recognize the importance of active listening skills
- Identify the elements that interfere with good communication
- Recognize personal values, beliefs, and attitudes towards death and dying
- Identify and demonstrate sensitive and effective ways of communicating with an ill person and their family
- Recognize the importance of maintaining confidentiality and how it applies to hospice volunteering
- Recognize how to effectively communicate the role of the volunteer and one's limits and boundaries
- Identify the value and uses of silence

Sections in this Chapter

1. Communication Skills
2. Communication Types
3. Barriers to Communication
4. Effective Communication Skills
5. How do I Start?
6. Confidentiality and Privacy

Section 1: Communication Skills

Introduction

See: Communication Skills video*

Watch Dr. Barry, living with ALS discuss communication tools with Judy Maddren.
Use the space below to record notes.

Dying and Death

In our Western society dying and death is still generally considered to be a taboo subject, therefore, talking about it can be very difficult.
Having knowledge about hospice palliative care and being comfortable enough to have a conversation about it are often two very different things.
Even many doctors and health care professionals have difficulty talking about dying.

See Client Interaction: Video 1*

Use the space below to record notes.

See Client Interaction: Video 2*

Use the space below to record notes.

Introduction

Although we will focus on communication with clients who are dying and their families, effective communication is, in fact, a life skill from which we can all benefit. Communication is central to the role of hospice volunteers.

Our Understanding

Effective Communication is one of your greatest gifts to clients and their families.
We need to be certain that we understand what we are hearing, and that what we are saying is not misunderstood.

Our Responsibility

As members of the hospice team, effective communication is 100% our responsibility for understanding what other people say, and making sure that other people understand us; it is not a 50/50 responsibility

Shared Moments

Through your ongoing visits with clients and families, the many conversations and shared moments have the potential to:

- Help reduce feelings of isolation
- Address fears and concerns
- Assist in finding meaning and personal growth
- Decrease feelings of loss of control

Conversations with clients and family members may also be filled with personal and confidential information.

Our Role

Volunteers need to be able to communicate client information effectively with hospice staff, other volunteers and professional providers who are partners in hospice palliative care.
As ambassadors of the hospice you are joining, your ability to communicate effectively about your role will help to raise much-needed awareness of hospice palliative care in your community.

Effective Communication: Reflection

See Video: Communication techniques used/not used by the volunteer*
Use the space below to record notes.

What positive communication techniques did Trudi use in this video?

What techniques could have been used by Trudi in this video?

See Video: Reflect on your personal experiences in discussing your volunteering*
Use the space below to record notes.

Section 2: Communication Types

What are the 4 Types of Communication?

1. Kinetic Communication
2. Symbolic Communication
3. Verbal Communication
4. Mindful Communication

Kinetic Communication

Facial Expression

In face-to-face conversations, changes in facial expression often reveal the attitudes of a person. This is true of both the speaker and the listener. A disapproving look will usually be registered by a speaker may change the discussion and can alter the results. This may cause the true nature of the original message to be lost

Tone of Voice

The tone of voice can be loud, soft, angry, calm or whining. Each tone sends a different message to the listener

Body Language

Non-verbal cues are in one's body language. These cues can include things like making eye contact, the distance between speaker and listener, the physical position of both parties, and the use of touch

Other examples might be: Looking repeatedly at one's watch, crossing of the arms, or looking away during the conversation. All of these examples can be impacted by the culture of both the speaker and the listener

Silence

Silence can be used as a tool to encourage further disclosure. If you avoid jumping into the conversation, when the speaker is finished they may add some important information as an afterthought. Nodding and saying "umhmm" demonstrates that you are listening and want to hear more.

Environment

The various environments within which we interact with clients can be anything from calm and quiet to very busy and distracting. This can significantly impact the quality of the interactions that we are able to have with the client and family. If possible, try to avoid noisy, distracting environments. Always ask permission to turn the TV or radio off (or down).

Verbal Communication

Verbal communication is the ability to express ideas or information using the spoken word. It involves listening to, absorbing and processing an idea or piece of information.

It is important to allow periods of silence between the expression, and absorption process. Oral communication must be clear, concise and not too complicated. It is important to match your words to the comprehension level of the person that you are speaking to.

Listening and Silence

- Being attentive to the words that a client is using will allow you to hear their whole message.
- It is important to focus on what the person is saying and no use their speaking time to develop your response
- Using the pauses of silence allows the speaker to add further information
- It is in these periods of silence that you can develop your response, now that you have heard the full message
- Volunteers are sometimes asked to record their observations by writing in a communication book that is left in the client's home

Symbolic Communication

Symbolic communication involves using metaphors (word pictures) or images to express complex feelings, and thoughts as if they were real experiences.

When the client makes a statement like "I feel like I am a river rushing over a big boulder", listen very carefully and try to see the picture that they are painting for you.

The speaker may be expressing, in images rather than words, what is happening and how they feel about it.

See Video 2.02 Communication Types – Story about Dock*
Use the space below to record notes.

Mindful Communication

Mindful communication includes being aware of the emotions and reactions that are happening within you while concentrating on the emotions that the client is expressing. You are not only hearing about the feelings of the other person, but you are also seeking to understand those feelings.

Experience over Acting

- It is natural to want to “help” or try to “fix” the situation. This may cause the volunteer to jump into the conversation by sharing their own experience or wanting to redirect the client’s thinking.
- Mindful listening is the art of experiencing these things, but not acting on them.

Observe

- Mindful listening requires that you closely observe the client’s body language, tone of voice, and use of words, without allowing other things to distract you.
- Be attentive. Try not to let your mind wander.

Be Present

- Listen effectively require concentration; just nodding or saying “umhmm” will indicate that you are still listening.
- We all tend to have “background chatter” that goes on in our heads and it is often difficult to calm that down. The ability to listen effectively requires concentration and practice.

See Video: 2.01 Anne Marie and Dorothy *

Identify what kinetic communication examples are being displayed. Use the space below to record notes.

Section 3: Barriers to Communication

See Video: Language Barriers*
Use the space below to record notes.

Language Barriers

If either the speaker or listener is unfamiliar with the language being spoken, it is difficult to transfer a message or provide information. When language is a barrier, it may be helpful to turn to family members who can translate for you.

Try to learn some of the key words that will help you to understand what the client wants. Gestures can also transmit a very simple message. Volunteers have managed quite well with clients who do not speak the same language, by using pictures or word/phrase cards that the family have helped to develop.

TIP: Playing a card game or board games will often allow you to develop a comfortable relationship, even if not much is actually said.

Cultural Barriers

Communication is fundamental to all human interaction. If volunteers are going to master the art and skill of sensitive communication, then they need to be aware of the role that their own culture and values play in their own culture and values play in their communication with clients and families.
Each person's culture is unique and often determines how we communicate with others.
For example, some cultures encourage eye contact when communicating with someone, while for other cultures, making eye contact may be seen as disrespectful. A comment like, "look at me when I am talking to you" could make the other person very uncomfortable and as a result, they may limit or avoid the interaction.

See Video: Cultural Barriers – Cultural Considerations*
Use the space below to record notes.

Culture is Everywhere

Your emotions and reactions can or may reflect your personal culture and life experience. You need to be aware of your own biases and attitudes so as not to project your own feelings onto the client. This requires suspending your own judgments.

This does not mean that you have to agree with what is being said, rather it means that you need to have the capacity to listen to another idea or opinion.

Watch your non-verbal response, too. A look that reveals your underlying opinion, may keep the other person from finishing their message.

Facets of Language

In this next section, we will look at varying forms of conversation and the appropriate approaches volunteers should utilize.

Advising and Judging

Clients often see their volunteer as a well-informed, non-judgmental resource, with training and experience in end of life care issues. Volunteers are also somewhat removed from the emotional impact that decisions may have both the client and the family. Thus, the asking for advice from a hospice volunteer is a fairly common occurrence. Each client is a unique individual. Most people have the internal resources within themselves to make decisions about their own concerns or issues. It may be flattering to be asked for your advice, but there can be many pitfalls.

Appropriate Volunteer Approach

A comment such as, “What do you think might be a solution to the problem?” or “What concerns you about that decision?”, can open the opportunity for more discussion. When someone is making decisions that are strongly opposed to your own values and beliefs, it can be very difficult to remain non-judgmental. This skill takes practice.

Remember

In all of your communication, the underlying message to yourself should be:

- I’m not here to fix, but I am here to listen
- I am going to try to help this person come to their own solutions
- I am only one member of a team and I can always ask the hospice staff for further possibilities and resources

Being Uncomfortable with Silence

Many people are uncomfortable with silence. Reassuring through ‘being there’ can enhance the process of meaningful interaction. Silence, by itself, can also be meaningful and comforting. Silence can be used as a tool to encourage further discussion and information. Resist the urge to jump and fill the space. The client may have more to add.

Appropriate Volunteer approach

If this is an area that you really struggle with, try counting silently to 15 while silence occurs.

Disagreeing

You do not have to agree with everything the client or family member says. Disagreeing closes the conversation down and can prevent the client from expressing their true feelings. The client and family will often make statements that indicate a state of mind or a value and belief. If you openly disagree with them, they may feel that you are negating their feelings or beliefs. In addition, by making assumptions we may negate another person’s real feelings. We often do not hear what the client says because we have drawn our own conclusions.

Appropriate Volunteer Approach

Your words or nonverbal gestures of acknowledgment let the speaker know that you are interested. Acknowledgment such as “Umhumm”, Okay and a nod of your head do not necessarily imply your agreement. For example: If someone tells you what he or she doesn’t like about you, your head nod doesn’t necessarily mean that you agree. It may just indicate that you are listening.

Defending

Sometimes the client will report the behaviour of another caregiver that has upset them.

Appropriate Volunteer Approach

Try not to dismiss what the client is saying, it is best to explore what the client perceives to be the problem.

Remember

If the client or family members express a concern regarding anyone on the health care team, what you do with that information is important. It is not your role to phone or confront the individual. Instead, you must share the information with your hospice coordinator. You also need to speak with the hospice coordinator if you have any concerns.

False Reassurance

False reassurance can make the client feel that their concerns are not being heard and are being dismissed as unimportant. As a result, this may shut down the opportunity for further discussion.
Stereotyped comments such as “It’s for your own good.” “It’s God’s will.” “At least he had a good life.” “Keep your chin up.” “Just listen to your doctors.” are common, but not helpful, when speaking with the dying persons or their family members or friends. These phrases are platitudes that can prevent further conversation for happening.

Appropriate Volunteer Approach

An appropriate answer to statements such as “I don’t think I’m going to get any better.” Would be “what worries you most about that?” This gives you, the listener, the opportunity to clarify what your client’s concerns are.

Concentration on Response

We are often anxious about responding appropriately and may have a tendency to focus on our response before hearing the message that’s being sent. If you form a response before the client is finished, you may miss the end of their message, which can often contain their main point.

Working at developing an answer, while the client is still speaking, is perhaps the greatest barrier to effective listening i.e. listening with your answer running. In addition, interjections, when your client is sharing their thoughts is not appropriate; this is not the time for interjecting one’s own message. This is the time for listening. Our own ‘words of wisdom’ are probably not needed at this moment and can distract the client from completing their thought.

Personal Emotional Response

Personal emotional responses may arise when a memory or emotion is triggered that causes the volunteer to cry (see Chapter 2: Role of Volunteer and Understanding of Professional Boundaries). There is nothing wrong with a volunteer welling up with tears during their visit, BUT, if at any time you find yourself being comforted by the client or family, you have gone beyond what is appropriate for your volunteer role.

Appropriate Volunteer Approach
If this happens, and sometimes it does, simply state that you would like to take a moment and gather yourself together. Leave the room (I.e. go to the bathroom etc.), wipe your face, calm your crying, and then return.

Another situation that may trigger a personal emotional response is when the client and/or family makes inappropriate or suggestive comments to you.

Appropriate Volunteer Approach
Although these situations are extremely rare, it is necessary for the volunteer to respond in a calm, professional manner. Ensure that your coordinator is also made aware, so that any necessary follow-up can occur.

Remember
If at any time you find yourself being comforted by the client or family, you have gone beyond what is appropriate for your volunteer role.

Using Jargon

Using jargon, or high-powered medical and/or psychological terms is not usually very helpful. When you converse with hospice clients, communication does not need to be complicated with a lot of short forms, medical terminology, and acronyms. If the client is not familiar with the words you are using, it can be a barrier to getting your message across.

Appropriate Volunteer Approach
Always try to match your level of vocabulary (choice of words) with theirs.

Setting/Atmosphere

Always ask for permission to make changes in the client's environment. A noisy, busy environment does not generally foster good communication.

Appropriate Volunteer Approach
Try to decrease or eliminate as many distractions as possible, for example: asking to turn off the tv or radio, or closing the door to decrease noise and other distractions.

See Video: Dorothy and Melissa 1*
Watch how Melissa, the volunteer, responds to her client. Use the space below to record notes.

See Video: Dorothy and Melissa 2*
Watch how Melissa responds to her client. Use the space below to record notes.

Family Barriers

Additional barriers to communication can stem from issues within the client's family. Some reasons for this may be the client or family's desire for wellness, a misunderstanding of the illness, and the strong emotions that can occur.

Desire for Wellness

Because the family members may deeply desire that the client will return to healthy living, they will often not participate in, nor entertain thoughts about planning for an eventual death.

Misunderstanding of Illness

There is often a misunderstanding of the illness itself, as well as prognosis, and any treatment options. These misunderstandings are more common when the news is bad and when clients and families are physically, emotionally or psychologically stressed.

Strong Emotions

Strong emotions such as anger, guilt, denial of the illness, the threat of loss or unfulfilled dreams may consume the clients and/or family. This can result in an inability or refusal to process information.

Section 4: Effective Communication

Examples of Effective Communication

Attentive Listening

A special effort must be made not to select or listen solely to what you, the listener, wants to hear. In order to get the full picture, it is important to focus on what the client is expressing. Attentive listening is a highly developed skill. It is an active process that requires energy, concentration and practice. It involves paying attention to the person's total message, both the spoken verbal messages and the nonverbal messages that modify what is spoken.

Sound clip: Demonstration of "attentive listening" *

Nonjudgmental Listening

Sometimes you will hear things that don't fit with your way of thinking. It is very important not to reveal your own feelings by your facial expression, or in your response. It is not about hiding your opinion; it is about being open enough to listen to a different way of thinking. Be aware of your body language, as it too can reveal what you are really thinking. These communication skills usually take some practice.

Acceptance

An accepting response implies that I accept who you are and how you think of things. I am not going to try to change your way of thinking, instead, I am going to listen to it. This type of response doesn't have to mean that you agree with what is being said.

Reflective Listening

In reflective listening, your statements refer back to the client. It reinforces their importance and that you are listening closely to them. Approach the conversation with the belief that the client has the ability to solve the problem for themselves. You must resist the temptation to offer advice or give opinions about what the client is saying. Instead, try asking questions.

Sound clip: Demonstration of "reflective listening" *

Paraphrasing/Restating/Clarifying

Test your understanding by "feeding back" what you have heard and felt. Be careful not to restate the obvious. This allows the client to clarify their thoughts and feelings if the volunteer has misunderstood. If things are unclear to you as you listen to the client, you may want to clarify by asking questions to be sure you get the real message.

Sound clip: Demonstration of "paraphrasing / restating / clarifying" *

Affirming Normalcy

Clients and families often raise concerns regarding how they are coping with their situation. Common questions families ask, and the appropriate responses that should be given by the volunteer.

Family Member

- “He doesn’t seem to want to eat anything that I make for him, I’m really worried.”
- “I really thought that I could manage this at home, but now I’m not sure.”

Client

- “I don’t know why my family can’t just let me go?”

Volunteer

- “I can see that you’re finding this difficult … many families find that …”
- “This must be hard for you … I’ve worked with other families who have had similar concerns …”

Remember, validating the feelings that are being expressed and affirming the normalcy of the situation can open the opportunity for further discussion.

W.A.I.T. and the Importance of Silence

A helpful concept to consider is the word “W.A.I.T.” or “Why Am I Talking?”
If we are mindful of our reasons for adding our own comments to the conversation, we can help to focus on listening versus talking.

Pause for 15 Seconds

- Silence is more than staying quiet or not interrupting while someone else is speaking. Pausing for 15 seconds (count silently to 15, if needed) before you start to talk, allow the client time to catch their breath, or gather their thoughts.
- They may want or need to continue the dialogue. If the message is complete, then this short break can give you time to form your response.
- This may be somewhat awkward for you in the beginning, but with practice, you will become more comfortable.

When Silence is Inappropriate

- Someone specifically asks for assistance
- When someone asks in a panic

Open-ended Questions

- To get things started try to ask open-ended questions that cannot be answered by “yes” or “no”. They often begin with “how” or “why”. Try to be cautious about asking too many questions in a row.
- This approach encourages the client to share more information

Giving Recognition

It is important to address your client as "Ms." or "Mrs./Mr." when you meet them initially.
On your first visit, you can establish how the person prefers to be addressed going forward. For example, "Shall I address you as Mrs. Smith or is there another name you prefer that I use."
Using 'pet' or 'family' names, without the invitation of the ill person and/or the family members, can create resentment.

Non-Traditional Communication

Coma

- Coma is a state of unconsciousness that may occur as the end of life nears.
- Touching, shaking or calling out usually cannot rouse a person who is in a coma. This does not mean that a person in a coma cannot hear and understand your voice or feel your touch.
- Coma is not always permanent. Some people will slip in and out of a coma; some will suddenly just wake up if only for a short time. Whatever the cause or duration of the coma, you must not allow it to keep you from continuing to communicate with the person.
- When someone we know or love goes into a coma, it can trigger feelings within us.
- We can feel hurt, cut off, helpless, depressed, confused, angry, and grief-stricken. It may feel like the person has changed and their life force and personality have been turned inward.
- Trust your "sixth sense" (i.e. your intuition) when you are trying to communicate with a person in a coma:
    - Speak normally
    - Use touch as a way of communicating
    - Coma is an inner experience
    - Be relaxed and calm inside yourself

Remember
Your touch, tone of voice, and inner feelings are all things the person in the coma may be able to sense.

Stroke

- Many people who have suffered a stroke may have difficulty with speaking or forming words and ideas. Some clients may be slow in processing their thoughts. Working with these clients often requires great patience.
- Always ask the family for tips on how they discern what the patient needs and wants. They are usually very aware of the non-verbal cues that the client uses to indicate their needs.
- Sometimes a pictograph can help but if the client is rehabilitating they may want to force themselves to accomplish the words no matter how long it takes. Being supportive of this process is very important.

Dementia/Alzheimer's

- Working with clients who are suffering from dementia requires a great deal of patience.
- This is a situation where working with the family and or other caregivers to learn the client's routines and non-verbal cues is very important. You can ask questions such as; "what does your dad do when he is hungry, or wants something in particular?" or "When he is agitated like this, what do you find helps him to calm down?"
- The family will likely know best how to interpret and respond to their behaviour.

Section 5: How Do I Start?

A Volunteer's Perspective

See Video: 2.05 Interview with Trudi*
Use the space below to record notes.

Communicating your Role

Each hospice may have variations in their policies as to what volunteers may or may not do with clients. It will be your responsibility to know what your role is, as outlined by your hospice.
As a hospice volunteer, it is very important that you are clear about what your volunteer role is and you are also expected to be able to clearly communicate that role to your client and their family.

Witnessing/Signing Legal Documents

- The volunteer must NOT sign or witness legal documents e.g. Wills, Power of Attorney (POA) documents etc.

Receiving Gifts

- Often clients with to express their gratitude in the form of a gift. A volunteer must decline accepting the gift.
- An appropriate response could be "Thank you for the lovely gesture, but the opportunity to spend time here with you is the gift that you already give to me. Getting to know you and sharing time with you is why I do this volunteer work."
- If the client persists, a volunteer may suggest that they contact the hospice about making a donation.

Defining roles may sometimes be a challenge for volunteers, because although in our supportive role, we want to help, we may find that we are unable to accommodate all of the clients and/or family's request.
We need to be aware of, and practice, tactful, sensitive responses to common requests that we may receive.

Six Techniques that will Assist You When Meeting with Your Client

1. Try to clear your mind of other things that have impacted on your day
2. Introduce yourself
3. Be sensitive to your client's reaction to your introduction and your role. Be prepared to sit quietly at the bedside and simply share the environment with the client or, if needed, make arrangements for a more suitable time.
4. You might try to utilize things in the room to develop early conversations (i.e. photographs, cards on display, plants, and furnishings, views from windows, colour or style of décor, garden and/or other surroundings)
5. Listen for the feelings that may be behind what is being said… as well as tone of voice and body language that your observe
6. Always ask permission … before touching a client or their family member(s).

Remain at Eye Level

Whether or not you look directly at the client, will depend on the client's comfort level. Cultural considerations may come into play. If you find it difficult to look at someone's eyes, try to look at the bridge of their nose instead. It may feel less intimidating, and they cannot usually tell the difference.

If possible, try to sit beside the person at a 45-degree angle. This allows them to look away from your eye contact if they wish. Try to sit or stand at the same level as your client. For example, if your client is in bed, or sitting down, do not stand over them while you talk.

If it is appropriate, you may want to go for walks with your client. The client will choose if, or when, eye contact is comfortable for them by stopping and looking at you when they speak.

Communicating and Being Yourself

Learning to be comfortable with situations that may feel uncomfortable can be a great asset as a hospice volunteer. We cannot have the answers for every situation. Acknowledge to yourself that you do not have to be in control of everything.

How can I show openness to my client?

You can show openness with the use of body positioning and facial expressions. Uncross your arms and sit comfortably and informally. Try to sit beside the client and remove any physical barriers, such as a pile of books. Facing a person directly opposite them may be very intimidating, as a result, can feel unsupportive.

What do I say when I don't know what to say or do?

When you don't know what to say or do, it is often best to say or do nothing. Just being present and honestly letting the other person know that you don't always know the answer, or the right thing to do can feel more supportive than relying on pat answers and instinctive actions.

How do I respond to a request for info that exists, but I personally don't know?

In cases where you don't know the answer to a request for information (about various community resources, for example), you can offer to contact the hospice for assistance in finding the answer for the client. Questions relating to medical, nursing or spiritual care should also be brought to the attention of the hospice coordinator who can relay them to the appropriate member of the health care team.

I always hear 'be yourself'. How do I do that in these scenarios?

Take the time to let the client get used to you and take the time to get used to them. Relationships cannot be rushed. Really try to be yourself.

Sometimes I feel the client doesn't want me to help. What should I do?

Remember that the client is in control and that as a support person; you can only help as much as you are allowed to. If you follow the mood of the client, you will have no difficulty laughing together, or seriously considering life's mysteries. Even if you choose your words with the utmost of care, the response that you get may not be the one that you are expecting. It is important that volunteers develop the ability to be comfortable with being uncomfortable.

See Video: Volunteers and Clients Tell Their Story*

Use the space below to record notes.

Scheduling

Volunteers may be discouraged from staying longer than their scheduled visit time, without permission from the hospice. If you extend your hours consistently it can become an expectation It may then become difficult to backtrack to your assigned shift time.

If you are providing respite care, and the family caregiver goes out to attend to errands etc., they often want to hear about your visit with the client when they return. This can sometimes result in the volunteers staying with the family for an extended time. If you notice this becoming a pattern, try saying something like this:

- "I always enjoy catching you up on how my visit with your mom went, but I'm finding that we don't always have enough time for me to do that before I need to get going."
- "I'm wondering if we can try to plan some time at the end of each visit to do that. This way it won't feel so rushed when we're saying our goodbyes?"

The reality is that you can't be there all day. You have the right to state that you have other responsibilities that you must attend to. i.e. picking up the kids from school, etc.

Always give the client a gentle warning when the end of your visit time is approaching. Summarize what you have discussed during your time together (if necessary) and arrange for your next visit.

See Video: Communication - Allotted Time Schedule *

Use the space below to record notes.

See Video: 2.05 Closing a Visit - A Volunteer's Approach *

Use the space below to record notes.

Sharing of Contact Information

As with many professionals, supportive client relationships, volunteers must not provide hospice clients or their family members with their personal contact information.

Clients may call frequently or at inappropriate times when it is not convenient for a volunteer to speak with them.

This may become a burden to the volunteer and can also result in the client's private information being inadvertently shared with other non-volunteer members of the household. This information includes address, phone number, and email.

Blocking your Phone Number

It is wise to block your phone number when calling the client to arrange your visit (check with your hospice or local phone service provider for instructions on how to do this).

Contacting the Hospice

If a client or family member wishes to contact the you they should be instructed to contact the hospice and a message can be relayed to the volunteer.

Confirming Visits

Routinely confirm each visit with their client, reducing the need for clients to contact them directly if there is a change in their health status or their availability for a visit.

How to Respond

If a client does ask you directly for your contact information, you can respond to this request by saying something like:

> *"Actually, the hospice prefers that I not share that information, but why don't I give you a call on Monday evening to confirm our next visit? If you need to get in touch with me before that, you can give the hospice a call and they'll pass the message along to me."*

Section 6: Confidentiality and Privacy

Confidentiality

Violating confidentially is a serious breach of ethics and hospice policy, and may result in the termination of a hospice volunteer.

Privileged Communications

Conversations with a client and/or their family member(s) are privileged communications. They must be received with confidentiality, respect, and a nonjudgmental attitude. This meets the basic need for privacy and the universal expectation that one's privacy will be respect.

Building a Protective Atmosphere

Confidentiality is fundamental to providing high-quality hospice palliative care. It creates an atmosphere of trust in which the ill person and family members are more likely to share information that is vital to their care and support. Protecting privacy and respecting confidentiality is an important factor in client and family satisfaction with care and support.

Simple Rules for Maintaining Confidentiality

Confidentiality must be maintained regarding anything you:

- See
- Hear
- Read
- Observe
- Or anything you already know about the client/family

Violating Confidentiality

Violating confidentiality is a serious breach of ethics and hospice policy, and may result in the termination of a hospice volunteer.

Limits to Confidentiality

Confidential client information can be shared within the team whenever this is an unacceptable risk of harm to the individual or someone else. As a key member of the team, you must share this information with your hospice coordinator.

Client statements such as, "I am going to end this." Or "I can't go on, I feel like killing myself.", can often be the result of uncontrolled pain, insomnia, or any number of other distressing symptoms that can be treated.

As a volunteer, you can reassure the client that the medical team will do their best to help them with these symptoms.

The Right to Privacy

Volunteers must not disclose information to anyone other than the other members of the hospice palliative care team unless directed by the client and/or the caregiver who is acting as a substitute decision-maker.
Respecting the right to privacy means that you do not disclose:

- Who you are caring for
- The status of the ill person and/or their family members
- Anything that is said to you by the client and/or family members
- Anything that you observe or overhear during your assignment
- Any information about how the person died
- Any details about how the family members are grieving

Disclosure of Confidential Information

Volunteers must not use or disclose any confidential information following the termination or their contract/placement with their agency and must acknowledge that their confidentiality agreement survives the termination of their volunteer relationship with the hospice.

Chapter 4:
Pain & Symptom Management

Objectives

- Recognize the unique experience of pain
- Recognize the impact of pain on the client or family and the importance of pain management
- Identify techniques to recognize client's pain
- Recognize the importance of assessment and each team member's role in assessing pain
- Identify various assessment tools
- Recognize various comfort measures that a volunteer can perform

Sections in this Chapter

1. What is pain and the importance of pain management
2. Sources and factors affecting client pain
3. Recognizing a client's pain

Section 1: What is Pain and the Importance of Pain Management

What is Pain?

- "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage."
- "Pain is whatever the experiencing person says it is, existing whenever he/she says it does"
- "Pain is a more terrible lord of mankind than even death itself."

What is "Total Pain?"

Dame Cicely Saunders, key contributor to the modern hospice movement, coined the term ''total pain'' and suggested that pain be understood as having physical, psychological, social, emotional and spiritual components.

The combination of these elements is believed to result in a "total pain" experience that is unique and specific to each client's particular situation.

Total Pain Diagram

The Importance of Pain Management

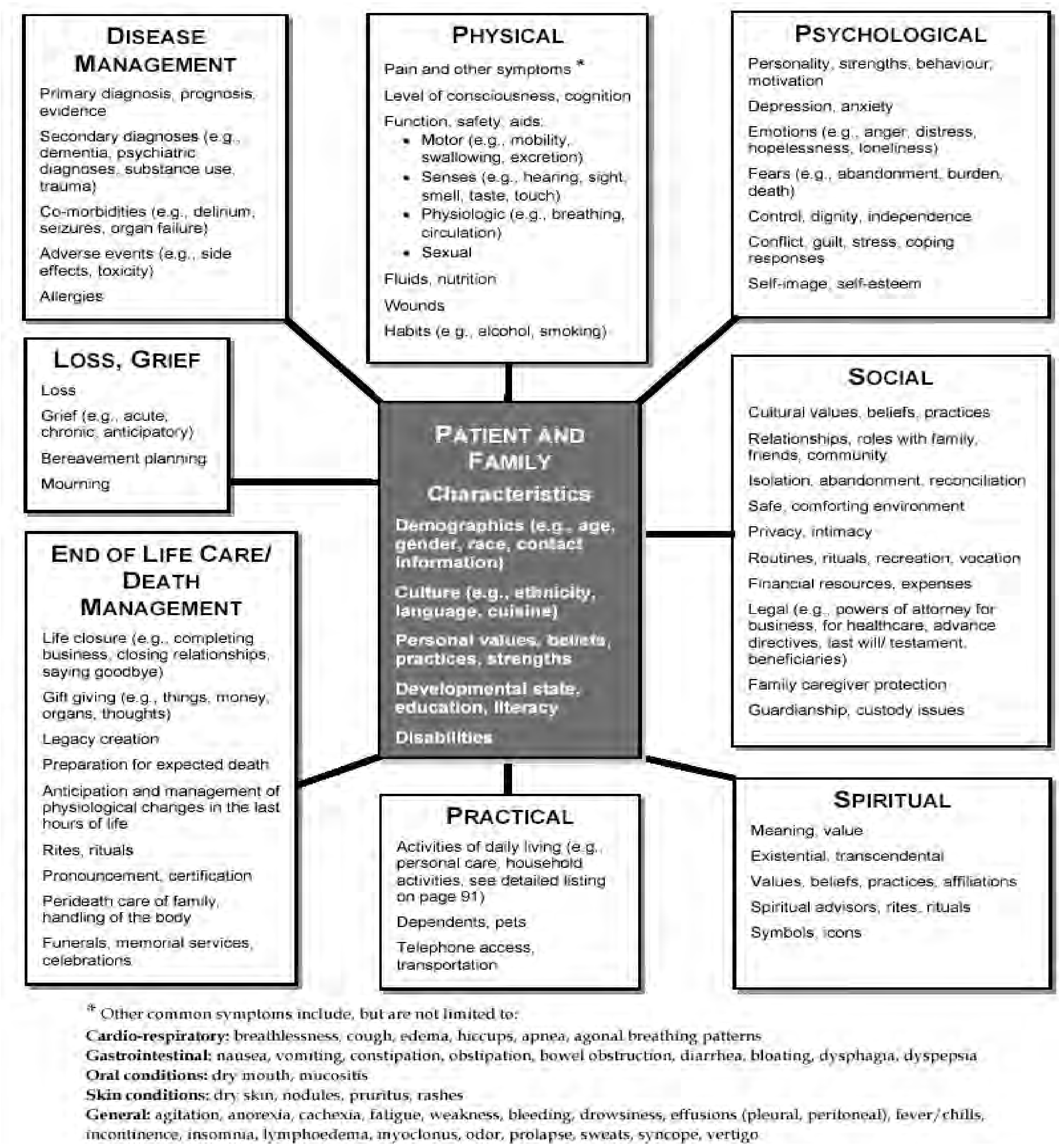
Unrelieved pain may cause:

- Unnecessary suffering
- Breakdown of body tissue
- Increase in metabolic rate
- Impaired blood clotting and increased water retention
- Impaired immune function
- “Fight or flight” alarm reaction
- Decreased ability to complete activities of daily living
- Depression and other negative emotions
- Feelings of isolation and separation

The health care professionals on the hospice palliative care team are responsible for treating pain and distressing symptoms. Volunteers can support clients/families by providing non-medical comfort measures that significantly contribute to the overall goal of pain and symptom management.

Practice Opportunity

Think about someone in your life -- a friend or family member -- who is or was coping with a serious illness. Reflect on the categories in the chart below (i.e. the eight "Domains of Issues" in Chapter 1: Introduction to Hospice Palliative Care) and identify one or two issues relating to each domain that are causing suffering for this friend or family member.



DISEASE MANAGEMENT

Primary diagnosis, prognosis, evidence

Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)

Co-morbidities (e.g., delirium, seizures, organ failure)

Adverse events (e.g., side effects, toxicity)

Allergies

PHYSICAL

Pain and other symptoms *

Level of consciousness, cognition

Function, safety, aids:

- Motor (e.g., mobility, swallowing, excretion)
- Senses (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual

Fluids, nutrition

Wounds

Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL

Personality, strengths, behaviour, motivation

Depression, anxiety

Emotions (e.g., anger, distress, hopelessness, loneliness)

Fears (e.g., abandonment, burden, death)

Control, dignity, independence

Conflict, guilt, stress, coping responses

Self-image, self-esteem

LOSS, GRIEF

Loss

Grief (e.g., acute, chronic, anticipatory)

Bereavement planning

Mourning

PATIENT AND FAMILY

Characteristics

Demographics (e.g., age, gender, race, contact information)

Culture (e.g., ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL

Cultural values, beliefs, practices

Relationships, roles with family, friends, community

Isolation, abandonment, reconciliation

Safe, comforting environment

Privacy, intimacy

Routines, rituals, recreation, vocation

Financial resources, expenses

Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)

Family caregiver protection

Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT

Life closure (e.g., completing business, closing relationships, saying goodbye)

Gift giving (e.g., things, money, organs, thoughts)

Legacy creation

Preparation for expected death

Anticipation and management of physiological changes in the last hours of life

Rites, rituals

Pronouncement, certification

Perideath care of family, handling of the body

Funerals, memorial services, celebrations

PRACTICAL

Activities of daily living (e.g., personal care, household activities, see detailed listing on page 91)

Dependents, pets

Telephone access, transportation

SPIRITUAL

Meaning, value

Existential, transcendental

Values, beliefs, practices, affiliations

Spiritual advisors, rites, rituals

Symbols, icons

* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Acute Versus Chronic Pain

Acute Pain

Acute pain is intense, sharp, localized and may last from one second to several weeks. Most people have experienced acute pain at some time in their lives, such as a toothache, appendicitis or a broken bone. This kind of pain usually ends in a relatively short time.

A client in acute pain will often exhibit restlessness and agitation along with muscular tension and perspiration. The client may moan and grimace, giving clear evidence of discomfort. It is also common for the client to shield, protect or massage the site. Acute pain is a warning from the body that something is wrong.

Characteristics of Acute Pain

- Definite pattern of onset
- Lasts for a limited time
- Observable signs
- Changes in vital signs
- Increased heart rate and blood pressure
- Facial grimace

Chronic Pain

Chronic pain is slow and continuous and usually fails to resolve quickly, lasting 3 to 6 months or longer. It can be a symptom of many conditions including arthritis, fibromyalgia, multiple sclerosis, shingles and/or other disorders. It is frequently dull or aching and usually is not localized.

It may vary in intensity or remain constant. Chronic pain may be as severe as acute pain. It can be associated with depression and anxiety. In someone with chronic pain, the body may have learned to compensate which may mean the person has fewer outward signs, symptoms or changes in vital signs.

Characteristics of Chronic Pain

- Poorly localized
- Fewer observable signs
- Variable characteristics
- Longer term

Section 2: Sources and Factors Affecting Client Pain

Common Sources of Pain

Clients may experience a variety of discomfort and pain as a direct result of their illness, treatment or both. Common sources of pain include:

- Bone infiltration by cancer that can result in fractures and generalized bone pain
- Nerve compression caused by tumor growth
- Ulceration and open infection of wounds
- Brain tumors causing headaches
- Muscle spasms and/or atrophy
- Bedsores
- Swelling caused by buildup of fluid (edema)
- Chemotherapy and radiation side effects
- Underlying conditions such as arthritis

Factors Influencing a Client's Response to Pain

- *Past experience* - A client's response to pain may be influenced by past experiences with pain.
- *Culture* - Clients may learn to express pain in the manner they have been shown by their cultural group.
- *Gender* - Societal norms may influence how clients demonstrate pain (e.g. men are expected to hide their emotions and women may be encouraged to cry).
- *Age* - With aging, clients may develop an increased tolerance to pain.
- *Significance/Meaning of Pain* - Pain may have specific meaning to an individual (e.g. punishment for past sins, part of life).
- *Fatigue* - When clients are tired, they may be more sensitive and indicate the pain is worse.
- *Depression* - When people are depressed, they may be more sensitive and may not be coping or managing well, so their pain may be worse.

Common Barriers and Myths Related to Pain

Barrier: Reluctance to report pain

Myth: Pain means the life-limiting illness is progressing. For example, the client says, "I have more pain so my disease must be getting worse."

Fact: **Pain can be due to illness or it can be unrelated to the illness** (i.e tendinitis rather than bone metastases).

Myth: Client does not want to burden loved ones. For example, the client says "I am reluctant to tell my daughter about my increase in pain. I just really don't want to worry her."

Fact: **Family and friends want to know their loved one is comfortable and pain free.** In addition, pain can interfere with sleep and rest, which are important to the body's ability to manage disease.

Myth: Complaining about pain means you are not a good patient.

Fact: **To provide good care, the medical team must be aware of all of a client's symptoms, including pain**.

Myth: If I report pain, I may have to go to the hospital for further tests and/or treatment. For example, you may find that your client complains of pain when you visit but won't tell the medical team because they don't want to go to the hospital for more tests.

Fact: **Reporting pain does not always mean more tests or treatment**.

Barrier: Cultural beliefs

Myth: All cultural groups manage pain in the same way, and will accept pain management as the team recommends and provides.

- Doctor: "I prescribed pain medication three weeks ago – but she hasn't taken any of it."

Fact: The perception and management of pain often varies among cultural groups. In addition, individuals within those cultural groups will have their own personal views that may influence the way they respond to pain. For some individuals, pain may be perceived to be a right of passage or an atonement so they may refuse pain medication. Some may value stoicism or the "strong, silent" reaction so expressing pain may demonstrate weakness. Others may prize the ability to endure great suffering as evidence of maturity and integrity.

Barrier: Mental health and/or the cognitively impaired client

Myth: Because clients with mental health or cognitive impairments may be unable to express their pain, the clinician will have to rely on objective observations.

- Daughter: It's impossible to tell is mom is in pain because of her dementia."

Fact: People may demonstrate pain by a change in facial expression, grimacing, a change in behavior, new behaviors, a change in body movements (e.g. rubbing a body part, rhythmic movements), **a change in posture or rapid gait (pace/step) or a change in appetite or interest in eating**.

Barrier: Use of medication

Myth: Clients who use narcotics will become addicted.

Fact: Clients who take narcotics for pain rarely if ever become addicted.

Myth: If strong medications like morphine are used too soon, they will not work later if the pain gets worse.

Fact: Strong medications like morphine stay effective as long as they are needed. If pain increases, the medication dose can be increased as much as needed.

Myth: Once strong medications like morphine are used to control pain, it means that death will soon follow (i.e. the person is actively dying).

- Spouse: I don't want my partner to take morphine. When my aunt was started on morphine, she died within the day."

Fact: **Controlling pain may result in longer life**. Pain can interfere with sleep and rest, so controlling pain is important to the body's ability to manage disease.

Myth: Strong medications, such as narcotics, have unpleasant side effects.

Fact: **The most common side effects are sleepiness, nausea and constipation**. **Sleepiness and nausea go away after a few days. Simple treatments are also available to control nausea and constipation.**

Barrier: Needles/shots

Myth: Shots will be needed to control pain.
Fact: At least 90% of pain can be relieved effectively using simple medications taken by mouth. Other treatments can help with the remaining pain.

Barriers to Providing Effective Pain Management

Misperceptions and biases

Health care providers may have varying levels of experience and knowledge regarding pain management. All team members may not share the concept of pain being "what the client says it is" and "occurring when the client says it does". Some use a holistic, whole-person approach while, for others, their own values, beliefs and biases may come into play.

How they perceive a client in pain will affect how they interact and provide care. For example, do they see the client as "complaining" or "needy" or "faking"? This perception may result in the health care provider not using a person-centered approach to manage pain.

Lack of adequate pain assessment

Health care providers may have different skill levels in assessing pain. Some will use many tools to assess the whole person with a view to assessing the total impact of pain (i.e. Domains of Issues). Some may allow their personal beliefs to influence their assessment. The health care provider's ability to assess pain may also be affected by the fact that a client may not feel comfortable reporting his or her level of pain accurately.

Fear of causing an addiction

Inexperienced health care providers may feel that the client will become addicted to pain medication, which may cause them to under-utilize pain medication and not manage pain appropriately.

Fear of accelerating dying or causing death

Inexperienced health care providers may be tentative and apprehensive about providing appropriate levels of pain medication for fear of speeding up the dying process or causing death.

If the volunteer has any concern that the client's pain is not being managed well or that the health care provider may not have the expertise to provide good pain management, then the volunteer must discuss his or her concerns with the hospice coordinator. It is the hospice coordinator's responsibility to raise the issue with the medical team.

Section 3: Recognizing a Client’s Pain

Indicators of Pain/Illness

There are a variety of signs that may indicate your client is experiencing pain. These include:

- Changes in appetite
- Changes in heart rate (pulse) or blood pressure
- Changes in respiration
- Moaning or grunting
- Sleep disturbances
- Anxiety, agitation, restlessness
- General body tension (e.g. clenched hands, hunched shoulders)
- Facial grimacing (e.g. tension, wrinkled brow)
- Strained or weakened tone of voice
- Change in usual demeanor, such as mood swings and being short tempered
- Withdrawal or lack of interest/participation in family or social events
- Remaining in bed and avoiding movement.

Common Assessment Tools in Hospice Palliative Care

The Palliative Performance Scale or PPS

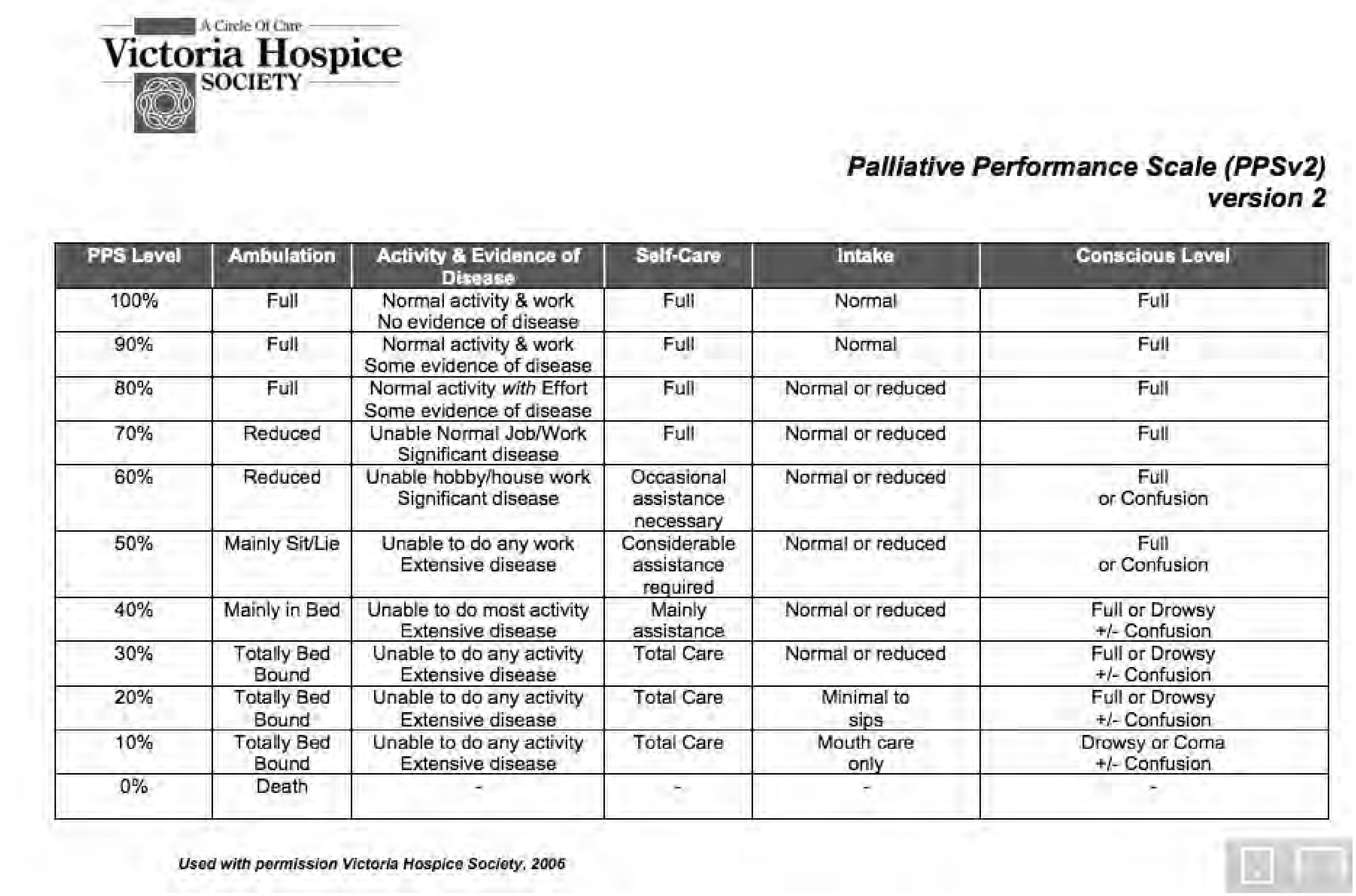
The Palliative Performance Scale is a reliable and valid tool used for palliative care clients. Developed by the Victoria Hospice Society, British Columbia, the PPS is an 11-point scale designed to measure a client’s functional performance throughout the illness. The measurement is read in decrements from 100% (total functioning) to 0% (death). Each level of activity -- including ambulation, activity, evidence of disease, self-care, intake and level of consciousness -- is assessed.

The PPS provides a framework for measuring progressive decline over the course of illness. It also provides a “best guess” projection of length of survival and serves as a communication tool for the team. The score will inform all health care providers about the client’s abilities relating to these particular activities, beginning with ambulation which is the key determinant, as the assessor reads the chart horizontally from left to right

It can also act as a workload measurement tool. For example, clients who score between 0 and 40% usually require more hands-on nursing care and their family members often need more support than those clients with higher PPS scores.

A copy of the PPS Tool is provided on the following page.

PPS Tool



A Circle Of Care
Victoria Hospice
SOCIETY

Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Used with permission Victoria Hospice Society, 2006

Edmonton Symptom Assessment Scale (ESAS)

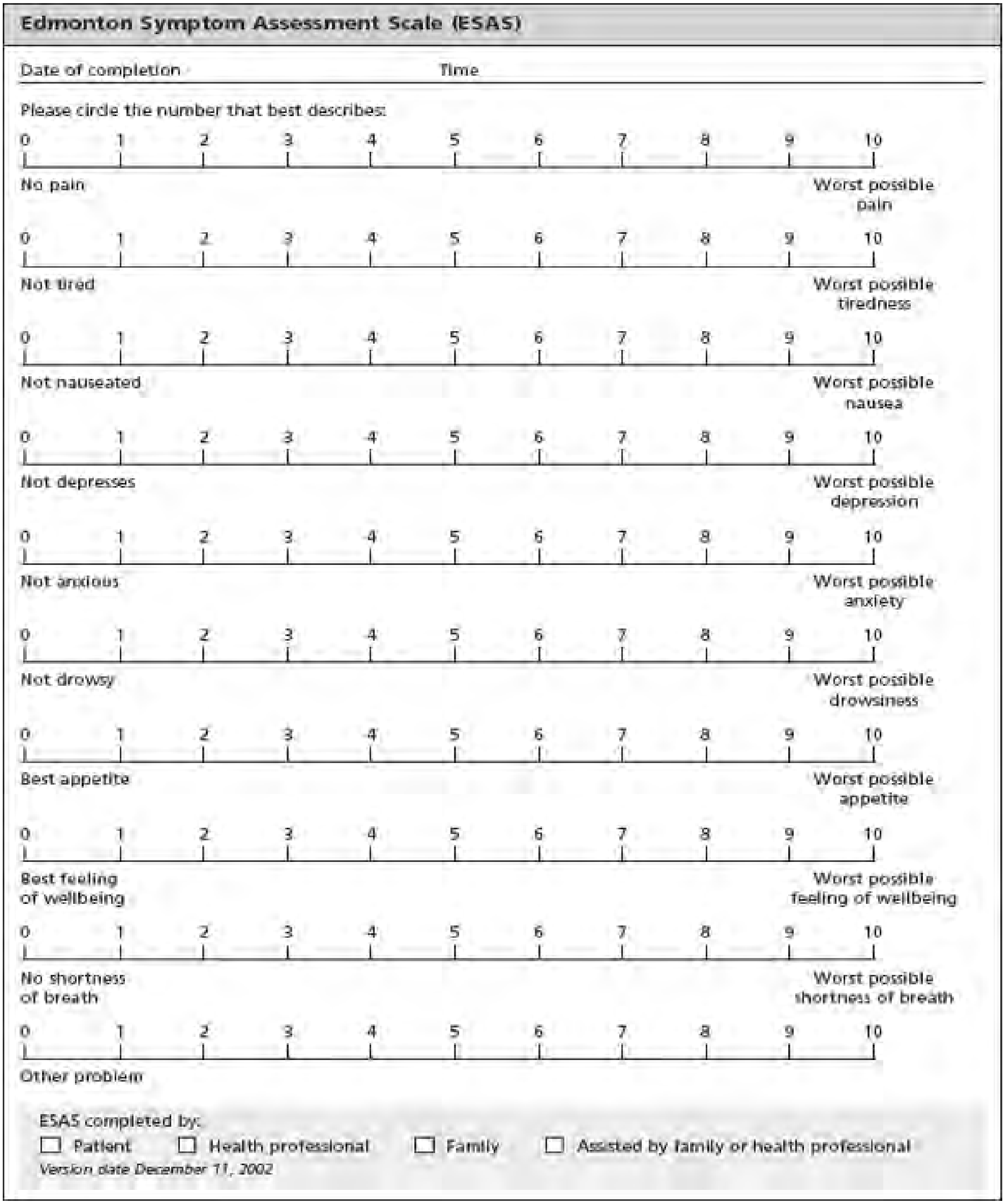
The Edmonton Symptom Assessment Scale is a universal tool that provides a clinical profile of pain and other symptoms. It is designed so that the client/family can administer the tool themselves. Clients are able to inform the hospice palliative care team directly about their symptoms related to the illness.

It is most useful when administered regularly, so it provides comparative information over time. It is designed to improve overall care and client/family satisfaction but it is only one part of a holistic clinical assessment.

This common tool and language allows clients an opportunity to communicate how they are feeling with regard to pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. Each symptom has a score value of 0 to 10 on the numerical scale - with 0 meaning that the symptom is absent and 10 meaning that it is the worst possible severity.

The ESAS can be used in whole or in part. For example, a care provider may only ask about pain: On a scale of 0 to10 with 10 being the worst pain you have ever experienced, what would you rate your pain at now?
A copy of the ESAS Tool is provided on the following page.

Edmonton Symptom Assessment Scale



Edmonton Symptom Assessment Scale (ESAS)

Date of completion Time

Please circle the number that best describes:

0 1 2 3 4 5 6 7 8 9 10
No pain | Worst possible pain

0 1 2 3 4 5 6 7 8 9 10
Not tired | Worst possible tiredness

0 1 2 3 4 5 6 7 8 9 10
Not nauseated | Worst possible nausea

0 1 2 3 4 5 6 7 8 9 10
Not depresses | Worst possible depression

0 1 2 3 4 5 6 7 8 9 10
Not anxious | Worst possible anxiety

0 1 2 3 4 5 6 7 8 9 10
Not drowsy | Worst possible drowsiness

0 1 2 3 4 5 6 7 8 9 10
Best appetite | Worst possible appetite

0 1 2 3 4 5 6 7 8 9 10
Best feeling of wellbeing | Worst possible feeling of wellbeing

0 1 2 3 4 5 6 7 8 9 10
No shortness of breath | Worst possible shortness of breath

0 1 2 3 4 5 6 7 8 9 10
Other problem

ESAS completed by:
☐ Patient ☐ Health professional ☐ Family ☐ Assisted by family or health professional

Version date December 11, 2002

Other Common Symptoms with Chronic and End-Stage Diseases

Common symptoms that people with chronic and end-stage diseases experience include:

- Shortness of breath
- Nausea and vomiting
- Fever and chills
- Diarrhea/constipation
- Headaches
- Sleep disturbances
- Skin breakdown
- Fatigue - no energy
- Edema - swelling in feet and/or legs
- Decline in functional ability (e.g. to walk or do every day activities)
- Confusion - not enough oxygen to the brain or too many toxins (i.e. urea, carbon dioxide) in the blood.
- Anxiety or panicky feeling
- Jaundice or yellow colouring of the skin
- Weight loss.

Section 4: Volunteer Role in Pain and Symptom Management

It is the medical team's role to assess and recommend treatment for the client. The volunteer's role is to communicate, support and advocate.

Under no circumstances will a volunteer recommend treatment or administer medication, regardless of any professional designation, training or other capacity.

Volunteers will utilize their communication skills to try to understand how the client is feeling, and may use some of the following practical measures when clients experience certain symptoms in order to enhance their comfort and well-being.

Shortness of breath

Shortness of breath is a common breathing problem that can be very frightening for both the client and family. Here are a few things that may help:

- If clients have difficulty breathing during an activity, stop the activity and ask them to sit down. 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.
- When clients are lying down, ask them which position helps improve their breathing. Usually sitting works best and propping client's arms on pillows will help to expand their chest.
- Breathe with the client by concentrating on slowing down the breathing and 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 help to decrease the sensation of breathlessness.
- If clients are using oxygen, remember that oxygen is considered a medication and so hospice medication policy applies. (See Module 2 Volunteer Role and Understanding Boundaries.) DO NOT attempt to adjust the airflow or refit the oxygen mask or prongs.
- For safety reasons, make sure that no one smokes or lights candles while the oxygen is being used
- Advise the family and the hospice coordinator if the client is still not comfortable or is experiencing breathing problems.

Nausea and Vomiting

Certain foods, drugs, scents or internal pressure from blocked intestines may cause nausea and/or vomiting. If clients vomit when the volunteer is with them, the volunteer can:

- Stay close to the client and offer whatever assistance he/she may need. Standard precautions should be observed (See Infection Prevention and Control Module) and the volunteer should be wearing disposable gloves.
- If possible, reposition (i.e. turn on side or sit up) the client (ask for assistance if available) and wipe the client's face with a cool damp cloth during and after an episode of vomiting; offer cool water or ice chips so that the client's mouth can be rinsed.
- Remove soiled linens (ask for help if the bed needs changing) and basin/bowls quickly, as the odour may prolong or induce vomiting.
- Wash hands thoroughly with warm, soapy water.
- If the volunteer is one of the small percentage of the population that vomits when they see, hear or smell vomit, the volunteer may ask for help from a family member and offer whatever help she/he can, as above.

Fever or chills

The volunteer may be matched with clients who experience periodic or continuing fevers or chills. The volunteer can help them be comfortable by:

- Covering the client who is shivering with extra blankets.
- Sponging the feverish client's face, neck arms and legs with a warm damp cloth and placing a towel under the head and neck to absorb extra sweat (note: standard precautions apply – gloves are needed).

Diarrhea

Diarrhea can come on very suddenly so volunteers may need to respond quickly. Foul odours and accidental soiling can cause clients great distress. Here are some measures volunteers can undertake:

- The volunteer should make sure that he/she knows where to quickly find the client's usual toileting facility (bedpan or commode) quickly - even if the volunteer does not regularly assist with toileting.
- It's important for the volunteer to remain calm and supportive, and to watch the client's body language, especially facial expressions. This is a very sensitive and potentially embarrassing event.
- Room deodorizers that do not add a scent to the air are the best choice.
- Remember Standard Precautions (See Infection Prevention and Control Module) – and wear disposable gloves.

Constipation

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

- Go for short walks, if the client is able to.
- Follow the dietary recommendations of the nurse or dietitian (e.g. consuming whole grains, fruits, vegetables).

Headaches

Headaches will be treated and monitored by the health care professionals. Volunteers can help by:

- Offering meditation or relaxation techniques.
- Keeping noise and distractions to a minimum.
- Using techniques that the client has found helpful in the past (e.g. darken the room).

Sleep disturbances

Many emotional, psychological and physical concerns may interfere with the client's ability to sleep. Volunteers can use their communication skills to listen and talk or spend quiet time with the client. You can also offer:

- Light back, hand and foot rubs (but not deep massage).
- Use of relaxation techniques and mental imagery to promote relaxation.
- A warm drink (nothing with caffeine).

If the client'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

Skin breakdown and mouth sores are medical problems that require treatment and monitoring by a health care professional. Volunteers can support clients by:

- Helping with repositioning the client to relieve pressure, when asked by the nurse or a family member.
- Encouraging the client to use lip balm, Vaseline or whatever has been prescribed for dry or cracked lips.
- Encouraging the client 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 client's and family's changing needs.

Other Ways Volunteers Can Help

The volunteer may learn about their clients' hobbies and interests and encourage them to engage in activities of their choice. There are also many techniques that can be adapted from everyday living and recreational activities that give clients/families a continuing sense of control and well-being.

Although the following list of activities are all part of the volunteer role, it's most important to acknowledge the value of just being present for the client and family.

The volunteer's presence is often the greatest gift they can give. Being present makes one more keenly aware, mindful and ready to be there for people, in whatever way they need (see Chapter 2: Volunteer Role and Understanding Professional Boundaries Module).

Listening

One of the most effective ways of helping a client/family to cope with fear, anxiety, loneliness and "the blues" is having someone who listens unconditionally and in an honest way. Listening involves paying attention to the person's total message, both spoken verbal messages and nonverbal messages that modify what is spoken. (See Communications Module.)

Recreation

Taking a walk, playing a game or watching a game that the client enjoys can be a point of connection. Sometimes the volunteer can get creative and "go to the ball game" or have "a night at the movies" with a client -- by recreating the atmosphere in the client's home. Volunteers are encouraged to use their imagination and have some fun with this!

Art, Crafts and Hobbies

Volunteers can encourage clients and families to continue to pursue their artistic, craft and hobby projects or take up new ones. Conversations may be easier and feelings can often be expressed through these activities, and the end product may become a cherished memento.

Music

Playing and listening to music can be both relaxing and comforting and may bring joy to clients and families. Volunteers can encourage clients to reminisce about past concerts or learning to play an instrument, and they can share musical interests that are both similar and different.

Laughter

It's easy to forget about laughter and how therapeutic it can be. When someone laughs, the body produces endorphins (natural pain killers). Laughter also reduces tension, causes a distraction, and may let feelings be expressed in different and less threatening ways. Watching a favourite video, reading a humorous book out loud or listening to a CD of a favourite comic may result in laughter and improve the feeling of well-being.

Relaxation

Volunteers may encourage clients and families to use deep breathing, visualization, meditation or prayer to promote relaxation. There are many relaxation recordings that bring the sounds of the forest or breaking waves to life. Volunteers may use these activities to take relaxing "journeys" with their client.

Complementary Therapies

Complementary therapies, which may be offered by volunteers in some hospice programs, may help alleviate a client's distressing symptoms. Such therapies may include, but are not limited to:

- Reiki
- Therapeutic touch
- Healing touch
- Massage
- Acupuncture
- Acupressure foot massage
- Reflexology
- Art and music therapy
- Mandala design
- Yoga
- Tai chi
- Pet therapy

Volunteers are not to provide any complementary therapies without the appropriate training, certification and approval/authorization from their hospice. Volunteers should find out what therapies are offered at their hospice organization and how clients can access them.

See Video: Volunteer Testimonial*

Use the space below to record notes.

Practice Opportunity: Self Reflection

Identify how you, in your volunteer role, might support a hospice client/family with any of the identified issues that may have been causing suffering. Remember that the client and family are always the center of care.

Chapter 5:
Understanding the Dying Process

Objectives

- Recognize dying as a holistic, natural process
- Recognize the common signs and symptoms that occur during the dying process
- Recognize when death occurs
- Recognize the importance of Do Not Resuscitate (DNR) orders
- Recognize the difference between a medical emergency and imminent death
- Recognize ways to support the client and family during the dying process and at time of death

Sections in this Chapter

1. Common Signs and Symptoms of the Dying Process
2. Medical Emergency versus Imminent (expected) Death

Section 1: Common Signs and Symptoms of the Dying Process

Death as a Holistic, Natural Process

When a person enters the final stage of the dying process, two different but inter-related dynamics occur. Physically, the body begins the final process of shutting down. Although it is technically unknown what happens to a person emotionally and spiritually during the dying process, many believe that the person's spirit begins to release from the body and detach from the physical, human environment.

During this profoundly sad and emotional time, hospice volunteers may play an important role in providing valuable support and guidance for family members.

The Dying Process

As death approaches, the client's appearance and behaviours may change. Although these changes often follow a predictable pattern, the process of physical decline is very individual.

It can last hours or days. During that time, the client may experience many ups and downs: periods of significant decline followed by sudden improvement and responsiveness. Because of these ups and downs, it is very difficult to accurately predict how much longer a client will live.

For that reason, volunteers must not speculate or make statements like: "It shouldn't be long now." The medical team will use a diagnostic tool, such as the Palliative Performance Scale (PPS), to determine how close the client is to death. (See Pain and Symptom Management Module.)

While the symptoms of dying may be disturbing to witness, they are normal and natural. The person who is dying is seldom in any real discomfort at this stage.

The best way to respond to these signs is to provide comfort and support including, for example, sitting with the client, holding his or her hand, listening to family members share stories or simply sitting in silence.

The Dying Process: Common Signs and Symptoms

- Social and Emotional
- Loss of Senses
- Appetite and Thirst
- Breathing Changes
- Skin
- Sleeping
- Dreams and Visions
- Delirium

Social and Emotional Signs and Symptoms

As death approaches, clients may become quieter and less interested in their surroundings. Clients and families may experience a range of emotions from peace and gratitude to guilt, sadness, anger and helplessness.

Clients may fear being abandoned or becoming a burden to their caregivers. They may also worry about losing their dignity and control as death approaches. Tears are a natural way to show feelings.

> **Volunteer Role:** As death approaches, the volunteer's final gift is to accept the dying experience and simply be present for clients and families as needed.

Loss of Senses

The client's senses may begin to fail. Eyesight is usually the first sense to go while hearing is the last. Everyone should be mindful of this and always speak in front of clients as though they are listening.

> Volunteer Role: Family members may find comfort in knowing their loved one can still hear. Volunteers can encourage them to continue to speak to their loved one, reminiscing and sharing loving memories. All should speak calmly and reassuringly in a normal voice tone (it is not necessary to speak loudly).

Appetite and Thirst

During their final days, clients may not be hungry or thirsty. They may produce less urine and experience incontinence (loss of control over bladder and bowels) and bloating or fluid retention. Clients' loss of appetite and thirst can be very difficult for families. Many family members see food as a way to care for or comfort their loved one so it can be very emotional for them when clients stop eating or drinking. However, consuming food or drink very near the end of life may actually cause clients more distress and discomfort as their bodies' digestive systems slow down. To help keep clients comfortable, they may be given ice chips or small sips of water to help keep their mouths moist.

> Volunteer Role: A volunteer might encounter the following scenario in their work with clients.

See Video: Volunteer Role Scenario & the following videos*

- **Volunteer Role – Comfort**
- **Volunteer Role – Education, Resources**
- **Volunteer Role – Normalize fears and allow emotions to be expressed**
- **Volunteer Role – Cultural Significance**

Take a moment to reflect on how you celebrate or use food to signify special occasions in your life.

What special food is used?

What emotions may be connected with that food?

What memories are associated with that food?

Imagine that your loved one is dying and unable to eat the food that he/she loves. How would this make you feel?

Breathing Changes

When clients are nearing end of life, their breathing patterns may change dramatically. Their breathing may be laboured and there may be unusually long pauses between breaths. It's also common for people to gasp, gurgle and develop noisy breathing, which is sometimes referred to as a "death rattle". These changes happen because of muscle weakness. Gradually clients become unable to swallow their saliva so fluid collects in their throat. Gurgling or noisy breathing is not painful or uncomfortable for clients but it can be distressing for families.

> <u>Volunteer Role</u>: A client who is breathless or struggling to breath may be more comfortable when the head of the bed is elevated. A gentle fan across the cheeks can be calming. If family members are very distressed by the client's breathing changes, the volunteer can encourage them to speak with a medical care team member who can explain the symptom(s).

See Video: Tracey Human's video on breathing at end of life*

Use the space below to record notes.

Skin

When they are dying, client's skin may become cool and feel clammy and damp, particularly in the arms and legs. Their lips may become bluish and their fingernail/toenail beds may be blackened. Clients often experience a drop in blood circulation, which causes the body to become purplish (mottled). Clients may not be aware of these symptoms and likely do not feel cold.

> <u>Volunteer Role</u>: Skin changes are a normal part of the dying process. If family members seem concerned about these changes, volunteers can share their understanding of the symptoms. Although clients may not feel cold, offering them a light blanket may make the family feel better.

Sleeping

As the end of life approaches, clients may spend more time sleeping. It may become more difficult to wake them. The difference between dreaming and wakefulness often blurs. As death nears, clients may slip into a coma and become unresponsive.

> <u>Volunteer Role</u>: Clients may tire very easily at the end of life and may not be interested in conversation. Volunteers may want to bring a book to read or a quiet activity, such as knitting or homework, to do while visiting with sleeping clients. Your presence can be very comforting for clients and may allow the family time away to care for themselves, knowing that their loved one is not alone.

Dreams and Visions

End-of-life dreams and visions are not uncommon and may hold profound meaning for clients and families. Dreams and visions of deceased loved ones may occur months, weeks, days or hours before death and generally seem to provide comfort for people who are dying. Clients may experience a reunion with deceased loved ones or the preparation for going somewhere. As death nears, the intensity and frequency of dreams and visions may increase and may provide comfort for clients and families making the transition through this stage of dying.

> Volunteer Role: It is important to understand that dreams and visions are not uncommon and should not be dismissed as being caused by medication or as meaningless nonsense. Volunteers can help by being present with clients and families and fully acknowledging their experience. Much has been written on the topic of dreams and visions at end of life. (See additional resources section at the end of this module.)

See Video: Sacred Dying by Megory Anderson*

Use the space below to record notes.

Delirium

When death is imminent, regardless of the excellent care clients may have received, it is not uncommon for them to experience an acute onset of terminal delirium in the final hours of living. The client may moan, groan, grimace and appear to be confused, restless and/or agitated. There are a range of medical causes responsible for delirium but, in general, it is the result of a build-up of toxins in the body, (i.e. infection).

If the delirium remains unmanaged, it can be very distressing for families and caregivers. They may interpret it as unbearable physical pain and/or emotional distress. However, it is a myth that pain suddenly develops during the last hours of life, when it previously had not been out of control. It is the responsibility of the medical team to use the many options available to treat the delirium.

> Volunteer Role: Although it is the medical team's responsibility to treat delirium, volunteers can help in a number of ways. They can try to calm and comfort clients by holding their hand, playing soothing music or reading to them. They can also encourage the family to talk with the medical team about the delirium so that they understand its causes and potential treatments. Volunteers may contact the hospice coordinator or, if appropriate, ask a medical team member to explain the situation to the family so they understand that their loved one's experience may be very different from what the family is observing.

Section 2: Medical Emergency vs. Imminent (expected) Death

What is a Medical Emergency?

Hospice volunteers are part of the hospice palliative care team along with the client and family members, health care professionals, unregulated care providers and friends of the client and family. Volunteers do not replace the family as the primary care persons. Your role is to support the client and family.

Generally speaking, a medical emergency occurs when clients:

- Suffer injuries from a fall or other type of accident
- Begin to choke
- Hemorrhage or bleed
- Experience a significant, sudden, unexpected change in their condition

The Volunteer's Role During a Medical Emergency

Hospice volunteers are not expected to assess the emergency but to:

- Exercise reasonable judgment
- Stay calm and do not panic
- Follow regular hospice emergency response procedure
- Reassure client and call 911 for assistance
- Call the clients emergency contact, inform them of what has happened, what steps have been taken and reassure them as needed. The client may also want to reassure them directly.
- Wait for assistance. If the emergency is a result of the client falling, do not try to help the client up from the floor. This requires assistance so wait for help to arrive. Try to make the client comfortable while you wait (i.e. get them a pillow or blanket).
- Notify the hospice coordinator and once the incident has been resolved, complete the required incident report.
- Be prepared. If there is a DNCR, have it available when emergency personnel arrive.

Summary

Volunteers are not expected to intervene personally in a medical emergency. The one exception to this rule may be when a regulated heath care professional is volunteering with hospice and is required be statute or professional regulations to intervene in a medical emergency. Check with your hospice policies and procedures about this exception. The volunteer must review, understand and follow their hospice's emergency policies and procedures whenever visiting with hospice clients.

Role of the Volunteer at the End of Life

Reduce Stress

- Keep the room warm, free from drafts but ventilated.
- Turn out lights that are not necessary. See that lights are not glaring and shining in the client's eyes.
- Avoid excessive noise. Radio or television may be audible, but not too loud.

Offer Comfort

- Reduce odours. Never smoke or wear scented products.
- Offer cool drinks and/or ice chips, if recommended in the client's care plan.
- Moisten the lips and mouth with a sponge often or brush the person's teeth. Use a soft brush only. Do not use commercial mouthwashes because they may contain alcohol.
- Gently rub the person's hands, elbows and heels with lotion as they can become very dry.

Provide Assistance

- Help the person turn from side to side every 2 hours. (Check hospice policy on this.)
- Keep sheets free from wrinkles. Make sure the top bedding isn't too tight over the client's feet.
- Brush the client's hair.
- Wash the client's face and hands as necessary. Put a cool cloth over the forehead, especially if the client is running a temperature.
- If the client/family requests other specialized services, contact the hospice coordinator

Summary

Every setting may differ on what is part of the volunteer role so volunteers must review their agency's policy.

Do Not Resuscitate (DNR) Orders

People who know they have a life limiting illness or who are near the natural end of their lives, can consent to no cardio-pulmonary resuscitation (CPR) in the event that their breathing or heart stops.

Once consent has been obtained for ‘no CPR’ a document, called a “Do not Resuscitate Confirmation” form (DNRC) should be completed.

DNRC Form

This form allows ambulance attendants, paramedics or other Emergency Medical Services to not initiate basic or advanced CPR but they will continue to provide necessary comfort measures.

If resuscitation is attempted, it is usually unsuccessful, and this will add to the distress for both clients and families.

A copy of the DNRC form is available on the next page.

How DNR Orders are Used

A DNRC form may already be in the client’s chart in their home or in the physician’s record. All clients in residential hospices are required to have consented to no CPR before admission.

Clients may change their mind, and consent for ‘no CPR’ can be cancelled at any time. If the DNRC cannot be located, EMS paramedics are required to perform CPR I the client is unable to state their wishes and regardless of the wishes of the client or family.

Once the DNRC form has been signed, it should be available to everyone involved in a client’s care. It should be kept somewhere where it will be easily seen by members of the hospice palliative care team. The DNRC form must be given to ambulance attendants, paramedics, or EMS if the client has to be transported by ambulance.

The DNR does not mean the person will not receive all other care required to manage comfort. The only difference is that CPR will not be carried out should a client’s heart or breathing stop.

Ontario Ministry of Health and Long-Term Care

Office of the Fire Marshal

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Do Not Resuscitate Confirmation Form

To Direct the Practice of Paramedics and Firefighters after February 1, 2008

Confidential when completed

When this form is signed by a physician (M.D.), registered nurse (R.N.), registered nurse in the extended class (R.N. (EC)) or registered practical nurse (R.P.N.), a paramedic or firefighter **will not** initiate basic or advanced cardiopulmonary resuscitation (CPR) (see point #1) and **will** provide necessary comfort measures (see point #2) to the patient named below:

Patient's name – *please print clearly*

Surname	Given Name

1. **"Do Not Resuscitate"** means that the paramedic (according to scope of practice) or firefighter (according to skill level) **will not** initiate basic or advanced cardiopulmonary resuscitation (CPR) such as:
   - Chest compression;
   - Defibrillation;
   - Artificial ventilation;
   - Insertion of an oropharyngeal or nasopharyngeal airway;
   - Endotracheal intubation;
   - Transcutaneous pacing;
   - Advanced resuscitation drugs such as, but not limited to, vasopressors, antiarrhythmic agents and opioid antagonists.
2. For the purposes of providing comfort (palliative) care, the paramedic (according to scope of practice) or firefighter (according to skill level) **will** provide interventions or therapies considered necessary to provide comfort or alleviate pain. These include but are not limited to the provision of oropharyngeal suctioning, oxygen, nitroglycerin, salbutamol, glucagon, epinephrine for anaphylaxis, morphine (or other opioid analgesic), ASA or benzodiazepines.

The signature below confirms with respect to the above-named patient, that the following condition (check one ☑) has been met and documented in the patient's health record.

☐ A current plan of treatment exists that reflects the patient's expressed wish when capable, or consent of the substitute decision-maker when the patient is incapable, that CPR not be included in the patient's plan of treatment.

☐ The physician's current opinion is that CPR will almost certainly not benefit the patient and is not part of the plan of treatment, and the physician has discussed this with the capable patient, or the substitute decision-maker when the patient is incapable.

Check one ☑ of the following:

☐ M.D ☐ R.N. ☐ R.N. (EC) ☐ R.P.N.

Print name in full

Surname	Given Name
Signature	Date (yyyy/mm/dd)

- Each form has a unique serial number.
- Use of photocopies is permitted only after this form has been fully completed.

4519-45 (07/10) 7530-5678

The Volunteer's Role

When visiting clients at home, it's imperative that the volunteer be aware if there is a DNR order in place and where the DNRC form is located in the event that 911 has to be called. If the volunteer is taking a client out of the home, the volunteer should ensure a copy of the client's DNRC form goes with them. If the DNRC cannot be located, EMS paramedics are required to perform CPR regardless of the wishes of the client or family.

Time of Death

What will happen at the time of death?

- There will be no response to any stimulation (shaking, calling the person's name).
- There will be no breathing and no pulse.
- Eyes will be fixed in one direction.
- Eyelids may be open or closed.
- There may be a loss of bladder or bowel control.
- There will be no pain.

What is my role at the time of death?

Regardless of whether a client's death is expected or unexpected, volunteers may feel anxious.

Remember:

- This is not an emergency. Stay calm and follow procedures that have been outlined. Be supportive to family members who will be grieving the loss of their loved one. The family should not have to comfort the volunteer.
- Volunteers must be aware of the client's and family's wishes, should death occur when the volunteer is alone with the client. This is very rare. Protocol may vary depending upon where the client is residing (e.g. community, residential hospice, hospital or long- term care home). Volunteers must be clear on what is expected of them so they can take the appropriate steps.

How can I help during this time?

It is important to ask for guidance from the family members. Some people may find it helpful to have volunteers help by:

- Making a cup of tea
- Answering the phone or greeting at the door
- Being a calm presence and listening to the feelings expressed by family members
- Acknowledging family members' pain and not shying away from it
- Simply being present

What should I do if I'm asked to leave?

The family may ask the volunteer to leave so they can grieve privately: that is okay. Do not take this as a personal rejection; respect the family's wishes and their need to be alone with their loved one. Be sure to notify the hospice that the client has died so that staff and other volunteers will not contact the family without being aware of the death.

Chapter 6:
Spirituality

Objectives

- Recognize the difference between religion and spirituality
- Explore personal concepts and attitudes towards spirituality
- Identify and understand clients' spiritual needs
- Recognize how death, dying and serious illness may affect both the client's and their family members' spirituality
- Respond appropriately to clients'/families' spiritual needs
- Identify the role (and limitations) of the volunteer in providing spiritual support to clients.

Sections in this Chapter

1. Spirituality and Religion
2. Spiritual Distress / Spiritual Resiliency
3. Spiritual Support

Section 1: Spirituality and Religion

A Focus on Spirituality

Although spiritual care is an integral part of hospice palliative care throughout the client's illness trajectory, it may become more of a focus as individuals approach death.

Clients/families may review and reflect on the meaning of their life, consider their religious or spiritual beliefs, evaluate choices they've made and/or search for meaning in their illness (e.g. Why me? Why now?).

Introduction

Spirituality is the aspect of humanity that refers to the way individuals make meaning and express purpose as well as the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.

Understanding Spirituality

Spirituality may be understood as the inherent human capacity to connect with something that transcends the physical world, such as God, creation, Allah, a higher power, nature, the universe, soul and spirit.

Spirituality may allow individuals to:

- derive meaning and purpose in most circumstances of life
- trust that the journey of life is unfolding as it should
- believe that they are becoming who they are meant to be.

Personal Nature of Spirituality

Spirituality is concerned with hope, love, quality of relationships and values. Just as no two people travel the journey through life in exactly the same way, one's spirituality is personal and unique.

Spiritual Thoughts

"Spiritual concerns are rarely expressed in overtly theological language. They are more likely to be phrased in terms of the meaning and purpose of life, loving and being loved, and hope or concern about the future."
– H. J. Clinebell

Religion

Religion is adherence to or practice of one or more aspects of a system of beliefs, values and relationships, within which people share identifiable rites, rituals, ceremonies, religious leaders, sacred objects and sacred literature.

Many religions believe in a supernatural or divine being or god. Religions often hold a certain world view or sense of cosmic order that has purpose and meaning.

Religion is a Relationship

- Religion is the relationship between an individual and a higher power or God(s), characterized by a belief in, reverence for and desire to please that higher power.
- If their religious needs are met, individuals with religious faith may be less likely to have unmet spiritual concerns.
- In the hospice palliative care setting, a client's faith, no matter how strong or weak, may influence and be influenced by everything they experience as death approaches.

How Religious Faith May Help

- Most religious faiths support the belief that biological death is not the end of life.
- Believers may be comforted that:
    - There is something to look forward to after death
    - Their wrong doing can be forgiven and good deeds can be credited.
- Clients/families often share the same faith.
- Religious faith may help clients/families cope more effectively.
- Religious faith may be a source of comfort that will help those left behind after someone dies.

Blaming Religion

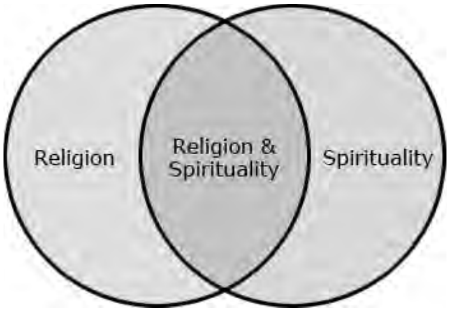
- Religion does not necessarily make living or dying easier but, for some, it may make both more meaningful. Religion may not provide all the answers individuals may seek. Clients/families may expect miracles, answers to unanswerable questions and/or immediate and sympathetic answers to their prayers.
- Clients/families with unrealistic expectations of their religious faith may be disappointed when their expectations are not met. They may blame their religion or God or they may direct their anger or disappointment at the professional caregivers, family members, religious leaders and even their volunteer(s).

Summary

Volunteers must have respect for the spiritual or religious beliefs, rites and practices of the client or family. You must also have respect for the manner in which they practice those beliefs, both while they are living and after their death.

Differences between Spirituality and Religion

Religion is an organized system of beliefs, practices, rituals and symbols, while spirituality is more of a personal quest for answers to questions about life and meaning. Not everyone will need religious care, but most will need spiritual support.



People can express their spirituality in many ways, formally or informally. 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.

RELIGION	SPIRITUALITY
Concerned with customs, doctrines, creeds, traditions	Concerned with what brings meaning to one's life
Public realm - religious institutions such as mosque, church, temple	Private realm - thoughts, feelings, experiences
Can be group or individual practice	More often about individual practice
Belief and faith in god or gods or supernatural beings	Belief in a connection with what brings meaning to life, such as nature, universe, science
What practices, rites and rituals should I follow?	Where do I find meaning?
What is right and wrong/true and false? Moral framework explains how to live	What moral values guide my life? Personal search for values
Expressed by: prayer, meditation, ritual, clergy, support from faith community	Expressed by: dream work, meditation, guided imagery, going into nature or activities that bring one meaning, peer support, may or may not include ritual
In common: faith, belief, awe, comfort, reflection, ethics	

Faith

Faith, which can be a part of both spirituality and religion, can be defined as a belief that is not based on proof and cannot be substantiated by fact.

Faith can be formed through instinct, intuition and/or experience. One can have faith in God, the doctrines of a religion, a personal relationship, an inanimate object, a person or a state of affairs.

Practice Opportunity

Think about what brings meaning, purpose and strength to your life.

- What kind of spiritual or religious practices do you have?
- How do you connect with a sense of the sacred?
- Do you consider yourself spiritual or religious or both?
- In what ways do you express this in your personal life?
- What could you draw strength from to support your work as a volunteer caregiver?

Section 2: Spiritual Distress and Spiritual Resiliency

Spiritual distress

Spiritual distress may occur when a person has the sense that life lacks meaning. Clients may experience a sense of hopelessness or feel that their level of pain has become intolerable and they can no longer be the kind of person they want to be.

Those in spiritual distress may ask questions or make statements like:

- What did I do to deserve this?
- Why am I being punished?
- Where will I go when I die?
- Did my life have meaning?
- I'm afraid when I'm alone with my thoughts.
- My life has no purpose.
- I just want to be left alone.
- I can't go on now that all hope is lost.
- I have no energy to cope anymore.

Those in spiritual distress may:

- Talk about what happens before or after death, and asking for spiritual or religious support
- Express feelings of fear (of pain, dying, leaving loved ones behind or falling asleep at night), despair, guilt regarding sin and punishment, anger at a higher power and/or hopelessness (talk about refusing food and water or being tired of waiting to die)
- Give non-verbal signs such as uncontrollable crying, isolating themselves, losing connections with others or with a higher power, and feeling lethargic.

See Video: Recognizing Spiritual Distress*

Use the space below to record notes.

Recognizing Spiritual Distress

To be able to identify a spiritual need or spiritual distress, volunteers should watch for the type of responses previously discussed. Volunteers can learn to recognize spiritual need by listening and being sensitive to small clues.

For example:

- Is the client generally content with what he/she has done in life?
- Is the client generally more forgiving of others?
- Can the client identify a purpose for their existence?
- Does the individual express a lot of bitterness, regret or anger? Those who are angry, anxious or hopeless are more likely to need more spiritual support.

Active Listening

By practicing their active listening skills (see Chapter 3: Communication Skills), volunteers may help clients/families express their concerns.

The questions clients ask may mean that the individual is frightened and seeking reassurance or wanting someone to be "present" with them in their reality (see Chapter 2: Role of Volunteer and Understanding Professional Boundaries).

Conversations About Death

Family members may be reluctant to talk with their loved one about death so the client may turn to the volunteer. The client may also be reluctant to burden family members with concerns about death.

Anxiety

Volunteers should watch for any increase in the client's anxiety as that may be a sign of spiritual need or distress. That anxiety may be expressed as anger towards a higher power, the medical team, family members or even the volunteer.

Assistance

When volunteers feel that clients/families are in spiritual distress they must contact the hospice for assistance. Some hospices have spiritual care coordinators or volunteers who have more experience supporting someone in spiritual distress and many may have spiritual care resources.

Practice Opportunity

Can you think of a time when someone around you may have been in spiritual distress?

What might spiritual distress look like for you?

What spiritual supports would bring you comfort?

What would bring meaning back to your life?

Spiritual Resiliency

Spiritual resiliency is finding or reconnecting with something that gives life meaning. People call on their spiritual resiliency to pull them through the darkest and most trying times of their life. When life gets difficult, people find spiritual resiliency gives them something to hold on to. By reconnecting with something that gives meaning to life -- meaningful moments, things and/or hopes -- people may transform and heal even in the midst of challenges, crises, illness, suffering, pain and grief.

Spiritual resiliency -- and what we hold on to in times of trouble -- looks different for everyone. It could be relationships, one's faith or religion, nature or sharing life experiences.

Some examples of spiritual resiliency include:

- Belonging to a caring community and feeling valued by others. This can be a group of family, friends, colleagues and/or caregivers (including the hospice palliative care team) that nurtures all members.

- Sharing life's stories, including those that involve shame, pain or grief -- may help people 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 an individual and help heal old wounds.

- Moments of transcendence or significant experiences. Enjoying a beautiful sunset or discovering a new insight or feeling a sense of awe and wonder can give meaning to life.

- 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 an individual faces a life-threatening illness.

Practice Opportunity

How can you recognize spiritual distress?

Section 3: Spiritual Support

Introduction

As client's progress through their illness and approach the end-of-life, they may reflect on the meaning of their lives and the choices they have made. They may share their thoughts with trusted family members, friends and very often with their hospice volunteers. Volunteers play an important role in helping clients reconnect to what gives meaning to their lives and develop spiritual resiliency.

Ways Volunteers Can Provide Support

- Allow the client to lead and define his or her need for spiritual care. Be sensitive when to approach and when to back off. Remember you are concerned about the client's needs and not your own.

- Accept the client unconditionally. Give clients space to speak openly and honestly about their intimate thoughts and feelings without judgment.

- Build trust. Keep whatever clients tell you confidential. (See Role of Volunteer and Understanding Professional Boundaries Module.)

- Treat all clients with dignity and value them for who they are. Be "present" and sit with them as they experience strong emotions. Avoid trying to fix them: they aren't broken.

- Respect the belief system of the client and their family. Respect client's/family's belief systems and respond according to their belief system (rather than your own)

- Listen patiently. Be comfortable with silence and allow clients to explore their past, present and future life experiences/stories -- more than once if they need to. When volunteers listen, it gives clients the opportunity to untangle their feelings and thoughts. (See Communications Skills Module.)

- Be able to sit with questions and not have the answers. Understand that, as part of their spiritual journey, clients may pose questions with few answers. Not having the answers may make volunteers feel inadequate because they aren't doing anything active, other than being "present". Remember that allowing clients to speak, cry or become emotional if they need to may help more than having all the answers.

- Recognize that spirituality includes all the life experiences of the client. Encourage them to talk about things they have done in their lives – things they feel proud of – so they can find meaning or value and have a sense of "getting their house in order." If clients want to discuss their end-of-life arrangements, volunteers can assist by offering to write them down.

- Know when the needs of the client or family may be beyond your role as a volunteer. Be aware of when clients are in spiritual distress and may benefit from being referred to a more formal spiritual care program. Some hospices have staff who coordinate spiritual care or the hospice coordinator may refer the client to an outside spiritual advisor.

Asking Open Ended Questions

See Video: Open-Ended Questions Volunteers Can Ask*
Use the space below record notes.

Some examples of open-ended questions include:
- What has been a source of strength for you in the past?
- What has helped to give you hope?
- When you are feeling discouraged, what keeps you going?
- Who have you looked up to during your life?
- What things have helped to bring you peace?
- Can you find strength in yourself?
- Who do you love? Who are you loved by?
- What is the funniest experience you have ever had? What is the worst?
- How has your illness affected your life plan?
- What guided your choices before your illness? What guides it now?
- Do you dream at night? If so, are there any dreams you would like to share

Volunteers should put these questions in their own words so they sound natural and fit their pattern of speaking. Becoming more familiar with your client will help you find questions to address his or her specific needs.

Legacy Work

A legacy is what one leaves behind after death.

People often think of legacies in financial terms, such as bequeathing assets to someone in a will. But legacies can also be people’s personal stories, values, hopes, love, wishes and advice.

Desire for Legacy

The desire to create and leave a meaningful legacy is as timeless as humankind. We all want to be remembered, and we want our lives to make a difference. This desire taps into our belief that we are part of something larger than just ourselves or our own lifetimes. It is a way to “live on” after we are gone.

Helping Clients

Legacy work can often help clients find meaning in their life in the present by leaving something of themselves for their loved ones.

Legacy Projects

Volunteers can help clients with legacy projects, such as:

- A Life Review: an exercise in self-reflection and re-construction
- A scrapbook of pictures for their loved ones
- A video to be played at a special occasion such as a birthday, anniversary, wedding or at their funeral
- Individual notes/letters to be given to each of their loved ones
- A blog or journal about the client’s thoughts and/or feelings about their life or their illness.

When clients express an interest in legacy work, volunteers should consult with the hospice coordinator because the hospice may have resources that can assist.

Staying within Your Role

Hospice volunteers may form a close bond with clients/families, and may witness them striving to find meaning in their situation and cope with spiritual distress.

When providing spiritual support you must stay within your role as a hospice volunteer.

You must:

- NOT disseminate religious/spiritual literature
- NOT attempt to convert clients/families to any religion, belief or spiritual practice
- Check with your hospice about policies and practices regarding religious and spiritual support. It is the volunteer’s responsibility to be aware of the hospice’s policies.

Practice Opportunity

See Video “Sacred Nature” by Edith Gagne (shared with permission) *

- *What gives you peace?*
- *Did you feel a connection to the music or images?*
- *Why or why not?*
- *Reflect on how nature can be a part of spirituality.*

Use the space below to record notes.

Chapter 7:
Grief and Bereavement

Objectives

- Identify the signs and symptoms of grief and the grieving process
- Recognize anticipatory grief, responses to grief, resilient and complicated grief patterns, and the tasks of mourning
- Identify factors that influence the grieving process
- Recognize how volunteers' own experiences with grief impacts their interactions with others who are grieving
- Recognize the volunteer role in providing support to people who are grieving.

Sections in this Chapter

1. Bereavement, Grief and Mourning
2. Grief and Grief Theory
3. The Nature of Grief

Section 1: Bereavement, Grief and Mourning

Definitions

Bereavement is the state or fact of being bereaved or deprived of something or someone; especially the loss of a loved one by death.

Grief is a multifaceted response to loss, particularly to the loss of someone or something that has died, where a bond or affection had formed. Grief is the feeling of deep sorrow and is mostly nonverbal. It's that invisible, intense, emotional pain we experience when we lose someone significant.

Mourning is the outward expression of grief or feelings in the company of others and when alone. Some conventional outward signs of grief for the dead include crying, funeral rituals, wearing a particular colour and other practices/behaviours held in common within a specific group.

Introduction

Grief and mourning can be experienced any time we lose someone or something significant to us. Many types of significant losses can cause grief, including death, divorce, loss of job, loss of home country, loss of health and body functioning, loss of socio-economic status, violence and war and retirement. Many of these losses are temporary or situational events, such as the grief we experience when friends move away, when family members live in another country for a while or when someone has to move out of town to seek a new job.

In the context of this training module, we will focus on grief and bereavement related to the death of someone significant.

Unlike some of the situations described above (e.g. friends moving away), death is not a temporary or situational event. It is irreversible: a normal condition. When faced with the death of a significant person, people can and do heal -- particularly when given the appropriate opportunity to grieve.

The grieving process is unique and different for each person who experiences the death of a loved one. There is no specific timeline for grief. Many people remember their loved one and feel that sense of loss for as long as they live. However, the initial intense feelings of grief and mourning usually subside gradually over time.

In the beginning, grief is often like a raw open wound that aches intensely. It can affect quality of life and every aspect of daily living. With time, most bereaved people recover from the emotional shock and trauma. The wound caused by the death and sense of loss gradually heals, leaving behind a scar. Instead of the initial, almost unbearable emotional pain, grief can become bittersweet. Through the grieving process, the bereaved person integrates memories of the loved one into his or her own life history, and these memories become a source of hope, inspiration and strength. The person finds new meaning and purpose, and may feel it's possible to move on with life.

See Video: Moving Past Grief, David Kessler*

Use the space below to record notes.

Section 2: Grief and Grief Theory

Four Tasks of Mourning

Accept Reality

This means knowing that the deceased person is no longer alive and won't be part of everyday life.

Experiencing Pain

This means that the grieving person may experience a variety of intense feelings and begin to work through them as part of the grieving process. These feelings can't be avoided forever.

Adjusting

The grieving person may struggle with all of the changes that happen as a result of the person dying, including all of the practical parts of daily living (e.g. more responsibilities at home if it is a parent who died) and all the effects of the loss on the grieving person's sense of who they are and how they see the world.

Finding Connection

This means beginning to acknowledge the value of the relationship with the person who died and everything learned from, disagreed with, and loved and respected about that person. The grieving person recognizes that he or she doesn't need to "forget" the loved one and that it is okay to invest in new relationships even though the loved one will be missed.

Five Stages of Grief

The five stages of grief are:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

See Video: The five stages of grief: Dr. David Kessler*

Use the space below to record notes.

Grief Land

In practice, there is no predetermined order for the grieving process. Imagine the five stages of grief and the four tasks of mourning as landmarks on a map of "Grief Land".

Although grief is a universal experience across cultures, every person enters Grief Land from a different direction, and takes a unique journey through grief.

Each person experiences loss and grief in his or her own unique personal way. Some may take more or less time. Some may experience challenges coping with depression, anger and other strong emotions.

Grief and the Volunteer

Volunteers may become:

- More aware of their past losses. Sometimes the client's/family's situation reminds volunteers of something in their own life, which can complicate the helping relationship.
- More aware of their privately-feared losses. If the loss is similar to one that volunteers fear, their apprehension can flare up, making it difficult for them to listen and provide support.
- More aware of their own suffering and death. If the client/family is similar to the volunteer in age, profession or family structure, the similarities may throw the volunteer off balance emotionally. (Adapted from Virginia Tyler of Evergreen Hospice in Oregon, 1990)

Common Human Experience of Grief and Empathy

The universal, common human experience of grief can be a source of great empathy. It allows volunteers to understand and share other's feelings. Empathy enables volunteers to provide valuable support to clients/families who are experiencing grief and bereavement.

Individuals in search of self-healing often feel drawn to activities, stories and studies that relate to their own personal experiences and/or issues. For example, when someone is experiencing a personal loss in their lives, they often like to read self-help books or feel particularly touched by a movie or book where the main character loses a loved one.

Before becoming a hospice volunteer, it is important to pause for a moment of self-reflection. Working with bereaved clients/families may well awaken our own losses, including any unresolved issues. If you have any unresolved issues, you are encouraged to take time to address them before becoming a hospice volunteer. If you do not, you may find yourself in a "co-dependent" relationship that will not help the client or family.
Alan Wolfelt, author of Healing the Bereaved Child (2013, Routledge, NY), explains the concept and dynamics of "co-dependent bereavement caregiver" as follows:

> "...The co-dependent grief gardener often confuses caregiving with caretaking. Caretakers (rescuers) often become overly attached to the people they attempt to help… If the bereavement caregiver focuses all of her energy on people and problems outside of herself, little time is left for self-understanding. As a consequence, one of the primary symptoms of the co-dependent bereavement caregiver is a lack of awareness of the dynamics of co-dependency. This lack of awareness may result in feelings of helplessness and frustration, which are in turn expressed in the form of obsessing and worrying about one's client… Now a vicious cycle is set in motion. The more the caregiver ruminates about the bereaved children's problems (obviously, worrying doesn't change anything), the higher the need becomes to rescue. Therefore, more inappropriate over-involvement occurs, with the focus staying outside of oneself."

Providing Support

It is very important that volunteers understand the central concepts of self-help, as well as the scope of the volunteer role, when providing grief and bereavement support:

We do not "change" people.

- People change their own behaviours
  - When they can
  - When they want to
- Sometimes a person can or has the ability to change but doesn't want to - for example, a healthy individual who can but doesn't want to do the dishes after a meal will pile up dirty dishes until there are no more dishes to use.
- Sometimes a person wants to change a behaviour but cannot or is unable to change it - for example, an individual who is in a wheelchair after a car accident and has two broken arms and a broken leg in a cast may want to do the dishes but is unable to do so.

Our role is not to "cure" clients/families from their grief.

- Clients/families go through the grief process themselves. Volunteers just support and facilitate their individual grieving process.

Volunteers do not "rescue" clients/families from their bereavement.

- Clients/families will stay bereaved as long as they live. They are on a personal journey. They learn to integrate their losses into their own life history through the hard work of grief.

(Adapted from: Volunteer Handbook and Training Manual, Hospice of Windsor and Essex Inc., Windsor, ON)

Practice Opportunity: Factors Affecting Grief

What influences grief and a person's mourning? Think about the various factors that might affect how a person would grieve the loss of a loved one. Use the space below to record your thoughts.

Signs and symptoms of grief

Grief may be expressed in a variety of ways including physical, emotional, cognitive, behavioral, spiritual, social and cultural. This will be explored in more detail below.

Physical Signs of Grief

- Crying and sighing
- Fatigue
- Weaker immune system resulting in an increase in minor viral infections
- Loss of appetite or overeating
- Sleep disturbances
- Body aches and pains
- Skin rashes
- Altered blood pressure, cholesterol and/or blood sugar levels

Emotional Signs of Grief

- Sadness
- Yearning
- Fear
- Anger
- Irritation and/or short temper
- Feelings of helplessness and dependence on others
- Guilt and/or relief
- Depression and/or anxiety

Cognitive Signs of Grief

- Racing and/or obsessive thoughts (e.g. “if only” and “what if”)
- Worries about the present and future
- Inability to concentrate or focus
- Forgetfulness
- Difficulty learning and/or retaining new information

Behavioural Signs of Grief

- Neglecting own appearance and self-grooming, neglecting self-care
- Procrastinating
- Increase in substance use - alcohol, cigarettes and/or medications/street drugs

Spiritual Signs of Grief

Questioning:

- The reason for your loss
- The meaning of your life
- The purpose of pain and suffering
- The purpose of life and death
- Spiritual and/or religious beliefs

Social Signs of Grief

- Feeling detached from others even when with people
- Isolating oneself from social contact
- Being hyper-sensitive to how people are treating you
- Behaving in ways that are unusual
- Carrying on as if nothing had happened
- Working too much
- Dating and/or partying to numb feelings of grief and loneliness

Cultural Signs of Grief

- Reviewing cultural beliefs and rituals
- Putting on a brave face
- Not expressing feelings of grief

See Video: Signs of Grief*
Use the space below to record notes.

Section 3: The Nature of Grief

Myths vs. Reality

Myth: All losses are the same.
Reality: Each person's experience of loss is unique.

Myth: People grieve in the same manner.
Reality: There is no perfect, right, correct or standard way to grieve a loss.

Myth: All men grieve like men and all women grieve like women. That’s just the way it is.
Reality: Although gender may play a role with how someone grieves, it has more to do with their style of grieving (e.g. intuitive, instrumental, blended).

Myth: Grief occurs in an orderly and predictable manner.
Reality: Grief is a chaotic process. It is a roller coaster ride with periods of highs and periods of lows.

Myth: Only family members grieve a loss.
Reality: Anyone attached to the person who has died may grieve.

Myth: People should leave their grieving at home.
Reality: We cannot control where we grieve.

Myth: A grieving person should be left alone.
Reality: A grieving person may need opportunities to share memories and receive support.

Myth: It is helpful to tell a person who is grieving to “be brave", "keep a stiff upper lip" and "deal with it" or that “everything happens for a reason” and “God doesn’t give us more than we can handle”
Reality: Sometimes it is better to just listen to someone who is grieving and not say anything.

Myth: A person can cope with a loss by ignoring or repressing the pain.
Reality: Painful experiences are part of living and generally do not get better if ignored.

Myth: One must talk about grief in order to express grief.
Reality: Each person must find what works best. For some that is talking, for others writing in a journal, volunteering time or building something. Not everyone needs to talk about their grief.

Myth: Bereaved people just need to express their feelings and to resolve their grief.
Reality: Grief is manifested physically, emotionally, spiritually, socially and intellectually.

Myth: The intensity of the grief expressed is a sign of how much you loved a person.
Reality: There are different ways of expressing grief; some people do it quietly, some loudly.

Myth: Expressing intense feelings of sorrow, anger, or hopelessness means one is losing control.
Reality: Expressing, talking or writing about intense feelings can be helpful.

Myth: A grieving person should be over their grief after two weeks.
Reality: There is no definite timeline for grief; it may take weeks, months, years or a lifetime for someone to process a loss. The time it takes depends on the person, the situation and the type of loss.

Myth: The grieving person should definitely be "over it" within two months.
Reality: There is no definite timeline for grief.

Myth: Grief declines over time in a steadily decreasing fashion.
Reality: Grief is more like a roller coaster ride with up times and down times.

Myth: Once over a loss, the grief is never experienced again.
Reality: A place, a smell, a song or a special date may trigger old memories, and people may re-experience their grief.

Myth: Grief ends after the funeral.
Reality: Many people believe that life should return to normal after the funeral service. However, after the funeral -- as shock and numbness give way to the reality of the loss -- the true grieving process may just be starting.

Grief and Bereavement

Each grieving person will have his or her own unique journey, process and time frame for grief. While a person's style of mourning is often influenced by gender, it is also influenced by a number of other factors, such as culture, age, personality, spiritual beliefs and the way the person has been socialized (which can be influenced by gender).

Clients/families should be encouraged to express their grief in ways that are comfortable for them. As they provide support for clients/families, volunteers may identify some common patterns or influences; however, it is important to acknowledge the individuality of each grieving person's experience. Each grieving style has its own advantages and disadvantages.

People are likely to use the same grieving style throughout their lives - although they can change over time. For example, teens tend to be either intuitive or instrumental grievers and, as they age, move to a more blended grieving style.

Intuitive Grievers

Intuitive grievers tend to:

- Experience grief through strong emotional reactions
- Express their inner feelings outwardly
- Adapt to the death by expressing and exploring their feelings
- Approach their grief with low physical energy
- Cope by taking time to grieve, adjusting slowly and sharing feelings

Although some people consider intuitive grief a more "feminine" approach to grieving, both men and women can and do grieve in this way.

Instrumental Grievers

Instrumental grievers tend to:

- Experience grief primarily through cognitive or physical activities
- Adapt to the death by thinking, doing tasks or working on project-based activities
- Approach their grief in a highly physical way
- Cope by readjusting/restoring normal routines, actively focusing on solving problems related to loss

Although some people consider instrumental grief a more “masculine” approach to grieving, both men and women can and do grieve in this way.

Blended Grievers

In reality, most people (men and women) grieve somewhere along the continuum between intuitive and instrumental grief. Their grief process tends to be a blend of intuitive and instrumental. Martin and Doka describe them as “blended grievers”.

Blended grievers borrow coping strategies of both intuitive and instrumental grieving. Their experience of grief may vary depending on their relationship to the deceased, the situation and the time that has passed since the loss.

Types of Grief

Anticipatory Grief

Anticipatory grief is a grief reaction that occurs before an impending loss. Both the client and family/friends may experience anticipatory grief, and these feelings may become more intense as the client’s health deteriorates. Anticipatory grief is most common during a long-term illness: both the client and family may experience anticipatory grief over a prolonged period of time.

Some people describe anticipatory grief as a “series of small deaths”, and it is particularly important to provide support for those struggling with anticipatory grief because it can affect the family’s relationship with the client. Family members may begin to distance themselves from their loved one in anticipation of their death

Disenfranchised Grief

People experience disenfranchised grief when society does not recognize or validate their loss and grieving process or says they shouldn’t be grieving. When people can’t find support for their grief, they feel they can’t talk about it and they become isolated. They may come to believe their feelings are wrong.

Disenfranchised grief may occur when:

- No one knows about the loss so it cannot be shared or mourned. For example, someone experiences the death of a boyfriend outside her culture, the loss of a partner in an illicit affair or the loss of an unannounced pregnancy.
- The relationship is not validated. For example, someone experiences the death of an ex-spouse, co-worker, a pet, an online friend (cyber loss), a same-sex partner, a step-child/step-parent, a foster child/foster parent, any other non-blood relationships (e.g. friends, boyfriend/girlfriend in-laws, neighbours) or the loss of a baby due to a miscarriage or stillbirth.
- Loss is not recognized. For example, someone experiences the grief that comes from infertility or loss of function.
- The griever is not recognized. For example, the grief experienced by the family of an ex-spouse is not recognized.

Resilient Grief

In the first few months after someone dies, grief is strong. People often experience intense yearning and intrusive thoughts about their loved one. However, people who experience resilient grief are able to manage these feelings. They do not interfere with their daily functioning. They return to work soon after the death and don't fall apart later. They seem to have less need to search for a new identity or new role.

According to recent studies, about 30 to 50% of mourners will experience resilient grief. People who are resilient grievers tend to have optimistic personalities. They have strong coping skills, and their coping style is more pragmatic and flexible. They may use coping techniques that would not be acceptable in other circumstances. Resilient grievers are more likely to report that talking about their loved one brings a sense of peace. They also report having few regrets about their relationship.

Experts on bereavement used to think that resilient grievers were masking or denying their grief. From their work with people experiencing anticipatory or disenfranchised grief, they were convinced that grief needs to be expressed and worked out -- or it can lead to serious physical, emotional and other symptoms. However, they now recognize that resilient grieving is a healthy coping style.

Complex/Complicated Grief

Faced with the loss of a loved one, a small number of people may experience complicated grief. Their grief affects their ability to function in their daily life long after the first few months. Surprisingly, it is not the suddenness or severity of the loss that will predict who will have difficulty coping. Instead, the grieving person's ability to cope is influenced by the way they coped with challenges before the loss.

Their coping skills may have already been strained before the death, or they may live in disruptive or chaotic circumstances or be dealing with addictions or mental illness. Because their lives are already complicated, a traumatic death (e.g., a homicide or watching a loved one suffer) may add a level of suffering that these mourners cannot tolerate.

Factors that might make grief more complicated include:

- Relationship is conflicted OR relationship is very close, long-term and exclusionary
- Mourner's personality is generally pessimistic
- Mourner has pre-existing mental health challenges and/or drug/alcohol addiction
- Death is sudden, traumatic or filled with suffering
- Death of a child
- Mourner is isolated or estranged from supports
- Coping skills cannot contain grief
- Mourner's life was defined by caregiving
- Mourner has developmental disabilities
- Mourner has experienced multiple losses in a short period of time (e.g. death of several people or other losses such as divorce, loss of health, loss of job, retirement)
- Mourner has a history of abuse and/or neglect during childhood and/or adolescence
- Mourner is experiencing disenfranchised grief (see previous section)

In an effort to cope with complicated grief, people may begin or increase risky activities. Some may slip into a clinical depression, and stop taking care of themselves physically. Their basic ability to function is impaired, and friends and family may see them as not safe.

Individuals experiencing any of the following signs or symptoms of complex/complicated grief may benefit from professional help:

- Prolonged intense sorrow that interferes with basic ability to function
- Inability to focus on little else than the loved one's death, and wishing they had died with their loved one.
- Feeling that life holds no meaning or purpose without their loved one
- Irritability or agitation, intolerance to noise and crowded places, severe mood swings
- Lack of trust in others, pushing others away and withdrawing from social activities
- Experiencing extreme emotions or not feeling anything at all
- Feelings of excessive guilt and self-blame
- Intrusive racing and/or obsessive thoughts, flashbacks, nightmares
- Inability to enjoy life or think back on positive experiences with the loved one
- Compromised cognitive functioning, illogical or unrealistic thoughts
- Inability to perform at, or withdrawal from, work or school
- Addictions such as gambling, alcoholism and/or use of street drugs
- Hallucinations
- Anti-social, unethical, risky and/or criminal behaviour
- Heightened depression and/or anxiety, suicidal thoughts and/or self-harm.

Many people who are grieving the loss of a significant person in their life may occasionally experience some signs or symptoms of complicated grief during the process of healthy grieving. This should not be a cause for alarm. Grief becomes complex and complicated when these signs and symptoms are “excessive or prolonged” or when individuals perceive any of these signs and symptoms as “too much”.

Bereavement Risk Assessment Tool

BRAT

Professional members of the hospice palliative care team can use a number of tools to assess factors that influence the nature and intensity of a person’s grief.
For example, the Bereavement Risk Assessment Tool or “BRAT” (developed by Victoria Hospice Society, 2008) is a psychosocial assessment tool that can help identify personal, interpersonal and situational factors that may place a caregiver or family member at greater risk for a significantly negative bereavement experience.

BRAT Assessments

Bereavement assessments must always be conducted by a hospice professional or team of professionals.
If applicable, hospice volunteers will be informed of any relevant information from the assessment of their client/family before starting grief support sessions. See the additional resources section of this module for an adapted sample copy of the BRAT.

Children, Adolescents and Grief

Volunteers do not provide specialized psychosocial support for children and adolescents in grief; however, it is important that volunteers understand how grief impacts children and adolescents and are aware of specialized support resources available in their community.

Children and adolescents experience loss and grief according to their stage of development, and a children’s chronological age does not necessarily indicate their emotional age.

Children Experience Grief

Children can be very aware of the disruption in their normal routines and lives caused by an illness or death, but may not ask questions or reveal their knowledge. Children and adolescents may or may not choose to participate in the experience of the death of a loved one.

Children may experience many of the same symptoms of grief as adults: sadness, fear, anger, guilt, enhanced feelings of vulnerability, helplessness, abandonment, numbness, anxiety, depression, compromised immune system, mood swings, social isolation and altered behaviour.

Children tend to experience grief in short spurts with periods of play in between. However, they may also experience complex/complicated grief.

Parent's Wishes

Like adults, children and adolescents may be influenced by the culture, social mores and norms of their external environment but they may also experience unique differences in their grief journey.

When given appropriate information and support, children and adolescents -- like adults -- can work through grief and integrate the loss of a loved one into their life story. Cultural norms and parenting styles will play a large part in how the family helps the child or adolescent to cope.

While many parents will be open and truthful about what is happening to the child's loved one, others may not embrace "truth-telling" and feel strongly about protecting the child from grief.

Volunteers' Role

It is not appropriate for hospice volunteers to impose their values if they conflict with those of the client/family. Volunteers can affirm the child's feelings and support the adult family members.

Adolescents may seek volunteers out and want to talk about their feelings or ask for information. If this situation arises, volunteers must always check with the parent and/or hospice coordinator.

See Video: Grief and Bereavement in Children – Camp Erin*
Use the space below to record notes.

Volunteer Role in Grief Support

The volunteer’s role is to walk beside the client/family in their grief process and not to direct it. Volunteers can help grieving clients and/or family members in many ways.

Provide Comfort

Make it clear that you are comfortable with the person's tears, which is a healthy way for men, women and children who are struggling with the intense feelings of grief to relieve stress.

When clients/families are comfortable with touch, holding their hand may help in moments of intense grief. Remember to ask permission! Clients may ask for hugs from people they trust. Some people find group hugs for family and friends helpful.

Note: volunteers must be aware of the potential miscommunication that may occur with touch when a client is lonely and vulnerable. Occasionally a volunteer may be asked to comfort a client with touch that is not appropriate. Remember personal boundaries (see Chapter 2: Role of Volunteer and Understanding Professional Boundaries) and talk to your hospice coordinator if anything feels uncomfortable.

Maintain or Create Traditions / Rituals

Many people with strong religious beliefs find comfort in prayer, customs, doctrines, creeds, and traditions. Some struggle with their religious roots and may question every part of their former beliefs. It may help the client most to just listen to their questions and not try to find answers.

Rituals, both religious or nonreligious, may comfort many bereaved people. Rituals include going to a special service, lighting a candle, having a special meal with the favourite dish of the loved one, organizing a celebration of life or taking a trip to a place that the loved one always wanted to go. Volunteers may be able to help bereaved people explore options that can help them work through their grief.

Listen

Listening to the story of the loss over and over may help grieving people to:

- Affirm the importance of the loss in their life and normalize their intense feelings
- Identify the areas of grief where they are having trouble coping
- Comfort themselves by talking about how important this person was in their life. Silencing or repressing grief by changing the subject, offering solutions or trying to cheer mourners up may intensify it.

Encourage

It may be helpful to encourage someone who is grieving to:

- Participate in light physical exercise in the sunshine – this can help people feel more positive. Light stretching relaxes muscles and may be calming.
- Eat healthy, get adequate sleep and drink fluids. The person may find it easier to cope when they balance their work, rest, leisure, physical exercise, private and social life. (See Care for the Caregiver module for more in-depth information.)
- Visit their doctor and dentist regularly.
- Embrace their grief as there is no way around the experience.

Normalize

The volunteer may play a role in normalizing the experience of grief and encouraging people to be patient with themselves. People who are grieving may find the roller-coaster of intense bouts of grief frightening, and it may help them to understand that these feelings may be a reflection of the intensity of their love for the person they lost.

The volunteer may also be able to help people integrate the life and memories of their loved one into their own life story, which is the goal of the hard work of grief.

Chapter 8:
Care for the Caregiver

Objectives

- Identify the different types of caregivers
- Recognize physical and psychological signs and symptoms of stress
- Recognize factors that influence stress, burnout and compassion fatigue
- Identify ways to cope with the special stressors of hospice volunteering
- Identify the self-care supports available to hospice volunteers.

Sections in this Chapter

1. Caregivers: The Types, Duties and Importance of Care for the Caregiver
2. Stress, Burnout and Compassion Fatigue
3. Strategies for Coping with Stress

Section 1: The Types, Duties and Importance of Care for the Caregiver

Self-Care Overview

Self-care is an important component of care for the caregiver. While caring for clients/families, caregivers need and deserve, and should actively seek ways and means to practice good self-care and maintain high quality of life.

Who is a Caregiver?

A caregiver is any member of the hospice palliative care team providing any care to a client with a life threatening or life-limiting illness, including but not limited to:

- Medical doctors
- Nurses
- Specialists such as physiotherapists, speech therapists, recreational therapists and oxygen technicians
- Health and lab technicians
- Personal support workers
- Chaplains and other spiritual support providers
- Family members, friends and neighbours
- Trained volunteers

Types of Caregivers

The Primary Caregiver

The primary caregiver is usually someone closely related to the client, such as a spouse, child, parent, sibling or close friend.

Power of Attorney

In some cases, the primary caregiver may also be the client's power of attorney. This caregiver may have the authority to make health related or financial decisions on behalf of the client if necessary.

Multiple Caregivers

Some clients may have no primary caregiver or may have several caregivers who are friends or family.

Summary

Although this module is designed for hospice volunteers, the concepts may also apply to other types of caregivers, especially primary caregivers who are often responsible for providing long hours, months and even years of continuous caregiving for their loved one.

What do Caregivers do?

Caregivers provide direct personal care and/or practical, psychosocial and spiritual support to hospice palliative care clients.

Direct personal care

Direct personal care includes, but is not limited to, any activities related to the client's physical care and comfort. Examples include: feeding, hydration, repositioning the client in bed, helping the client move, personal hygiene, dressing, monitoring devices such as pain pumps, probes and colostomy bags, and administering medication.

Practical support

Practical support may include day to day tasks, such as light homemaking duties, meal preparation, organizing, correspondence and shopping assistance.

Psychosocial and spiritual support

Psychosocial and spiritual support includes, but is not limited to, any activities related to the client's psychological, emotional, cognitive, social, and spiritual support and comfort.

Respite

Respite care is for family caregiver(s). It is one of the important functions of the hospice volunteer.

Summary

- Remember: As discussed in Module 2 - Volunteer Role & Understanding Professional Boundaries, some of the activities listed above must only be performed by health care professionals or family.
- Hospice palliative care organizations often have different rules about what volunteers are allowed to do.
- Volunteers must review the policies of their specific hospice.

See Video: A Caregiver's Testimonial*

Use the space below to record notes.

Why is Care for the Caregiver Important in Hospice Palliative Care?

Being a caregiver can be both challenging and rewarding.

To be able to provide the best care possible, caregivers must constantly be mindful and vigilant about their own physical, emotional, psychological, cognitive, social and spiritual well-being. Lack of attention to their own well-being can result in stress and other health risks for caregivers, which can have a negative impact on the quality of care the client receives. To be able to help others, hospice volunteers need to practice good self-care. Volunteers can also help other caregivers by sharing their knowledge and information about the importance of good self-care practices. When volunteers practice good self-care, other caregivers also benefit. In the end, everybody wins.

Section 2: Stress, Burnout and Compassion Fatigue

Stress

Stress is the body's response to any kind of demand. It is a mix of physical, mental and/or emotional reactions that cause physical or psychological tension. Stress is not always negative: it can be triggered by good or bad experiences.

How the Body Reacts

When someone experiences stress, the body reacts by releasing chemicals into the bloodstream, muscles and brain. These chemicals temporarily give the person more energy and strength, which is helpful if the stress is in response to physical danger. Stress can be negative or unhealthy when:

- It happens in response to something emotional.
- It is due to prolonged physical and mental fatigue.
- The person has no outlet for the extra built up energy.
- The person isn't getting adequate physical rest and/or sleep.
- There is no resolution for the stressors affecting the person's emotional and psychological well-being.

Unfortunately, most caregivers of people with a life-threatening or life-limiting illness experience this kind of unhealthy stress almost daily.

Signs of Stress

There are many common signs of unhealthy stress that all caregivers, including hospice volunteers, may experience. Being aware of your own signs of stress can be an early warning that you need to address the cause(s). Although hospice volunteers are not directly involved in the stress that client families experience, they will frequently be exposed to them in their volunteer role. It is important for hospice volunteers to understand what stress is, its symptoms, and how to practice good self-care.

Physical signs of stress

- Low energy
- Headaches
- Upset stomach including diarrhea, constipation and nausea
- Aches, pains and tense muscles
- Chest pain and rapid heartbeat
- Insomnia
- Frequent colds and infections
- Loss of sexual desire and/or ability

Emotional signs of stress

- Moodiness
- Irritability, impatience and short temper
- Agitation and inability to relax
- Feeling overwhelmed
- Sense of loneliness and isolation
- Depression or general unhappiness

Cognitive signs of stress

- Memory problems
- Inability to concentrate
- Poor judgment
- Seeing only the negative
- Anxious or racing thoughts
- Constant worrying

Behavioural signs of stress

- Increased or decreased appetite
- Sleep disturbances
- Isolating oneself from others
- Procrastinating or neglecting responsibilities
- Substance abuse
- Nervous habits such as nail biting or pacing

Social signs of stress

- Increasing isolation
- Loss of motivation to participate in social and recreational activities
- Poor support from family members and friends
- Feelings of social rejection, abandonment, indifference or neglect
- Life becomes a long list of "to-do's" with no breaks

Summary

Primary caregivers provide long hours of physically demanding and emotionally taxing caregiving. Serious illness in the family may disrupt caregivers' personal routine, causing them to give up studies or work to take care of a loved one.

This personal stress may be compounded by financial concerns, such as additional expenses, tight family budgets and debt.

Primary caregivers may also be sleep deprived, isolated and struggling with their loved one's anticipated death. Unfinished business, fear of death, loss of purpose and meaning, and other issues may also be weighing on caregivers' minds.

See Video: Compassion Fatigue*
Use the space below to record notes.

Compassion Fatigue

Compassion fatigue is also referred to as “vicarious trauma” or secondary trauma. In simple words, compassion fatigue occurs when caregivers are repeatedly exposed to sad, shocking or traumatic events.

Post-Traumatic Stress Disorder (PTSD)

Compassion fatigue can be understood as a form of PTSD-- one that does not become chronic or severe if given the proper attention and self-care. Common PTSD-like symptoms include:

- Flashbacks
- Intrusive or racing thoughts
- Nightmare

Compassion fatigue may also include the physical aspects of burnout.

Hospice Volunteers and Compassion Fatigue

Primary caregivers can develop compassion fatigue during the ups and downs of a loved one’s life-threatening or life-limiting illness. These symptoms can be common among all caregivers of hospice palliative care clients in settings where loss and grief are a constant presence. Hospice volunteers who listen to the many sad and traumatic experiences of their clients/families may be at risk of developing compassion fatigue.

Compassion Fatigue Symptoms include:

- Nervous system hyperarousal
- Sleep disturbances
- Increased emotional intensity
- Decreased cognitive ability
- Impaired behaviour and judgment
- Isolation and loss of morale
- Depression
- Loss of self-worth
- Poor emotional modulation
- Impacted self-identity, worldview, beliefs and spirituality
- Loss of hope and meaning, existential despair
- Anger toward perpetrators or causal events

Summary

The symptoms of stress, burnout and compassion fatigue are similar because compassion fatigue is the consequence of a specific type of prolonged stress.

See Video: Breathe*

Use the space below to record notes.

Section 3: Strategies for Coping with Stress

Strategies for Coping with Stress

Caregivers can enhance their own personal health and well-being by adopting healthy self-care habits. When they do, they are able to provide better quality care for their client.

Physical self-care

- Have an annual physical check-up
- Eat a balanced healthy diet
- Drink lots of liquids
- Get regular light physical exercise, such as walking
- Get enough daily good quality sleep
- Get enough hours of rest every week

Emotional self-care

- Be gentle/patient with oneself and others
- Acknowledge and express feelings to supportive people who understand
- Have a good cry
- Ask for help and look for support from trustworthy friends, family members, and professional counsellors

Cognitive self-care

- Be aware of changes in thought patterns, behaviours and emotions
- Avoid making life-changing decisions in a crisis (e.g. selling property, quitting job, divorcing, moving out)
- Avoid alcohol, nicotine and street drugs
- Do not use psychotropic medication without medical supervision (self-medication)
- Practice mindfulness, relaxation and meditation
- Continue learning and engaging in healthy activities and hobbies

Social self-care

- Maintain regular social contact (this does not include interaction at work)
- Ask for hugs from family and friends
- Create a supportive circle of care: friends, family members, spiritual and professional counsellors
- Avoid long periods of isolation
- Do not allow verbal, psychological or physical abuse - if necessary, ask for help
- Use prayer and ritual if it is helpful

Psychological self-care

- Act from own set of principles, values and goals
- Ask for support
- Seek opportunities for solitude and self reflection
- Journal about your experiences
- Value self

Summary

You may need to:

- Acknowledge your feelings and seek support when necessary
- Ask for help
- Take part in volunteer support groups
- Get help in setting realistic expectations for your volunteer role. To do this, review Chapter 2 - Volunteer Role & Understanding Professional Boundaries.
  - Review the 5 steps to healthy boundaries
  - Review the 5 strategies for saying no
- Hang on to your sense of humour

See Videos: H.A.L.T. and **H.E.R.E.***
Use the space below to record notes.

Chapter 9:
Family

Objectives

- Recognize the concept of the family as a system
- Recognize how roles in the family may change in response to illness and death
- Recognize the impact of a life-threatening or life-limiting illness on the family unit
- Identify the volunteer role in assisting and supporting the family

Sections in this Chapter

1. The Family Unit
2. Family Reactions
3. Volunteer Role

Section 1: The Family Unit

Definition of Family

- A group of individuals closely related by blood, marriage or friendship ties; characterized by a continuum of stability, commitment, mutual decision-making and shared goals. (Berkley & Hanson 1993)
- Family can also be defined as those closest to the person in knowledge, care and affection. Family may include the biological family, the family of acquisition (related by marriage/contract) and/or the family of choice (including friends, neighbours and sometimes even pets).
- The person with the life-limiting illness defines who will be involved in his or her care and/or be present at the bedside.
- Family consists of people who are tied emotionally, spiritually, economically and socially to one another. Members are brought together through different circumstances -- including birth, marriage, choice and/or friendship -- to form a complex system that functions according to both fixed and changing internal and external influences.

Roles with the Family Unit

Within a family unit, roles can be defined by culture and relationships.

Each family will be unique in terms of:

- The role of individual family members
- Strengths and vulnerabilities
- Leadership style and decision-making process
- Members' established patterns of transaction
- Gender roles
- Family resources

Additional items each family will be unique in terms of:

- Family rules, norms and expectations
- Family values and beliefs
- Quality of emotional relationships
- Internal communication (e.g. family meetings, open sharing of all information, protection of vulnerable members)
- External communication (e.g. who speaks for the client/family)
- Degree of family flexibility/rigidity
- Dependence, interdependence and individual freedom of each family member

Role of the Family in Care

The role of the family in care will include:

- Decision-making
- Communication
- Advocacy
- Truth spoken in love
- Reconciliation of past/current conflicts
- Personal and practical care
- Flexibility to meet needs
- Emotional and psychosocial support

Section 2: Family Reactions

The Phases of Reaction

Early Phase

Families are usually in shock.

- Families may be highly disorganized.
- Most common reactions are fear and denial.
- Families may blame others or the dying person for the illness.

Middle Phase

Families usually adjust to the illness.

- Families may feel frightened and express their fears.
- Families may be occupied with caring for the dying person.
- Family members may feel exhausted, drained and/or impatient with the dying person.
- Some family members may feel guilt that there is not enough time or energy to attend to everyone in the family.
- Some family members may need “time out” periods to restore their energy.

Final Phase

Families are usually confronted with the reality that death is near.

- Families may find themselves once again disorganized and in shock.
- Family members may feel useless since they are no longer doing things for the dying person.
- Some family members may feel strong disappointment and frustration that the disease is finally taking over.
- Most common emotions are sorrow, depression and anxiety.
- Some families may withdraw from the dying person or become aggressive to hide their feelings.
- Many families will mourn for the loved one in anticipation of the death.
- Not all family members will accept the death.

Shifting Roles

The family’s experience with a life-limiting illness, caregiving and grieving cannot be completely understood within a medical framework alone. In hospice palliative care the family plays a dual role.
On one hand, family members receive care and support from the hospice palliative care team and, on the other, they provide care and support for the client.

The changes that occur within the family system because of the illness will be unique to each particular family.

Role Changes

The biggest impact on the family is the role changes that occur as family members respond to the dying person’s needs and prepare for their life after the person’s death.

Role changes are not limited to responsibilities for household and family tasks.
Emotional roles within the family may also change, and the family may need professional support or a referral to other community resources to cope with these changes.

Depending on the person's illness and its trajectory, family members may provide different levels of care, including personal care, assistance with feeding, dressing or walking and management of bathroom routines. Family members may also provide emotional and spiritual support for loved ones.

Taking on New Roles

Over the course of the illness, families may have to take on responsibilities for other family member(s) that they never imagined having -- including picking up some of the roles previously held by the dying person.

Children may become caregivers for parents, spouses may take on intimate care tasks and the familiar "couple" relationship may be put on hold.

When family members become caregivers, the normal rhythm of household routines and family interactions can be disrupted -- affecting family members both personally and socially.

Families may also be faced with decisions that they do not want to make. As they adjust to these unique and changing roles, it is important for family members to receive information and support.

Strength and Resilience

At the same time that family members are trying to provide care and support for their loved one, they have stories, experiences and "baggage" that they may bring to the table. They also have strengths and resilience. Clients/families are "experts" in their own lives, stories and strengths.

Concerns

Families may experience many emotions including avoidance/denial, fear, anxiety, guilt and/or anger.
They may experience and be grieving many losses, such as the person's loss of physical health and functioning, their own loss of roles or responsibilities within the family unit, their loss of dreams for the future and a loss of trust/faith in how "things are meant to be".

They may experience physical and/or emotional strain from medical tests and appointments, which can create anxiety in both the client and family. As the disease progresses and the person experiences ongoing discomfort, pain, loss of physical control or changes in physical appearance, both the person and family may experience feelings of powerlessness.

Family members may 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 client actually dies. Disenfranchised grief, in which the grieving person's loss is not recognized or validated, may cause further crisis within a family. (See Module 7 – Grief and Bereavement.)

The entire family must adjust to the multiple losses and new roles within their family structure in an attempt to gain new harmony and balance. However, efforts to deal with anticipatory grief may be complicated by the fact that not all family members will experience the same emotions at the same time

Many concerns that families experience will not magically disappear when the person dies.

That is why hospice palliative care has the greatest impact when it is in place early in the client's illness and continues to support the family through the period of bereavement.

See Video: Concerns*
Use the space below to record notes.

Complexities of Coping

When clients and families first hear the shocking news of a life-threatening or life-limiting illness, they may only absorb a limited amount of information.

Although giving family members information can help demystify the situation and reduce anxiety, their ability to really hear what is being said and assimilate it may be complicated by their emotional reactions.

Coping Mechanisms

Faced with these emotions, families may use coping and problem-solving mechanisms that have worked for them in the past. In fact, their past experiences as individuals and as a family unit will often determine how they cope when faced with an illness that disrupts family routines. For example, family members may want to shield/protect each other from the diagnosis for personal or cultural reasons. This “shielding” may be done by the dying person or any members of the family. However, past coping mechanisms may not be enough. Just at a time when their capacity to learn new skills may be threatened by a shock of a life-limiting illness, they may need to find different ways to respond to the physical and social changes occurring within the family unit.

Influencing Factors

The ability of family member(s) to cope with the illness may be influenced by factors such as:

- Age
- Functional abilities
- Financial constraints
- Ability of other family members to support their loved one - physically, emotionally and socially
- Previous relationships and roles
- Experience with and perception of health issues
- Culture and ethnicity
- Religion and spirituality
- Geography
- Available support for client and caregiver

Exacerbated Feelings

Pre-existing family conflicts/tensions may be exacerbated by the illness and lead to:

- Caregiver stress (often due to unequal sharing of caregiver duties based on historical roles)
- Guilt about past relationship issues
- Financial worries (due to the person’s or family member’s inability to work)
- Conflicts distracting family members from focusing on the person’s care

Caregiver Burden

Caregiver burden is the emotional, social, economic and physical impact that living with a dying person can have on the way of life and health of the family members and friends providing care. Family caregivers may experience burden related to fatigue and isolation from friends and routine activities but sometimes their love and/or sense of duty blinds them to their own needs for self care.

Many complex factors influence caregiver burden including gender, coping skills, experience in the role of caregiver, profession and social networks. Caregiver burden can also be affected by family dynamics or tensions. When a family unit has to reorganize to care for someone who is dying, the process is not always smooth.

Cooperation among family caregivers can be strained or may break down. Resentment, anger and frustration can surface. Within families there are power structures, hierarchies and conflicts relating to power. The stress of the illness may intensity all the same issues that caused conflict in the past. Some family members may take advantage of the turmoil to pursue longstanding issues. The family may have a complex history of substance abuse, financial difficulties, mental illness or disability, or cycles of power within families can lead to abuse, addiction or poverty.

Signs of caregiver burn out include:

- Need for control
- Exhaustion
- Lack of patience
- Resentment towards the loved one who is dying
- Substance abuse
- Excessively concerned or unconcerned
- Treating the person who is dying like a child -- especially if he/she is a senior
- Having minimal eye contact with the person or care team members (remember not to confuse this with cultural deference)
- Blaming the client

Abuse and Neglect

Caregiver burnout can sometimes look like abuse or neglect, and abuse or neglect can be masked as caregiver burnout. It often takes a professional to be able to distinguish between the two.

Detection of abuse or neglect is sometimes difficult because it may be difficult to isolate the signs of abuse or neglect from the effects of the terminal illness. Sometimes, there may be abuse or neglect that does not show the standard signs.

When family members are experiencing caregiver burnout, they may become angry, frustrated and resentful -- and volunteers can become the target of those negative feelings. Volunteers need to be sensitive to the situation in the client's home and the caregiver's well-being; they also need to trust their own instincts.

Signs of Abuse and Neglect to Watch for:

- Unexplained client injuries in various stages of healing, grip marks
- Delay in seeking treatment for their loved one
- Withdrawal, low self-esteem, extreme passivity, apathy expressed by the client whenever the caregiver is present
- Unexplained discrepancy between income and standard of living
- Lack of attention to client/caregiver personal hygiene

Factors contributing to possible abuse/neglect by a caregiver:

- 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
- Client dependency on the caregiver
- Lack of caregiver recognition

Section 3: Volunteer Role

Working with the Family

Working with a client also means working with the family: the people who are emotionally significant to that person. Significance does not necessarily mean a positive, healthy relationship. There will always be conflict and tension within families, and volunteers need to take this into consideration before working with clients.

Volunteers will encounter many dynamics, including those relating to power, control, conflict, emotional issues, mental health issues and trauma. These dynamics often intersect and interact, and may influence end-of-life care and planning. Within each family there are (often unspoken) rules, values, roles, attitudes and norms that govern behaviour and interactions.

Volunteers can play a supportive role by being aware of these factors and trying to assist family members by:

- Remaining non-judgmental
- Affirming normalcy
- Paying attention to feelings and changing moods
- Listening to family members and just “being there” for them
- Accepting it when a family member expresses anger and frustration
- Accepting different grieving patterns (see Module 7 - Grief and Bereavement)
- Offering to stay with the client so that family can take a break and look after themselves

Additional factors to assist family members include:

- Providing attention to children
- Sharing their knowledge about any comfort measures that may help the client feel more comfortable
- Advocating for the client and family by being alert to their changing care needs and reporting them to the hospice coordinator
- Bringing any concerns about the caregiver’s abilities to continue to provide care to the hospice coordinator
- Helping family members with unfamiliar tasks
- Helping family members be creative with opportunities to be together as a family (e.g. help to prepare a “picnic” lunch/supper or an “evening at the cinema” – favourite video and popcorn - in the person’s room).

Methods to Provide Support

The volunteer can best provide support by:

- Actively listening
- Demonstrating their interest and concern to the client/family
- Reporting any client/family issues to their hospice coordinator

It is not the role of the volunteer to provide family or marital counselling or to intervene in financial or legal matters.

How to Manage Volatile Situations

I am worried about a family's emotional reaction. What should I do?

Volunteers who become concerned about the family's emotional reactions should communicate their concerns to the hospice coordinator so the team that they can help the family get professional assistance. Hospice palliative care is a team effort. The role of the volunteer is to provide emotional and practical support for the family. Volunteers must remove themselves from any situation where they feel unsafe and communicate any safety concerns to the hospice coordinator immediately.

Are there policies in place for referring clients/families when there is suspected abuse?

Yes. Hospices have policies and procedures in place for referring clients/family to the professional care team members or to community resources for dealing with suspected abuse. Volunteers must review their hospice's polices, which will reinforce their role as a volunteer, describe the limits to volunteer involvement with clients/families and prevent them from feeling responsible for meeting all the family's needs.

Does it reflect poorly on me if I need to be removed from a situation?

Never. In some cases, the volunteer must be removed from the setting because of a volatile family situation. This does not reflect badly on the volunteer for future placements.

Do I have to report child abuse and/or neglect?

Every person has a legal duty to report suspected child abuse and/or neglect. Volunteers are responsible for reporting suspected child abuse or neglect directly to the Children's Aid Society and to their coordinator. This is an anonymous process and the Children's Aid Society is responsible for determining whether or not child abuse or neglect is occurring. The legislation has been designed to encourage timely intervention and to facilitate this anonymous process.

See Video: Volunteers Support, They Don't Fix*
Use the space below to record notes.

Volunteers Can Help

Volunteers can help by:

- Being aware of the caregiver's stress level and how much of a burden they feel their caregiving role is becoming to them
- Contacting the hospice coordinator about providing information to the caregiver about community resources that can help them with finances, counselling and caregiver support groups
- Helping caregivers to recognize the signs of burn out
- Encouraging caregivers to stay healthy and helping them to achieve this in practical ways (i.e. not just saying it and not creating opportunities)
- Helping caregivers confront any negative feelings and find appropriate ways to deal with them including seeking professional counselling and/or spiritual care.

Practice Opportunity

Take a moment now and try to identify some of the services that may be available in your community.

- How might these agency's services help hospice clients and their families?
- How might the agencies be connected with the hospice's services?
- How might you manage the urge to "recommend" services and "give advice" to the family as opposed to contacting the hospice coordinator with any information that you may be aware of?

Use the space below to record your thoughts.

Comfort Needs of the Family

Below is a list of areas families may experience a range of need when their loved one is coping with a life-threatening of life-limiting illness.

- Information about the health status of loved one, services and care plan
- Opportunity to question what is happening, medical decisions and options
- Information about options of care for their loved one and support for family
- Opportunity to vent emotions, both positive and negative, with being judged
- Opportunity to help and contribute to the comfort of their loved one
- Reassurance that they are doing the best that they can.

Family Member Bill of Rights

In caring for the client we must remember that there is a standard of care afforded to the family and highlighted by their Bill of Rights.

See Video: Family Member Bill of Rights*

Use the space below to record notes.

As a relative to a dying person, I have the right to:

- Enjoy my own good health without feeling guilty. It is not my fault that someone I love is dying.
- Choose whom I will talk to about my relative's disease. If someone's feelings are hurt because I do not wish to answer their questions, it is not my fault.
- Know what is going on in our family, even if I am a child.
- Be told the truth about my relative's disease, condition and prognosis in words I can understand.
- Disagree or get angry with someone, even if they are dying. Sickness does not stop someone from being human.
- Feel what I am feeling, not what someone else says I "should" be feeling.

- Look after my own needs, even if they do not seem as great as the needs of my dying relative. I can take a "time out" without feeling disloyal.
- Get outside help for my dying relative and family members if we cannot cope by ourselves.
- Get help myself, even if others in my family choose not to get help.
- Maintain hope, in whatever form that might be. No one has the right to take my hope away from me.

The Family Dance

The “Family Dance” is a metaphor for the dynamics or patterns of a family relationship. More often than not, the patterns are unspoken beliefs and roles that govern each family member’s behaviour and interactions with one another. You can liken a family’s dance to their own unique culture.

Families Know Best

Some dance moves may actually serve a positive and protective function for family members. Behaviours and family dances are built over time and cannot be undone easily. No matter what professional role the volunteer holds outside their hospice, the volunteer is there to solely bear witness to the client/family experience.

There may be times when volunteers will observe behaviour that they don’t understand, so it may be helpful to remember the following two points:

1) That “every family has a dance” that it is their way of being or functioning
2) Each family has its own steps and they know how to move with one another.

Notable Dance Moves

- **Distance Monitoring.** Distancing is the emotional and physical distance norms that are learned as a child. These patterns can affect how comfortable a family member is connecting emotionally or physically with the family member who is ill. What may be seen by an outsider as a problem may just be the normal pattern for that family.
- **Reciprocity** is exchanging similar behaviours. When two dancers both put forward the same foot, they will stumble on each other’s feet, however it can be a great pattern when good is exchanged for good.
- **Interactional Synchrony** is a pattern that happens when a family member learns the rhythm of the other and modifies their steps to fit those rhythms. Family stress may increase as each member tries to adapt to the changes associated with the illness. The music may get faster and louder under difficult circumstances. Changing steps may seem clumsy and feet, as well as feelings, may be stepped on causing pain and discomfort to all concerned. The volunteer comes into a family’s life at a time of crisis and observes patterns that may or may not reflect who the family members really are or were before the illness. Volunteers have the honour and privilege of being invited to watch a family’s dance as one member begins to do his or her steps differently due to illness or grief. This may be a time when the whole dance changes especially if one member has to sit down on the dance floor.
- **Compassionate Observer.** As compassionate observers, volunteers may also have an opportunity to share with family members their understanding of the naturalness of tears that may cause family members to stumble on the dance floor and the frustration of each family member when an ill or bereaved member sits on the dance floor and everyone else must change their dance steps to accommodate them.

Summary

The boundaries of confidentiality are important when working with a family. Every aspect of knowledge of the family is confidential -- including what you see, hear, come to know or already know about the family and the client. (See Module 2 - Volunteer Role and Understanding Professional Boundaries.)

Volunteers must not participate in this family dance or they will not be able to bear witness to the whole family's dance.

Volunteers may lose their ability to provide valuable "outside perspective" when invited to share their observations. If volunteers step out onto the "family dance floor", they may lose objectivity.

As volunteers are bearing witness to the family dance, they need to:

- Be clear and honest about their own needs
- Learn to see and value their own dance
- Consciously strive to be in a dance that nurtures and supports themselves.

Chapter 10:
Ethics

Objectives

- Recognize the basic principles of ethics
- Identify the policies, procedures and legislation that provide a framework for ethical decision-making in hospice palliative care
- Recognize some of the ethical dilemmas clients, families and volunteers face
- Recognize the role of the volunteer in ethical decision making

Sections in this Chapter

1. Ethical Principles
2. Ethical Decision Making
3. Ethical Issues in Hospice Palliative Care
4. Limits to the Volunteer Role and the Importance of Boundaries

Section 1: Ethical Principles

Introduction

Before discussing the topic of ethical principles, it is important to explore the concept of morals. Morals are beliefs pertaining to character, values or conduct – the distinction between good and bad. An act or behaviour can be said to be moral, immoral or amoral.

Amoral: Unawares of or indifferent to the principle of right and wrong; unconcerned with the rightness or wrongness of something, lacking a moral sense.

Immoral: Not conforming to accepted standards of morality. Deliberately violating accepted principles of right and wrong.
Moral: Conforming to the principles of right and wrong behaviour and the goodness or badness of human character. Holding or manifesting high principles for proper conduct.

Amoral Versus Immoral - What's the Difference?

Both terms have to do with right and wrong; however amoral means having no sense or being unaware or the principles of right and wrong, whereas the term immoral describes someone who knows the difference, doesn't care and says, "mwah ha ha" while twirling a mustache.

Factors that Influence the Morality of an Act

Some factors that can influence the morality of an act include:

- Our intentions – what are we trying to do?
- The possible results or consequences of our actions
- The value society places on this act. What are the norms in society on which we base our actions?
- Our relationship to this person. Is this act within our jurisdiction or role?
- The agreement that exists between you and the other person. Do you have their full, informed consent and permission?
- Our Knowledge. Do you have all of the information that you need to make an informed decision? Ignorance is not a valid excuse for doing wrong. What are your assumptions? Have they been tested to confirm they are correct?

Definitions

Ethics

Ethics is the science of morals. Ethics is a system of principles and rules of conduct to determine right from wrong actions when values clash. It is an explicit critical reflection on moral beliefs, choices, practices and problems of persons and communities.

Values

Values are important and lasting beliefs or ideals, shared by the members of a society or group about what is good or bad and desirable or undesirable. Values may have a major influence on a person's behaviour and attitude and serve as broad guidelines in all situations (e.g. Confidentiality). By themselves, values don't tell us what we ought to do; they have corresponding ethical principles that are meant to guide action.

Ethical Principles

Ethical principles provide a general framework within which particular ethical dilemmas may be analyzed. (e.g. respect for privacy).

Ethical Issues

According to bioethicists, an "ethical issue" is any situation in which you:

- Encounter conflicting values, beliefs, goals or difficult alternatives
- Are unsure about what we should do or why we should do it
- Are concerned that rights are being violated or persons not being respected
- Are concerned with fairness or justice
- Have conflicting obligations or responsibilities

Signs of an Ethical Issue:

- My gut tells me something's wrong
- Conflict arises between team members
- There are no easy or right answers to the problem
- I start questioning my own or others' basic beliefs like religion, culture or 'up-bringing'
- I can't sleep at night or I take my volunteer concerns home with me

The Paradox Between Good and Bad and Right and Wrong

Sometimes an act can be the "right thing to do" and it's also (in one's own perspective) a "good" thing. Other times, we may have to do something that we feel is "bad", in order to complete a "right" act.

For example, we may believe that lying is a morally "bad" thing to do yet, in certain situations, lying feels like the "right" thing to do. For instance, a friend changes her hairstyle from beautiful long hair to a short style. She asks me how I like it, but I really don't! Not telling her the truth seems like the "right" thing to do in this situation because it feels "wrong" to risk hurting her feelings with an honest answer.

Practice Opportunity

Think of a situation in our life where you may have faced this type of paradox: when an act felt like the "right" think to do but you had to do something you felt was "bad" or "wrong" to complete that act.

Use the space below to record your notes.

Possible Sources of Ethical Knowledge

Who or what are our possible sources of ethical knowledge?

- Family
- Society
- Friends
- Conscience
- The Media
- Teachers
- Cultural Groups
- Church/Faith Community
- Government
- Laws
- Personal experience
- Hospice philosophy of care and values

Practice Opportunity

Reflect on the moral/ethical lessons you may have learned about right and wrong.

Use the space below to record notes.

Section 2: Ethical Decision Making

Overview

Ethical decision making involves:

- Deciding what we should do (which decisions are morally right or acceptable)
- Explaining why we should do it (justifying our decision in moral terms)
- Describing how we should do it (the method or manner of our response)

Ethical decision making should be collaborative, consultative and non-adversarial because:

- The stakes are often high at end of life
- There is often different knowledge and expertise among team members
- It is important to get different perspectives … especially ones different from our own

We know when we've been successful in making an ethical decision when we:

- Recognize an ethical issue when faced with it
- Are equipped with and use tools, resources and education to address ethical issues that arise
- Know where to get help

Values and Guiding Principles in Ethical Decision Making

Within healthcare, several values and principles guide all providers actions and decisions.

Accountability: Volunteers are accountable to the client/family and to the hospice.

Autonomy: Each individual has a right to make decisions regarding their own life and wellbeing. Volunteers "respect their client as a rational individual" who can make decisions.

Beneficence: Actions must help and there is a moral obligation to provide help. Most people volunteer in hospice palliative care with the intention of "doing good" for clients/families.

Confidentiality: Volunteers may only disclose client/family information to those individuals who have a right to the information (i.e. members of the hospice palliative team).

Client Centered Care: Volunteers must provide care that focuses on the needs of the client/family.

Conflict of Interest: Volunteers must disclose any real or perceived conflicts of interest.

Dignity: Honouring the dignity of morally valuable beings. Volunteers must respect the value of the clients/families within whom they work.

Integrity: Volunteers must be honest and trustworthy.

Justice: All clients must be treated equitably and fairly and without discrimination. When deciding where to place volunteers and for how long, hospices must be fair.

Non-Maleficence: Not to inflict harm intentionally – "do no harm". Volunteers must be careful not to cause harm to clients and/or family or the hospice in their volunteer work.

Protection of the Vulnerable: Volunteers must understand the vulnerability of clients/families and recognize their own position of power in the volunteer/client relationship.

Additional Guidelines

Hospices and hospice volunteers are also subject to applicable legislation such as:

- Professional Codes of Ethics
- The Canadian Charter of Rights and Freedoms
- The Long-Term Care Act and Bill of Rights
- The Mental Health Act
- The Ontario Charter of Rights
- The Public Hospitals Act
- The Regulated Health Care Professions Act
- Child abuse legislations (Ontario Child and Family Services Act)
- Laws related to substitute decision making/consent to receive treatment and advocacy, medical assistance in dying, suicide, and illegal substance (criminal code)

Volunteers should also consider the guiding principles and philosophy of Hospice Palliative Care:

- Dying/death is a normal process: the final stages of living and growth
- Support is holistic
- Information is a right
- Choice is a right
- Continuity of care is provided across all care settings.

When acting on behalf of the hospice, volunteers are expected to be aware of and abide by the hospice's policies and procedures.

Values and Guiding Principles: Framework

The values, principles and additional guidelines listed above can help inform ethical decision-making; however, they may not be the most practical tools because volunteers must make judgements about which principle and/or law is more important in a given situation. This can leave the door open to bias and may be too theoretical to meet the practical demands of everyday life.

Instead, volunteers and health care providers can use a framework to help them deal with the day-to-day challenges of any particular ethical dilemma. Two possible frameworks are outlined below.

Case by Case

A case-based approach recognizes the influences of a specific situation on any decision-making and uses the principles that applied in previous similar cases to help solve an ethical dilemma.

Real World

A real-world approach requires the provider or volunteer to examine the current situation, the relationships among those involved in the decision, the rights and opportunities of those involved in the decision and factors (e.g. economic, historical, geographical) that may influence decision making. This approach relies less on abstract concepts and more on what makes concrete sense.

Section 3: Ethical Issues in Hospice Palliative Care

Ethical Issues in Hospice Palliative Care

In their day-to-day interactions with clients and families, volunteers may encounter ethical dilemmas. Often the ethical and moral dilemmas that hospice volunteers confront arise from conflicts between their own personal values, morals and decisions and those of the client, family members and other care team members and/or the policies and procedures of the hospice.

To avoid the problems these differences may create, the hospice has developed a framework for volunteers that reflects its mission, values, policies and procedures.

One of the purposes of volunteer training is to give you the opportunity to explore your own values and be aware that others may have very different values – which need to be respected.

You may find it stressful to work with clients and families who look and act very differently than yourself. Whenever you encounter ethical problems or challenges, you should speak with the coordinator at your local hospice.

Potential Areas of Ethical Dilemma (Part One)

There are 14 areas of potential ethical dilemma that we will discuss within hospice palliative care. In this section, we will explore the first seven potential areas of ethical dilemma:

1. Food and Hydration
2. Managing Difficult Pain and Symptoms
3. Truth Telling and Improving Communication
4. Informed Consent
5. Family Caregiving
6. Advance Care Planning
7. Do Not Resuscitate (DNR) Orders

Food and Hydration

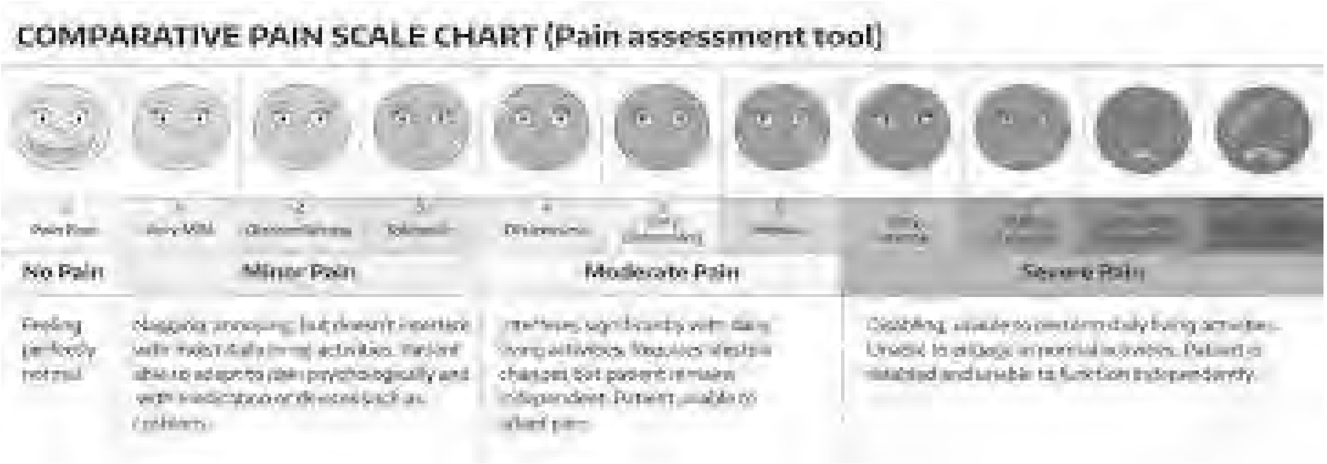
Health care professionals need to discuss the best ways to provide nutrition and the advantages and disadvantages of different options with the client/family

__Potential Ethical Issue__: A client may decide to stop eating and/or drinking and this decision may be difficult for both family members and health care providers to accept. Decisions about feeding tubes can also cause ethical turmoil.

Managing Difficult Pain and Symptoms

When clients experience pain and suffering/shortness of breath, nausea and other troublesome symptoms, ethical issues may arise. The amount and frequency of medication may become a focus of debate.

__Potential Ethical Issue__: A health care professional may fear that efforts to control a client’s pain may hasten death. A client may choose to endure pain and symptoms because of a cultural belief or a feeding that they deserve to be punished for some past misdeed. It can be very difficult for family members and health care professionals to watch a person suffer.



Truth Telling and Improving Communication

Whenever the physician or other health care professional must give the client “bad news”, the issue of truth telling arises. In these situations, providers may be tempted to avoid truth telling to save the client pain, but it’s important to recognize the client’s right to make decisions about his or her life and wellbeing. All clients have the right to accurate information about their diagnosis, the risk and benefits of treatments, and their prognosis.

Potential Ethical Issue: The client may choose not to know the truth, and the client’s choice must be respected. Harm can be done by “truth telling” without compassion.

Informed Consent

Specific requirements and processes must be in place to assure health care professionals obtain informed consent from clients. Informed consent falls under the Health Care Consent Act (1996).

Potential Ethical Issue: A client may refuse treatment or choose a treatment that they provider does not believe is best.

Family Caregiving

As the client’s illness progresses, family members may experience a perceived or real burden or caregiving, the challenges with coping and the consequences of long-term caregiving (e.g. families not sharing the workload evenly, some caregivers refusing help out of a need to do it all).

Potential Ethical Issue: A caregiver may experience difficulty coping with caregiving responsibilities and may ask team members to keep secrets about how they are feeling to spare the ill person or to fulfill some personal agenda. Team members may question the motivation of a caregiver if they feel the decisions being made are not in the client’s best interest.

Advance Care Planning

In order to understand Advance Care Planning as a potential ethical dilemma, we must first explore the concept of Substitute Decision Making.

Substitute Decision Making: As illnesses progress, clients may not be mentally capable or may become mentally incapable of making decisions regarding their life and well being (e.g. the client becomes unconscious). When clients are no longer capable of making their own decisions, health care professionals are required to turn to a substitute decision maker (SDM). There are guidelines outlining who may be a SDM and to help SDMs act in the best interest of the client (i.e. consider client's wishes, rely on the client's values and opinion).

Substitute decision makers are only turned to when a client is mentally incapable of making a decision. Before a substitute decision-maker can be used, the "capacity" of the client must be assessed by a health care professional and evaluated with respect of the situation requiring a decision.

See Video: Substitute Decision Making *
Use the space below to record notes**.**

In Ontario, there are two ways to determine your SDM:

1. Confirming your automatic future SDM from the hierarchy (see additional resources section)
   OR
2. Choosing someone else to act as your SDM by preparing a Power of Attorney for Personal Care (a legal document).

Substitute Decision Making & Advance Care Planning: In Ontario, advance care planning involves deciding who will make future health care decisions for you if you are unable to. This will be your substitute decision maker (SDM). Advance Care Planning also involves discussing your wishes, values and beliefs with your SDM and loved ones, which will help them understand how you would like to be cared for in the event you are mentally incapable of making healthcare decisions for yourself.

<u>Potential Ethical Issue</u>: An SDM may make treatment or care decisions that do not align with the client's wishes, values or beliefs. This may occur accidentally (lack of awareness) or deliberately (the SDM ignores the client's wishes, values or beliefs).

Do Not Resuscitate (DNR) Orders

A resuscitation order is most often referred to as a Do Not Resuscitate (DNR) or Allow Natural Death (AND) order. It may be part of the client's care plan for hospice palliative care. The decision to complete a DNR or AND order should be made between the client and/or SDM and the physician.

<u>Potential Ethical Issue</u>: If a family member does not respect the client's wishes and calls emergency services, they must respond aggressively if the DNR-Confirmation form is not available. Volunteers may experience an ethical dilemma when their values and beliefs differ greatly from the choices that the client or family members have made.

Potential Areas of Ethical Dilemma (Part Two)

In this section, we will explore the remaining potential areas of ethical dilemma (listed below).

8. Withholding and/or Withdrawing Life Sustaining Treatments
9. Client Non-Compliance
10. Medical Assistance in Dying
11. Suicide
12. Conflict of Interest
13. Confidentiality
14. Gifts

Withholding and/or Withdrawing Life Sustaining Treatments

Respect for client autonomy requires that health care professionals respect the right of clients to reuse treatment.

Potential Ethical Issue: It can be very difficult for the family and for the health care provider when they think the client should continue to receive treatment.

Client Non-Compliance

Respect for client autonomy requires that health care professionals respect that right of clients to discontinue or disregard recommended treatments.

Potential Ethical Issue: A client may make choices that seem to go against the medical team's recommendation (e.g. diabetic client chooses to eat donuts).

Medical Assistance in Dying (MAID)

The issue of medical assistance in dying (also referred to as physician assisted death, assisted suicide or euthanasia) is currently a highly emotional and contested topic in Canada. The Supreme Court (February 2015) stated that physician assisted death would not be a crime for "a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."

The Canadian Hospice Palliative Care Association's position is as follows:

- Hospice palliative care does not hasten or prolong death
- Hospice palliative care strives to end suffering not life
- Canadians need universal access to hospice palliative care including good pain and symptom management
- All clients deserve access to information about end-of-life options, including medical assistance in dying
- Please refer to the HPCO website www.hpco.ca to read the official provincial stance on medical assistance in dying

Potential Ethical Issue: A health care professional and/or a family member may have difficulty supporting an individual who chooses to pursue this option to hasten their own death.

Suicide

This issue of suicide in hospice palliative care can be highly emotional. Respect for client autonomy requires that team members respect the right of clients to make decisions about their end of life experience.

Potential Ethical Issue: A health care professional and/or family member may have difficulty supporting an individual who chooses to pursue this option to hasten their own death.

Conflict of Interest

Everyone on the hospice palliative care team must always act in the best interest of the client/family and must disclose any real or perceived conflicts on interest. Volunteers must also act in the best interest of the hospice organization. Volunteers will serve without remuneration and will not profit directly from their volunteer position. All potential volunteers must disclose any personal, business, commercial or financial interest where such interest may be construed as being in real, potential or apparent conflict with their regular duties. Volunteers must inform their coordinator of any subsequent conflicts, once their placement has begun.

Potential Ethical Issue: A volunteer may engage in activities with clients/families that would result in personal gain for the volunteer or the volunteer's family members or friends (e.g. selling products or services, referrals). A volunteer must never appear to be using his or her volunteer position for personal or monetary gain. Any selling of products or promoting of the volunteer's or other person's business or service is strictly prohibited and may be grounds for dismissal.

Confidentiality

Respect for the client's privacy is paramount to quality care and governed by both provincial and federal legislation as well as hospice policy

Potential Ethical Issue: A client may ask that information shared with one provider not be disclosed to others. Confidentiality can be particularly difficult for a volunteer if the client lives in a small community where everyone knows everyone else. Neighbours and friends of the dying person and family may know the volunteer and ask for information about the client/family. In those situations, the volunteer should always suggest that they talk directly to the client/family.

Gifts

Volunteers must not give or receive gifts from clients/families (see module on Role of Volunteer and Understanding Professional Boundaries).

Potential Ethical Issue: If it becomes public knowledge that a volunteer has accepted a gift or bequest, the volunteer could become involved in potential legal disputes over ownership of a client's property and/or conflict with the family may occur. Additionally, if a volunteer gives a gift to his or her client, the client may feel the need to reciprocate. Remember - the greatest gift a volunteer can give is their presence.

Volunteer Code of Ethics

1. Respect the client's and family's right to privacy
2. Obey strict confidentiality
3. Uphold the objectives of the hospice organization
4. Refrain from offering any medical advice related to treatments or care plans, which must always remain the client's and family's decision
5. Be regular, reliable, consistent
6. Be patient and calm regardless of how difficult a situation may become
7. Be aware of your own personal beliefs related to faith, life or culture – never try to impose your beliefs on clients or family members
8. Avoid judging clients or family members
9. Be aware of your own limitations, strengths and weaknesses
10. Be willing to accept help from other members of the hospice staff or care team.
11. Always do your volunteer work to the best of your ability
12. Offer only what you can sustain, within the boundaries of the role and your own limitations.

Section 4: Limits to the Volunteer Role and the Importance of Boundaries

The Importance of Boundaries

Hospice volunteers may form a close bond with clients and families. Volunteers must walk a fine line between seeming like a client's or family's "friend" and being a friendly presence in their life.

Volunteers must remember that they are members of the interdisciplinary hospice palliative care team and are accountable for their conduct, practice and quality of care.

Key Things to Remember About the Volunteer Role

Support, Don't Fix

Remember, volunteers support; they do not fix. Volunteers are not social workers or family counselors. It is NOT the volunteer's role to provide family or martial counseling or to intervene in financial or legal matters. Volunteers are there to offer support to clients and families, respecting the ways in which people choose to cope.

Set Boundaries and Communicate Them

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.

As a volunteer, it's important to set boundaries with the person and family and to clearly define the volunteer role and what the volunteer can and cannot do. When volunteers are not clear about their boundaries, they may find themselves becoming more involved than they want to be.

Take Care of Yourself

If volunteers allow their boundaries to get pushed too often, they may begin to feel overwhelmed and resentful. By maintaining personal boundaries, it may feel that the focus is on meeting one's own needs before meeting the needs of others; however, this is not selfish. It is a way to ensure that volunteers maintain a healthy balance so that they have something to give others. Volunteers must check that they are not trying to be indispensable – always coming to client's/family's rescue.

Chapter 11:
Psychosocial Issues and Impact of Illness

Objectives

- Recognize personal attitudes and feelings about death and recognize individual biases
- Recognize some of the common needs, challenges and issues faced by clients/families
- Recognize ways that volunteers can assist clients/families to cope with emotional and
- psychosocial issues
- Identify the common ways in which illness may impact clients/families
- Recognize some basic treatments, both traditional and complementary
- Identify the most common illnesses encountered in hospice palliative care.

Sections in this Chapter

1. Psychosocial Issues and Common Fears in Hospice Palliative Care
2. How Volunteers Can Help
3. General Treatment/Therapy Regimes
4. Common Illnesses in Hospice Palliative Care

Section 1: Psychosocial Issues and Common Fears in Hospice Palliative Care

Personal Attitudes About Death

Dying well is a is a highly individualized and personal experience that may be influenced by any of the following personal factors:

- Personality
- Gender
- Ethnic background
- Social class
- Culture
- Spiritual beliefs
- Societal views of dominant culture
- Media

It is no one's role to tell another person how to die well.

There are, however, some experiences that may contribute to "dying well" for most people:

- Having pain managed at a level that is acceptable to the ill person
- Operating at the highest possible level of functioning
- Resolving long-standing conflicts
- Satisfying final wishes
- Achieving a sense of control
- Relinquishing control over care to significant others.

Coincidentally, these common characteristics of "dying well" are also an integral part of hospice palliative care.

Supporting the Client

The challenge for hospice volunteers is to provide support while not directing or interfering with the client's or family's choices. It can be particularly difficult to provide this kind of support in situations where families have unspoken cultural or social rules that are not obvious to the volunteer and/or volunteers have deeply held beliefs, practices and biases.

Expressing Emotion

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

Many cultures, social classes and even individuals do not openly express emotions. Some may have taboos about dying and death and/or do not subscribe to the commonly accepted notions of "dying well".

Volunteer Responsibility

Some clients may seek out advice and answers to many complex and fundamental questions. Others may exhibit a wide variety of emotions that are shaped by their family history.

In their role as facilitators in the client's/family's home, volunteers must remain non-judgmental. Volunteers are not expected to have all the answers or to 'fix' the client's or family's emotional and/or psychosocial problems/concerns, but they do need to know who to contact to get help for clients/families. It is also the volunteer's responsibility to know the policies of their local hospice.

Volunteer Expectations

This module is designed to provide hospice volunteers with the knowledge and understanding of clients' and families' psychosocial needs, which will help them to fulfill their role.

It also provides practical information about the most common diseases, the "course of the disease" and what volunteers should expect during their client's final journey

Volunteers are not expected to become experts in diseases and their management. They should focus on providing support for clients.

Psychosocial Issues and Common Fears in Hospice Palliative Care

When a loved one is dying, emotions such as fear, guilt, resentment and hope can have a powerful impact on the whole family. Their behaviour may be influenced by issues such as unfinished business, complicated family dynamics, personality traits, and biases and beliefs about death.

See Video: The Truth of It. Larry Librach, Toronto Palliative Care Physician and Patient*
Use the space below to record notes.

Common Fears

Each person who is diagnosed with a life-limiting or life-threatening illness will have a unique reaction and experience a variety of fears about the illness and impending death. Despite individual differences, most individuals describe a cluster of common fears and concerns. To support someone who is dying, volunteers need to understand these common fears.

Fear #1 - Physical pain and mutilation: The fear of pain and/or physical mutilation is often the primary concern for people facing the end of their life. Both the presence of pain and the fear of future pain may cause anxiety for the client and family. Clients may need reassurance that the hospice palliative care team will do their best to keep them comfortable with medication, massage, cleanliness, exercise (when possible) and diet.

There are common misconceptions about pain control such as: good pain control will shorten the client's life and the notion that pain and dying are inseparable. Although the act of dying may occasionally be painful, that is usually the exception to the rule. (See Module 4 - Pain and Symptom Management.)

Because of these misconceptions or other beliefs, clients may need encouragement not to "be brave" about pain and to ask for information about the benefits of good pain control on quality and length of life. Volunteers can encourage the client/family to ask questions and report pain to the doctor, nurse or other professional caregivers.

See Video: Impact of Pain on Other Symptoms*
Use the space below to record notes.

Fear #2 - Isolation and loneliness: Faced with dying, many people fear isolation and loneliness. Some may be afraid to go to sleep -- not because they may die, but because they may die alone.

As clients near end of life, they may have few visitors and feel isolated from friends, family and former caregivers (i.e. physicians, nurses and others who may have been actively involved in the early stages of the client's diagnosis and treatment). They may also be dealing with the sadness of failed expectations about friends, family, job or career.

Feelings of loneliness or isolation may be directly related to the experience of pain: a person's pain may be more intense when he or she is left alone (see Chapter 4 - Pain and Symptom Management).

To help reduce a client's fear of isolation or loneliness, it is not necessary for volunteers to have long conversations with the person about those fears. The simple presence of another person is all that most people need to feel comfortable and be reassured that they are not alone.

Fear #3 - Increasing Dependence on Others: Dependence on others can be a major source of suffering for someone who is dying. It may represent a series of gradual losses. Many clients suffer more distress from their inability to function than they do from physical pain.

Sometimes it is possible to help people cope with this kind of suffering by offering them other ways to see their increasing dependence. For example, one person who was dying acknowledged their dependence on others by saying: "The last gift I can give to others is to allow them to give to me."

Fear #4 - Anticipatory Grief: As they face death, many people may actively grieve that they will no longer be alive or that their life has not been what they expected it to be. They may grieve the fact that life is ending earlier than they wanted and/or that they are leaving family and friends with whom they have shared their lives.

Other causes of anticipatory grief include: unfinished business; family issues; concerns with material assets; guilt and regret around what was done/not done to self and/or others; unfulfilled plans, unrealized hopes and/or dreams; and gradual loss of body functioning.

As clients experience their own anticipatory grief, they may remember the many family members and friends who have died before them. Remembering the loss of these family and friends may intensify their grief (see Chapter 7 - Grief and Bereavement).

Fear #5 - Meaningfulness and Search for Meaning: Some clients may experience the fear that their life has been meaningless or that life itself is meaningless. Most people do not wish to live forever but do wish for their living to have some purpose or meaning. Hence the following questions may arise:

"Why me? Why now? What did I do to deserve this? What am I being punished for?"

People at the end of life may want to review their life, evaluate it, and search for some kind of meaning in their illness and suffering. When life begins to slip away, simply having been alive is not enough for most people. They often experience a strong human desire to have led a life that has been meaningful and useful: a sense that life has counted for something. When clients are able to find value in their life, then they will feel gratitude for their life experiences and be able to preserve and even strengthen that sense of meaning. Volunteers can help clients find value in their lives by listening to stories about things they have done that gave them pride and feelings of accomplishment.

Fear #6 - The Future of Loved Ones: Some clients may be able to discuss their own illness and impending death with a sense of calm and peace, but they become very distressed when speaking of their family and loved ones.

They may worry about the effects that the illness has had on their loved ones, fear the sense of impending separation, fear for their loved one's future and/or regret not having time to see their own children/grandchildren grow up.

Fear # 7 - The Process of Death and Afterwards: Many people may fear the process of death. Both clients and families may need reassurance that, when pain and symptoms are controlled, death may come as an easy process. Some may want to participate in plans for their memorial or funeral.

Some may not realize the value of these rituals for their friends and family and may wish to spare their family the pain of such events, insisting that no acknowledgement of their passing be made. Some may also want to talk about their concept of an afterlife and concerns about what will happen to them spiritually (see Chapter 6 – Spirituality).

Signs that a Client/Family May Need Professional Help

Any of the following signs can be "red flags" and may indicate that the client and/or family need additional support (e.g. social work, family counselling):

- History of domestic violence
- History of substance abuse and/or addictions, including alcohol, drugs and/or gambling
- Unemployment
- Financial pressures and/or debt
- Homelessness
- History of criminal charges and/or felony
- History of abuse or neglect
- History of mental illness and/or hallucinations
- History of cognitive or physical disability
- History of traumatic events (violence, murder, fatal car accidents, unexpected death, war, ethnic/cultural/religious persecution, etc.)

Additional signs or "red flags" include:

- Long-standing personality factors (depression, anxiety, dependent personality)
- History of suicidal attempts or suicide of significant loved one
- Verbal, psychological, sexual or physical abuse and/or aggressiveness
- Promiscuity, bullying, disrespect, threats
- Multiple or concurrent issues/crises in the life of the client/family
- Multiple deaths in a short period of time, or history of multiple significant deaths
- Spiritual anger, distress, lashing out
- Wishing to die and planning how to do it - both suicide and euthanasia.

Regardless of their professional credentials, volunteers must never offer therapy, interventions and/or social welfare services to clients/families. If any aspect of the client's or family's behaviour or thoughts makes the volunteer feel uneasy during their visits, the volunteer must contact their hospice coordinator for assistance.

Section 2: How Volunteers Can Help

Listening and Being Present

Chances are that the client's and family's greatest need is to be heard, acknowledged and validated by others. During a crisis, people may need to talk about their experience repeatedly. It is their attempt to make sense of what is happening and to vent emotional pressure. When people are fearful or in pain, they may not benefit from someone around them doing a lot of talking. They may need someone who simply listens to them.

They may not be looking for advice. False hope or clichés are not helpful. Instead they may be looking for empathy, understanding and comforting presence. (See Module 2 - Role of Volunteer and Understanding Professional Boundaries.)

See Video: The Power of Empathy by Dr. Brune Brown*
Use the space below to record notes.

Touching and Allowing Questions

Touching with Permission

- Always ask for permission first
- Clients who are living with a life-limiting or life-threatening illness may perceive themselves -- or be perceived by others -- as repulsive, freaky, dirty or unclean. This experience can be very painful and isolating. When people feel isolated, touch can be a powerful comfort.
- When appropriate, volunteers may put an arm around a client, hold the person's hand, give a hug or wipe away the client's tears. These physical gestures can mean so much and often say more than a thousand words.

Allowing questions to be unanswered

- Clients and family members may ask questions about many of their concerns, but they may not really expect to receive answers.
- Asking for explanations may simply be a way of expressing anguish, fear, uncertainty and a search for meaning.
- Clients and families likely know that volunteers do not have answers to their difficult philosophical questions. No one likely does. What is important is that they are listened to when they indicate they want to talk or be heard.

Section 3: General Treatment/Therapy Regimes

Conventional, Complementary and Alternative Treatments/Therapies

Conventional or mainstream treatments are those that are currently accepted and widely used in the Canadian health care system. They include surgery, radiation therapy, dialysis and chemotherapy. These treatments are administered by regulated health care professionals such as doctors, nurses and radiation therapists. In general, scientific research has shown that conventional treatments are safe and effective for most people.

The terms complementary and alternative therapy are often used interchangeably, however they have very distinct and different meanings.

Complementary Therapy vs. Alternative Therapy

Complementary therapies are typically used *together with* conventional treatments whereas alternative therapies are typically used *instead of* conventional treatments. For example, in cancer treatment, when clients practice meditation to help with anxiety before undergoing radiation therapy, meditation is being used as a complementary therapy. If a client chooses to decline having radiation therapy and meditates instead, in the belief that meditation will cure the cancer, the meditation is being used as an alternative therapy.

The Purpose of Complementary Therapies

Complementary therapies are not intended to treat the disease itself. Their purpose is to help improve overall health and well-being. These therapies may help clients cope physically and emotionally with conventional treatments such as having acupuncture to help with nausea caused by chemotherapy or practicing yoga to feel more relaxed and sleep better while living with ALS.

Research has shown that a number of complementary therapies can be used safely while having conventional treatments. They lessen treatment side effects, such as nausea and fatigue, and they can also help clients cope with stress, anxiety and other challenges they may face during their end-of-life journey.

According to studies, many people living with cancer have used at least one complementary therapy as part of their cancer treatment. The same is likely true with other life-threatening and life-limiting diseases. Some people feel that using a complementary therapy helps them gain a sense of control and feel more involved with their health care choices. Others feel that complementary therapies may help improve their quality of life.

Examples of Complementary Therapies

- Acupuncture
- Aromatherapy
- Art therapy and/or expressive arts therapy
- Ayurveda
- Biofeedback
- Chiropractor
- Energy therapy
    - Reiki,
    - Therapeutic touch
    - Healing touch
    - Magnetic healing therapy

- Guided imagery
- Hypnosis
- Massage therapy
    - Swedish massage
    - Deep tissue massage
    - Myotherapy,
    - Lymphatic drainage
    - Oncology massage
- Reflexology
- Meditation
- Music therapy
- Naturopathic medicine
- Tai chi
- Yoga

Note: Only qualified practitioners of complementary therapies may use them with their assigned hospice client(s). Volunteers must check their hospice's policies about the use of complementary therapies.

Section 4: Common Illnesses in Hospice Palliative Care

Introduction

The focus of volunteer support is not on the illness, but on the person. Many concepts discussed in this chapter will apply to all types of illnesses.

However, this section briefly describes some common illnesses volunteers may encounter in hospice palliative care.

Common Illnesses in Hospice Palliative Care

ALS (Amyotrophic Lateral Sclerosis)
Alzheimer's Disease
Multiple Sclerosis (MS)
Parkinson's Disease
Cirrhosis (Liver Disease)
Congestive Heart Failure (CHF)
Chronic Obstructive Pulmonary Disease (COPD)
Huntington's Disease
Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS)
Kidney (Renal) Failure
Cancer

ALS (Amyotrophic Lateral Sclerosis)

- ALS, also known as Lou Gehrig's Disease, is a neurodegenerative disease where the nerve cells that control the muscles die. The "living wires" that connect the brain to the muscles degenerate, leading to a loss of mobility, speech and eventually the ability to breathe.
- Common symptoms are progressive loss of muscle function -- starting with limbs and eventually affecting swallowing, speech and respiratory function -- and depression.
- There is currently no known cure for ALS or any effective treatment. In Canada, there are approximately 2500 to 3000 people living with ALS at any given time: each year about 1000 people will succumb to the disease and 1000 will be newly diagnosed. After diagnosis with ALS, people live - on average - two to five years.

See Video: Brothers Bob and Barry live with ALS*
Use the space below to record notes.

Alzheimer’s Disease

- Alzheimer's Disease is the most common type of dementia. It is a progressive, neurodegenerative, irreversible condition in which brain cells gradually degenerate and cause a steady decline in memory and mental function. Dementia symptoms worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. Alzheimer’s Disease is fatal.
- Alzheimer’s Disease eventually affects all aspects of a person’s life: how they think, feel and act. Each person is affected differently. It is difficult to predict symptoms, the order in which they will appear or the speed of their progression.
- Some changes that may occur as the disease progresses include:
    - Cognitive and functional abilities: a person’s ability to understand, think, remember and communicate may be affected.
    - Emotions and moods: a person may appear apathetic and lose interest in favourite hobbies. Some people become less expressive and more withdrawn.
    - Behaviour: a person may have reactions that seem out of character such as repeating the same action or words, hiding possessions, physical outbursts and restlessness.
    - Physical abilities: the disease can affect a person’s coordination and mobility, to the point of limiting their ability to perform day-to-day tasks such as eating, bathing and getting dressed.

- At the end-stage of Alzheimer’s Disease, common symptoms are: difficulty with most basic functions such as walking, talking, toileting and swallowing; a loss of desire or ability to eat and drink, which can lead to weight loss, dehydration and urinary tract infections; increase in infections due decreased mobility such as pneumonia; and skin breakdown.
- Those with Alzheimer's Disease live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions. There is currently no known cure for Alzheimer’s Disease but treatments and lifestyle choices may significantly slow progression of disease.

See Video: Truth Telling in Alzheimer’s*
Use the space below to record notes.

Multiple Sclerosis (MS)

- Multiple sclerosis (MS) is thought to be an autoimmune disease of the central nervous system (i.e. brain, spinal cord). The disease attacks myelin, the protective covering of the nerves, causing inflammation and damage. Myelin is necessary to transmit nerve impulses through nerve fibres. If damage to myelin is slight, nerve impulses travel with minor interruptions; however, if damage is heavy and if scar tissue replaces the myelin, nerve impulses may be completely disrupted, and the nerve fibres themselves can be damaged.
- MS can cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment and mood changes.
- At the end-stage of MS, common symptoms are: fatigue; bowel and bladder disturbances; vision problems; changes in brain function; changes in sexual function; pain; depression or mood swings; deteriorating respiratory functioning; shallow and inefficient breathing, which can lead to complications such as pneumonia; shortness of breath and presence of respiratory secretions; pain caused by muscle spasms, neuropathic (nerve) pain, and pain caused by immobility.
- MS may remain stable for long periods, decline and then stabilize again. There is currently no known cure for MS but people living with MS can expect a normal or near-normal lifespan, thanks to improvements in symptom management and MS disease-modifying therapies.

Parkinson's Disease

- Parkinson's Disease is a variable, slow, progressive, neurodegenerative disorder of the nervous system that affects movement. Movement is normally controlled by dopamine, a chemical that carries signals between the nerves in the brain. When cells that normally produce dopamine die, the symptoms of Parkinson's appear.
- The most common symptoms of Parkinson's Disease are: tremors, slowness and stiffness; impaired balance; rigidity of the muscles; fatigue; soft speech; problems with handwriting; stooped posture; constipation; sleep disturbances; depression; difficulty swallowing; sexual problems; and cognitive changes.
- At the end-stage of Parkinson's Disease, common symptoms are: severe rigidity; difficulty eating and swallowing; bladder and bowel problems; urinary tract infections; difficulty breathing; pneumonia; fractures related to falls; hallucinations and dementia.
- There is currently no known cure for Parkinson's Disease but those affected by it can expect to live a normal lifespan. Treatment may include various medications, therapies and surgery.

Cirrhosis (Liver Disease)

- Cirrhosis is scarring of the liver. Scar tissue forms because of injury or long-term disease. Scarred liver tissue is not able to function like healthy liver tissue does: to make protein, help fight infections, clean the blood, help digest food and store energy. Cirrhosis develops when the factors that damage the liver are present over a long period of time.
- The major causes of cirrhosis are:
    - Chronic alcoholism
    - Viral infections caused by chronic viral hepatitis (types B, C and D)
    - Metabolic diseases
    - Inherited diseases such as Wilson's Disease and hemochromatosis
    - Biliary cirrhosis resulting from diseases such as Primary Biliary Cirrhosis (PBC) and Primary Sclerosing Cholangitis (PSC)

  - Toxic hepatitis caused by severe reactions to prescribed drugs or prolonged exposure to environmental toxins
  - Repeated bouts of heart failure with liver congestion.
- As liver function decreases, the body produces fewer proteins such as albumin, which results in fluid accumulation in the legs (edema) or abdomen (ascites). Individuals with cirrhosis may bleed and bruise easily due to a decrease in proteins required for blood clotting. Some people may even experience intense itching due to products that are deposited in the skin. In the later stages of cirrhosis, jaundice may occur and gallstones are more common because insufficient levels of bile are able to reach the gallbladder.
- A cirrhotic liver no longer removes toxins effectively leading to toxin accumulation in the blood, which in turn can impair mental function and lead to personality changes and possibly coma.
- At the end-stage of cirrhosis of the liver, common symptoms are: 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 (extreme drowsiness) and coma.

Congestive Heart Failure (CHF)

- Congestive Heart Failure (CHF) occurs when the heart cannot pump blood normally. As a result, there is not enough blood flow to provide the body's organs with oxygen and nutrients. The term "heart failure" does not mean that the heart stops beating completely, but that the heart is not working as efficiently. CHF specifically refers to the stage in which fluid builds up around the heart causing it to pump inefficiently.
- CHF develops when ventricles cannot pump blood in sufficient volume to the body. Eventually, blood and other fluids back up inside the lungs, abdomen, liver and lower body.
- There is currently no known cure for CHF and common symptoms at the end-stage are: shortness of breath; swelling in feet and ankles; fatigue; anxiety; fluid in lungs (coughing); and insomnia (inability to sleep).

See Video: Understanding Heart Failure*
Use the space below to record notes.

Chronic Obstructive Pulmonary Disease (COPD)

- Chronic Obstructive Pulmonary Disease (COPD) is a lung disease that includes chronic bronchitis and emphysema. In 80 to 90% of cases, it is caused by smoking. Other causes of COPD can include:
    - genetic reasons (alpha-1 antitrypsin deficiency)
    - occupational dusts and chemicals
    - second-hand smoking
    - frequent lung infections as a child
    - fumes and smoke produced by burning wood, fuel and other biomass (animal dung, crop residues); for example, during the process of cooking.
- COPD develops over time. In most cases, COPD is diagnosed in people over 40 years of age. Someone with COPD may not realize that they are becoming more short of breath until it becomes very hard to do simple tasks like walking up stairs. When people have COPD, their lungs are obstructed or blocked, making it hard to breathe.
- In chronic bronchitis, airways become swollen and can be filled with mucus; in emphysema, the air sacs (alveoli) in the lungs are damaged. Both conditions are characterized by difficulty breathing. At the end-stage of COPD, common signs and symptoms are: blue colour to the skin and nail beds, shortness of breath, restlessness, anxiety, fatigue, reliance on oxygen, and needing to sleep sitting up.

Huntington’s Disease

- Huntington’s Disease is an inherited disease-causing degeneration (breakdown) of nerve cells in the brain. It affects functional abilities such as movement and cognitive functioning (thinking). It may be at the root of a few psychiatric disorders that affect patients who are coping with Huntington’s Disease.
- The most common signs and symptoms of Huntington’s Disease are:
    - emotional turmoil (depression, apathy, irritability, anxiety, obsessive behaviour);
    - cognitive loss (inability to focus, plan, recall or make decisions, and impaired insight);
    - physical deterioration (weight loss, involuntary movements, diminished coordination, difficulty walking, talking, swallowing)
- There are significant variations in symptoms, and not every person will experience all of the symptoms to the same degree. Symptoms also vary with each stage of the disease. At the end-stage of Huntington’s Disease, common symptoms are: confinement to bed, muscle rigidity, difficulty communicating, difficulty swallowing, injuries related to falls, weight loss, heart failure, infection and aspiration pneumonia.

Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS)

- Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is caused by a retrovirus, which infects a type of white blood cell that is part of the immune system.
- The retrovirus causes: progressive deterioration of the immune system; increased susceptibility to infections and tumour growth; progressive deterioration of the nervous system; seizures; and sensory and motor changes.
- HIV/AIDS is transmitted through various modes, such as: unprotected sexual contact; needle sharing for intravenous drug use; from mother to baby during pregnancy, childbirth and breastfeeding; and needle stick injury in healthcare workers. Although there is currently no known cure for HIV/AIDS, treatments can improve the client's quality of life and lifespan.

- Clients with end-stage HIV/AIDS may experience:
  - Weight loss
  - Anorexia
  - Neuropathy
  - Fatigue
  - Weakness
  - Nausea
  - Vomiting
  - Anxiety
  - Depression
  - Dementia
  - Confusion
  - Fever
  - Skin issues
  - Dyspnea (shortness of breath)
  - Cough
  - Multisystem failure.

See Video: HIV AIDS: Then and Now*
Use the space below to record notes.

Kidney (Renal) Failure

- Kidney (renal) failure happens when the kidneys stop functioning. Kidney failure can happen very suddenly (called acute renal failure) or slowly over time. In most cases, kidney failure is permanent. This is called end-stage renal disease or ESRD. Diabetes and high-blood pressure cause most cases of ESRD. Other causes include:
  - autoimmune diseases (like lupus and IgA nephropathy)
  - genetic diseases (like polycystic kidney disease)
  - injuries
  - some medicines or other drugs.

- The main function of the kidneys is to filter wastes and extra fluid from the blood. If the kidneys fail, treatments such as dialysis or a kidney transplant are usually needed to continue living. These treatments help replace the job of the kidneys.
- There are 2 types of dialysis:
  - Hemodialysis (also called hemo) uses a machine to clean the blood. During treatment, the patient's blood travels from their body through the dialysis machine, and back to their body. While it is in the machine, their blood goes through a special filter (called a dialyzer), which removes waste and fluid.
  - Peritoneal dialysis (also called PD) uses the lining of the abdomen (called the peritoneum) and a special solution (called dialysate). A tube (called a catheter) is placed into the abdomen. Through this tube, a new solution is put into the abdomen and the old solution out is drained out. This is called an exchange.
- At the end-stage kidney (Renal) failure common signs and symptoms are: decreased urine output, confusion, pain in the lower back, weakness and fatigue and presence of blood in the urine.

Cancer

- Cancer is a disease that starts in the cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs, the liver and so on. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy. Sometimes the instructions get mixed up, causing the cells to form lumps or tumours, or spread through the bloodstream and lymphatic system to other parts of the body.
- Tumours can be either benign (non-cancerous) or malignant (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening.
- Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called metastases.
- The first sign that a malignant tumour has spread (metastasized) is often swelling of nearby lymph nodes, but cancer can metastasize to almost any part of the body. It is important to find malignant tumours as early as possible.
- Cancers are named after the part of the body where they start. For example, cancer that starts in the bladder but spreads to the lung is called bladder cancer with lung metastases.
- There are four main types of cancer:
  - Carcinoma. The most common type of cancer, carcinomas may start in the bowel, breast, cervix, lungs, kidneys, ovaries, prostate gland or skin.
  - Leukemia. Cancer of white blood cells.
  - Lymphoma. Cancer of the lymphatic system, which consists of the spleen, lymph nodes and lymph vessels. The lymph system carries food, oxygen, and water to the cells in the tissues.
  - Sarcoma. Cancer that starts in the muscles, bones, and cartilage. Cartilage is a tissue at the extremities of bones that grows to form new bones.

See Video: Candid Testimonials About Living with Cancer*
Use the space below to record notes.

- The three main conventional treatment options for cancer are: surgery, radiation therapy and chemotherapy. Other types of treatments, such as hormonal therapy, biological therapy or stem cell transplant may also be used for some types of cancer. Cancer treatment is given by cancer specialists (oncologists). Some specialize in surgery, some in radiation therapy and others in chemotherapy (drugs). These doctors work with the person with cancer to decide on a treatment plan.
- Patients with cancer are given individual treatment plans based on their type of cancer, the cancer's characteristics, the stage of the cancer, and their personal situation and wishes. Sometimes, two people with the same cancer may be given very different treatments.
- Cancer treatment may be given for a number of reasons. Sometimes, the goal of treatment can change over time.
- Main treatment goals are:
  - *Prevention (prophylaxis)* - Treatment is given to prevent the growth of cancer cells or to remove pre-cancerous tissue that could turn into cancer.
  - *Cure* - Treatment is given to cure the cancer.
  - *Control* - Treatment is given to control the tumour and stop cancer from growing and spreading. It may also reduce the risk of the cancer coming back (recurring).
  - *Palliation (palliative)* - When cure is not possible, treatment is given to:
    - Temporarily shrink tumours
    - Reduce symptoms, such as bleeding, pain or pressure
    - Treat problems caused by cancer or its treatment
    - Improve a person's comfort and quality of life.

Chapter 12:
Cultural Considerations

Objectives

- Recognize the components of culture
- Recognize how one's own culture impacts the care of others
- Recognize a safe, respectful and culturally inclusive environment
- Recognize the role that culture plays in dying and death
- Identify one's own belief system and its influences

Sections in this Chapter

1. Diversity
2. Culture and Personal Culture
3. Impact of Culture on Volunteer Caregiving
4. Underserved Cultures

Section 1: Diversity

Key Diversity Terms

Some of the attitudes, beliefs and practices that prevent us from valuing the diversity of clients/families include ableism, ageism, discrimination, heterosexism, homophobia, marginalization, prejudice, racism, racialization sexism, and stereotyping.

All these types of discriminatory attitudes can happen occasionally (in individual circumstances) or be more pervasive because they are reinforced systemically through policies or procedures.

- *Ableism* **-** is discrimination in favor of able-bodied people
- *Ageism* - is stereotyping and discriminating against individuals or groups on the basis of their age. The term was coined in 1969 by Robert Neil Butler to describe discrimination against seniors but it can be applied to any age groups or situations (eg: discrimination against youth)
- *Discrimination* – is the differential treatment of individuals or a group. Discrimination is the result of negative attitudes, values, or beliefs that lead to actions or behaviours that limit others' opportunities.
- *Heterosexism* – is a system of attitudes, biases, and discrimination in favour of opposite-sex sexuality and relationships. It can include the presumption that other people are heterosexual or that opposite-sex attractions, and relationships are the only norm and, therefore, superior.
- *Homo/bi/transphobia* – is an extreme and irrational aversion to homosexual, bisexual and transgender people. It can also mean hatred of LGBTQ people, their lifestyle, sexual behaviour, gender identity, gender expression and/or culture. Homo/bi/transphobia sometimes leads to expressions of hostility and acts of violence (eg: gay bashing)
- *Marginalization* – is a process of socially isolating someone or reducing their social standing in the community. When groups of people are socially marginalized they usually have less access to the social, health, political or economic benefits of society because of their membership in an identifiable group (eg: recent immigrants, people who are homeless, people who use substances)
- *Prejudice* – is a set of attitudes held by one person or group about another person or group that casts the other in an inferior light.
- *Racialization* – is the differential treatment of individuals or groups based on race, ethnicity, language, economics, religion, culture and/or politics/ When people experience racialization, they are being treated outside the norm and are receiving that unequal treatment based on physical or social characteristics.
- *Racism* – is an attitude as well as specific actions through which one group exercises power over others on the basis of skin colour and/or racial heritage. The effect of racism is to marginalize and oppress some people and groups while advantaging other
- *Stereotyping* – is a generalized conception of a group of people that results in them being consciously or unconsciously categorized – often in a negative way (eg: lazy) – without regard for individual differences.
- *Systemic Discrimination* – the discrimination that happens because of (often seemingly neutral) policies, practices and procedures that have different and often unintended effects on different groups.

Section 2: Culture and Personal Culture

Culture Defined

Culture is defined as a set of shared attitudes, values, goals, beliefs, and practices that characterize an institution, organization, or group. Culture exists in a workplace, the region where you are born, and the family, which you were born. Every group of people may have a unique culture.

The term "culture" refers to the patterns of human behaviour that occur within racial, ethnic, religious, or social groups – including thoughts, communications, actions, customs, beliefs, values, and institutions. Culture is "the way we do things around here" - it is what happens in our homes and in our work or school environments.

We are all programmed by cultural "software" that determines our behaviour and attitudes. Culture affects everything – from how we make decisions to our understanding of the nature and meaning of illness and death.

Although the part of the world we come from influences our culture, it is not the sole factor determining culture. All aspects of our identity, including race, age, gender and ability, help to create our personal culture.

The Iceberg Concept of Culture

Like an iceberg, nine-tenths of culture is out of our conscious awareness. This "hidden" part of culture has been called "deep culture".

Culture – Everything About Me

The Way I Live

- Customs, habits, traditions, food and its meaning
- Music, clothing
- Religious practices
- Children rearing
- Family structures and relationships

The Way I View Things

- Beliefs
- Spirituality
- Health beliefs
- Perceptions
- Attitudes
- Values

The Way I Communicate

- Meaning of language
- Interaction patterns
- Communications
- Verbal and non-verbal

Ethnocentrism

Ethnocentrism is the belief that one's own ethnics group or culture is superior: it is the tendency to measure and judge all other groups or cultures in relation to one's own.

Ethnocentrism may be overt or subtle. Although ethnocentrism is a natural tendency in human nature, it had developed a negative connotation – largely because it is used to justify discrimination against others.

See Video: Ethnocentrism in Sociology: Definition and Examples*
Use the space below to record notes.

Cultural Sensitivity

Cultural sensitivity is an understanding of another group's culture and a familiarity with the group's cultural characteristics, history, values, belief systems and behaviour (Adapted from Adams, 1995).

It is the quality of being accepting of other cultures. People who are culturally sensitive are aware that there could be differences between their culture and another person's culture, and that these differences could affect their relationship and the way they communicate with each other.

Checklist Approach

Cultural sensitivity can be a kind of "checklist" approach to understanding cultural differences. While being aware of cultural differences (and similarities) can be a useful starting point, it can also have negative consequences because it tends to be "other focused". Some of these consequences include judgement, stereotyping, and ethnocentrism.

A person who is approaching a situation from a cultural sensitivity perspective may believe one or more of the following myths:

1. *Everyone who looks and sounds the same is the same.*
   Making conclusions only based on cultural patterns can cause people to become desensitized to differences within a given culture. (Garcia Coll et al., 1995; Greenfield, 1994; Harkness, 1992; Long & Nelson, 1999; Ogbu, 1994)

2. *Any problem or differences between people can be solved by learning more about the other person or group.*
   This assumption may not take into account the complex interplay of power dynamics in relationships and how multi-layered culture and identity really are. Many factors – such as age, gender, who you are within the community, income level, sexual orientation and caste by birth – can affect how people identify themselves within their culture.

3. *This is what they do in the THAT culture.*
   Making assumptions that a person is behaving in a certain way because of their culture can lead XXX

See Video: Examples of Judgement and Ethnocentrism*

Use the space below to record notes.

Cultural Competence/Cultural Humility

Cultural competence is the ability to understand, respect, and work effectively with persons/groups with difference cultural backgrounds including age, gender, and sexual orientation.

It is the knowledge, interpersonal skills and behaviours that enable a person or program to work effectively in cross-cultural situations by understanding, appreciating and respecting differences and similarities in beliefs, values, and practices within and between cultures.

People who are culturally sensitive have enough awareness of cultural issues, power, and privilege to be sensitive and open, to learn and to function well (i.e. maintain good volunteer skills).

Cultural competency may not mean that a person has an exhaustive knowledge of any give culture, but it does imply that the person is mentally, emotionally and spiritually open to differences and is able to work effectively in a cross-cultural situation.

Culturally Competent Practice Principles

Hospice palliative care encourages and supports the following principles of cultural competency:

- Understanding how culture and power affect our lives
- Acknowledging that we live in a society where people are treated inequitably
- Recognizing that this inequitable treatment put individuals and groups in different positions
- Accepting that every person has an equal right to quality care and services
- Recognizing that organizational principles and practices are necessary to support and ensure equitable treatment of staff, volunteers, and clients.

See Video: Miniature Earth*

Use the space below to record notes.

Cultural Sensitivity

Aspects of Culture	Stereotypical “Western” Culture	“Non-Western” Culture
Sense of self and space	Informal Handshake May hide weaknesses and present strengths Gives and expects compliments	Formal Hugs, bows, handshakes May not hide weaknesses May deny compliments and appear uncomfortable
Communication and language	Explicit, direct communication Emphasis on content – meaning found in words Uncomfortable with silence Eye contact is a sign of trustworthiness and attention Provides as much information as available Courtesy words are important in speech Saying “yes” usually means agreement to proceed	Implicit, indirect communication Emphasis on context – meaning found around words Long silences are common Sustained eye contact may be seen as disrespectful May answer questions without elaborating or explaining Courtesy words may be omitted Saying ”yes” may not always mean agreement as “no” may not be a respectful option
Dress and appearance	“Dress for success” ideal Wide range in accepted dress	Dress seen as a sign of position, wealth, prestige Religious rules govern dress
Food and eating habits	Eating as a necessary – widespread use of fast food	Dining as a social experience Religious rules guide food choices
Time and time consciousness	Linear and exact time consciousness Promptness is valued – time = money	Elastic and relative time consciousness Time spent enjoying relationships is valued
Relationships, family, friends	Focus on nuclear family Focus on responsibility for self Youth is valued, age is seen as handicap	Focus on extended family Focus on loyalty and responsibility to family Age is given status and respect
Values and norms	Individual orientation Independence Preference for direct confrontation in case of conflict	Group orientation Conformity Preference for harmony

Cultural Sensitivity

Aspects of Culture	Stereotypical "Western" Culture	"Non-Western" Culture
Beliefs and attitudes	Egalitarian Authority can be challenged Individuals control their destiny Gender equity	Hierarchical Respect for authority and social order Individuals accept their destiny Different roles for men and women
Mental processes and learning style	Linear, logical, sequential Focus on problem-solving	Lateral, holistic, simultaneous Accepting of life's difficulties
Work habits and practices	Emphasis on task Rewards based on individual achievement Work has intrinsic value	Emphasis on relationships Rewards based on seniority, relationships Work is a necessity of life
Conflict	"Fight" or "flight" options equal	Face saving is important so "fight" option may be preferable
Advice	Advice given both unsolicited and when asked for	Advice may only be given when asked for
Emotions	Emotional displays avoided	Emotions more likely to be displayed publicly

Cultural Competence Continuum

Cultural competence builds on the concepts of cultural sensitivity and cultural awareness and refers to the ability of healthcare to apply knowledge and skill appropriately in interactions with clients.

- Cultural Destructiveness
- Cultural Incapacity
- Cultural Blindness
- Cultural Sensitivity
- Cultural Competence
- Cultural Proficiency or Humility

See Video: Cultural Humility*

Use the space below to record notes.

Section 3: Impact of Culture on Volunteer Caregiving

Personal Culture

How do you think your personal culture may affect your volunteer role?

We all have unique cultural perspectives that we bring with us even when visiting clients and, while these perspectives may be right for us, they are not the only ways of seeing and understanding the world

It is important to be aware and mindful of the fact that you may experience things differently than other people; and be open to hear, see, feel and respect the culture of those into whose homes and rooms you have the honour of being invited. Volunteers must remember this when journeying with those who are dying.

Cultural Competence/Cultural Humility

Like the person who is dying, your attitude towards death and dying will depend on your beliefs and practices, your values and experiences. It's important to think about all of these beliefs and values and how they may affect your reaction to the client's or family's way to coping with death and dying and their decision-making processes

Cultural Humility in Hospice Work

The following are examples of why cultural competence and cultural humility is important in hospice work:

- Because we work with all types of people: Ontario's population is very diverse ethnically, economically and in terms of lifestyle.
- Everyone has a right to non-judgemental palliative care support. Clients/families are vulnerable and we don't want to add to their burden.
- If we have strong views, we need to be aware of them and be able to leave them at the door. It's not about us!
- Cultural competence is basic good customer service skills

Actions that Support

- Develop a relationship of trust by interacting with openness, understanding and a willingness o hear difference perspectives.
- Create a welcoming environment that reflects and respects the diverse communities you work with and serve
- Examine your own values, beliefs and assumptions, power and privilege
- Recognize actions that exclude people such as stereotyping, prejudice, discrimination and racism
- Recognize your own cultural biases
- Reframe your thinking to better understand other worldviews
- Become familiar with core cultural elements of diverse communities
  (A cultural competence guide for primary health care professionals in Nova Scotia)

Being Aware

Although it's important for volunteers to recognize and respect differences, it's even more important for them to be aware of their own social identity (i.e. their culture, race, gender, ability).

It's also important for volunteers to acknowledge the privileges and opportunities they have because of who they are, and to recognize how their privileges might affect how clients/families see or perceive them and their ability to connect with the volunteer or their willingness to ask the volunteer for help.

Respect and Acceptance of Others

- Volunteers should be aware how their judgements may affect how they listen to others
- Volunteers must treat others with respect and honour their differences

See Video: Diversity Concepts with Dr. Maura Cullen*

Use the space below to record notes.

Potential Differences

Examples of how volunteers may differ from their clients/families

- How is "proper behaviour" defined?
- How are respect and disrespect shown?
- Who makes what decisions and in what circumstances?
- What should be communicated directly or indirectly?
- What is the hierarchy in relationships?
- How is time understood and used?
- How does one interact with a person in authority?
- What is embarrassing or shameful?
- What, when and how does one eat and drink (eg: offering food as a kind gesture)?
- What is the usual reaction or behaviour to sickness and health?
- What or who is clean or dirty?
- What are the roles of men and women? How should each behave?
- Is privacy desirable or undesirable? When (eg: during personal care/toileting)?
- What language, dialect and tone of voice is used?
- What facial expressions and other non-verbal behaviour and gestures are used? When?

See Video: Don't Assume – ASK!

Use the space below to record notes.

Suggestions for Volunteer/Client Interactions with regards to cultural humility

- "How would you like to be greeted?" (e.g. Is shaking hands or bowing customary?)
- "What do you prefer to be called? How do you like to be addressed?"
- "How shall I say your name?" (In some cultures it is disrespectful to use the person's first name.)
- "What do I need to know about you and your family to provide good support?"
- "We want to give the best care to your mother. Are there things that we should or shouldn't do as we give care?"
- "Who makes the decisions in your family?"
- "Will you accept care from someone of the opposite sex?"
- "What is your understanding of ______?"
- "What would be helpful to you right now?"
- "Show me _____."
- "Tell me more about …"

Summary

As you have learned in this chapter, culture can be unique to a workplace, a family, a geographic unit, a religious faith and an individual. To examine the role that culture can play in end-of-life care, let's explore some examples of specific cultural groups that are traditionally underserved in many settings

Section 4: Underserved Cultures

Introduction

People of all cultures are important and deserve thoughtful, culturally competent hospice palliative care. In this module, we focus particular attention on two specific cultural groups that are traditionally underserved in many settings: Indigenous people and people who are lesbian, gay, bisexual, transgender or queer/questioning (LGBTQ).

Members of both these cultures have experienced systemic discrimination over many years and may be highly distrustful of the health care system, including hospice palliative care.

In this part of the module, we provide some basic information on both Indigenous and LGBTQ culture, highlighting how individuals may share common aspects of culture and still be different in how they express or live their culture.

We strongly encourage volunteers who are asked to support people who are members of these cultures to seek out more information *your hospice can help) and to be aware of and address any biases or stereotypes they have about indigenous or LGBTQ people.

Indigenous Perspectives on Death and Dying

- We understand who we are –
- We know where we came from –
- We are spirit having a human experience –
- We accept and understand our destiny here on Mother Earth
  (Ian Anderson Continuing Education Program in End-of-Life Care)

Indigenous Diversity

Canada's Constitution identifies and recognizes 3 distinct categories of Indigenous Peoples:

1. Inuit
2. Métis
3. First Nations

Indigenous cultures are shaped by their relationship with the earth and the natural world. Indigenous people have a very holistic view of life and see traditional foods as "medicine". Their culture perspective can affect medical decisions.

See Video1: Indigenous Culture – Relationship with Mother Earth*
Use the space below to record notes.

See Video 2: Indigenous Culture – Traditional Foods are Medicine*
Use the space below to record notes.

See Video 3: Indigenous Culture – Culture Affects Medical Decisions*

Use the space below to record notes.

When Providing Support for Indigenous Clients and Families

- Be aware of the influences of culture
- In 2006, about 242,495 Indigenous people lived in Ontario; in 2011 about 1.4 million Indigenous people lived in Canada. Most First Nations people in Ontario – about 70% - live off - reserve.
- Geographically, Indigenous groups are diverse. There are more than 600 First Nations/Indian bands in Canada and over 60 Indigenous languages reported by First Nations people (StatsCan). Different Indigenous bands live in each part of the country.
- For example, Waterloo Region is currently on the traditional land of the Neutrals, Anishinaabe and Haudenosaunee. Thunder Bay in the Turtle Islands is considered Anishinabek territory.
- There is no single “native” culture in Canada. Indigenous people in Canada have diverse cultural and spiritual beliefs systems and traditions.
- Take care not to generalize about Indigenous culture; just as 2 Canadians of European descent may have little in common, 2 Indigenous people may have little in common.
- Remember that “tradition” is not easily measured. Don’t assume a person is traditional because he/she is Indigenous.
- Many traditional Indigenous attitudes and beliefs differ from the viewpoints of other Canadians
- It is important to understand that beliefs about end-of0life vary and are diverse within Indigenous communities
- Don’t assume a Christian Indigenous person will have the same attitudes towards death and dying that a Christian Euro-Western person would
- The process of end of life is uniquely individual, while being informed by cultural and family beliefs and practices
- Family, community and respectful interpersonal relationships are important to many Indigenous people. In some Indigenous cultures, it is common to involve family and community members in decision making around end-of-life issues (Kelly, L., Mintz, A., 2007). In others, autonomy is highly valued and respected.
- In these cultures, all people are entitled to make their own decisions. When outsiders try to advise, persuade or instruct, their actions can be seen as infringing on the client’s autonomy.

See Video 4: Inter-relationship Between the Physical and Spiritual World*

Use the space below to record notes.

Influence of Indigenous Culture at End-of-Life

Indigenous culture plays a huge role in dying rituals and in beliefs about what happens after the dying process.

At the end of life, a traditional Indigenous person may ask for the ceremonies, medicine and prayers that will guide their spirit back to the spirit world.

A spiritual leader or medicine person close to the dying person will conduct the ceremonies.

Family and clan members – including aunts, uncles, “adopted” family members, community members – may be present.

“Medicine” in this context means spiritual power: a combination of ability and authority held by an elder or healer. It is linked to an ability to do ceremony and provide guidance and healing.

For many indigenous people, a “good death” is one where they meet death with dignity and composure.

LGBTQ

Culture is a set of shared attitudes, values, goals, beliefs and practices that characterize an institution, organization or group. LGBTQ culture is sometimes not thought of as a culture unto itself. Like all people, members of the LGBTQ community have their own beliefs, values and social norms.

LGBTQ individuals may experience aspects of their LGBTQ culture, as well as the values, beliefs and social norms that they learned as a part of the culture in which they were raised or live – including, in some cases, internalized homophobia and heterosexism.

History of LGBTQ in Canada

1969	Consensual sex between same sex adults was removed from the Criminal Code of Canada.
1973	Homosexuality is no longer classified as a mental illness. There is no longer criminal prosecution for being gay
1974	Gays and lesbians permitted to immigrate to Canada
1996	Sexual orientation added to the Canadian Human Rights Code
2003	Ontario legalizes same sex marriage
2012	Toby’s Law added gender identity expression to Ontario Human Rights Code
2016	Introduction of Bill C-16. Proposed legislation would update the Canadian Human Rights Act and the Criminal Code to include the terms “gender identity” and “gender expression”

LGBTQ Definitions

- Gender Identity: does not always correspond to biological sex. It is a person's self image or belief about being male or female.
- Intersex: a term used to replace "hermaphrodite". Someone who is intersex possesses some blend of male and female physical sex characteristics
- Queer (and Questioning): Traditionally, "queer" was a derogatory and offensive term for members of the LGBTQ community; however, many LGBTQ people have reclaimed this word and use it proudly to describe their identity. Some transsexual and transgender people identify as queer, others do not. When volunteering with LGBTQ individuals:
    - Use the same words that clients use to describe themselves, their relationships and their identity.
    - Use gender-neutral language (eg: partner, significant other).
- Sexual Orientation: is how someone thinks of oneself in terms of one's emotional, romantic or sexual attraction for another person:
    - Gay: men interested in men
    - Lesbian: female interested in female
    - Bisexual: interested in both male/female
- Transsexual: is a person who has an intense lifelong conviction of being the opposite sex to his or her birth-assigned sex. A female-to-male transsexual is someone who has assigned female at birth but feels like a male and identifies as a (transsexual) boy/man
- Transgender: an umbrella term for a person whose gender identity does not match society's expectations of someone wit their physical sex characteristics or its gender norms or masculine and feminine. The term often includes transsexuals, transgender, cross dressers, and two-spirit and intersex people.

See Video: Generation Silent*
Use the space below to record notes.

Challenges for Aging LGBTQ Seniors

Think back to the history of the LGBTQ culture. Many of our clients will be seniors who grew up during the decades where being LGBTQ was stigmatized.

Recently, being LGBTQ has become more accepted in Canadian culture, but barriers still exists – especially for clients who may need to go into long0term care facilities where they will live with other seniors who may still not be comfortable with LGBTQ individuals.

Clients may face different challenges at end of life depending on their sexual orientation or gender identity. For example, family members who do not agree with their lifestyle may not visit or support them.

Volunteers supporting LGBTQ individuals need to treat them with the same respect and non-judgmental attitudes as they would treat anyone else.

Chapter 13:
Infection Prevention and Control

Objectives

- Identify the parts of the chain of infection
- Recognize ways of breaking the chain of infection
- Recognize the role of the volunteer in preventing the spread of infection
- Identify 2 types of hand hygiene
- Identify Personal Protective Equipment (PPE)
- Identify the basics of general cleaning and food safety

Sections in this Chapter

1. Chain of Infection
2. Breaking the Chain of Infection
3. Hand Hygiene
4. Routine Practices
5. Transmission of Respiratory Infection
6. Other Infection Control Measures

Section 1: Chain of Infection

Everyone Has a Role in Infection Prevention and Control (IPAC)

Often, we think of preventing infection as the role of health care providers. We expect that healthcare providers will always approach their clients with clean hands and always use clean equipment.

However, without the support of everyone else who comes in contact with the client, including the volunteer, it is very difficult to prevent the spread of germs and infections.

Preventing infections is a key part of the safe care. Infections can be serious and may even lead to death. Some people are more likely to get infections. There are many factors that increase the risk of a person getting an infection. Being older or very young, having an underlying illness and crowded living conditions are some of these factors. Antibiotic resistance, new infectious organisms, and complex treatments are also factors

All of these factors have heightened the need to identify, prevent, control and treat infections in a coordinated fashion in order to improve client and community safety and to decrease health care costs.

A coordinated approach to prevent infections involves everyone, from those individuals who work to ensure that the environments where healthcare is provided are clean and safe, to those that provide care.
When we all come together in a coordinated and timely fashion, we can identify, prevent and control infection to improve client and community safety.

The 6 Links in the Chain of Infection

1. Infectious Agent

The first link in the chain of infection is the “infectious agent” or germ. Germs are always around us in the air, soil, water, on our skin etc. Germs are everywhere! Germs may be:

- Bacteria such as MRSA, Shingella, VRE, C. difficile, Salmonella, Group A Streptococcus
- Viruses such as influenza, Hep. B, HIV, Ebola
- Parasites such as Giardia, Malaria, Lice
- Fungi such as Candida, Aspergillus

Not all germs are harmful. Some bacteria are necessary to digest food or compose organic material and to return nutrients to the soil to support the growth of plants and trees
Germs that cause illness and disease are often referred to as pathogens

2. Reservoir

The second link in the chain of infection is the “reservoir” or hiding place. This is where the germs live and grow. Humans can be a hiding place for germs. Not everyone will have symptoms of infection. You cannot tell by looking at someone whether or not they are infected or are carriers of infectious germs. It is necessary to consider all body fluids from all individuals as contaminated or potential sources of infections. Objects can also be reservoirs for germs such as:

- Pooling water around taps and sinks
- Doorknobs
- Light switches
- Food

Think about all the objects we touch in a day! You cannot always tell by looking at objects if they are contaminated with germs that may cause infection. In fact, objects may look clean and still have many germs on their surfaces that are transferred to our hands when we touch them.

3. Portal of Exit

The third link in the chain of infection is the "portal of exit" or the way out. Germs can exit the human body in the following ways:

- The respiratory tract – when we cough or sneeze, the germs we may have in our nose, mouth or respiratory tract leave our body and enter into the environment around us
- The genital and urinary tracts – the fluids that exit our bodies during sex or when we use the washroom.
- The intestinal tract – the germs that leave our bodies when we use the toilet or vomit
- Our skin and the mucous membranes of our eyes, nose, or mouth.
- From mother to child via the umbilical cord
- Blood and all other body fluids are ways that germs can leave our bodies and enter the environment

4. Mode of Transmission

The fourth link in the chain of infection is "mode of transmission" or how germs move. The most common way germs move is through *direct* and *indirect* contact. For example, the hands of the volunteer by direct contact with clients or indirect contact with their environment or equipment.

Volunteers might:

- Transfer bacteria to the next person they meet/touch if they have not cleaned and disinfected their hands between clients.
- Transmit a germ causing infection to themselves when they touch their eyes, mouth or nose with contaminated hands.

There are many modes of transmission, including:

- Droplets – coughs and sneezes. Droplet transmission occurs when large respiratory droplets created by coughing or sneezing travel through the air and land in the eyes, nose or mouth of another person. They can also land on a surface. When we touch these surfaces, the germs can travel to our hands, our faces or the next person we touch. Influenza is a good example of a disease that is transmitted by these large droplets
- Airborne – In airborne transmission, smaller particles, such as those produced by a person with TB generated by coughing and sneezing are suspended in air. Anyone breathing that air may be at risk for that infection
- Vector – Some infections can be transmitted by insects. Mosquitoes can spread West Nile virus and ticks can spread Lyme Disease.
- Vehicle of Transmission – This occurs when items such as food, water or other substances (eg: medication), and medical equipment are contaminated and multiple people are exposed to the item. Both drinking and recreation water may be vehicles of transmission. In hospitals, residential hospices and even in the home, dirty cleaning cloths and shared equipment are common vehicles.

5. Portal of Entry

The fifth link in the chain of infection is the "portal of entry" or the way in. Human portals of entry include:

- Skin that is not intact including cuts, rashes, and open wounds
- Mucous membranes of our eyes, nose, and mouth
- Respiratory tract
- Intestinal tract
- Genital and Urinary Tracts

6. Susceptible Host

The sixth link in the chain of infection is the "susceptible host". This can be any one of us at some point in time. Some people are more vulnerable than others to becoming infected after being in contact with germs. Infants are vulnerable because their immune systems are still developing and building a defense to protect them. Elderly persons are more vulnerable because people's immune systems weaken with age. Individuals with chronic conditions such as diabetes and those undergoing chemotherapy or radiation are also more vulnerable to developing an infection.

Examples of things that can make our immune system unable to fight off a germ include:

- Chronic illness
- Stress
- Weakened immune system related to age
- Lack of immunity related to new infections like H1N1
- Chemotherapy and radiation

Summary

Infection prevention and control competency is a key component of providing safe quality care in any setting.

A coordinated approach to prevent infections involves everyone, from those individuals who work to ensure that the environments where hospice care is provided are clean and safe, to those that provide care.

The first step in preventing infection is to understand the chain of infection.

Section 2: Breaking the Chain of Infection

As mentioned earlier, there are six links in the chain of infection. We can stop the spread of infection by breaking one of the links in the chain.

Infectious Agent

To break this link in the chain of infection, it is necessary to remove or destroy germs. Here are some examples of how to break this link:

- When a hospital or a residential hospice environmental service staff or janitor cleans a surface with soap and plenty of elbow grease, germs are removed from the surface. Cleaning is then followed by disinfecting to kill or destroy germs on the surface.
- Safe food handling practices that include storing food at the correct temperature and cooking food to specific temperatures destroy the germs. Washing hands often and at the correct times while preparing food removes germs from your hands.
- Water treatment is a complex process that destroys germs in water making it safe to drink

Reservoir

There are many reservoirs or places germs can hide. Humans can be hiding places for germs. To prevent becoming a hiding place or reservoir for germs, avoid infection by being vaccinated, and washing your hands frequently.

When people are ill, they are a reservoir for the germ causing their illness. We all have a responsibility to stay at home and avoid others when we are ill.

Keeping environments clean and free of clutter helps to eliminate places in the environment where germs can hide. Even cleaning tools can become hiding places for germs when they are not cleaned and stored correctly.

For example, a kitchen rag becomes a great hiding place for germs to hide and grown and when it is used to wipe off a table top or counter, it can spread germs instead. Following safe food handling practices and protecting water sources are important to prevent germs from living and growing in these resources that we all need.

Portal of Exit

Covering wounds and practicing cough etiquette are ways to prevent germs from leaving our bodies, contaminating our environments and infecting others. These actions prevent germs from entering the environment or coming into contact with other, essentially breaking this link in the change of infection.

Mode of Transmission

The ways that germs move can be prevented.

Direct and Indirect Contact: Your hand can offer comfort and healing. They can also be the way germs move. Contact is the most common mode of transmission in healthcare settings. The hands of healthcare providers, support staff, volunteer, clients, and visitors have contact with many objects, surfaces and individuals in a day. Cleaning your hands correctly with alcohol-based hand rub and washing your hands with soap and water when they are visibly dirty, reduces the transmission of infection. The medical term must ensure that medical equipment is properly cleaned and disinfected or sterilized, and that environments are clean. This also reduces transmission by direct and indirect contact.

Droplets: Do it into your sleeve! When you cough into your sleeve or a tissue you are preventing the droplets from travelling one or two meters through the air and landing on others or objects. Once the droplets are on others and objects in the environment, they are one link closer to finding a portal of entry to the next susceptible host.

Airborne: You may come into contact with clients who have an infection that is airborne. You will be shown about the use of a mask or other personal protective equipment (PE) if it is necessary for your protection. Your hospice will be sure that you are not placed in a situation where it is unsafe for you.

Vehicles: To prevent equipment from being a vehicle for germs, it must be either cleaned, cleaned and disinfected, or cleaned and sterilized. The medical team will be responsible for keeping medical equipment clean and sterilized. Family members and visitors must be careful not to expose the client to infections that they may be carrying by not sharing towels, sheets, cloths, dishes etc. when they have an infection. Volunteers must not visit a client when they have an infection that could be contagious.

Portal of Entry:

There are many ways to stop germs from entering our bodies. When we eat food and drink water that we know is safe or when we wear the correct personal protective equipment (PPE) we are preventing germs from entering our bodies. You may see the medical team use a wide variety of PPE in a hospital setting. In a hospice or in the home, the ones volunteers will see and potentially use are gloves and masks.

Susceptible Host

Staying healthy by eating well and flowing a healthy lifestyle, and keeping chronic illness under control help our bodies be ready to fight germs that may make us ill. Choosing to get the flu shot and other immunizations help to protect you and prevent you from becoming ill. However, in healthcare, we are also concerned about the clients we care for who may be vulnerable and more likely to become ill. Prevent illness and staying at home when you are ill are ways to protect others who may not be able to fight the germs and recover from illness quickly.

Summary

Although all 6 links are needed for an infection to occur, you need to break only one to prevent it. We should all play a role in breaking the chain of infection.

Section 3: Hand Hygiene

When to Perform Hand Hygiene

Before

- Eating or preparing food, or assisting someone to eat
- Changing activities such as when you stop working to take coffee or smoke break
- Touching your eyes or other mucous membranes
- Putting on disposable glove

After

- Using the washroom
- Touching a pet
- Contact with body fluids or contaminated items such as used tissues
- After blowing your nose, sneezing or coughing into your hands, even used a tissue
- Handling garbage and other waste when hands are soiled
- Removing disposable gloves

Soap and Water vs. Alcohol-based Hand Sanitizer

When to use soap and water

- Hands are visibly dirty, visibly soiled with blood or other bodily fluids
- After using the rest room
- You care for someone with an undiagnosed case of diarrhea

The technique for hand washing with soap and water is as follows:

- Wet hands with water
- Apply enough soap. Soap should cover all surfaces. Some manufacturers recommend a specific amount of soap
- Rub hands together vigorously covering all surfaces of the hands and fingers for 15 seconds
- Rub palms
    - Palm to palm
    - Palm to back of each hand
- Rub Fingers
    - Rub thumbs
    - Interlace fingers to clean between fingers
    - Knuckles to palm
    - Rub finger tips in palm to clean under nails
- Using a rotational motion vigorously wash the back of hands and palms
- Rinse hands under running water and dry thoroughly with a disposable towel
- Use the towel to turn off the faucet

The entire procedure takes about 40-60 seconds.
If soap and water aren’t available, use alcohol-based hand sanitizer and wash your hands with soap and water as soon as you are able. It is also acceptable to use a disposable skin wipe to remove dirt and then use alcohol-based hand sanitizer.

When to use Alcohol-based Hand Sanitizer

- Alcohol-based hand sanitizer is the preferred method of hand hygiene in health care as it is more effective, less irritating to skin and take less time to use than washing hands with soap and water.
- Use alcohol-based hand sanitizer in the following situations if hands are not visibly soiled:
  - After glove removal
  - Before and after touching the client
  - After contact with objects in the client's environment
  - Before handling an invasive device for patient care whether gloves are used or not
- If alcohol-based hand sanitizer is not available, wash hands with soap and water

To clean your hands with alcohol-based hand sanitizer:

- Hands should be dry and not be visibly soiled
- Apply enough product to palm of hand
- Rub hands together, covering all surfaces of hands and fingers
- Rub palms:
  - Palm to palm
  - Palm to back of each hand
- Rub Fingers:
  - Rub thumbs
  - Interlace fingers to clean between fingers
  - Knuckles to palm
  - Rub finger tips in palms to clean under nails
- Rub until hands are dry, about 15-20 seconds

Hand and Skin Care

Appropriate hand hygiene includes caring for hands and skin. Prevention of skin breakdown will minimize the spread of infection. Here are some guidelines for hand and skin care:

- Avoid using hot water
- Look for hand lotions that are scent free with water as the first ingredient on the ingredients list
- After hand washing or hand rubbing, let your hands dry completely before putting on gloves
- Take care of your hands
  - Hand lotions and creams should be used at least daily to reduce irritant contact dermatitis
  - Use a protective hand cream or lotion
- Volunteers prone to allergies or adverse reactions should use alternative products.

Nail Care

Appropriate hand hygiene includes cleaning and trimming fingernails, which may harbor dirt and germs and can contribute to the spread of infections. Here are some guidelines for nail care

- Keep natural nails clean and short (not showing beyond the end of the finger tip)
- Anyone providing care to other should not wear artificial nails, extenders or enhancements

Summary

As you proceed with providing care in your community, remember that good hand hygiene practices save lives.

Section 4: Routine Practices

Routine practices are measures that are used at all times in the care of all clients to prevent and control transmission of infections in all care settings.

Routine practices are based on the premise that all bodily fluids, mucus membranes may contain pathogens.

Routine practices are based on the assumption that ALL blood, bodily fluids (except sweat and tears), feces, urine, vomit, respiratory secretion, undiagnosed rashes and non-intact skin may be potentially infectious, even when a person has no symptoms.

Routine Practice Activities

Activities that should be done routinely with all clients to prevent and control the spread of infection include:

- Practicing hand hygiene
- Using gloves and other Personal Protective Equipment
- Cleaning and disinfecting surfaces, equipment, and furniture properly and on a routine basis
- Handling linens and waste properly
- Handling needles and sharps properly. The medical team and family are responsible for this. Volunteers are not to handle sharps and/or needles at any time.

Goals of Routine Practices

The goal of routine practice is to prevent the spread of infections from:

- Client to client
- Client to volunteer
- Volunteer to client
- Volunteer to volunteer
- Volunteer to family and community

Elements of Routine Practices

There are five key categories that outline what practical steps we can take to prevent and control the spread of infection. These categories are:

- Environmental controls
- Administrative Controls
- Point of Care Risk Assessment (PCRA)
- Hand Hygiene
- Personal Protective Equipment (PPE)

Environmental Controls

These measures are used to reduce the risk of transmission of infections to clients, health care workers, volunteers or visitors. Most are not the responsibility of the volunteer. They include:

- Appropriate placement and bed spacing for clients/residents. Accommodate clients in a way that minimizes the risk of infection. Client transport must be done safely to minimize transmission to others
- Cleaning of equipment and the environment must be done according to the facility guidelines. Ensure that equipment that is being used by more than one client/resident I properly cleaned between uses. Soiled linen must be handled carefully, in the same way for all clients. Wear appropriate PPE; ensure that the laundry is free of sharps. After handling the linen, perform hand hygiene
- Waste management – waste should be disposed of according to facility policies
- Sharps – sharps are to be disposed of in designated sharps containers. Be sure to use and replace sharps containers according to manufacturer's instructions. Sharps containers should be placed at or near the point-of-use to permit safe one-handed disposal. Sharps containers must be rigid, puncture resistant, closable and leak proof. They should also be resistant to impact rupture and corrosion. Do not recap, bend or break needles. Prevent injury by using safety-engineered needles. Manage exposures to sharps injuries according to the facility guidelines. Volunteers are not to handle sharps and/or needles at any time. Manage blood and body fluids according to protocol

Administrative Controls

These include activities such as education about infection control, immunization programs for staff/volunteers and clients, policies and procedures, respiratory etiquette for staff/volunteers and clients, and other related activities.

Point of Care Risk Assessment (PCRA)

The key to implementing routine practices is the assessment of risk before each client interaction, taking into consideration client circumstances and tasks to be performed to determine which measures are required to prevent exposure. The PCRA should be continuous and based on changes in clients, environment, and tasks.

In institutional settings, PCRA is often the responsibility of the facility and/or the medical team, however, volunteers may encounter situations where they need to respond appropriately. For example, you enter into a client's bedroom and there is a used tissue on a chair. Before picking it up, you consider the risk and what resources you have available such as gloves. You carefully pick it up and throw it into the garbage then perform hand hygiene.

Hand Hygiene

"Adherence to hand hygiene recommendations is the single most important practice for preventing the transmission of microorganisms in health care, and directly contributes to patient safety"
(Hand hygiene practices in healthcare settings, PHAC, 2012)

Use:

- Soap and water or
- Alcohol-based hand sanitizer (70-90% concentration)

Personal Protective Equipment (PPE)

PPE is an important part of infection prevention. However, an effective approach includes all relevant elements of routine practices such as hand hygiene and administrative measures such as education and scheduling of clients. A focus PPE only may result in the failures to include other very important elements of routine practices. The most effective approach includes many different elements.

Barriers worn to decrease exposure risk and prevent transmission of infectious agents include gloves, eye protection, makes, N95 respirators, and glows/aprons. They should be sufficient and easily accessible

In rare occasions where protective equipment is required in a volunteer placement, volunteers will be given special training on proper procedures for use.

Gloves should:

- Be worn when there is a risk of contact with blood, body fluids, secretions, excretions, non-intact skin, mucous membranes, undiagnosed rash or contaminated surface or objects
- Be worn if you have a cut, open sore, cracks on your fingers
- Not be a substitute for hand hygiene

Remember that:

- Hand hygiene should be performed each time gloves are removed
- Gloves should never be washed
- Gloves should be discarded (into the garbage) immediately after use
- Gloves must fit…like a glove
- Gloves must be changed if the care activity with the client has changed

Always change gloves:

- If torn or heavily soiled
- If the care activity with the client has changed
- After being used on a client – never reuse

Avoid touching:

- Your face or adjusting additional glasses or goggles (PPE) with contaminated gloves
- Surfaces with gloves

Gowns protect health care providers from splashes of blood or other body fluids. Long sleeved gowns protect uncovered skin and clothing.

Gowns should:

- Be appropriate to the situation
- Be worn prior to performing the given task
- Be worn properly, e.g. tied at the top and around the waist
- Be discarded after removal

Masks protect the mucous membranes exposure to splashes of blood, bodily fluids, secretions, and excretions. A health care provider should put on a mask when within two metres of a coughing client. The client should also wear a mask when outside their room if tolerated, to limit spread of infectious respiratory secretions

Remember that:

- Disposable masks should be disposed of immediately after task and must not be reused after the task.
- A mask should be changed if it becomes moist, wet or soiled.
- You should not allow the mask to hang or dangle around your neck.

Steps to putting on a surgical mask:

1. Clean your hands
2. Take mask from box by ear looks
3. The bendable metal edge of the mask is the top – colour side faces out.
4. Place looks around ears
5. Pull corner of mask down so mask bottom covers your mouth and chin. Do not touch the front of the mask
6. Pinch the metal strip of mask so it molds to shape of your nose

To safely remove a surgical mask:

1. Clean your hands
2. Carefully remove the elastics and put the mask in the waste receptacle
3. Clean your hands

N95 Respirators are used when providing care to clients on airborne precautions. They should also be worn for aerosol-generating procedures such as sputum induction. Health care providers must be fit tested prior to wearing the N95 respirators.

Eye Protection is worn together with masks to protect the mucous membranes of the eyes when performing a task that is likely to generate splashes of blood, body fluids, secretion, excretions or chemicals. For example, a janitor who is pouring chemicals should wear eye protection to protect the mucous membranes of the eyes. Eye protection is also used when the individual is within 2 meters of a person coughing. Please note that prescription eye glasses are not suitable for eye protection.

See video by Alberta Health Services*

Use the space below to record notes.

Summary

On occasion, there may be settings where a hospice volunteer is placed, for which there may be additional requirements for special protective equipment including masks, gowns and eye protection.

If this situation arises, your hospice will provide the required information to you directly to be certain of your safety as you provide support.

Remember to apply routine practices at all times when providing care to all clients in all healthcare settings.

Section 5: Transmission of Respiratory Infection

Clients, healthcare providers, volunteers and visitors with coughing, sneezing or other signs and symptoms of respiratory infections could potentially pass on their infections. According to the public health agency of Canada influenza causes approximately 3,500 deaths a year in Canada (2015). Respiratory infections can be spread through droplet transmission, direct contact, and indirect contact with contaminated hand or surfaces. When an adult coughs or sneezes droplets can be generated from the respiratory tract. These droplets can be propelled a distance of up to 2 meters.

Cough Etiquette is Easy

If you do not have a tissue

- Cough or sneeze into your upper sleeve
- Do NOT use your hands

Cough Etiquette is Easy!

Cover your mouth and nose with a tissue when you cough or sneeze.

Put the used tissue in a waste basket.

Perform hand hygiene with soap and water or Alcohol based hand rub.

Section 6: Other Infection Control Measures

Cleaning the Client's Home/ Residential Hospice Room

Although most volunteers will not be involved in cleaning in the client's home or residential hospice room, the follow information may be helpful to understand.

Requirements

- Always clean with a detergent before using disinfectant
- Cleaning requires friction (just like hand washing)
- Equipment should be cleaned and disinfected between each use

  <u>Do</u>
  - Follow manufacturer's instructions
  - Clean on a regular basis
  - Wear gloves when cleaning up blood or body fluids

  <u>Don't</u>
  - Mix chemicals
  - Clean with dirty supplies

Food Safety

Food Safety is an important aspect of infection prevention; several key approaches are outlined below.

Clean Hands and Surfaces

- Wash your hands
- Wash cutting boards, knives, utensils and counter tops with hot soapy water after preparing each food
- For surfaces, after cleaning, wipe with ½ teaspoon of bleach in one litre of water

Food Storage

- Bacteria can spread from raw foods to cooked foods
- If there are juices, store on a plate or on the bottom shelf of the refrigerator
- Store cooked or ready to eat food about raw food
- Store food off the ground

Prevent Cross-Contamination

- Never place cooked food on a plate that help uncooked meat, poultry or seafood
- Use one cutting board for raw meat, poultry or seafood and another for foods that are ready-to-each such as salads, fruits etc.
- Wash cutting boards, knives, utensils between use

Cook Thoroughly

- Use a thermometer to measure the internal temperature of cooked meat and poultry to make sure that it is cooked all the way through
- Cook until juices run clear (no blood)
- Cook ground beef, such as hamburger, thoroughly. If it's grey inside, it's safe.
- See safe cooking temperature chart derived from the Toronto Pubic Health website

Chill – Keep it Cold

- Keep food at cold temperatures ≤ 4°C/40.0°F
- Freezer temperatures should be ≤ 18°C/0.0°F
- Do not overstuff the refrigerator
- Do not defrost food at room temperature. For a quick thaw place in airtight package and put inter cold water or thaw in the microwave if cooking right away
- Separate large amounts of leftovers into small, shallow containers for quicker cooling
- Refrigerate or freeze foods/leftovers within 2 hours of purchase or use
- Marinate foods in the refrigerator

Chapter 14:
Body Mechanics and Assists

Objectives:

- To learn about basic body mechanics
- To understand when it is appropriate and when it is not appropriate to assist a client
- To recognize the possible risks posed when assisting a client
- To practice basic skills for safely assisting clients
- To learn the key elements of back safety
- To learn how to prevent and/or respond to a client fall

Sections in this Chapter:

1. Introduction
2. Body Mechanics - Assisting a Client
3. Wheelchair Safety
4. Falls
5. Body Mechanics - Bending, Reaching, Sitting, Standing
6. Practice Opportunity

Note: In addition to the written content of this chapter, each volunteer must receive an opportunity to practice the skills described.

Section 1: Introduction

Since most volunteers are unsupervised by hospice staff during their visits with clients, volunteer safety is both a hospice and a volunteer responsibility. Hospice volunteers may be called upon to assist with tasks that address the physical needs of clients such as repositioning, sitting up, transferring to a wheelchair or helping the client to the washroom. Your hospice coordinator will assess the physical state of the client and will communicate this to you before you visit the client. Your coordinator will also give you a debrief about the tasks you may have to undertake while visiting the client.

These activities involve risk to both the client and the volunteer. Hospices that follow HPCO standards engage in a robust risk management process and have general liability insurance. Another component of managing risk is learning how to safely assist clients.

The purpose of this chapter is to provide basic education about how to safely assist clients. Although the volunteer scope of practice is determined by hospice policy and the client's care plan, HPCO requires that all direct-service volunteers receive training on how to safely assist clients. This practical training is required so that, if a situation warrants an immediate compassionate response, the volunteer can respond in a way that maximizes their own safety and that of the client.

Even though hospices determine their own policy regarding the volunteer scope of practice, there are some situations where volunteers must never proceed with assisting a client (see below).

- When the client is immobile (the goal is to "assist", not "lift")
- When you feel unsure or uncomfortable with the procedure, especially if some time has passed since your training in body mechanics and practical care

Section 2: Body Mechanics - Assisting a Client

Definition

Body mechanics is the coordinated effort of muscles, bones and nervous system to maintain balance, posture and body alignment during movement (bending and walking). Paying attention to how these systems work will help to prevent injury.

The most common injuries associated with hands-on care are back injuries, particularly the lower back. There are many factors related to these injuries including poor body mechanics and not caring for ourselves as caregivers.

The importance of proper body mechanics when you are assisting someone (or lifting objects) cannot be stressed enough. It is important not to take risks that could result in injury. You must consider your own safety before you attempt to assist a client.

Principles

There are three important principles associated with assisting a client.

1. **Know your body** and how it works with and against the force of gravity. You are the best judge of your body's capabilities. Muscles and bones work together every day to support and create movement. Listen to your body and respect its limitations. Get to know your body by exploring your:
    a. Centre of gravity
    This point is located at the middle of your body, in the pelvic region.
    b. Line of balance
    This is an imaginary line, from head to foot, that divides your body into two equal parts.

    c. Base of support
    This is the space between your feet that bears the weight of your body.

    The more comfortable you are with your own center of gravity, sense of balance and base of support, the easier it will be to assist someone physically and respect your own limitations.

2. **Take your time**. Never rush into assisting someone. Always take a few moments to think about the movement before you start. Look at where you are and where you want to go. Imagine the movements before you proceed. Make sure any obstacles or barriers are moved out of the way. You want a clear path during the move. Your destination should be in clear view.

3. **Obtain permission before assisting the client**. Make sure that the client understands the direction and purpose of the movement. Talk it out step by step. Count in unison to three before the movement begins, so that you both move at the same time.

These principles will be explored further on the following pages.

Assisting a Client

There are two phases to assisting a client outlined below.

Before

Before assisting your client, review the case notes provided by your care coordinator and 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?
- Has the client's status changed since I saw them last? Progressions or fluctuations?
- Does the client have any injuries that may impact their movement?
- Do I have the contact number in case of emergency? Access to cell phone if in remote area?
- Is the chair, wheelchair or walker close by? Are the brakes engaged?
- Is the client able to use his or her own strength to participate in the move?
- Am I wearing appropriate footwear?

As you prepare to assist the client be sure to:

- Maintain neutral alignment of spine
- Keep the person close to your body
- Break the task down into smaller steps
- Determine the direction in which you are transferring the client

During

When assisting the client, you should always:

- <u>Bend your knees, keep your back straight, and lift with your leg muscles</u>. When assisting a client, or moving a heavy object, you can reduce the strain on your back by keeping your line of balance close to your center of gravity. You can do this by bending your knees, keeping your back straight and tucking in your chin. This keeps you from leaning forward or backward which moves your line of balance away from your center of gravity.
- <u>Place your feet shoulder width apart to broaden your base of support</u>. This distributes the extra weight you're bearing and decreases the strain on your back muscles.
- Get close to the person you are assisting. This keeps your center of gravity in your line of balance, and gives you the greatest potential for using muscle power.
- <u>Monitor the client's state and facial expressions</u>. Your client may not be able to verbally express pain. By monitoring the client's state and facial expressions, you can gain insight as to how they are feeling. For example, a grimace may indicate that the client is uncomfortable or in pain.
- <u>Let your arm and leg muscles to do the work.</u> These are nature's mechanical levers, and if you use them you can prevent unnecessary back injuries. When you're using your arms, keep the client close to your body: short levers require the least amount of work. Your strength in assisting a client comes from pushing rather than pulling. Use your legs and arms, not your back, when assisting the client to move.

- Never attempt to assist a client if you think it's unsafe to do so on your own. Two people are almost always better than one. If you know your back is weak or injured, do not attempt to assist. You must think of yourself and your back first.
- Do not twist. Turn with your feet, pivot or step, but never twist your body.
- Always do the least amount of work to complete the move. Ask the client to use their own strength as much as possible.
- Shift don't lift – When repositioning the client, slide or push rather than pull

If the client starts to slip, let them gently down to the floor. Bend your knees, keep your back straight and go with the fall, protecting your client's head as much as possible.

If you injure yourself, seek professional help right away. Don't wait until it is convenient or until the injury is so painful you can no longer function properly. Back injuries need attention. The longer you wait to take care of yourself, the greater the potential for chronic back problems.

After a fall, whether or not an injury (to you or the client) occurred, you must always report it to your hospice supervisor.

Remember: If you do not feel you can safely perform the task, ask for assistance or wait until assistance arrives.

Section 3: Wheelchair Safety

If your client uses a wheelchair, it is important to follow these guidelines:

1. Always move at a slow pace.
2. Always ensure that the client's feet are on the foot rests and their hands are away from the wheels when you are pushing the chair.
3. Whenever possible, the client should be encouraged to propel their own wheel chair. If they are using their feet to propel the chair, the footrests should be removed.
4. Always ensure that the brakes are locked for ALL transfers.
5. Always ensure that the footrests are up and/or swung away during transfers.
6. Always back down a ramp
7. If the ramp is steep, get a second assistant.
8. Always back in and out of an elevator
9. Be aware that, when seated in a wheelchair, many clients are unable to reach the elevator buttons.
10. When climbing a curb, you should step on the tipping bar to lift the front casters onto the curb. Push the chair forward until the large wheel is in contact with the curb, then the chair can be pushed and lifted slightly with minimal effort. If the wheel chair has rear anti-tippers, these must be turned upwards before the wheelchair can go up or down the curb.

Section 4: Falls

Engaging in proper body mechanics when assisting a client will help to prevent falls. However, sometimes a fall cannot be prevented.

What to do if the Client Falls

1. Do not panic
2. Do not attempt to stop a client from falling
3. Protect the head

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

Do not try to help the client up from the floor. This requires assistance.

Inform the family members of what happened and reassure them the client is comfortable. The client may also want to reassure them directly.

Notify the hospice supervisor and complete the required Incident Report.

What to do if you Find the Client on the Floor

Say the client's name and ask about wellbeing – are you OK? Have you hurt yourself?

Do not try to help the client up from the floor. This requires help.

Reassure them and call for assistance. Unless this is a medical emergency, you do not need to call 911. Inform the family members of what happened and reassure them. The client may also want to reassure them directly.

Notify the hospice supervisor and complete the required Incident Report.

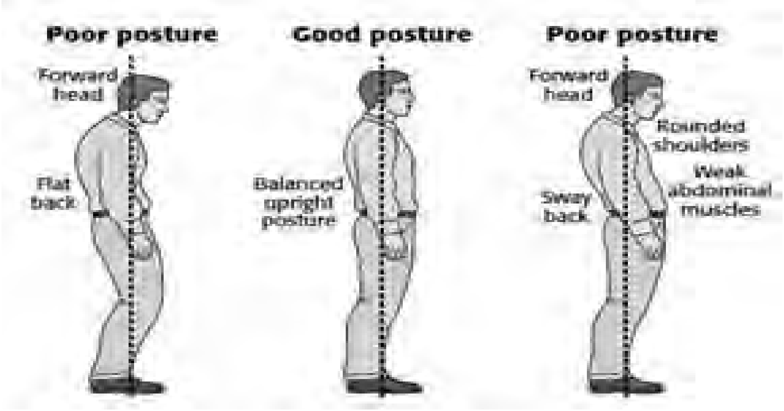
Section 5: Body Mechanics - Bending, Reaching, Sitting, Standing

As a volunteer, you may be asked to engage in various tasks where maintaining good body mechanics is important. For example, you may be asked to move an object in your client's home, complete a task using a computer, etc. The proper body mechanics for various positions and movements are outlined below.

Note: regardless of the task you are performing, you must always maintain the natural curves of your spine to prevent injury.

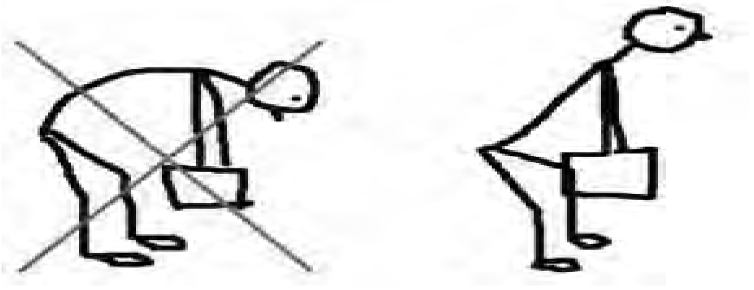
When Standing

- Help balance your spine by placing one foot on a stool.
- Keep your knees slightly bent, pelvis tilted forward.
- Avoid slouching, which can put a strain on your vertebrae.



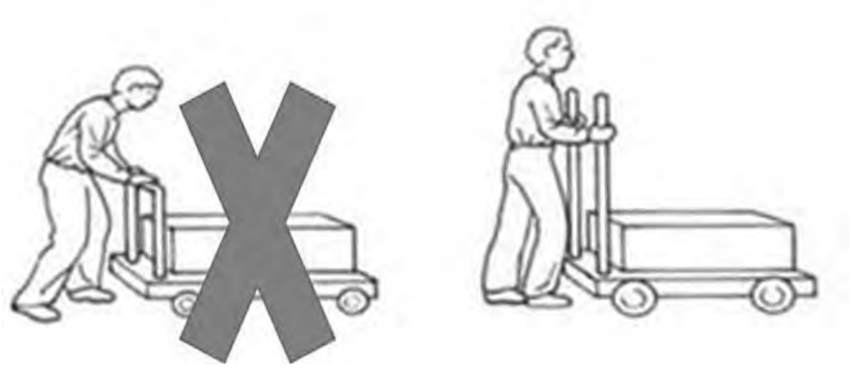
When Bending

- To bend safely, kneel down on one knee.
- Bend your knees and hips, not your back.
- When leaning forward, remember to keep your back straight



Pushing vs. Pulling

- Stay close to the load, don’t lean forward.
- Use both arms.
- You can push twice as much as you can pull, so push rather than pull when possible.



When Sitting

- Sit in a chair that allows both feet to be flat on the floor.
- Keep your monitor at or slightly below eye level.
- Use a lumbar support for your lower back.

When Reaching

- Reach only as high as is comfortable – don't stretch.
- Use a stool/ladder if needed.
- When reaching down, support your upper body with one arm.

Section 6: Practice Opportunity

The hospice will provide an opportunity to practice these techniques in person. During the practice session, please take a turn as the client and as the volunteer so that you can appreciate the sensation of being assisted by another person. The practice session must include, at minimum:

- Turning and/or sitting up in bed
- Repositioning in a chair
- Sitting to standing, standing to sitting
- Getting in and out of a wheelchair (or a commode)

Use the space below to record your notes and observations from the practice session.

Chapter 15:
Orientation to Your Local Hospice

Introduction

This chapter outlines specific information that you need to know about your local hospice. It is possible that some of this information is covered in other chapters. Space is provided in this chapter to take notes at any point in your training program. By the end of your training program, you should be able to answer all the questions below.

Definition

Hospice Volunteers are an integral part of providing Hospice Palliative care services. A community hospice recruits, screens and trains volunteers according to provincial standards. Volunteers are supervised to provide emotional, social and spiritual support to those who are living with a life-threatening or terminal illness and their families.

Hospice volunteers may work in a variety of service areas including, but not limited to:

- Visiting in the client's home
- Residential Hospice care
- Grief and Bereavement support (1:1 support, Groups)
- Day Hospice
- Complementary Therapy
- Spiritual Care
- Children’s Support
- Wellness programs

Getting Started

What is a meaningful assignment in the context of hospice volunteering?

What You Need to Know About Your Local Hospice

To meet provincial standards for screening and training of volunteers, your hospice must ensure that you have all the information you need about the hospice, your scope of practice, your rights, your responsibilities and general information about “how things work”.

To assist with this, we have included excerpts from HPCO’s Visiting Hospice Standards (2014) below. Space is provided below each statement for you to take notes and some questions have been included to guide you in your note taking.

General Hospice Information

The hospice must assign a designated staff member or senior volunteer to be directly responsible for volunteer management and ongoing support/supervision of volunteers.

Name and title of my designated supervisor:

Contact Information:

The hospice volunteer training program should include an overview of your local hospice and its’ programs.

Use the space below to take notes about the general information provided (eg. programs offered, partnerships in the community, history of the hospice, how people access the service etc.)

Administrative Requirements

Position descriptions are in place for all volunteer roles in the hospice.
Have I received a position description?

Volunteers are advised of any administrative requirements they must meet (e.g. how often to submit reports).
What administrate requirements do I need to follow?

All staff and volunteers must receive education on privacy and confidentiality and must sign a confidentiality agreement with the Hospice.
Have I signed a confidentiality agreement?

The hospice will ensure that volunteers understand the extent to which the organization's insurance covers them (if at all) for the activities of their role.
What type of insurance does my local hospice have & to what extent does it cover my volunteer role?

Volunteer Scope of Practice

The hospice must inform volunteers of their role and its limitations, including but not limited to:
(check each item off once it has been addressed in your training)

- ☐ Controlled acts
- ☐ Assistance with medical equipment and assistive devices (e.g. use of hoyer lifts)
- ☐ Provision of transportation to service recipients (who are able to enter/exit the vehicle on their own or with limited assistance)
- ☐ Identification, prevention and reduction of risk
- ☐ Response to emergency situations
- ☐ Response to abuse/harassment
- ☐ Acceptance of gifts/gratuities
- ☐ Communication between hospice and volunteer
- ☐ Reporting of unusual incidents
- ☐ Conflict of interest
- ☐ Response to physical care needs (lifts, transfers, toileting, emptying urine bag)
- ☐ Response to unexpected change in service recipient's condition (including unexpected death of client)

With respect to each of these issues, do I understand my role?

Do I have any questions that I want to address with my supervisor?

Visiting Clients

The hospice evaluates the match between volunteer and client as required or requested by the volunteer and/or the client. The volunteers and clients are informed of this procedure.

What do I do if I am unhappy with the match I have been assigned to?

When offered a match that doesn't seem quite right for me, is it okay to refuse the assignment?

A designated staff or experienced volunteer is available to accompany a volunteer for any visit to a service recipient, where the volunteer feels there is a need.
How do I arrange to have someone accompany me?

The volunteers have access to appropriate support while on duty for the hospice, after regular office hours. This support may be offered from another organization. The volunteer is aware of how to access this support.
How do I access this support?

Ongoing Education and Support

The volunteers have access to regular support regarding their role with the hospice.
What support options are available at my local hospice?

The hospice promotes and provides continuous educational opportunities to the volunteer
What training and education opportunities are available while I am volunteering with hospice?

Volunteers who are not actively assigned to a service recipient continue to receive support and are included in ongoing education opportunities
How does my local hospice stay connected when volunteers aren't actively assigned to a client?

Feedback & Recognition

All volunteers are given regular opportunities to offer and receive feedback.

How will the hospice let me know how I'm doing in my role as a hospice volunteer?

How can I raise issues, concerns and/or provide feedback to the hospice and to whom?

The hospice monitors and evaluates each volunteer's ability to practice in their role.

How does my local hospice monitor and evaluate my performance as a hospice volunteer?

Under what circumstances might a volunteer be terminated?

How does the hospice ensure that all volunteers are treated fairly?

The contribution of volunteers is acknowledged and recognized.

What processes are in place at my local hospice to do this?

Post-Training One-On-One Meeting/Orientation with Supervisor

The hospice is responsible for ensuring that each volunteer is fully prepared for their role. In order to do this, it is recommended that volunteers meet with their supervisor after their orientation. This meeting provides an opportunity to address any questions you may still have and to confirm that all the training topics have been understood.

Date and time of post-training one-on-one meeting/orientation with my supervisor:

____

Conclusion

Congratulations on the completion of HPCO's Hospice Volunteer Training curriculum!

Individuals and families in communities throughout the province benefit from the valuable contribution of volunteers who support quality of life for individuals and their families in a variety of settings.

The 15 topics covered in this training curriculum are a prerequisite for individuals who wish to donate their time as a hospice palliative care volunteer in Ontario. There are additional screening and training processes that are required to become a hospice volunteer. Be sure to communicate with your hospice coordinator to discuss next steps.

Hospice Palliative Care Ontario (HPCO) is a membership association providing leadership and guidance in the field of hospice palliative care. HPCO has been offering volunteer training based on standards of care in Ontario for more than 20 years.

We envision a future where every person and family in the province of Ontario can quickly and easily access the finest standard of hospice palliative care when it is required.

Hospice palliative care volunteers really are the heart of hospice. Your contribution and the support you offer individuals and families when it matters most is an invaluable one.

Welcome to Ontario’s growing hospice palliative care community!