

**Manitoba Palliative Care
Volunteer Education Manual**



ACKNOWLEDGMENTS

Manitoba Provincial Palliative Care Network (Manitoba PPCN) 2011

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The Story of the Butterfly:

“In 1945, at age 19, she left her protected home environment and worked as a cook, a carpenter, a mason, and a relief worker as part of a voluntary mission of the Swiss International Voluntary Service of Peace. She worked in a variety of European countries and recalls frequently an improvised clinic in Poland in a straw covered hut where she and other women provided patients with care and love, even though they had a minimum of medications or other medical resources. It was at this time that she was privileged to see Majdanek, the infamous concentration camp where she first experienced the gas chambers, the drawings of butterflies made by the doomed children on the walls of the barracks, and the trainloads of childrens’ shoes that were left behind. This was the background, the context in which Elisabeth first conceived her life long work with the sick and the dying”.

“Elisabeth Kubler-Ross Introduces HOSPICE” by James Ewens and Patricia Herrinton

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Session 1

Introduction to Palliative Care

Learning Objectives:

- Define palliative care and its basic elements.
- Explore how our past experiences with suffering, dying and death may influence care for people who are dying.
- Describe how palliative care can enhance the quality of living while people are dying and the volunteer role.
- Introduction of team and team work

Session 2

Understanding the dying person and their family

Learning Objectives:

- Examine the process of dying and the effects on the individual and their family from an emotional, spiritual and cultural perspective.
- Differentiate between spirituality and religion.
- Develop awareness of some of the spiritual issues surrounding dying and death.
- Explore ways to provide holistic care to dying persons and their families.

Session 3

COMMUNICATION: LISTENING AND RESPONDING

Learning Objectives:

- Explore the communication needs of the dying person
- Learn ways of communicating more effectively
- Learn suggested tips on how to handle communication issues
- Discuss verbal and non-verbal communication skills
- Increase our awareness of the effects of life threatening illness on families
- Explore the communication needs of the dying person's family

Session 4

THE PHYSICAL NEEDS OF THE DYING PERSON

Learning Objectives:

- The physical changes and needs of the dying person
- Pain and other symptoms that a dying person may experience
- Comfort measures
- The signs of approaching death

Session 5

THE GRIEVING PROCESS

Learning Objectives:

- Explore the various types of loss that people experience.
- Explore the grieving process.
- Examine the factors that influence a person's grief experience
- Become aware of your own grief
- Discuss strategies to assist people through grief

Session 6

COMPLETING THE CIRCLE

Learning Objectives:

- Review the role of the palliative care volunteer
- Identify mechanisms for self care
- Discuss relevant legal issues

SESSION 1

INTRODUCTION TO PALLIATIVE CARE



Session 1: Introduction to Palliative Care

Welcome: Introduce yourself.

Housekeeping:

- Ground rules & confidentiality
- Break times & refreshments
- Location of washrooms
- Course timelines and goals
- Handout course materials
- Name tags

Facilitator Guidelines:

A safe environment is very important in giving the participant the degree of comfort and trust that allows learning and growth. As you know, memories around death can be very personal and emotionally charged. Participants should be reassured at the beginning of the sessions that emotions are part of being human and are acceptable in this environment.

If participants find that something covered in class brings up painful memories, they should not be afraid of tears or strong emotions. Give advance thought to how you will provide a balance of “space” and “support”. Some participants may need personal space that allows for temporary withdrawal from the group. Others, in some situations, may require the opportunity to talk about their feelings in the supportive environment you have created in the group.

Active listening, honesty and respect for the experiences and contributions of participants create an effective learning climate.

Meet, Greet and Break the Ice!

Roundtable self-introductions: *Ask participants to share a little about themselves as they take turns around the group: name, where they are from, hopes and expectations from course*

Ice Breaker: *Ask participants to visualize or write 5 words that they immediately associate with the word “death” or the phrase “terminal illness”. Ask them to share these thoughts and feelings. Exercise can be discussion only or responses can be recorded on flipchart/white board.*

Introduce the volunteer education:

The modules will highlight aspects of palliative care:

- Introduction to palliative care
- Understanding the dying person and their family (emotional, cultural and spiritual)
- Communication (listening and responding)
- Physical Care of the Dying
- Loss, Grief, and Bereavement
- Completing the Circle

Each participant will receive:

- Volunteer education manual
- Regional handouts – volunteer orientation and brochures

The Story of the Butterfly:

“In 1945, at age 19, she left her protected home environment and worked as a cook, a carpenter, a mason, and a relief worker as part of a voluntary mission of the Swiss International Voluntary Service of Peace. She worked in a variety of European countries and recalls frequently an improvised clinic in Poland in a straw covered hut where she and other women provided patients with care and love, even though they had a minimum of medications or other medical resources. It was at this time that she was privileged to see Majdanek, the infamous concentration camp where she first experienced the gas chambers, the drawings of butterflies made by the doomed children on the walls of the barracks, and the trainloads of childrens’ shoes that were left behind. This was the background, the context in which Elisabeth first conceived her lifelong work with the sick and the dying”.

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Goals for taking the volunteer education program:

Ask the participants to write their personal goals (hopes and expectations) for taking the volunteer education program on a piece of paper. We will review these goals during Session 6 and hope that your goals have been met

Session 1 Learning Objectives:

Introduction to the Philosophy of Palliative Care:

- Define palliative care and its basic elements
- Explore how past experiences with suffering, dying and death may influence care people of who are dying.
- Describe how palliative care can enhance the quality of living while people are dying and the volunteer’s role

Handout: Palliative Care Program Brochure and any other regional brochures**Introduction to Reflective Exercise and Reflective Questions:**

Warm-up Exercise

Our care of people with life-threatening illnesses and their families is often influenced by our own history, including our personal and work experiences with dying and death. Death is very personal, and it is critical to be aware of how our experiences and beliefs may influence care.

Lead participants through the following exercise. Before starting, tell participants:

In the following exercise share only what you feel comfortable sharing. You are not obligated to share with the group because many people are not comfortable openly sharing their feelings and experiences. This exercise may bring up feelings of anxiety. Please take this exercise at whatever pace and level of involvement feels right for you.

Exercise Instructions: This is a suggested wording. Speak slowly and calmly to the group:

Get comfortable in your chair with your feet on the floor. Take a deep relaxing breath. Gently close your eyes and continue to breathe deeply for a few breaths. Become aware of your breathing. Breathe slowly.

Now gently take yourself back to a time when you were with someone who was dying. Try to recall as much detail as you can. This may have been a positive or a negative experience. It may have been a patient, a family member, a friend or a member of your community.

- Remember who was there.....(3 second pause)
- What were the expressions on their faces?.....(3 second pause)
- What were you hearing?...(3 second pause)
- What were people saying?.....(3 second pause)
- What were the sounds in the room?....(3 second pause)
- What were you feeling?....(3 second pause)
- What were you thinking?....(3 second pause)
- What did you say?....(3 second pause)
- How did you react?....(3 second pause)
- How do you feel the person who was dying felt?....(3 second pause)
- How do you think others in the room felt?.....(3 second pause)

Explain to Participants: I am going to let you reflect on those questions during a moment of silence.

After the moment of silence: Now, gently-taking your time-let go of the images in your mind and come back to this room.

Ask participants either to turn to the person next to them and to share their experiences with the other person (2 minutes) or if they would prefer do as a large group discussion. Remind them that they are not obligated to share their experiences. Returning back to a large group, ask for volunteers who are willing to share their experiences (6 minutes)

Ask participants as a group: What are some common feelings and responses which emerge from this exercise? List these on the left side of a flip chart or whiteboard.

Then ask participants: What do you think the feelings of the person who was dying might have been? And list them on the right side of the flip chart. Note that these feelings will often be similar.

Key Lessons to Reinforce from the Reflective Exercise

- Dying is a universal experience that at some point we will all go through.
- Positive experiences with dying show us that we can make a great difference in the lives of people who are dying and their families.
- Negative feelings and experiences with dying should remind us that we need to be careful about how we approach our work as volunteers with the dying and learn more about how our experiences influence the care we provide.

The Steps to Self-Awareness

To understand how someone with a life-threatening illness is feeling, it is important to put oneself in the person's shoes. It's also important to distinguish one's own feelings from those of the person. Steps to do this include:

- Become aware of our own feelings
- Imagine what the person's feelings are
- Try putting yourself in his/her shoes
- Accept the feelings-do not try to hide, ignore or avoid them
- Search for patterns in the way that you react to the experiences of these situations
- Try to understand them and learn from them.

Self awareness:

I must acknowledge my wounds
before I can sit with your pain.

I must befriend my losses
before I can sit with your grief.

I must consider my own death
before I can sit with you as you die.

- Dame Cecily Saunders

Relationships

- Relationships can be described as all that goes on between and among people, their feelings, thoughts and actions. It includes not only things we are aware of but also what we are not.
- Old established family relationships are reviewed as death approaches. These relationships may change based on the ability of the patient and family to communicate effectively about past, present and future issues
- It has been said that...

- *“The great acts of love are done by those who are habitually performing small acts of kindness.”*

- The four main components of caregiver/patient relationship are...
 - Trust
 - Respect
 - Intimacy
 - Power

The 5 Things of Relationship Completion

As described by Ira Byock in his book “Dying Well”(2011), the dying person may need to express the following:

I forgive you

Forgive me

Thank you

I love you

Goodbye

Video: Facing the Fears: Making the Journey or another video of your choice

Facilitator preface: when the DVD refers to “Hospice Care”- explain that care is provided in acute & long term care facilities and in people’s homes. There are no hospices in the rural MB.

Discussion following the DVD:

What things did you learn about Palliative Care?

Key Points: Dignity, Communication, Guilt, Choice

What is Palliative Care?

Ask participants what their understanding is.....

Below are two definitions of Palliative Care and Hospice Palliative Care. The World Health organization created a definition of Palliative Care in 2002 that has been used around the world.

WORLD HEALTH ORGANIZATION DEFINITION of PALLIATIVE CARE (2002)

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

**National cancer control programs: policies and managerial guidelines, 2nd ed. Geneva, World Health Organization, 2002*

World Health Organization Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

Palliative care can be provided in tertiary care facilities, in community health centres and even in children's homes

DEFINITION OF HOSPICE PALLIATIVE CARE – Canadian Hospice Palliative Care Association (A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice March 2002)

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

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

Hospice palliative care aims to:

- **treat** all active issues
- **prevent** new issues from occurring
- **promote** opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening 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.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

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

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

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

Hospice palliative care can be provided on its own or, in some cases, with curative care.

For example, a patient may be receiving hospice palliative care for cancer while, at the same time, receiving curative care for a respiratory infection.

The Origins of “Hospice Palliative Care”

Dame Cicely Saunders first conceived of the modern hospice movement in the United Kingdom in the mid 1960’s to care for the dying. Balfour Mount coined the term “palliative care” in 1975 so that one term would be acceptable in both English and French as he brought the movement to Canada.

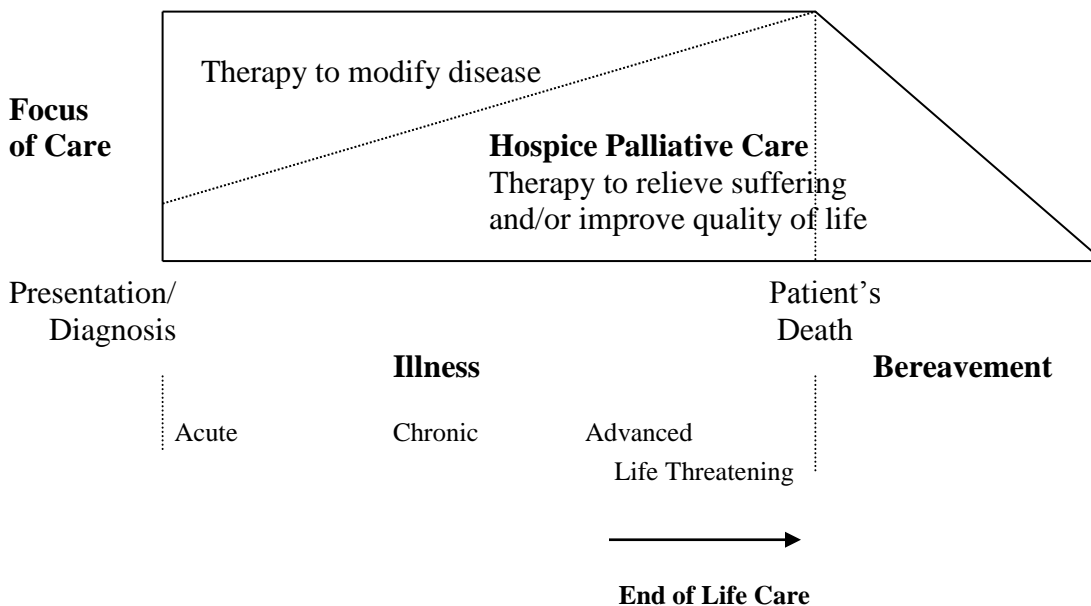
Both hospice and palliative care movements have flourished in Canada, and internationally. Palliative care programs developed primarily within larger healthcare institutions, while hospice care developed within the community as free-standing, primarily volunteer programs. Over time, these programs gradually evolved from individual, grass roots efforts to a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with, or dying from, an illness.

To recognize the convergence of hospice and palliative care into one movement, and their common norms of practice, the term “hospice palliative care” was coined. While hospice palliative care is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life, individual organizations may continue to use “hospice, palliative care”, or another similarly acceptable term to describe their organization and the services they are providing. This region recognizes the term “palliative care”

The Role of Hospice Palliative Care During Illness

While hospice palliative care has grown out of and includes care patients at the end of life, today it should be available to patients and families throughout the illness and bereavement experiences. The following figure illustrates the typical shift in focus of care over time.

Figure 1:



The top line represents the total “quantity” of concurrent therapies. The dashed line distinguishes therapies intended to modify disease from therapies intended to relieve suffering and/or improve quality of life (labeled Hospice Palliative Care). The lines are straight for simplicity. In reality, the total “quantity” of therapy and the mix of concurrent therapies will fluctuate based on the patient’s and family’s issues, their goals for care and treatment priorities. At times, there may not be any therapy in use at all.

Some aspects of hospice palliative care may also be applicable to patients and families at risk of developing an illness.

Hospice Palliative Care:

- is not just for people in the terminal or “end stage” of an illness.
- begins when someone is first diagnosed with a life-threatening illness (when curative treatments are not an option). This may be months and even years before the patient dies.
- In some cases, treatments directed at modifying the illness are very appropriate and may be the focus of care. However, care should always include attempts to improve quality-of-life, ensure comfort and alleviate distress...
- Many individuals and families will not “self-identify” with the language of palliative care. Family members will often say things like “Mom is not palliative yet” or “I am not palliative!” even though they are clearly living with a life-threatening illness.
- With some illnesses the process of decline will not be as clear and straightforward as in many cancer-related deaths. People with illnesses such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and Alzheimer’s disease (and other progressive dementias), will likely experience many “peaks and valleys”, where they appear close to death but then recover. This is a common challenge in providing hospice palliative care and being part of the care team.
- Within hospice palliative care, there are clear phases of decline that the health care team will assess and use to make decisions about care, including:
 - Acute: acute palliative crisis and problems (e.g., pain crisis)
 - Stable: symptoms and problems under control or tolerable, despite disease progression (slow or fast)
 - Terminal: last few weeks and days
 - Last hours: body starts to shut down and prepare for death

According to a study of 126 people with chronic life-threatening illnesses conducted by the University of Toronto’s Joint Centre for Bioethics, there are five domains that are important to people who are dying and their quality of life, including:

- Achieving adequate pain and symptom management
- Avoiding inappropriate prolonging of dying
- Achieving a sense of control
- Relieving burden
- Strengthening relationships with loved ones.

Another US study reported that people identified the following as **important for a “good death”**:

- Pain and symptom management
- Clear decision-making
- Preparation for death
- Completion of life tasks
- Ability to contribute to others
- Affirmation of the whole person.

Both studies highlight the importance of good pain and symptom management. A volunteer has an important role to play as part of the team in communicating about things she/he sees that would be helpful to pain and symptom management.

Both studies also reinforce that people who are dying want to be involved in decision making, be aware of what is happening, and focus on relationship issues. Sometimes people receiving hospice palliative care will communicate things to their volunteer that they will not readily share with their home care nurse, family physician or visiting palliative care physician. It is important for volunteers to be thoughtful about the role they can play to ensure that any issues identified by the person are addressed, either with the person and family or with other members of the care team.

You matter because you are you
And you matter until the last moment of your life
We will do all that we can
Not only to help you die peacefully
But also to live until you die
- Dame Cecily Saunders

Ethics: What is it?

- We have all developed certain values in life
- Some values we share with others
- Some of our values clash
- Ethics is about finding a way forward when values clash
- Sometimes it is not clear what the best way forward might be

4 Ethical Principles:

- Do good (Beneficence)
- Do no harm (Non-Maleficence)
- Choice (Autonomy)
- Justice

In ethical decision-making the “process” is just as important as the “end result”.

“Reflecting on our discussion this session what do you see as the implications for volunteers”?

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?”

JOURNAL/LOG/DIARY WRITING

PURPOSE: To help you to clarify, explore, deal with your experiences, thoughts, feelings as a means of personal growth and to be more understanding of those you wish to be helpful to.

TIPS

Remember you are writing for no one but yourself. You can share some or none of what you write with someone else.

This is not intended to be a factual report of what happened but rather your thoughts, feelings, and experiences in response to what you heard, said and took part in. Keep it personal.

Write in the first person as you write a diary. The following phrases might be useful to you for beginnings of sentences and/or paragraph:

I learned that I.....

I expected that I.....

I like that I.....

I dislike that I....

I felt.....when.....

I am concerned that.....

I thought about.....

I felt.....about.....

I realized that I.....

I discovered I.....

I relearned that I.....

I was surprised that I.....

I was pleased that I.....

I was displeased that I.....

Your journal/diary/log does not have to be perfect. It may even take sometime before you can be honest even with yourself.

Some questions/entries which might be useful “starters”:

How did I feel about the day as a whole? Specific incidents?

What out of all I heard/learned got most reaction from me?

What is living in me tonight that is drawing my attention?

“I’m not sure I should be volunteering for Palliative Care. I might be afraid of dying”.

“My life started when....”

“This phase of my life started when.....”

What did I contribute to this group today?

Am I comfortable in this group?

What helped me today?

Perspectives on Dying – Handout – **Optional**

Personal Questionnaire

1. **My first involvement with dying was with**

a. grandparent or great-grandparent	e. friend or acquaintance
b. parent	f. stranger
c. brother or sister	g. public figure
d. other family member	h. pet

2. **When I was young, the subject of dying was talked about in my family**

a. openly	d. as though it were a taboo subject
b. with some sense of discomfort	e. never recall any discussion
c. only when necessary and then	
with an attempt to exclude me	

3. **My childhood concept of what happens after death is best described as**
- a. heaven and hell
 - b. after-life
 - c. a sleep
 - d. cessation al all physical and mental activity
 - e. mysterious and unknowable
 - f. reincarnation
 - g. something other than the above
 - h. can't remember
4. **Today, my concept of what happens after death is**
- a. heaven and hell
 - b. after-life
 - c. a sleep
 - d. cessation al all physical and mental activity
 - e. mysterious and unknowable
 - f. reincarnation
 - g. something other than the above
 - h. no concept
5. **My present attitudes toward dying have been mostly influenced by**
- a. death of someone close
 - b. specific reading
 - c. religious upbringing
 - d. introspection and mediation
 - e. ritual (e.g. funerals)
 - f. TV, radio or motion pictures
 - g. longevity of my family
 - h. my health and physical condition
6. **The role that religion has played in the development of my attitudes about dying is**
- a. very important
 - b. rather important
 - c. somewhat, but not major
 - d. relatively minor
 - e. nothing at all
7. **I think about dying**
- a. very frequently
 - b. occasionally
 - c. rarely
 - d. never

8. To me, death means
- a. the end; the final process of life
 - b. the beginning of a life after death
 - c. a joining of the spirit with a universal consciousness
 - d. a kind of endless sleep; rest and peace
 - e. termination of this life but with survival of the spirit
 - f. don't know
9. To me, the most disagreeable aspect of my death would be I'd
- a. no longer be able to have experiences
 - b. be afraid of what might happen to my body
 - c. be uncertain of what might happen to me if there is a life after death
 - d. no longer be able to provide for my family
 - e. cause grief to my relatives and friends
 - f. not be able to complete all plans and projects
 - g. die painfully
10. I feel that the cause of the most deaths
- a. results directly from the conscious efforts of the persons who die
 - b. has a strong component of conscious or unconscious participation by the persons who die (in their habit and use, misuse, non-use or abuse of drugs, alcohol, medicine, etc)
 - c. is not discernible; they are caused by events over which individuals have no control
11. I, _____, believe that psychological factors can influence or even cause a person to begin dying.
- a. firmly
 - b. tend to
 - c. do and don't
 - d. don't

- 12. When I think of dying, or when circumstances make me aware of my own mortality, I feel**
- a. fearful**
 - b. discouraged**
 - c. depressed**
 - d. purposeless**
 - e. resolved in relation to life**
 - f. pleasure, in being alive**
 - g. a sense of purpose and meaning**
 - h. other**

SESSION 2

UNDERSTANDING THE DYING PERSON AND THEIR FAMILY



Session 2: Understanding the Dying Person and Their Family

Welcome:

Ask if there are any questions from Session 1

Learning Objectives:

- Examine the process of dying and the effects on the individual and their family from an emotional, spiritual and cultural perspective.
- Differentiate between spirituality and religion
- Develop awareness of some of the spiritual issues surrounding dying and death
- Explore ways to provide holistic care to dying persons and their families

The dying have always been teachers of great lessons, for it's when we are pushed to the edge of life that we see life most clearly. In sharing their lessons, the dying teach us much about the preciousness of life itself.

Kubler-Ross & Kessler, *Life Lessons*

LESSONS of DEATH

Dying and death can teach us things that we know intellectually and emotionally, but sometimes forget to put into practice.

- To value relationships & to say “Thank you”, “I value your friendship”, or “I love you” more often
- To straighten out our priorities & become less materialistic
- To postpone less (seize the moment!)
- The lesson of kindness (those you least expect will show up to help you in your times of need)
- To be more aware of gifts and blessings (be thankful for a blue sky, bright snow, Northern lights, a visit from old friends)
- The importance of risking (asking for forgiveness or saying “I love you” when you have never said it before)
- The value of vulnerability (asking for help when you need it)

EXERCISE - EMOTIONAL REACTIONS

The purpose of this exercise is to highlight that people express their emotions in a variety of ways. Each person is unique, and there are no set rules to determine how someone should exhibit a specific emotion.

Ask participants to get into pairs or small groups of 3 to 5 people.

Ask each group to assign one person to be the recorder.

- Instruct the groups to list different ways people express their feelings for each emotion listed on the handout.
- Tell participants that they will have 5 minutes to come up with as many responses as possible.
- After the time has elapsed, ask each group the number of responses they recorded.
- Get groups to spontaneously call out answers. Record responses on a flip chart.

Emotion Possible responses:

Sadness	Withdraw	Pace	Act jittery	Cry	Become agitated	
Pain	Complain	Cry	Moan	Become hysterical	Grin and bear it	
Fear	Become agitated	Laugh	Cry	Joke	Fidget	Hide
	Become hysterical	Faint				
Joy	Jump and dance	Smile	Cry	Hug	Laugh	Joke
Nervous	Bite finger nails	Talk a lot	Fidget	Break out in a rash		
	Mumble	Become excited				

Shock	Become forgetful	Slow down	Stare into space	
Anger	Scream	Argue with others	Become aggressive	Stutter
	Refuse to talk	Raise voice	Become hysterical	

End the exercise by reinforcing that:

- There are a variety of ways to express one's emotions
- How a person shows feelings depends on his personality, cultural background and past experiences
- Emotional reactions to illness and death and dying will be discussed further in this workshop.
- People will react as they usually react

Understanding the dying person's experience

Death is the ultimate experience of loss. The knowledge of impending death requires a total adjustment in personal goals, feelings and relationships with others.

People confronting a life-threatening illness experience many changes and limits.

Serious illness may change their physical body which in turn reduces their capabilities and independence. Plans for the future are relinquished, and many goals and ambitions have to be discarded. Being "different" from others can be isolating and often leads to feelings of fear, despair and depression.

Quality care for the dying person addresses emotional, physical, psychological, social and spiritual needs. Although these needs vary with the individual, research (VanBommel, 1989) suggests that people who are dying have similar desires:

1. To be pain free
2. To be alert and aware of what is happening to them
3. To have the companionship of their family and friends
4. To be accepted as the person they have always been
5. To maintain their individuality
6. Not to die alone

7. Not to be a burden on their family
8. To have familiar things around them: photos, plants, music, flowers, favorite food
9. To be cared for and remembered with love and respect
10. To have their family continue living and loving after their death

Although generalizations can be made about the process of dying, it is inappropriate to assume that every person will face death in the same way.

People are unique and their life and death experience is just as distinct.

What are some of the fears of the dying person?

THE SEVEN FEARS OF DYING

1. **Fear of the Process of Dying:** People are concerned as to whether death will be painful and whether they will be anxious and frightened. They are concerned about their body image. This is especially true of the cancer patient who has lost weight and who looks in the mirror and sees his changing image and wonders what is going to happen to his body as death approaches.
2. **Fear of the Loss of Control:** Life threatening illness gradually makes people more dependent. The father can no longer provide for his family, the mother can no longer care for her home and the child can no longer play with his friends. As the disease progresses, we thrust the person into a health care system that makes the person and family more dependent. This is especially true in the hospital where we frequently make people wait in admitting departments and then when they get to their room, we take their clothes and medications away. We tell them who can visit and when. They are told when meals will be served and when they will receive personal care. People and their families must be allowed to be active participants in the treatment program.
3. **Fear of Loss of Loved Ones:** They are concerned about what is going to happen to them. Will there be sufficient money to put the children through school? Will my wife have to return to work? What will my children do when they grow up?
4. **Fear of Others Reactions to Them:** **“I never knew what fear was until I saw it in the eyes of the people taking care of me.”** – Ted Rosenthal. The importance of non-verbal communication can never be over-emphasized.
People read how we are reacting to their illness more clearly than we can imagine.
5. **Fear of Isolation:** People are fearful of the aloneness of dying. They sense isolation by the frequency of our visits, by the length of our visits and by our body language. Physicians often have less meaningful things to say as disease progresses, and studies have shown that frequently it takes longer for the nurse to answer the bell of a dying patient than the bell of a patient in the next room who is going to get better.

6. **Fear of the Unknown:** People wonder what to expect in the way of physical suffering. It is often here that people begin to question their faith system and wonder if there is life after death, and if there is, what it is like.

7. **Fear that Life has been Meaningless:** Ted Rosenthal said death is “the time when mind’s own camera is forever turned on self”. It is the time we look back at our life to see what meaning it has had. Has the world been better because we are part of it? For the person who feels his life has been meaningless, it is important that we help him to identify the positive aspects of his life. If a person feels this life has been meaningless, he then must ask the question why he was created in the first place. This thought can be devastating.

It is suggested that we look at life as one. Symbolically, the butterfly, caterpillar, and cocoon communicate this to me. We can only fully appreciate the butterfly and the caterpillar as we appreciate what has gone on in the cocoon. Accordingly, we can only fully appreciate this life and the life to come when we look at death as part of the life cycle, that part, that cocoon, which we all must pass through sometime so that we may all become butterflies.

*Thomas R. Leicht, MD – Address of the Institutes of Hospices, The Catholic Health Association. St. Louis, MO.

Treat the other person’s faith gently;

It is all they have to believe with.

RELIGION

Religion refers to a system of beliefs, values, and practices or observances to which a person adheres, and holds in common with an identifiable group.

The practice of religion may include public worship, prayer, meditation, rituals (at birth, marriage and death, for example) ceremonies, and sacraments. Gilbert (1998) says that religion functions to move us “beyond the ‘I’ into the realm of the ‘we’”

SPIRITUAL HEALTH

People seek meaning in order to live authentically with each other. This can become a particular set of spiritual beliefs, guiding the ultimate purpose of our life.

Spirituality contributes to health in many ways. It is how a person searches for meaning, through religion and/or belief in a god, through relationships with family, or participation in naturalism, rationalism, humanism and the arts. This can affect how people who need health care as well as how health care providers understand health and illness.

In caring for the whole human being, there is a need to focus on each aspect of what makes a person human. The most visible is our body. The second aspect is that of thinking, engaging our minds. A third aspect is feeling, which emerges in emotions and forms the dynamic energy of our relationships. And the fourth aspect of self is the spiritual. Its definitions are constantly evolving as understanding of this vital area of health care changes.

Healing is rooted in the concept of wholeness. A physical health care need, such as an illness, may be a symptom of a deeper and more complex need for healing the whole person. In health care, there is growing awareness that spiritual care is a vital aspect of care for the whole person

- In clinical practice, individuals often define their spirituality or philosophy of life as a personally held set of beliefs, values and core relationships around which they organize their sense of who they are and their place in the scheme of things.
- A person's experience of spirituality may include or exclude any particular religious affiliation or public observance.
- While religious adherence and observance may provide an individual with a helpful way to express his/her personal spirituality, this is often not the case.
- Spirituality, then, may refer to transcendence and mystery, a search for something beyond the self or a deeper meaning of the self.

(Manitoba Health 2011)

Video: Spiritual Care – if you have one.....

Discussion questions on Spirituality

1. What are your feelings about your own death?
2. What are your feelings about someone else's death?
3. What is your own philosophy about life and death?
4. What are your spiritual beliefs about dying and death? How do you find meaning in dying and death?
5. How did/do your life's losses affect you?
6. How does loss affect the way you deal with care receivers?
7. What makes you uncomfortable about death?
8. What makes you comfortable about death?
9. How do you find meaning in life?

SPIRITUAL STRUGGLES

Even though spiritual struggles are very unique, there are common themes that arise:

- Mortality
- Loss of Control
- Loss of Hope and Trust
- Change in Roles, Identity, and Self-worth
- Feeling of Abandonment
- Search for Meaning and Purpose

The most important elements of providing spiritual support are listening to the client, developing an understanding of their spiritual perspective and responding to any formal or informal requests for assistance, dialogue and simply being present with the client.

OFFERING SPIRITUAL SUPPORT

- Compassionate presence
 - Listening
 - Empathy
 - Vulnerability
 - Touch
- Hear the person's story (encouraging the person to share stories from their life); affirm self worth and identity
- Explore meaning
- Ensure dignity and respect (of the person's belief system)
- Use religious resources as appropriate (e.g. read from the Bible or praying with)
- Share personal beliefs only as requested; do not try to convert a person or family to one's own beliefs.

Some questions can really help the individual who is dealing with a serious loss, like the death of a loved one or a disease. Here are some good questions to ask:

- When you are upset, what makes you feel better?
- What things have given you strength before?
- What tough times have you gotten through in the past and how did you make it?
- What people are still important to you?

A person's faith is rarely something he's willing to share with many people. That's why asking questions like the ones above are a good idea. Such questions get the individual thinking positive thoughts about how they have managed through other life struggles.

The important thing to remember when asking these questions is not to expect any answers. Individuals may wish to think in silence, and that is okay. If they do answer your questions, listen quietly. Don't judge their answers or interrupt them.

Understand that individuals who have become unsure about their faith might get angry. Or, their loss might cause so much sadness that they have nothing to say, but want you just to be near them.

They might have their own questions to ask, such as:

- What is the point of living?
- Who needs me anymore?
- Why do things like this happen to me?
- What did I do to deserve this?

You may feel completely helpless around a person who is asking questions like these. You may not have the answers and you may not quite know what to say. It's okay to tell him, "I don't know, but I'm here for you and I want to listen". Be a sensitive listener

Circle of Life Exercise

This exercise provides a helpful way of understanding what is and has been important in a person's life, the sense of fulfillment and /or regrets, and the losses for the person who is dying.

Provide each participant with a blank piece of paper and crayons:

1. **Your Life:** Make a list of the facets of your life which are most important to who you are. These may include family, friends, work, money, travel, hobbies, physical health, fitness, volunteer work, spirituality/religion, etc.

2. **The Circle:** Draw a circle and mark the center. What is at the center of your life? Write or draw this at the center.
3. **The Parts:** Now considering each of the important facets of your life, draw in the “slices” of the pie - the more important that facet is for you, the bigger the slice.
4. **Present Fulfillment:** Consider each facet of your life you have drawn in - and starting at the centre of the circle colour in how fulfilled you are in this area of your life today. For example, if you consider physical health/fitness important, yet you are not exercising regularly, then you would color in only part of that slice.
5. **Discrepancies:** How do you feel about the discrepancies between what is an important part of your life and the lack of fulfillment in that area? Are there changes that you want to make to have this area of your life be more fulfilled?

Allow time for the participants to turn to the person beside them and share their circles with each other.

6. **Loss with illness:** Imagine that you have been diagnosed with a terminal illness, and you are at the stage where you are no longer able to go out of your home and you are spending more and more time lying down. Which of the areas of your life will fall out of the picture? How would you feel about these losses? What will fill these spaces? What facets of your life will come into focus and become larger “Pieces of the pie”? At this time you can draw a new circle with sections that reflect these changes in roles, activities, and what becomes ever more important.

Again, turn to the person beside you and share how the circle of your life would change in this situation

Hand out: Regional Cultural Brochures

WORKING with PEOPLE from DIFFERENT CULTURES

Current research suggests that death is both a subjective and culturally based experience. Culture shapes beliefs about the meaning of death, and the care of the sick. For example, some ethnic groups may feel free to cry and express their sadness when death occurs, while other groups may consider a display of emotion unacceptable.

People from various spiritual backgrounds also have differing and unique practices and beliefs related to death. Even within a single religion, believers may vary in the way they observe certain practices.

Given Canada's multicultural society, it is important for helpers to understand and respect the spiritual and cultural practices of dying persons and their families. A good way to learn about another person's culture is through observation and inquiry.

Useful questions to ask include:

- Are there last rites in the person's culture or religion?
- Are there rules or practices around dying and death?
- What types of rituals are performed?

An understanding and respect for the dying person's religious and cultural values enables the volunteer to be more supportive.

Understanding a Person's Culture

Self Reflection exercise

Think about your culture

- Ethnic origin
- Language spoken/written
- Foods
- Music
- Religious/spiritual beliefs
- Values, behaviors, interests
- What element of your culture is most important to you?

Take some time for group discussion.....

Respecting Cultural and Spiritual Beliefs

- A person's cultural roots, ethnic background and spiritual heritage will impact on his/her attitudes towards death.
- Families pass rituals and beliefs about death from generation to generation
- Ethnic groups differ from each other in what they believe and in how they behave.
- There is a vast range of responses to the expression of pain, suffering and grief. The ways in which these are expressed reflects the background of the dying person and his/her family
- It is impossible to know about every culture – it is important to ask questions.

- In the last three decades, Canada's population has changed dramatically in diversity of ethno-cultural backgrounds. Immigration patterns and the coming of age of second and third generation descendants have contributed to this change.
- Most of us have an immigration story, whether recent or generations old. Some people immigrated to Canada voluntarily, while others were forced to flee their home country. Many came for better educational, social, and economic opportunities, particularly for their children. It is important to keep this in mind and to avoid stereotyping all immigrants as belonging to one group.
- In many larger urban centres, there are cultural communities that support people to retain their culture and their native language. Many people whose first language is not English or French may have difficulty accessing health services or understanding directions given to them by health professionals.
- Various situations bring people to Canada and will determine their relationship to either mainstream services or those targeted at certain communities. Many immigrants may have much in common with other Canadians due to the economic, social and educational privileges that they enjoyed in their country of origin. For these people, accessing health and other services may not be as difficult as for those who are less privileged. Some people have had very negative experiences with government services-either in their country of origin or in Canada. This can lead to a mistrust of "formal" police, medical or social services.
- Do not assume that all immigrants, or even all members of a particular nationality, have the same immigration story and follow the same traditions.
- Many cultures have specific rituals or traditions surrounding the death experience. See handouts for examples of "traditional" practice but be aware that many families have developed their own version of the tradition. It is important to respect the family's practice.
- Be sensitive to the way in which a patient's past may affect his reaction to the care given in the present. If you encounter resistance to care, try-where possible-to find out if this is related to experiences in the person's country of origin or in Canada. You may be able to then show how the current service is different from the previous one and reduce the person's or family's fears.
- A community's attitudes, values and beliefs can be as strong as those held in the country of origin and can often conflict with those of mainstream Canadian society. Such conflict may result in greater resistance to outside influences. Services that are considered threatening to cultural values, beliefs and traditions will meet with little success.
- Values around care giving vary from community to community as well as from family to family. In some cultures, it is perfectly acceptable to seek and receive help with care giving responsibilities from people outside of the family. In other cultures, certain illnesses-dementia, for example-are treated with shame. These differences can have an impact on the delivery of all health and social care.
- When appropriate, describe the care or services being offered as a personal support to the person receiving the care. You can often reduce a person's or family's reluctance to access services by reassuring them that the family's role will not be replaced. It can help to describe how the services will personally benefit the family caregiver(s) and ultimately the person receiving the care.
- Take the time to understand the basic values of the person's cultural group. Knowing about basic attitudes towards health care, body function, gender roles and religious/dietary laws can help avoid problems delivering care. Remember, these basic attitudes may not reflect the individual's personal beliefs.
- There are no clear-cut rules on how a person should react to a life-threatening illness. People do not go through the process of dying according to any textbook.

- Many immigrant groups and visible minorities have experienced discrimination in Canada and perhaps in their country of origin. People who have experienced discrimination or racism will be quick to perceive these same attitudes within the agencies they turn to for help. On the other hand, many immigrants have enjoyed positive relationships with community care providers such as midwives, healers, or herbalists and they will continue to seek care from similar helpers in their new setting.

DVD: Completing the Circle

House of Four Rooms

*There is an Indian belief
that everyone
is a house of four rooms:
a physical
a mental
an emotional
and a spiritual
most of us tend to live in
one room
most of the time,
but unless we go into
every room every day,
even if only to keep it aired,
we are not complete.*

Rumer Godden

“Reflecting on our discussion this session what do you see as the implications for volunteers”?

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?"

END-of-LIFE CULTURAL TRADITIONS and RITUALS

Please note that this is a general overview of traditional religious practices. Communities may adapt these rituals and/or individuals may have specific rituals and practices based on their personal beliefs.

Aboriginal (Traditional)

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> Traditional aboriginal teachings offer a unique spiritual perspective on dying and death as a sacred part of life's journey. Living the Medicine Wheel, living in balance and in harmony – trying hard during lifetime to do what is right – prepares an individual each and everyday to be ready to return to the Creator. In preparation for death there are many diverse aboriginal ceremonies such as smudging, the sweat lodge and fasting. Traditional communication patterns may include long periods of silence or long pauses in sentences while clients think of what they want to say. 	<ul style="list-style-type: none"> Some clients may fast as part of their end-of-life tradition. 	<ul style="list-style-type: none"> Autopsies are not permitted in the traditional belief.

Christianity

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> Most Christians believe in God and within God there are three coequal persons Father, Son and Holy Spirit 	<ul style="list-style-type: none"> There are no special dietary requirements 	<ul style="list-style-type: none"> Typically the body is displayed for viewing for people to offer prayers.

Buddhism

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> • The image of the Buddha should always be in view of the person who is dying. • Buddhist patients appreciate visits from a monk or nun. • Quietness and privacy for meditation is important. • Chanting and Incense is preferred but not necessary. 	<ul style="list-style-type: none"> • Vegetarianism is strongly recommended. • Fasting is done during the afternoon on festival days. 	<ul style="list-style-type: none"> • Body may be handled as per normal protocol. • Contact relatives as soon as possible so they can request prayers from the monk at the altar.

Hindu

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> • God manifests Himself or Herself in several forms. • Killing of living things is not favored. • Believe that goal is to break free of imperfect world and reunite with God. • A priest is usually brought in to read scriptures. • A sacred thread is placed around the neck or ankle for dying; sprinkled with River Ganges water; a leaf of sacred basil on the tongue; some may choose to lie on the floor with incense burning around them or die at home. 	<ul style="list-style-type: none"> • Most people who practice Hindu are vegetarian; those who are not must avoid beef products. • Strict vegetarians do not eat meat, eggs, meat or anything produced from animals 	<ul style="list-style-type: none"> • Let the family wash and dress the body. If the family is not available, wrap the body in a clean sheet. • The body must not be left alone until cremation. • All threads, amulets, belts or rings are removed.

Islam

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> Islam, an Arabic word, means peace, purity, obedience and total submission to the one and only One God and His laws. Allah, the Supreme and Eternal, Creator and Provider, Merciful and Compassionate. Allah has no father or mother, no sons or daughters. He has not fathered anyone nor was He fathered. None is equal to Him. 	<ul style="list-style-type: none"> Eat meat of cattle slaughtered the Muslim way and “Jewish Kosher” meat. Muslims fast during the month of Ramadan if there are no medical contraindications 	<ul style="list-style-type: none"> As death approaches, the person should, if possible, recite the Creed (Shahabad). Others may help the person if necessary After death, the person’s eyes should be shut, his/her mouth closed with a bandage running under the chin and tied over the head and his arms and legs should be straightened. A close Muslim relative or friend will proceed to clean the body. Only a wife and husband can wash their partners; all other washing must be done by someone of the same sex. The body must be shrouded and buried.

Judaism

Philosophy/Belief/Rituals	Diet/Fasting	After death
<ul style="list-style-type: none"> Existence of one indivisible God by whose will the universe and all that is in it was created, God has a Covenant relationship with humans and, if one obeys God’s laws, one may achieve salvation. Strong family ties. 	<ul style="list-style-type: none"> People who practice Judaism are Kosher. This means they do not eat pork. 	<ul style="list-style-type: none"> Practices at death seek to: honor dignity of body; assist bereaved through process using laws of the whole mourning ritual; affirm basic belief that life and death are part of God’s plan. Body must not be left unattended from death until burial. Burial takes place 24-28 hours after death. Opposed to autopsies

SESSION 3
COMMUNICATION
LISTENING AND RESPONDING



Session 3: COMMUNICATION: LISTENING AND RESPONDING

Welcome:

Ask if there are any questions from Session 2

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around. It’s overwhelming to consider the continuous opportunities there are to make our love felt.”

Leo F. Buscaglia

Learning Objectives:

- Explore the communication needs of the dying person
- Learn ways of communicating more effectively
- Learn suggested tips on how to handle communication issues
- Discuss verbal and non-verbal communication skills
- Increase our awareness of the effects of life threatening illness on families
- Explore the communication needs of the dying person’s family

Supportive communication in palliative care involves “being” and “listening”.

The most important thing the volunteer can give a dying person and his family is the gift of presence. This refers to the volunteer’s ability to simply be with the patient and family, and to listen to their reactions, feelings and concerns in a non-judgmental way. In the face of death, a volunteer cannot change the circumstances nor take away the emotional pain, listening and being there may be the volunteer’s most valuable role.

- Communicating with the dying person is most helpful when it helps maintain realistic hope. Avoid statements such as “everything will be fine” or “you are going to get better”. Such statements can isolate the dying person and increase his/her anxiety.
- Hope can change from day-to-day. For example, the person who is in the terminal phase of an illness may hope to be pain-free or hope to live to achieve a short-term goal, such as seeing a grandchild’s first birthday. The volunteer should foster and support realistic hope.

- The dying person may want to talk about death or reminisce about life. If a patient dwells on the disappointments in his life, ask about some positive memories. For example ask, “Tell me about some of the happier times in your life,” or “tell me about your family”. As a rule, the volunteer should allow the patient to talk about these issues and not change the subject.
- It is important to allow the patient to talk about dying, so the volunteer should avoid statements that prevent the person from discussing death. For example, never say, “Let’s not talk about that” or “You are just upsetting yourself”. The volunteer is often in a unique role in that the dying person may feel more comfortable discussing the subject of death with the volunteer than with a family member.
- However, not every person will choose to talk about death or intimate feelings. This is acceptable and must be respected. The volunteer must accept the way the person is feeling at the time and not try to force conversation or set expectations for him/her.
- In the final days of caring, non-verbal communication may be used more than spoken words. For example, changes in breathing, tears, opening or fluttering eyelids, or changing the grip of a hand hold, may all convey certain information. The volunteer needs to be sensitive to subtle non-verbal cues. Caring gestures, such as holding the person’s hand or stroking his/her forehead, may be appropriate.
- Nonverbal communication can also send messages to patients without the volunteer being aware. In fact, nonverbal communication can often send a stronger message to the patients than words. Nonverbal communication can show a contradiction in communication. For example, if a volunteer disapproves of a choice that the patient is making, the volunteer’s face may indicate that disapproval even when the volunteer is verbally supportive.
- The volunteer must also be sensitive to the messages she/he is sending to the dying person. Terminally ill persons rarely have difficulty hearing. Even people who are semi-conscious may still be aware of their surroundings and capable of hearing and understanding. Therefore, it is important not to talk about the dying person in his/her presence without acknowledging and involving the person in the conversation.
- Difficult conversations are inevitable with patients who are dying, and it is important to acknowledge they will occur and learn how to manage them. Many people try to change the subject, but the topic that is being avoided will likely resurface. It is important to be prepared with examples of what to say and what not to say.

Exercise:

The purpose of this exercise is to encourage participants to put themselves in the dying person’s situation. Many dying people spend a lot of time lying down and talking to others from a horizontal position. This can foster feelings of vulnerability and loss of control.

1. Request that participants get together in pairs.
2. Ask one of the partners to lie down on the floor and the other to stand. In this position, participants should carry on a short conversation and then switch.
3. At the end of the exercise, ask participants to share their experience with the group. (e.g. What was it like talking to someone from a lying down position? How did it make you feel? Were you comfortable? How did you feel in the standing position? Were you more in control of the conversation? Were you comfortable talking down to someone?)
4. Ask participants how they could facilitate communication with people who are bedridden. (Possible responses: Sit in a chair beside the bed; bend over or kneel when talking so you are at eye level.)

Communication Tips

- **Always be honest** and upfront with someone who is dying and the family. Do not say anything that is not true. For example, avoid common clichés such as “everything will work out” or “you’ll be back to your old self in no time”.
- **Be nonjudgmental.** Everyone deals with things differently and manages their feelings in different ways. Being nonjudgmental means listening to the person with an open mind and understanding that everyone will cope with illness in different ways based on past experiences and personal beliefs.
- **Support hope** as much as possible. For example, a patient may say, “I’m going to beat this disease.” An inappropriate response would be: “I think you are being unrealistic; your cancer is terminal.” An honest and more appropriate response that supports hope would be, “It’s good that you have a positive outlook.”
- **Silence is important.** People often feel the need to fill silence with idle chatter. Patients may be tired, have nothing to say, may not have the energy to continue a conversation, or may be thinking of something painful or sensitive. (Buckman)
- **Accept the patient’s and family’s reactions and feelings.** Do not argue with the person who is in denial. Denial may be a defense mechanism that enables the person to cope, and helpers have no right to take that away. Do not take anger or resentments personally. Individuals may alleviate some of the anger and frustration they feel by directing it at volunteers. In this situation, discussing feelings and being supportive can be helpful. For example, a family member who lashes out at the volunteer may fully expect an argument. An appropriate response to diffuse the situation would be, “You sound upset. Let’s talk about it.”
- **Disclose accurate and appropriate information.** Because volunteers spend a lot of time with people who are dying and their families, they may be asked questions that they cannot answer. Rather than avoiding the questions and providing an untrue answer, volunteers should acknowledge the importance of the question and direct the patient to the person who can address the concerns. For example, if a patient asks the volunteer if his illness is terminal, she could respond by saying, “It sounds like you are very concerned about your illness. Your doctor will be able to answer your medical questions. Let’s write down your concerns and you can ask the doctor at your next visit.”
- **Respect the patient’s personal space.** Each person will have certain rules regarding how close people get to one another during conversation. It can be very uncomfortable if the helper gets too close, or the patient may feel rejected if the helper maintains too much distance.
- **Ensure confidentiality.** Patient confidentiality should be maintained and reinforced. It is appropriate to share information with other team members. Volunteers should explain to patients’/patients’ families that they will discuss information that is important to their care with other members of the palliative care team. It is also a good practice to inform the patient/family when information is going to be shared. For example, if the patient is confiding in you about their pain, you could respond, “I want to mention your pain to the nurse so she/he can help you.”
-

What makes a good communicator?

Communicating is more than just speaking words; it requires a number of interpersonal skills. Effective communicators are sensitive to both verbal and non-verbal cues, and they work hard at facilitating open communication between themselves and their patients. Volunteers must feel comfortable with the communication techniques they use.

Effective communicators are good at:

- **Active Listening**

Being an active listener means using appropriate eye contact, attentive body language and verbal following.

- **Eye Contact**

Dying persons may receive messages of rejection constantly. Some friends and family have a difficult time looking at a person who is wasting away or who is disfigured from the illness. Good eye contact conveys the message that the dying person is accepted and valued.

- **Attentive Body Language**

A good listener is perceived as attentive and interested through the following gestures:

- relaxed posture
 - leaning slightly forward
 - head nodding
 - interested facial expression
 - warm, animated tone of voice
 - appropriate closeness.

- **Verbal Following**

The good listener should interject periodically and say something to the person speaking that demonstrates that he/she has been paying attention.

- **Empathizing**

Empathizing refers to the ability to put oneself in someone else's situation. Those working in palliative care will be more effective at communicating if they try to understand what the patient and family are going through. This understanding can result in more sensitivity to the feelings and actions of people who are dying and their families.

- **Using Open-Ended Statements**

Open ended questions are more effective in eliciting conversation than closed-ended questions. For example, a closed-ended question such as, "Are you feeling good" will result in a "no" or "yes" answer. The same question can be reworded to be open-ended such as, "How are you feeling today?" This will promote more discussion.

Specialized Communication

Communications with physically or mentally impaired patients can be frustrating and difficult. It is important to listen, speak clearly and use nonverbal communication (e.g., body language) to communicate with patients.

ElderCare Online offers the following tips for dealing with patients who are deaf, hearing impaired, visually impaired, aphasic (difficulty with speech) or living with Alzheimer's or a related disorder.

Communicating with the Hearing Impaired

- If the person wears a hearing aid and still has difficulty hearing, the hearing aid may need to be checked.
- Wait until you are directly in front of the person, you have that individual's attention and you are close enough to the person before you begin speaking.
- Be sure that the individual sees you approach; otherwise your presence may startle the person.
- Face the hard-of-hearing person directly and be on the same level with him/her whenever possible.
- If you are eating, chewing or smoking while talking, your speech will be more difficult to understand.
- Keep your hands away from your face while talking.
- Recognize that hard-of-hearing people hear and understand less well when they are tired or ill.
- Reduce or eliminate background noise as much as possible when carrying on conversations.
- Speak in a normal fashion without shouting. See that the light is not shining in the eyes of the hearing impaired person.
- If the person has difficulty understanding something, find a different way of saying the same thing, rather than repeating the original words over and over.
- Use simple, short sentences to make your conversation easier to understand.
- Write messages if necessary.
- Allow ample time to converse with a hearing impaired person. Being in a rush will compound everyone's stress and create barriers to having a meaningful conversation.

Communicating with the Deaf

- Communicating with the deaf is similar to communicating with the hearing impaired.
- Write messages if the person can read.
- Use a pictogram grid or other device with illustrations to facilitate communication.
- Be concise with your statements and questions

- Utilize as many other methods of communication as possible to convey your message (i.e. body language)
- Spend time with the person, so you are not rushed or under pressure.

Communication with the Visually Impaired

- If you are entering a room with someone who is visually impaired, describe the room layout, other people who are in the room, and what is happening.
- Tell the person if you are leaving. Let him/her know if others will remain in the room or if he/she will be alone.
- Use whatever vision remains.
- Allow the person to take your arm for guidance.
- When you speak, let the person know whom you are addressing.
- Ask how you may help: increasing the light, reading the menu, describing where things are, or in some other way.
- Say the person's name before touching. Touching lets a person know that you are listening.
- Allow the person to touch you.
- Treat him/her like a sighted person as much as possible.
- Use the words "see" and "look" normally.
- Legal blindness is not necessarily total blindness. Use large movement, wide gestures and contrasting colors.
- Explain what you are doing as you are doing it, for example, looking for something or putting the wheelchair away.
- Describe walks in routine places. Use sound and smell clues.
- Encourage familiarity and independence whenever possible.
- Leave things where they are unless the person asks you to move something.

Communicating with Patients with Aphasia

Aphasia is a total or partial loss of the power to use or understand words. It is often the result of a stroke or other brain damage. Expressive aphasics are able to understand what you say; receptive aphasics are not. Some victims may have a bit of both kinds of the impediment. For patients with aphasia who are expressive, trying to speak is like having a word "on the tip of your tongue" and not being able to call it forth.

- Be patient and allow plenty of time to communicate with a person with aphasia.
- Be honest with the individual. Let him/her know if you can't quite understand what he/she is telling you.
- Ask the person how best to communicate. What techniques or devices can be used to aid communication?
- Allow the aphasic to try to complete his/her thoughts, to struggle with words.
- Avoid being too quick to guess what the person is trying to express.
- Encourage the person to write the word he/she is trying to express and read it aloud.

- Use gestures or pointing to objects if helpful in supplying words or adding meaning.
- A pictogram grid is sometimes used. These are useful to "fill in" answers to requests such as "I need" or "I want." The person merely points to the appropriate picture.
- Use touch to aid in concentration, to establish another avenue of communication and to offer reassurance and encouragement.

Communicating with patients with Alzheimer Disease or Related Disorders

- Always approach the person from the front, or within his/her line of vision – no surprise appearances.
- Speak in a normal tone of voice and greet the person as you would anyone else.
- Face the person as you talk to him/her.
- Minimize hand movements that approach the other person.
- Avoid a setting with a lot of sensory stimulation, like a big room where many people may be sitting or talking, a high-traffic area or a very noisy place.
- Maintain eye contact and smile. A frown will convey negative feelings to a person.
- Be respectful of the person's personal space and observe his/her reaction as you move closer. Maintain a distance of one to one and a half feet initially.
- If a person is a pacer, walk with him/her, in step with him/her while you talk.
- Use distraction if a situation looks like it may get out of hand (e.g., if the person is about to hit someone or trying to leave the home/facility).
- Use a low-pitched, slow speaking voice which older adults hear best.
- Ask only one question at a time. More than one question will increase confusion.
- Repeat key words if the person does not understand the first time around.
- Nod and smile only if what the person said is understood.

The Art of Being Present

As you are coming into people's space, meeting the patient and family, it may be helpful to have some reminders about how to build a comfortable working relationship. This is a process that begins with the first visit and continues throughout your contact.

- **Place yourself at the same level as the person with whom you are visiting.** *Sit down, if only for a few minutes.*
- **Say the person's name.** *Establish, with the person, how they wish to be addressed. They may prefer the use of their first name, or they may find that patronizing. A "pet" name is usually the prerogative of a special relationship.*
- **Hearing your own name spoken is very grounding, especially when spoken by one who cares for you.** *Do you remember how good it felt to hear your name incorporated into a song at a campfire? It feels particularly good to be known and called by name when you find yourself dependent and in a depersonalizing environment.*
- **Offer the opportunity for privacy and uninterrupted time for unhurried discussion.** *Several brief discussions may be better than a single lengthy one.*

- **Be yourself. Take time to settle in. Let the person take your measure.** *This is a relationship; it cannot be one-sided.*
- **Observe and match mood and behaviour.** *Do not pit your peace against anger, your exuberance against depression, your openness against protectiveness.*
- **Be guided by the patient about how much contact is comfortable.** *Some people want eye contact or physical contact. Others find it intrusive.*
- **Find common ground as you share time together.** *For example: explore interests, patients' preferences in music, their background.*
- **Heaviness, sadness, anger, frustration, may need to be acknowledged before any further issues are raised.**
- **Be specific about how you can help and what is going to happen.**
- **Set boundaries.** *Boundaries help people to feel safe: they need to know what they can and cannot expect from you. Outline how often you will be coming and what you expect to be doing.*
- **Respond to opportunities to talk about death.** *Not speaking of death suggests that it is too terrible to talk about.*
- **Be respectful.**

The following questions will be good to review following a volunteer visit:

Self Reflection

Did I carefully listen to the person?

Do I have a sense of what the person values and what is important to that person?

Even if I had only five minutes to be with the person, did I give my full attention?

Did I attempt to imaginatively explore options?

Did I invite opportunities for the person to reminisce and reflect on the past?

Did I respond as one human to another, by offering gestures of care and compassion?

What did I hear? What did I observe?

What emotions were expressed?

What was I feeling?

What concerns, if any, were uppermost in the person's consciousness?

Is there any information I need to know?

What feelings or thoughts were aroused in me by this encounter?

Don't Be Too Shy To Ask

- What is this experience like for you?
- How is your loved one reacting to all of this?
- Do you think about what happens "after"?
- Do the people you love know what they mean to you, and why?
- Are you ever afraid?
- Are you having any interesting dreams/ideas/revelations?
- How do you prefer to spend this time?
- Does this experience have any special meaning for you, in a spiritual sense?
- What do others consider to be your major accomplishments?
- What do you consider to be your major accomplishment?
- Do you have any regrets?
- Do you have any unfinished business?
- Do you have any last wishes?
- What do you wish people will say about you when you're gone?
- What people do you prefer to see most?
- Is there anyone you haven't seen that you would like to see?
- What have been the hardest parts of this journey?
- What have been the easiest parts of this journey?
- What have been the most surprising parts of this journey?
- What are you learning through all of this?

Understanding Hope

Reflect on the following questions.

Allow 5-10 min following for sharing among 2-4 people

1. When you think about hope, the words that come to mind are?
2. When do you feel the most hopeful?
3. What is the current state of your hope on a scale from 1-10 (1= low hope, 10 = high hope)?
4. What helps your hope?
5. Think of a situation from the past that has strengthened my hope is?
6. How has your hope changed over time?
7. If a picture that reminded you of hope was hanging on your bedroom wall when you wake each morning, what would that picture be? Why?
8. What do you do to feel more hopeful when you are feeling down?
9. What beliefs support your hope?
10. What most threatens your hope?
11. What behaviors do you repeatedly do that supports your hope?
12. What changes in your actions, language or behavior would send a message to others that you have become more hopeful?

Fostering Hope

Learning to live with a life limiting illness involves clients, their loved ones and health care providers in a continuous process of ‘meaning making’ and adaptation as they transition:

- From goals of cure to comfort care
- Through shifts in hopes and expectations
- With personal, psychosocial and spiritual issues
- Possibly between care settings (home, hospital, residential care facility and/or hospice residence)

Clients and families require time to adjust and cope with each change. At any stage it is possible that a client’s expressed understanding or disease experience may be different from others, including family members and/or care providers. Identifying and appreciating the ‘truth’ about an illness within the context of the client’s experience and from the perspective of their loved ones helps to ensure that their values, goals, priorities and preferences will be heard and respected. Throughout the progress of their illness, clients and families may even express hope for outcomes that appear to be unrelated to what is expected based on test results and physical functioning.

While health care providers have an obligation to provide clients and families with accurate information about their disease, prognosis, treatment and/or care options (to the degree desired by client and family) it is not their responsibility to ensure that hope is ‘realistic.’

If hope is defined solely in terms of cure or remission of disease, the hopes of terminally ill clients might be viewed as a form of denial or false reality. Hope for palliative clients needs to be understood and supported as a dynamic process that shifts from hope for a cure to:

- Hope for survival.
- Hope for comfort.
- Hope for the energy to keep going.
- Hope for dignity.
- Hope for intimacy, reconciliation with what gives meaning.
- Hope for a better day or better moments.
- Hope for a peaceful death.
- Hope that surviving family will not suffer after patient’s death.
- Hope for an afterlife.

For those in the terminal phase of an illness, hope can be a powerful coping mechanism, an inner resource necessary to endure life circumstances. Hope can provide the psychological and physical energy required to endure suffering and achieve goals. It can help people find meaning and direction, “...to stay engaged in the living while shouldering the burden of an uncertain future.” It is crucial to approach each client as a living human being who has the need and the right to maintain a sense of hopefulness, and to be cared for by those who can maintain a sense of hopefulness, however changing this may be, until the moment of their death.

Health care providers can foster hope by:

- Being authentic.
- Facilitating caring relationships.
- Using humor and play.
- Encouraging determination and courage.
- Assisting clients and families to establish short-term, attainable goals.
- Supporting spirituality.
- Engaging in reminiscing.
- Being physically present in crisis.
- Listening attentively.
- Managing pain and other symptoms.

It is through these types of activities that health care providers can sustain their own sense of hope while supporting the evolution of client and family hope from a curative focus to one that transcends the illness experience.

Video: June Callwood**Questions:**

Things the interviewer did well.....

How did you feel?

What did you think about her response to having a funeral?

FAMILIES OF DYING PERSONS

Families have changed a great deal over the years. Traditionally, we think of mother, father and children as the nucleus of the family, with extended family members (e.g., grandparents, aunts, uncles) playing a supportive role. Today the Canadian family is no longer “traditional”: dual income households, single parents, same sex parents, divorce and cultural diversity have all shaped what a family is today.

Families are also more dispersed geographically across Canada, which means that family members may not be physically present to care for their loved ones and are trying to manage care from a distance. These factors also affect family dynamics. Families form their own norms as well as their own way of managing, and the death of a loved one can challenge the “normal” way of doing things.

When someone is faced with a life threatening illness, families are often called on to make significant decisions during a time of significant emotional stress. During this time, unresolved family issues may resurface that cause tensions and may result in the family system breaking down. Overwhelming stress and the thought of what will happen after death may lead to disagreements between family members, particularly siblings. Who will care for the pets? Who will manage the bills? Who will arrange for bills? There may be a perception that some siblings are not doing an adequate share of the work.

A life-threatening illness affects all members of the family, even those who live outside the home or far away. Overwhelmed by the realization that they are going to lose someone, family members may struggle to find various ways to cope. During the illness, the family can be as deeply disturbed by the events as the dying person. The most difficult task for family members is dealing with their own emotions.

Some families are able to deal with the stressful situation, while others become completely overwhelmed. Some families are able to compensate for the loss of an important family member; other families may be irreparably crippled by the loss. During an impending death, unresolved issues may resurface and cause a great deal of tension. Families may find that trying to cope with an imminent loss as well as unsettled issues hinders decision-making processes.

In long-term care facilities, other patients may have played the role of family in the dying person's life. They may be experiencing some or all of the same reactions to the person's imminent death as other family members. In some cultures, death is not a topic that is openly discussed so it is important to approach the topic carefully. For example, some people of Chinese descent may believe that it is important to keep negative information from the patients and these wishes must be respected.

Question for the group:

What do you think influences how a family copes with the illness? (Possible responses: past experience, the dying person's role in the family, the seriousness and length of the illness, the presence of family and outside social support, financial situation and cultural differences.)

THE IMPACT OF LIFE-THREATENING ILLNESS ON FAMILIES

Life-threatening illness affects not only the person who is dying but the entire family system including the biological family, the family of acquisition, and the family of choice and friends. The prospect of death and the loss of a family member places the family in a state of imbalance or chaos.

During the period of serious illness, the family can be as deeply disturbed and upset as the dying person. Among the most difficult tasks the family faces is dealing with their own emotions. No family who has lived with a life threatening illness can survive the ordeal unchanged; however, the changes will be distinct for each family system.

Some families may actually pull together and function better, while others may break apart and never recover "normal" functioning again. In the stressful situation of watching a loved one die, it is not unusual for unresolved conflicts and resentments to surface.

The way in which families cope with a serious illness depends upon several factors:

1. Past experiences (people tend to rely on ingrained coping strategies).
2. The dying person's role in the family. Coping may differ depending upon the person's contribution to the family system (e.g., wage earner, primary homemaker).
3. The length of the illness. Prolonged illness can be emotionally and financially taxing.
4. The presence of social supports
5. Cultural differences. Culture can affect the type of emotion expressed, verbal communication and willingness to accept outside help.

Just as a person with a life threatening illness progresses from a state of health, to sickness, to dying, a family also progresses through various stages. Each family is unique and will respond to illness and eventual death in his or her own way.

COMMUNICATION AND THE FAMILY

When a loved one is dying, family members often become concerned about their ability to cope and fearful of the unknown, and they may need someone to talk with. It is not so much the thought of death that is fear provoking to the family, but the imagined effects of the disease such as choking, suffocating and uncontrolled pain. Supporting the family means offering a friendly ear, being non-judgmental and providing genuine reassurance.

Spending time with the family and reviewing the care plan can help reassure them that the dying person is being well looked after. This process also includes the family in the care team and gives them more control over decisions that will affect them.

In working with families, it is sometimes difficult to understand all interactions that occur. The dying person and his family have a history together which will affect how each person copes and communicates. Dealing with death is stressful and can trigger emotions and reactions that are rooted in long standing relationships.

For example, an adult child may be unable to comfort a dying person. The volunteer may see this as cruel or unacceptable given the parent's condition. However, the adult child's reaction may be related to resentments over past wrong doings or conflicts. Facing death does not heal past wounds or alter relationships. It is important to respect and to try to understand each person's issues.

All families have unspoken rules about how people should behave and what emotions they can express in a given situation. For example, in certain families men are expected to be strong and not cry; in others, both men and women are encouraged to express emotion.

The A, B, C, and D of DIGNITY CONSERVING CARE

The notion of dignity conserving care, while emerging primarily from palliative care, applies across the broad spectrum of medicine. Whether patients are young or old, and whatever their health problems, the core values of kindness, respect, and dignity are indispensable. Just as the simple “A, B, C” mnemonic (airway, breathing, and circulation) effectively summarizes the fundamentals of critical care, an easily remembered core framework of dignity conserving care—the A, B, C, and D of dignity conserving care—may remind practitioners about the importance of caring for, as well as caring about, their patients.

ATTITUDES

Questions to be asked

- How would I be feeling in this patient's situation?
- What is leading me to draw those conclusions?
- Have I checked whether my assumptions are accurate?
- Am I aware how my attitude towards the patient may be affecting him or her?
- Could my attitude towards the patient be based on something to do with my own experiences, anxieties, or fears?
- Does my attitude towards being a healthcare provider enable or disable me to establish open and empathic professional relationships with my patients?

Actions to be taken

- Make a conscious effort to make these questions a part of your reflection on the care of each and every patient
- Discuss the issue of healthcare providers' attitudes and assumptions, and how they influence caring for patients, as a regular part of case reviews and clinical teaching
- Include ongoing professional development activities that have you challenge and question your attitudes and assumptions as they might affect patient care
- Create a culture among your colleagues and within your healthcare setting in which acknowledgement and discussion of these issues becomes a standard part of providing care

BEHAVIOURS

Disposition

- Treat contact with patients as you would any potent and important clinical intervention
- Professional behaviors towards patients must always include respect and kindness
- Lack of curative options should never rationalize or justify a lack of ongoing patient contact

Facilitating communication

- Act in a manner that shows the patient that he or she has your full and complete attention
- Always invite the patient to have someone from his or her support network present, particularly when you plan to discuss or disclose complex or “difficult” information
- Personal issues should be raised in a setting that attempts to respect the patient's need for privacy
- When speaking with the patient, try to be seated at a comfortable distance for conversation, at the patient's eye level when possible
- Given that illness and changing health status can be overwhelming, offer patients and families repeated explanations as requested
- Present information to the patient using language that he or she will understand; never speak about the patient's condition within their hearing distance in terms that they will not be able to understand
- Always ask if the patient has any further questions and assure them that there will be other opportunities to pose questions as they arise

COMPASSION***Getting in touch with one's own feelings requires the consideration of human life and experience***

- Reading stories and novels and observing films, theatre, art that portray the pathos of the human condition
- Discussions of narratives, paintings, and influential, effective role models
- Considering the personal stories that accompany illness
- Experiencing some degree of identification with those who are ill or suffering

Ways to show compassion

- An understanding look
- A gentle touch on the shoulder, arm, or hand
- Some form of communication, spoken or unspoken, that acknowledges the person beyond their illness

Dignity website: Dr. Harvey Chochinov 2011

“Reflecting on our discussion this session what do you see as the implications for volunteers”?

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?”

SESSION 4

THE PHYSICAL NEEDS OF THE DYING



Session 4: THE PHYSICAL NEEDS OF THE DYING PERSON

Welcome:

Ask if there are any questions from Session 3

Learning Objectives:

- Raise awareness of :
 - the physical changes and needs of the dying person
 - pain and other symptoms that a dying person may experience
 - comfort measures
 - the signs of approaching death

Take a few minutes for group discussion:

Consider how you would feel if you were in the dying person's shoes...

- You are sick and very weak
- You can no longer bathe or dress yourself without help
- You have always been a private person, you have always been strong and independent
- Now you need help with the most basic personal care

How do you feel about having someone help you with a bath?

How can the volunteer make you feel more comfortable with receiving the most basic personal care?

PHYSICAL NEEDS

- some illnesses will advance rapidly, others will advance gradually
- activities such as walking, eating, breathing, sleeping, going to the bathroom, may eventually become difficult
- a person's body will change in appearance due to problems such as fluid retention, muscle waste, hair loss, pallor or jaundice
- a person may exhibit one, all, or none of the physical symptoms such as pain, lack of appetite, shortness of breath, body odour and skin problems

COMMON SYMPTOMS:

SYMPTOMS	HELPFUL HINTS
LACK OF APPETITE	<ul style="list-style-type: none"> • serve favorite foods, in small portions • ensure comfortable environment • provide companionship during meals • do not “nag”
WEAKNESS	<ul style="list-style-type: none"> • plan activity and exercise to conserve energy
DRY MOUTH	<ul style="list-style-type: none"> • provide mouth care, frequent small sips of fluid, ice chips to suck on
FEVER	<ul style="list-style-type: none"> • apply cold compresses • keep room well ventilated
DIFFICULTY BREATHING	<ul style="list-style-type: none"> • provide reassurance • elevate the patient’s head with pillows to decrease exertion used to breathe • increase air movement in the room. • promote calm, relaxed atmosphere
NAUSEA/VOMITING	<ul style="list-style-type: none"> • clean up the vomit and the patient • ventilate and deodorize the room • rinse and clean the person’s mouth
CONSTIPATION	<ul style="list-style-type: none"> • increase fluid intake • add bran, prunes or prune juice to the diet • encourage exercise • request laxative such as milk of magnesia
INSOMNIA	<ul style="list-style-type: none"> • plan relaxing night time activities such as reading, or watching television
SKIN PROBLEMS	<ul style="list-style-type: none"> • ensure proper body alignment • turn person frequently • keep skin dry and clean • massage skin gently
INCONTINENCE	<ul style="list-style-type: none"> • toilet patient on a regular basis • if incontinent only during sleep, wake to use toilet • Adult incontinence products can be used by the patient

NUTRITION PROBLEMS/SOLUTIONS

Some terminally ill people eat fairly well and continue to lose weight while others lose their appetite and are either unable to tolerate small amounts of food or are comfortable with little intake.

People who do not feel like eating often feel guilty or feel they are disappointing their loved ones.

Because of the progression of the illness, the person's body is unable to use or metabolize the food they eat, and the person continues to lose weight.

Some medications and treatments for the person's disease can cause nausea or lack of appetite. Other medications may relieve these side effects.

Family and friends are often concerned when the person who is dying no longer feels like eating. In the early stages of the illness, family members may think that by eating more, the person will gain weight/strength and feel better. In the later stages of the illness, family members see lack of appetite and weight loss is a sign of approaching death.

Family members often spend a lot of time and energy trying to find something the person may eat, encouraging the person to try to eat more or, in some cases, attempting to force feed the person.

Families/friends may express anger and demand that "something be done before the person starves to death". People who do not feel like eating do not feel hunger, and therefore are not suffering from a lack of food intake. In fact, for people nearing the end of life, eating often causes discomfort.

Any of a number of symptoms – such as changes in sense of taste, feeling full, difficulty swallowing, a dry or sore mouth, constipation, diarrhea, pain or fatigue -- can keep people from wanting to eat so it is important to try to minimize those symptoms and to try accommodate the person's ability to eat.

Questions for the Group:

- **What behaviors have you observed in family members who are distressed when their loved one's intake declines?**

Consider other activities that family members could do with their loved one that does not involve food.....

It is very important to acknowledge how difficult it is for family members to watch the changes occurring in their loved one – particularly when there is little that can be done to “reverse” or slow down these changes.

Through gentle, non confrontational communication, the volunteer can encourage family members to talk about their concerns, ask questions and receive information that will help them understand the changes and why they are occurring. When family members have questions related to medical care, the volunteer should refer them back to the nurse or physician.

There are a number of activities that family members can do with the ill person that do not involve food, such as mouth care, reading, going for a short walk/wheelchair ride, reminiscing, scheduled visits from friends/ family, music. (Note: any activity should be done for short periods of time that the person can manage.)

Nutrition in the end stages of life can be an emotionally laden topic for clients and their families

Dietary intake may be influenced by physical changes, cultural preferences and personal taste

As the disease progresses, it is normal for appetite and intake to diminish

Refer to the brochure: Food for Thought

MOUTH CARE

NOTE: wear gloves when doing mouth care

Mouth problems are common in persons with life threatening illness due to the disease process and medication/treatment regimes

The volunteer can help the person to keep the mouth clean and moist. Some people will be able to clean their teeth and tongue or rinse their mouth. If this is not possible, volunteers can use small toothettes to clean and moisten the gums and teeth. Avoid alcohol based mouthwashes and acidic or citrus foods/drinks. Always rinse dentures with cool water before placing in the client's mouth. Vaseline should not be used if the person is receiving oxygen.

Depending on the condition of the person's mouth, the mouth care routine may be completed every two hours. Anyone who is unable to clean their mouth or who is eating or drinking infrequently will require regular mouth care.

DIFFICULTY BREATHING

Shortness of breath is the client's perception of having difficulty breathing or not getting enough air.

Difficulty breathing and shortness of breath may be due to anxiety, progression of disease, or impending death.

Breathing problems are frightening for the dying person and for family members.

As death approaches, the rate and pattern of breathing usually changes.

Comfort Measures:

- Help person pace activities to prevent breathlessness as much as possible. Provide assistance with moving, washing and dressing as required.
- Remind person to take prescribed medications to prevent or ease shortness of breath. These medications may be taken regularly or “as necessary”.
- Open a window for fresh air.
- Do not wear perfume.
- Warm lemon and honey drinks can help reduce mucus.
- Humidifiers may loosen mucus and make it easier to cough up.
- Provide calm, relaxed atmosphere to reduce anxiety provoking situations.
- Relaxation tapes and massage may help decrease anxiety.
- Position the person according to their preference. One side may be better than another. A high-sitting position is usually best.
- Use electric fan to move air across the person’s face.
- Remain with the person when they are having difficulty breathing; be calm; coach the person to breathe regularly and relax.
- Remove constrictive clothing or bedding.
- Mouth care.

SKIN CARE**People who are dying often experience skin problems or breakdown due to:**

- Decreased nutritional intake, changes in metabolism and lack of repositioning
- Sliding (shearing) on sheets, which causes skin tears and may predispose people to infections
- Thin, fragile and easily torn skin, which is common in old age
- Lack of oxygen to the tissue at pressure points, which results in pressure sores.

Even with the best care, people who are dying may experience skin problems and breakdown. Because the body is compromised by the illness, the skin becomes weak, susceptible to sores and slow to heal. Often the most difficult problem is pressure sores or bedsores: ulcers that occur on the skin at points where pressure is applied. Bony areas, such as the elbow, heel, ankle, shoulder blades, head, buttocks and hips, are most prone to pressure sores. The best intervention is prevention.

Comfort Measures:

- Turning the person regularly to shift body position
- Keeping skin dry and clean
- Ensuring clothing is loose fitting
- Keeping linens wrinkle free and dry
- Massaging very gently

GENERAL APPEARANCE AND HYGIENE

It is important to help the dying person maintain their personal care. As the disease progresses, body odour may be more prevalent which can be distressing and embarrassing.

Measures to decrease odour may include:

- Keep the room well ventilated
- Use room deodorizers
- Sprinkle cornstarch lightly on the linen to enhance freshness

Other personal care activities such as washing, brushing and styling the hair or shaving can help enhance the person's sense of well-being. A life threatening illness can be very destructive to the self-image. Honest compliments can help lift the person's spirits.

When providing any type of personal care, the volunteer should be:

- Sensitive
- Patient
- Reassuring
- Respectful

PAIN

Pain is a physical sensation relayed to the brain through the nervous system.

Pain is a subjective experience. Two people experiencing the same type of pain may react differently. It is important to listen to the person: they are the expert regarding their pain.

The feeling of pain may be worse if the person is having other physical symptoms. Worry, fear, boredom and loneliness may also make the experience of pain worse. Pain may not always remain at constant levels. Some people will have significant exacerbation of their pain; they may have periods when pain spontaneously becomes more intense.

Physical pain

Physical pain is an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder. Physical pain is not the only type of pain.

Acute pain and chronic pain are two very different kinds of pain. Each involves different responses.

Question for the Group: Can you give an example of acute pain and chronic pain

Acute pain

Most people have experienced acute pain at some time in their lives: toothaches, appendicitis, broken leg, pinched nerve.

Acute pain is intense, sharp, localized, and may last from one second to several weeks. This kind of pain usually ends in a relatively short time.

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

Chronic pain

Chronic pain is slow and continuous, and does not resolve quickly.

Chronic pain is a symptom of arthritis and other similar disorders which last more than six months. It is frequently described as dull or aching and is not usually localized. It may vary in intensity or remain constant.

Chronic pain may be as severe as acute pain.

Breakthrough pain

Breakthrough pain is pain that reemerges before the next dose of pain medication.

It is a spontaneous episode or manifestation of pain experienced by people even though they are taking regular pain medication. These episodes of pain may be caused by movement (also referred to as **incidental pain**) but they may also indicate only that the dose or potency of the routine pain medication prescribed for pain management is inadequate.

Pain medication taken regularly creates a barrier which keeps pain at an acceptable level (i.e., the patient does not feel or perceive any pain). In some cases, however, pain may break through this barrier. When that happens, the person must take an additional dose of medication to lessen the pain.

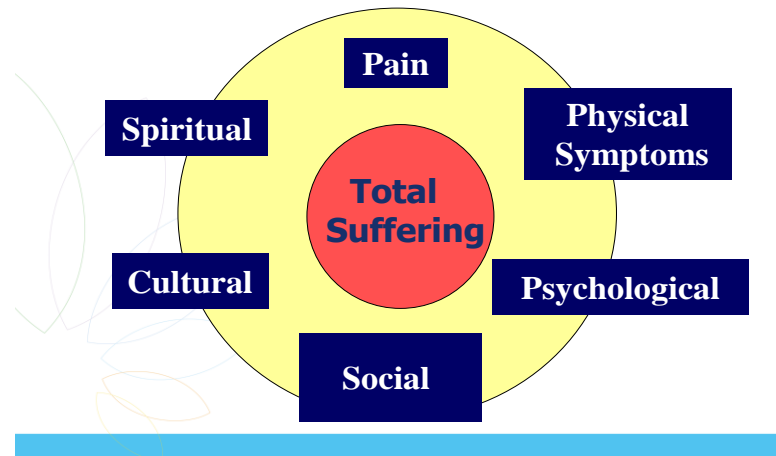
Pain is what the person says it is**FACTORS THAT AFFECT HOW PEOPLE EXPERIENCE OR REACT TO PAIN**

CULTURAL BACKGROUND	Individuals will react to pain in a manner which they have learned as acceptable within their group.	If the family values “stoicism,” the person will be silence If family values expressiveness, the person may cry and moan.
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GENDER	A society's attitudes can influence the way a male should react to pain versus how a female should respond and react to pain.	A woman may be allowed to cry. Men are expected not to cry.
MEANING OF PAIN	Pain is determined by the interpretation of what the pain means to the person.	Some people may interpret pain as a punishment for past sins. Some people do not see pain as evil or negative but part of life.
LIFE EXPERIENCES	An individual's previous experiences with pain will influence how they respond to pain.	A person who has suffered from chronic migraines, for example, will respond to pain in life threatening illness differently than someone who has never suffered.

Although pain and symptom management is the first priority in Palliative Care, it is not the ultimate goal. The ultimate goal is to address total pain and suffering, as described by Woodruff (1993). The total pain concept addresses not just physical pain and symptoms but also the emotional, social, cultural, and spiritual aspects of pain that can accompany the dying process.

Total Suffering: Woodruff



Multi-faceted Components of Pain

Pain must be considered in relation to the whole person. These types of pain often interact so it is important to understand the different types of pain that someone can feel.

Physical pain: Physical pain is an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder.

Emotional pain: This pain can take the form of anxiety, depression, fear or guilt as a result of the issues people face at the end of life.

Spiritual pain: This pain can result from a real or perceived sense of disconnection from a religious belief system or from one's spiritual life. As a person facing death tries to make meaning out of their new reality and find hope, this void may cause pain.

Social pain: People facing the end of life may have become isolated from friends and family for various reasons. Their usual support networks may not be involved in their care, and this can cause a sense of isolation resulting in social pain.

Financial pain: People may worry about financial issues which impact on family during the illness and into bereavement.

Cultural pain: A person's culture may affect their concept of health and may not be understood by their health care professionals.

Video: Making Hard Decisions

HEALTH CARE DIRECTIVES/ADVANCE CARE PLANNING

Health Care Directive

A written legal document in which you tell health care providers what care you want and who you choose to make decisions for you if you are unable to do so, Health Care Directives are only used when an individual is no longer capable of making health related decisions.

Advance Care Planning

The overall process of dialogue, knowledge sharing and informed decision-making that needs to occur at any time when future or potential life threatening illness treatment options and goals of care are being considered or revisited.

Goals of Care

The goals of care are the intended purposes of health care interventions and support as recognized by a client/patient or substitute decision maker and the health care team.

Where can I get more information?

If you have questions, or would like to receive more information about Advance Care Planning, there are a number of resources for you. Each regional health authority has developed policies regarding the completion of Health Care Directives and Advance Care Planning or you may talk with your doctor and other health care providers. You may also call Manitoba Health and ask about Health Care Directives, or visit their website at www.gov.mb.ca/health/livingwill.

Other definitions that may enter discussion:

Proxy

A proxy is a family member or friend that you trust to speak for you to doctors and other health care providers. A proxy's role is to communicate your wishes and beliefs so that they are respected as decisions made about your medical care and treatment. You may decide to name more than one person to be your proxy.

Power of Attorney

A power of attorney is someone who will become responsible for your legal and financial affairs in the event that you cannot do so. You can choose in advance who this will be and it can be recorded in a written document. It is important to know that this person will not have control over your health care or personal decisions.

Enduring Power of Attorney

The law indicates that if you become mentally incompetent and or not able to manage your own financial affairs, the power of attorney is not valid. An enduring power of attorney is similar to a power of attorney except that it is valid in the case you become mentally incompetent.

THE PROCESS OF DYING AND THE LAST HOURS OF CARE

In the last stage of a life threatening illness, many people will experience a myriad of emotions. What people believe may or may not happen after death varies widely, depending on cultural and religious backgrounds.

- As death nears, the person who is dying tends to withdraw from daily activities.
- It is important to create an environment that is suitable for that individual and their lifestyle and culture.

Question for the group

What kind of things can you do to promote a comfortable environment?

Some family members become troubled toward the end of the dying person's life because they feel they are not doing enough. Many exhausted family members, who have watched their loved ones struggle, will long to have the ordeal end. The expression of such a desire may create feelings of guilt. It is important not to be judgmental.

Resources: “What to Expect at the End of Life”, “When Death is Near” (these may vary from region to region)

APPROACHING DEATH

Many changes can occur as the body slows down and prepares for the final stages of life. Please remember that each situation is different and not necessarily all of these signs and symptoms will occur in all dying persons.

- Sleeps longer, sometimes having difficulty waking. Eventually slips into a coma (a sleep-like state where the patient is unable to respond to the world around him).
- Reduced intake, decreased appetite.
- Becomes confused and unable to recognize familiar people or surroundings.
- Weakness becomes profound, with difficulty responding verbally, difficulty swallowing or “forgetting” to swallow.
- Breathing becomes more irregular and shallow. Periods when breathing stops for 10-30 seconds or longer.
- Breathing sounds wet or moist – may even rattle.
- Pulse becomes irregular, weak and then absent.
- Hands and feet become cool. Skin color may be pale, bluish or mottled (patches of dark and light areas.)
- Urine output will decrease or even be absent for 24-48 hours. May lose bladder control.
- Bowel movements may be absent, or there is uncontrolled oozing of soft or liquid stool.

Atmosphere and Surroundings

- Be with the person as calm presence.
- People may want to reminisce, pray, and be silent.
- Let family cry and express feelings.
- Touch, holding hands, and hugging may be appropriate.
- Be sensitive to particular style of the dying person and their family.

Question for the group:

What have your experiences been being with a dying person? What do you feel is the distressing part of being with a person at the point of death? (*Possible responses: not knowing the moment of death, witnessing the family's grief, body deterioration, feeling helpless.*)

Allow time for the group to discuss any feelings, concerns and anxieties.

WHEN DEATH OCCURS

These are general suggestions. Considerations must be given to cultural, religious, and spiritual values.

- At the moment of death the life force and consciousness leave the body.
- There will be no response.
- There will be no movement.
- There will be no pain.
- All signs of the effort of “leaving the body” will be gone.
- Eyes are fixed in one direction. They may be open or closed.
- The jaw may be slack.
- There may be loss of control of bowel or bladder.

After someone has died family and friends may wish to stay by the bedside and say whatever words seem appropriate. There is no harm in touching the person's body and there should be no rush to move the person until everyone has had a chance to say their final goodbyes.

Support family in calling other family members, friends and any spiritual advisor they wish to have present.

“Reflecting on our discussion this session what do you see as the implications for volunteers”?

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?

SESSION 5

LOSS, GRIEF and BEREAVEMENT



Session 5: THE GRIEVING PROCESS

Welcome:

Ask if there are any questions from Session 4

The focus of this session will be on exploring the various types of loss that people experience, the grieving process, and the factors that influence a person's grief experience.

Learning Objectives:

- Explore the various types of loss that people experience.
- Explore the grieving process.
- Examine the factors that influence a person's grief experience
- Be aware of your own grief
- Discuss strategies to assist people through grief

Margaret Mead

When someone is born, we rejoice

When someone is married, we celebrate

When someone dies,

We pretend that nothing has happened....

Resources: Regional manuals or brochures

Loss:

Question for the group:

Consider your own life and how often you have experienced loss. What kind of loss have you experienced?

(Possible responses: death of a parent, brother, sister, or child; a job, a familiar neighbourhood, a home; some physical ability; a pet; something you owned that was important to you [wedding ring, favourite earrings]; health, friendship, family, role, identity, independence; country, finances; direction, sight, energy, interest, ability to make decisions, hope.)

Can you identify anything helpful that you have learned as a result of these losses?

LOSS

As people and their family deal with a life-threatening illness, they often experience a number of different types of losses. These include losses they have experienced in the past, losses in the present and future losses. For example, a person who is dying may relive the loss of losing a loved one, may believe he/she has lost some of their value as a person because they can no longer fill their role as a parent or perform to their usual capacity at work, and grieve future losses such as having grandchildren or missing a holiday with family and friends.

People can experience a number of losses including: (Rando, 1984)

- Loss of control

- Loss of independence
- Loss of productivity
- Loss of security
- Loss of various types of psychological, physical and cognitive abilities
- Loss of predictability and consistency
- Loss of experiences
- Loss of future existence
- Loss of ability to complete plans and projects
- Loss of dreams and hopes for the future
- Loss of significant others
- Loss of familiar environment and possessions
- Loss of aspects of the self and identity
- Loss of meaning

People experience loss in different ways. It is important for the volunteer to listen and not to pass judgment on people's various experiences or the way they experience this loss

Reflect on the Circle of Life – Session 2 (this exercise is not included again in the volunteer manual)

Circle of Life Exercise

This exercise provides a helpful way of understanding what is and has been important in a person's life, the sense of fulfillment and /or regrets, and the losses for the person who is dying.

7. **Your Life:** Make a list of the facets of your life which are most important to who you are. These may include family, friends, work, money, travel, hobbies, physical health, fitness, volunteer work, spirituality/religion, etc.
8. **The Circle:** Draw a circle and mark the center. What is at the center of your life? Write or draw this at the center.
9. **The Parts:** Now considering each of the important facets of your life, draw in the “slices” of the pie - the more important that facet is for you, the bigger the slice.
10. **Present Fulfillment:** Consider each facet of your life you have drawn in - and starting at the centre of the circle colour in how fulfilled you are in this area of your life today. For example, if you consider physical health/fitness important, yet you are not exercising regularly, then you would color in only part of that slice.
11. **Discrepancies:** How do you feel about the discrepancies between what is an important part of your life and the lack of fulfillment in that area? Are there changes that you want to make to have this area of your life be more fulfilled?
12. **Loss with illness:** Imagine that you have been diagnosed with a terminal illness, and you are at the stage where you are no longer able to go out of your home and you are spending more and more time lying down. Which of the areas of your life will fall out of the picture? How would you feel about these losses? What will fill these spaces? What facets of your life will come into focus and become larger “Pieces of the pie”? At this time you can draw a new circle with sections that reflect these changes in roles, activities, and what becomes ever more important.

Again, turn to the person beside you and share how the circle of your life would change in this situation.

GRIEF

Anticipatory grief

Anticipatory grief is the sadness and grieving that occurs before the actual loss. You anticipate losses that may or may not occur when the person dies. Anticipatory grief ends when the death or loss actually occurs.

Grief

A natural emotional response experienced in anticipation of, during and after a loss. It is part of a healing process that helps a person let go of the past and adjust to life without the loved one who has died.

There is no set time frame for grieving and it varies from person to person. For example, people may experience intense or mild grief reactions. For some, grief begins immediately while for others it is a delayed response. In some cases, grieving can be brief while for others it goes on for years. Some people may grieve privately, while others are more public about their grief.

Bereavement

Bereavement is the normal, essential psychological reaction to a death (including sadness, loneliness, anger, fear and guilt). Individuals resolve painful emotions and gain a degree of acceptance of their loss.

Mourning

Mourning is the process of incorporating the experience of the loss of a loved one into our ongoing lives.

It is the outward acknowledgement of our loss.

Mourning Needs and Tasks

- Acknowledge the reality of the loss
- Experience the pain of the loss
- Remember the person who died
- Develop a new identity
- Search for meaning
- Receive ongoing support from others

GRIEF REACTIONS

Grief is complex. We show our grief physically, emotionally, behaviorally, intellectually, and spiritually. It can be helpful to know that what we are experiencing in grief is “normal”. Listed below are some of the common reactions people may experience.

Physical reactions

- Weakness and fatigue
- Rapid heartbeat
- Changes in sleep patterns
- Decreased resistance to illness

- Increased blood pressure
- Increase or decrease in activity
- Changes in self-care
- Weight and appetite change

Emotional reactions

- Numbness
- Confusion
- Sadness
- Guilt
- Yearning for what is lost
- Despair & hopelessness
- Helplessness
- Feeling of being lost & alone
- Anger
- Bitterness-vengefulness
- Peacefulness
- Relief

Behavioral reactions

- Searching for what was lost
- Detached from surroundings
- Disorientated to time and place
- Crying
- Unable to concentrate
- Forgetfulness
- Blameful of others
- Withdraw from friends & activities
- Finishing “unfinished business”
- Seeking & providing forgiveness

Intellectual reactions

- Altered self-esteem
- Problem-solving
- Repeated review of the event & death
- Increase/decrease of dreams
- Hyperactivity
- Suicidal thoughts
- Search to understand the loss
- Wisdom
- Disbelief/denying or avoiding reality of loss
- Creativity
- Attending to practical needs

Spiritual reactions

- Pessimism or realism
- Destruction of ideals/beliefs
- Emptiness/reason to live challenged
- Search for meaning
- Acceptance
- Forgiveness
- Experiences of connectedness, wholeness, rebirth
- Compassion

What hurts one, hurts the whole

OTHER FACTORS IN THE GRIEF RESPONSE

Everyone mourns losses in an individual way. There are many factors that may influence the grieving process.

Nature of the attachment

More intense grief responses occur when someone has lost an individual who was very close to him/her. A very dear friend, a lifelong partner, or a child are examples of such close attachments. He/she needs to adjust to his/her new life without this significant person.

Previous losses

The way an individual has dealt with previous losses will affect the successful completion of the bereavement process.

Spiritual & Cultural factors

Every individual has his/her own belief system and cultural heritage that will contribute to his/her ability and methods for dealing with loss e.g. expressions of grief, acknowledgement.

Current stresses

Grief is difficult for everyone but, if everything else in your life is stable and comfortable, then getting through grief will be a little bit easier. If, on the other hand, you are grieving a death and have financial problems, an addiction problem and trouble at work you will not be able to focus solely on dealing with your grief, and you may have more difficulty with the impact of the loss.

Social support

Isolation and loneliness are serious hindrances when dealing with grief. A strong social network that includes people to rely on for practical matters and matters of the heart, are critical for an individual in this difficult time.

Disenfranchised grief

Grief that is not often acknowledged e.g. miscarriage, death of ex-spouse, AIDS/HIV

Accumulated Grief

A series of losses over a period of time.

Developmental stage of family and family members

Whether there are young who are also grieving and need support makes a difference in how grief is experienced.

ELEMENTS OF HEALING

- Try to remember, try not to forget.
- Good memories (I remember when...stories) are important.
- You need support from both inside and outside your family.
- Learning about the experience of others gives insight into your own story.
- Assume whatever you are going through is normal.
- Share the pain of your darkness.
- Be sensitive to the fact that people grieve differently.
- Sharing with those who have been there has a special meaning.
- Feel free to protest the “why” of death but know that this question may never be answered.
- Take time and space for yourself and work through your guilt over doing so.
- Take time to laugh and to cry.
- Take the initiative and make things happen for yourself; work, activity, exercise.
- Talk about your feelings with someone you trust and will maintain your confidence.
- Life will never be like it was. You will need to create a new life, make new choices, develop new friendships.
- Reach out and help others. Beware of dwelling on yourself.
- Confront guilt by realizing you did the best you could. (“All things considered, with no rehearsal for what you went through, you did the best you could.”)
- Through dreams, visions and other means, it is possible to experience the comforting and reassuring presence of your loved one(s).
- Seek spiritual comfort from a greater power (e.g. God, Jehovah, Great Spirit, etc.)
- There is nothing wrong with talking to the dead.
- Persons who have been down the road before you can be symbols of hope.
- Your experience of death may cause others to make significant changes for the better in their lives and relationships.

Adopted from: Rev. Kenneth Czillinger discusses his “Elements” in an eight cassette album from N.C.R. cassettes entitled “A TIME TO GRIEVE.” Available at most religious book stores. He is well known nationally for his work with bereaved people. Permission to reprint granted by Rev. Czillinger.

HOW to HELP OTHERS THROUGH GRIEF

Be there

Grieving people need support and presence much more than they need advice. Stay connected to them.

Listen - Avoid Judgment

Grieving people often need to tell their stories over and over. Listening without judgment or interruption can be the most important gift you can give. This often takes a long time and many visits.

“You should....” and “You shouldn’t....” are not appropriate or helpful.

Avoid “clichés” and easy answers

“Only the good die young”, “Time heals all wounds”, “It’s God’s will” are generally not comforting. “I’m sorry”, “I care”, or “You’re in my thoughts”, may be a better response.

Use touch

Touch can say in silence what words cannot express.

Silence is golden

Sometimes there are no words for grief and no words that bring enough comfort to take away the pain. Silence can demonstrate your trust and acceptance.

Send a sympathy card

- **Acknowledge the loss.** Mention the person’s name, how you learned of the loss and your immediate feelings (shock, sadness, dismay, etc.)
- **Express your sympathy.** Share sorrow in an honest and sincere fashion. Show care and understanding of how difficult the situation must be. It is okay to use the words, “dead” and “died”.
- **Recount a memory** about the person who died as they are very much valued.
- **Offer assistance.** Offering help need not be part of a condolence letter, but if offered, it should be kept specific.
- **Close the letter with a thoughtful word or phrase.** Final words in a condolence letter are especially useful. They should reflect your true feelings. Honest expressions of your thoughts and feelings convey best to the bereaved.

Accept and encourage the expression of feelings

Reassure the person that grief has many feelings...the feelings are like barometers that indicate the weather inside our thoughts. Expressing them and looking at both sides of them can help to change the weather.

Tears are healing

Don’t be afraid to cry. Your tears are a tribute to both the deceased and to their loved ones.

Yes, they may cry with you, but their tears may be a healthy release.

Offer opportunities for remembering

- Special events:
 - Anniversary of the death
 - Christmas
 - Mothers Day/Fathers Day
 - Deceased Birthday
 - Deceased Wedding Anniversary
- Say the deceased person’s name
- Share memories

Help the person find support

Who is supportive, who is not? Where does the person feel comfortable?

Stay in Touch

- Grief does not end at the funeral.

- After a death, relationships may change.
- Sometimes people don't know how to relate to the one who is grieving.

Allow the person to grieve at his or her own pace – Be Sensitive

Grief is as individual as each person. No one can judge the length of time it takes. No one should conform to other people's needs or ways. Encourage people to listen to their own process of grief.

Provide for times of lightheartedness

Grief can be like swimming upstream. Sometimes you just need to take a break to regroup.

Believe in the person's ability to recover and grow – Be Patient

Your hope and faith may sometimes be needed when hope fails.

Your trust in their ability to heal is essential. Listen, but do not push.

Time does not heal all wounds.

- The grief process should not be rushed... there is not a standard time frame to follow.
- "Get on with your life"; "Aren't you over it yet?"; "It's time to put it behind you and move on." These are unfair and unrealistic.
- Reassure the grieving person that grief work takes time and that they may be expecting too much of themselves too early.

Ritual

In our society some leave-takings are accompanied by rituals (e.g. funerals), and some are left without any formal ceremony to help us acknowledge a passing through (transitions) or passing away (ending). We can discover, rediscover or invent rituals to help us formalize and honor a special good-bye experience.

The VOLUNTEER'S GRIEF

- It is important to acknowledge your grief.
- A volunteer may experience grief before or after a patient dies.
- Practicing self-care may help a volunteer avoid burnout

Take a few moments to review a history of your losses. Spend some time reflecting on your answers. This reflection can pay dividends later on in helping you understand your grief experiences.

1. The first death I can remember was the death of: _____

2. I was age: _____

3. The feelings I remember I had at the time were: _____

4. The first funeral (wake or other ritual service) I ever attended was for: _____

5. I was age: _____

6. The thing I remember about the experience is: _____

7. My most recent loss by death was(person, time, circumstances): _____

8. I coped with the loss by: _____

9. The most difficult death form me was the death of: _____

10. It was difficult because: _____

11. Of the most important people in my life who are now living, the most difficult death for me would be the death of: _____

12. It would be the most difficult because: _____

13. My primary style of coping with loss is: _____

Adapted from Worden, Grief Counseling & Grief Therapy

Tips for coping with grief

- Express your grief.
- Attend the person's funeral.
- Write a condolence to the person's family.
- Talk about feelings with family, friends, colleagues, other team members.
- Talk about feelings with your coordinator.
- If you are a religious person, remember the person in your prayers.

Video: Sesame Street

Check CVH video library

CHILDREN'S GRIEF - BASIC NEEDS

- Need for information that is clear and understandable to them
- Need to feel involved and important
- Need for reassurance about the grief of adults around them
- Need for their own thoughts and feelings
- Need to maintain their own age-appropriate interests and activities.

Talking with Children about Death

- Death should not be a “hush-hush” topic with children. Relying upon euphemistic phrases such as “she passed away” ...”He’s gone to sleep”... are often more harmful than helpful. *DEATH IS A NATURAL and NORMAL CONSEQUENCE OF LIVING*. It should not be a taboo subject for thought or discussion.
- Virtually every child will experience the death of a friend, a pet or a family member (or knows someone who has had such an experience and shared it with them). Children do develop thoughts and ideas about death at an early age. They also learn quickly who they can and cannot talk with about those thoughts and ideas!
- **Ages 3-5:** These children do not yet accept death as a permanent process. Death has an ending and they often ask questions such as...”When will Grandma come back?” They fear separation more than death.
- **Ages 5-9:** These children are beginning to understand that death is permanent, but it is not yet universal. Death is often personified and given powers to select those who are to die.
- **Ages 9-12:** Death, for these children, is permanent, personal and universal. They understand they, too, will die.. SOMEDAY. They are fascinated with the whole concept of death and find details of death events appealing.
- **Ages 12+:** Most adolescents have reached adult levels of understanding about death.
- Many adolescents have very intense emotions about death and do spend time thinking about death.
- Children should be offered opportunities to talk about death as they experience it in their everyday world. The death of flowers, leaves, pets and relatives should be addressed as a natural occurrence in the scheme of life.
- Children should be included in the rituals of death whenever possible and appropriate. They should be offered the opportunity to participate if they so desire.
- Expressions of sadness and grief should be shared. They can participate in the support of family and friends and should be included in family visits and conversations.
- Children’s questions about death should be answered as honestly as possible. It is important to try to discover what is behind the question being asked and to respond appropriately. Do not feel obligated to have all the answers! Sometimes, wondering and exploring are more important than

answering. Do not ignore questions, however. Some type of response is always needed as children will create answers for questions not heard and explored.

CHILDREN and CHANGE

GRIEF is a natural and normal reaction to loss and change. It is a physical, emotional, spiritual and psychological response. The death of a loved one is perhaps the most devastating loss one may experience. Yet, grief occurs following *ANY* change in our lives. Even positive changes can bring a momentary grief response....

We cannot always know what a child is thinking or feeling. We must take cues from their behavior. A child grieves his losses with the same hurt as an adult...perhaps for different reasons, but the hurt is just as deep and no less painful simply because the surface area is smaller.

Children tend to cope with change by expressing themselves in ways of behaving. They *ACT OUT* their feelings and fears rather than talk about them. They may not always understand *WHY* they hurt, but they can clearly identify *THAT THEY HURT!* All children react differently, but some of the most common expressions of grief in children (whether they are coping with a death, divorce, abandonment, family move or friendship dissolution) are:

- Anger
- Feelings of Abandonment
- Guilt
- Apparent Denial
- Bodily Distress
- Temper Outbursts
- Regression
- Silence
- Withdrawal
- Panic
- Depression
- Overactivity
- Behavior Changes
- Disinterest in previously engaging activities
- 'Model Behaviors'
- Increased Dependency upon Significant Adults

Don't tell me that you understand

Don't tell me that you know,

Don't tell me that I will survive,

How I will surely grow.

Don't tell me this is just a test,

That I am truly blessed,

That I am chosen for this task,

Apart from all the rest.

Don't come at me with answers,

That can only come from me,

Don't tell me how my grief will pass,

That I will soon be free.

Don't stand in pious judgment

Of the bonds I must untie,

Don't tell me how to suffer,

And don't tell me how to cry.

**My life is filled with selfishness,
My pain is all I see,
But I need you; I need your love,
Unconditionally.**

**Accept me in my ups and downs,
I need someone to share,
Just hold my hand and let me cry,
And say, “My friend, I care.”**

Joanetta Hendel

FUNERAL CONSIDERATIONS

Funeral and burial considerations vary amongst individuals, cultures and faith traditions.

Often funerals and memorial services are pre-planned. Many funeral homes supply pre-planning services. A pre-planned funeral and/or memorial service can protect your family members and/or loved ones from having to make decisions that can be emotionally or financially stressful during a difficult time. Pre-planning can also better facilitate individual wishes.

There are steps that can be taken to prepare for a funeral and memorial service.

- Discuss plans and ideas with family members and/or loved ones

- Discuss plans with a Spiritual Care Provider
- Choose a funeral home and funeral director

There are things to consider in planning a funeral and/or memorial service.

- Will there be a service?
- What type of service will it be? Graveside? Memorial? Funeral?
- When will the service be held? Weekday? Weekend?
- Where will the service be held? Church? Chapel? Funeral Home? Home? Camp? Garden?
- What will the service include? Music? Readings?
- Who will officiate? Spiritual Care Provider? Member of the Clergy? Friend? Family Member?
- Will there be a viewing?
- Will it be a burial or cremation? Will cremation be scattered, buried, or kept?
- Where will the burial be located?

A funeral/memorial service provides an opportunity to celebrate and honour the life of a loved one. For the family members and loved ones that are left behind, this can be an important aspect in the healing process.

Should Children and Teens Attend the Funeral and/or Memorial Service?

All who loved the person who died should be invited to participate in the funeral and/or memorial service. This includes children. Children can even help plan the funeral. Children should be invited to attend but never forced.

Most children are not afraid of death and funerals.

“Any child old enough to love is old enough to grieve and to mourn... and should have the same right and privilege to be included in the ceremony as anyone of any age!”

- Alan D. Wolfelt, Ph. D.

“Reflecting on our discussion this session what do you see as the implications for volunteers?”

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?”

SESSION 6

COMPLETING THE CIRCLE



Session 6: Completing the Circle

Welcome:

Ask if there are any questions from Session 5

We have addressed:

- Introduction to palliative care
- Understanding the dying person and their family (Emotional, Cultural and Spiritual)
- Communication (listening and responding)
- Physical Care of the Dying
- Loss, Grief, and Bereavement

In this session we will look at “Completing the Circle”

Learning Objectives:

- Review the role of the palliative care volunteer
- Identify mechanisms for self care
- Discuss relevant legal issues

Take a few minutes to go around the table and have the participants identify 1 or 2 things that they learned or relearned that has had the greatest impact for them.

Review the goals that the volunteers identified at the first session

Video: Dying for Care – 17 minutes

Allow time following for volunteers to relate to any of the statements made in the video.

The Role of the Palliative Care Volunteer – (slide)

There is no way to measure the depths of a volunteer's contribution in Palliative Care. By establishing a supportive relationship with the person who is dying and the family with the hope of lessening fear, isolation, and promoting quality of life. Your presence, your support, and your caring will have great meaning to the dying person and to family members. The experience will change you forever.

- Palliative Care Volunteers enhance the services provided by the Health Care Professional on the Palliative Care team.
- Palliative Care Volunteers provide the gentle touch, a compassionate ear, and extra care and compassion for a terminally ill patient.
- They are involved through the stages of illness, through death and the bereavement process.
- The role of the volunteer may be challenging, and at times draining, but always rewarding.
- Palliative Care Volunteers are given support and encouragement throughout the journey.

How Do We Help the Dying Person and Their Family?

- Listen to music together
- Read aloud, share a magazine
- Play cards and board games
- Look at photographs together
- Go for a walk
- Life review with words, pictures, music, story-telling
- Make a memory album
- Reminisce about fond memories, write them down
- Discuss previous hobbies, interests
- Do some simple craft work
- Watch a video
- Spend some quiet time together
- Walk the dog
- Relieve caregivers for short periods
- Help with outings, shopping, transportation
- Help write letters, mail letters
- Make a small snack and beverage

The Do's of Volunteer Work

- be available
 - be patient and let your concern show
 - let the person who is dying, family members and friends express their feelings
 - apply common sense
 - be caring and affectionate
 - be honest and accepting
 - be sensitive to the person's need for privacy
 - try to interest the person in recreational activities, if appropriate
 - be yourself
 - contact the volunteer supervisor if you can't make your shift
 - be aware of your limits to help
 - let the person to be at the stage they are in
 - be near the person to help but don't take away their independence
 - take care of yourself
 - be aware that people's interest and ability to visit fluctuates due to illness and medication
 - feel comfortable to use the words dying and death (this may give permission to the person and family to have more open discussions)
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The Don'ts of Volunteer Work

- be aggressive
- be overly cheerful
- give advice
- be judgmental or critical
- assume you know how the other person feels
- discuss the person's condition with others without their permission
- take the focus off the person by talking of your own similar problems
- be afraid of your own similar problems
- be afraid to say, "I don't know"
- hesitate to call for help
- take it personally should the person or family refuse a visit
- dispense medication

Friend or Volunteer, Is There a Difference?

By Jeanette Browne, Volunteer Services Coordinator, Trinity Home Hospice, Toronto

Yes, indeed there is!

Hospice volunteers are motivated by many things. It could be a need to give back to their communities, to learn a new skill or to make a difference to others. Whatever their reason, they have chosen to do this work with a hospice.

Having made that decision, they then become part of the organization's team and must follow the conventions that govern it. One of these conventions is to provide quality care, while still maintaining an appropriate distance. What seems to be in question is determining: "what is appropriate distance?"

We want all hospice volunteers to be compassionate: to feel deeply for their clients while working with the rest of the team to alleviate pain and suffering. Successful volunteers do this while maintaining personal boundaries. The boundaries define the role of volunteer as one of engaging in friendly and compassionate acts without becoming "a friend".

A successful friendship requires both giving and taking; it assumes that there will be mutual support. This relationship is one of balance, with each party taking turns being the giver or recipient of care. Friendships are rooted in the past and look to the future.

A hospice volunteer/client relationship differs dramatically from a friendship. Volunteers do not expect reciprocal support from their client. While volunteers do their utmost to advocate for and support the client's autonomy, they are nevertheless, in the home to be a caregiver. There is a natural imbalance to the relationship. It is inappropriate to expect to have our own needs met.

Other differences illustrate this further. Volunteers visit according to schedule and their actions are limited by policies. Friends visit when they wish and may act according to the direction of the client. Volunteers may not accept gifts. Friends can be the recipients of great generosity.

Let us always remain clear about the value and importance of the hospice volunteer role. The care given is valuable in and of itself. It is unnecessary to paint this work with the brush of friendship to increase its value in the eyes of the client.

“COMPANIONING”

(Adapted from Dr. Alan Wolfelt's Guiding Model for Counseling the Bereaved)

Dr. Wolfelt describes the word ‘companion’, by breaking it down into its original Latin roots. ‘Com’ means ‘with’ and ‘pan’ means ‘bread’. Someone you would share a meal with, a friend, and equal. He takes the liberty with the noun “companion” and made it into the verb ‘companioning’ because it so well captures the type of relationship required in providing bereavement care.

- **Companioning** is about honouring the spirit; it is not about focusing on the intellect.
- **Companioning** is about curiosity; it is not about expertise.
- **Companioning** is about learning from others; it is not about teaching them.
- **Companioning** is about walking alongside; it is not about leading.
- **Companioning** is about being still; it is not about frantic movement forward.
- **Companioning** is about discovering the gifts of sacred silence; it is not about filling every painful moment with words.
- **Companioning** is about listening with the heart; it is not about analyzing with the head.
- **Companioning** is about bearing witness to the struggles of others; it is not about directing those struggles.
- **Companioning** is about being present to another person’s pain; it is not about taking away the pain.
- **Companioning** is about respecting disorder and confusion; it is not about imposing order and logic.
- **Companioning** is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

THE UNIQUE STRESSES OF PALLIATIVE CARE (SLIDE)

Palliative care may be difficult work both physically and emotionally. This work is unique and may contribute to stress.

The purpose of this exercise is to encourage participants to examine their own personal stresses. The exercise also highlights factors that cause stress in your current life. It is important to be aware that the stresses associated with being a palliative care volunteer may increase your personal stress.

Stress is defined as “demand placed upon mental and physical energy”.

People have a limited amount of energy available to deal with stressful situations. If a person’s energy supply is not replenished the outcome is exhaustion or burn-out.

Recognizing the symptoms of burn-out is the first step to preventing it from getting out of control.

THE STRESS TEST

1. Personal Involvement Checklist

- I cancel personal activities because of work.
- I regularly speak to one or more of my patients outside of work hours.
- I routinely spend more time with my patients than assigned.
- When feeling pressured, I do things myself rather than ask for help.
- Friends and family often turn to me for help and advice.
- My main source of satisfaction is my work.
- I go out less socially than I used to.
- My family problems have been increasing.

2. Frustration Checklist

- I have difficulty communicating with patients and their families.
- I have difficulty communicating with my supervisor.
- I feel unable to help my patients who are in distress.
- I am unclear about what is expected of me. My work is being criticized by patients and/or my supervisor.
- I always give support, but seldom receive any support myself.
- I feel that I am unable to function effectively.
- I feel tension between myself and patients.
- I get angry with patients and families.

3. Over-extending Checklist

- I feel overwhelmed with my own flaws.
- I feel guilty if I say “no” when asked to help.
- I feel overwhelmed with patient needs and amount of work.
- I feel I’m not doing a good job.
- I feel crabby, resentful, sarcastic.
- I feel exhausted.
- I feel lonely and isolated.
- I feel behind in my responsibilities.
- I indulge in food or alcohol or cigarettes.
- I feel I do not have someone to speak to regularly about my work experiences.
- I cannot slow down.

4. Physical Checklist

- Sleep disturbances
- Stomach problems.
- Back pain.
- Recurrent respiratory infections.
- Headaches.
- Other health problems.....

THE WARNING SIGNS OF BURNOUT (slide)

Mental / Emotional Symptoms:

- Disillusioned with work
- Withdrawal
- Negative or cynical attitude
- Lack of patience (short “fuse”)
- Mood swings
- Short attention span
- Change in personality

Physical Symptoms

- Fatigue / exhaustion
- Headaches
- Gastrointestinal problems

Behavioral Symptoms

- Increase in sick time
- Lateness
- Avoidance of patients
- Conflicts with others
- Substance abuse
- Changes in eating and sleeping patterns.

12 Suggestions for Taking Care of Yourself (slide)

By Thomas Wright, LMFT

1. Learn to air your feelings.

Don't keep them bottled up inside you. Share your sorrows and disappointments with someone you trust. Remember, expressed feelings are changed feelings.

2. Avoid comparing yourself with others by admiring their gifts and ignoring your gifts.

This kind of envy causes self-disgust. Put no one's head higher than your own.

3. Form a small group of people you can call on for emotional support.

Agree to "be there" for each other. Offer advice only when it is asked for. Listen without interrupting. Take turns talking and listening.

4. Take time to play.

Remember that play is any activity that you do just because it feels good. Remind yourself that you deserve to take time to play.

5. Don't forget to laugh, especially at yourself.

Look for the humor in things around you. Let your hair down more often. Do something silly and totally unexpected from time to time.

6. Learn to relax.

You can find books, tapes, programs, classes, instructors and other materials to teach you how to relax. Relaxation improves the mind, helps the body heal, and feels so much better than stress and tension.

7. Protect your right to be human.

Don't let others put you on a pedestal. When people put you on a pedestal, they expect you to be perfect and feel angry when you let them down.

8. Learn to say no.

As you become comfortable saying no to the unreasonable expectations, requests or demands of others you will discover that you have more compassion. When you do say yes to others, you will feel better about yourself and the people you're responding to.

9. Change jobs if you are miserable at work.

First, try to figure out if the job is wrong for you or if certain people are causing you to feel miserable at work. Try paying more attention to the things you enjoy about your job and less attention to the things that annoy you. Remember that all jobs have some unpleasant aspects.

10. Stretch your muscles.

Break a sweat. Go for a walk. Ride a bike. Park farther from the door. Take the stairs. You don't need fancy clothes, club memberships or expensive equipment to add exercise to your daily life.

11. Practice being a positive, encouraging person.

Each time you give others a word of encouragement you not only feel better, but you build up your best self.

12. Pay attention to your spiritual life.

Slow down. Practice sitting quietly. Listen to your inner voice. Spend time thinking about the things which bring peace, beauty and serenity to your life. Find the courage to follow your own spiritual path if a traditional religion has not been helpful for you.

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SELF-CARE PLAN

Give time for the volunteers to answer the questions:

Things I really enjoy doing:

Things I find very relaxing:

Something I have always wanted to do but never had time for:

People I like to be around:

List ideas of enjoyable activities that you can reasonably do between work and settling into your home:

Identify one new activity that you enjoy doing that you will incorporate into your weekly routine:

Name one person you enjoy talking with, but rarely have the time to do so:

Pick a regular time to call this person. When and how often will you promise yourself to call?

Whom to talk with when I have had a good day:

Things to avoid when I have had a bad day:

Things to avoid when I have had a good day:

Everything I need to know about life, I learned from Noah's Ark ...

1. Don't miss the boat.
2. Remember that we are all in the same boat.
3. Plan ahead. It wasn't raining when Noah built the Ark.
4. Stay fit. When you're 600 years old, someone may ask you to do something really "Big".
5. Don't listen to critics; just get on with the job that needs to be done.
6. Build your future on high ground.
7. For safety's sake, travel in pairs.
8. Speed isn't always an advantage. The snails were on board with the cheetahs.
9. When you're stressed, float a while
10. Remember, the Ark was built by amateurs, the Titanic by professionals
11. No matter the storm, when you are with a Higher Power, there's always a rainbow waiting.

Remember that amateurs built the ark...professionals built the Titanic

“Reflecting on our discussion this session what do you see as the implications for volunteers”?

Note to facilitators: Please consider the following:

Do you see potential for boundary confusion?

Do you see potential for relationship building with other members of the team?

Do you see potential for any safety concerns (any risk management issues)?

Do you see potential ethical implications?”

Facilitator: Discuss the expectations of your Regional Palliative Care Volunteer Program

Set up dates for interviews