

MODULE 4: EMOTIONAL/PSYCHOLOGICAL ISSUES AND SUPPORT

LEARNING OBJECTIVES:

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

COMPETENCIES:

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

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

1. WHAT IS A GOOD DEATH?

Dying is a very intimate, personal experience.

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

However, most people believe that dying well includes:

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

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

Gallasch, 1996

2. THE EMOTIONAL/PSYCHOLOGICAL NEEDS OF THE DYING PERSON

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

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

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

Gallasch, 1996

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

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

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

3. THE VOLUNTEER'S ROLE IN EMOTIONAL SUPPORT

People who are dying and their families need:

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

To provide effective emotional support, the volunteer must:

- be in tune with his or her own feelings and emotions about death and dying
- give people the freedom to express what they need to express

- be sensitive to people with special needs, such as people who been in abusive relationships or who are estranged from their families
- acknowledge their sense of loss
- give people the time they need to come to terms with their fears and confusion.

WHEN TO ASK FOR HELP?

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

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

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

4. THE VOLUNTEER'S ATTITUDES AND BELIEFS ABOUT DEATH AND DYING

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

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

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

5. THE ROLE OF CULTURE AND SPIRITUAL BELIEFS

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

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

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