



## Module 4

# PSYCHOSOCIAL & SPIRITUAL CARE

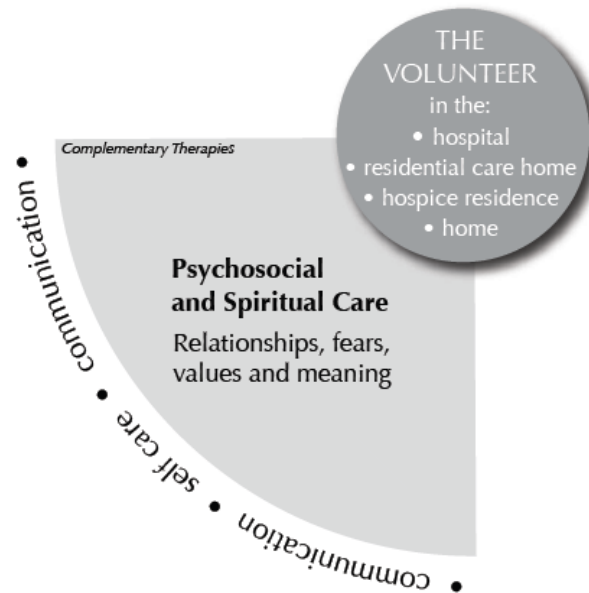
### *The Way of the Heart*

*“Let us not underestimate how hard it is to be compassionate. Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely and broken. But this is not our spontaneous response to suffering.*

*What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant (caregivers), we want to earn our bread by making a real contribution.*

*This means first and foremost doing something to show that our presence makes a difference. And so we ignore our greatest gift, which is our ability to enter into solidarity with those who suffer.”*

*Henri Nouwen*



Though interconnected, there are distinctions between psychosocial, and spiritual care that warrant separate attention. To facilitate training, this module has been divided into two sections with spiritual care presented on its own. This provides the option to integrate the two sections or refer to them individually

### A. Psychosocial Care

#### Learning Outcomes

Upon completion of the Psychosocial Care Module, the volunteers will:

1. Understand what is involved in the psychosocial care of their clients.
2. Understand and respect how their clients may respond emotionally and socially to their illness.
3. Understand and respect how their client's family and friends may respond emotionally and socially.
4. Acknowledge and respect their own psychosocial preferences and needs.
5. Recognize and respect the limitations and healthy boundaries around psychosocial care of their client and family.



### **Definition of Psychosocial Care**

Psychosocial care tends to the emotional well-being of the client and family and honors and supports their relationships with those close to them and those involved in their care.

Psychosocial care enriches the quality of a client's day-to-day life.

Hospice volunteers play a key role in the psychosocial care of their clients and families. It can be the most challenging and rewarding aspect of their work. Above all, volunteers will need to listen and communicate well and be comfortable and confident in their ability to be present for, and responsive to, the clients and families they support.

The volunteer's training in loss, grief and bereavement (Modules Five and Six) will be integral to Psychosocial Care. In other words, volunteers will be attentive to and comfortable with the client, family or friend as they express their feelings of grief, loss and/or loneliness



### Psychosocial Care and the Role of the Hospice Volunteer in Different Settings

Setting	Psychosocial Care	Volunteer Role
Hospital Hospice Residence Residential Care Home	<ul style="list-style-type: none"><li>• Staff in all three settings may be skilled in integrating compassionate psychosocial care with medical, personal and practical care.</li><li>• Staff may be time-limited in their ability to provide this care.</li><li>• This care may also be provided by social workers and counsellors.</li></ul>	Volunteer involvement may include: <ul style="list-style-type: none"><li>• Being with the client and/or family either in silence or sharing activities.</li><li>• Providing information on support options outside these settings when asked.</li><li>• Knowing who to approach within these settings to obtain information or have questions answered.</li></ul>
Home	Professional care providers may be involved with the psychosocial care of patients in the home, although their time may be limited.	While personal and practical care are being tended to, the presence of the volunteer in the home is reassuring and supportive and includes: <ul style="list-style-type: none"><li>• Providing respite to family members.</li><li>• Visiting with the client and/or family members.</li><li>• Sharing activities with client and/or family.</li><li>• When appropriate, sharing knowledge of supports and resources or finding out about resources when asked.</li></ul>



### Training

#### Orientation and Basic Training

1. Provide an overview of psychosocial care, including a description of how this care is managed in each stage of the journey and in each of the settings where your volunteers will be working.
2. Provide an overview of psychosocial care in relation to:
  - family dynamics
  - children
  - teens
  - cultural diversity
3. Provide an opportunity for volunteers to explore their own feelings around illness, loss and grief.
4. Ensure that volunteers understand and respect their own personal limitations and boundaries.
5. Integrate with the module on loss, grief and bereavement.
6. Incorporate a practicum or “job shadowing” component to allow volunteers to learn on the job, in all settings, from an experienced volunteer.

#### Ongoing Training

1. Provide additional workshops or sessions on psychosocial care:
  - in different cultures
  - on family dynamics
  - of children and teens (both as clients and family members)
  - of people with disabilities, dementia, etc.
  - of marginalized people (poverty, homelessness, addictions)
  - in relation to sexuality and intimacy
  - and non-cancer illnesses such as AIDS (Acquired Immune Deficiency Syndrome), HepC (Hepatitis C), cardiovascular disease, diabetes, renal failure, etc.
2. Provide ongoing opportunities for volunteers to explore their own needs and limitations around psychosocial care of their clients and families.
3. Strengthen their communication skills.



### **B. Spiritual Care**

#### **Learning Outcomes**

In relation to spiritual care, the volunteer will:

1. Understand what is involved in the spiritual care of their clients.
2. Understand and respect their clients' needs and preferences around spiritual care.
3. Understand and respect the needs of their client's family and friends around spiritual care.
4. Respond appropriately to the spiritual needs of their clients and family.
5. Recognize and respect their limitations and boundaries in relation to spiritual care.
6. Be aware of and understand other resources available.

#### **What is Spiritual Care?**

Spirituality encompasses our view of life and the purpose and meaning we bring to it. For some, spirituality relates to a specific set of beliefs, values or practices. The spiritual care needs of each client will be determined by their uniquely individual perspective. At the end of life, a person's spiritual perspective may change. Spirituality involves faith and possibly religion.



### Spiritual Care and the Role of the Hospice Volunteer in Different Settings

Setting	Spiritual Care	Volunteer Role
Hospital Hospice Residence Residential Care Home Home	Spiritual care may be provided by spiritual leaders or supports of the clients' own choosing, including their faith community, family and friends.	Volunteers may contribute to spiritual care by: <ul style="list-style-type: none"><li>• Sitting quietly with their client, listening to music, reading spiritual/inspirational material, when asked.</li><li>• Being present when the client wishes to talk.</li><li>• Participating in spiritual practice with the client if invited and if comfortable doing so.</li><li>• Exploring with the client and/or the family what is important to them.</li><li>• Providing support to the client and family, when asked, with preparations for funeral or memorial services.</li><li>• Supporting young children and teens in expressing their feelings.</li><li>• Providing information on spiritual supports when asked.</li><li>• Knowing who to approach to obtain information or have questions answered.</li></ul>



### Training

#### Orientation and Basic Training

1. Provide an overview of spiritual care, including a description of how this care is managed in each of the settings where the volunteers will be working.
2. Provide an overview of spiritual care in relation to:
  - The different ways that clients respond spiritually to illness, death and grief.
  - How families, including children, may respond spiritually.
  - How different religions approach illness, grief, death and bereavement.
3. Provide an opportunity for volunteers to explore their own spirituality around illness, grief and loss.
4. Explore a range of ways that volunteers may support the spiritual needs of clients and families.
5. Ensure that volunteers understand and respect their own personal limitations.
6. Integrate this module with the module on loss, grief and bereavement.
7. Incorporate a practicum or “job shadowing” component to allow volunteers to learn on the job, in all settings, from an experienced volunteer.

#### Ongoing Training

1. Enrich the volunteers’ basic training, with workshops or sessions on spirituality:
  - in different cultures
  - of young children and teens (both as client and family member).
2. Invite a range of leaders from different religions to speak to the volunteers about their beliefs and rituals around illness, grief, death and bereavement.
3. Support the volunteers to continue exploration of their own needs and limitations around spiritual care of their clients and families.
4. Support volunteers to strengthen their communication skills, particularly around listening, silence, being present and body language.
5. Provide a range of resources or, sources for resources, on spirituality of loss, grief and bereavement.



# **RESOURCES**

## **Module 4**

### **PSYCHOSOCIAL AND SPIRITUAL CARE**

## **RESOURCES**

- **The Needs of the Dying**
- **Fears About Death and Dying**
- **Practice Scenarios ~ Palliative Support**
- **Practicing Cultural Competence: Skills For Care Providers**
- **Strategies for Working With Families From Different Backgrounds**
- **Religion & Spirituality**
- **Kubler-Ross' Stages of Grief Reaction and Spiritual Struggle**
- **From Christian Roots to Secular Service**

## THE NEEDS OF THE DYING

- *The need to be treated as a living human being.*
- *The need to maintain a sense of hopefulness, however changing its focus may be.*
- *The need to be cared for by those who can maintain a sense of hopefulness, however changing this may be.*
- *The need to express feelings and emotions about death in one's own way.*
- *The need to participate in decisions concerning one's care.*
- *The need to be cared for by compassionate, sensitive, knowledgeable people.*
- *The need to expect continuing medical care, even though the goals may change from "cure" to "comfort" goals.*
- *The need to have all questions answered honestly and fully.*
- *The need to seek spirituality.*
- *The need to be free of physical pain.*
- *The need to express feelings and emotions about pain in one's own way.*
- *The need of children to participate in death.*
- *The need to understand the process of death.*
- *The need to die in peace and dignity.*
- *The need not to die alone.*
- *The need to know that the sanctity of the body will be respected after death.*

Reprinted with permission from  
"The Needs of the Dying" by David Kessler  
Harper Collins Publishers (1997)

➤ [www.DavidKessler.org](http://www.DavidKessler.org)

## **FEARS ABOUT DEATH AND DYING**

### **Volunteer contact with terminally ill people**

The most valuable thing you have to offer someone else is YOU. Being consciously aware of and able to exhibit helpful behavior makes the contact stronger, but what the person you visited remembers most clearly is you, not what you did or said.

### **When we look at our fears about death and dying, we realize two things:**

1. A death that might be fearful and unwelcome to one person is desired by another; e.g. someone may fear to die suddenly without the chance to say good-bye to family and friends. Another may fear the awareness of impending death and wish to die suddenly.
2. The specific deaths that people fear are varied. But there are common themes. These include fear of being:
  - a burden,
  - in pain,
  - helpless and out of control,
  - pitied,
  - treated as weak or less than human or,
  - abandoned.

No one can take away another person's fears. Sharing our fears with another may be a relief, so the volunteer can assist by listening. We must be sure, however, not to contribute to the client's fears. For example, if the volunteer does not notify the client that he/she cannot keep an appointment the client may feel abandoned by the volunteer and/or a burden to the volunteer.

### **The three most common fears of a Palliative Client are:**

- uncontrollable pain;
- dying alone; and
- having their life viewed without meaning.

(Excerpt from material prepared by Victoria Association for the Care of the Dying)

## **PRACTICE SCENARIOS ~ PALLIATIVE SUPPORT**

- A. I've never been away from Joe for more than a couple of days. And I always left meals already prepared in the fridge and freezer when I did go away. I did all the grocery shopping and I'm the one who balances the cheque book. The neighbors and the kids have been keeping him feed and the house in groceries since I've been sick, but they can't do that forever. I guess he's going to have to learn how to do those things now.
1. What are possible feelings of the speaker?
  2. What are possible concerns or content behind what has been said?
  3. What is one response that would reflect content?
  4. What is one response that would check assumptions?
  5. What is one response that would clarify feelings?
- B. Just before my dad died he talked about seeing a light and people he knew. Some say there is life after death. I never believed all that hooey. I think he was just hallucinating, maybe brought on by wishful thinking or a fear of there being nothing after you die. What do you think?
1. What is one response that would reflect what has been said and then effectively put the question back to the speaker to answer?
  2. Do you think the speaker has any concerns or fears? If so, what do you think they might be?
  3. What do you think the motivation is for asking for your thoughts on the issue?
  4. How can you respond without being evasive or disrespectful?

## **PRACTICING CULTURAL COMPETENCE SKILLS FOR CARE PROVIDERS**

1. Self Awareness
2. Cultural Knowledge
3. Individual Focus and Attention
4. Don't Assume!
5. Ask questions – be interested
6. Be respectful – what customs and traditions are important?
7. Encourage the practice of traditions
8. Involve the family
9. Use an interpreter
10. Ask about and negotiate the treatment/care plan
11. Listen carefully
12. Consider non-verbal communication as Dr. Bowman states “emotional control is not always indifference and emotional expression not always hysteria”
13. Maintain Adaptability and Flexibility

*Sources: Bowman: Dr. K. “Cross cultural Considerations” presentation to Fraser Health Nov. 2004  
Victoria Hospice Society et al TRANSITIONS...2003, Health Profession Press*

## **STRATEGIES FOR WORKING WITH FAMILIES FROM DIFFERENT BACKGROUNDS**

1. Watch friends and family members. Pay attention to their actions, ways of communicating, etc.
2. Reserve judgment. Do not measure people by your standards.
3. Take note of the environment. If you're not sure about the significance of something, ask.
4. For a culture that is completely foreign to you ... seek out some resources that you could use to familiarize yourself with customs/beliefs. Books, videos, multicultural society, etc.
5. Talk to other volunteers and nurses who have been with Hospice a long time. Draw on their experience.
6. Never assume that all immigrants, First Nations, particular religious groups, etc. have the same experience and customs. Check out what you think you know.
7. Remain aware of compounding issues.
8. Become familiar with resources to which you can refer the family should they have difficulty. Your hospice organization will have access to the community services directory.
9. If in doubt, ask!

## RELIGION AND SPIRITUALITY

Although the two are not mutually exclusive, it is good to get a sense of the differences between religion and spirituality. The following chart was prepared by Art Anderson for the Chilliwack Hospice Volunteers and Awareness Group.

<b>Religion</b>	<b>Spirituality</b>
Concerns the customs, doctrines, creeds, rituals, writings, and traditions of a particular faith tradition.	Concerns an individual's or community's engagement in the work of developing and maintaining a sense of communion with the holy, the transcendent, the beyond.
Frequently is institutionalized, in a more or less hierarchical fashion, involving designated "holy persons" who have distinctly defined roles within the institution, while the majority of the faithful see themselves as participants, followers, or even spectators within the life and program of the institution.	May be institutionalized (as in a monastic order, or a Quaker meeting), but may also be experienced as a relatively solitary journey, with more of a "heart" connection to a fairly small community of mutual support and accountability.
Tends to be a matter of the head.	Tends to be a matter of the heart.
Often centered around regular communal worship and certain sacred writings.	Often centered around symbolic ritual and personal and communal experiences of spiritual engagement with the holy, while still honoring the importance of sacred writings.
Tends to focus on what is right.	Tends to focus on what is real.
Valuable in sustaining a faith tradition over many generations.	More concerned with depth of spiritual experience and the real outcomes of that experience in the lives of individuals and communities of the present.
May be inward looking and self-serving, or outward looking and self-giving.	May be inward looking and self-serving, or outward looking and self-giving.



## **KUBLER-ROSS' STAGES OF GRIEF REACTION AND SPIRITUAL STRUGGLE**

We can look at Kubler Ross' stages of grief reactions as another way to try to understand some dimensions of spiritual struggle and growth. These stages are:

1. *Denial*: The individual refuses to believe that the loss is happening. Serves as a buffer in helping the client mobilize defenses to cope with the situation.
2. *Anger*: The individual resists the loss. Anger is often directed at family and health care providers.
3. *Bargaining*: The individual attempts to postpone the reality of the loss. Serves as a plea for an extension of life or the chance to "make everything right".
4. *Depression*: The individual realizes the full impact of the loss. Serves as the preparation for the impending loss by working through the struggle of separation.
5. *Acceptance*: The individual comes to terms with the loss. Serves as a form of detachment exemplified by a void of emotion or Interest in worldly activities.

From: *Shelley Yeager, "Lecture Notes on Loss, Grief, Death and Dying: See  
[www4.allencol.edu/~sey0/loss1a.html](http://www4.allencol.edu/~sey0/loss1a.html)*

Not everyone experiences all these stages. People experience the different stages in their own way and order, often jumping from one "stage" to another and back and forth rather than in a smooth forward journey from "1." to "5."

When people are working through these reactions to loss, there is often a great deal of spiritual suffering. It is important that we don't try and take the suffering away by trying to impose our own spiritual solutions onto their spiritual struggles.

Each person needs to come to terms with their own losses in their own way. We're there to walk with them in that journey, not to tell them what to think, feel or believe.

## FROM CHRISTIAN ROOTS TO SECULAR SERVICE

It is important to acknowledge where and how hospice and palliative care began, and it was indeed the Christian churches that pioneered this invaluable work.

It is equally important to acknowledge the changing world we live in and to keep up with the times.

- It is paramount that every individual feels welcome and comfortable at hospice.
- Each and every person has their own religious, spiritual, agnostic or atheist beliefs.
- We make no judgment on the validity of anyone's beliefs
- We acknowledge the right of each individual to exercise their beliefs and to be free of discrimination or harassment based on those beliefs.
- We acknowledge the right of each individual to question their own beliefs and go through their own questions without judgment or influence toward a particular belief.
- The Hospice Society will make every effort to accommodate the spiritual needs of each guest.
- One member of the Palliative Care Team is a chaplain or priest who acts as a spiritual advisor. Any guest is welcome to speak with this person or to any other spiritual advisor of their choosing.

Volunteers are NOT here to give spiritual advice, share their own spiritual beliefs or influence a guest who is questioning their own faith. **This work is left to those who are appropriately trained.**