

MODULE 8: GRIEF AND BEREAVEMENT

LEARNING OBJECTIVES:

1. Understand grief as a normal part of life and how people cope with grief
2. Understand the diversity and complexity of the grief experience
3. Understand current grief and bereavement theory and practice
4. Understand the role of the volunteer in support people who are grieving
5. Be aware of grief and bereavement resources in the community

COMPETENCIES:

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

- Discuss examples of the human experience that may evoke a grief response
- Describe some of the losses that people might experience during the process of dying and how they may react and cope
- Describe some of the losses that families experience when someone is dying and how they may react and cope
- Identify personal, social and cultural factors that affect how people grieve
- Discuss what helps or hinders a grieving person
- Be able to identify complex grief and know when to link someone with other services

1. WHAT IS GRIEF AND BEREAVEMENT?

Grief, mourning and bereavement part of the human response to death.

Grief is a natural response to any type of loss and a source of stress for anyone experiencing a loss. People need both physical and emotional energy to cope with the changes brought on by loss. In our society, grief is almost always seen in terms of “work” or “tasks” that must be accomplished in order to cope with the new situation created by loss. Although there are some common physical, emotional and behavioural signs of grief, each individual grieves each loss uniquely.

Anticipatory Grief is the grief someone experiences in anticipation of death. The dying person and family may experience this anticipated loss of life as well as all the opportunities that are lost when death will occur. During this period of anticipatory grief, the person and family will often deal with unfinished business and/or begin to mourn.

Mourning is a process that helps individuals cope with grief. It involves rituals – such as burial rites and memorial services -- that reflect cultural and social norms and practices. During this mourning period, a grieving person undertakes the “tasks of grief”.

Tasks of Grief generally include:

- acceptance of the reality of the loss
- the experience of emotional pain and suffering
- adjustment to living without the loved one
- letting go.

When someone moves on with their life, builds new relationships and settles into new patterns of living, it is generally accepted that they have completed these four tasks.

Physical, Emotional and Behavioural Signs of Grief

- Tightness in the throat
- Disturbed sleep patterns
- Loss of energy
- Changes in appetite
- Palpitations and/or chest pain
- Loss of sexual desire
- Numbness
- Sadness
- Anger
- Fear
- Guilt
- Disorientation
- Crying and sighing
- Restlessness
- Wanting to die
- Abusing alcohol or drugs

Bereavement is the state of suffering a loss. A bereaved person is someone who has experienced the recent loss of a loved one through death and who is going through the process of mourning.

NEEDS OF PEOPLE WHO ARE GRIEVING

Everyone grieves differently and will have different needs. But most grieving people need and value:

- being alone and yet having company and being with others
- the opportunity to express their feelings without embarrassment – this often requires “permission” from those who are not bereaved
- the opportunity to tell and re-tell the stories of the life and death of the loved one
- information about what is normal (am I going crazy or is this normal to feel the way I do?)
- the gift of presence – just being there and being able to be counted upon
- permission to be self-absorbed and not feel guilty about it
- being able to laugh and not feel guilty about having fun
- permission to experience and express a roller coaster of feelings
- help with basic needs like grocery shopping, housekeeping and meal preparation.

We have all experienced loss in one way or another. All of us have mourned and grieved for some of those losses and we've done so in a way that reflects our background and outlook. Volunteers will witness grief in a variety of forms. You'll see family and friends who “pull away” and distance themselves from a person they care for and you'll see outpourings of emotion and hear tales of regret and sorrow. Loss and grief affects each of us differently.

Gallasch, 1996

MYTHS ABOUT GRIEF

Sometimes our ability to help people who are grieving is affected by common myths about grieving, including:

- Keeping busy is the best remedy for dealing with the death of a loved one.
- The less the subject of the death of a loved one is brought up, the easier it will be for the grieving person to adjust.
- Time heals.

The role of the volunteer is to support the bereaved person - not to try to “take away the pain”.

- The person who openly expresses their feelings about the death of a loved one is better able to cope than the person who keeps to him/herself.
- Usually, three months after the death, family members will adjust and begin to seem normal again.
- The best thing to do is to forget about the dead person.
- If the loss is not the first, the person usually heals faster. They have been there and the second time is easier.
- Because of the duration of the illness, family members and friends should have an easier time coping: they expected the person to die.
- Personal belongings should be disposed of as soon as possible. This way there are no painful reminders around the home to upset family members.
- People who visit the gravesite are just living in the past and refusing to move on.
- It's best to protect young children from death and not express your emotions in front of them.
- Wait until the child is older and then explain to them what has happened to their loved one.
- Having many sympathetic people around tends to prolong grief.

Grief takes time – at least a year and a half -- and people grieve in different ways. They need support and understanding, and the chance to talk when they want to and to express their grief in their own way.

How Volunteers Can Help People Who are Grieving

- Be with the griever in their pain; don't shy away from it
- Affirm and reaffirm the griever's value as a person
- Allow the person to express anger, even towards you.
- Explain the process of grieving, and explain that the emotions they are experiencing are natural
- Reassure the grievers that they will survive and the pain will diminish, and encourage them to recognize the good that remains after the loss
- Help the person decide what to do with mementos/reminders
- Plan a schedule with the grievers and help them keep to it
- Help with the necessary decision-making, but don't make the griever's decisions
- Give comfort in ways that you would appreciate
- Bring "aliveness" to the person: plants, children, pets, people
- Plan for difficult events such as anniversaries and holidays
- Encourage the person to develop and maintain friendships and connections
- Watch for escape into addictive patterns and behaviours
- Recognize the griever's vulnerability and help prevent exploitation
- Recognize and reinforce each sign of returning strength
- Try to find ways in which the griever can give as well as receive
- Help the family deal with practical concerns such as bills and the funeral

Grieving is a personal journey and people's needs will vary. Volunteers should never make assumptions about how people will handle grief or tell them what they should do. Volunteers can help by using their communication skills and just being themselves.

2. STAGES IN THE NORMAL GRIEF PROCESS

Shock. Some people never go through a prolonged stage of shock and are able to express their emotions immediately. Others say they feel numb and no emotions or tears will come. Sometimes there is denial. Gradually the bereaved person becomes aware of what has happened and is able to cry or show emotion.

Emotional Release. Many people begin at this point. It is good to cry in grief, but some people may need permission to cry.

Pre-occupation with the Deceased. The bereaved person may try to think of other things but finds him/herself unable to shift her/his mind from thoughts about the deceased. This is normal.

Physical Distress. Symptoms such as tightness in the throat, shortness of breath or a hollow feeling in the stomach may come in waves lasting from 20 minutes to a full hour.

Hostile Reactions. People who are grieving often display a disconcerting loss of warmth in relationships and a tendency to respond with irritability and anger. This anger is often directed at the doctor, nurse or clergy, and these feelings can make the bereaved feel that he or she is going insane.

Guilt: There is always some sense of guilt in grief. The bereaved think of the many things that they felt they could have or should have done, but didn't. They accuse themselves of negligence. If there was any unresolved anger with the person who died, the bereaved person will feel guilty.

Depression: People may feel there is nothing to live for and that nothing seems worthwhile. They feel helpless/hopeless.

Withdrawal: People who are grieving often withdraw from social relationships and they sometimes find normal daily routines are disrupted.

Re-entering Relationships: Over time, the person readjusts to his/her new environment (without the person who has died) and forms new routines and relationships.

Resolution and Readjustment to Reality: The person gradually readjusts – although there will be times when grief reappears even when the person may have thought it was “all over”.

HELPING PEOPLE MANAGE THE STAGES OF GRIEF

The role of the volunteer is to be there when the grieving person wants to talk. Volunteers will listen and may hear the same fears, emotions and stories over and over again. The repetition is part of integrating the past with the present, remembering and saying good-bye. As a volunteer, it's okay to show your emotions. If you're at ease showing how you feel, it can make it easier for the person who is grieving.

- Help the person who is grieving:
 - express their pain and sorrow, and talk about their feelings of love, guilt and hostility
 - understand their emotional reactions
 - accept the pain of bereavement and find meaning in their suffering
 - talk about new ways of interacting with people and new modes of living
 - set short-term, realistic goals for themselves as they work through their grief process.
- Help with routine tasks if the person is having trouble concentrating on day-to-day things.
- Recognize when to keep silent. Don't try to fill empty spaces with words.
- Relax and keep your sense of humour and perspective. More than anything else, bereaved people need contact with these qualities. You may be the only one providing it.

When talking with the bereaved, respond with empathy. For example: "How can I be of help?" or "I wish I could take the pain away." Avoid clichés such as: "I know how you feel." or "You will marry again." or "You'll get over it." or "The person who died wouldn't want to see you cry."

3. PROMOTING HEALTH AND WELL-BEING FOR PEOPLE WHO ARE GRIEVING

Volunteers should not give advice but they can point out things people who are grieving can do to protect their own health.

PHYSICAL HEALTH

- Exhaustion makes you susceptible to illness, so pay attention to nutrition, rest and exercise.
- Eat lightly, even if you have no appetite.

- Sleeplessness is common, so relax by reading, writing letters or a journal, knitting, and try to take naps in the day.
- Start small with exercise - take a walk, or garden - and gradually gain momentum.
- If you have symptoms of an illness or people are telling you to see a doctor, consult one - even if you feel it isn't necessary.
- Pamper yourself: sleep in, buy yourself something special.
- Feel free to cry as tears are healing and help to lift burdens.

EMOTIONAL HEALTH

- Accept or ask for help. People usually want to help, but are unsure what to do.
- Be aware that severe emotions are okay.
- Make it known when you don't want company.
- Try to find someone who has been through a similar experience: they understand.
- Don't feel that you have to put up a brave front.
- Numbness at first is normal.
- Seek new and different relationships if needed, but at your own pace. Avoid trying to replace the lost person quickly.
- Don't feel guilty about feeling happy.
- Take private time to get in touch with yourself and the changes in you.

INTELLECTUAL HEALTH

- Avoid hasty major life decisions within the first year. If this is necessary, seek advice from an impartial trusted source.
- Don't let others take control of your life.
- Don't idealize the dead person as this makes mourning difficult. Realize both their strengths and their weaknesses.
- Temporary lapses of memory are normal.
- Avoid losing yourself in work: you need relationships with family and friends.

SPIRITUAL HEALTH

- Personal faith can be a source of comfort, but maintaining faith can also be difficult.
- Remember that it is okay to have a sense of humour.

- Let creativity come through in music, poetry and photography.
- Reaching out and helping others can be good therapy.
- Read, meditate and try to understand your faith.

4. WHAT IS COMPLICATED GRIEF?

Complicated grief is the usual process of grief complicated by other issues. Many factors influence how an individual will grieve. Some people, in addition to grieving the loss of someone, will also be coping with:

- severe depression
- drug or alcohol dependency or both
- a history of mental illness
- developmental disabilities
- chronic health problems
- history of sexual or physical abuse
- suicidal history and/or plans
- multiple or other unresolved losses.

SIGNS OF COMPLICATED GRIEF

Some signs of grief are quite subtle, such as simply not eating or sleeping or being edgy or overreacting to small or minor annoyances. These may just be normal responses to grief or they may signal that the person has some underlying issues that are getting in the way of normal grieving.

Other signs are less subtle. Drinking too much can be a sign of complicated grief as can saying things like “I wish I could die”. Statements like this should not be taken lightly. It’s best to talk to the person about it to see whether this statement is a suicide threat. One approach can be to ask the person how they would do this (i.e. die). If it appears that he/she has a plan, then get professional help, as soon as possible. If it is an emotional response to their pain and loss, then active listening and continued support should help. Volunteers should keep their supervisor and team aware of any signs of complicated grief.

SIGNS THAT PEOPLE NEED PROFESSIONAL BEREAVEMENT SUPPORT

People who are experiencing complicated grief need professional counseling and support. The following High Risk Bereavement Inventory is included in this manual,

courtesy of Dr. Michele Chaban, Director of the Psychosocial-Spiritual Program, The Temmy Letner Centre for Palliative Care, Mount Sinai Hospital, Toronto, Ontario. This inventory, developed by Stephen Fleming, lists social, psychological, situational, physical and spiritual factors that may indicate the need for professional support for a bereaved person. Volunteers can use it as a guide when supporting bereaved people. Volunteers should be aware of the risk factors and contact their supervisor if they have any concerns about the person they are helping

Social Factors:

- perceived reduction in quantity and frequency of contact with old friends (i.e. becoming isolated)
- young, married childless spouse
- young children or adolescent dependent children
- anticipated loss of major social roles as a consequence of loss of dying person
- quality of marriage
- few activities, interests or hobbies
- poor contact and relationships with family members.

Psychological Factors:

- previous history of depressive or mental illness
- perceives environment as failing to meet needs and/or actively unhelpful (totally negative)
- past history of poor coping with major crises
- increasing consumption of sedatives, tranquilizers, alcohol or tobacco (watch for use of valium, sleep or “nerve” medication)
- increased intimacy with the dying person during terminal illness
- anticipatory grief (poses immediate post-death risk)
- complete denial of illness or its terminality (i.e. pretends it does not exist. Note: watch for cultural influence which mitigates denial).
- acknowledges any of the following feelings:
 - What will I do now?
 - I’m worried I might have a nervous breakdown.

- It's not real.
- I can't get myself to do things.
- I feel empty.
- I wouldn't care if I died tomorrow.
- I don't want to live without him/her.
- I can't stand being alone.
- presence of strong self-reproach, self-depreciating remarks and anger at self, particularly with respect to relationship with dying person
- made a pact with the ill person to take own life and has a plan how to do it
- inhibition of feelings, unable to acknowledge or talk about feelings of impending loss
- perception that dying person received "poor care"
- altered mental functioning, extreme difficulty in concentrating, remembering, making decisions
- severe depression.

Situational Factors:

- sudden unexpected death or short fatal illness (under two months)
- untimely death – premature or post mature, dying person does not die on schedule
- young bereaved (55 and under)
- ethnicity: not a cultured to prevailing attitudes toward bereavement and mourning (may not know what is expected or allowable for these in our culture)
- low socio-economic status
- multiple life crises, concurrent losses or problems:
 - loss of income
 - financial problems
 - job loss
 - divorce
 - difficulties with children
 - pregnancy
 - marital conflict
 - recent marriage
 - recent loss of another close family member or friend.

Physical Factors:

- poor health before the illness of the dying person
- deterioration of health
- poor sleep patterns
- poor eating habits.

Spiritual Factors:

- perceived lack of help from faith, religion, church, God or clergy.

5. HELPING CHILDREN COPE WITH GRIEF

Parenting styles and cultural norms will play a large part in how a family helps a child cope with grief. While many parents will be open and truthful about what is happening, others will feel strongly about protecting the child from grief. Even when volunteers disagree with the family's approach, it is not appropriate for them to impose their values on the family. The volunteer's role is to affirm the child's feelings and support the adult family members.

Children understand death in different ways at different developmental stages. Children can be very aware of the disruption to their normal routines and lives but may not ask questions or reveal their knowledge. Adolescents may seek the volunteer out and want to talk about their feelings or ask for information. Always check with the parent before recommending any materials or resources.

Listening is the oldest and perhaps most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to affect the most profound changes in the people around us.

Rachel Naomi Remen, 1996

Children should be allowed to share in grief and attend the funeral or wake but only if they want to. They might feel angry at being abandoned, scared of being alone, confused, or guilty that they might have caused the death. You can help by answering questions honestly, helping them express emotions, reassuring them that it is okay to feel the way they do, and being patient if they bring up the subject of death again and again.

Most hospice palliative care programs provide special training and screening for volunteers who work with children.

6. HELPING OLDER PEOPLE COPE WITH GRIEF

It is easy to underestimate the effect of grief on older people because they are “used to it”. Older people may have developed ways of coping with grief but that doesn’t make grief easier for them. In fact, cumulative losses over a lifetime can lead to severe grief or “bereavement overload”.

With age, older people are already experiencing losses in their income, health, independence and status. The death of a spouse can be devastating for an older person because it can mean the loss of the last close relationship and source of physical affection. Although older people may be more realistic about death, they often have an intense fear of dying – in particular, dying alone. Older people may also be more reluctant to talk about how they feel or express their grief.

It may help to explore their “history of loss” by asking about the people they have lost, and how they came to terms with the loss. Older people need opportunities to describe their losses and find meaning in the losses and change. Talking about their experiences and acknowledging their pain and distress can prevent further depression. However, volunteers must walk a fine line between supporting an older person and encouraging self-pity. Genuine grief work lifts despair and bring relief.

