

JOURNEY THROUGH GRIEF

PART ONE: ANTICIPATORY GRIEF - THE AWARENESS OF DYING

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GENERAL DESCRIPTION: A CEU Online Course designed for health care professionals to better enable them to provide care and support in a variety of grief and loss situations. Included will be methods of coping with three distinctive phases: Anticipatory Grief, Acute Grief and Acceptable Grief.

PURPOSE: This course is designed to help you understand the dynamics of the grief process. Included are suggestions for coping with each of the three distinctive phases of grief and loss. The ultimate goal is to share with you the hope for healing, restoration and the future based upon faith in God.

COURSE OUTLINE:

PART ONE: ANTICIPATORY GRIEF - THE AWARENESS OF DYING

- A. The Definition of Thanatology
- B. The Stages of Death and Dying
- C. The Dynamic and Transition of Hope

PART TWO: ACUTE GRIEF – THE REALITY OF DEATH

- A. The impact of Death and the Bereavement Process
- B. The Stages of Grief and Community Resources
- C. The Steps in the Grieving Process

PART THREE: ACCEPTABLE GRIEF - THE GRIEF PROCESS

- A. The Phases of the Grief Process, Healing and Restoration
- B. The Distinction between Normal and Abnormal Grief Reactions
- C. The Strategies and Spiritual Resources for Coping with Grief

PART ONE: ANTICIPATORY GRIEF – THE AWARENESS OF DYING

Definition of Terms

ADVANCE DIRECTIVES - legal documents to direct end of life care, includes the Durable Power of Attorney, Living Will, and Organ Donations.

ANTICIPATORY GRIEF – the term used to describe the awareness of dying, when death is inevitable; the beginning or initial act of grief.

DEATH - the termination of physical life - deceased or dead.

DYING - the ending or termination of physical life.

GRIEF - the intense emotional suffering caused by dying and death; process of healing the wound suffered by death.

HOSPICE – medical and support care for the dying person and family members usually at home or in a loving and supportive environment.

PALLIATIVE CARE - a treatment approach that improves the quality of life of patients and their families facing life-threatening illness, the treatment of pain and other physical, psychosocial and spiritual concerns.

THANATOLOGY - the Science or Psychology of Death which investigates the circumstances surrounding death, the grief experienced by the deceased's loved ones, and larger social and spiritual attitudes towards death.

My Journey Through Grief

It was early January 1965. Our son, Mike, had made an eventful three-week early arrival into the world. He was delicate and fragile and stayed in the hospital an additional week before he gained enough weight to be released.

Caught up with our first child and a bitter Indiana winter, we were shocked when my father called from California. "Your mother has been diagnosed with cancer in the pallet behind her nose. She has been admitted to the City of Hope in Duarte, near where we live. They will begin radiation treatments." The City of Hope was the leading cancer treatment center in California.

This was the beginning of my "Journey through Grief." My initial reaction was shock and numbness. I couldn't believe it. Although Mother had complained about having a cough and stuffy nose for the past several weeks I thought this would soon pass. But it didn't and her physician referred her to specialists who performed the biopsy and discovered the malignancy.

My mother, Vernie (Louvernia) began a series of treatments. For Dad, it became a routine of frequent trips to the medical center for treatments. Everything seemed to progress well and for a time she appeared to be in remission. We prayed for her healing and kept in contact with her.

Further tests soon revealed that Mother's cancer had metastasized and spread to her lymph glands and other organs. Following radiation she went through varied drug treatments. Nothing seemed to stop the progression of the deadly disease. Yet, we continued to pray for Mom's healing.

In October, I talked with Mom by phone one evening. She said that she had pneumonia but didn't seem concerned. Yet, within 48 hours, her condition changed. She had a stroke and was admitted again to the City of Hope.

Late one Friday, the phone rang. "David, if you want to see Mom alive, you need to fly out here right away." It was CS, my older brother. Mom had lapsed into a coma and was dying.

I was overcome with grief and stumbled through the motions of making airplane reservations, leaving for the airport within a few hours. As I flew across the country I was crying and praying that I could get there in time to see Mom once more. I arrived three hours before she died.

Mother did not respond. She was laying in the hospital bed in a large oxygen tent. I couldn't get to her. I felt helpless! Nor could I pray or weep. I was in a state of shock.

My immediate focus was to support Dad. He appeared helpless. The physician said that Mother had extensive brain damage. He encouraged us to prepare for her death and to let her die.

Purpose

The purpose of this part of the course is to help you with your own grief experiences and enable you to provide the caring support to those patients who are dying and family members experiencing their "Journey through Grief." We will provide information and resources to assist you in caring for the dying and giving support to grieving family members.

Introduction

Dying, death and grief are a part of humanity. No one can escape the dynamics of this experience. How we cope and go through the grief process is the critical factor towards healing and restoration.

Dr. Elisabeth Kubler-Ross, a noted author and psychiatrist, wrote a classic best seller entitled *On Death and Dying*. In this remarkable volume, she opened the door to the varied human emotions, which surround those who are dying and facing death. She identified the distinctions between the person who faces death and the loved ones or extended family. In most cases, each one goes through a grief process, though everyone may be on different tracks at any one time. The ideal goal is for each one to move together towards the acceptance of the reality of death.

"Dying is nothing to fear," Dr. Kubler-Ross stated. "It can be the most wonderful experience of your life. It all depends on how you have lived. If you live each day of your life right, then you have nothing to fear."⁽¹⁾

Stages of Death and Dying⁽²⁾

A. Denial - The immediate reaction is "No, Not Me!"

1. There must have been a wrong diagnosis.
2. This may involve seeking another opinion or asking for further tests to verify an accurate diagnosis and prognosis.
3. This may delay any attempts to provide surgery or treatment that may be crucial to arrest the progression of disease to other parts of the body.

B. Anger - The normal response is "Why Me?"

1. The awareness of the diagnosis is realized.
2. There are varied responses, which may include anger towards God.

*"Expressing our aggravation is a bit like taking out the trash," Georgia Shaffer wrote. "Our anger, irritations, and frustrations need to be discarded or recycled. Just be careful where they're dumped."*³

C. Bargaining - The response is "Not Now!"

1. Time is crucial in this stage.
2. Time is needed to complete personal goals - graduation of a loved one, birth of a grandchild, visits by family and close friends.
3. Time is urgent in an intense search for a cure, seeking other treatment options, praying for healing and remission of the disease process.

"I'm sorry, but there's nothing else we can do," the doctor said to Georgia Shaffer, as she coped with cancer. "I desperately wanted him to prescribe something - anything - to give me back my strength." ⁴

D. Depression - The response is "Oh Me!"

1. The awareness of dying is beginning to settle in with feelings of helplessness and hopelessness.
2. Focus is on less pain and relief from discomfort.
3. It is a time with a lot of introspection and self-preoccupation.

"The transplant, chemotherapy, and radiation had taken their toll on my stamina and endurance," Georgia Shaffer added. "As the doctor walked out of the room, my desire for a quick recovery walked out with him and hopelessness settled in my heart.

"On the ride home, I felt numb. Unaware of my surroundings, I had no idea how to deal with these feelings of loss.... Although I knew depression accompanies grief, I had no clue how intense and debilitating it could be.... It's like a dark oppressive cloud remains fixed over me." ⁵

E. Acceptance - The response is "O.K.!"

1. Desire for family support.
2. Need to make final arrangements for death.
3. Focus on unfinished business and preparation for the transition from this life to the next.

Not everyone goes through all the stages.... People don't usually go through the stages in a neat, sequential order. Anger and depression are likely to occur over and over throughout the dying process. Some people have great trouble reaching acceptance and a few never do. Others who have had a long, painful illness may not only accept death but desperately wish for it. Being aware of the stages is a great help in understanding patients and their journey into death. ⁶

Caregivers Go Through Stages of Death and Dying

“When someone we love faces death, we, too, are likely to pass through the psychological stages of dying.... Slowly, and with much emotional pain, we come to the acceptance stage.... Knowing the stages helps us understand some of our own feelings and see that we and the dying person may be at different places.... Sensitivity to what is said and what is left unspoken helps us know what stage the dying person is at and how best to sustain and comfort.”⁷

The Dynamic and Transition of Hope

The term "HOPE" is not mentioned by Dr. Kubler-Ross but is important especially for a person with faith in God. HOPE moves through each stage to the ultimate hope which is eternal life. In our review of the Stages of Dying, we note the specific transitions of HOPE:

- A. **Denial** - The HOPE is to find a second opinion or to have further tests to verify an accurate diagnosis and prognosis.
- B. **Anger** - The HOPE is to find a cure, seeking other treatment options, healing and remission of the disease process.
- C. **Bargaining** - The HOPE is for more time to complete personal goals in the immediate future.
- D. **Depression** - The HOPE is for less discomfort and pain relief.
- E. **Acceptance** - The HOPE is for family support and preparation for the end of this life and transition to eternal life.

*"Looking back it was my relationship with God, my friends, and the psychologist that gave me hope to continue," Georgia Shaffer reflected on her grief journey. "God took all that was lost and used it to transform my life."*⁸

Fears about Dying and Death

- A. Intense pain - No one wants to die in intense pain and suffering. The dying need care and comfort. Modern medicine can alleviate the pain and suffering of the dying.
- B. Indignity - The focus for the dying is to have privacy. The dying do not want to die alone. They want to have a dignified death.
- C. Isolation - The dying fear separation from loved ones. The focus is on providing support by family members, close friends and the clergy.

Qualities of Dignified Dying and Death

“One tends to die as one has lived. One tends to live as one perceives death to be. One tends to live his life in accordance with his perception of the meaning of death.”⁹

“The concern for dying a good death has always been related to the concern for living a good life...to die well requires greater moral stamina than to live well...we are also asking if we can morally omit the number of things we now can do which prolong the dying process...two principles which now increasingly conflict: the prolonging of life and the relief of suffering.”¹⁰

A. Courage

1. The dying person needs to be allowed to courageously face the reality of dying and facing death.
2. The dying person needs to control the place and options in the dying process.
3. The dying person needs to hear words of comfort and encouragement from family members, friends and the clergy.

B. Love

1. Create a climate of LOVE and trust in which honest communication takes place.¹¹
2. Allow a dying person to make personal decisions to show consideration for others.
3. Provide the dying person an opportunity to find meaning and purpose in having a dignified death.

C. Hope

1. Comfort and less pain as death approaches.
2. Care and support for family members following death.
3. Certainty of a future HOPE of Eternal life.

Giving and Receiving Forgiveness

A. Memories of Broken Relationships

1. The dying process heightens emotions and stirs the memory.
2. Broken relationships and estrangements bring troubled memories to the surface
3. Hurt-filled memories create a desire to forgive and to be forgiven.

B. Forgiveness and Reconciliation

1. When someone you love is dying, time is precious.
2. Today may be the only opportunity to make amends and heal broken relationships.
3. Focus on forgiveness and reconciliation before death.

C. Role of Caregiver or Clergy

1. The caregiver, clergy or family member may need to encourage the dying person to seek forgiveness and reconciliation.
2. It is not uncommon for entire families to want to have their pastor or a chaplain to assist in a ritual of forgiveness and reconciliation.
3. This experience results in healing, peace of mind and heart. ¹²

Family Responses to the Dying Person

The dying person who has the most difficult time is aware of how seriously ill he/she is but realizes the family may not want them to know. Either they try to protect the person from knowing the reality of the situation or have not yet accepted the facts themselves. As a result they may be artificially cheerful and hold out unrealistic hopes to the dying person. Families who deny the reality of the situation may deprive the dying person of whatever comfort and reassurance the loving family may give.¹³

- A. It is a significant part of the grief process to provide the dying person with adequate time to make final plans and prepare for death.
 1. Most people know when they are dying. They have difficulty expressing it to their family. If there is a problem about facing death, it is usually with family and friends, not with the dying person.¹⁴
 2. Encourage the dying person and family to bring closure to any unfinished issues, including organ donations, preparation and the disposition of the body and estate plans.
 3. The dying person needs to discuss with family matters pertaining to organ donations, funeral or memorial services.
 - a. The ultimate gift to family members is for the dying person to make personal wishes known verbally or in writing.
 - b. By making advance funeral arrangements the family members will be relieved of the added burden, both emotional and financial after the death of the loved one.
 - c. Consult with a local funeral director to assist with pre-paid funeral arrangements or have an insurance policy for these expenses.¹⁵
- B. Importance of "Death Talk" between the dying person and family.
 1. Allow the dying person to openly share fears and hopes with family members.
 2. Encourage the dying person and family members to move towards acceptance of death.
 3. Maintain an open conversation about death and dying.
- C. Give an opportunity for the dying person and family members to say final words and good-byes to each other.
 1. Encourage the dying person to give expressions of love to family and close friends.
 2. Allow the dying person to give farewell words to family and friends.
 3. Ask a chaplain or pastor to assist the dying person and family members to bring closure as death approaches. Some may gather around the bed for a final prayer and song together.

Hospice Care

Hospice is a concept of care that involves health professionals and volunteers who provide medical, psychological, and spiritual support to terminally ill patients and their loved ones. Hospice stresses quality of life—peace, comfort, and dignity. It is balanced with the sanctity of life for the dying patient.

A principal aim of hospice is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice services are available to persons who can no longer benefit from curative treatment; the typical hospice patient has a life expectancy of six months or less.

Hospice programs provide services in various settings: the home, hospice centers, hospitals, or skilled nursing facilities. Patients' families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

The following resources may offer assistance for people seeking hospice care and information:

The National Hospice and Palliative Care Organization (NHPCO) is a membership organization representing programs and professionals that provide hospice and palliative care in the United States. NHPCO's mission is to lead and mobilize social change for improved care at the end of life. NHPCO offers publications, information about how to find a hospice, and information about the financial aspects of hospice.

The Hospice Association of America (HAA) is an advocate for hospice organizations. It serves hospices that are freestanding and community-based, as well as those affiliated with home care agencies and hospitals. HAA also distributes a number of publications about hospice to consumers. Topics include information about the history of hospice, the benefits of choosing a hospice program, hospice-related statistics, and locations of hospice organizations.

The Hospice Education Institute (HEI) serves a wide range of individuals and organizations interested in improving and expanding hospice and palliative care throughout the United States and around the world. The Institute works to inform, educate, and support people seeking or providing care for the dying and the bereaved. HOSPICELINK, a service of the Institute, maintains a computerized database and up-to-date directory of all hospice and palliative care programs in the United States. HOSPICELINK helps patients and their families find hospice and palliative care programs, and provides general information about the principles and practices of good hospice and palliative care. ¹⁶

Support Groups and Resources

SUPPORT GROUPS offer an important emotional and spiritual base for dying persons and family members.

- A. In the initial stage, following the diagnosis and treatment process both the patient and spouse or other family members may share together with a small, confidential group of others who are experiencing the dynamics of a terminal disease and facing the approach of death. This support network can provide encouragement and prayer support as the patient and family members cope with the disease and dying process.
- B. As the process moves into the dying phase the patient may be unable to participate directly but is aware of supportive friends who are going through similar experiences.
- C. The family members continue to rely on the support group up to the dying person's death and may continue with a grief support group after the death of the loved one.¹⁷

GROUPS or NETWORKS include:

Cancer Hope Network provides individual support to cancer patients and their families by matching them with trained volunteers who have recovered from similar cancer experiences. Such matches are based on the type and stage of cancer, treatments used, and other factors.

National Cancer Institute (NCI) Resources provides a comprehensive listing of support groups and resources. Contact the Cancer Information Service at 800-4-CANCER (422-6237) or at the NCI's Web site: www.cancer.gov.¹⁸

Sequel to My Journey through Grief

Mother died a few minutes after midnight, October 10, 1965. Although I was mentally prepared for her death, I was not emotionally ready to let her go. No one helped me to work through my grief process. I suffered alone. This grief experience made a significant impact on my life and ministry.

Twelve years later, as a Chaplain resident in an acute care medical center I ministered to dying patients and their grieving family members. I finally dealt with my own grief over Mother's death with the help of my peers and Chaplain supervisor.

Across more than forty years, since Mother's death, I have counseled and ministered with hundreds of individuals and families, using my own grief experience, in helping them in their "Journey through Grief."

The Journey Home

Bill Bright, best-selling author and founder of Campus Crusade for Christ, in his last days of his life, wrote an inspiring journal of his life as he confronted death with courage and calmness and looked ahead with unbridled enthusiasm for the next life. Bright reflected, "I have been hit with the certainty that I am in the grips of terminal illness.... I am not sure why hearing something specific from a physician makes terminal seem more final, but it does that.... My first wake-up call to the possibility of terminal disease came with the diagnosis of prostate cancer in 1993. Then, in 1998, I became aware that my incurable disease, pulmonary fibrosis, had begun its stranglehold on my lungs.... So I was reasonably prepared when the physician told me I would die a terrible death with an incurable disease. He said it would be worse than a heart attack or cancer: 'You will choke to death....' The physicians gave me no hope.... So Vonette and I prepared....

I know my last breath is something to look forward to because the next breath after that one I will draw in the awesome glory of my precious Savior and almighty God in the celestial air of Heaven. I join with Paul in saying, 'We are of good courage...and prefer rather to be absent from the body and to be at home with the Lord.' (*2 Corinthians 5:8, The Holy Bible, NASB*)."

In his final moments, Bright concluded, "My eye of faith can see just beyond the sunset to my home in the glorious presence of our matchless Creator-God and Savior, the Lord Jesus Christ. Soon, it will all be right. Thank you for taking part of the journey with me." ¹⁹

Summary

In this first part of the course, I began with my own Journey through Grief related to the illness of my Mother. We have reviewed the definition of terms, particularly Thanatology, the psychology or science of death and focused on the first part, "Anticipatory Grief – The Awareness of Dying."

We discussed five Stages of Grief – Denial, Anger, Bargaining, Depression, and Acceptance. Included were Caregivers Go through Stages of Death and Dying. An added dimension is the Dynamic and Transition of Hope.

We denoted the Fears of Dying and Death and Qualities of Dignified Dying and Death. An important dimension is Giving and Receiving Forgiveness. Also, we presented Family Responses to the Dying Person. Included is Time to make Final Plans and prepare for Death. We identified Hospice Care for the Dying and Family members. Included were Support Groups and Resources.

This session concluded with the Sequel of my Journey through Grief and the inspiring story of a dying man and his wife who shared their own personal account of The Journey Home.

NOTES

1. Selected Quotes by Elisabeth Kubler-Ross. Used with written permission from the Elisabeth Kubler-Ross Foundation. (www.elisabethkublerross.com and www.ekrfoundation.org)
2. Outline of Stages of Death and Dying taken from Elisabeth Kubler- Ross, On Death and Dying. Used with written permission from the publisher.
3. Georgia Shaffer, from A Gift of Mourning Stories, p. 27. Used with permission from the author and Servant Publications. (www.GeorgiaShaffer.com)
4. Shaffer, *ibid.*, p. 43.
5. Shaffer, *ibid.*, p. 43.
6. Ron DelBene, with Mary & Herb Montgomery, Near Life's End, What Family and Friends Can Do, p. 12. www.delbene.org. Used with permission from the authors.
7. DelBene, *ibid.*, p. 13.
8. Shaffer, *op. Cit.*, p. 47.
9. Chaplain John Sims, Lecture on "Death and Dying" at Baptist Medical Centers, Princeton Hospital, Birmingham, Alabama, 1978.
10. James B. Nelson and Jo Anne Smith Rohricht, from Human Medicine, Ethical Perspectives on Today's Medical Issues, p. 144. Used with permission from the publisher.
11. DelBene, *op. cit.*, p 15.
12. DelBene, *ibid.*, p. 23,25.
13. DelBene, *ibid.*, p. 14
14. DelBene, *ibid.*
15. Excerpts taken from Let The Choice Be Mine, A Personal Guide To Planning Your Own Funeral, a booklet written and published by Cathy Robertson, p. 1. Used with permission from the author.
16. 1Hospice Resources available through the following agencies:
The National Hospice and Palliative Care Organization (<http://www.nhpco.org>),
Hospice Association of America (<http://www.nahc.org/HAA/home.html>),
The Hospice Education Institute (<http://www.hospiceworld.org>).
17. Excerpts taken from When Your Friend Is Dying, by Betsy Burnham, p. 81. Used with permission of the publisher.
18. Cancer Hope Network – Contact: 1-877-HOPENET-467-3638 or the website: (<http://www.cancerhopenetwork.org>)
19. National Cancer Institute (NCI) Resources – Provides a comprehensive listing of organizations and support groups - www.cancer.gov.
20. Excerpts taken from The Journey Home - Finishing with Joy, by Bill Bright, p. 2, 5, 7, 9-10, 162. Used with permission from the publisher.

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QUESTIONS FOR REFLECTION

1. What is it like to see someone dying?
2. What do the dying need and want?
3. Reflect on your own experience of Anticipatory Grief.
4. What were your feelings and how did you deal with that experience?
5. Who were your support persons and how were they helpful?
6. How do you feel about your own death or someone you love who is dying?

EXERCISE: Take some time now to develop your own Grief Timeline. Begin with the earliest memory of a grief experience, including date or your age and relationship to you, continuing to the most recent grief experience.

Example:

	X	X	X	X	X
Age/Date	9/1948	17/1956	26/1965	28/1967	56/1995
	Maternal Grandmother	Paternal Grandmother	Mother	Paternal Grandfather	Granddaughter / Father-in Law

1. Identify the one(s) that you had the most difficulty with, which may also be unresolved.
2. Describe any changes in your life that occurred.
3. What is needed to complete your grief process?