

## **END OF LIFE ISSUES**

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### **The Journey Through Caregiving**



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## ❖ DEALING WITH GRIEF

Enduring loss alters our lives irreversibly, but the **grieving** process helps us recover and grow through the experience. This module explores what grief is, how people experience it, and how to deal with the grieving process. The last part of the module looks at issues such as advance directives and legal alternatives when caring for a terminally ill loved one.

**A number of factors can determine how you will handle grief. Some of these include:**

- The way your family handled grief in the past.
- Sources of support that you and/or your family sought, such as your spiritual beliefs, cultural background, and the traditions and rituals that were part of your past.
- Your relationship with the loved one who has passed away.
- Your ability to handle stressful experiences in life.
- Your experiences with working through decisions regarding insurance and medical forms.
- Support from relatives and friends.

## **How can I begin the grieving process before the death?**

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As your loved one's condition grows progressively worse, family members and friends will begin the grieving process. Changes in the loved one's personality, memory, mental capacity, and physical abilities will warn family members and friends that the loved one is nearing death. These changes may hinder the way you relate to your loved one. Through this downward progression comes the grief of "losing" the elder, who they were, their hopes, dreams and plans for the future to the illness or condition. This kind of grief is referred to as anticipatory grief, meaning that your grief is present before death actually occurs.

As difficult as it is to know that your loved one is terminally ill or may not have a long time to live, this can be a precious time to restore, reflect, and cherish the moments. Accepting the fact that your loved one is facing death helps you to take advantage of the time to repair old wounds, share wonderful memories, and enjoy the past.

The emotional benefits of "saying good-bye," "asking forgiveness," and "saying thank you" will give both you and your loved one a serene feeling of closure.

It is important to be sensitive to discussions regarding end of life decisions that your loved one may wish to cover. Although the care recipient may seem initially uncomfortable with the discussions, you need to determine if you are the reason they are holding back. For instance, do you change the subject or become busy with nonessential tasks to avoid having such a discussion?

Important issues such as life support wishes and “do not resuscitate” (DNR) orders can be discussed through open ended questions such as “Mom, since the doctor has given us a potential time frame before you die, the hospital needs to know your wishes regarding life.” In order to get complete answers, you may find yourself asking several questions. Since your loved one might tire easily or find it hard to speak, you may need to have several short discussions instead of long talks.

Some loved ones will discuss final arrangements needed upon death, but others may wish to avoid these discussions. Those individuals comfortable with discussing these details may in fact already have recorded their wishes or desires for their funeral or memorial service. If your loved one does not wish to discuss these issues, do not force them, and wait until they are ready to express their wishes.

Many resources refer to the dignity needed in caring for a terminally ill person. This dignity will often translate into the sensitive, compassionate, and confident knowledge of a well prepared caregiver. With this in mind, do not be afraid to hope for tomorrow, to discuss today, and to remember the treasured memories of the past. It will be important to recognize and understand the impact that grieving may have on the attitudes and behavior of others. Remember to communicate openly and honestly in order to discover spiritual resources, to provide pain relief, and to allow families to participate in a peaceful and dignified death of their loved one.

## **Will each family member handle the death of our loved one in the same way?**

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People handle grief in a number of different ways. There is no hard and fast formula for when grief begins and how it ends. Dealing with the loss of a loved one will be a unique experience for each family member. Others should not expect a certain type of reaction, or put limits on a grieving relative. It is important not to judge the way a loved one expresses their feelings about their emotions, pain, or the impending death. The feelings that family members are experiencing are honest, and should not be looked down upon in any way. No one ever had a dishonest emotion at a time such as this.

Grieving can be a lonely personal experience. It can be hard for family members to express their feelings. They may feel confused or guilty about their own feelings of grief, making it difficult to discuss with others.

People that do handle grief well usually have strong bonds with relatives and friends who can readily share the memories of the highs and the lows. They have had a relationship with their loved one that was meaningful and rewarding. Core to their relationship may have been a spiritual foundation that gives them strength to face the future. These people often are more resilient and have reservoirs on which to draw.

As in all grieving experiences you may now be in the situation of having to make countless decisions, grieve alone, or be the “rock” for a variety of family members. This can be an overwhelming feeling. Despite the duties you need to perform during a loss, it is also necessary to allow yourself time to grieve. Crying is a healthy expression of that grief and has many healing properties both at the time of loss and in the future when

something will trigger a memory that causes sorrow. Allowing emotions to flow will prevent them from getting backed up and will make it easier to remain patient and caring of ourselves. Working through our grief forever changes us, but also allows us to claim increased wisdom.

Whereas these issues may relate to a variety of grief situations, the experience of grief does differ when the death is expected verses unexpected. Not being able to prepare for an unexpected death means we are not given the opportunity to impart to our loved ones our love and gratitude, or to share an emotional farewell. For the most part those who have been caregiving for a loved one are expecting death, yet even though we know that our loved one is dying, it is still surprising that the feelings we experience may be as intense as they are when death is sudden.

## What are the stages of grief?

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Stages of grief can be described as phases that we pass through as we lose someone or something of value to us. The stages of grief may be experienced by both the caregiver and the dying loved one. It is important to realize that some stages may come and go several times before we move on in the healing process. There is not a predictable time frame or way that this is done. Stages can occur simultaneously, at any time and sometimes change from one hour to the next. Those involved in the caregiving situation will not all experience the same stages of grief at the same time. This can cause a lot of frustration within the family. Each loved one must be understanding and respectful of their other family members and the stage of grief they are experiencing. Loved ones might spend a whole day feeling happy, only to have their grief return in the evening.

**Denial** can initially protect us from the final reality of death. It is a natural way for the body to absorb the shock. The mind tends to block out all thoughts of the deceased during this stage of mourning. It is as if the mind cannot handle that much pain at one time, therefore you are not able to focus on the actual death and the trauma leading up to it. Slowly, over time, the mind will begin to experience the depth of your loss.

**Anger** can serve as a way to focus on the injustice of the situation rather than “diving head long” into sadness and depression. Many will pose the questions, “Why me? What have I done to deserve this?” Anger for many provides initial relief from the devastating pain and loss. Your anger

### Common stages of grief include:

- Denial
- Anger
- Bargaining
- Depression
- Isolation
- Acceptance

may manifest itself as general grouchiness or full-blown anger. It may appear as envy of someone with a strong, healthy body or resentment toward the health care establishment. You may be angry at your loved one for leaving you or for not caring for themselves properly so they might have lived longer.

For many of us anger is a difficult and exhausting emotion. We tend to suppress our anger because it is not well accepted socially. Yet, anger is a healthy emotion, and denying it creates stress, which will only compound into negative consequences.

Recognizing the anger that you have is one thing, but deciding what to do about it is another. The following are some simple ideas that may help you to release some of your anger: expressing your feelings by writing them down, talking with your friends about how you feel, crying, beating pillows with your fists, or screaming. It is important to find what works for you and through these channels express your anger.

**Bargaining** is often associated with trying to find some way to remain in control and to change what has occurred. We may feel guilty for some bad behavior that we did in the past, and that through the death of our loved one we are being punished for this act. We naturally tend to associate death and illness with punishment. Therefore, we try to figure out how to be “good” so all the pain and fear will go away.

**Depression** is perhaps the most common stage of grief. Those who have experienced the tremendous loss of their loved one will feel a flood of emotions. These feelings can be overwhelming and cause you to lose interest in the many details of everyday life. You may be uninterested in watching TV, reading the newspaper, eating, or talking with your friends.

This is normal and you don't need to be afraid of these feelings. As you work through your grief, you will slowly feel like doing these activities again.

If you are showing more serious signs of depression that is not getting better a year after the death, you may have left a healthy stage of grieving and become clinically depressed. If this happens, please get help immediately.

**Isolation** is a lonely feeling. You may feel that no one understands what you are going through, that no one has ever felt as much pain as you do right now, and that nobody cares. In a certain sense you are right- no one does understand. The grief that you feel is unique and has never been experienced by anybody else. The way you experience loss will be different than someone else.

**Acceptance** is the last stage of grief. You will realize that you are reaching the stage of acceptance when you begin to take an interest in everyday activities. When this happens you may also experience feelings of betrayal as you move away from the relationship you once had with your loved one. It cannot be predicted when you will reach this stage, it all depends on the emotional relationship you had with your loved one. Acceptance does not mean forgetting your loved one or the relationship you once shared, but rather moving forward in life and making new plans for the future. As healing begins, the feelings of desperation will decrease and restoration will increase in its own time.

Remember that your loved one wants you to remember the good things and release the pain and sorrow that initially accompany the loss. As this happens, you become more comfortable with yourself and your future.

Seeking a professional counselor and/or joining a support group may be crucial to resolution and generally beneficial for recovery.

## **What are the legal issues related to the death of a loved one?**

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The first step in the legal process is to locate the will, insurance policies, trusts, tax returns, checkbooks, bank accounts, and information about stocks, bonds and real estate. Check desks, file cabinets, and safe deposit boxes.

In order to complete the filing of various claims for financial recovery after a death, request at least twelve original copies of certified death certificates from the funeral home or the probate court. If the death was your spouse, copies of the marriage license or certificate, military discharge papers, social security numbers of all family members, and birth certificates of minor children will be needed to collect benefits.

The easiest way to access cash is from checking and savings accounts, money market funds, certificates of deposit, mutual funds, stocks, and bonds. Be aware however, that penalties may be imposed if you use this money prematurely.

**All banks** should be notified immediately upon the death of your loved one. Often no one will have access to accounts or safe deposit boxes until an administrator is appointed. Find out what the access rules are to your loved ones funds and documents. Requests for access to insurance policies or other legal documents usually must be signed and witnessed.

**Social Security/ Veterans Benefits** are available to survivors to replace, in part, family earnings when a wage earner dies. A surviving dependent spouse can collect the deceased's full social security retirement

benefits at the age of 65, or reduced benefits at age 60. Unmarried children may collect benefits if they are under 18 or if they are 19 and are still in school. A small death benefit to assist with funeral expenses is also available. **Life insurance** is usually payable to a specific beneficiary, and should be immediately and automatically available to the beneficiary.

**Employer policies** are usually not known about because policies are not stored in the home. Question the benefits specialist in the personnel department of the loved one's employer about all benefits, sick leave, accrued vacation time, unpaid bonuses and the final paycheck.

**Creditors**, their addresses, and the amounts owed should be compiled and a complete list made. Then consider the amount remaining after paying immediate expenses. From these figures, determine how much, if anything, can be paid on bills in the near future.

**An Attorney** with experience in estate planning and settlement issues should be obtained if an estate needs to be settled. It is important that you do not make any major financial decisions about the remainder of the estate for about a year or after some of the grief has subsided.

## **What are advance directives (including living wills)?**

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Caring for loved ones to the end of their lives means that there will be discussions about advance directives for “end of life” care. Since medical science has reached advanced levels of extending the length of lives, understanding your loved ones’ desires is important. Remaining comfortable in the final days of life might be what they desire over new “medical marvels.” Regardless of the answer, if possible, it is important to discuss with the care recipient what those choices will be. At the very least these answers concerning advance directives will help make sure that the health-care providers continue to give care with dignity and respect following the wishes of the care-recipient.

A living will states the chosen degree of life support. Living will forms are available from a variety of sources. A national organization called Choice in Dying (1-800-989-WILL) or your local hospital or Hospice organization will have the forms needed to complete the advance directives for the care recipients’ family and health-care providers.

Decisions about treatment, funeral and burial arrangements, and donation of organs, can be hard to discuss with care recipients. But putting off making advanced directive decisions until care recipients are unable to express their wishes makes the dying and grieving process more difficult.

Caregivers should take the time to document the information in whatever manner it is received and inform other family members. Some of the saddest and most disagreeable moments for families of care recipients often happen when communication is not open and information is shared secretly instead of directly and honestly.

## **To die at home or in the Hospital?**

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People of all ages are haunted by images of dying in an intensive care unit. However, respecting a relative's wish to die at home is not always possible. For instance, holding back from calling an ambulance when a loved one goes into severe respiratory distress goes against instinctive impulses to take rescuing measures. When the dying process moves more slowly, sustaining a person's last weeks and days at home can be exhausting. Waking several times a night to administer pain medications or help someone to the bathroom is physically draining. Feeling helpless while watching a spouse or parent deteriorate adds emotional fatigue to this nightly weariness.

When their relative pleads, "Promise me I can die in my own bed," family members often do not realize that community services for carrying out such wishes are limited. Hospice programs to support the families of people who choose to die at home are not available in all communities, and Medicare restricts these services to the last six months of life. Even when someone's condition qualifies for Medicare-covered hospice services, home visits by hospice nurses and aides only supplement the family's efforts. The majority of round-the-clock care must still be carried out by family members and friends. Although hospice agencies increasingly make use of volunteers to provide time off for family caregivers, such relief is for short periods of time and is constrained by the volunteer's schedule.

The dilemma is that when dying people and families resort to a hospital at the end stage of life, they forfeit much of their control over their medical options. For instance, a wife caring for her husband at home may

decide, after considerable discussion with him, to stop administering antibiotics for his pneumonia in order to respect his desire to die naturally. If she becomes frightened and hospitalizes him at the last minute, she may encounter resistance to their chosen strategy. For example, hospital staff may disagree with a request to continue withholding antibiotics, claiming that doing so constitutes inappropriate or unethical care. She and her husband become, at that juncture, captives of the health care system and of the legal establishment that judges its actions.

Since laws about end-of-life choices vary from state to state, specific documents for implementing these choices also differ. The following list explains the types of documents related to end-of-life directives and decisions:

1. Durable Power of Attorney for Health Care

A person designates another to make health care decisions in the event the person becomes incapacitated or unable to communicate.

2. Living Will

A person signs this document to express a wish not to have life prolonged when terminally ill.

3. Advance Directive

A person states which treatments would be unacceptable with any illness, not only when terminally ill.

Ideally, completing these documents serves as an opportunity for older people, their physicians, and their families to discuss end-of-life choices.

## ❖ RESOURCES

### Activities

The “Restoring Moments” that follow below are meant to be a creative way for caregivers to reflect on their caregiving experiences and explore new ways to deal with their grief.

#### **RESTORING MOMENTS I**

With grief comes many different feelings going on in you at the same time. That is why you may cry about something sad and, at the same time, laugh at how crazy it all seems. The feelings that seem to come and go at different times and that can be intense or subtle include: resentment, fear, loneliness, confusion, sadness, anger, fatigue, disappointment or helplessness.

Whether or not you want it, feel like it, or are ready for it, grief takes place when you suffer a loss. You can ignore your feelings or even find ways to run from them, but the grief will still occur. It is important to take care of yourself in the grieving and healing process.

Maybe you have close friends that you can share your feelings with who will just let you talk while they listen. As you share memories of your loved one, you may find yourself either crying or laughing or both. This is part of the healing process.

Make a point of listening to soothing music. Or take off your shoes and walk on the grass or through a stream of water. Keep your senses alive and do whatever you need to do to work through the grief.

## **RESTORING MOMENTS II**

There is an old Swedish proverb, “Shared joy is double joy, and shared sorrow is half-sorrow.”

In times when we are lost in feelings of grief, getting help is so important. If the loss of your loved one was very tragic and totally unexpected you should not hesitate to get professional counseling to help you deal with the situation.

Your health and mental well-being are so important and it is up to you to solicit the help that is needed to make a smooth transition through the grief process.

Sometimes taking “time out” from your grief to do some pleasure reading, to cook a meal, or to wash the floor can be comforting. Just don’t get so involved with some small aspect of life that you drown yourself in your work or in something else that keeps you from facing reality.

**You are very important! Take care of yourself!**

### **RESTORING MOMENTS III**

As you slowly move through the predictable stages of healing from the loss of a loved one, there will come a time when you are tired of feeling down. You wonder if the grief will ever pass. These are normal feelings.

Your grieving will ease up and your ability to function will improve. Grief gets better in its own time.

You need to be sure to get proper sleep, good meals, and exercise. Try not to make any major decisions for at least six months.

Surround yourself with caring people who have your best interests in mind. As your healing progresses you begin to have moments when you feel like your old self and are looking forward to the future. You may be inclined to get into projects, new relationships, or a flurry of activities before you are really ready. Anything you do to rush the process will only prolong your recovery. You must be patient and you must rest so your body, mind, and spirit gradually recover from the shock of your loss.

As you heal, your optimism will also grow. There are a number of actions you can take when you're feeling restless and impatient. You can get some exercise, sit down and meditate, and/or call up a friend and talk about it.

Probably, almost without knowing it, you will be back in the routines of daily life. Occasionally, there will still be those moments of remembering, but they will be softer and more quiet.

One other step that is very important is to forgive yourself or anyone else that may have unknowingly spoken words that caused you pain. Forgiveness relieves one of the burdens of revenge and sets you free from extra baggage that can weigh you down. In grief, as in life, everyone always does the best they can and still no one manages to do it perfectly. Everyone deserves forgiveness, and that includes you.

## **Audiovisual Materials**

Medical Audio Visual Communications Inc., (Producer). (1998). *Palliative care/ End-of-life issues* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool St., Niagara Falls, NY 14305)

Medical Audio Visual Communications Inc., (Producer). (1998). *Planning for the future* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool St., Niagara Falls, NY 14305)

Medical Audio Visual Communications Inc., (Producer). *The caregivers' journey: Healing* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool St., Niagara Falls, NY 14305)

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Furman, J., & McNabb, D. (1997). *The dying time*. New York, NY: Bell Tower.

Sankar, A. (1999). *Dying at home*. Baltimore, MD: Johns Hopkins University Press.

## **Organizations**

### **North Dakota Department of Health Hospice Facilities**

Ashley Medical Center Hospital  
612 Center Avenue N  
Ashley, ND 58413

Heartland Hospice  
30 West 7<sup>th</sup> St  
Dickinson, ND 58601

Medcenter One Home Health and Hospice  
402 East Main Ave  
Bismarck, ND 58501

Hospice of Red River Valley  
702 28<sup>th</sup> Ave N  
Fargo, ND 58102

St. Alexius Hospice  
1120 E Main Ave  
Bismarck, ND 58501

Altru Home Services Hospice  
1380 S Columbia Rd.  
Grand Forks, ND 58206

Presentation Hospice  
800 N 4<sup>th</sup> St  
Carrington, ND 58421

Sakakawea Hospice  
510 8<sup>th</sup> Ave NE  
Hazen, ND 58545

Mercy Hospice  
1031 7<sup>th</sup> St  
Devils Lake, ND 58301

Dakota Prairie Hospice  
505 2<sup>nd</sup> Ave S  
Hettinger, ND 58639

Jamestown Hospital Hospice  
419 5<sup>th</sup> St NE  
Jamestown, ND 58401

Trinity Hospitals- Hospice  
1015 S Broadway  
Minot, ND 58701

Linton Hospital Hospice  
518 N Broadway  
Linton, ND 58552

Heart of America Hospice  
800 Main Ave S  
Rugby, ND 58368

Mercy Hospice  
1301 15<sup>th</sup> Ave W  
Williston, ND 58801

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- Samples, P. (1999). *Daily comforts for caregivers*. Minneapolis, MN: Fairview Press.
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