Bereavement and End of Life Issues
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Study helps: When you scroll over the yellow sticky notes you will receive study helps.

Introduction

Most, if not all people, suffer the loss of a loved on at some point. The strength of those feelings, what we call grief, are commensurate to such factors as the closeness of the relationship to the deceased, the circumstances of the passing, the age of the person who passed, and the life-circumstances of the survivor. Every culture, and every person, experiences grief differently. Some of those who suffer loss will only require time to recover from their sadness. Others will need some level of professional help to work through their grief.

Closely related to bereavement are the years leading up to it: End of Life years. This time is often filled with illness and disability, requiring care. This, too, is a loss—the loss of previous functioning and independence, both for the person receiving care, the loved ones providing care, and others who have had close relationships with the individual that are now being redefined. When considering all of these factors, and the many issues that attend bereavement and the end of a life, it can be a very complicated matter.

This course will provide the participant training in various issues surrounding grief, how to assist those suffering from grief and end of life and obtain knowledge of resources that can assist those in this time of life and circumstances.

Chapter 1. Bereavement

A. When Some Dies

National Institute on Aging (2017), *What Happens When Someone Dies*. Retrieved January 8,2020 https://www.nia.nih.gov/health/what-happens-when-someone-dies

When death comes suddenly, there is little time to prepare. In contrast, watching an older person become increasingly frail may mean that it's hard to know when the end of life begins because changes can happen so slowly. But, if you do know death is approaching and understand what will happen, then you do have a chance to plan.

Listen carefully to what doctors and nurses are saying. They may be suggesting that death could be soon. You might also ask—how much time do you think my loved one has left, based on your experience with other patients in this condition?

Just as each life is unique, so is each death. But, there are some common experiences very near the end:

- Shortness of breath, known as dyspnea
- Depression
- Anxiety
- Tiredness and sleepiness
- Mental confusion or reduced alertness
- Refusal to eat or drink

Each of these symptoms, taken alone, is not a sign of death. But, for someone with a serious illness or declining health, these might suggest that the person is nearing the end of life.

In addition, when a person is closer to death, the hands, arms, feet, or legs may be cool to the touch. Some parts of the body may become darker or blue-colored. Breathing and heart rates may slow. In fact, there may be times when the person's breathing becomes abnormal, known as Cheyne-Stokes breathing. Some people hear a death rattle, noisy breathing that makes a gurgling or rattling sound. The chest stops moving, no air comes out of the nose, and there is no pulse. Eyes that are open can seem glassy.

Should there always be someone in the room with a dying person?

Staying close to someone who is dying is often called keeping a vigil. It can be comforting for the caregiver to always be there, but it can also be tiring and stressful. Unless your cultural or religious traditions require it, do not feel that you must stay with the person all the time. If there are other family members or friends around, try taking turns sitting in the room. Some people almost seem to prefer to die alone. They appear to slip away just after visitors leave.

After death, there may still be a few shudders or movements of the arms or legs. There could even be an uncontrolled cry because of muscle movement in the voice box. Sometimes there will be a release of urine or stool, but usually only a small amount since so little has probably been eaten in the last days of life.

Call 911 or not?

When there is a medical emergency, such as a heart attack, stroke, or serious accident, we know to call 911. But, if a person is dying at home and does not want CPR (cardiopulmonary resuscitation), calling 911 is not necessary. In fact, a call to 911 could cause confusion. Many places require EMTs (emergency medical technicians) who respond to 911 calls to perform CPR if someone's heart has stopped.

Consider having a non-hospital DNR (Do Not Resuscitate order) if the person is dying at home. Ask your doctor or the hospice care team who you should call at the time of death.

B. Mourning the Death of a Spouse

National Institute on Aging (2017), *Mourning the Death of a Spouse*. Retrieved January 8,2020
https://www.nia.nih.gov/health/mourning-death-spouse

When your spouse dies, your world changes. You are in mourning—feeling grief and sorrow at the loss. You may feel numb, shocked, and fearful. You may feel guilty for being the one who is still alive. At some point, you may even feel angry at your spouse for leaving you. All of these feelings are normal. There are no rules about how you should feel. There is no right or wrong way to mourn.

When you grieve, you can feel both physical and emotional pain. People who are grieving often cry easily and can have:

- Trouble sleeping
- Little interest in food
- Problems with concentration
- A hard time making decisions

In addition to dealing with feelings of loss, you also may need to put your own life back together. This can be hard work. Some people feel better sooner than they expect. Others may take longer.

As time passes, you may still miss your spouse. But for most people, the intense pain will lessen. There will be good and bad days. You will know you are feeling better when there are more good days than bad. Don’t feel guilty if you laugh at a joke or enjoy a visit with a friend.

There are many ways to grieve and to learn to accept loss. Try not to ignore your grief. Support may be available until you can manage your grief on your own. It is especially important to get help with your loss if you feel overwhelmed or very depressed by it.

Family and compassionate friends can be a great support. They are grieving, too, and some people find that sharing memories is one way to help each other. Feel free to share stories about the one who is gone. Sometimes, people hesitate to bring up the loss or mention the dead person's name because they worry this can be hurtful. But, people may find it helpful to talk directly about their loss. You are all coping with the death of someone you cared for.

Charlie and Doug's Story

Shortly after Charlie's husband Doug died, his friends started coming over with dinners and memories to share. They would sit around Charlie's dining table for hours remembering Doug's humor and kindness. Soon, Doug's friends were joining them with their own recollections. It was so like old times that it almost seemed Doug had just stepped out of the room. Those evenings together helped Charlie, as well as the others, start to heal after their loss.

For some people, mourning can go on so long that it becomes unhealthy. This can be a sign of serious depression and anxiety. Talk with your doctor if sadness keeps you from carrying on with your day-to-day life. Support may be available until you can manage the grief on your own.

How Grief Counseling Can Help

Sometimes people find grief counseling makes it easier to work through their sorrow. Regular talk therapy with a grief counselor or therapist can help people learn to accept a death and, in time, start a new life.

There are also support groups where grieving people help each other. These groups can be specialized—parents who have lost children or people who have lost spouses, for example—or they can be for anyone learning to manage grief. Check with religious groups, local hospitals, nursing homes, funeral homes, or your doctor to find support groups in your area.

An essential part of hospice is providing grief counseling to the family of someone who was under their care. You can also ask hospice workers for bereavement support at this time, even if hospice was not used before the death.

Remember to take good care of yourself. You might know that grief affects how you feel emotionally, but you may not realize that it can also have physical effects. The stress of the death and your grief could even make you sick. Eat well, exercise, get enough sleep, and get back to doing things you used to enjoy, like going to the movies, walking, or reading. Accept offers of help or companionship from friends and family. It's good for you and for them.

Remember that your children are grieving, too. It will take time for the whole family to adjust to life without your spouse. You may find that your relationship with your children and their relationships with each other have changed. Open, honest communication is important.

Mourning takes time. It's common to have rollercoaster emotions for a while.

Let major decisions wait, if possible.

Try to delay major life decisions until you are feeling better. You don't want to decide to make a big change, like selling your home or leaving your job, when you are grieving and perhaps not thinking clearly.

Taking Care of Yourself While Grieving

In the beginning, you may find that taking care of details and keeping busy helps. For a while, family and friends may be around to assist you. But, there comes a time when you will have to face the change in your life.

Here are some ideas to keep in mind:

- **Take care of yourself.** Grief can be hard on your health. Exercise regularly, eat healthy food, and get enough sleep. Bad habits, such as drinking too much alcohol or smoking, can put your health at risk.
- **Try to eat right.** Some widowed people lose interest in cooking and eating. It may help to have lunch with friends. Sometimes, eating at home alone feels too quiet. Turning on the radio or TV during meals can help. For information on nutrition and cooking for one, look for helpful books at your local library or bookstore or online.
- **Talk with caring friends.** Let family and friends know when you want to talk about your spouse. They may be grieving too and may welcome the chance to share memories. Accept their offers of help and company, when possible.
- **Visit with members of your religious community.** Many people who are grieving find comfort in their faith. Praying, talking with others of your faith, reading religious or spiritual texts, or listening to uplifting music also may bring comfort.
- **See your doctor.** Keep up with visits to your healthcare provider. If it has been awhile, schedule a physical and bring your doctor up to date on any pre-existing medical conditions and any new health issues that may be of concern. Let your healthcare provider know if you are having trouble taking care of your everyday activities, like getting dressed or fixing meals.

Does Everyone Feel the Same Way After a Death?

Men and women share many of the same feelings when a spouse dies. Both may deal with the pain of loss, and both may worry about the future. But, there also can be differences.

Many married couples divide up their household tasks. One person may pay bills and handle car repairs. The other person may cook meals and mow the lawn. Splitting up jobs often works well until there is only one person who has to do it all. Learning to manage new tasks—from chores to household repairs to finances—takes time, but it can be done.

Being alone can increase concerns about safety. It’s a good idea to make sure there are working locks on the doors and windows. If you need help, ask your family or friends.

Facing the future without a husband or wife can be scary. Many people have never lived alone. Those who are both widowed and retired may feel very lonely and become depressed. Talk with your doctor about how you are feeling.

Make Plans and Be Active

After years of being part of a couple, it can be upsetting to be alone. Many people find it helps to have things to do every day. Whether you are still working or are retired, write down your weekly plans. You might:

- Take a walk with a friend.
- Visit the library.
- Volunteer.
- Try an exercise class.
- Join a singing group.
- Join a bowling league.
- Offer to watch your grandchildren.
- Consider adopting a pet.
- Take a class at a nearby senior center, college, or recreation center.
- Stay in touch with family and friends, either in person or online.

Getting Your Legal and Financial Paperwork in Order

When you feel stronger, you should think about getting your legal and financial affairs in order. For example, you might need to:

- Write a new will and advance directive.
- Look into a durable power of attorney for legal matters and health care, in case you are unable to make your own medical decisions in the future.
- Put joint property (such as a house or car) in your name.
- Check on changes you might need to make to your health insurance as well as your life, car, and homeowner’s insurance.

- Sign up for Medicare by your 65th birthday.
- Make a list of bills you will need to pay in the next few months: for instance, State and Federal taxes and your rent or mortgage.

When you are ready, go through your husband's or wife's clothes and other personal items. It may be hard to give away these belongings. Instead of parting with everything at once, you might make three piles: one to keep, one to give away, and one "not sure." Ask your children or others to help. Think about setting aside items like a special piece of clothing, watch, favorite book, or picture to give to your children or grandchildren as personal reminders of your spouse.

Going Out After the Death of a Spouse

Having a social life on your own can be tough. It may be hard to think about going to parties or other social events by yourself. It can be hard to think about coming home alone. You may be anxious about dating. Many people miss the feeling of closeness that marriage brings. After time, some are ready to have a social life again.

Here are some things to remember:

- Go at a comfortable pace. There's no rush.
- It's okay to make the first move when it comes to planning things to do.
- Try group activities. Invite friends for a potluck dinner or go to a senior center.
- With married friends, think about informal outings like walks, picnics, or movies rather than couple's events that remind you of the past.
- Find an activity you like. You may have fun and meet people who like to do the same thing.
- You can develop meaningful relationships with friends and family members of all ages.
- Many people find that pets provide important companionship.

Take Care of Yourself

- Get help from your family, friends, or professionals if you need it.

- Be open to new experiences.
- Take time to adjust to life without your spouse.

C. After Someone Dies

What to Do After Someone Dies

National Institute on Aging (2017), *What to Do After Someone Dies*. Retrieved January 8,2020 https://www.nia.nih.gov/health/what-do-after-someone-dies

Nothing has to be done immediately after a person’s death. Take the time you need. Some people want to stay in the room with the body; others prefer to leave. You might want to have someone make sure the body is lying flat before the joints become stiff and cannot be moved. This rigor mortis begins sometime during the first hours after death.

After the death, how long you can stay with the body may depend on where death happens. If it happens at home, there is no need to move the body right away. This is the time for any special religious, ethnic, or cultural customs that are performed soon after death.

If the death seems likely to happen in a facility, such as a hospital or nursing home, discuss any important customs or rituals with the staff early on, if possible. That will allow them to plan so you can have the appropriate time with the body.

Some families want time to sit quietly with the body, console each other, and maybe share memories. You could ask a member of your religious community or a spiritual counselor to come. If you have a list of people to notify, this is the time to call those who might want to come and see the body before it is moved.

As soon as possible, the death must be officially pronounced by someone in authority like a doctor in a hospital or nursing facility or a hospice nurse. This person also fills out the forms certifying the cause, time, and place of death. These steps will make it possible for an official death certificate to be prepared. This legal form is necessary for many reasons, including life insurance and financial and property issues.

If hospice is helping, a plan for what happens after death is already in place. If death happens at home without hospice, try to talk with the doctor, local medical examiner (coroner), your local health department, or a funeral home representative in advance about how to proceed.

Arrangements should be made to pick up the body as soon as the family is ready and according to local laws. Usually this is done by a funeral home. The hospital or nursing facility, if that is where the death took place, may call the funeral home for you. If at home, you will need to contact the funeral home directly or ask a friend or family member to do that for you.

The doctor may ask if you want an autopsy. This is a medical procedure conducted by a specially trained physician to learn more about what caused the death. For example, if the person who died was believed to have Alzheimer’s disease, a brain autopsy will allow for a definitive diagnosis. If your religion or culture objects to autopsies, talk to the doctor. Some people planning a funeral with a viewing worry about having an autopsy, but the physical signs of an autopsy are usually hidden by clothing.

What about organ donation?

At some time before death or right after it, the doctor may ask about donating organs such as the heart, lungs, pancreas, kidneys, cornea, liver, and skin. Organ donation allows healthy organs from someone who died to be transplanted into living people who need them. People of any age can be organ donors.

The person who is dying may have already said that he or she would like to be an organ donor. Some States list this information on the driver's license. If not, the decision has to be made quickly. There is no cost to the donor's family for this gift of life. If the person has requested a Do Not Resuscitate (DNR) order but wants to donate organs, he or she might have to indicate that the desire to donate supersedes the DNR. That is because it might be necessary to use machines to keep the heart beating until the medical staff is ready to remove the donated organs.

Learn more about organ donation resources for older donors and advance care planning.

D. Uncomplicated Bereavement and Grief

Uncomplicated Grief

Grief and loss are part of life and is experienced by most of us at some point in life. People deal with grief in many different ways, and not necessarily going through a predictable group of 'stages,' although some do.

How people grieve can depend on the circumstances of the loss (e.g., sudden death, long illness, death of a young person) as well as past experiences of loss. There is no time limit on grief - some people get back to their usual routine fairly quickly, others take longer. Some people prefer time alone to grieve, others crave the support and company of others.

Below are just some of the range of experiences which can be part of uncomplicated grief:

- Symptoms of depression or anxiety, such as poor sleep, lowered appetite, low mood, feeling of anxiety - for some people the anxiety will be more obvious, for others the depression.
- A sense of the loss not quite being ‘real’ at first, or refusal to believe it has occurred
- Feeling disconnected from others, sense of numbness
- Guilt about not initially feeling pain about the loss
- Worries about not grieving ‘normally’ or ‘correctly’
- Mood swings and tearfulness
- Guilt about interactions with the person who has died (e.g. *I should have spent more time with her* or *I wish we didn’t have that argument)*
- Waves of sadness or anger which can be overwhelming and sometimes suddenly triggered by reminders
- Seeking reminders of the person who has died, e.g. being in their home or with their belongings, or perhaps at times even feeling you see or hear the deceased person
- Guilt about gradually getting back to ‘normal’ life and at times not ‘remembering’ to feel sad

Coping with Uncomplicated Grief

Most people going through the pain described above will eventually adjust to the loss and return to normal life, although of course carrying some sadness about the loss. Most people do not require medication or counselling to manage uncomplicated grief and should simply be supported to go through their individual grief process. It is important to maintain a healthy diet and some physical activity during this time. Some people may find it helpful to engage in counseling or to attend groups with others who have suffered a recent loss.

Complicated Grief

Complicated grief is a general term for describing when people adjust poorly to a loss. **This is very difficult to define, as there is no standard which limits what is normal or healthy grief**.

Below are some warning signs which *may* suggest that a person is not coping well with grief and may be at a greater risk of the grieving process taking longer to resolve or being more difficult:

- Pushing away painful feelings or avoiding the grieving process entirely
- Excessive avoidance of talking about or reminders of the person who has died
- Refusal to attend the funeral
- Using distracting tasks to avoid experiencing grief, including tasks associated with planning the funeral
- Abuse of alcohol or other drugs (including prescription)
- Increased physical complaints or illness
- Intense mood swings or isolation which do not resolve within 1-2 months of the loss
- Ongoing neglect of self-care and responsibilities

Again, it is important to emphasize that there are no ‘rules for grieving’ and that many of the items above may occur as part of uncomplicated grief. However, people who are coping very poorly one month after a loss may continue to cope poorly 1-2 years later, so if these warning signs are present then it is often worthwhile seeking some help early on, to increase the chances of adjusting in the long term.

Coping with Complicated Grief

Psychological therapy can support people to safely explore feelings of grief and connect with painful feelings and memories, paving the way for resolution. Therapy may also support people to use strategies such as relaxation, engaging in positive activities, and challenging negative thoughts, in order to combat the associated symptoms of anxiety and depression.

Antidepressant medication may also be used to alleviate depression associated with grief, and this can be useful in conjunction with psychological strategies.

Tranquilizing medications can interfere with the natural grieving process.

Although early help is recommended, health professionals are able to support people to work through complicated grief even years after the loss.

E. Coping With Grief After a Disaster or Traumatic Event

Grief is the normal response of sorrow, heartache, and confusion that comes from losing someone or something important to you. Grief can also be a common human response after a disaster or other traumatic event. This tip sheet contains information about grief, the grieving process, and what happens when the process is interrupted and complicated or traumatic grief occurs. It also offers tips and resources for coping with both types of grief.

Grief is a part of life. It is a strong, sometimes overwhelming reaction to death, divorce, job loss, a move, or loss of health due to illness. It can also occur after disasters or other traumatic events. If you are experiencing grief, you may feel empty and numb, or unable to feel joy or sadness. You may also feel angry. **You may experience physical reactions, including the following:**

- Trembling or shakiness
- Muscle weakness
- Nausea and trouble eating
- Trouble sleeping or difficulty breathing
- Dry mouth

While grieving, you may have nightmares, withdraw socially, and not want to participate in your usual activities. Eventually, you may also notice positive changes in yourself from your experience of loss, such as the following:

- Becoming more understanding and tolerant
- Having increased appreciation for relationships and loved ones
- Feeling grateful for the presence of those in your community who are loving and caring
- Experiencing enhanced spiritual connection

- Becoming more socially active ƒ Getting involved in advocacy to help people who have experienced similar losses

How Long Does Grief Usually Last? Grief is different for every person and every loss. The manner of the death or loss and your personal circumstances can affect how long you experience grief. If you are experiencing grief now, it may be difficult to imagine an end to the pain you are feeling. Even though your life may not be the same as it was before, the grief will eventually ease, and the grieving process will allow you to accept the loss and move forward with your life.

Coping With Grief

You can take steps to help yourself cope with grief. Talking to others who understand and respect how you feel—family members, faith leaders, people you trust—is a helpful way to cope with your grief. Recognize that although you might still have these feelings over a long period, they will likely be less intense over time. Try to take care of yourself physically by exercising, eating healthy meals, and getting enough sleep. Allow yourself to feel joy and sadness, and to cry when you need to.

Going through the grieving process and healing from loss does not mean forgetting about loved ones who have died. You may still feel deeply connected to the person you have lost, but you will also be able to imagine a life without him or her. You will start to be reengaged in daily life and reconnected to others. When moving out of grief, you may start to experience the following:

- Feeling the pain of your loss without resisting or avoiding it
- Adjusting to a new reality in which your loved one is no longer present
- Forming new relationships

If you are not experiencing these changes and adjustments after many months, and you feel “stuck” in your deep and overwhelming feelings of loss, then you may be experiencing what is known as complicated or traumatic grief.

What Is Complicated or Traumatic Grief?

After a disaster or other traumatic event, many factors can disrupt the normal process of grieving, raising the risk for complicated or traumatic grief. Whether a disaster is natural or human-caused, grief at the loss of loved ones may be compounded by sorrow and anger at the loss of home and possessions, as well as fear or anxiety about the loss of a sense of safety and security in the community. In some cases, meeting immediate physical needs after a disaster may take priority over grieving the loss of life, which can delay, prolong, or complicate the normal grieving process. Complicated or traumatic grief is grief that does not end and does not help you make progress toward getting back to your usual activities and routine. For most people, intense feelings of grief will lessen gradually over time, beginning to ease within 6 months of the loss. But if you're experiencing complicated or traumatic grief, you may not feel any reduction of grief over many months or even years. Your feelings of sadness, anger, and loneliness may even become more intense over time.

These are some of the symptoms of complicated or traumatic grief:

- Feeling deeply angry about the death or loss
- Being unable to think about anything but your loved one
- Not wanting any reminders of your loved one at all
- Having nightmares or intrusive thoughts
- Feeling deep loneliness and longing for the person you lost
- Feeling distrustful of others
- Feeling unable to maintain regular activities or fulfill responsibilities
- Feeling bitterness about life and envying others not affected by grief
- Being unable to enjoy life or remember happy times with your loved one

If you are experiencing any of these symptoms, you may need to seek help in order to move forward and begin the healing process. You can find help by using the resources listed on this page, talking to a doctor, or seeing another health care professional.

F. Models of Grief

Grief can vary between individuals. However, there are still global trends in how people cope with loss. Psychologists and researchers have outlined various models of grief. Some of the most familiar models include the five stages of grief, the four tasks of mourning, and the dual process model.

1. *Elizabeth Kubler Ross and the Five Stages of Grief*

“The Kübler-Ross model, commonly known as the five stages of grief, was first introduced by Elisabeth Kübler-Ross in her 1969 book, On Death and Dying.

The progression of the states is Denial, Anger, Bargaining, Depression, and Acceptance.

1. Denial – "I feel fine."; "This can't be happening, not to me." Denial is usually only a temporary defense for the individual. This feeling is generally replaced with heightened awareness of situations and individuals that will be left behind after death.

2. Anger – "Why me? It's not fair!"; "How can this happen to me?"; "Who is to blame?" Once in the second stage, the individual recognizes that denial cannot continue. Because of anger, the person is very difficult to care for due to misplaced feelings of rage and envy. Any individual that symbolizes life or energy is subject to projected resentment and jealousy.

3. Bargaining – "Just let me live to see my children graduate."; "I'll do anything for a few more years."; "I will give my life savings if..." The third stage involves the hope that the individual can somehow postpone or delay death. Usually, the negotiation for an extended life is made with a higher power in exchange for a reformed lifestyle. Psychologically, the individual is saying, "I understand I will die, but if I could just have more time..."

4. Depression – "I'm so sad, why bother with anything?"; "I'm going to die... What's the point?"; "I miss my loved one, why go on?" During the fourth stage, the dying person begins to understand the certainty of death. Because of this, the individual may become silent, refuse visitors and spend much of the time crying and grieving. This process allows the dying person to disconnect oneself from things of love and affection. It is not recommended to attempt to cheer up an individual who is in this stage. It is an important time for grieving that must be processed.

5. Acceptance – "It's going to be okay."; "I can't fight it, I may as well prepare for it." In this last stage, the individual begins to come to terms with their mortality or that of their loved one. Kübler-Ross originally applied these stages to people suffering from terminal illness, later to any form of catastrophic personal loss (job, income, freedom). This may also include significant life events such as the death of a loved one, divorce, drug addiction, the onset of a disease or chronic illness, an infertility diagnosis, as well many tragedies and disasters.

Kübler-Ross claimed these steps do not necessarily come in the order noted above, nor are all steps experienced by all patients, though she stated a person will always experience at least two. Often, people will experience several stages in a "roller coaster" effect—switching between two or more stages, returning to one or more several times before working through it. Significantly, people experiencing the stages should not force the process. The grief process is highly personal and should not be rushed, nor lengthened, on the basis of an individual's imposed time frame or opinion. One should merely be aware that the stages will be worked through and the ultimate stage of "Acceptance" will be reached.”

2. Four Tasks of Mourning

Psychologist J. W. Worden also created a stage-based model for coping with the death of a loved one. He divided the bereavement process into four tasks:

1. To accept the reality of the loss

There are basic ways one can accept the reality of a loss: going through the rituals of a funeral or memorial, beginning to speak about (and think about) the person in past tense, etc.

On a more complex level, there is accepting the reality of the significance of the loss. For example, one may speak of someone in the past tense and accept their death but may downplay the significance of their relationship with that person, denying the impact the loss will have. On a basic level they may have accepted the reality of the loss, but on a deeper level, they will not have accomplished this task until they have fully accepted the depth of the relationship and correlating impact.

Another common struggle with this task is around acceptance of the mechanism of the death. A death by suicide, overdose, or other stigmatized death may present challenges to accomplishing this task if family or friends are unable to acknowledge or accept the reality of how the person died.

2. **To work through the pain of grief**

   Rather than attempting to identify all the emotions of grief that one may experience and need to work through, Worden's model acknowledges that each person and each loss will mean working through a range of different emotions. From sadness, fear, loneliness, despair, hopelessness, and anger to guilt, blame, shame, relief, and countless others, there are many emotions a griever contends with. What is important in this task is acknowledging, talking about, and understanding these complex emotions in order to work through them. The danger, of course, is denying one's feelings and avoiding them. This tendency can be exacerbated by society's discomfort with the feelings that accompany grief, so the griever may feel like they shouldn't feel or acknowledge these difficult emotions.

3. **To adjust to life without the deceased**

   This readjustment happens over an extended period of time and can require internal adjustments, external adjustments, and spiritual adjustments.

   It may take a significant period of time just to realize the different roles their loved one performed or internal and spiritual adjustments that are required. This can be especially difficult for widows, who may need to learn a wide array of new skills and tasks, ranging from bill paying, parenting, and taking care of the home, to environmental changes, such as living alone, doing things alone, and redefining the self without the other person.

   This can also mean adjusting to a new spiritual environment, which may have been changed by the experience of death. This task requires developing the necessary skills to move confidently forward in the altered environment – internal, external, and spiritual.

4. To maintain a connection to the deceased while moving on with life

To find an appropriate, ongoing connection in our emotional lives with the person who has died while allowing us to continue living. Like the other tasks, this can mean varying things to various grievers. But it often means allowing for thoughts and memories, while beginning to meaningfully engage in things that bring pleasure, new things, or new relationships. not accomplishing this task is to *not live.* It is the sense that life stopped when that person died and that one is not able to resume life in a meaningful way, with a different sense of connection to the person who has died. This last task can take a long time and be one of the most difficult to accomplish. (Worden, 2008)

3. The Dual Process Model

As an alternative to the linear stage-based model, Margaret Stroebe and Hank Schut developed a dual process model of bereavement. They identified two processes associated with bereavement:

Loss-oriented activities and stressors are those directly related to the death. These include:

- Crying
- Yearning
- Experiencing sadness, denial, or anger
- Dwelling on the circumstances of the death
- Avoiding restoration activities

Restoration-oriented activities and stressors are associated with secondary losses. They may involve lifestyle, routine, and relationships. Restoration-oriented processes include:

- Adapting to a new role
- Managing changes in routine
- Developing new ways of connecting with family and friends
- Cultivating a new way of life.

Stroebe and Schut suggest most people will move back and forth between loss-oriented and restoration-oriented activities.

Chapter 2. Treatment for Grief

A. Complicated grief therapy as a new treatment approach

Abstract

Complicated grief therapy (CGT) is a relatively new psychotherapy model designed to address symptoms of complicated grief. Drawn from attachment theory and with roots in both interpersonal therapy (IPT) and cognitive-behavioral therapy, CGT includes techniques similar to prolonged exposure (repeatedly telling the story of the death and in vivo exposure activities). The treatment also involves focusing on personal goals and relationships. CGT has been demonstrated to be effective in a trial in which participants with complicated grief were randomly assigned to CGT or IPT; individuals receiving CGT responded more quickly and were more likely to respond overall (51 % vs 28%). This article briefly summarizes the conceptual underpinnings of CGT, discusses the empirical evidence for its efficacy, describes its techniques, and presents a case example of a client treated in a 16-session manualized CGT protocol. The article concludes with a description of future research directions for CGT.

Keywords: *bereavement*, *traumatic grief*, *treatment*, *psychotherapy*, *cognitive behavior therapy*

Description of the treatment

Facilitating recovery from loss has been a staple of psychotherapy since long before the entity known variously as “complicated grief,” “traumatic grief,” “complicated bereavement,” “prolonged grief disorder,” or “pathologic grief” was identified as a form of suffering distinct from normal bereavement or depression. Clinicians have described numerous forms of treatment for bereavement-related distress, relying on different conceptualizations of the problem and different therapeutic techniques,[1,2] including medications,[3,5]supportive therapy,[6,7] client-centered therapy,[8] meaning-oriented therapy,[9] brief dynamic therapy,[10,11] cognitive therapy,[12] cognitive behavioral therapy (CBT),[13-17]interpersonal therapy (IPT),[18] pastoral counseling,[19] play therapy,[20] logotherapy,[21] writing therapy,[22,23] Internet-administered therapy,[24,25] virtual reality,[26] and hypnosis.[27-29] These treatments have been tested with children.[30-34] and adults[10,22,35] and have included interventions for inpatients,[36] refugees,[17] couples,[37]parents,[35] and those bereaved by war,[38] natural disasters,[39] accidents,[23] suicide,[40] and violence.[41]

Relatively few of these interventions have targeted complicated grief (CG) symptoms specifically rather than depression and distress more generally. Three review articles have described the literature on these CG-specific interventions.[42-41] The most recent, a meta-analysis of randomized, controlled trials, found a pooled standard mean difference (a measure of effect size) of -0.53 (95% CI: -1.00 to -0.07) favoring interventions targeting complicated grief relative to supportive counseling, IPT, or wait list.[43] The four interventions that were more efficacious than the comparison condition were all based, at least in part, on cognitive-behavioral principles. [14,24,45]An interpretive intervention focused on increasing clients* insight about conflict and trauma related to their loss was not efficacious.[46,47] The effects of the CG interventions appeared to grow larger at follow-up, although long-term data were only available from a single study.[14]

One form of complicated grief therapy (CGT) with strong empirical support has roots in both IPT and CBT[45]CGT is based on **attachment theory, which holds that humans are biologically programmed to seek, form, and maintain close relationships**. Attachment figures are people with whom proximity is sought and separation resisted; they provide a ”safe haven“ of support and reassurance under stress and a ”secure base“ of support for autonomy and competence that facilitates exploration of the world. In acute grief following the loss of an attachment figure, the attachment system is disrupted, often leading to a sense of disbelief, painful emotions, intrusive thoughts of the deceased individual, and inhibition of the exploratory system.[48] With successful mourning, the individual moves from a state of acute grief to integrated grief in which the finality of the loss is acknowledged, the trauma of the loss is resolved, emotions become more positive or bittersweet, the mental representation is revised to encompass the death of the attachment figure, and the exploratory system is reactivated, with life goals revised to integrate the consequences of the loss. This occurs through a ”dual-process model,“ with both loss- and restoration-focused activities.

In CG, the process of transition from acute grief to integrated grief is derailed.[49] Clients with CG typically experience prolonged, intense painful emotions; rumination, often around themes of self-blame; and maladaptive behaviors, including avoidance of triggers to the extent that functioning is disrupted.[50] Although the causes are not yet understood, the mechanism is believed to be incomplete processing of information about the death. **Specifically, the mental representation of the attachment figure is disrupted, such that the loss is acknowledged in declarative memory but not in implicit memory.** This leads to a lack of acceptance of the finality of the loss.

Moreover, the exploratory system does not re-engage, such that the grieving individual can become distanced from other people and the world generally.

Thus, the basic principle underlying CGT is that grief is a natural, adaptive process.[51] This implies that treatment of CG involves removing the impediments to successful resolution of the grieving process. Through a variety of loss- and restoration-focused techniques, the therapist works to facilitate the progress of grief to help the client come to terms with the death.

A number of investigations have provided empirical support for this model of treatment. After initial pilot studies showed promising results,[52,53] CGT was compared with standard IPT in a randomized trial with 83 adult outpatients with complicated grief.[45]Participants in both conditions received 16 individual sessions of psychotherapy. Treatment response was defined as a score of 1 or 2 (“very much improved” or “much improved”) on the interviewer-rated Clinical Global Impression Improvement scale and as time to a 20-point or better decrease in scores on the self-reported Inventory of Complicated Grief. Response rates were higher (51 % vs 28%) and time to response faster in the CGT group than in the IPT group.

A secondary analysis examining the impact of naturalistic pharmacotherapy on participants in this trial found that response rates in the CGT group were higher among those taking antidepressant medications, and that this effect was mediated by reduced attrition among those taking medications.[54] Among patients receiving CGT, 42% of those not taking antidepressants, vs only 9% of those taking such medication, terminated the trial prematurely. By contrast, in the IPT condition, only 30% of those taking medications and 23% of those not taking medications dropped out. **These data suggest that CGT may be a challenging treatment, particularly for individuals who are not also taking medication.**

Investigators have subsequently tested CGT with Japanese women bereaved by violent death[55] and in substance abusers[56]; results suggest that the benefits of treatment are not restricted to Western cultures or individuals without comorbid drug or alcohol abuse.

Description of the treatment

As noted above, the theory includes elements drawn from both IPT and CBT. In general, the CBT techniques target the loss-related processes and focus on symptoms of painful intrusive memories and behavioral avoidance. The IPT elements focus on restoration by helping clients re-establish relationships and connection with valued life goals.

Although CGT can be flexibly applied in clinical practice, the manualized form tested in research studies consists of 16 sessions, each approximately 45 to 60 minutes long. Each session is structured, with an agenda that includes reviewing the previous week's activities, doing work in session, and assigning tasks for the coming week. The treatment is typically divided into three phases. In the introductory phase, which usually takes place over the first three sessions, the primary goals are to establish a strong therapeutic alliance, obtain a history of the client's interpersonal relationships, provide psychoeducation about the model of complicated grief, and describe the elements of treatment. A supportive person usually attends the third session. In the intermediate phase, which typically comprises sessions 4 to 9, the client performs a number of exercises inside and outside of the session designed to come to terms with the loss and address restoration of the capacity for joy and satisfaction in life. In the final sessions (10 to 16), the therapist and client review progress and collaboratively decide how to use the remaining sessions to complete the work and consolidate treatment gains. For some clients, this portion of the treatment may resemble IPT. A more detailed, session-by-session description follows.

Session 1

The goals of the first session are to welcome clients and orient them to CG and its treatment. Consistent with CGT's roots in interpersonal therapy, the primary focus of session 1 is to obtain an interpersonal history including early family relationships, other losses, the relationship with the deceased and the story of the death, and current relationships. The therapist and client discuss the client's current life situation, including stressors and coping resources. The therapist also provides a very brief introduction to the rationale and processes involved in CGT. Finally, the therapist introduces between-session assignments (sometimes known as homework): the grief monitoring diary, on which clients record daily triggers and less distressing moments; interval plans, which can include at-home practice of CG exercises as well as individualized activities designed to help clients move closer to their aspirations; and a handout that describes in detail the model of CG and an overview of the treatment.

Session 2

In the second session, the therapist and client review the grief monitoring diary, examining triggers throughout the week and times when grief was relatively manageable to look for patterns. They also use the handout to discuss the model of CG and ways in which it relates to the client's situation. The therapist then provides an overview of the treatment. Finally, the client is encouraged to think about personal aspirations, activities that have the potential for reawakening the capacity for joy and meaning in life. The client is also given another copy of the CGT handout to provide to a supportive person who will attend the third session.

Session 3

Usually session 3 includes a supportive person such as a family member or close friend, either in person or, if necessary, by telephone. The rationales for including a supportive person are that individuals experiencing complicated grief often lose a sense of connection with others, which the treatment aims to help restore; an outside perspective on the client and the way that grief is affecting his or her life can be helpful for the therapist; and a friend or family member can facilitate the treatment by understanding what the client is doing and why, and providing support throughout the process, which is often difficult and painful. During the session, this individual is asked to describe the client since the death, his or her reactions to grief, and any avoided situations or activities. The therapist then provides an overview of the CG model and treatment to the support person. The client and support person discuss ways in which the latter can be helpful as the client progresses through the treatment. During the last

15 minutes or so, the client is seen alone to review the grief monitoring diary and provide an update on goal work.

Session 4

The heart of CGT begins in this session, with the introduction of imaginal revisiting. Imaginal revisiting is a core element of CGT that in some ways resembles prolonged exposure, an empirically supported therapy for trauma and post-traumatic stress disorder (PTSD).[57,58] In this technique, the client briefly (for approximately 5 minutes) visualizes and tells the story of when he or she became aware of the loved one's death into a tape recorder and then debriefs with the therapist. The goal of the exercise is to help the client come to terms with the loss by processing it at an emotional level and integrating that emotional processing with the rational knowledge that the loved one has died. In the debriefing portion of the exercise, the client describes what he or she observed while telling the story; the function of this discussion is to encourage the client to reflect on the story from the vantage point of the present. The client then participates in another visualization exercise in which the story is put away. Finally, clients identify a reward they can give themselves for doing the hard, painful work of revisiting, both in session and during the assignment of listening to the tape every day between sessions. Other elements that continue throughout the treatment include the grief monitoring diary and restoration-oriented work to help the client move toward a personal goal that is unrelated to grief, in order to begin to visualize life with the capacity for joy and satisfaction without the loved one who died.

Session 5

This session includes a review of the grief monitoring diary, imaginal revisiting, and restoration work. Situational revisiting is a new element introduced during this session, in which the client identifies activities or places previously avoided because they trigger grief or serve as reminders of the loved one. The client is encouraged to engage in a situational revisiting activity every day.

Sessions 6 to 9

In addition to reviewing the grief monitoring diary, imaginal and situational revisiting, and aspirations work, the client completes a series of forms identifying pleasant memories and positive aspects or characteristics of the person who died as well as unpleasant memories/less positive aspects. Clients usually bring photographs and other mementos to some of these sessions.

Session 10

In this session, the therapist uses one or more structured questionnaires, such as the Inventory for Complicated Grief, to help the client evaluate progress and identify “stuck” points. Together, they decide on a direction for the remainder of the treatment. These can include work on other losses or IPT-oriented relationship work related to interpersonal disputes or role transitions.

Sessions 11 to 16

In these sessions, clients continue to complete grief monitoring diaries, situational revisiting exercises, and aspirations work. Although typically imaginal revisiting work is no longer necessary (as determined by distress ratings remaining low throughout the exercise), additional exercises may be conducted if needed. One final exercise that can be helpful in bringing a sense of closure and closeness with the deceased loved one is the imaginal conversation. In this exercise, the client imagines that the loved one has just died but is able to hear and speak. The client then engages in an imaginal conversation, playing both the role of the self and also of the loved one. During this conversation, the client can ask questions and, speaking as the dead person, can respond and/or offer reassurance. Although this exercise is optional (and best performed in cases in which the relationship was positive), it can be a moving and meaningful experience for clients.

If the client is experiencing CG from multiple losses, exercises such as imaginal and situational revisiting may be performed around another death. Usually the progress of therapy for treating other losses is faster after completion of the process for the initial, most distressing loss. Clients may also choose to engage in other work that is less directly related to CG and is usually consistent with the IPT targets of role transition or relationship conflict. Techniques can include standard IPT techniques such as close analysis of problematic interactions and role plays.

The final task of sessions 11 to 16 is termination with the therapist. For some clients, this is seen as a positive development, a “graduation” marking the progress from intense and debilitating grief to a sense of healing and wholeness. For other clients, discussion is required to process the feelings of loss of the therapeutic relationship.

Case example

The client, “Ann,” was a 52-year-old woman mourning the loss of her husband 4 years previously from a sudden cardiac arrest. She had been abused in childhood, and the only truly satisfying relationship of her life had been with her husband, whom she met in her late 30s. She described him as a soul mate and best friend. They had chosen not to have children and in her words, “were everything to each other.” In addition to her emotional loss, her financial status deteriorated dramatically after his death, resulting in major life changes and a drop in her standard of living. She indicated that her husband had left their financial affairs in disarray, with records stored in boxes in the closet, but she did not feel capable of sorting through the boxes and dealing with the estate or taxes.

At the outset of therapy, Ann met criteria for major depression and PTSD as well as CG. She described crying every night, with great difficulty sleeping. She felt isolated from other people and did not socialize with former friends or colleagues at work. She stated that spending time with people she used to spend time with as part of a couple was too painful, and that although she knew it was irrational, she found herself feeling envious and resentful of other people's relationships. She reported that she spent hours every day engaged in reveries about her life with her husband; her inattentiveness had drawn reprimands from her supervisor and she was now worried about losing her job, which she detested but needed for financial reasons. She had nightmares and flashbacks about waking to discover her husband's body in their bed. She also reported episodes of rage, usually triggered by hearing about what she perceived as medical malpractice or instances of poor medical care. She held her husband's physicians responsible for his death because they never diagnosed his heart problem. Although she had formerly been a talented amateur musician, playing guitar in a local band, she had not played since her husband's death. She told the therapist that although she would never consider suicide, she could not imagine a future for herself without her husband.

Ann was able to complete the grief monitoring diary and rapidly recognized a pattern: although she disliked her job, work was a useful distraction from the pain she experienced as unrelenting in the evenings and on weekends. She found the description of CG in the handout reassuring, because it gave a name to her experiences. She saw many aspects of herself and her situation in the material. Upon hearing about the revisiting exercises, particularly the imaginal revisiting, she became very anxious. She asked many questions about how telling the horrifying story of waking up in bed next to her deceased husband could possibly be helpful. In addition to explaining several times the ways in which this technique facilitates healthy grieving, the therapist also repeatedly reassured Ann that she would not be going through this experience alone.

Because she did not have any close friends who lived locally, she arranged to have her sister attend the third session by conference call. She was surprised at how supportive her sister was. The sister indicated that she was aware that Ann was suffering a great deal but had not known how to help and was “afraid to make things worse by saying the wrong thing.” She agreed to text Ann every day and talk with her twice a week, including the evening of her therapy appointments.

Ann initially had difficulty with imaginal revisiting. At the beginning of session 4, she asked a lot of questions about the rationale and procedures for the exercise; most of these were the same questions she had asked during session 2. The therapist normalized her concerns and praised her willingness to do something painful to help resolve her grief and come to terms with the loss. Because Ann was so hesitant to begin, the therapist also told her only to spend 2 minutes during the first exercise. Ann did so and was, as she expected, very distressed. During the debriefing process, Ann sobbed as she expressed her guilt over having slept through her husband's passing and her agony at not knowing whether she could have saved him had she been awake. She also expressed anger toward her husband's primary care doctor, who had performed routine annual physical examinations but had never diagnosed cardiac problems. She was able to perform the visualization exercise aimed at putting the story away and reported a decrease in distress to manageable levels. Although she agreed to listen to the tape between sessions and scheduled a telephone check-in with her therapist after completing the exercise the first time, when the time came, Ann told the therapist she was not yet ready.

After doing the imaginal revisiting exercise again in session 5, Ann reported that it was still very distressing, but she was willing to try listening to the tape at home. She and the therapist talked about ways Ann could reward herself for her hard work. She decided she would try to play her guitar, which had always been very pleasant. This time, she was able to complete the imaginal revisiting several times during the week and reported that although it was painful, it was less hard than she had imagined it would be. Throughout the next 6 sessions, she continued to engage in exercises and spent most of the debriefing time focused on the issues of guilt, uncertainty, and anger, which Ann and the therapist agreed were the key factors contributing to her CG.

In contrast to the imaginal revisiting, Ann took a great deal of satisfaction from the situational revisiting, which began in session 5. She began by dining in a few of her husband's favorite restaurants that she had not visited since his death. She opted for lunches rather than dinners, invited acquaintances from work to accompany her, and found that rather than being distressed, she enjoyed both the food and the company. She then began the task of going through the files and dealing with the financial and tax issues. Although this was clearly not pleasant, Ann felt very proud of herself for taking responsibility and was able to make progress over the course of her treatment.

During session 2, Ann had identified playing in a band as one of her aspirations, and she began playing guitar again as a reward for doing the imaginal revisiting. She was soon back in her former routine of daily practice. After 2 months, she reported to her therapist that she had attended an informal jam session at a local bar and met a couple of musicians who were looking for a guitarist. They began practicing together and by the end of treatment had made plans to appear together as a band at the same bar for a performance that had the potential to turn into a monthly gig. Ann was delighted to be playing regularly and had begun to consider her new bandmates as friends.

Ann's ninth session was the week of what would have been her 10th wedding anniversary. The therapist began discussing this potentially painful time several weeks in advance. Two weeks before the anniversary, the therapist provided Ann with a handout on dealing with difficult times. With mixed feelings, Ann made plans to leave town for a long weekend to attend a music festival that she knew her late husband would not have enjoyed. Although she reported feeling very sad, she did enjoy the festival and felt relieved that she had not spent the time “moping” at home.

By the end of treatment, Ann had made a great deal of progress. She no longer met criteria for major depression, PTSD, or complicated grief. Although she continued to experience some moments and even days of sadness, these were not prolonged or incapacitating. She no longer experienced nightmares or flashbacks. She no longer felt guilty and felt much less angry toward doctors and the medical profession. She no longer avoided pictures or places that reminded her of her husband. She now considered her bandmates and several of her coworkers as friends and had forged a closer relationship with her sister. She had also made progress on disentangling her financial affairs, although some of the issues were still unresolved. She was playing guitar in a band once again, which gave her great satisfaction.

Termination with the therapist was an easy process for Ann. She expressed gratitude for the help and accepted praise for her hard work, particularly in sticking with the imaginal revisiting exercise, which she was able to acknowledge helped reduce the power and pain of the memory of finding her husband's body. She agreed that she was doing much better and did not feel the need for further counseling at this time.

Current and future directions for research on complicated grief therapy

Research on CGT is ongoing. One currently unresolved issue is the role of pharmacotherapy in the recovery from CG. One investigation based on naturalistic data suggested that concurrent use of antidepressant medications may facilitate CGT by enabling clients to tolerate the painful work of imaginal and situational revisiting.[54] An open-label pilot study suggested that selective serotonin reuptake inhibitors may be sufficient to treat CG even in the absence of psychotherapy.[5]Because CGT is a challenging treatment not yet widely available, a finding that medication alone is sufficient to alleviate suffering in many individuals would have important public health significance.

Currently, a large-scale trial is underway in four sites to investigate these questions. Clients with CG as indicated by a score of 0 or more on the Inventory of Complicated Grief[59] are randomly assigned to citalopram, pill placebo, CGT plus placebo, or CGT plus citalopram. The primary aim is to determine whether citalopram is more effective than placebo in reducing the symptoms of CG, as measured by the Clinician Global Impression - Improvement.[60]

Another area ripe for exploration is the disseminability of CGT. Drawing as it does from both IPT and CBT, it can be challenging to learn for therapists who have a strong background in one model but not in the other. Like other therapies that deal with intense pain, it can also be emotionally draining. To date, the process for obtaining the requisite skills to conduct CGT competently has involved a multi-day didactic workshop followed by intensive supervision of at least two cases, with an expert supervisor listening to audiotapes on an hour-for-hour basis. This level of training and supervision may not be readily available for all potential therapists. It would be of interest to investigate whether a less stringent, time -intensive training process is sufficient to produce good outcomes; such a finding would greatly increase the public health significance of this promising new therapy.

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B. Historical Bereavement Intervention Programs

THE MUTUAL SUPPORT APPROACH

Mutual support or self-help groups are associations of people who share the same problem, predicament, or life situation and who unite for the purpose of mutual aid. This element of commonality is solely what determines inclusion in the group. [14] **All decisions about content, organization, and external relationships are made by the participants.** [43]

Mutual support groups provide their members with:

- person-to-person exchange based on identification and reciprocity
- access to a body of specialized information

- an opportunity to share coping techniques based on realistic expectations for optimal functioning
- an increased sense of personal worth, by focusing on how similar members are to others confronting the same situation
- reinforcement for positive change and maintenance of effort toward change through feedback on performance
- an arena for advocacy and social change
- an opportunity for education, not only of other persons with similar problems, but also professionals and the public
- an opportunity to help others by giving concrete aid and providing a role model
- help for the helpers who themselves are aided by assisting others [36] and by activism toward shared goals. [16,50]

Mutual help groups have been organized as alternative care-giving systems, as adjuncts to the professional care-giving system, and as strategic independent elements in interdependent networks of formal and informal care-giving systems in communities. [7,17]

In recent years there has been an increase in the number of independent mutual support groups and of voluntary associations with support groups concerned with acute and chronic life-threatening illnesses. A few deal with a single issue, such as the ''National Committee on Treatment of Intractable Pain," which advocates legislation to permit the use of heroin in control of terminal cancer pain. Most groups are concerned with specific categories of persons, such as parents of children with cystic fibrosis, families of relatives with Huntington's disease, or parents of premature infants. A few, like "Make Today Count" and "Candlelighters," are concerned with the overall needs of adults and children as they face the uncertainty associated with a variety of diseases, especially cancer. Such organizations offer support, education, and practical advice to their members during the course of an illness. It is unclear whether and how these groups offer systematic help with bereavement when death actually occurs, but there is informal support given among a smaller network of individual members.

Post-bereavement mutual support groups fall into two categories: (1) those that help people deal with personal grief, with the problems resulting from bereavement, and with the reorganization of their lives around the new status of being a single person (e.g., "THEOS" and the various widow-to-widow programs); and (2) those that attempt to help survivors cope with a grief made particularly difficult by the circumstances of the death, e.g., suicide, homicide, or the death of a child. Some groups (e.g., "Compassionate Friends" or "Seasons") focus primarily on support; others (e.g., "Parents of Murdered Children," "Military Widows," ''Vietnam Veterans," "Mothers Against Drunk Driving," "Sudden Infant Death Syndrome"), in addition to giving support, are committed to advocacy and social and political action to remedy the circumstances that caused the death of a family member or adversely affect the lives of survivors. The modalities of communication in both kinds of groups include one-to-one outreach, group meetings, peer counseling by telephone or by mail, and periodic conferences for members and professionals.

Almost all groups have developed literature—based on their own experiences and sometimes in collaboration with professionals—to educate others in similar circumstances, the general public, and health professionals. Many organizations have periodic newsletters with information on, for example, the types of services and benefits offered members; the grief process and its impact on marriage and family, including guidance for sibling grief; suggestions for the behavior of friends, relatives, and health professionals; community resources; reference lists and resource materials dealing with the latest scientific findings on causes and treatments; personal experiences of survivors; and public policy issues.

According to Parkes, [32] **the assumption that underlies mutual support bereavement groups is that "the person best qualified to understand and help with the problems of a bereaved person is another bereaved person."**

The organization that best exemplifies this approach is the Widow-to-Widow program.

The Widow-to-Widow Model

The original Widow-to-Widow Program was a demonstration-research project conducted by Phyllis Silverman under the direction of Gerald Caplan at the Laboratory of Community Psychiatry at Harvard University from 1964 to 1974. Extensive library research, observation, and interviews with widowed persons and community agencies were done in order to learn about the bereavement process, existing services, and widows' perceptions of themselves. This background research revealed several important findings that provided the rationale for the structure and content of the program. Existing services at that time were generally limited to traditional counseling by mental health practitioners. Relatively few widows sought out these services because they did not view their upset and practical problems as "mental illness." When they did seek such help it was typically several years after the bereavement, and grief was rarely identified as the presenting problem, although delayed grief reactions might be uncovered during therapy. [42]

It also became apparent that the bereavement process was not over in a few weeks or months but that it extended over a period of years; that guilt and anger were not identified by widows as the critical issues needing attention, although these were the common therapeutic foci; and that bereavement was best thought of not as a "crisis" but as a "transition." The death of a spouse initiated a critical life transition, marked by a sudden change in social status (from wife to widow) and requiring major changes in self-concept, roles, and tasks. With these observations in mind, Silverman considered how best to assist people in this transition and when to intervene. [43,44]

Because it is not always possible to identify in advance which *individuals* are at risk and because people seemed reluctant to ask for help, it was decided that the intervention should be based on a public health approach rather than a clinical model. Thus, the program was designed for the entire *population* at risk and used an outreach rather than a selfreferral approach. [46]

The next question had to do with the timing of intervention. Immediately following bereavement widows are likely to be numb and to act reflexively. Clergy, funeral directors, family, and friends are there to help with the specific tasks of the funeral and mourning rituals. Only somewhat later, during the phase Silverman [43] calls "recoil," does the meaning of the loss begin to become real. But by then family and friends have often gone home, expecting that the widow is over the worst and can manage on her own.

This period of recoil seemed the ideal time to offer help to widows with practical problems, management of extreme and profound feelings, and a general reordering of their lives. Thus, it was decided: (1) that help should not be offered until at least three to six weeks after the bereavement; (2) that in order to be accepted by the entire population at risk, it should be offered by another widow in the neighborhood who could serve as a role model during this critical transition; and (3) that help should be offered initially on a one-to-one basis because the recently bereaved were not often ready for group interactions for several months. Mutual support groups were useful later.

The goals of the program centered around change, not around "recovery." It was discovered in talking to widows that they never "recovered" in the sense of returning to all prebereavement baselines, but that a successful outcome depended on their ability to adapt and alter their images and roles to fit their new status. Although emotional support from a person who has also been through the experience was considered important, the women's more fundamental need was to learn how to change. Thus, in addition to emotional support, the intervention provided specific information about various practical concerns and about bereavement, as well as helping the widows develop alternate coping strategies. [44]

The original program was funded by the National Institute of Mental Health and the national and Massachusetts associations of funeral directors. It was designed by Silverman, who convened a forum in which the widow aides could pool their experiences as widows reaching out to new widows, discuss coping mechanisms, and develop strategies for program development. Silverman provided sanction, legitimization, and technical assistance when appropriate. Over time, the widow aides became very knowledgeable about such issues as insurance, finances, employment opportunities, housing, and community health and social services. As the program developed, social and educational group activities were started by the widow aides.

The initial program, which was conducted in a heterogeneous community in Boston from 1967 to 1970, was limited to widows under age 60. In 1971, it was replicated with elderly Jewish women. [47] There are now programs all over the United States, Canada, and the United Kingdom. In 1973, the American Association of Retired Persons (AARP), in conjunction with the National Retired Teachers Association, established the Widowed Persons' Service. Using materials and consultants from the Widow-to-Widow Program, the AARP began a national effort to develop mutual help programs in communities throughout the country. There are now more than 135 local AARP programs. Groups under different auspices, such as Community Contact for the Widowed of Toronto, [37] are also modeled after the original Widow-to-Widow Program.

It should be noted, however, that there is substantial variation in the application of the original model. Some programs offer only group support while others also provide one-to-one outreach. Some groups have no professional involvement while others have a substantial amount. Professionals may act as occasional consultants, provide routine backup support for the volunteers, train volunteers, or run support groups.

It is also interesting to note that there are very few mutual support groups for widowers or other groups of bereaved men. The reasons for this are not entirely clear. On several site visits it was suggested that men do not readily avail themselves of such services, preferring to deal with their problems alone….

PSYCHOTHERAPEUTIC INTERVENTIONS FOR THE BEREAVED

For individuals who feel overwhelmed by the painful emotions attributable to grieving or who are experiencing pathologic or distorted grief reactions, psychotherapeutic intervention may be warranted. As used here, psychotherapy refers to verbal techniques used by mental health professionals to assist the bereaved. Psychotherapeutic methods and approaches encompass a wide range.

- The service providers most commonly are psychiatrists, psychiatric social workers, or clinical psychologists, who may practice either independently or as part of teams in medical centers, in counseling agencies, or in programs specifically aimed at helping the bereaved.
- In certain settings assistance may also be provided by psychiatric nurses and specially trained counselors, including pastoral counselors.
- Individuals may refer themselves or may be referred by friends, clergy, or medical personnel.
- Treatment may be brief and time-limited—ranging from 6 sessions (often described as "crisis intervention") to 20 or 30 sessions—or it may be long-term and open-ended.
- Therapy may be dynamic, behavioral, or systems-oriented and may be offered to individuals, families, or groups of similarly bereaved persons.

… a number of theories guide psychotherapy with the bereaved. The particular training and orientation of the clinician, as well as an assessment of the individual client's or patient's needs, usually determine the type of help that is offered. Despite the individuality of methods and approaches, mental health practitioners generally share certain characteristics: nonjudgmental support and compassion and a wish to help the bereaved person or family resume adequate functioning and sense of well-being.

Psychotherapists with a psychodynamic or psychoanalytic perspective may be inclined to focus on the individual. They may help the bereaved patient to uncover, in a safe and self-accepting way, hostile feelings toward the deceased that had been kept out of awareness but that had taken a toll on the individual's psychologic well-being. They may also assist the bereaved to modify extremely negative self-perceptions that go beyond the relationship with the deceased. Typically these clinicians assume that pathologic grief reactions derive largely from preexisting factors in the bereaved person and features of the relationship with the deceased, such as inappropriate or immature defensive and coping strategies, preexisting emotional instability, a history of unresolved prior losses, and an especially ambivalent or dependent relationship. The treatment goal is to clarify any neurotic conflicts that have rendered the person vulnerable to pathologic grief, and to help the person work through troubling emotions and trains of thought. [23,59]

A behaviorist may conceptualize the problem in a similar way, but focus less attention on the internal personality characteristics of the patient and more attention on specific behaviors. The therapist may try to ''desensitize" the bereaved person who seems incapable of accepting and mourning the loss. The therapist may help the person construct and gradually accomplish a scale of increasingly difficult tasks (e.g., facing photographs of the deceased or visiting the gravesite) that imply an increased ability to relinquish the deceased.

Cognitive approaches are designed to remove obstacles to normal grieving by assisting the bereaved to "re-grieve" the loss in their own imagination. [27,54] By reliving the loss and reexperiencing feelings toward the deceased, the bereaved are helped to revise their images and to restructure the meaning of the loss.

There are a number of different interpersonal approaches to psychotherapy that deal directly with a family system or that focus on the psychosocial context of the individual patient. For example, therapists with a family or systems approach are primarily concerned with the impact of the loss on the family system, that is, how the death affects roles and communication patterns among the survivors. They are likely to treat the couple (in the case of a child's death, for example) or surviving family as the "patient," helping to identify and ameliorate patterns of communication and behavior that are putting strain on individual family members.

By contrast, the newly developed Interpersonal Therapy is designed to treat individual patients who have depression associated with abnormal grief reactions. This "is a focused, short-term, time-limited therapy that emphasizes the current interpersonal relations of the depressed patient while recognizing the role of genetic, biochemical, developmental, and personality factors in causation of and vulnerability to depression." [18] Proponents of this therapy point out that it is similar to other therapies in terms of techniques but different in terms of specific strategies for accomplishing tasks. **Treatment proceeds in three stages. First, the depression is explained to the patient and related to current and past interpersonal relationships, and major problem areas are identified. The goals of the second phase are to facilitate the grieving process, to assist the patient in developing relationships to substitute for what has been lost, to make the necessary role transitions, and to restore self-esteem.**

Finally, the end of therapy is discussed explicitly and the patient is helped to recognize his or her independent competence.

THE ROLE OF MEDICATIONS

Medications (pharmacologic interventions) may be used alone or in conjunction with any of the psychosocial approaches just described. Pharmacologic interventions have potential clinical value as well as important theoretical implications regarding the nature of the bereavement process. **The medications used to assist the bereaved are almost always psychopharmacologic agents from three classes of drugs: (1) anti-anxiety drugs, (2) hypnotics, and (3) antidepressants.**

Anti-Anxiety Drugs

These drugs also are known as "minor tranquilizers," "anxiolytics," and ''sedatives." The most commonly prescribed drugs in this class are benzodiazepines, which are most often prescribed by primary care physicians to relieve symptoms of anxiety, fear, tension, "stress," or psychic pain. Controlled studies indicate they are of value in reducing distress in acute stress and situational neurotic reactions. However, no controlled studies have yet been conducted specifically on bereaved persons. Numerous surveys report that bereaved persons use these drugs rather frequently, particularly during the early weeks of grief when subjective distress is greatest.

Hypnotics

Since insomnia is one of the common symptoms of grief, it is not surprising that many studies report use of hypnotics (sleeping pills) by many bereaved persons. Some of these hypnotics require a prescription (especially barbiturates and hypnotic benzodiazepines) while others do not. No studies have been directed specifically at evaluating the efficacy of any of these drugs in bereaved persons. [12,49]

Antidepressants

Tricyclic antidepressants and monoamine oxidase inhibitors have been shown to be effective in relieving symptoms and other manifestations of clinical depression in a large number of controlled studies. [19,28] Because the symptoms of grief may include sadness, hopelessness, bodily complaints, insomnia, and other features similar to clinical depression, it is not surprising that these drugs are prescribed for some grieving persons. In actual clinical practice, however, they are used relatively infrequently—far less frequently than anti-anxiety drugs and hypnotics.

Theoretical Issues

As indicated above, the possible value of psychopharmacologic medication for relieving the symptoms of acute grief is not substantiated by current evidence. But even if systematic studies were to demonstrate the efficacy of any of these drugs in reducing some of the distressing symptoms of grief, controversy would continue over their appropriate use. This controversy derives from different theoretical perspectives as to the "normality" or adaptive value of grief.

Many clinicians and theorists who view grief as normal believe that the use of drugs to reduce distress will interfere with the adaptive value of "grief work," and that failing to grieve or suppressing grief predisposes the individual to later mental disorder or medical disease. [28] Little evidence has been systematically collected to support this view.

Other clinicians and theorists are concerned over the possible impact of the intense distress of grief on biologic processes and functional activity. Viewing grief itself as a stressor, they support the use of psychopharmacologic drugs to relieve discomfort and to promote coping skills. However, even these clinicians tend to recommend caution—"The final resolution of loss is better accomplished by psychological help than by the use of drugs. Although drugs may be helpful in treating the ... bereaved, their use is adjunctive, symptomatic, and limited in time." [8]

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Chapter 3. Grief, Bereavement, and Coping With Loss

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Grief, Bereavement, and Coping With Loss (PDQ®)

Overview

People cope with the loss of a loved one in different ways. Most people who experience grief will cope well. Others will have severe grief and may need treatment. There are many things that can affect the grief process of someone who has lost a loved one to cancer. They include:

- The personality of the person who is grieving.
- The relationship with the person who died.
- The loved one's cancer experience and the way the disease progressed.

- The grieving person’s coping skills and mental health history.
- The amount of support the grieving person has.
- The grieving person’s cultural and religious background.
- The grieving person’s social and financial position.

This summary defines grief and bereavement and describes the different types of grief reactions, treatments for grief, important issues for grieving children, and cultural responses to grief and loss. It is intended as a resource to help caregivers of cancer patients.

Bereavement and Grief

Bereavement is the period of sadness after losing a loved one through death.

Grief and mourning occur during the period of bereavement. Grief and mourning are closely related. Mourning is the way we show grief in public. The way people mourn is affected by beliefs, religious practices, and cultural customs. People who are grieving are sometimes described as bereaved.

Grief is the normal process of reacting to the loss.

Grief is the emotional response to the loss of a loved one. Common grief reactions include the following:

- Feeling emotionally numb.
- Feeling unable to believe the loss occurred.
- Feeling anxiety from the distress of being separated from the loved one.
- Mourning along with depression.
- A feeling of acceptance.

2. Types of Grief Reactions

a. Anticipatory Grief

Anticipatory grief may occur when a death is expected.

Anticipatory grief occurs when a death is expected, but before it happens. It may be felt by the families of people who are dying and by the person dying. Anticipatory grief helps family members get ready emotionally for the loss. It can be a time to take care of unfinished business with the dying person, such as saying “I love you” or “I forgive you.”

Like grief that occurs after the death of a loved one, anticipatory grief involves mental, emotional, cultural, and social responses. However, anticipatory grief is different from grief that occurs after the death. Symptoms of anticipatory grief include the following:

- Depression.
- Feeling a greater than usual concern for the dying person.
- Imagining what the loved one's death will be like.
- Getting ready emotionally for what will happen after the death.

Anticipatory grief may help the family but not the dying person.

Anticipatory grief helps family members cope with what is to come. For the patient who is dying, anticipatory grief may be too much to handle and may cause him or her to withdraw from others.

Anticipatory grief does not always occur.

Some researchers report that anticipatory grief is rare. Studies showed that periods of acceptance and recovery usually seen during grief are not common before the patient’s actual death. The bereaved may feel that trying to accept the loss of a loved one before death occurs may make it seem that the dying patient has been abandoned.

Also, grief felt before the death will not decrease the grief felt afterwards or make it last a shorter time.

b. Normal Grief

Normal or common grief begins soon after a loss and symptoms go away over time.

During normal grief, the bereaved person moves toward accepting the loss and is able to continue normal day-to-day life even though it is hard to do. Common grief reactions include:

- Emotional numbness, shock, disbelief, or denial. These often occur right after the death, especially if the death was not expected.
- Anxiety over being separated from the loved one. The bereaved may wish to bring the person back and become lost in thoughts of the deceased. Images of death may occur often in the person's everyday thoughts.
- Distress that leads to crying; sighing; having dreams, illusions, and hallucinations of the deceased; and looking for places or things that were shared with the deceased.
- Anger.
- Periods of sadness, loss of sleep, loss of appetite, extreme tiredness, guilt, and loss of interest in life. Day-to-day living may be affected.

In normal grief, symptoms will occur less often and will feel less severe as time passes. Recovery does not happen in a set period of time. For most bereaved people having normal grief, symptoms lessen between 6 months and 2 years after the loss.

Many bereaved people will have grief bursts or pangs.

Grief bursts or pangs are short periods (20-30 minutes) of very intense distress. Sometimes these bursts are caused by reminders of the deceased person. At other times they seem to happen for no reason.

Grief is sometimes described as a process that has stages.

There are several theories about how the normal grief process works. Experts have described different types and numbers of stages that people go through as they cope with loss. At this time, there is not enough information to prove that one of these theories is more correct than the others.

Although many bereaved people have similar responses as they cope with their losses, there is no typical grief response. The grief process is personal.

c. Complicated Grief

There is no right or wrong way to grieve, but studies have shown that there are patterns of grief that are different from the most common. This has been called complicated grief.

Complicated grief reactions that have been seen in studies include:

- Minimal grief reaction: A grief pattern in which the person has no, or only a few, signs of distress or problems that occur with other types of grief.
- Chronic grief: A grief pattern in which the symptoms of common grief last for a much longer time than usual. These symptoms are a lot like ones that occur with major depression, anxiety, or post-traumatic stress.

Factors that Affect Complicated Grief

Whether the death is expected or unexpected.

It may seem that any sudden, unexpected loss might lead to more difficult grief. However, studies have found that bereaved people with high self-esteem and/or a feeling that they have control over life are likely to have a normal grief reaction even after an unexpected loss. Bereaved people with low self-esteem and/or a sense that life cannot be controlled are more likely to have complicated grief after an unexpected loss. This includes more depression and physical problems.

The personality of the bereaved.

Studies have found that people with certain personality traits are more likely to have long-lasting depression after a loss. These include people who are very dependent on the loved one (such as a spouse), and people who deal with distress by thinking about it all the time.

The religious beliefs of the bereaved.

Some studies have shown that religion helps people cope better with grief. Other studies have shown it does not help or causes more distress. Religion seems to help people who go to church often. The positive effect on grief may be because church-goers have more social support.

Whether the bereaved is male or female.

In general, men have more problems than women do after a spouse's death. Men tend to have worse depression and more health problems than women do after the loss. Some researchers think this may be because men have less social support after a loss.

The age of the bereaved.

In general, younger bereaved people have more problems after a loss than older bereaved people do. They have more severe health problems, grief symptoms, and other mental and physical symptoms. Younger bereaved people, however, may recover more quickly than older bereaved people do, because they have more resources and social support.

The amount of social support the bereaved has.

Lack of social support increases the chance of having problems coping with a loss. Social support includes the person's family, friends, neighbors, and community members who can give psychological, physical, and financial help. After the death of a close family member, many people have a number of related losses. The death of a spouse, for example, may cause a loss of income and changes in lifestyle and day-to-day living. These are all related to social support.

Treatment of Grief

Normal grief may not need to be treated.

Most bereaved people work through grief and recover within the first 6 months to 2 years. Researchers are studying whether bereaved people experiencing normal grief would be helped by formal treatment. They are also studying whether treatment might prevent complicated grief in people who are likely to have it.

For people who have serious grief reactions or symptoms of distress, treatment may be helpful.

Complicated grief may be treated with different types of psychotherapy (talk therapy).

Researchers are studying the treatment of mental, emotional, social, and behavioral symptoms of grief. Treatment methods include discussion, listening, and counseling.

Complicated grief treatment (CGT) is a type of grief therapy that was helpful in a clinical trial.

Complicated grief treatment (CGT) has three phases:

- The first phase includes talking about the loss and setting goals toward recovery. The bereaved are taught to work on these two things.

- The second phase includes coping with the loss by retelling the story of the death. This helps bereaved people who try not to think about their loss.
- The last phase looks at progress that has been made toward recovery and helps the bereaved make future plans. The bereaved's feelings about ending the sessions are also discussed.

In a clinical trial of patients with complicated grief, CGT was compared to interpersonal psychotherapy (IPT). IPT is a type of psychotherapy that focuses on the person's relationships with others and is helpful in treating depression. In patients with complicated grief, the CGT was more helpful than IPT.

Cognitive behavioral therapy (CBT) for complicated grief was helpful in a clinical trial.

Cognitive behavioral therapy (CBT) works with the way a person's thoughts and behaviors are connected. CBT helps the patient learn skills that change attitudes and behaviors by replacing negative thoughts and changing the rewards of certain behaviors.

A clinical trial compared CBT to counseling for complicated grief. Results showed that patients treated with CBT had more improvement in symptoms and general mental distress than those in the counseling group.

Depression related to grief is sometimes treated with drugs.

There is no standard drug therapy for depression that occurs with grief. Some health care professionals think depression is a normal part of grief and doesn't need to be treated. Whether to treat grief-related depression with drugs is up to the patient and the health care professional to decide.

Clinical trials of antidepressants for depression related to grief have found that the drugs can help relieve depression. However, they give less relief and take longer to work than they do when used for depression that is not related to grief.

Children and Grief

A child's grief process is different from an adult's.

Children do not react to loss in the same ways as adults. These are some of the ways children's grief is different:

- Children may seem to show grief only once in a while and for short times. This may be because a child is not able to feel strong emotions for long periods of time. A grieving child may be sad one minute and playful the next. Often families think the child doesn’t really understand the loss or has gotten over it quickly. Usually, neither is true. Children’s minds protect them from what is too much for them to handle emotionally.
- Mourning is a process that continues over years in children. Feelings of loss may occur again and again as the child gets older. This is common at important times, such as going to camp, graduating from school, getting married, or having children.
- Grieving children may not show their feelings as openly as adults. Grieving children may throw themselves into activities instead of withdrawing or showing grief.
- Children cannot think through their thoughts and feelings like adults. Children have trouble putting their feelings about grief into words. Strong feelings of anger and fears of death or being left alone may show up in the behavior of grieving children. Children often play death games as a way of working out their feelings and worries. These games give children a safe way to express their feelings.
- Grieving adults may withdraw and not talk to other people about the loss. Children, however, often talk to the people around them (even strangers) to see how they react and to get clues for how they should respond to the loss.

- Children may ask confusing questions. For example, a child may ask, "I know grandpa died, but when will he come home?" This is a way of testing reality and making sure the story of the death has not changed.

Several factors can affect how a child will cope with grief.

Although grief is different for each child, several factors can affect the grief process of a child:

- The child's age and stage of development.
- The child's personality.
- The child's previous experiences with death.
- The child's relationship with the deceased.
- The cause of death.
- The way the child acts and communicates within the family.
- How stable the family life is after the loss.
- How the child continues to be cared for.
- Whether the child is given the chance to share and express feelings and memories.
- How the parents cope with stress.
- Whether the child has ongoing relationships with other adults.

Children at different stages of development have different understandings of death and the events near death.

Infants

Infants do not recognize death, but feelings of loss and separation are part of developing an awareness of death. Children who have been separated from their mother may be sluggish and quiet, may not respond to a smile or a coo, may have physical symptoms (such as weight loss), and may sleep less.

Age 2-3 years

Children at this age often confuse death with sleep and may feel anxiety as early as age 3. They may stop talking and appear to feel overall distress.

Age 3-6 years

At this age children see death as a kind of sleep; the person is alive, but only in a limited way. The child cannot fully separate death from life. Children may think that the person is still living, even though he or she might have been buried. The child may ask questions about the deceased (for example, how does the deceased eat, go to the toilet, breathe, or play?). Young children know that death is physical, but think it is not final.

The child’s understanding of death may involve "magical thinking". For example, the child may think that his or her thoughts can cause another person to become sick or die.

Grieving children under 5 may have trouble eating, sleeping, and controlling the bladder and bowel.

Age 6-9 years

Children at this age are often very curious about death, and may ask questions about what happens to the body when it dies. Death is thought of as a person or spirit separate from the person who was alive, such as a skeleton, ghost, angel, or bogeyman. They may see death as final and scary but as something that happens mostly to old people (and not to themselves).

Grieving children can become afraid of school, have learning problems, show antisocial or aggressive behavior, or become overly worried about their own health and complain of imaginary symptoms. Children this age may either withdraw from others or become too attached and clingy.

Boys often become more aggressive and destructive (for example, acting out in school), instead of showing their sadness openly.

When one parent dies, children may feel abandoned by both the deceased parent and the living parent, whose grief may make him or her unable to emotionally support the child.

Age 9 and older

Children aged 9 and older know that death cannot be avoided and do not see it as a punishment. By the time a child is 12 years old, death is seen as final and something that happens to everyone.

Grief and Developmental Stages

Age	Understanding of Death	Expressions of Grief
Infancy to 2 years	Is not yet able to understand death.	Quietness, crankiness, decreased activity, poor sleep, and weight loss.
	Separation from mother causes changes.	
2-6 years	Death is like sleeping.	Asks many questions (How does she go to the bathroom? How does she eat?).
		Problems in eating, sleeping, and bladder and bowel control.
		Fear of being abandoned.
		Tantrums.

Age	Understanding of Death	Expressions of Grief
	Dead person continues to live and function in some ways.	"Magical thinking" (Did I think or do something that caused the death? Like when I said I hate you and I wish you would die?).
	Death is not final.	
	Dead person can come back to life.	
6-9 years	Death is thought of as a person or spirit (skeleton, ghost, bogeyman).	Curious about death.
		Asks specific questions.
		May have fears about school.
	Death is final and scary.	May have aggressive behavior (especially boys).
		Worries about imaginary illnesses.
	Death happens to others, it won’t happen to me.	May feel abandoned.
9 and older	Everyone will die.	Strong emotions, guilt, anger, shame.
		Increased anxiety over own death.
		Mood swings.

Age	Understanding of Death	Expressions of Grief
	Death is final.	Fear of rejection; not wanting to be different from peers.
	Even I will die.	Changes in eating habits.
		Sleeping problems.
		Regressive behavior (loss of interest in outside activities).
		Impulsive behavior.
		Feels guilty about being alive (especially related to death of a brother, sister, or peer).

Most children who have had a loss have three common worries about death.

Children coping with a loss often have these three questions:

Did I make the death happen?

Children often think that they have "magical powers". If a mother is irritated and says, "You'll be the death of me" and later dies, her child may wonder if he or she actually caused the mother's death. Also, when children argue, one may say (or think), "I wish you were dead." If that child dies, the surviving child may think that those thoughts caused the death.

Is it going to happen to me?

The death of another child may be very hard for a child. If the child thinks that the death may have been prevented (by either a parent or a doctor) the child may fear that he or she could also die.

Who is going to take care of me?

Since children depend on parents and other adults to take care of them, a grieving child may wonder who will care for him or her after the death of an important person.

Talking honestly about the death and including the child in rituals may help the grieving child.

Explain the death and answer questions.

Talking about death helps children learn to cope with loss. When talking about death with children, describe it simply. Each child should be told the truth using as much detail as he or she is able to understand. Answer questions in language the child can understand.

Children often worry that they will also die, or that their surviving parent will go away. They need to be told that they will be safe and taken care of.

Use the correct language.

When talking with the child about death, include the correct words, such as "cancer," "died," and "death." Using other words or phrases (for example, “he passed away,” “he is sleeping,” or “we lost him”) can confuse children and cause them to misunderstand.

Include the child in planning and attending memorial ceremonies.

When a death occurs, children may feel better if they are included in planning and attending memorial ceremonies. These events help children remember the loved one. Children should not be forced to be involved in these ceremonies, but encourage them to take part when they feel comfortable doing so. Before a child attends a funeral, wake, or memorial service, give the child a full explanation of what to expect. A familiar adult or family member may help with this if the surviving parent's grief makes him or her unable to.

There are books and other resources with information on helping a grieving child.

The following books and videos may be helpful with grieving children:

1. Worden JW: **Children and Grief: When a Parent Dies**. New York, NY: The Guilford Press, 1996.
2. Doka KJ, ed.: **Children Mourning, Mourning Children**. Washington, DC: Hospice Foundation of America, 1995.
3. Wass H, Corr CA: **Childhood and Death**. Washington, DC: Hemisphere Publishing Corporation, 1984.
4. Corr CA, McNeil JN: **Adolescence and Death**. New York, NY: Springer Publishing Company, 1986.
5. Corr CA, Nabe CM, Corr DM: **Death and Dying, Life and Living**. 2nd ed., Pacific Grove: Brooks/Cole Publishing Company, 1997.
6. Grollman EA: **Talking About Death: A Dialogue Between Parent and Child**. 3rd ed., Boston, MA: Beacon Press, 1990.
7. Schaefer D, Lyons C: **How Do We Tell the Children? Helping Children Understand and Cope When Someone Dies**. New York, NY: Newmarket Press, 1988.
8. Wolfelt A: **Helping Children Cope with Grief**. Muncie: Accelerated Development, 1983.
9. Walker A: **To Hell with Dying**. San Diego, CA: Harcourt Brace Jovanovich, 1988.
10. Williams M: **Velveteen Rabbit**. Garden City: Doubleday, 1922.
11. Viorst J: **The Tenth Good Thing About Barney**. New York, NY: Atheneum, 1971.

12. Tiffault BW: **A Quilt for Elizabeth**. Omaha, NE: Centering Corporation, 1992.
13. Levine JR: **Forever in My Heart: a Story to Help Children Participate in Life as a Parent Dies**. Burnsville, NC: Mountain Rainbow Publications, 1992.
14. Knoderer K: **Memory Book: a Special Way to Remember Someone You Love**. Warminster, PA: Mar-Co Products, 1995.
15. de Paola T: **Nana Upstairs and Nana Downstairs**. New York, NY: GP Putnam's Sons, 1973.

Cultural Responses to Grief and Loss

Cultures have different ways of coping with death.

Grief felt for the loss of loved ones occurs in people of all ages and cultures. Different cultures, however, have different myths and mysteries about death that affect the attitudes, beliefs, and practices of the bereaved.

Individual, personal experiences of grief are similar in different cultures.

The ways in which people of all cultures feel grief personally are similar. This has been found to be true even though different cultures have different mourning ceremonies and traditions to express grief.

Cultural issues that affect people who are dealing with the loss of a loved one include rituals, beliefs, and roles.

Helping family members cope with the death of a loved one includes showing respect for the family's culture and the ways they honor the death. The following questions may help caregivers learn what is needed by the person's culture:

- What are the cultural rituals for coping with dying, the deceased person's body, and honoring the death?
- What are the family's beliefs about what happens after death?
- What does the family feel is a normal expression of grief and the acceptance of the loss?
- What does the family consider to be the roles of each family member in handling the death?
- Are certain types of death less acceptable (for example, suicide), or are certain types of death especially hard for that culture (for example, the death of a child)?

Death, grief, and mourning are normal life events. All cultures have practices that best meet their needs for dealing with death. Caregivers who understand the ways different cultures respond to death can help patients of these cultures work through their own normal grieving process.

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Chapter 4 End of life Issues

A. Providing End of Life Care

Providing Care and Comfort at the End of Life

The following information was retrieved from:

National Institute on Aging (2017), Providing Care and Comfort at the End of Life. Retrieved January 8, 2020. https://www.nia.nih.gov/health/providing-comfort-end-life

Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes.

You are probably reading this because someone close to you is dying. You wonder what will happen. You want to know how to give comfort, what to say, what to do. You might like to know how to make dying easier—how to help ensure a peaceful death, with treatment consistent with the dying person's wishes.

A peaceful death might mean something different to you than to someone else. Your sister might want to know when death is near so she can have a few last words with the people she loves and take care of personal matters. Your husband might want to die quickly and not linger. Perhaps your mother has said she would like to be at home when she dies, while your father wants to be in a hospital where he can receive treatment for his illness until the very end.

Some people want to be surrounded by family and friends; others want to be alone. Of course, often one doesn't get to choose. But, avoiding suffering, having your end-of-life wishes followed, and being treated with respect while dying are common hopes.

Generally speaking, people who are dying need care in four areas—physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Their families need support as well. In this section, you will find a number of ways you can help someone who is dying. Always remember to check with the healthcare team to make sure these suggestions are appropriate for your situation.

What is End-of-Life Care?

At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually fading. For some older people, the body weakens while the mind stays alert. Others remain physically strong, but cognitive losses take a huge toll. Although everyone dies, each loss is personally felt by those close to the one who has died.

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen only in the moments before breathing ceases and the heart stops beating. Older people often live with one or more chronic illnesses and need a lot of care for days, weeks, and even months before death.

When a doctor says something like, “I’m afraid the news is not good. There are no other treatments for us to try. I’m sorry,” it may close the door to the possibility of a cure, but it does not end the need for medical support. Nor does it end the involvement of family and friends.

There are many ways to provide care for an older person who is dying. Such care often involves a team. If you are reading this, then you might be part of such a team.

Being a caregiver for someone at the end of life can be physically and emotionally exhausting. In the end, accept that there may be no perfect death, just the best you can do for the one you love. And, the pain of losing someone close to you may be softened a little because, when you were needed, you did what you could.

End-of-Life: Providing Physical Comfort

There are ways to make a person who is dying more comfortable. Discomfort can come from a variety of problems. For each, there are things you or a healthcare provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

- Pain
- Breathing problems
- Skin irritation
- Digestive problems
- Temperature sensitivity
- Fatigue

Pain. Watching someone you love die is hard enough, but thinking that person is also in pain makes it worse. Not everyone who is dying experiences pain, but there are things you can do to help someone who does. Experts believe that care for someone who is dying should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.

Don't be afraid of giving as much pain medicine as is prescribed by the doctor. Pain is easier to prevent than to relieve, and severe pain is hard to manage. Try to make sure that the level of pain does not get ahead of pain-relieving medicines. Tell the doctor or nurse if the pain is not controlled. Medicines can be increased or changed. If this doesn't help, then ask for consultation with a palliative medical specialist who has experience in pain management for seriously ill patients (see *What Are Palliative Care and Hospice Care?*).

What About Morphine and Other Painkillers?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling of shortness of breath. Pain medication can make people confused or drowsy. You might have heard that giving morphine leads to a quicker death. Is that true? Most experts think this is unlikely, especially if increasing the dose is done carefully. Successfully reducing pain and/or concerns about breathing can provide needed comfort to someone who is close to dying.

Struggling with severe pain can be draining. It can make it hard for families to be together in a meaningful way. Pain can affect mood—being in pain can make someone seem angry or short-tempered. Although understandable, irritability resulting from pain might make it hard to talk, hard to share thoughts and feelings.

Breathing problems. Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this dyspnea (disp-NEE-uh). Worrying about the next breath can make it hard for important conversations or connections. Try raising the head of the bed, opening a window, using a humidifier, or having a fan circulating air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

People very near death might have noisy breathing, sometimes called a death rattle. This is caused by fluids collecting in the throat or by the throat muscles relaxing. It might help to try turning the person to rest on one side. There is also medicine that can be prescribed that may help clear this up. Not all noisy breathing is a death rattle. It may help to know that this noisy breathing is usually not upsetting to the dying person, even if it is to family and friends.

Skin irritation. Skin problems can be very uncomfortable. With age, skin naturally becomes drier and more fragile, so it is important to take extra care with an older person's skin. Gently applying alcohol-free lotion can relieve dry skin and be soothing.

Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. A lip balm could keep this from getting worse. A damp cloth placed over closed eyes might relieve dryness. If the inside of the mouth seems dry, giving ice chips (if the person is conscious) or wiping the inside of the mouth with a damp cloth, cotton ball, or specially treated swab might help.

Sitting or lying in one position puts constant pressure on sensitive skin, which can lead to painful bed sores (sometimes called pressure ulcers). When a bed sore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head.

Turning the person from side to back and to the other side every few hours may help prevent bed sores. Try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. Ask if a special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. The causes and treatments for these symptoms are varied, so talk to a doctor or nurse right away. There are medicines that can control nausea or vomiting or relieve constipation, a common side effect of strong pain medications.

If someone near death wants to eat but is too tired or weak, you can help with feeding. To address loss of appetite, try gently offering favorite foods in small amounts. Or, try serving frequent, smaller meals rather than three big ones.

You don't have to force a person to eat. Going without food and/or water is generally not painful, and eating can add to discomfort. Losing one's appetite is a common and normal part of dying. Swallowing may also be a problem, especially for people with dementia. A conscious decision to give up food can be part of a person's acceptance that death is near.

Temperature sensitivity. People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. For example, someone who is too warm might repeatedly try to remove a blanket. You can take off the blanket and try a cool cloth on his or her head.

If a person is hunching his or her shoulders, pulling the covers up, or even shivering—those could be signs of cold. Make sure there is no draft, raise the heat, and add another blanket. Avoid electric blankets because they can get too hot.

Fatigue. It is common for people nearing the end of life to feel tired and have little or no energy. Keep activities simple. For example, a bedside commode can be used instead of walking to the bathroom. A shower stool can save a person's energy, as can switching to sponging off in bed.

Meena's Story

At 80, Meena had been in a nursing home for 2 years after a stroke, when her health declined, and she was no longer able to communicate her wishes. Meena's physician, Dr. Torres, told her family she was dying. She said that medical tests, physical therapy, and intravenous treatments were no longer really needed and should be stopped because they might be causing Meena discomfort. Dr. Torres also said that checking vital signs (pulse, blood pressure, temperature, and breathing rate) was interrupting her rest and would no longer be done regularly.

Then, Meena developed pneumonia. Her family asked about moving her to the hospital. Dr. Torres explained that Meena could get the same care in the familiar surroundings of her nursing home. Besides, the doctor said, a move could disturb and confuse her. The family agreed to leave Meena in the nursing home, and she died 2 days later surrounded by those close to her.

Experts suggest that moving someone to a different place, like a hospital, close to the time of death, should be avoided if possible.

B. ***End-of-Life: Managing Mental and Emotional Needs***

Complete end-of-life care also includes helping the dying person manage mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious. It is important to treat emotional pain and suffering. Encouraging conversations about feelings might help. You might want to contact a counselor, possibly one familiar with end-of-life issues. If the depression or anxiety is severe, medicine may help.

A dying person may also have some specific fears and concerns. He or she may fear the unknown or worry about those left behind. Some people are afraid of being alone at the very end. This feeling can be made worse by the understandable reactions of family, friends, and even the medical team. For example, when family and friends do not know how to help or what to say, sometimes they stop visiting. Or, someone who is already beginning to grieve may withdraw.

Doctors may feel helpless because they can't cure their patient. Some seem to avoid a dying patient. This can add to a dying person's sense of isolation. If this is happening, discuss your concerns with the family, friends, or the doctor.

The simple act of physical contact—holding hands, a touch, or a gentle massage—can make a person feel connected to those he or she loves. It can be very soothing. Warm your hands by rubbing them together or running them under warm water.

Try to set a comforting mood. Remember that listening and being present can make a difference. For example, Gordon loved a party, so it was natural for him to want to be around family and friends when he was dying. Ellen always liked spending quiet moments with one or two people at a time, so she was most comfortable with just a few visitors.

Some experts suggest that when death is very near, music at a low volume and soft lighting are soothing. In fact, near the end of life, music therapy might improve mood, help with relaxation, and lessen pain. Listening to music might also evoke memories those present can share. For some people, keeping distracting noises like televisions and radios to a minimum is important.

Often, just being present with a dying person is enough. It may not be necessary to fill the time with talking or activity. Your quiet presence can be a simple and profound gift for a dying family member or friend.

Spiritual Needs at the End of Life

People nearing the end of life may have spiritual needs as important as their physical concerns. Spiritual needs include finding meaning in one's life and ending disagreements with others, if possible. The dying person might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help.

Many people find solace in their faith. Others may struggle with their faith or spiritual beliefs. Praying, talking with someone from one's religious community (such as a minister, priest, rabbi, or imam), reading religious texts, or listening to religious music may bring comfort.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children can share how their father has influenced the course of their lives. Grandchildren can let their grandfather know how much he has meant to them. Friends can relate how they value years of support and companionship. Family and friends who can't be present could send a recording of what they would like to say or a letter to be read out loud.

Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone. Some doctors think it is possible that even if a patient is unconscious, he or she might still be able to hear. It is probably never too late to say how you feel or to talk about fond memories.

Always talk to, not about, the person who is dying. When you come into the room, it is a good idea to identify yourself, saying something like, "Hi, Juan. It's Mary, and I've come to see you." Another good idea is to have someone write down some of the things said at this time—both by and to the person who is dying. In time, these words might serve as a source of comfort to family and friends. People who are looking for ways to help may welcome the chance to aid the family by writing down what is said.

There may come a time when a dying person who has been confused suddenly seems clear-thinking. Take advantage of these moments, but understand that they might be only temporary, not necessarily a sign he or she is getting better. Sometimes, a dying person may appear to see or talk to someone who is not there. Try to resist the temptation to interrupt or say they are imagining things. Give the dying person the space to experience their own reality.

C. End-of-Life: Planning Ahead

Many practical jobs need to be done at the end of life—both to relieve the person who is dying and to support the caregiver. Everyday tasks can be a source of worry for someone who is dying, and they can overwhelm a caregiver. Taking over small daily chores around the house—such as picking up the mail or newspaper, writing down phone messages, doing a load of laundry, feeding the family pet, taking children to soccer practice, or picking up medicine from the pharmacy—can provide a much-needed break for caregivers.

A person who is dying might be worried about who will take care of things when he or she is gone. Offering reassurance—"I'll make sure your African violets are watered," "Jessica has promised to take care of Bandit," "Dad, we want Mom to live with us from now on"—might provide a measure of peace. Reminding the dying person that his or her personal affairs are in good hands can also bring comfort.

Everyone may be asking the family, "What can I do for you?" It helps to make a specific offer. Say to the family, "Let me help with . . . " and suggest something like bringing meals for the caregivers, paying bills, walking the dog, or babysitting. If you're not sure what to offer, talk to someone who has been through a similar situation. Find out what kind of help was useful.

If you want to help but can't get away from your own home, you could schedule other friends or family to help with small jobs or to bring in meals. This can allow the immediate family to give their full attention to the person who is dying.

If you are the primary caregiver, ask for help when you need it and accept help when it's offered. Don't hesitate to suggest a specific task to someone who offers to help. Friends and family are probably anxious to do something for you and/or the person who is dying, but they may be reluctant to repeatedly offer when you are so busy.

Keeping close friends and family informed can feel overwhelming. Setting up an outgoing voicemail message, a blog, an email list, a private Facebook page, or even a phone tree can reduce the number of calls you have to make. Some families create a blog or website to share news, thoughts, and wishes. Listed at the end of this article are some organizations that make setting up such web pages easy and secure. Or, you can assign a close family member or friend to make the updates for you. These can all help reduce the emotional burden of answering frequent questions.

Questions to Ask About Providing Comfort at the End of Life

Family and friends can provide comfort and ease to someone nearing the end of life. Here are some questions to help you learn more.

Ask the doctor in charge:

- Since there is no cure, what will happen next?
- Why are you suggesting this test or treatment?
- Will the treatment bring physical comfort?
- Will the treatment speed up or slow down the dying process?
- What can we expect to happen in the coming days or weeks?

Ask the caregiver:

- How are you doing? Do you need someone to talk with?
- Would you like to go out for an hour or two? I could stay here while you are away.
- Who has offered to help you? Do you want me to work with them to coordinate our efforts?
- Can I help, maybe . . . walk the dog, answer the phone, go to the drug store or the grocery store, or watch the children (for example) . . . for you?

D. Palliative Care and Hospice Care

The following information was retrieved from:

National Institute on Aging (2017), What Are Palliative Care and Hospice Care? Retrieved January 8, 2020 https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

What Are Palliative Care and Hospice Care?

Many Americans die in facilities such as hospitals or nursing homes receiving care that is not consistent with their wishes. To make sure that doesn't happen, older people need to know what their end-of-life care options are and state their preferences to their caregivers in advance. For example, if an older person wants to die at home, receiving end-of-life care for pain and other symptoms, and makes this known to healthcare providers and family, it is less likely he or she will die in a hospital receiving unwanted treatments.

Learn more about advance care planning.

Caregivers have several factors to consider when choosing end-of-life care, including the older person's desire to pursue life-extending or curative treatments, how long he or she has left to live, and the preferred setting for care.

Read more about where end-of-life care is given.

Understanding Palliative Care

Doctors can provide treatment to seriously ill patients in the hopes of a cure for as long as possible. These patients may also receive medical care for their symptoms, or palliative care, along with curative treatment.

Who can benefit from palliative care?

Palliative care is a resource for anyone living with a serious illness, such as heart failure, chronic obstructive pulmonary disease, cancer, dementia, Parkinson's disease, and many others. Palliative care can be helpful at any stage of illness and is best provided from the point of diagnosis.

In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life. **Palliative care can be provided along with curative treatment and does not depend on prognosis.**

A palliative care consultation team is a multidisciplinary team that works with the patient, family, and the patient's other doctors to provide medical, social, emotional, and practical support. The team is made of palliative care specialist doctors and nurses, and includes others such as social workers, nutritionists, and chaplains.

Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home. Medicare, Medicaid, and insurance policies may cover palliative care. Veterans may be eligible for palliative care through the Department of Veterans Affairs. Private health insurance might pay for some services. Health insurance providers can answer questions about what they will cover. Check to see if insurance will cover your particular situation.

Ariana's Story

Adriana developed anemia while she was being treated for breast cancer. A palliative care specialist suggested she get a blood transfusion to manage the anemia and relieve some of the fatigue she was experiencing. Controlling her symptoms helped Adriana to continue her curative chemotherapy treatment. Treating her anemia is part of palliative care.

In palliative care, you do not have to give up treatment that might cure a serious illness. Palliative care can be provided along with curative treatment and may begin at the time of diagnosis. Over time, if the doctor or the palliative care team believes ongoing treatment is no longer helping, there are two possibilities. Palliative care could transition to hospice care if the doctor believes the person is likely to die within 6 months (see What does the hospice 6-month requirement mean?). Or, the palliative care team could continue to help with increasing emphasis on comfort care.

Understanding Hospice Care

Increasingly, people are choosing hospice care at the end of life. Hospice can be provided in any setting—home, nursing home, assisted living facility, or inpatient hospital.

Tom's Story

Tom, who retired from the U.S. Air Force, was diagnosed with cancer at age 70. As his disease progressed and breathing became more difficult, he wanted to explore experimental treatments to slow the disease. Through the palliative care provided by the Veterans Health Administration, Tom got treatment for his disease and was able to receive the care and emotional support he needed to cope with his health problems. The palliative care program also helped arrange for assistance around the house and other support for Tom's wife, making it easier for her to care for him at home. When the experimental treatments were no longer helping, Tom enrolled in hospice. He died comfortably at home 3 months later.

At some point, it may not be possible to cure a serious illness, or a patient may choose not to undergo certain treatments. Hospice is designed for this situation. The patient beginning hospice care understands that his or her illness is not responding to medical attempts to cure it or to slow the disease's progress.

Like palliative care, hospice provides comprehensive comfort care as well as support for the family, but, in hospice, **attempts to cure the person's illness are stopped.** Hospice is provided for a person with a terminal illness whose doctor believes he or she has 6 months or less to live if the illness runs its natural course.

Hospice is an approach to care, so it is not tied to a specific place. It can be offered in two types of settings—at home or in a facility such as a nursing home, hospital, or even in a separate hospice center.

Read more about where end-of-life care can be provided.

Hospice care brings together a team of people with special skills—among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together with the person who is dying, the caregiver, and/or the family to provide the medical, emotional, and spiritual support needed.

A member of the hospice team visits regularly, and someone is always available by phone—24 hours a day, 7 days a week. Hospice may be covered by Medicare and other insurance companies; check to see if insurance will cover your particular situation.

Dolores' Story

Choosing hospice does not have to be a permanent decision. For example, Dolores was 82 when she learned that her kidneys were failing. She thought that she had lived a long, good life and didn't want to go through dialysis, so Dolores began hospice care. A week later, she learned that her granddaughter was pregnant. After talking with her husband, Dolores changed her mind about using hospice care and left to begin dialysis, hoping to one day hold her first great-grandchild. Shortly after the baby was born, the doctors said Dolores' blood pressure was too low. At that point, she decided to re-enroll in hospice.

It is important to remember that stopping treatment aimed at curing an illness does not mean discontinuing all treatment. A good example is an older person with cancer. If the doctor determines that the cancer is not responding to chemotherapy and the patient chooses to enter into hospice care, then the chemotherapy will stop. Other medical care may continue as long as it is helpful. For example, if the person has high blood pressure, he or she will still get medicine for that.

Although hospice provides a lot of support, the day-to-day care of a person dying at home is provided by family and friends. The hospice team coaches family members on how to care for the dying person and even provides respite care when caregivers need a break. Respite care can be for as short as a few hours or for as long as several weeks.

Annie and Maria's Story

Eighty-year-old Annie had advanced metastatic melanoma and asked for help through a hospice program so she could stay in the home she had lived in for more than 40 years. After Annie died, hospice continued to support her family, offering bereavement counseling for a year. Hospice services greatly reduced the stress of caregiving for

Annie's family. This was especially true for Annie's wife, Maria, who weathered the sadness of her loss without her own health declining.

Families of people who received care through a hospice program are more satisfied with end-of-life care than are those of people who did not have hospice services. Also, hospice recipients are more likely to have their pain controlled and less likely to undergo tests or be given medicines they don't need, compared with people who don't use hospice care.

What does the hospice 6-month requirement mean?

Some people misinterpret their doctors' suggestion to consider hospice. They think it means death is very near. But, that's not always the case. Sometimes, people don't begin hospice care soon enough to take full advantage of the help it offers. Perhaps they wait too long to begin hospice; they are too close to death. Or, some people are not eligible for hospice care soon enough to receive its full benefit.

In the United States, people enrolled in Medicare can receive hospice care if their healthcare provider thinks they have less than 6 months to live should the disease take its usual course. Doctors have a hard time predicting how long an older, sick person will live. Health often declines slowly, and some people might need a lot of help with daily living for more than 6 months before they die.

Talk to the doctor if you think a hospice program might be helpful. If he or she agrees, but thinks it is too soon for Medicare to cover the services, then you can investigate how to pay for the services that are needed.

What happens if someone under hospice care lives longer than 6 months? If the doctor continues to certify that that person is still close to dying, Medicare can continue to pay for hospice services. It is also possible to leave hospice care for a while and then later return if the healthcare provider still believes that the patient has less than 6 months to live.

E. Healthcare Decisions

The following information was retrieved from:

National Institute on Aging (2017), *Understanding Healthcare Decisions at the End of Life*. Retrieved January 8, 2020 https://www.nia.nih.gov/health/understanding-healthcare-decisions-end-life

Understanding Healthcare Decisions at the End of Life

It can be overwhelming to be asked to make healthcare decisions for someone who is dying and is no longer able to make his or her own decisions. It is even more difficult if you do not have written or verbal guidance (see *Advance Care Planning: Healthcare Directives*). How do you decide what type of care is right for someone? Even when you have written documents, some decisions still might not be clear since the documents may not address every situation you could face.

Two approaches might be useful. One is to put yourself in the place of the person who is dying and try to choose as he or she would. This is called substituted judgment. Some experts believe that decisions should be based on substituted judgment whenever possible.

Joseph and Leilani's Story

Joseph's 90-year-old mother, Leilani, was in a coma after having a major stroke. The doctor said damage to Leilani's brain was widespread and she needed to be put on a breathing machine (ventilator) or she would probably die. The doctor asked Joseph if he wanted that to be done. Joseph remembered how his mother disapproved when an elderly neighbor was put on a similar machine after a stroke. He decided to say no, and his mother died peacefully a few hours later.

Another approach, known as best interests, is to decide what would be best for the dying person. This is sometimes combined with substituted judgment.

Ali and Wadi's Story

Ali's father, Wadi, is 80 and has lung cancer, as well as advanced Parkinson's Disease. He is in a nursing facility and doesn't seem to recognize Ali when he visits. Wadi's doctor suggested that surgery to remove part of a lung might slow down the course of the cancer and give Wadi more time. But, Ali thought, "What kind of time? What would that time do for Dad?" Ali decided that putting his dad through surgery and recovery was not in Wadi's best interests. After talking with Wadi's doctors, Ali believed that surgery would not improve his father's quality of life but would cause him pain and discomfort.

If you are making decisions for someone at the end of life and are trying to use one of these approaches, it may be helpful to think about the following questions:

- Has the dying person ever talked about what he or she would want at the end of life?
- Has he or she expressed an opinion about how someone else was being treated?
- What were his or her values in life? What gave meaning to life? Maybe it was being close to family—watching them grow and making memories together. Perhaps just being alive was the most important thing.

As a decision-maker without specific guidance from the dying person, you need as much information as possible on which to base your actions. You might ask the doctor:

- What might we expect to happen in the next few hours, days, or weeks if we continue our current course of treatment?
- Why is this new test being suggested?
- Will it change the current treatment plan?
- Will a new treatment help my relative get better?
- How would the new treatment change his or her quality of life?
- Will it give more quality time with family and friends?
- How long will this treatment take to make a difference?
- If we choose to try this treatment, can we stop it at any time? For any reason?
- What are the side effects of the approach you are suggesting?
- If we try this new treatment and it doesn't work, what then?
- If we don't try this treatment, what will happen?
- Is the improvement we saw today an overall positive sign or just something temporary?

It is a good idea to have someone with you when discussing these issues with medical staff. Having someone take notes or remember details can be very helpful. If you are unclear about something you are told, don't be afraid to ask the doctor or nurse to repeat it or to say it another way that does make sense to you. Keep asking questions until you have all the information you need to make decisions. Make sure you know how to contact a member of the medical team if you have a question or if the dying person needs something.

Sometimes, the whole family wants to be involved in every decision. Maybe that is the family's cultural tradition. Or, maybe the person dying did not pick one person to make healthcare choices before becoming unable to do so. That is not unusual, but it makes sense to choose one person to be the contact when dealing with medical staff. The doctors and nurses will appreciate having to phone only one person.

Even if one family member is named as the decision-maker, it is a good idea, as much as possible, to have family agreement about the care plan. If you can't agree on a care plan, a decision-maker, or even a spokesperson, the family might consider a mediator, someone trained to bring people with different opinions to a common decision.

In any case, as soon as it is clear that the patient is nearing the end of life, the family should try to discuss with the medical team which end-of-life care approach they want for their family member. That way, decision making for crucial situations can be planned and may feel less rushed.

Common End-of-Life Concerns

Maybe you are now faced with making end-of-life choices for someone close to you. You've thought about that person's values and opinions, and you've asked the healthcare team to explain the treatment plan and what you can expect to happen.

But, there are other issues that are important to understand in case they arise. What if the dying person starts to have trouble breathing and a doctor says a ventilator might be needed? Maybe one family member wants the healthcare team to do everything possible to keep this relative alive. What does that involve? Or, what if family members can't agree on end-of-life care or they disagree with the doctor? What happens then?

Here are some other common end-of-life issues. They will give you a general understanding and may help your conversations with the doctors.

If someone says "do everything possible" when someone is dying, what does that mean? This means that if someone is dying, all measures that might keep vital organs working will be tried—for example, using a ventilator to support breathing or starting dialysis for failing kidneys. Such life support can sometimes be a temporary measure that allows the body to heal itself and begin to work normally again. It is not intended to be used indefinitely in someone who is dying.

What can be done if someone's heart stops beating (cardiac arrest)? CPR (cardiopulmonary resuscitation) can sometimes restart a stopped heart. It is most effective in people who were generally healthy before their heart stopped. During CPR, the doctor repeatedly pushes on the chest with great force and periodically puts air into the lungs. Electric shocks (called defibrillation) may also be used to correct an abnormal heart rhythm, and some medicines might also be given. Although not usually shown on television, the force required for CPR can cause broken ribs or a collapsed lung. Often, CPR does not succeed in older adults who have multiple chronic illnesses or who are already frail.

What if someone needs help breathing or has completely stopped breathing (respiratory arrest)? If a patient has very severe breathing problems or has stopped breathing, a ventilator may be needed. A ventilator forces the lungs to work. Initially, this involves intubation, putting a tube attached to a ventilator down the throat into the trachea or windpipe. Because this tube can be quite uncomfortable, people are often sedated with very strong intravenous medicines. Restraints may be used to prevent them from pulling out the tube. If the person needs ventilator support for more than a few days, the doctor might suggest a tracheotomy, sometimes called a “trach” (rhymes with “make”). This tube is then attached to the ventilator. This is more comfortable than a tube down the throat and may not require sedation. Inserting the tube into the trachea is a bedside surgery. A tracheotomy can carry risks, including a collapsed lung, a plugged tracheotomy tube, or bleeding.

How can I be sure the medical staff knows that the patient has a DNR (Do Not Resusitate) order? Tell the doctor in charge as soon as the patient or person making healthcare decisions decides that CPR or other life-support procedures should not be performed. The doctor will then write this on the patient’s chart using terms such as DNR (Do Not Resuscitate), DNAR (Do Not Attempt to Resuscitate), AND (Allow Natural Death), or DNI (Do Not Intubate). DNR forms vary by State and are usually available online.

If end-of-life care is given at home, a special non-hospital DNR, signed by a doctor, is needed. This ensures that if emergency medical technicians (EMTs) are called to the house, they will respect your wishes. Make sure it is kept in a prominent place so EMTs can see it. Without a non-hospital DNR, in many States EMTs are required to perform CPR and similar techniques. Hospice staff can help determine whether a medical condition is part of the normal dying process or something that needs the attention of EMTs.

DNR orders do not stop all treatment. They only mean that CPR and a ventilator will not be used. These orders are not permanent—they can be changed if the situation changes.

Should pacemakers (or similar devices) be turned off when someone is dying? A pacemaker is a device implanted under the skin on the chest that keeps a heartbeat regular. It will not keep a dying person alive. Some people have an implantable cardioverter defibrillator (ICD) under the skin. An ICD shocks the heart back into regular rhythm when needed. The ICD should be turned off at the point when life support is no longer wanted. This can be done at the bedside without surgery.

What does it mean if the doctor suggests a feeding tube? If a patient can't or won't eat or drink, the doctor might suggest a feeding tube. While a patient recovers from an illness, getting nutrition temporarily through a feeding tube can be helpful. But, at the end of life, a feeding tube might cause more discomfort than not eating. For people with dementia, tube feeding does not prolong life or prevent aspiration.

As death approaches, loss of appetite is common. Body systems start shutting down, and fluids and food are not needed as before. Some experts believe that at this point few nutrients are absorbed from any type of nutrition, including those received through a feeding tube. Further, after a feeding tube is inserted, the family might need to make a difficult decision about when, or if, to remove it.

If tube feeding will be tried, there are two methods that could be used. In the first, a feeding tube, known as a nasogastric or NG tube, is threaded through the nose down to the stomach to give nutrition for a short time. Sometimes, the tube is uncomfortable. Someone with an NG tube might try to remove it. This usually means the person has to be restrained, which could mean binding his or her hands to the bed.

If tube feeding is required for an extended time, then a gastric or G tube is put directly into the stomach through an opening made in the side or abdomen. This second method is sometimes called a PEG (percutaneous endoscopic gastrostomy) tube. It carries risks of infection, pneumonia, and nausea.

Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

Should someone who is dying be sedated? Sometimes, for patients very near the end of life, the doctor might suggest sedation to manage symptoms that are not responding to other treatments and are still making the patient uncomfortable. This means using medicines to put the patient in a sleep-like state. Many doctors suggest continuing to use comfort care measures like pain medicine even if the dying person is sedated. Sedatives can be stopped at any time. A person who is sedated may still be able to hear what you are saying—so try to keep speaking directly to, not about, him or her. Do not say things you would not want the patient to hear.

Are antibiotics helpful when someone is dying? Antibiotics are medicines that fight infections caused by bacteria. Lower respiratory infections (such as pneumonia) and urinary tract infections are often caused by bacteria and are common in older people who are dying. Many antibiotics have side effects, so the value of trying to treat an infection in a dying person should be weighed against any unpleasant side effects. If someone is already dying when the infection began, giving antibiotics is probably not going to prevent death but might make the person feel more comfortable.

Diego's Story

Diego was 83 and had lived in a nursing home for several years with advanced Parkinson's disease. One day, he choked on some food, causing him to inhale a small amount into his lungs. As a result, Diego developed aspiration pneumonia. The doctors assured his wife that they could keep Diego comfortable without antibiotics, but she wanted them to try treating his pneumonia. He died a few days later despite their efforts.

Do patients have the right to refuse treatment? Choosing to stop treatment that is not curing or controlling an illness, or deciding not to start a new treatment, is completely legal—whether the choice is made by the person who is dying or by the person making healthcare decisions. Some people think this is like allowing death to happen. **The law does not consider refusing such treatment to be either suicide or euthanasia, sometimes called mercy killing.**

What happens if the doctor and I have different opinions about care for someone who is dying? Sometimes medical staff, the patient, and family members disagree about a medical care decision. This can be especially problematic when the dying person can't tell the doctors what kind of end-of-life care he or she wants. For example, the family might want more active treatment, like chemotherapy, than the doctors think will be helpful. If there is an advance directive explaining the patient's preferences, those guidelines should determine care.

Without the guidance of an advance directive, if there is a disagreement about medical care, it may be necessary to get a second opinion from a different doctor or to consult the ethics committee or patient representative, also known as an ombudsman, of the hospital or facility. Palliative care consultation may also be helpful. An arbitrator (mediator) can sometimes assist people with different views to agree on a plan.

The doctor does not seem familiar with our family's views about dying. What should we do? America is a rich melting pot of religions, races, and cultures. Ingrained in each tradition are expectations about what should happen as a life nears its end. It is important for everyone involved in a patient's care to understand how each family background may influence expectations, needs, and choices.

Your background may be different from that of the doctor with whom you are working. Or, you might be used to a different approach to making healthcare decisions at the end of life than your medical team. For example, many healthcare providers look to a single person—the dying person or his or her chosen representative—for important healthcare decisions at the end of life. But, in some cultures, the entire immediate family takes on that role.

It is helpful to discuss your personal and family traditions with your doctors and nurses. If there are religious or cultural customs surrounding death that are important to you, make sure to tell your healthcare providers.

Knowing that these practices will be honored could comfort the dying person. Telling the medical staff ahead of time may also help avoid confusion and misunderstanding when death occurs. Make sure you understand how the available medical options presented by the healthcare team fit into your family's desires for end-of-life care.

Questions to Ask When Making Healthcare Decisions

Here are some questions you might want to ask the medical staff:

- What is the care plan? What are the benefits and risks?
- How often should we reassess the care plan?
- If we try using the ventilator to help with breathing and decide to stop, how will that be done?
- If my family member is dying, why does he or she have to be connected to all those tubes and machines? Why do we need more tests?
- What is the best way for our family to work with the care staff?
- How can I make sure I get a daily update on my family member's condition?
- Will you call me if there is a change in his or her condition?

Communicating with Your Healthcare Team

Make sure the healthcare team knows what is important to your family surrounding the end of life. You might say:

- In my religion, we . . . (then describe your religious traditions regarding death).
- Where we come from . . . (tell what customs are important to you at the time of death).
- In our family when someone is dying, we prefer . . . (describe what you hope to have happen).

F. Dementia

End-of-Life Care for People with Dementia

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As they reach the end of life, people suffering from dementia can present special challenges for caregivers. People can live with diseases such as Alzheimer's or Parkinson's dementia for years, so it can be hard to think of these as terminal diseases. But, they do cause death.

Making Difficult End-of-Life Decisions for a Person with Dementia

Dementia causes the gradual loss of thinking, remembering, and reasoning abilities, making it difficult for those who want to provide supportive care at the end of life to know what is needed. Because people with advanced dementia can no longer communicate clearly, they cannot share their concerns. Is Uncle Bert refusing food because he's not hungry or because he's confused? Why does Grandma Sakura seem agitated? Is she in pain and needs medication to relieve it, but can't tell you?

As these conditions progress, caregivers may find it hard to provide emotional or spiritual comfort. How can you let Grandpa know how much his life has meant to you? How do you make peace with your mother if she no longer knows who you are? Someone who has severe memory loss might not take spiritual comfort from sharing family memories or understand when others express what an important part of their life this person has been. Palliative care or hospice can be helpful in many ways to families of people with dementia.

Sensory connections—targeting someone's senses, like hearing, touch, or sight—can bring comfort. Being touched or massaged can be soothing. Listening to music, white noise, or sounds from nature seem to relax some people and lessen their agitation.

When a dementia like Alzheimer's disease is first diagnosed, if everyone understands that there is no cure, then plans for the end of life can be made before thinking and speaking abilities fail and the person with Alzheimer's can no longer legally complete documents like advance directives.

Learn more about legal and financial planning for people with Alzheimer's disease.

End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of care he or she would prefer. Someone newly diagnosed with Alzheimer’s disease might not be able to imagine the later stages of the disease.

Alma and Silvia’s Story

Alma had been forgetful for years, but even after her family knew that Alzheimer’s disease was the cause of her forgetfulness, they never talked about what the future would bring. As time passed and the disease eroded Alma’s memory and ability to think and speak, she became less and less able to share her concerns and wishes with those close to her.

This made it hard for her daughter Silvia to know what Alma needed or wanted. When the doctors asked about feeding tubes or antibiotics to treat pneumonia, Silvia didn’t know how to best reflect her mother’s wishes. Her decisions had to be based on what she knew about her mom’s values, rather than on what Alma actually said she wanted.

Quality of life is an important issue when making healthcare decisions for people with dementia. For example, medicines are available that may delay or keep symptoms from becoming worse for a little while. Medicines also may help control some behavioral symptoms in people with mild-to-moderate Alzheimer’s disease.

However, some caregivers might not want drugs prescribed for people in the later stages of Alzheimer’s. They may believe that the person’s quality of life is already so poor that the medicine is unlikely to make a difference. If the drug has serious side effects, they may be even more likely to decide against it.

When making care decisions for someone else near the end of life, consider the goals of care and weigh the benefits, risks, and side effects of the treatment. You may have to make a treatment decision based on the person’s comfort at one end of the spectrum and extending life or maintaining abilities for a little longer at the other.

With dementia, a person’s body may continue to be physically healthy while his or her thinking and memory are deteriorating. This means that caregivers and family members may be faced with very difficult decisions about how treatments that maintain physical health, such as installing a pacemaker, fit within the care goals.

Dementia's Unpredictable Progression

Dementia often progresses slowly and unpredictably. Experts suggest that signs of the final stage of Alzheimer's disease include some of the following:

- Being unable to move around on one's own
- Being unable to speak or make oneself understood
- Needing help with most, if not all, daily activities, such as eating and self-care
- Eating problems such as difficulty swallowing

Because of their unique experience with what happens at the end of life, hospice and palliative care experts might be able to help identify when someone in the final stage of Alzheimer's disease is in the last days or weeks of life.

Support for Dementia Caregivers at the End of Life

Caring for people with Alzheimer's or other dementias at home can be demanding and stressful for the family caregiver. Depression is a problem for some family caregivers, as is fatigue, because many feel they are always on call. Family caregivers may have to cut back on work hours or leave work altogether because of their caregiving responsibilities.

Many family members taking care of a person with advanced dementia at home feel relief when death happens—for themselves and for the person who died. It is important to realize such feelings are normal. Hospice—whether used at home or in a facility (such as a nursing home)—gives family caregivers needed support near the end of life, as well as help with their grief, both before and after their family member dies.

Caregivers, ask for help when you need it. Learn about respite care.

Questions to Ask About End-of-Life Care for a Person with Dementia

You will want to understand how the available medical options presented by the healthcare team fit into your family's particular needs. You might want to ask questions such as:

- How will the approach the doctor is suggesting affect your relative's quality of life? Will it make a difference in comfort and well-being?
- If considering home hospice for your relative with dementia, what will be needed to care for him or her? Does the facility have special experience with people with dementia?
- What can I expect as the disease gets worse?

G. Caregivers

1. Family Caregivers

How to Share Caregiving Responsibilities with Family Members

Retrieved from
https://www.nia.nih.gov/health/how-share-caregiving-responsibilities-family-members

Caring for an older family member often requires teamwork. While one sibling might be local and take on most of the everyday caregiving responsibilities, a long-distance caregiver can also have an important role.

As a long-distance caregiver, you can provide important respite to the primary caregiver and support to the aging family member.

Talk About Caregiving Responsibilities

First, try to define the caregiving responsibilities. You could start by setting up a family meeting and, if it makes sense, include the care recipient in the discussion. This is best done when there is not an emergency. A calm conversation about what kind of care is wanted and needed now, and what might be needed in the future, can help avoid a lot of confusion.

Decide who will be responsible for which tasks. Many families find the best first step is to name a primary caregiver, even if one is not needed immediately. That way the primary caregiver can step in if there is a crisis.

Agree in advance how each of your efforts can complement one another so that you can be an effective team. Ideally, each of you will be able to take on tasks best suited to your skills or interests.

Consider Your Strengths When Sharing Caregiving Responsibilities

When thinking about who should be responsible for what, start with your strengths. Consider what you are particularly good at and how those skills might help in the current situation:

- Are you good at finding information, keeping people up-to-date on changing conditions, and offering cheer, whether on the phone or with a computer?
- Are you good at supervising and leading others?
- Are you comfortable speaking with medical staff and interpreting what they say to others?
- Is your strongest suit doing the numbers—paying bills, keeping track of bank statements, and reviewing insurance policies and reimbursement reports?
- Are you the one in the family who can fix anything, while no one else knows the difference between pliers and a wrench?

Consider Your Limits When Sharing Caregiving Responsibilities

When thinking about who should be responsible for what, consider your limits. Ask yourself the following:

- How often, both mentally and financially, can you afford to travel?
- Are you emotionally prepared to take on what may feel like a reversal of roles between you and your parent—taking care of your parent instead of your parent taking care of you? Can you continue to respect your parent's independence?
- Can you be both calm and assertive when communicating from a distance?
- How will your decision to take on caregiving responsibilities affect your work and home life?

Be realistic about how much you can do and what you are willing to do. Think about your schedule and how it might be adapted to give respite to a primary caregiver. For example, you might try to coordinate holiday and vacation times. Remember that over time, responsibilities may need to be revised to reflect changes in the situation, your care recipient's needs, and each family member's abilities and limitations.

How to Support a Local Caregiver from Far Away

A spouse or the sibling who lives closest to an aging parent often becomes the primary caregiver. Long-distance caregivers can help by providing emotional support and occasional respite to the primary caregiver. Ask the primary caregiver what you can do to help. Staying in contact with your parents by phone or email might also take some pressure off your parent or sibling. Just listening may not sound like much help, but often it is.

Long-distance caregivers can also play a part in arranging for professional caregivers, hiring home health and nursing aides, or locating care in an assisted living facility or nursing home (also known as a skilled nursing facility).

Long-distance caregivers may find they can be helpful by handling things online—for example, researching health problems or medicines, paying bills, or keeping family and friends updated. Some long-distance caregivers help a parent pay for care; others step in to manage finances.

How to Help a Parent Who Is the Primary Caregiver

A primary caregiver—especially a spouse—may be hesitant to ask for help or a break. Be sure to acknowledge how important the caregiver has been for the care recipient. Also, discuss the physical and emotional effects caregiving can have on people. Although caregiving can be satisfying, it also can be very hard work.

Offer to arrange for respite care. Respite care will give your parent a break from caregiving responsibilities. It can be arranged for just an afternoon or for several days. Care can be provided in the family home, through an adult day services program, or at a skilled nursing facility.

The ARCH National Respite Locator Service can help you find services in your parents' community. You might suggest contacting the Well Spouse Association. It offers support to the wives, husbands, and partners of chronically ill or disabled people and has a nationwide listing of local support groups.

Your parents may need more help from home-based care to continue to live in their own home. Some people find it hard to have paid caregivers in the house, but most also say that the assistance is invaluable. If the primary caregiver is reluctant, point out that with an in-home aide, she may have more energy to devote to caregiving and some time for herself. Suggest she try it for a short time, and then decide.

In time, the person receiving care may have to move to assisted living or a nursing home. If that happens, the primary caregiver will need your support. You can help select a facility. The primary caregiver may need help adjusting to the person's absence or to living alone at home. Just listening may not sound like much help, but often it is.

H. Advanced Care Planning

National Institute on Aging (2017), *Advance Care Planning: Healthcare Directives*. Retrieved January 8,2020 https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives

Advance Care Planning: Healthcare Directives

Advance care planning is not just about old age. At any age, a medical crisis could leave you too ill to make your own healthcare decisions. Even if you are not sick now, planning for health care in the future is an important step toward making sure you get the medical care you would want, if you are unable to speak for yourself and doctors and family members are making the decisions for you.

Many Americans face questions about medical treatment but may not be capable of making those decisions, for example, in an emergency or at the end of life. This article will explain the types of decisions that may need to be made in such cases and questions you can think about now so you're prepared later. It can help you think about who you would want to make decisions for you if you can't make them yourself. It will also discuss ways you can share your wishes with others. Knowing who you want to make decisions on your behalf and how you would decide might take some of the burden off family and friends.

What Is Advance Care Planning?

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know—both your family and your healthcare providers—about your preferences. These preferences are often put into an *advance directive*, a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want.

An advance directive also allows you to express your values and desires related to end-of-life care. You might think of it as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

Medical Research and Advance Care Planning

Research shows that advance directives can make a difference, and that people who document their preferences in this way are more likely to get the care they prefer at the end of life than people who do not.

Advance Care Planning Decisions

Sometimes decisions must be made about the use of emergency treatments to keep you alive. Doctors can use several artificial or mechanical ways to try to do this. Decisions that might come up at this time relate to:

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (IV, or intravenous, fluids)
- Comfort care

What is CPR? Cardiopulmonary resuscitation might restore your heartbeat if your heart stops or is in a life-threatening abnormal rhythm. It involves repeatedly pushing on the chest with force, while putting air into the lungs. This force has to be quite strong, and sometimes ribs are broken or a lung collapses. Electric shocks, known as defibrillation, and medicines might also be used as part of the process. The heart of a young, otherwise healthy person might resume beating normally after CPR. Often, CPR does not succeed in older adults who have multiple chronic illnesses or who are already frail.

Using a ventilator as emergency treatment. Ventilators are machines that help you breathe. A tube connected to the ventilator is put through the throat into the trachea (windpipe) so the machine can force air into the lungs. Putting the tube down the throat is called intubation. Because the tube is uncomfortable, medicines are often used to keep you sedated while on a ventilator. If you are expected to remain on a ventilator for a long time, a doctor may perform a tracheotomy or "trach" (rhymes with "make"). During this bedside surgery, the tube is inserted directly into the trachea through a hole in the neck. For long-term help with breathing, a trach is more comfortable, and sedation is not needed. People using such a breathing tube are not able to speak without special help because exhaled air does not go past their vocal cords.

Using artificial nutrition and hydration near the end of life. If you are not able to eat, you may be fed through a feeding tube that is threaded through the nose down to your stomach. If tube feeding is still needed for an extended period, a feeding tube may be surgically inserted directly into your stomach. Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

If you are not able to drink, you may be provided with IV fluids. These are delivered through a thin plastic tube inserted into a vein.

Artificial nutrition and hydration can be helpful if you are recovering from an illness. However, studies have shown that artificial nutrition toward the end of life does not meaningfully prolong life. Artificial nutrition and hydration may also be harmful if the dying body cannot use the nutrition properly.

What is comfort care at the end of life? Comfort care is anything that can be done to soothe you and relieve suffering while staying in line with your wishes. Comfort care includes managing shortness of breath; limiting medical testing; providing spiritual and emotional counseling; and giving medication for pain, anxiety, nausea, or constipation.

Learn more about hospice care and other healthcare decisions you may need to make at the end of life.

Getting Started with Advance Care Planning

Start by thinking about what kind of treatment you do or do not want in a medical emergency. It might help to talk with your doctor about how your current health conditions might influence your health in the future. For example, what decisions would you or your family face if your high blood pressure leads to a stroke? You can ask your doctor to help you understand and think through your choices before you put them in writing. Discussing advance care planning decisions with your doctor is free through Medicare during your annual wellness visit. Private health insurance may also cover these discussions.

If you don't have any medical issues now, your family medical history might be a clue to help you think about the future. Talk with your doctor about decisions that might come up if you develop health problems similar to those of other family members.

In considering treatment decisions, your personal values are key. Is your main desire to have the most days of life? Or, would your focus be on quality of life, as you see it? What if an illness leaves you paralyzed or in a permanent coma and you need to be on a ventilator? Would you want that?

What makes life meaningful to you? If your heart stops or you have trouble breathing, would you want to undergo life-saving measures if it meant that, in the future, you could be well enough to spend time with your family? Would you be content if the emergency leaves you simply able to spend your days listening to books on tape or gazing out the window?

But, there are many other scenarios. Here are a few. What would you decide?

- If a stroke leaves you unable to move and then your heart stops, would you want CPR? What if you were also mentally impaired by a stroke—does your decision change?

- What if you are in pain at the end of life? Do you want medication to treat the pain, even if it will make you more drowsy and lethargic?
- What if you are permanently unconscious and then develop pneumonia? Would you want antibiotics and to be placed on a ventilator?

For some people, staying alive as long as medically possible, or long enough to see an important event like a grandchild's wedding, is the most important thing. An advance directive can help to make that possible. Others have a clear idea about when they would no longer want to prolong their life. An advance directive can help with that, too.

Your decisions about how to handle any of these situations could be different at age 40 than at age 85. Or, they could be different if you have an incurable condition as opposed to being generally healthy. An advance directive allows you to provide instructions for these types of situations and then to change the instructions as you get older or if your viewpoint changes.

Do You or a Family Member Have Alzheimer's Disease?

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease. Advance planning can help people with Alzheimer's and their families clarify their wishes and make well-informed decisions about health care and financial arrangements.

Learn more about legal and financial planning for people with Alzheimer's disease.

Making Your Advance Care Wishes Known

There are two main elements in an advance directive—a living will and a durable power of attorney for health care. There are also other documents that can supplement your advance directive. You can choose which documents to create, depending on how you want decisions to be made. These documents include:

- Living will
- Durable power of attorney for health care
- Other advance care planning documents

Living will. A living will is a written document that helps you tell doctors how you want to be treated if you are dying or permanently unconscious and cannot make your own decisions about emergency treatment. In a living will, you can say which of the procedures described in the Decisions That Could Come Up section you would want, which ones you wouldn't want, and under which conditions each of your choices applies.

Durable power of attorney for health care. A durable power of attorney for health care is a legal document naming a healthcare proxy, someone to make medical decisions for you at times when you are unable to do so. Your proxy, also known as a representative, surrogate, or agent, should be familiar with your values and wishes. This means that he or she will be able to decide as you would when treatment decisions need to be made. A proxy can be chosen in addition to or instead of a living will. Having a healthcare proxy helps you plan for situations that cannot be foreseen, like a serious auto accident.

Some people are reluctant to put specific health decisions in writing. For them, naming a healthcare agent might be a good approach, especially if there is someone they feel comfortable talking with about their values and preferences. A named proxy can evaluate each situation or treatment option independently.

Other advance care planning documents. You might also want to prepare documents to express your wishes about a single medical issue or something not already covered in your advance directive. A living will usually covers only the specific life-sustaining treatments discussed earlier. You might want to give your healthcare proxy specific instructions about other issues, such as blood transfusion or kidney dialysis. This is especially important if your doctor suggests that, given your health condition, such treatments might be needed in the future.

Medical issues that might arise at the end of life include:

- DNR orders
- Organ and tissue donation
- POLST and MOLST forms

A **DNR (do not resuscitate) order** tells medical staff in a hospital or nursing facility that you do not want them to try to return your heart to a normal rhythm if it stops or is beating unsustainably using CPR or other life-support measures. Sometimes this document is referred to as a DNAR (do not attempt resuscitation) or an AND (allow natural death) order. Even though a living will might say CPR is not wanted, it is helpful to have a DNR order as part of your medical file if you go to a hospital. Posting a DNR next to your bed might avoid confusion in an emergency situation. Without a DNR order, medical staff will make every effort to restore your breathing and the normal rhythm of your heart.

A similar document, called a **DNI (do not intubate) order,** tells medical staff in a hospital or nursing facility that you do not want to be put on a breathing machine.

A **non-hospital DNR order** will alert emergency medical personnel to your wishes regarding measures to restore your heartbeat or breathing if you are not in the hospital.

Organ and tissue donation allow organs or body parts from a generally healthy person who has died to be transplanted into people who need them. Commonly, the heart, lungs, pancreas, kidneys, corneas, liver, and skin are donated. There is no age limit for organ and tissue donation. You can carry a donation card in your wallet. Some states allow you to add this decision to your driver's license. Some people also include organ donation in their advance care planning documents.

At the time of death, family members may be asked about organ donation. If those close to you, especially your proxy, know how you feel about organ donation, they will be ready to respond. There is no cost to the donor's family for this gift of life. If the person has requested a DNR order but wants to donate organs, he or she might have to indicate that the desire to donate supersedes the DNR. That is because it might be necessary to use machines to keep the heart beating until the medical staff is ready to remove the donated organs.

Learn more about organ and tissue donation.

POLST and MOLST forms provide guidance about your medical care preferences in the form of a doctor's orders. Typically you create a POLST (Physician Orders for Life-

Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) when you are near the end of life or critically ill and know the specific decisions that might need to be made on your behalf. These forms serve as a medical order in addition to your advance directive. They make it possible for you to provide guidance that healthcare professionals can act on immediately in an emergency.

A number of states use POLST and MOLST forms, which are filled out by your doctor or sometimes by a nurse practitioner or physician's assistant. The doctor fills out a POLST or MOLST after discussing your wishes with you and your family. Once signed by your doctor, this form has the same authority as any other medical order. Check with your state department of health to find out if these forms are available where you live.

Advance Care Planning: Pacemakers and ICDs

Some people have pacemakers to help their hearts beat regularly. If you have one and are near death, it may not necessarily keep you alive. But, you might have an ICD (implantable cardioverter-defibrillator) placed under your skin to shock your heart back into regular beatings if the rhythm becomes irregular. If you decline other life-sustaining measures, the ICD may be turned off. You need to state in your advance directive what you want done if the doctor suggests it is time to turn it off.

How to Choose Your Healthcare Proxy

If you decide to choose a proxy, think about people you know who share your views and values about life and medical decisions. Your proxy might be a family member, a friend, your lawyer, or someone in your social or spiritual community. It's a good idea to also name an alternate proxy. It is especially important to have a detailed living will if you choose not to name a proxy.

You can decide how much authority your proxy has over your medical care—whether he or she is entitled to make a wide range of decisions or only a few specific ones. Try not to include guidelines that make it impossible for the proxy to fulfill his or her duties. For example, it's probably not unusual for someone to say in conversation, "I don't want to go to a nursing home," but think carefully about whether you want a restriction like that in your advance directive. Sometimes, for financial or medical reasons, that may be the best choice for you.

Of course, check with those you choose as your healthcare proxy and alternate before you name them officially. Make sure they are comfortable with this responsibility.

Making Your Healthcare Directives Official

Once you have talked with your doctor and have an idea of the types of decisions that could come up in the future and whom you would like as a proxy, if you want one at all, the next step is to fill out the legal forms detailing your wishes. A lawyer can help but is not required. If you decide to use a lawyer, don't depend on him or her to help you understand different medical treatments. Start the planning process by talking with your doctor.

Many states have their own advance directive forms. Your local Area Agency on Aging can help you locate the right forms. You can find your area agency phone number by calling the Eldercare Locator toll-free at **1-800-677-1116** or by visiting https://eldercare.acl.gov.

Some states require your advance directive to be witnessed; a few require your signature to be notarized. A notary is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, or local library, or call your insurance agent. Some notaries charge a fee.

Some states have registries that can store your advance directive for quick access by healthcare providers, your proxy, and anyone else to whom you have given permission. Private firms also will store your advance directive. There may be a fee for storing your form in a registry. If you store your advance directive in a registry and later make changes, you must replace the original with the updated version in the registry.

Some people spend a lot of time in more than one state—for example, visiting children and grandchildren. If that's your situation, consider preparing an advance directive using forms for each state—and keep a copy in each place, too.

What to Do After You Set Up Your Advance Directive

Give copies of your advance directive to your healthcare proxy and alternate proxy. Give your doctor a copy for your medical records. Tell close family members and friends where you keep a copy. If you have to go to the hospital, give staff there a copy to include in your records. Because you might change your advance directive in the future, it's a good idea to keep track of who receives a copy.

Review your advance care planning decisions from time to time—for example, every 10 years, if not more often. You might want to revise your preferences for care if your situation or your health changes. Or, you might want to make adjustments if you receive a serious diagnosis; if you get married, separated, or divorced; if your spouse dies; or if something happens to your proxy or alternate. If your preferences change, you will want to make sure your doctor, proxy, and family know about them.

Talking About Your Advance Care Wishes

It can be helpful to have conversations with the people close to you about how you want to be cared for in a medical emergency or at the end of life. These talks can help you think through the wishes you want to put in your advance directive.

It's especially helpful to talk about your thoughts, beliefs, and values with your healthcare proxy. This will help prepare him or her to make medical decisions that best reflect your values.

After you have completed your advance directive, talk about your decisions with your healthcare proxy, loved ones, and your doctor to explain what you have decided. This way, they are not surprised by your wishes if there is an emergency.

Another way to convey your wishes is to make a video of yourself talking about them. This lets you express your wishes in your own words. Videos do not replace an advance directive, but they can be helpful for your healthcare proxy and your loved ones.

Be Prepared

What happens if you have no advance directive or have made no plans and you become unable to speak for yourself? In such cases, the state where you live will assign someone to make medical decisions on your behalf. This will probably be your spouse, your parents if they are available, or your children if they are adults. If you have no family members, the state will choose someone to represent your best interests.

Always remember: an advance directive is only used if you are in danger of dying and need certain emergency or special measures to keep you alive, *but you are not able to make those decisions on your own*. An advance directive allows you to make your wishes about medical treatment known.

It is difficult to predict the future with certainty. You may never face a medical situation where you are unable to speak for yourself and make your wishes known. But having an advance directive may give you and those close to you some peace of mind.

I. Getting Your Affairs in Order

National Institute on Aging (2017), *Getting Your Affairs in Order*. Retrieved January 8,2020
https://www.nia.nih.gov/health/getting-your-affairs-order

Ben's Story

Ben has been married for 47 years. He always managed the family's money. But since his stroke, Ben is not able to walk or talk. His wife, Shirley, feels overwhelmed. Of course, she's worried about Ben's health. But, on top of that, she has no idea what bills should be paid or when they are due.

Louise's Story

Across town, 80-year-old Louise lives alone. One night, she fell in the kitchen and broke her hip. She spent a week in the hospital and 2 months in a rehabilitation nursing home. Even though her son lives across the country, he was able to pay her bills and handle her Medicare questions right away.

That's because, several years ago, Louise and her son made a plan about what he should do in case Louise had a medical emergency.

Preparing and Organizing Legal Documents for the Future

No one ever plans to be sick or disabled. Yet, it's this kind of planning that can make all the difference in an emergency.

Long before she fell, Louise put all her important papers in one place and told her son where to find them. She gave him the name of her lawyer, as well as a list of people he could contact at her bank, doctor's office, insurance company, and investment firm. She made sure he had copies of her Medicare and other health insurance cards. She made sure her son could access her checking account and safe deposit box at the bank. Louise made sure Medicare and her doctor had written permission to talk with her son about her health and insurance claims.

On the other hand, Ben always took care of family money matters, and he never talked about the details with Shirley. No one but Ben knew that his life insurance policy was in a box in the closet or that the car title and deed to the house were filed in his desk drawer. Ben never expected that his wife would have to take over. His lack of planning has made a tough job even tougher for Shirley.

What Exactly Is an "Important Paper"?

The answer to this question may be different for every family. Remember, this is a starting place. You may have other information to add. For example, if you have a pet, you will want to include the name and address of your veterinarian. Include complete information about:

Personal Records

- Full legal name
- Social Security number
- Legal residence
- Date and place of birth
- Names and addresses of spouse and children
- Location of birth and death certificates and certificates of marriage, divorce, citizenship, and adoption
- Employers and dates of employment
- Education and military records
- Names and phone numbers of religious contacts
- Memberships in groups and awards received

- Names and phone numbers of close friends, relatives, doctors, lawyers, and financial advisors
- Medications taken regularly (be sure to update this regularly)
- Location of living will and other legal documents

Financial Records

- Sources of income and assets (pension from your employer, IRAs, 401(k)s, interest, etc.)
- Social Security and Medicare/Medicaid information
- Insurance information (life, health, long-term care, home, car) with policy numbers and agents' names and phone numbers
- Names of your banks and account numbers (checking, savings, credit union)
- Investment income (stocks, bonds, property) and stockbrokers' names and phone numbers
- Copy of most recent income tax return
- Location of most up-to-date will with an original signature
- Liabilities, including property tax— what is owed, to whom, and when payments are due
- Mortgages and debts—how and when they are paid
- Location of original deed of trust for home
- Car title and registration
- Credit and debit card names and numbers
- Location of safe deposit box and key

Steps for Getting Your Affairs in Order

- **Put your important papers and copies of legal documents in one place.** You can set up a file, put everything in a desk or dresser drawer, or list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check each year to see if there's anything new to add.

- **Tell a trusted family member or friend where you put all your important papers.** You don't need to tell this friend or family member about your personal affairs, but someone should know where you keep your papers in case of an emergency. If you don't have a relative or friend you trust, ask a lawyer to help.
- **Discuss your end-of-life preferences with your doctor.** He or she can explain what health decisions you may have to make in the future and what treatment options are available. Talking with your doctor can help ensure your wishes are honored. Discussing advance care planning decisions with your doctor is free through Medicare during your annual wellness visit. Private health insurance may also cover these discussions.
- **Give permission in advance for your doctor or lawyer to talk with your caregiver as needed.** There may be questions about your care, a bill, or a health insurance claim. Without your consent, your caregiver may not be able to get needed information. You can give your okay in advance to Medicare, a credit card company, your bank, or your doctor. You may need to sign and return a form.

Important Legal Documents You May Need as You Age

There are many different types of legal documents that can help you plan how your affairs will be handled in the future. Many of these documents have names that sound alike, so make sure you are getting the documents you want. Also, State laws vary, so find out about the rules, requirements, and forms used in your State.

Wills and ***trusts*** let you name the person you want your money and property to go to after you die.

Advance directives let you make arrangements for your care if you become sick. Two common types of advance directives are:

- A ***living will*** gives you a say in your health care if you become too sick to make your wishes known. In a living will, you can state what kind of care you do or don't want. This can make it easier for family members to make tough healthcare decisions for you.

- A ***durable power of attorney for health care*** lets you name the person you want to make medical decisions for you if you can't make them yourself. Make sure the person you name is willing to make those decisions for you.

For legal matters, there are ways to give someone you trust the power to act in your place.

- A ***general power of attorney*** lets you give someone else the authority to act on your behalf, but this power will end if you are unable to make your own decisions.
- A ***durable power of attorney*** allows you to name someone to act on your behalf for any legal task, but it stays in place if you become unable to make your own decisions.

Help for Getting Your Legal and Financial Papers in Order

You may want to talk with a lawyer about setting up a general power of attorney, durable power of attorney, joint account, trust, or advance directive. Be sure to ask about the lawyer's fees before you make an appointment.

You should be able to find a directory of local lawyers on the Internet or at your local library, or you can contact your local bar association for lawyers in your area. Your local bar association can also help you find what free legal aid options your State has to offer. An informed family member may be able to help you manage some of these issues.

Frequently Asked Questions About Getting Your Affairs in Order

Getting your affairs in order can be difficult, but it is an important part of preparing for the future, for you and your loved ones. It is important to gather as much information as possible to help ease the process. Here are a few questions that you may have and some answers that can help.

Who should you choose to be your healthcare proxy?

If you decide to choose a proxy, think about people you know who share your views and values about life and medical decisions. Your proxy might be a family member, a friend, your lawyer, or someone with whom you worship. Learn more about selecting a healthcare proxy.

My aging parents can no longer make their own healthcare decisions. How do I decide what type of care is right for them?

It can be overwhelming to be asked to make healthcare decisions for someone who is no longer able to make his or her own decisions. Get a better understanding of how to make healthcare decisions for a loved one, including approaches you can take, issues you might face, and questions you can ask to help you prepare.

How do you help someone with Alzheimer's or dementia get their affairs in order?

A complication of diseases such as Alzheimer's is that the person may lack or gradually lose the ability to think clearly. This change affects his or her ability to participate meaningfully in decision making and makes early planning even more important. Read these legal and financial planning tips for people with Alzheimer's disease.

I am considering becoming an organ donor. Is the process different for older adults?

There are many resources for older organ donors and recipients available from the U.S. government. Find information for potential donors and transplant recipients over age 50, including how to register to be a donor.

I want to make sure my affairs are in order before I die, but I'm not sure where to begin.

The National Institute on Aging has free publications that can help you and your loved ones discuss key issues at the end of life, including finding hospice care, what happens at the time of death, managing grief, preparing advance directives, and other information.

Conclusion

Bereavement and issues that come towards and at the end of life are some of the most painful feelings we experience. As has been illustrated by the variety of topics covered, it is a complicated time in many different ways. Having a helping professional that possesses knowledge, and compassion, can greatly assist those who struggle through the end of their life, and their survivors.

End of the course!

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