

Bereavement and End of Life Issues

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4 CE Credits / Contact Hours

Important Note: We recommend printing the test and completing it as you read to prepare for the online post-test. As you go through the course, hover over or click the yellow 'sticky notes' to reveal helpful study tips. Enjoy the course!

Introduction

Bereavement and end-of-life issues touch every human life, yet they remain among the most challenging experiences to navigate. Grief is not a single event but a process shaped by personal history, cultural meaning, and the circumstances of loss. Research shows that most individuals experience “uncomplicated grief,” a natural, though painful, process that gradually allows adaptation and integration of the loss into daily life (Stroebe & Schut, 2024). However, a subset experience prolonged or complicated grief, which can significantly impair functioning and requires more specialized intervention (Shear, 2025).

The course begins with an exploration of bereavement, including the death of a spouse, loss after disasters, and the wide variety of grief models that illuminate this human experience. Understanding the distinctions between normal grief and clinical concerns allows practitioners to provide sensitive and evidence-based care. Recent literature emphasizes the importance of cultural responsiveness and trauma-informed approaches, especially in contexts of sudden or collective loss (Rosenblatt, 2024).

The second section introduces treatment approaches, including Complicated Grief Therapy, a structured method with growing empirical support (Shear, 2025). Participants will also examine historical and contemporary bereavement interventions, reflecting on how theory has evolved alongside clinical practice.

The course then expands to broader coping with loss and concludes with end-of-life

considerations. End-of-life care requires not only medical management but also attention to psychological, social, and spiritual needs. Palliative and hospice care emphasize quality of life, dignity, and holistic support (National Hospice and Palliative Care Organization [NHPCO], 2024). Planning ahead, advance directives, and caregiver support are increasingly recognized as critical components of compassionate care (World Health Organization, 2025).

By the end of this course, learners will be equipped to understand bereavement processes, recognize when grief requires clinical intervention, and support individuals and families through the profound challenges of end-of-life care.

Chapter 1. Bereavement

A. When Someone 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.

Margaret and Henry's Story

When Henry passed away after fifty-two years of marriage, Margaret felt as though the very center of her life had been taken from her. The house they had shared—once full of laughter, the smell of Henry's favorite coffee brewing, and the rhythm of his footsteps—now felt unbearably quiet. Each morning she still caught herself setting out two coffee cups, only to realize with a pang that there was no one to share the second.

In the days after the funeral, Margaret's friends began stopping by. Some brought casseroles or fresh bread, others carried small bouquets from their gardens. At first Margaret thought the visits were simply acts of kindness meant to fill her refrigerator and freezer. But soon she realized they were giving her something far more precious: companionship and stories.

They gathered around her dining room table, the same one where Henry had presided over countless family dinners, birthday celebrations, and Sunday roasts. At first the conversations were tentative, but one by one, memories of Henry began to surface. Her neighbor Mary recalled how Henry always shoveled not only his own driveway but hers as well, even after a snowstorm left him exhausted. Another friend remembered Henry's booming laugh during their church outings, while Margaret's sister recounted his habit of quietly slipping money into the pockets of young college students in need.

Before long, Henry's closest friends began joining these gatherings. They brought their own recollections—his golfing buddy told of the time Henry “accidentally” let him win after a long losing streak, and his longtime coworker described how Henry once stayed late every evening for a month to cover for a colleague whose wife was ill. The stories flowed, each one a reminder of the many layers of kindness, humor, and love that had defined Henry's life.

For Margaret, these evenings became a lifeline. Listening to others share their memories helped her see Henry not only through her own eyes but through the eyes of everyone who had loved him. At times, the laughter around the table was so genuine and full that it felt as though Henry had just stepped into another room and would return any minute.

What surprised Margaret most was how much these gatherings also helped others. Friends who had been grieving in their own quiet ways found comfort in remembering Henry together. Sharing stories transformed the ache of loss into a kind of collective healing, where everyone present could both cry and laugh without apology.

Over time, Margaret began to look forward to these evenings. They did not erase her grief, but they softened it. They reminded her that Henry's life was woven into the hearts of many, and that those threads continued to hold her even in his absence. Sitting at the dining table, surrounded by stories, laughter, and tears, Margaret discovered a truth: while death had ended Henry's life, it had not ended his presence. His love and legacy lived on, not only in her memory but in the community that gathered faithfully around her table.

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.

Although grief is universal, gender, cultural background, and life stage can influence how people adjust after spousal loss. Studies show men are more prone to social isolation, while women often face economic strain and caregiving burdens (Parkes & Prigerson, 2024; U.S. National Institute on Aging, 2025). Individual differences shape recovery.

Robert's Story

Robert had been married to Elaine for more than forty years. She had always managed the household—the meals, the laundry, the family gatherings—while Robert focused on his work as a contractor and handled the cars and finances. When Elaine died suddenly of a heart attack, Robert found himself at a complete loss.

In the weeks that followed, his grown children stopped by with casseroles, but when they returned to their busy lives, the house grew painfully quiet. Robert realized he had never really learned how to cook more than a grilled cheese sandwich. Meals became an afterthought, and he began skipping them altogether. The silence at the dinner table, once filled with Elaine's chatter, felt unbearable.

He also noticed the loneliness creeping in. Elaine had been his bridge to social life—inviting friends over, reminding him of birthdays, encouraging visits with neighbors. Without her, Robert rarely picked up the phone. The isolation grew, and he found himself sinking into sadness. At his daughter's urging, he began attending a men's grief support group at the community center. Sharing memories with other widowers helped Robert feel less alone, and little by little,

he began finding his footing—learning how to prepare simple meals, asking for help when he needed it, and letting himself reconnect with others.

Maria's Story

Maria lost her husband, Carlos, after his long struggle with Parkinson's disease. For years she had been his caregiver—organizing medications, driving him to appointments, and helping him through the difficult nights when tremors kept him awake. After his death, Maria was left with a mix of emotions: deep sadness, yes, but also exhaustion and an overwhelming sense of “what now?”

Carlos had always taken care of the bills, the taxes, and the insurance paperwork. Maria had trusted him with those responsibilities, but now, alone at seventy-two, she faced stacks of envelopes she didn't understand. She also worried about money. Without Carlos's pension, her income was tighter than she had expected, and she feared she might not be able to afford to stay in their home.

Maria's loneliness was compounded by her new worries. Some nights she lay awake, listening to every creak in the house, wondering if she was safe. She missed the comfort of knowing Carlos was beside her. Her adult son began helping her with the financial paperwork, and her daughter encouraged her to talk with a grief counselor. With support, Maria slowly began to adjust, learning new skills and leaning on family when needed.

Aisha's Story

When Aisha's husband, Samir, passed away after a brief illness, the loss felt almost unbearable. Married for more than thirty years, they had raised three children together and built a life filled with family gatherings, laughter, and

shared faith. In the quiet of her home, Aisha felt the weight of his absence deeply. She worried about the future—managing household repairs, keeping

track of bills, and adjusting to the silence of nights without him beside her.



But unlike some widows who face grief in solitude, Aisha's cultural and religious community became her anchor. Within hours of Samir's death, extended family members, neighbors, and friends gathered to comfort her. They prepared meals, read prayers, and shared stories about Samir's generosity

and humor. The funeral rituals, rooted in her faith, gave Aisha a sense of structure. There was comfort in knowing that centuries-old traditions guided her through each step of mourning.

In the weeks that followed, her community continued to surround her. Relatives helped with practical matters, like arranging auto repairs or paying bills, while women from her faith circle visited regularly to cook meals and pray with her. Though Aisha felt waves of sadness and fear, she also felt supported—reminded that her grief was shared, not carried alone.

Her story illustrates how cultural and spiritual traditions can provide meaning, reduce isolation, and shape how grief is experienced. For Aisha, the rituals affirmed her bond with Samir while gently guiding her toward healing. Even in her most painful moments, she knew she was not alone; her faith and her community carried her forward.

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.

Story 1: Helen's Quiet Goodbye

When Helen's husband, Walter, died at home after a long illness, she was both prepared and completely unprepared. Hospice had been helping for weeks, and she knew this day was coming, but when the moment arrived, the silence in the room was almost too much to bear.

Her daughter, Emily, encouraged her not to rush. "We don't have to do anything right away," she reminded Helen. Together, they stayed with Walter's body for a while, straightening his blanket and placing his hands gently on his chest before his joints stiffened. Helen sat in the chair beside him, holding his hand, grateful for a few last moments of stillness after the long struggle.

They called their pastor, who came and offered a prayer. Family members arrived throughout the afternoon, each taking turns to sit quietly, share memories, and weep. It was hours later—when Helen felt ready—that Emily phoned the funeral home. Because hospice had been involved, the nurse handled the necessary paperwork and official pronouncement of death, easing Helen’s burden. The transition from those sacred, quiet hours at home to the practical next steps felt natural and gentle, allowing Helen to grieve at her own pace.

Story 2: The Rodriguez Family’s Vigil

When Mr. Rodriguez passed away in the hospital after a sudden stroke, his wife and children were shocked. They had not had time to prepare for rituals or paperwork, and the thought of leaving him so quickly was painful. But because they had spoken with the hospital staff earlier about their cultural traditions, the nurses made arrangements to give the family more time.



They gathered around his bed, singing hymns in Spanish and reciting prayers passed down through generations. His eldest son called relatives, and soon cousins, aunts, and uncles began arriving to say goodbye. The hospital chaplain joined them, guiding the family in

their rituals while offering comfort.

Eventually, the doctor came to officially pronounce death and explain the next steps. The family chose to forgo an autopsy because of their religious beliefs, and the staff respected that decision. When they were ready, the hospital contacted the funeral home on their behalf. Though the day was filled with grief, the Rodriguez family felt grateful for the time they were given to honor their father in the way their culture had always taught them—through togetherness, ritual, and prayer.

Story 3: David's Family and the Autopsy Decision

When 68-year-old David passed away suddenly at home, his wife, Marianne, and their two adult children were left stunned. He had seemed healthy aside from mild memory lapses, which doctors had suggested might be “early cognitive changes.” His death came without warning, and along with grief came a flood of questions. At the hospital, after David had been officially pronounced dead, the attending physician gently asked Marianne if the family would consider an autopsy. “It may help us understand why David died so suddenly,” he explained. “If he did have Alzheimer’s disease or another neurological condition, an autopsy could give a definitive answer. That knowledge might also help your children and grandchildren in the future.”

The request left Marianne torn. Her faith community did not forbid autopsies, but she worried it might disturb David’s dignity. She also wondered whether it would affect plans for a funeral with a viewing. Her daughter, Ellen, wanted clarity—she hoped that knowing more about her father’s death might help protect her own health someday. Her son, Mark, was more hesitant. “Dad never liked hospitals or medical procedures,” he said quietly. “Wouldn’t this go against what he would have wanted?” The family spoke with the doctor again, who reassured them that the procedure would not interfere with how David’s body would look at the funeral. He explained that autopsies are done respectfully, and clothing typically covers any signs. He also emphasized that declining an autopsy was entirely their choice.

After much discussion, Marianne decided to proceed. “I think your father would want us to understand,” she told her children. “And if this helps us, or others, in the future, then it is a final gift he can give.”

Weeks later, the autopsy confirmed that David had advanced Alzheimer’s disease and revealed a sudden heart arrhythmia as the cause of death. Though the answers did not ease the grief, they brought clarity. For Ellen and Mark, the findings underscored the importance of monitoring their own health. For Marianne, it offered

peace of mind that she had honored her husband while also helping her family.

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 Prolonged Grief

Uncomplicated Grief

Grief and Adaptation

Grief and loss are universal parts of life, and nearly everyone will encounter them in some form. People grieve in many different ways, and it does not always follow a predictable pattern or sequence of "stages." Instead, how someone experiences grief is often shaped by the nature of the loss—whether sudden or expected, whether involving a young or older person—as well as past experiences and the resources they have for support. There is no fixed time frame for grief. Some people

find themselves returning to routines sooner, while others need much more time. Some seek solitude, while others find comfort in community (Stroebe & Schut, 2024).

For most people, this process is what clinicians describe as *uncomplicated grief*. It may include sadness, anxiety, changes in sleep or appetite, **waves of anger**, or moments of numbness and disbelief. People may experience guilt over past interactions, sudden bursts of emotion triggered by reminders, or even brief sensations of hearing or seeing their loved one. These reactions are natural, even if they feel unsettling. Over time, most individuals adapt to the loss, gradually reconnecting with daily life while still carrying a sense of missing the person who has died. Support, compassion, healthy routines, and sometimes counseling or peer groups can ease this process (Rosenblatt, 2024).

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died. Support, compassion, healthy routines, and sometimes counseling or peer groups can ease this process (Rosenblatt, 2024).

Story 1: Evelyn's Quiet Healing

When Evelyn's younger brother died unexpectedly from a heart condition, she felt as though the ground had shifted beneath her feet. At first, the grief came in waves: disbelief when she passed his empty chair at family dinners, sudden tears in the grocery store when she spotted his favorite cereal, and long nights when sleep simply wouldn't come.

But Evelyn also noticed small moments of adaptation. After several weeks, she returned to her morning walks, carrying her brother's old sweatshirt with her. The routine steadied her, and the quiet time outdoors became a way to remember him. She joined a local bereavement support group, where she found comfort in sharing her feelings with others who had also lost loved ones. Though sadness remained, Evelyn discovered she could both honor her brother's memory and continue living fully herself. Over time, she laughed more easily, slept more deeply, and embraced life with the bittersweet awareness of her loss.

Story 2: James and the Empty House

James lost his wife, Margaret, after her long battle with cancer. Their home, once filled with her humming as she worked in the garden or read aloud from the newspaper, now felt impossibly quiet. James struggled with simple tasks like preparing meals or paying bills—things Margaret had always done with ease. He often felt guilty for moments of relief after her long illness, as if taking comfort meant he was forgetting her.

Yet slowly, James found a way forward. He began attending weekly breakfasts with his old coworkers, something he had stopped while caring for Margaret. He planted roses in the garden, choosing the bright yellow variety Margaret loved most. On some evenings, he still felt a sudden rush of grief, even imagining he heard her voice. But those experiences no longer unsettled him; instead, they reminded him of their deep bond. With time, James realized that grief had softened into something he

could carry—a presence in his life, but not an anchor holding him back.

The following are two **contrasting stories that illustrate complicated grief**, written in the same warm, narrative style so they can be taught side-by-side with the uncomplicated grief examples.

Story 3: Linda's Endless Restlessness

When Linda's teenage daughter died in a car accident, the shock was so great that even months later, she struggled to believe it had really happened. She avoided her daughter's room, refusing to touch a single item, but at the same time she could not stay away. Every evening she sat on the bed, scrolling through old photos and replaying the night of the accident in her mind.



Sleep eluded her, and she often wandered the house at night, restless and anxious. Friends gently encouraged her to join a support group, but Linda pushed them away, insisting no one could understand. She stopped attending church, withdrew from work, and rarely answered phone calls.

What began as the raw pain of grief seemed to harden into something unyielding. Even after

a year, Linda felt just as lost as she had the day of the accident, unable to imagine a future without her daughter. Her grief had not softened with time but had deepened into despair, keeping her from reconnecting with life.

Story 4: Samuel's Quiet Isolation

Samuel's wife, Clara, died of complications after surgery. At first, his family rallied around him, bringing meals and offering companionship. But as weeks turned into months, Samuel pulled away. He refused to talk about Clara, insisting he was "fine," even though he had stopped eating well, skipped medical appointments, and lost interest in the hobbies he once loved.

He avoided places that reminded him of her, like the park where they had walked their dog, or the café where they met friends on Sundays. Yet he also felt haunted—sometimes convinced he heard her footsteps in the hall. The contradiction left him unsettled and anxious.

Two years later, Samuel's grief still gripped him tightly. He had not adapted to Clara's absence; instead, he lived in a cycle of avoidance and yearning. His children worried, urging him to speak with a counselor. Samuel's story shows how grief can become prolonged and complicated, interfering with health, relationships, and the ability to move forward.

These stories highlight the difference: **Evelyn and James** experienced grief that softened with time (uncomplicated), while **Linda and Samuel** struggled with prolonged, disruptive grief that kept them from adapting (complicated).

Prolonged Grief Disorder

For some, however, grief remains intense and unrelenting.  **The DSM-5-TR identifies Prolonged Grief Disorder as a condition in which the pain of loss persists beyond 12 months in adults (or six months in children), leading to significant distress and functional impairment (American Psychiatric Association, 2022).** Warning signs include overwhelming longing, persistent avoidance of reminders, isolation, or ongoing inability to re-engage with life. Recent research underscores that without support, prolonged grief may worsen mental and physical health outcomes (Shear, 2025; Parkes & Prigerson, 2024). Therapy can provide a safe space to process grief, strengthen coping, and restore meaning. Some may also benefit from medication to alleviate co-occurring

depression or anxiety, though tranquilizers are discouraged because they can interfere with the natural grieving process (World Health Organization, 2025). While there are no strict “rules” for grieving, knowing when to reach out for help can make the difference between carrying grief as part of life and feeling consumed by it.

Story: Caroline’s Long Shadow of Loss

Caroline lost her husband, Michael, to cancer nearly two years ago, but for her the grief has never eased. Each morning she wakes expecting to hear his voice, and each night she falls asleep clutching his old sweater. Friends encouraged her to return to the book club she once loved, but she avoids it, saying it would feel wrong to enjoy herself without Michael.

At family gatherings, Caroline finds herself retreating to a quiet room, unable to bear the laughter that reminds her of the joy she no longer feels. She avoids driving past the hospital where Michael was treated, and she still hasn’t packed away his belongings. In fact, she spends hours each week sitting in his study, convinced that leaving things untouched keeps him close.

Her adult children are concerned. They notice how isolated she has become, declining invitations, skipping medical appointments, and losing weight. Caroline insists she is “just not ready,” but her sadness feels more like paralysis. What began as love and longing has become unrelenting pain, interfering with her health and her ability to live daily life.

When her daughter gently suggested therapy, Caroline was hesitant. “I should be able to manage this,” she said. Yet with time, she agreed to meet with a grief counselor. In therapy, she began exploring her overwhelming yearning and learning gentle ways to re-engage with life while still honoring Michael’s memory.

Caroline’s story reflects **Prolonged Grief Disorder**—a form of grief where adaptation is stalled and the loss dominates daily existence. With support, she is beginning to understand that seeking help is not a betrayal of her husband, but rather a way to carry her love for him forward without being consumed by it.

Clinical Reflection: Understanding Prolonged Grief Disorder

Caroline's experience illustrates how **Prolonged Grief Disorder (PGD)** differs from the natural course of grief. According to the *DSM-5-TR* (American Psychiatric Association, 2022), PGD is diagnosed when the **intense pain of loss persists beyond 12 months in adults** (or six months in children) and causes significant impairment in daily functioning.

Key warning signs of PGD include:

- **Persistent yearning or longing** for the deceased that does not lessen with time.
- **Avoidance of reminders** of the death (e.g., refusing to pass the hospital or touch belongings).
- **Isolation and withdrawal** from social activities or supportive relationships.
- **Difficulty re-engaging with life**, such as declining invitations, neglecting health, or abandoning hobbies.

In Caroline's case, her avoidance of social contact, retreat from joyful activities, and fixation on her husband's belongings signal that her grief has stalled rather than gradually integrated into her life. This pattern illustrates how PGD can affect both **mental health** (e.g., depression, anxiety) and **physical well-being** (e.g., weight loss, fatigue).

Treatment often involves **Complicated Grief Therapy (CGT)** or other evidence-based psychotherapies that help individuals process painful emotions, restore a sense of purpose, and reconnect with life while still honoring the deceased.

Medication may be considered for co-occurring depression or anxiety, though tranquilizers are discouraged because they may interfere with the natural grieving process (World Health Organization, 2025; Shear, 2025).

Key Takeaway: While there is no single "right" way to grieve, prolonged and debilitating grief should not be dismissed as normal. Recognizing when grief has become **consuming rather than adaptive** is essential so that individuals can receive timely support and regain a sense of balance.

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 *f* 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

THE FIVE STAGES OF GRIEF

The Kubler-Ross model first introduced the five stages of grief in 1969.



Denial
"I feel fine." "This can't be happening, not to me."



Anger
"Why me? It's not fair!"
Who is to blame?"



Bargaining
"Just let me live to see my children graduate."



Depression
"I'm so sad, why bother with anything?"
I'm going to be okay.



Acceptance
"It's going to be okay." "I can't fight it, I may as well prepare for it."

People may experience these stages in any order, and some stages may be revisited.
Not everyone will experience all five stages.

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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."

Case Study: Margaret's Journey Through Loss

Margaret was sixty-eight when her husband, Thomas, died suddenly from a heart attack. They had been married for over forty years, raising two children and sharing the rhythms of daily life. His death left her stunned, adrift in a silence that felt unbearable.

Denial.

In the first weeks after Thomas's passing, Margaret found herself repeatedly setting out his coffee cup in the morning and listening for the sound of his footsteps. "He'll be back soon," she thought, even as she stared at the empty chair across the kitchen table. Friends gently reminded her of the reality, but Margaret clung to the small routines that made it feel as though nothing had changed. This denial gave her a buffer, a fragile space where she could survive the raw shock of loss.

Anger.

As the funeral cards stopped arriving and her children returned to their own lives, Margaret's grief shifted. Anger bubbled to the surface. She snapped at her daughter for not calling often enough and grew bitter toward friends whose husbands were still alive. In her prayers, she demanded, "Why him? Why me?" The anger was difficult for her family to witness, but it was an expression of her recognition that life would not return to what it once was.

Bargaining.

In quieter moments, Margaret turned to bargaining. She whispered promises to God—if only Thomas could somehow return. "I'll volunteer more. I'll be better," she pleaded. At other times, she found herself replaying the days before his death, wondering if she had missed warning signs or could have pushed him to see a doctor sooner. Bargaining gave her a temporary sense of control, though it often led to guilt when she couldn't "undo" what had happened.

Depression.

Months later, the weight of absence pressed down heavily. Margaret stopped gardening, something she and Thomas had always loved to do together. She declined invitations and spent long afternoons sitting in the living room, weeping quietly. “What’s the point?” she confided to her doctor. This stage was not simply sadness—it was a profound recognition of the depth of her loss, a withdrawal that allowed her to grieve fully.

Acceptance.

Gradually, Margaret’s days began to take on new meaning. She joined a local grief support group, where she heard others share their stories of loss. She began to accept that while Thomas would never return, she could carry his memory forward. She took comfort in planting a rosebush in his honor, finding peace in tending something that reminded her of him. Acceptance did not mean she stopped missing Thomas, but rather that she found ways to live with his absence while holding on to love.

Reflection

Margaret’s story shows how the **five stages of grief**—denial, anger, bargaining, depression, and acceptance—can unfold over time. Her journey was not linear; she moved back and forth between stages, sometimes revisiting anger or denial even as she worked toward acceptance. The Kübler-Ross model offers a framework for understanding her experience, but it also reminds us that grief is deeply personal and cannot be rushed. Ultimately, Margaret’s process led her to a place where grief and love coexisted, allowing her to move forward while honoring her husband’s memory.

Case Study: Daniel’s Unexpected Diagnosis

Daniel was thirty-two, newly married, and just beginning his career as an architect when he was diagnosed with an aggressive autoimmune disorder that left him unable to continue working. For Daniel, the diagnosis felt like the sudden collapse of

the future he and his wife had imagined together.

Denial.

At first, Daniel dismissed the doctor's words. "It can't be that serious," he insisted, continuing to draft designs late into the night. When his hands began to shake uncontrollably, he told himself it was just fatigue. Denial helped him hold on to the life he knew, even as his illness progressed.

Anger.

When the reality became undeniable, anger surfaced. He lashed out at his wife, frustrated at her attempts to help. Seeing friends post about promotions and travel on social media only deepened his resentment. "Why me?" he fumed, blaming fate, doctors, even his own body for betraying him.

Bargaining.

Daniel then turned inward, trying to negotiate with himself and with God. "If I can just make it through this year, I'll change my habits. I'll eat healthier, exercise more, pray more," he promised. He scoured the internet for experimental treatments, convinced that if he tried hard enough, he could outmaneuver his illness.

Depression.

As the months passed, the weight of the illness became inescapable. Daniel sank into despair, grieving not only his health but also the future he had envisioned. He mourned the career he loved, the children he and his wife had planned, and the independence that was slipping away. He often sat silently in the living room, unable to summon energy or interest in the world around him.

Acceptance.

With time, and the support of therapy, Daniel began to shift. He could not change his illness, but he could choose how to live with it. He took up photography, capturing small details of beauty that he once overlooked. He and his wife talked openly about adjusting their dreams, focusing on what they could still enjoy together rather than what had been lost. Acceptance did not erase the sadness, but it gave Daniel a path toward peace and purpose.

Reflection

Daniel's journey illustrates how the **five stages of grief** extend beyond bereavement. Illness, disability, and other major life changes can provoke the same cycle of denial, anger, bargaining, depression, and eventual acceptance. Like Margaret's story, Daniel's experience was not linear—he sometimes revisited anger or bargaining when symptoms worsened. Yet, moving through the stages allowed him to integrate his loss into a new way of living, showing that acceptance can mean adaptation rather than resignation.

2. *Four Tasks of Mourning*

Case Study: Elena's Path Through Worden's 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

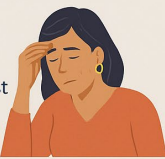
To find an appropriate, ongoing connection in our emotional lives with the person who has died while allowing us to continue living. Like the other tasks, this can mean varying things to various grievers. But it often means allowing for thoughts and memories, while beginning to meaningfully engage in 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)

Elena was forty-five when her younger brother, Marco, died unexpectedly from an overdose. The loss was devastating not only because of their close bond but also

Case Study: Elena's Path Through Worden's Tasks of Mourning

Psychologist J. W. Worden also created a stage-based model for coping with the death of a loved one.

- 1 To accept the reality of the loss**
Elena went to the funeral and slowly began to acknowledge her husband's death.
- 2 To work through the pain of grief**
She talked with a therapist about her sadness and anger.
- 3 To adjust to life without the deceased**
Elena took on new responsibilities and found her own routine.
- 4 To maintain a connection to the deceased while moving on with life**
She regularly looked at old photos, while reconnecting with friends.



because of the stigma that surrounded the way he died. Friends and extended family often avoided talking about it, which left Elena feeling isolated in her grief. Her journey over the next two years reflected the challenges—and possibilities—outlined in Worden's model of mourning.

Task 1: Accepting the Reality of the Loss.

At Marco's funeral, Elena stood by his casket in disbelief. She could say the words—"my brother died"—but deep down she struggled to accept the full significance of what that meant. For months, she caught herself picking up the

phone to call him. Even harder was coming to terms with the cause of death. Some relatives whispered about “a heart problem,” but Elena knew the truth. She realized that part of acceptance meant speaking honestly about Marco’s addiction, even when it was uncomfortable. Over time, she found strength in attending a bereavement group where others openly discussed losses by suicide and overdose.

Task 2: Working Through the Pain of Grief.

Elena’s emotions were complex and often overwhelming. She felt guilt for not recognizing how much Marco was struggling, anger at the drugs that took him, shame when others judged, and deep sadness that he was gone. Some days she avoided the pain by throwing herself into work, but in counseling she learned to sit with her grief instead of running from it. Journaling helped her name emotions she could not speak aloud, while group therapy reminded her she wasn’t alone in feeling conflicted.

Task 3: Adjusting to Life Without the Deceased.

Marco had always been the one to help Elena fix things around the house, and his absence forced her to learn practical skills she had never needed before. More profoundly, Elena had to redefine her identity as a sister without her brother. Spiritual questions also arose: “Where is Marco now? Does he know I love him?” Conversations with her pastor helped her rebuild a sense of meaning and resilience. Slowly, she began to trust that she could live in a world without Marco’s physical presence, even though the adjustment was painful.

Task 4: Maintaining a Connection While Moving Forward.

A turning point came when Elena planted a tree in her backyard in Marco’s memory. She found comfort in sitting beneath it, talking to him, or simply being quiet. At the same time, she allowed herself to laugh again, to travel with friends, and to imagine a future that included joy. Remembering Marco no longer meant being trapped in grief—it became part of her ongoing story. By holding his memory close while engaging fully in life, Elena discovered a new way of being connected without being bound.

Reflection

Elena's story highlights how Worden's tasks of mourning are not rigid steps but ongoing challenges that unfold differently for each person. Accepting reality, working through pain, adjusting to a changed life, and finding an enduring connection to the deceased represent milestones that can help individuals integrate their loss and continue living meaningfully.

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 an Evidence-Based Approach

Overview

Complicated Grief Therapy (CGT) is a structured psychotherapy developed to address the intense, persistent symptoms of grief that do not ease over time. In the *DSM-5-TR*, this condition is recognized as **Prolonged Grief Disorder (PGD)** (American Psychiatric Association, 2022). CGT builds on attachment theory and integrates principles from interpersonal therapy (IPT) and cognitive-behavioral therapy (CBT). It includes techniques such as retelling the story of the death, gradually confronting avoided reminders, and re-engaging in meaningful activities.

CGT has shown strong effectiveness in clinical trials. In one study, participants receiving CGT improved more quickly and had higher overall response rates (51%) compared with those treated with IPT alone (28%) (Shear, 2025). These findings highlight CGT as one of the most effective grief-specific interventions currently available.

Description of the Treatment

Grief is a natural, adaptive process. However, in prolonged grief, the transition from acute grief to an integrated form of mourning is disrupted. Individuals often experience overwhelming longing, intrusive thoughts, avoidance of reminders, and a sense of being “stuck” in their grief. CGT works by identifying and removing barriers to adaptation while supporting both **loss-oriented** (facing painful emotions and memories) and **restoration-oriented** (rebuilding life goals and relationships) activities—a balance described in the *dual-process model of coping with bereavement* (Stroebe & Schut, 2024).

Treatment is typically delivered in a 16-session, manualized format. Core components include:

- **Psychoeducation** about grief and its natural course.
- **Imaginal exposure**, where clients revisit the story of the loss to process painful memories.
- **Situational revisiting**, where avoided places or activities are approached gradually.
- **Goal setting**, to help clients reconnect with personal values, relationships, and future hopes.
- **Meaning-making**, encouraging reflection on the significance of the relationship and life after loss.

Research and Applications

Since its development, CGT has been tested across diverse populations, including individuals bereaved by suicide, accidents, natural disasters, and violent death.

Studies suggest it is effective across cultures and can be combined with antidepressant medication when co-occurring depression is present (Parkes & Prigerson, 2024; WHO, 2025). Research continues to explore adaptations of CGT, including group-based formats, digital delivery, and integration with mindfulness practices.

CGT offers a compassionate, evidence-based framework for helping individuals move from a state of unrelenting pain toward one of integrated grief. The goal is not to “get over” the loss, but to carry it forward in a way that honors the bond with the deceased while allowing renewed engagement with life.

Description of the Treatment

Complicated Grief Therapy (CGT), now most often described as a treatment for **Prolonged Grief Disorder (PGD)**, integrates principles from both interpersonal therapy (IPT) and cognitive-behavioral therapy (CBT). The CBT components focus primarily on the *loss-related aspects* of grief—such as intrusive memories,

avoidance behaviors, and emotional triggers—while the IPT elements support *restoration*, helping clients re-engage with relationships, roles, and meaningful life goals.

Although CGT can be adapted flexibly in practice, the manualized version used in clinical trials typically includes **16 sessions of 45 to 60 minutes each**. Sessions are structured, with clear agendas that involve reviewing the previous week's progress, engaging in therapeutic exercises, and setting individualized assignments for the week ahead.

Treatment is generally organized into **three phases**. The **introductory phase** (sessions 1–3) centers on building a strong therapeutic alliance, gathering a detailed interpersonal and loss history, providing psychoeducation about PGD and the CGT model, and outlining the treatment process. A supportive family member or friend is usually invited to attend the third session to strengthen connection and encourage external support.

The **intermediate phase** (sessions 4–9) introduces targeted grief interventions such as imaginal revisiting, situational exposure to avoided reminders, and activities designed to honor the relationship while fostering renewed engagement with life. Clients are encouraged to balance **loss-oriented work** (processing painful emotions and memories) with **restoration-oriented tasks** (reconnecting with sources of joy, meaning, and purpose).

The **final phase** (sessions 10–16) focuses on consolidating gains, reviewing progress, and tailoring treatment to address ongoing challenges. Clients may explore additional relational themes, unresolved aspects of other losses, or interpersonal transitions. For some, this phase resembles IPT's emphasis on role changes and relationship conflicts. The closing sessions prepare clients for life beyond therapy, ensuring they leave with practical tools for continued growth, resilience, and integration of the loss.

Case Study: Maria's Path Through Complicated Grief Therapy

Maria was 54 when her husband, David, died suddenly from a heart attack. Married

for more than thirty years, she described him as her “anchor and compass.” In the months following his death, Maria was overwhelmed by a grief that never seemed to ease. Even a year later, she reported nightly crying spells, overwhelming guilt about “not noticing the signs,” and a refusal to enter their shared bedroom, which she had closed off since his passing. Though her children urged her to rejoin social activities, Maria avoided friends, isolating herself in the house. She felt “frozen in time,” unable to imagine a life without David.

Recognizing the persistence and intensity of her symptoms, Maria’s physician referred her to therapy. She began **Complicated Grief Therapy (CGT)**, a structured treatment designed to address **Prolonged Grief Disorder (PGD)**.

Introductory Phase (Sessions 1–3).

In the first sessions, Maria’s therapist focused on building rapport and validating her experience, explaining that while grief is universal, hers had become prolonged and distressing in ways that are treatable. Together, they reviewed Maria’s personal history, the depth of her relationship with David, and the challenges she faced since his death. In session three, Maria’s daughter joined, providing support and learning how to encourage her mother’s healing without pressuring her. This step helped Maria feel less alone and opened communication within the family.

Intermediate Phase (Sessions 4–9).

The middle sessions introduced grief-focused interventions. Maria engaged in **imaginal revisiting**, recounting the story of the night of David’s death, recording it, and listening to it between sessions. Although painful, she reported that this exercise helped her gradually confront the reality of his loss rather than avoiding it. She also practiced **situational exposure**, walking past the closed bedroom door until she could enter the room and begin reorganizing David’s belongings. Alongside this loss-oriented work, her therapist encouraged restoration tasks: Maria began attending church again, rejoined a quilting group she once loved, and set a goal of planning a trip with her sister.

Final Phase (Sessions 10–16).



As Maria progressed, therapy shifted toward consolidation. She reflected on her gains: being able to speak openly about David without collapsing into despair, reconnecting with friends, and even laughing without guilt. In later sessions, she explored her evolving identity as a widow, her

shifting roles with her adult children, and her hopes for the future. A final exercise involved writing a letter to David, expressing both her sorrow and her gratitude for their years together. She described this as a turning point, recognizing that love for him could remain while she moved forward with her life.

At termination, Maria expressed both sadness at ending therapy and confidence in her ability to continue applying what she had learned. She carried forward strategies for coping with emotional triggers, reminders of her support system, and a renewed sense of purpose.

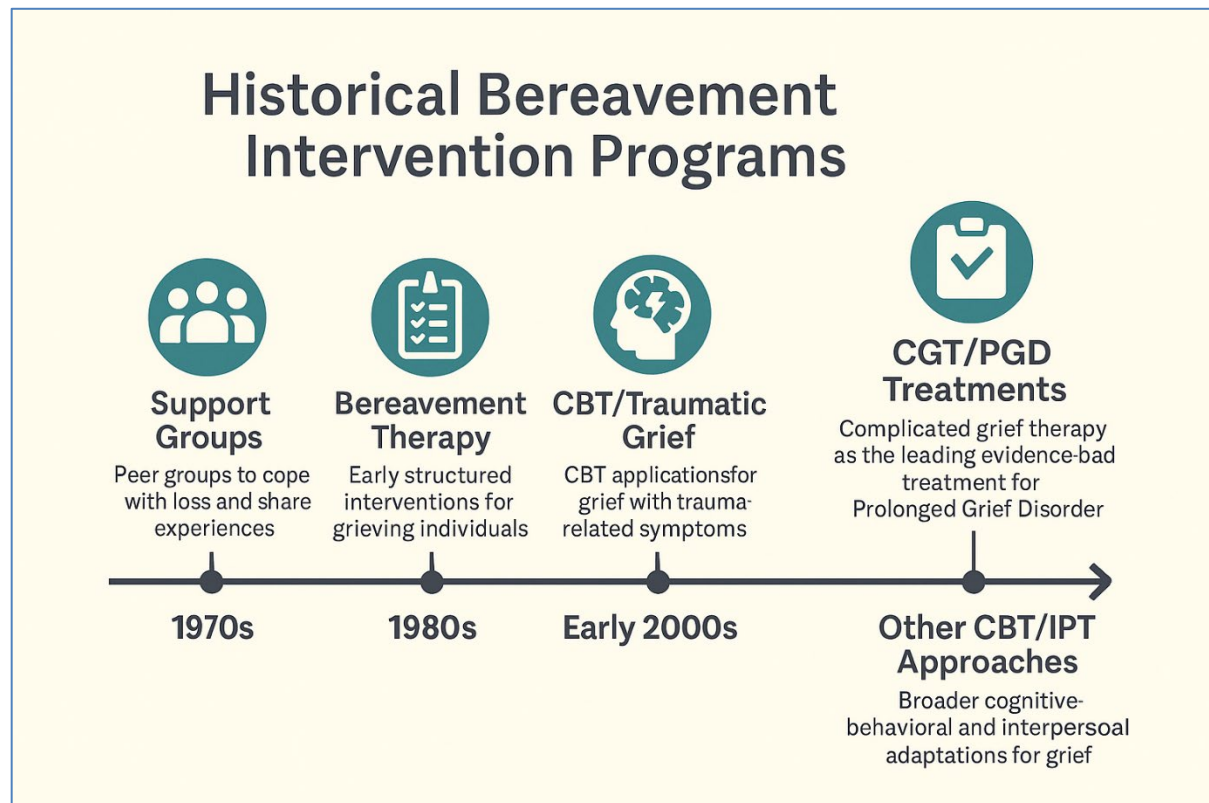
Reflection

Maria's case highlights how CGT provides a **balance of loss-oriented and restoration-oriented work**, helping clients integrate the reality of loss while re-engaging with meaningful roles and goals. Structured phases, supportive involvement of loved ones, and targeted therapeutic exercises enabled Maria to transition from feeling “stuck in grief” to living with resilience and ongoing connection to her late husband.

B. Historical Bereavement Intervention Programs

Efforts to support grieving individuals have existed for centuries, though formalized psychological interventions are a relatively recent development. Early bereavement care often centered on pastoral counseling, community rituals, and mutual aid. In the mid-20th century, the field began to recognize grief as a distinct area of clinical

concern, leading to structured intervention programs. These early efforts laid the foundation for today's evidence-based approaches.



One of the most influential early frameworks was **Elisabeth Kübler-Ross's (1969) five stages of grief**, which—though not empirically validated as a universal sequence—brought widespread attention to the psychological experience of loss. Around the same time, **John Bowlby's attachment theory** highlighted the biological and relational underpinnings of grief, shaping therapeutic perspectives on loss and adaptation. By the 1970s and 1980s, interventions began incorporating these theories into structured counseling approaches, such as **supportive therapy**, **client-centered therapy**, and **brief dynamic psychotherapy** (Institute of Medicine, 1984).

During the late 20th century, clinicians experimented with diverse modalities, including **logotherapy**, **writing therapy**, **play therapy** for children, and early uses

of **cognitive-behavioral techniques**. These interventions were often offered in hospitals, hospices, refugee programs, and trauma recovery settings. Bereavement groups also became common, providing normalization, shared meaning-making, and opportunities for social support. Research from this era showed that group interventions helped reduce isolation and fostered resilience, although outcomes varied depending on facilitator skill and participant needs.

By the early 2000s, meta-analyses revealed that many generic bereavement interventions had only modest effects, particularly for individuals experiencing *uncomplicated grief*. However, they often provided meaningful support and validation. Importantly, this body of work clarified that grief is not itself a pathology requiring treatment in most cases, but that targeted interventions are crucial for those at risk of persistent distress (Wetherell, 2012).

These historical programs set the stage for more precise treatments like **Complicated Grief Therapy (CGT)**, which emerged in the early 21st century. Where earlier approaches focused broadly on comfort, support, or meaning-making, CGT offered a structured, empirically tested method specifically designed for individuals experiencing enduring and disruptive grief symptoms.

Chapter 3. Grief, Bereavement, and Coping With Loss

Overview

Every person experiences grief in their own way. While most people gradually adapt and find ways to live with loss, others may struggle with more intense and enduring grief that requires professional support. The way a person copes is shaped by many factors: their personality, the relationship with the deceased, the circumstances of the death, and their past experiences with loss. Social support, cultural and spiritual beliefs, and overall mental health also play important roles in shaping how grief unfolds.



Grief is a natural process, not an illness. For many, the presence of caring family, friends, and community is enough to allow adjustment over time. For others, especially when grief is complicated by trauma, stigma, or preexisting vulnerabilities, therapy can provide a structured path toward healing.

Bereavement, Grief, and Mourning

Bereavement is the period that follows the death of a loved one, encompassing the sadness, disruption, and reorientation that come with loss. **Grief** refers to the inner emotional response to the death, while **mourning** describes the outward expression of grief, often influenced by cultural, spiritual, and family traditions. There is no single “right” way to grieve; grief is shaped by context and individuality.

Common grief reactions include disbelief or numbness, anxiety over separation, sadness and yearning, or periods of anger and guilt. Over time, many people also experience bittersweet acceptance—a recognition that life has changed, but can continue with new meaning.

Types of Grief Reactions

Anticipatory Grief. This form of grief may occur when a death is expected, as in progressive illness. Families may find themselves preparing emotionally, saying important goodbyes, or resolving unfinished business. While anticipatory grief can sometimes help relatives cope, it does not necessarily lessen the grief that follows the death.

Normal Grief. Often called *common grief*, this is the natural process that begins soon after a loss. It can involve waves of sadness, disrupted sleep or appetite, crying, bursts of longing, or moments of disbelief. Over time—often within 6 months to 2 years—most bereaved individuals find these reactions become less intense and less frequent.

Prolonged Grief Disorder. In some cases, grief does not ease with time. The *DSM-5-TR* describes **Prolonged Grief Disorder** as a condition in which yearning, avoidance, or distress persist beyond cultural expectations and interfere with daily functioning (American Psychiatric Association, 2022). Risk factors include sudden or

violent death, limited support, younger age, and certain personality or coping styles.

Children and Grief



Children grieve differently than adults. Their ability to understand and express loss evolves with age and development. Young children may confuse death with sleep, rely on magical thinking, or fear abandonment. Older children and adolescents gradually understand death as final and universal but may struggle with anger, guilt, or identity disruption. Supporting grieving children involves honesty, reassurance, and inclusion. Using clear words like “death” and “died” helps prevent confusion. Encouraging children to participate in rituals, answer their questions with age-appropriate honesty, and

reassuring them about safety and care are all essential. Grief for children is not a single event but a process that may resurface at milestones such as birthdays, graduations, or other life transitions.

Treatment of Grief

Most individuals experiencing normal grief do not require formal treatment, though supportive counseling or groups can be helpful. For those with **Prolonged Grief Disorder**, evidence-based therapies such as **Complicated Grief Therapy (CGT)**

and **grief-focused Cognitive Behavioral Therapy (CBT)** have demonstrated effectiveness in reducing symptoms and improving daily functioning (Shear, 2025). These therapies combine loss-focused work, such as revisiting memories or avoided situations, with restoration-focused work, like reconnecting to life goals and relationships.

Medication may sometimes support treatment when depression or anxiety are also present, but psychotherapy remains the cornerstone of care. The goal is not to erase grief, but to help individuals carry their loss in a way that allows for healing, meaning-making, and continued connection to life.

Cultural Responses to Grief and Loss

Although grief is a universal human experience, the ways it is understood, expressed, and supported vary widely across cultures. Every community carries its own traditions, stories, and spiritual beliefs that shape how death is perceived and how mourning unfolds. Rituals may involve prayer, music, food, storytelling, or specific practices related to the body of the deceased. These customs are deeply meaningful, serving to honor the life of the loved one and to support those left behind.

At the personal level, feelings of grief—such as sadness, longing, or disbelief—are remarkably similar across cultures. What differs is the outward expression of these feelings. In some cultures, grief is shown through visible expressions such as wailing or public lament; in others, quiet reflection or restraint is considered the norm. Neither approach is more or less valid—they simply reflect different ways of giving shape to loss.

For professionals and caregivers, cultural sensitivity is essential. Respecting cultural rituals and family practices not only validates the grieving person's identity but also strengthens trust and support. Helpful questions to guide care include:

- What rituals are important for preparing for death, caring for the body, and honoring the deceased?

- What beliefs guide the family's understanding of what happens after death?
- How does the family define appropriate expressions of grief?
- What roles are expected of family members in mourning and decision-making?
- Are certain deaths, such as suicide or the death of a child, especially difficult or viewed differently within this culture?

Every culture has developed practices that help its members cope with the inevitability of loss. By learning and honoring these practices, caregivers can provide compassionate, culturally informed support that helps individuals and families navigate grief in a way that feels authentic and healing.

Table: Cultural Considerations in Grief and Mourning

Culture/Tradition	Common Rituals and Practices	Beliefs/Meaning-Making	Caregiver Considerations
Western/Christian	Funerals with prayers, hymns, burial or cremation; wakes or visitations.	Death often viewed as transition to eternal life; emphasis on resurrection/afterlife.	Respect for religious rituals (prayer, scripture, sacraments). Sensitivity to denominational differences.
 Jewish	Immediate burial, "Shiva" (7-day mourning at home), recitation of Kaddish, covering mirrors.	Emphasis on honoring the deceased and comforting the living. Afterlife beliefs vary.	Respect time-bound rituals; offer support without interrupting Shiva.
 Muslim	Body washed and wrapped; prayers	Death as return to God; emphasis on	Ensure modesty in handling the body;

Culture/Tradition	Common Rituals and Practices	Beliefs/Meaning-Making	Caregiver Considerations
 Hindu	at mosque; burial within 24 hours facing Mecca. Mourning often observed for 40 days.	accountability and eternal life.	accommodate prayer and community mourning customs.
	Cremation usually within 24 hours; rituals led by eldest son; ashes often scattered in sacred rivers.	Belief in reincarnation; rituals support the soul's journey.	Respect for fire rituals and fasting periods; awareness of caste/family roles in rituals.
Buddhist	Chanting, meditation, offerings; cremation common; monks may guide ceremonies.	Death seen as transition in cycle of rebirth; importance of detachment and mindfulness.	Quiet, respectful presence valued; allow space for chanting or incense rituals.
Indigenous Traditions	Ceremonies vary widely; storytelling, drumming, or smudging rituals often central.	Death integrated with cycles of nature and ancestral presence.	Seek guidance from community elders; avoid assumptions—rituals are highly diverse.
 Latino/Latin American	Novenas (9 days of prayer), Día de los Muertos, altars (ofrendas) with	Strong Catholic influences blended with indigenous traditions; ongoing connection with	Recognize importance of extended family; respect ongoing

Culture/Tradition	Common Rituals and Practices	Beliefs/Meaning-Making	Caregiver Considerations
	food and photos. Wakes with	deceased.	memorial practices.
African/Caribbean	singing, dancing, storytelling; funeral celebrations; ancestor veneration.	Belief in ongoing presence of ancestors; death not an end but a transition.	Support communal expressions of grief; respect rituals of honoring ancestors.
Asian (Chinese, Korean, Japanese)	Ancestral altars, incense, offerings; mourning clothing (white/black); Buddhist, Taoist, or Shinto influences.	Strong emphasis on filial piety; maintaining connection with ancestors.	Respect rituals at altars; inquire about family-specific traditions.

Note: These examples highlight common practices within broad cultural groups, but they are not universal. Families vary widely in their beliefs and traditions based on region, denomination, migration history, and personal choice. The most effective approach is to ask respectful, open-ended questions and allow individuals to define what feels authentic for them.



Case Study 1: Miriam's Jewish Family

Miriam was 68 when her husband, Aaron, died after a long battle with cancer. Within hours, her adult children arranged for a burial the next day, following Jewish tradition. Friends and extended family gathered quickly to sit **Shiva**—seven days of mourning observed in Miriam's home. Mirrors were covered, meals were brought in by the community, and daily prayers,

including the **Kaddish**, were recited.

For Miriam, Shiva provided a structured space to grieve openly while surrounded by loved ones. Visitors shared stories about Aaron, which comforted her even as she cried. At times, she wished for quiet, but she also knew that silence would leave her feeling alone. After Shiva ended, her grief did not vanish, but she carried forward the strength of her community's support.

Clinical note: Caregivers supporting Jewish families should respect time-bound practices like Shiva and avoid interrupting prayer rituals. Practical support—such as delivering meals—often conveys care more effectively than words alone.

Case Study 2: Amina's Muslim Community

Amina, a 42-year-old mother of three, lost her father unexpectedly. Within hours, her family gathered to perform the **ghusl** (ritual washing of the body) and wrap him in simple white cloth. He was buried the same day, facing Mecca, after prayers at the mosque. For Amina, these rituals reinforced the belief that her father had returned to God and that his soul's journey continued.

Mourning extended for forty days, with relatives and neighbors visiting daily to read from the Qur'an and offer condolences. Amina found comfort in the structure, but also felt the weight of expectation to remain strong in her faith. Her grief was expressed not only in

tears but in prayer and charity on behalf of her father's soul.

Clinical note: Providers working with Muslim families should be aware of the importance of modesty, rapid burial, and community-based mourning. Making space for prayer or quiet reflection can be as meaningful as direct counseling.

Case Study 3: Rajesh's Hindu Tradition

Rajesh was 29 when his mother, Meera, died after complications from diabetes.

Following Hindu custom, he, as the eldest son, carried the responsibility of leading her cremation rituals within 24 hours. Surrounded by family, he lit the funeral pyre, an act that symbolized releasing his mother's soul for its journey toward rebirth.

Later, Rajesh and his family gathered at the river to scatter her ashes, believing this sacred act helped her spirit move peacefully into the cycle of reincarnation. Extended mourning included fasting, wearing white, and observing a 13-day ritual period where prayers were recited daily. For Rajesh, grief was expressed through ritual duties, but he also found comfort in the spiritual belief that his mother's soul would return in another form.

Clinical note: For Hindu families, respecting the significance of cremation, fasting, and ritual purity is vital. Caregivers should also recognize the role of family hierarchy, particularly the responsibilities of the eldest son.

Summary:

- Miriam's story shows how Jewish mourning emphasizes **community presence and ritualized timeframes**.
- Amina's experience highlights how Muslim grief practices focus on **returning the soul to God and collective prayer**.
- Rajesh's journey illustrates how Hindu rituals blend **family responsibility with spiritual beliefs in reincarnation**.

Together, these cases demonstrate that while grief is universal, the **rituals, meanings, and expressions of mourning are deeply shaped by culture and faith**.

Chapter 4 End of life Issues

Facing the end of life brings profound challenges—not only for the person who is dying, but also for their family, caregivers, and community. It is a time that touches on practical decisions, emotional needs, spiritual concerns, and the deepest of human relationships. While every individual's journey is unique, thoughtful care and planning can ease suffering, preserve dignity, and help families find comfort and meaning in even the most difficult moments.

End-of-life issues encompass a wide range of concerns. Medical care decisions may involve choosing between aggressive treatment, palliative care, or hospice services. Emotional and psychological needs—such as anxiety, fear, sadness, or unresolved conflict—often become more prominent, requiring sensitive support. Practical matters, such as advance directives, estate planning, and daily caregiving, also come to the forefront. Families may struggle with anticipatory grief, questions of faith, or balancing the desire to extend life with the importance of quality of life.

Healthcare professionals play a central role in guiding individuals and families through this time. Compassionate communication, cultural sensitivity, and a willingness to engage in honest conversations are essential. Research consistently shows that people who engage in advance care planning and receive early palliative support experience less distress, better symptom management, and improved family outcomes (World Health Organization, 2025; National Hospice and Palliative Care Organization, 2024).

This chapter explores the key dimensions of end-of-life care, including palliative and hospice services, mental and emotional support, advance care planning, decision-making, dementia-related concerns, and the role of caregivers. It emphasizes not only the medical and practical aspects of care, but also the importance of preserving dignity, fostering connection, and supporting resilience for all involved.

A. Providing End-of-Life Care

End-of-life care is most effective when it honors the whole person, supports the family, and integrates medical, emotional, social, and spiritual needs. The primary goal is not only to relieve suffering, but also to preserve dignity, nurture connection, and guide patients and families through one of life's most profound transitions.

1. Core Principles

The foundation of good end-of-life care begins with what matters most to the person who is dying. This means exploring their values, hopes, and fears, as well as understanding how they define a good day. Care should anticipate potential problems, address them proactively, and include the entire spectrum of physical, emotional, social, and spiritual concerns. Families are seen as part of the unit of care, and interdisciplinary teamwork—from physicians and nurses to social workers, chaplains, and volunteers—ensures that no one is left to carry the weight of loss alone.

2. Communication and Planning

Conversations are central to end-of-life care. Clinicians are encouraged to speak openly and compassionately about prognosis, acknowledging uncertainty and helping families prepare for different scenarios. Advance care planning plays a key role, allowing patients to document their preferences through health care proxies, living wills, or medical orders such as POLST. These discussions clarify code status, treatment priorities, and important cultural or religious considerations, ensuring that care aligns with the person's values.

3. Symptom Management

Comfort is often the most pressing need at the end of life. Pain is managed with both medications and non-drug approaches, while breathlessness can be eased with low-dose opioids, fans, and breathing techniques. Delirium and agitation are addressed by identifying underlying causes and creating a calm environment. Nausea is treated according to its source, constipation is prevented proactively, and distressing symptoms such as anxiety, insomnia, and terminal secretions are managed with both medical and supportive measures. Fatigue and appetite changes are reframed, shifting the focus from prolonging life to ensuring comfort and quality in the time that

remains.

4. Psychosocial and Spiritual Support

End-of-life care is also about meaning. Therapists, chaplains, and caregivers help individuals reflect on their life story, create legacies, and engage in rituals that align with their cultural or spiritual background. Compassionate attention to guilt, anger, or unresolved relationships can foster healing. Asking families what traditions are important ensures that care is culturally sensitive and personally meaningful.

5. Caregiver Support

Caregivers often experience their own emotional and physical toll. They benefit from education about what to expect, guidance on medications, and reassurance that exhaustion and mixed emotions are normal. Providing respite and preparing caregivers for anticipatory grief helps them stay present and supported. When caregivers feel cared for, they are better able to care for their loved one.

6. Coordination Across Settings

As illness progresses, people may move between hospitals, clinics, nursing facilities, and home. Seamless transitions are vital, with clear communication between teams and documentation of goals and preferences. Hospice care becomes central when life expectancy is limited, while palliative care should be offered much earlier, even alongside disease-directed treatments. A reliable after-hours plan reduces crises and unnecessary hospital visits, giving families peace of mind.

7. Ethical and Legal Considerations

End-of-life decisions often involve difficult ethical questions. Informed consent, decision-making capacity, and the involvement of surrogates must be addressed with sensitivity. Non-beneficial treatments may need to be discontinued, and choices about devices such as defibrillators or dialysis should be aligned with patient goals. In rare cases of unrelenting suffering, **palliative sedation** may be considered. In regions where medical aid in dying is legal, clinicians can provide neutral information while continuing to offer unwavering support, regardless of the decision.

8. Medications, Nutrition, and Hydration

As the body weakens, some medications no longer provide benefit and can be safely discontinued. Alternate routes for essential medicines, such as sublingual or

transdermal, are often used when swallowing becomes difficult. Eating and drinking usually diminish in the final days, and the focus shifts to comfort rather than sustaining nutrition. Families may need reassurance that declining intake is a natural part of the dying process and not something that hastens death unnecessarily.

9. The Last Days to Hours

The final stage of life often brings recognizable changes, including reduced appetite, increased sleep, **altered breathing patterns**, and cool extremities. Families are prepared for these changes so they can understand what is happening and feel less alarmed. Gentle care—such as moistening the mouth, repositioning for comfort, and surrounding the person with familiar voices and music—provides dignity and peace. Loved ones are encouraged to sit close, speak words of connection, and offer permission to let go when the time is right.

10. After-Death Care and Bereavement Support

Immediately after death, families should be given space, privacy, and **respect for their cultural and spiritual practices**. Practical guidance on next steps, such as contacting a funeral home or disposing of medications, is provided clearly and gently. Just as importantly, families are connected to bereavement resources, including hospice follow-up, community groups, and counseling, so that support continues long after the patient's death.

11. Quality, Safety, and Equity

End-of-life care must also be safe and equitable. Clear medication instructions, **culturally appropriate care**, and attention to language and accessibility ensure that no one is excluded. Regularly checking in on caregiver stress and using symptom scales help guide care. Teams that learn from feedback and debrief together are best able to improve the quality of the care they provide.

At its heart, end-of-life care is about asking one central question: *Given who this person is, and what matters most to them, how can we help today?*

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

The end of life is as much an emotional and spiritual journey as it is a medical one. Alongside physical symptoms, people often face profound questions about meaning, identity, and relationships. Anxiety, sadness, and fear are common, but they do not affect everyone in the same way. Some may experience peace and acceptance, while others struggle with anger, regret, or despair. Sensitive, compassionate attention to these needs is an essential part of quality care.

For many, **anxiety** arises from uncertainty about the dying process, the fear of pain, or concern for loved ones who will remain. Providing clear information about what to expect, offering reassurance that symptoms will be managed, and encouraging open conversation can reduce much of this fear. Relaxation techniques, mindfulness practices, and supportive presence from trusted caregivers also help calm restlessness and worry.

Evelyn's Story

Evelyn was 73 when her lung cancer advanced to its final stages. Though she had accepted that she was nearing the end of life, she often felt waves of anxiety that kept her awake at night. "I'm not afraid of dying itself," she told her hospice nurse one afternoon, "I'm afraid of *how* it will happen. Will it hurt? Will my family be okay without me?"

Her nurse listened carefully and explained what Evelyn could expect as her illness progressed. She reassured her that pain medication would be available whenever she needed it, and that the hospice team would remain attentive to her comfort. Evelyn's eyes softened with relief. For the first time, she felt she could ask the questions that weighed most heavily on her heart.

Together, they invited Evelyn's daughter into the conversation. The nurse encouraged them to speak openly about worries for the future, which gave Evelyn comfort in knowing her family was prepared. Later that evening, her daughter guided her through a simple breathing exercise they had learned together, and Evelyn noticed her restlessness ease.

Over the following weeks, Evelyn added small practices to her daily routine: listening to gentle music, closing her eyes during guided meditations, and holding her granddaughter's hand as she drifted off to sleep. These moments reminded her that she was not alone.

Although the anxiety never disappeared entirely, Evelyn discovered that clear information, honest conversation, and supportive presence gave her courage. She no longer felt consumed by uncertainty but instead found peace in trusting that her needs would be met and her family would carry her love forward.

1. Margaret's Perspective (the Patient)

Margaret, 81, lay awake most nights replaying the same thought: *What if my pain gets too bad? What if I can't catch my breath?* Her doctor gently explained that her hospice team could anticipate changes and adjust medications quickly to keep her comfortable. This clear explanation helped Margaret relax. She began practicing guided imagery—imagining herself walking through her garden—whenever her chest tightened. “It’s not the end that scares me anymore,” she told her chaplain, “it’s the unknown. And now, it feels a little less unknown.”

2. John's Perspective (the Spouse)



When John's wife, Elena, became ill, his greatest anxiety was not for himself but for her. He worried constantly that she might be in pain but too weak to tell him. The hospice nurse noticed his tension and walked him through the signs of discomfort he might see, reassuring him that pain would be treated promptly. She encouraged John to sit quietly with Elena, holding her hand even when words

were few. That quiet presence eased both their fears, turning their evenings into times of calm rather than restlessness.

3. Sophia's Perspective (the Nurse)

Sophia had cared for many patients at the end of life, but she always remembered Mr. Ramirez. He was a dignified man in his late sixties who feared leaving his family unprepared. He asked her bluntly, "What will happen to me? What will they see?" Sophia answered openly, describing how his body might change and assuring him that medications could manage distress. She encouraged his family to talk about their memories together. She watched the tension lift from his face as he realized that his final gift to his children was not avoidance, but openness.

💡 Together, these stories show how anxiety about death is deeply human—whether it's fear of pain, of leaving loved ones behind, or of not knowing what lies

ahead. But they also reveal how honesty, presence, and small acts of care can replace fear with peace.

Depression and sadness may deepen as illness progresses, especially if a person feels a loss of independence, purpose, or connection. Emotional pain can be as profound as physical pain, and should be addressed with the same seriousness. Supportive counseling, opportunities to talk about regrets and accomplishments, and involvement in activities that bring comfort—such as listening to music, prayer, or simply sitting outdoors—can restore moments of joy. In some cases, antidepressant medications or brief courses of counseling therapies are appropriate, especially when hopelessness interferes with quality of life.

Story 1: Harold's Garden

Harold, a retired teacher, had always taken pride in tending his vegetable garden. When his Parkinson's disease advanced to the point that he could no longer stand steadily, he felt useless. "I can't even plant a tomato anymore," he said, staring out the window. His sadness deepened into long silences, and he began refusing visits from friends.

A hospice social worker encouraged Harold to talk about his years of teaching and the students he had mentored. She also arranged for volunteers to bring potted plants indoors, so Harold could care for them from his chair. Slowly, Harold found joy in nurturing those small plants and sharing stories about "lessons from the garden." Though his illness continued to progress, these moments gave him a renewed sense of purpose.

Story 2: Rosa's Music

Rosa, 69, was in the late stages of heart failure. As her fatigue worsened, she began saying she felt “like a burden” to her children. She admitted she no longer wanted to get out of bed and cried often. Her doctor recognized signs of clinical depression and started a low-dose antidepressant, while her chaplain arranged for visits from a local choir.

The first time the singers arrived, Rosa cried—but this time the tears were of recognition and relief. Hymns she had loved since childhood filled her living room, and her family gathered around, singing softly with her. The music became a weekly ritual, easing her sadness and helping her reconnect with her faith and loved ones.

Story 3: Samuel’s Porch

Samuel, 82, had always been independent. When his cancer left him reliant on others for basic needs, his sadness deepened into hopelessness. “What’s the point anymore?” he whispered to his nurse. She sat with him on the porch, where he could feel the sun on his face and hear the birds in the yard.

Over several weeks, Samuel’s nurse and counselor encouraged him to share both his regrets and his proudest accomplishments: building a family business, raising three children, and teaching his grandchildren how to fish. This life review gave Samuel a sense of completion. Though the sadness remained at times, the combination of supportive counseling, time outdoors, and medication for depression allowed him to find moments of calm and dignity in his final months.

✦ These stories show how depression in serious illness is not simply “feeling sad” but a profound emotional weight that deserves attention and care—through

counseling, medication when needed, and simple yet powerful acts of connection and meaning.

Reflection for Clinicians and Caregivers

The stories of Harold, Rosa, and Samuel remind us that **emotional suffering can be just as significant as physical pain** at the end of life. It often arises not only from illness itself, but from a perceived loss of independence, purpose, or connection. Left unaddressed, these feelings can deepen into depression and hopelessness, robbing patients of quality of life in their final months.

Several lessons stand out:

1. Validation and Presence Matter

Simply sitting with patients, listening without judgment, and acknowledging the depth of their sadness can reduce isolation. Patients need to know their feelings are real and worthy of care.

2. Life Review as Healing

Encouraging patients to reflect on their lives—both regrets and accomplishments—can foster meaning, closure, and a renewed sense of purpose. Structured reminiscence therapy, storytelling, or even informal conversations can be deeply therapeutic.

3. Restoring Joy through Simple Acts

Activities that engage the senses—gardening, music, prayer, or feeling the sun on one's face—help reconnect patients to what once brought comfort. These small, familiar rituals can restore dignity and calm.

4. Clinical Interventions Have a Place

When sadness deepens into clinical depression, brief courses of therapy or medications such as antidepressants may be necessary. Treating depression is not about “prolonging life at all costs” but about **restoring comfort and quality of life** in whatever time remains.

5. Support for Families

Caregivers often feel helpless when witnessing a loved one's sadness. Inviting them into rituals—like Rosa's family singing hymns—can transform grief into shared meaning and ease the emotional burden for everyone.

Ultimately, **attending to emotional pain is an act of compassion equal to managing physical symptoms**. Clinicians, chaplains, social workers, and families all play vital roles in creating an environment where patients can feel understood, valued, and comforted in their final journey.

Many people nearing the end of life also wrestle with **spiritual or existential distress**. Questions such as “Why me?”, “What happens after I die?”, or “Have I lived a meaningful life?” may surface. Chaplains, spiritual leaders, or culturally grounded rituals can provide guidance and comfort. Even for those who do not identify with a faith tradition, meaning-making exercises such as writing letters, recording stories, or reflecting on the impact they have had on others can provide a sense of legacy and peace.

Families, too, carry heavy emotional burdens. Anticipatory grief often brings waves of sadness even before the death occurs. Loved ones may experience guilt, anger, or conflict as they face the reality of saying goodbye. Including families in conversations, validating their emotions, and connecting them with support groups or counseling can prevent them from feeling isolated.

Ultimately, the goal of attending to mental and emotional needs at the end of life is not to erase sadness or fear but to **walk alongside individuals and families**, offering presence, reassurance, and tools for coping. By addressing the whole person—mind, body, and spirit—caregivers can help create an environment where peace, connection, and dignity are possible, even in life's final chapter.

C. End-of-Life: Planning Ahead

Planning for the end of life is an act of care for oneself and for loved ones. **It can ease uncertainty, prevent conflict,** and ensure that medical decisions reflect a

person's values and wishes. While these conversations can be difficult, they are often a source of comfort, giving individuals and families a sense of clarity and control during an unpredictable time.

Advance care planning involves talking about the kind of medical treatment a person would or would not want if they became too ill to speak for themselves. This may include decisions about resuscitation, life support, or artificial nutrition and hydration. Documenting these wishes in **advance** directives, living wills, or state-specific medical orders such as POLST or MOLST helps clinicians honor a person's voice when they can no longer express it directly (World Health Organization, 2025; National Hospice and Palliative Care Organization, 2024). Naming a health care proxy or decision-maker is equally important, ensuring that someone trusted can act on the person's behalf.

Planning also extends beyond medical decisions. Practical preparations such as organizing financial records, creating or updating a will, and arranging funeral or memorial preferences can reduce stress for surviving family members. **Some** individuals find great meaning in **leaving legacy projects**—letters, recordings, or keepsakes—that reflect their life and values. These acts provide reassurance that their memory and influence will continue.

There is also a deeply personal side to planning ahead. For some, it involves conversations about forgiveness, reconciliation, or passing on family stories. For others, it may mean choosing how and where they want to spend their final days—whether at home, in hospice, or in a hospital setting. These choices affirm autonomy and dignity, allowing individuals to shape the final chapter of their lives in ways that align with their deepest priorities.

For families, planning ahead provides a roadmap. Instead of being forced to make decisions in the midst of crisis, loved ones can focus on providing comfort and being present. For clinicians, clear planning helps guide care teams in offering treatment that is both compassionate and appropriate.

Ultimately, advance care planning is about creating space for honest conversations,

documenting choices, and honoring what matters most. When individuals and families engage in this process, they not only prepare for the future but also enrich the present, finding peace in the knowledge that their voices will be respected and their values upheld.

Story 1: Margaret's Advance Directive

Margaret had always been practical. In her late seventies, after watching a close friend struggle through months of aggressive treatment she didn't want, Margaret decided to have a frank conversation with her family. Sitting at her kitchen table with her daughter and son, she said, "I don't want you guessing what I'd want if I can't speak for myself. Let's put it in writing."

Together, they met with her doctor to review options for life-sustaining treatments, including resuscitation and ventilator use. Margaret shared her values: comfort, time with her grandchildren, and the ability to remain at home if possible. With the help of a social worker, she completed an advance directive and designated her daughter as her healthcare proxy.

Months later, when Margaret had a sudden decline, her children felt an enormous sense of relief knowing exactly what their mother wanted. Instead of making agonizing choices in the dark, they could focus on being present with her, honoring the clear wishes she had given them.

Story 2: Robert and Helen's Financial and Legal Planning

Robert and Helen, married for over fifty years, had lived through many ups and downs together. When Robert was diagnosed with Alzheimer's disease, Helen's first instinct was to handle everything quietly. But their eldest son encouraged them to talk openly about the future.

With the help of an elder law attorney, Robert and Helen organized their legal and financial affairs. They created a will, set up a durable power of attorney, and consolidated important documents—bank records, insurance policies, and

passwords—into a folder their children could access. Robert also wrote letters to his grandchildren, wanting them to remember his words even after he could no longer speak clearly.

When Robert's illness advanced and Helen became overwhelmed with caregiving, the family's planning made all the difference. Bills were paid on time, medical decisions were guided by Robert's documented wishes, and Helen could lean on her children for help without feeling she had failed. The foresight gave their family not only practical guidance but also peace of mind, turning a difficult season into one of unity and care.

D. Palliative Care and Hospice Care

When serious illness advances, two approaches—palliative care and hospice care—become essential in supporting both patients and families. Although they share many of the same values and practices, they differ in timing and scope. Understanding these differences helps individuals and caregivers make informed choices that align with personal goals and priorities.

Palliative care is specialized medical care focused on relief from the symptoms, pain, and stress of serious illness. It can be provided at any stage of disease and may be given alongside treatments aimed at curing or slowing the illness. The focus is on improving quality of life by addressing the whole person—physical comfort, emotional well-being, spiritual needs, and practical support. Palliative care teams often include physicians, nurses, social workers, chaplains, and other specialists who collaborate to create a comprehensive care plan. Research shows that integrating palliative care early not only improves comfort but also reduces hospitalizations and strengthens family coping (World Health Organization, 2025).



Hospice care, by contrast, is a specific form of palliative care designed for the final months of life, typically when a physician certifies that life expectancy is six months or less if the disease follows its usual course. Hospice shifts the focus from curative treatment to comfort, emphasizing dignity, symptom control, and emotional and spiritual support. Care is usually provided in the home, though hospice services are also available in dedicated facilities, nursing homes, and hospitals. Families play a central role, with hospice offering training, equipment, medications, and 24/7 support. After death, hospice also provides bereavement services for loved ones, often for up to a year.

Both palliative and hospice care share a common philosophy: that living well at the end of life is just as important as living long. They recognize that comfort, connection, and meaning matter deeply, and that patients and families deserve compassionate support tailored to their unique values and cultures. The decision to integrate palliative care early or transition to hospice when the time is right can relieve suffering, provide reassurance, and allow individuals to spend their final days in the way they most wish—whether at home, surrounded by family, or in a setting where their needs are fully met.

Eleanor's Story: Finding Comfort in Hospice

Eleanor was 84 when her heart failure worsened. She had been in and out of the hospital several times in just a few months, each stay leaving her weaker and more anxious. “I just want to be at home,” she whispered to her daughter, Maria, after yet another night of restless sleep in a noisy hospital ward.

Her doctor suggested hospice, explaining that the focus would shift from fixing her illness to keeping her comfortable, honoring her wishes, and supporting her family. At first, Maria felt guilty. Hospice sounded like “giving up.” But when the hospice nurse visited their home, she patiently explained that hospice meant more care, not less. Eleanor would receive medications to ease her breathlessness, a hospital bed to help her rest, and regular visits from nurses, aides, and even a chaplain if she wished.

As the weeks passed, Eleanor began to relax. The nurse adjusted her medication so she could sit in her favorite chair by the window without gasping for breath. A volunteer came each week to play the piano, filling the house with music Eleanor had loved since childhood. Maria, no longer overwhelmed by constant medical crises, found herself able to sit with her mother, hold her hand, and simply be present.

One evening, as the sun set and the piano music drifted through the house, Eleanor told Maria, “This feels like peace. I’m not afraid anymore.” When she passed away weeks later, it was in her own home, surrounded by love, not machines.

For Maria, hospice was not about surrender—it was about dignity, comfort, and the gift of meaningful time together.

E. Healthcare Decisions

Making healthcare decisions at the end of life is often one of the most challenging tasks for patients, families, and clinicians. These decisions touch on profound questions of autonomy, dignity, and quality of life. While medicine can extend life in

remarkable ways, not every intervention aligns with what matters most to the individual. **Thoughtful, compassionate decision-making helps ensure that care reflects personal values** rather than simply the possibilities of medical technology.

For patients who are able to speak for themselves, clear and ongoing conversations are vital. Some may prioritize comfort and time at home, while others wish to pursue every available treatment, even when chances of recovery are slim. Many people fall somewhere in between, hoping for more time while also wishing to avoid unnecessary suffering. Clinicians play a key role in helping patients understand likely outcomes, weigh benefits and burdens, and consider how treatments might affect their ability to live in accordance with their goals.

When patients are no longer able to make decisions, loved ones or legally appointed surrogates are asked to step in. This role can be both an honor and a heavy burden. Surrogates are encouraged to use the principle of **substituted judgment**—making choices based on what the patient would have wanted—rather than on what they themselves might choose. When a patient’s wishes are unknown, decisions are made using the **best interest standard**, focusing on what would most likely support the person’s dignity, comfort, and values.

Cultural and religious beliefs often shape end-of-life choices. For some families, stopping treatment may be seen as giving up, while for others, it is understood as a way of letting nature take its course. Sensitive, respectful dialogue ensures that these deeply held beliefs are honored. Providing language access, inviting faith leaders into discussions, and asking families directly about their perspectives helps build trust and prevents misunderstanding.

Ethical dilemmas sometimes arise around interventions such as resuscitation, ventilator support, feeding tubes, or dialysis. In these moments, it is essential for healthcare teams to provide honest information, create space for reflection, and support families as they navigate conflicting emotions. Ethics consultations or family meetings can be invaluable in helping all parties find common ground.

Ultimately, healthcare decisions at the end of life are about aligning care with values. By centering the patient's voice, honoring cultural and spiritual traditions, and providing families with support and guidance, these decisions can bring a sense of peace and integrity, even in the midst of loss.

Daniel's Story: Choosing What Matters Most

Daniel was 79 when his lung disease grew worse. For years, he had lived independently, driving to the park each morning and cooking meals for his grandchildren on weekends. But as his condition advanced, even walking across the room left him breathless. One winter morning, Daniel was rushed to the hospital after collapsing at home.

In the intensive care unit, doctors explained the options: he could be placed on a ventilator, which might extend his life, but he might never regain the strength to breathe on his own again. Without it, he might live for days or weeks, but with greater comfort and fewer invasive procedures.

Daniel's children gathered at his bedside, torn between wanting to "do everything" and honoring their father's values. They remembered how often he had said, "I don't want to be kept alive by machines. I just want time with you, in peace." With the guidance of a palliative care doctor, the family held an honest conversation about autonomy, dignity, and what quality of life meant to Daniel.

Together, they decided against intubation. Instead, his care team focused on easing his breathing with oxygen, medication, and supportive presence. Daniel was transferred home, where hospice helped manage his symptoms. His grandchildren visited daily, reading to him and holding his hand.

When Daniel passed away a week later, it was not in the chaos of a hospital room, but quietly, in his own bed, surrounded by family. His children later said the hardest part was making that decision—but it was also the greatest gift they could give: care that honored who their father was, not just what medicine could do.

F. Dementia

End-of-Life Care for People with Dementia

Dementia and End-of-Life Care

Dementia presents profound challenges for families and care teams, especially near the end of life. Unlike illnesses with a shorter trajectory, dementia often unfolds over years, eroding memory, communication, and independence bit by bit. Families describe this as a “long goodbye,” marked by grief over not only the eventual death but also the many smaller losses along the way.

The Challenge of Decision-Making

As dementia advances, individuals lose the ability to express their needs clearly. Families may be left interpreting behaviors: is refusal to eat a sign of no appetite, difficulty swallowing, or confusion? Is restlessness an expression of pain? These uncertainties make caregiving both demanding and emotionally heavy.

Emotional and spiritual care also requires creativity. Loved ones may no longer recognize family members or understand words of comfort, yet connection is still possible. Touch, music, familiar rituals, or simple presence often soothe when conversation no longer can.

Planning Ahead

Because dementia gradually diminishes decision-making capacity, **advance care planning** should begin as early as possible. When individuals are able, they can share preferences about treatments like feeding tubes, antibiotics, or hospitalizations. Such conversations reduce uncertainty and ensure that care aligns with values rather than guesses. Without them, families—like Silvia caring for her mother Alma—may be left to navigate life-prolonging choices without knowing what their loved one would have wanted.

Balancing Comfort and Treatment

Decisions often involve balancing quality of life against prolonging life. Medications may help earlier on, but their benefit diminishes in late-stage disease, when side effects can outweigh improvements. Families may be asked about interventions like

pacemakers or hospitalizations and must consider whether these would add comfort or only extend suffering. Hospice and palliative care teams offer guidance, helping families focus on comfort and dignity.

The Final Stages

Advanced dementia often brings complete dependence: immobility, difficulty swallowing, and loss of speech. Comfort becomes the central goal, with attention to positioning, mouth and skin care, and maintaining a soothing environment. Hospice providers are skilled in recognizing when someone is nearing the final days or weeks and can prepare families for what lies ahead.

Supporting Caregivers

Caring for someone with dementia is often described as a marathon. The emotional and physical demands are constant, and caregivers may experience exhaustion, depression, or guilt. Relief when death comes is not unusual, and it does not diminish love. Hospice and palliative services support families as well as patients, offering respite, counseling, and bereavement care.

Dementia Subtypes and End-of-Life Considerations

Alzheimer's disease. The most common dementia, Alzheimer's typically begins with memory loss and gradually affects language, reasoning, and personality. In late stages, individuals may lose the ability to walk, swallow, or recognize loved ones. Comfort care focuses on preventing infections, easing swallowing difficulties, and maintaining dignity in daily routines.

Frontotemporal dementia (FTD). Unlike Alzheimer's, FTD often begins with personality, behavior, or language changes rather than memory loss. Families may struggle with disinhibition, apathy, or compulsive behaviors. End-of-life care must balance safety and support for caregivers while addressing behavioral symptoms that may persist even late into the disease.

Lewy body dementia. Marked by fluctuating cognition, vivid hallucinations, sleep disturbances, and Parkinsonian motor symptoms, Lewy body dementia can be particularly distressing for families. Sensitivity to medications—especially antipsychotics—requires careful management. Comfort care often involves non-drug approaches, reassurance, and attention to both movement and perception-related

symptoms.

Parkinson's disease dementia. Many people with long-standing Parkinson's disease eventually develop dementia, characterized by slowed thinking, memory difficulties, and visual-spatial problems. End-of-life care must consider both motor limitations and cognitive decline, with attention to preventing falls, easing rigidity, and supporting communication as abilities wane.

Key reminder: Dementia may steal memory and recognition, but it does not erase a person's humanity. Even in the final stage, presence, love, and gentle care affirm the dignity of the individual and provide comfort for families walking this difficult path together.

G. Caregivers

Family Caregivers

Caring for an older family member is both a privilege and a challenge. Rarely can one person carry the responsibility alone; most families discover that caregiving works best when it becomes a shared effort. While a sibling who lives nearby may take on the majority of daily tasks, long-distance caregivers have an important role as well, offering emotional support, financial oversight, or occasional respite. When families approach caregiving as a team, everyone benefits—the older adult receives more consistent support, and no single caregiver becomes overwhelmed.

Talking About Caregiving Responsibilities

The first step toward effective teamwork is open communication. Families are often reluctant to discuss caregiving until a crisis arises, but planning ahead makes the journey smoother. Scheduling a family meeting—whether in person or virtually—creates space to clarify what kind of care is needed now and what may be required

in the future. Including the care recipient in these conversations, when possible, ensures that their preferences guide decisions.

Together, family members can decide who will serve as the **primary caregiver**, the point person who coordinates day-to-day responsibilities. Even if this role is not needed immediately, identifying one person in advance helps avoid confusion in emergencies. From there, tasks can be divided based on strengths, interests, and availability.

Considering Strengths and Limits

Every caregiver brings unique talents to the table. One sibling may excel at researching treatments and keeping relatives updated, while another is comfortable speaking with doctors and interpreting medical information. Someone else may be the family “numbers person,” capable of managing bills, bank accounts, and insurance forms, while another is naturally hands-on and skilled at home repairs. Dividing tasks based on these strengths allows everyone to contribute in meaningful ways.

Equally important is recognizing limits. Families should ask honest questions: How often can each person travel? How will caregiving affect work or family responsibilities? Is everyone prepared for the emotional shift that comes with caring for a parent who once cared for them? Being realistic about time, finances, and emotional capacity prevents burnout and reduces tension later. Responsibilities will evolve as needs change, so flexibility is key.

Supporting Local Caregivers from Afar

Often, the spouse or child who lives closest to the older adult becomes the default caregiver. Long-distance family members can still make a significant impact. Something as simple as regular phone calls or video chats can relieve loneliness for the care recipient and give the local caregiver a much-needed break. Long-distance

relatives can also research community services, arrange professional caregivers, or help explore assisted living or nursing home options.

Technology makes remote caregiving more practical than ever. Online banking allows long-distance caregivers to manage finances. Secure patient portals provide updates from healthcare providers. Group emails, shared calendars, or family chat threads keep everyone informed and involved, reducing misunderstandings and ensuring care feels coordinated.

Supporting a Parent Who is the Primary Caregiver



When the primary caregiver is also a spouse, the challenges can be particularly heavy. Many hesitate to ask for help, worrying that it reflects poorly on their dedication. Families should acknowledge the caregiver's devotion while also recognizing the physical and emotional toll caregiving can bring. Open conversations about fatigue, stress, and loneliness are vital.

Offering **respite care** is often one of the most meaningful forms of support. Even a short break—an afternoon off, a weekend of coverage, or an adult day services program—can renew a caregiver's strength. In-home aides can provide assistance

with daily tasks, allowing caregivers to preserve energy for the moments of connection that matter most. If a spouse is reluctant to accept outside help, suggesting a trial period may ease the transition.

Eventually, circumstances may require a move to assisted living or a nursing facility. Such transitions can be emotionally difficult, leaving the primary caregiver to adjust not only to the absence of their partner at home but also to a new way of expressing care. Family members can help by participating in the search for a facility, offering companionship during the adjustment period, and providing a listening ear. Sometimes, simply being present—whether in person or through regular check-ins—is the most powerful gift of all.

Maria's Story: Walking Beside Her Father

When Maria's father, Jorge, was diagnosed with advanced Parkinson's disease, she quietly stepped into the role of primary caregiver. At first, the tasks seemed simple—helping him organize his medications, driving him to appointments, making sure he ate well. But as the months passed, his needs grew. He began needing assistance with bathing, walking, and eventually even getting out of bed.

Maria often said caregiving felt like “a second full-time job.” She worked part-time as a teacher, and after her classes she would rush home to check on her father. Some days, exhaustion left her in tears, but she rarely let Jorge see her cry. Instead, she greeted him with a smile, read him the newspaper, and made sure he felt heard when he shared stories from his younger years.

What weighed on Maria most was not the physical labor but the emotional load. She worried about doing everything “right,” about whether he was comfortable, and about how long she could keep up the pace. One evening, after her father had a particularly difficult day, she confided in a friend, “I love him more than anything, but sometimes I feel like I'm drowning.”

With encouragement, Maria reached out to a local caregiver support group and discovered respite care services. For the first time in months, she allowed herself a weekend off while trained aides stayed with Jorge. That break gave her the strength to return renewed, with more patience and tenderness.

Jorge once told her quietly, “I know this isn’t easy, but having you here makes me feel safe.” Those words reminded Maria why she had chosen to be by his side. Caregiving was hard, but it was also an act of love—a final chapter they were writing together, filled with dignity, devotion, and connection.

H. Advanced Care Planning

Advance care planning is not just for older adults. At any age, a sudden illness or injury can leave a person unable to speak for themselves. Planning ahead helps ensure that medical care reflects one’s values and preferences, reduces uncertainty for families, and guides clinicians when time is short or decisions are complex. Advance care planning is a process, not a one-time form: it involves learning about possible choices, reflecting on what matters most, discussing wishes with loved ones and clinicians, and documenting preferences in legally recognized ways.



What is advance care planning?

Advance care planning (ACP) begins with understanding the kinds of decisions that might arise in a serious illness—both in emergencies and as conditions progress. People then share their preferences with family and health professionals and record them in advance directives that

take effect only if the person lacks decision-making capacity. Because priorities can change, ACP documents should be treated as living documents and revised when health, circumstances, or views evolve.

Research shows that people who complete ACP are more likely to receive care that aligns with their wishes and that families experience less decisional burden. Many clinicians now raise ACP routinely; Medicare covers ACP conversations during the Annual Wellness Visit and at other clinically appropriate times.

Decisions that often arise

Serious illness may prompt choices about life-sustaining treatments and comfort-focused care:

- **Cardiopulmonary resuscitation (CPR):** Forceful chest compressions, defibrillation, and medications may restore circulation in some people, especially those who are younger and otherwise healthy. In frail older adults or those with multiple illnesses, CPR is less likely to be successful and can cause injury such as rib fractures.
- **Ventilators (intubation/assisted breathing):** A breathing tube is placed through the mouth or, for longer support, via a tracheostomy. Sedation is commonly needed. Ventilation may be appropriate for a short, reversible problem; for advanced, progressive illness, the burdens may outweigh benefits.
- **Artificial nutrition and hydration:** Tube feeding or IV fluids can be helpful during short-term recovery. Near the end of life—especially in advanced dementia—artificial nutrition typically does not prolong life or improve comfort and can introduce complications. Assisted oral feeding focused on comfort is often preferred.
- **Comfort-focused care (palliative measures):** Relief of pain, breathlessness, anxiety, nausea, and other symptoms; minimizing unnecessary tests; and providing emotional and spiritual support. Comfort care can be provided in any setting and may be combined with disease-directed treatments or become the primary goal.

Getting started

Begin by talking with your clinician about how current conditions—or family health history—might shape future decisions. Clarify what quality of life means to you. Many people consider best-, worst-, and most-likely scenarios and ask: What outcomes would I accept? Which would I not? Your answers may differ at age 40 versus 85, or if living with a serious, progressive illness. Revisit decisions over time.

Questions to consider:

- If a stroke left me unable to speak or move, would I want CPR if my heart stopped?
- If a ventilator could bridge me through a reversible problem, would I choose it? What if ongoing ventilation were likely?
- If I were dying and in pain, would I want medications that might cause drowsiness to keep me comfortable?
- If I were permanently unconscious and developed pneumonia, would I want antibiotics and intubation?

For people living with cognitive disorders (e.g., Alzheimer's disease), early ACP helps ensure future decisions reflect their own values when they cannot speak for themselves.

Making your wishes known

Most states recognize two core ACP documents; you can complete one or both:

- **Living Will:** Describes the treatments you would or would not want in specific situations (for example, preferences about CPR, ventilation, tube feeding).
- **Durable Power of Attorney for Health Care (Health Care Proxy/Agent):** Names a trusted person to make decisions if you cannot. A proxy is invaluable when situations arise that no form can predict. Many people also name an alternate proxy.

Other medical orders and designations can supplement directives:

- **DNR (Do Not Resuscitate) and DNI (Do Not Intubate)** orders instruct clinicians in hospitals or facilities not to start CPR or mechanical ventilation. Some states

offer out-of-hospital DNR/DNI orders that EMS can honor at home.

- **POLST/MOLST** (Physician/Medical Orders for Life-Sustaining Treatment) translate a person's current goals into actionable medical orders (e.g., resuscitation status, hospitalization, artificial nutrition). These are designed for people with serious illness or frailty and are completed with a clinician.
- **Organ and tissue donation** preferences can be recorded on a driver's license, donor registry, and in ACP documents. If you want donation to proceed even if you have a DNR, note that your wish to donate takes precedence so teams can preserve organs appropriately.

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Devices and life-sustaining technology

Some people have implanted cardiac devices. Implantable cardioverter-defibrillators (ICDs) can be deactivated to prevent shocks that may be distressing near the end of life; this does not stop the heart, it only prevents shocks. Pacemakers typically do not need deactivation, because they support a slow rhythm rather than “keeping someone alive,” but preferences should be discussed and documented.

Choosing a health care proxy

Select someone who understands your values, can communicate clearly under stress, and is willing to advocate for you. Talk through your priorities—comfort, independence, time at home, religious or cultural practices—and give your proxy permission to use judgment if circumstances differ from what's written. Clear guidance helps your proxy act with confidence rather than guess.

Making it official

Use your state-specific forms (available from health departments, Area Agencies on Aging, or major health systems). Some states require witnesses or notarization. Provide copies to your proxy, alternate, clinicians, and local hospital; upload to patient portals when possible. Some states and health systems offer secure registries for rapid access in emergencies. If you spend significant time in more than one state, consider completing forms for each and keep copies in both locations.

After you complete your documents

Review and update your plans periodically—many use “the 5 Ds”: every Decade, with a new Diagnosis, a significant Decline, after a Death in the family, or Divorce/relationship change. When you revise, share the updates with your proxy, family, and clinicians and replace older versions in records and registries.

Talking about your wishes

Conversations are as important as forms. Share your values and “deal-breakers” with your proxy and loved ones; invite questions. Let your care team know what a good day looks like for you and what you fear most. Some people record a short video summarizing their wishes; while not legally binding, it can powerfully convey your voice and support your proxy in moments of uncertainty.

If there is no advance directive

If you become unable to decide and have no directive, state law designates a decision-maker (often spouse, adult children, or parents). Completing ACP ensures the right person is chosen and that they have clear guidance. Remember: ACP documents are used only when you cannot speak for yourself. You may never need them—but having a plan offers peace of mind for you and relief for those who love you.

I. Getting Your Affairs in Order

Planning for the future is one of the greatest gifts you can give to yourself and your loved ones. When legal, financial, and personal matters are organized, it eases stress during times of crisis and ensures that decisions reflect your wishes. Too often, families discover how difficult things can become when this



step is delayed.

Case Story: Ben and Shirley

For forty-seven years, Ben was the quiet backbone of his family's financial life. A retired engineer, he had always prided himself on keeping things in order. Bills were paid on time, taxes filed early, investments carefully balanced, and insurance policies neatly stored away in his desk drawer. Ben handled these responsibilities with confidence, and Shirley, his wife, trusted him completely. "Ben has always taken care of us," she often said, never doubting that everything was in good hands.

Then, in the space of a single afternoon, everything changed. Ben suffered a massive stroke while working in the garden. He survived, but the damage left him unable to walk or speak. In an instant, the man who had always been so capable and reliable was now vulnerable and dependent. Shirley, shaken by the fear of losing him, devoted her attention to his medical care. She visited the hospital daily, spoke with his doctors, and coordinated rehabilitation efforts. But within a week,

another reality settled over her: she had no idea how to manage the financial side of their lives.

The mortgage payment was due, but Shirley didn't know which bank held the loan or when the payment deadline was. Medical bills began arriving in the mail, and she wasn't sure whether they should be paid immediately or whether Medicare would cover them. She knew Ben had a life insurance policy, but she didn't know where it was filed or even which company had issued it. A pile of unopened mail stacked up on the kitchen counter, each envelope feeling like a reminder of how unprepared she was.

Shirley's feelings were conflicted—grief for her husband's condition, guilt for not knowing more about their financial life, and shame for feeling overwhelmed. She found herself lying awake at night worrying about money when all she wanted was to be present for Ben. Well-meaning friends encouraged her to “just take it one step at a time,” but the truth was that every step felt like stumbling in the dark.

Her son, Michael, flew in from another state to help. Together, they began piecing things together. They searched through Ben's desk and discovered the car title, property deed, and an insurance policy stuffed into a file marked “Miscellaneous.” They found online banking passwords scribbled on scraps of paper in a drawer. Slowly, they gained a clearer picture of Ben and Shirley's financial world, but the process was frustrating and exhausting. Every call to a bank, insurance company, or doctor's office required documentation—sometimes notarized—and without legal documents like a power of attorney already in place, Shirley often hit dead ends.

Months later, as Ben remained in rehabilitation, Shirley reflected on how much harder the situation had been than it needed to be. If she and Ben had taken the time to talk through their finances, to organize documents, and to name a trusted representative legally, she could have devoted her energy to being by his side rather than scrambling to untangle decades of paperwork.

Shirley eventually found her rhythm. With Michael's help, she set up automatic bill payments, consolidated accounts, and met with a lawyer to establish her own durable power of attorney and healthcare proxy. But she carried with her the stress of those first few months, when grief and uncertainty were magnified by disorganization.

Ben's story is not unique. Many families discover, too late, that the absence of preparation leaves loved ones vulnerable at the very moment they most need clarity and support. His case reminds us that **getting your affairs in order is not simply about money—it is about care, dignity, and peace of mind for the people we love most.**

Case Story: Louise

At 80 years old, Louise was fiercely independent. A retired school librarian, she lived alone in the same cozy bungalow where she had raised her children. She enjoyed tending her flower beds, meeting friends for weekly bridge games, and calling her son, David, who lived across the country, every Sunday afternoon. She valued her independence, but she was also practical. Years earlier, after watching a close friend struggle when her husband suddenly passed, Louise decided she would not leave her family guessing if something happened to her.

So, Louise made a plan. She gathered her important documents—her will, insurance policies, Medicare information, bank account numbers, and passwords—and placed them in a neatly labeled folder in her desk. She gave David a copy of the list and told him exactly where to find the originals. She also provided written permission for her doctors, bank, and insurance company to speak with David if needed. Together, they met with her lawyer, updated her advance directives, and talked openly about her preferences for care. “I don’t want you to worry or wonder,” she told her son. “If something happens, I want you to know what to do.”

Several years later, that preparation proved invaluable. One winter evening, Louise slipped on her kitchen floor and fractured her hip. A neighbor found her and called

an ambulance. Louise spent a week in the hospital and two months in a rehabilitation nursing home. Because she had already shared her plan, David knew exactly how to step in. From across the country, he was able to pay her bills, speak with Medicare about her claims, and coordinate with the rehab facility about her discharge.

For Louise, the relief was immense. She didn't have to worry about missed payments, lapses in insurance, or whether her son knew how to manage things. She could focus fully on her recovery, confident that her affairs were being handled. For David, the planning spared him the stress of searching through papers or making tough choices without guidance. Instead of feeling burdened, he felt grateful for his mother's foresight.

When Louise eventually returned home, she updated her files again, adding new contacts and reviewing her advance directives. She encouraged her friends to do the same. "It's not about expecting the worst," she would tell them. "It's about giving your family the gift of peace of mind."

Louise's story shows the opposite side of Ben's. While Ben's lack of preparation left Shirley overwhelmed, Louise's careful planning turned a potential crisis into a manageable challenge. The difference was not luck but foresight: she recognized that illness and emergencies are part of life and chose to prepare long before she needed to.

Her story reminds us that getting your affairs in order is not only about legal and financial documents—it is about protecting relationships, easing burdens, and ensuring that families can focus on care and connection rather than confusion and stress.

Ben's Story illustrates this. Ben had managed his family's finances for nearly five decades. When a sudden stroke left him unable to walk or speak, his wife

Shirley faced not only the heartbreak of his illness but also the overwhelming task of sorting out bills, insurance policies, and bank accounts she had never handled. The absence of preparation left her struggling at a time when she most needed to focus on Ben's care.

In contrast, **Louise's Story** shows how thoughtful planning can make all the difference. At 80, Louise lived independently until a fall left her with a broken hip and months of recovery. Because she had carefully organized her documents and shared them with her son, he was able to immediately step in, pay her bills, manage her insurance, and speak with her doctors—even from across the country. Louise's foresight spared her additional worry and allowed her family to support her with confidence.

What Counts as an “Important Paper”?

Important documents vary from family to family, but they usually include personal, financial, and legal records. Personal records include full legal name, Social Security number, date and place of birth, marital records, employment history, military service, education, and contact information for close friends, relatives, doctors, lawyers, and advisors. Financial records include sources of income, Social Security and Medicare information, insurance policies, bank accounts, investments, tax returns, debts, mortgages, property deeds, car titles, and credit card information. Legal documents—such as wills, trusts, living wills, and powers of attorney—are essential. Keeping an updated medication list and healthcare directives is also critical, particularly for those with chronic illnesses.

Steps to Get Organized



The first step is to gather all important papers in one safe and accessible location. This may be a file cabinet, a locked desk drawer, or a secure home safe. If originals are stored in a bank's safe deposit box, keep copies at home as well. Review documents annually to ensure they remain current.

Second, designate a trusted family member, friend, or attorney who knows where your documents are kept. You do not need to share every personal detail, but someone should be prepared to locate and use them in an emergency.

Third, grant permission in advance for healthcare providers, banks, and insurance companies to speak with your chosen representative. Without written authorization, even close family members may be blocked from accessing information.

Finally, talk with your doctor about your preferences for medical care at the end of life. Medicare and many private insurers cover advance care planning conversations, giving you the opportunity to think through your wishes with professional guidance.

Legal Documents for the Future

Several documents can ensure your choices are honored:

- **Wills and trusts** determine how money and property are distributed after death.
- **Living wills** specify what medical treatments you do or do not want if you cannot speak for yourself.
- **Durable powers of attorney for healthcare** allow you to name a trusted proxy to make decisions on your behalf.
- **Durable powers of attorney for finances** let you appoint someone to handle legal and financial matters even if you become incapacitated.
- **General powers of attorney** grant similar authority but end if you lose decision-making ability.

Because laws vary by state, it is wise to consult with an attorney or your local bar association. Free legal aid may also be available for older adults through state and community programs.

Special Considerations

- **Alzheimer's disease and other dementias:** Because decision-making capacity declines gradually, it is critical to complete legal and financial planning early.
- **Healthcare proxies:** Choose someone who understands your values and is willing to advocate for you under stress. Consider naming an alternate.
- **Organ donation:** Older adults can still register as donors; age does not automatically disqualify you. If donation is important to you, record it in your documents and on your driver's license.

Common Questions

Many people wonder where to start. The answer is: begin with conversations. Ask yourself what matters most. Talk with your family, your proxy, and your doctor. Share your wishes, write them down, and review them regularly—at least every few years or whenever there is a major change in your health or family situation.

Getting your affairs in order may feel overwhelming, but it is ultimately an act of love. It eases the burden on those you leave behind and gives you peace of

mind that your affairs—financial, legal, and personal—will be handled exactly as you intend.

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!