



Walk With Me

A companion for life's last journey



Walk With Me

The diagnosis of a life-limiting illness often unleashes a “rollercoaster” experience that results in emotional upheaval and feelings of uncertainty. Following the diagnosis, it is natural for patients, family members and friends to experience a wide range of emotions, to have many questions, and to wonder what to expect as the illness progresses. Although each person’s journey at the end of life is unique, there are common themes and occurrences.

Knowing what to expect allows patients and their loved ones to plan for and cope with changes as they occur. This booklet is intended to address the frequently asked questions and provide helpful information. Not everyone will experience all of the things described. Your Gilchrist Care team can provide specific information and support.

For questions, please call 844-774-0242.

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*"Only when you drink from the river of silence
shall you indeed sing*

*And when you have reached the mountain top,
then you shall begin to climb*

*And when the Earth shall claim your limbs,
then shall you truly dance."*

—Kahlil Gibran
The Prophet

The Hospice Philosophy

The hospice concept of care affirms life. The essence of this philosophy is well-stated by Dr. Cicely Saunders, the founder of modern-day hospice:

"You matter because you are you. You matter to the last moment of life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

In the face of terminal illness, when there is nothing more that can be done to cure the disease, there is still much that can and should be done for the patient and family. Gilchrist helps individuals and families face the physical, emotional, social, financial and spiritual aspects of their lives, and the patient's impending death, in an atmosphere of support and acceptance.

The hospice care team recognizes dying as a natural process and neither hastens nor postpones death. Our goal is to enhance the end of life by providing care that allows people to live life to the fullest, in peace and without pain, in the place that provides the most solace.

Signs of Approaching Death

As people move toward the final stage of life, their bodies begin the natural process of shutting down. This process will end when all of the physical systems have ceased to function. The individual will undergo a series of natural physical changes which are not medical emergencies and do not require invasive interventions.

Gilchrist's team will assist everyone involved in preparing for these changes, and will aid in providing comfort and support as the end of life approaches. Not every person will experience all of the symptoms described, nor will the symptoms occur in a particular order. Symptoms include the following:

Withdrawal and decreased socialization

As people begin the process of letting go, they may show decreased interest in current events, family news and even visitors. They may wish to see only a few specific people, and it is not unusual for them to withdraw from those they love. They may desire time alone. It is important to honor their wishes and to keep in mind that this is a natural part of the process of separating and letting go.

Fluid and food decrease

Patients may want little or no food or fluid and usually do not suffer from hunger or thirst. This decrease in intake is a natural process and means the body is conserving the energy which would be expended in processing food and fluid. Forcing food or drink or attempting to coax patients into eating or drinking may increase anxiety or cause discomfort. Small chips of ice, sorbet or frozen juice may be refreshing in the mouth. Tothettes, tiny sponges attached to sticks that are sometimes referred to as "lollipops," may help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also be soothing.

Sleeping

As death approaches, a person may spend more and more time sleeping and may appear to be uncommunicative or unresponsive. At times, they may be difficult to arouse. This is a natural change and is due, in part, to increasing fatigue and weakness related to the illness. Increased sleeping may also be related to changes in metabolism. Sitting quietly with your loved one and holding their hand may be comforting. Shaking, speaking loudly, or talking about them as if they cannot hear you is not helpful. Speak directly to the person as you normally would. Even though there may be no response, always assume you are heard.

Vision-like experiences

A person may speak to – or claim to have seen or spoken to – people who have already died. They may refer to places not presently accessible or visible to family and may make reference to “going home.” This does not indicate a hallucination or drug reaction, and the individual is probably not referring to any earthly home. Detachment from the physical world is beginning. Affirmation of the experience and reassurance that these experiences are natural is helpful. Contradicting, explaining away, or arguing about what the person claims to see or hear is not helpful. Most vision-like experiences bring comfort. The Gilchrist team can assist if distress or fear is noted.

*“Hold on to my hand
even when I have gone from you.”*

—Nancy Wood
Many Winters

Urine decrease

Urine output naturally decreases and can become very dark in color due to the decrease in circulation through the kidneys. Consult your Gilchrist nurse to determine whether there may be a need to insert or irrigate a catheter.

Incontinence

A loss of urine or bowel control may occur as muscles controlling those bodily functions begin to relax or weaken. Calm reassurance that this is natural can be very comforting. Discuss with your Gilchrist nurse how to keep the individual clean and comfortable, and what can be done to protect the bed.

Congestion

This symptom may be more distressing to family members than to patients. The sound of the congestion does not indicate that they are in pain or that they are short of breath. There may be rattling sounds coming from the chest and these sounds may become very loud. This change is due to the inability to cough up or swallow normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Wiping the mouth with a cool, moist cloth may bring comfort. Your Gilchrist nurse may also recommend medication to decrease the secretions.

Coolness and change in skin color

As death approaches, hands, arms, feet and legs may be increasingly cool to the touch. The underside of the body may become dark blue. This is referred to as mottling. This is a natural indication that the circulation of blood to the extremities is decreasing. Although the skin may feel cool to the touch, patients may not feel chilled and may be quite comfortable. If the patient complains of coldness, offering a blanket may increase physical comfort. For safety reasons, do not use an electric blanket or heating pad.

Breathing pattern changes

Irregular breathing, panting, and periods of not breathing may occur. Changes in breathing are very common and indicate a decrease in circulation to the internal organs. While these changes are not usually bothersome to the patient, they can be distressing to family members. Elevating the head may provide relief. It may also be helpful to hold the patient's hand and speak in a soft and soothing voice.

Disorientation

Patients may seem confused about the time, place and identity of people around them. Identify yourself by name before you speak rather than asking the patient to guess who you are. Speak softly and clearly.

Restlessness

It is common for patients to make restless or repetitive motions. The apparent restlessness is due, in part, to the decrease in oxygen circulation to the brain and to metabolism changes. It is not helpful to restrain such motions. Patients may be calmed if spoken to in a quiet, natural way. Lightly massaging the person's forehead, reading aloud, or playing soft music may be soothing. Medication may also be prescribed to relieve restlessness.

Knowing When Death Has Occurred

The death of a hospice patient is not an emergency; nothing needs to be done immediately. The signs of death include such things as no breathing, no heartbeat, no response, release of bladder and bowel, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. When death has occurred, family members may find it comforting to sit quietly, sing, pray, cry or wail. There is no one "right way" to be or behave at this time.

What To Do at Time of Death

Call Gilchrist Hospice Care to report the death. It is not necessary to contact the police or emergency services. Gilchrist's staff will need the person's name, a family member's name, and the telephone number. A hospice nurse is on-call 24 hours a day, seven days a week and will come to assist if needed or desired. Gilchrist staff will notify the physician of the death and will assist in contacting the funeral home. Family members may assist in preparing the body by bathing or dressing. The body does not have to be moved until the family is ready.

*"Because I can no longer ignore death,
I pay more attention to life."*

-Treya Killam Wilber

Anticipatory Grief

When we realize death is approaching, the awareness and acceptance of that fact is accompanied by periods of denial. We emotionally and physically prepare for, or anticipate, how the loss will affect us, both individually and as a family unit. It is not uncommon to also grieve for what has already been lost: altered relationships, lifestyles, and dreams for the future. Grief for these losses is experienced by both patients and family members.

While each of us will react differently, there are some aspects of anticipatory grief that are commonly experienced. Many people feel separation anxiety at the prospect of being left alone; a sense of helplessness because we are unable to make our loved ones well; and anger, which can be directed in many ways – at the disease, at the god of their faith, at the medical community, or even at the person who is dying. Sometimes we become so emotionally and physically exhausted by the process of coping and caregiving that we begin to wish for death to occur as a way of release from our suffering. Naturally, guilt is then commonly experienced in the midst of these complicated emotions.

The many emotions felt in anticipation of a death can be extremely difficult to navigate in the midst of all of the other overwhelming events that are taking place. Gilchrist's social workers and chaplains are available to talk through these feelings.

It is important to remember that feelings of grief are natural. In spite of its confusing and painful nature, anticipatory grief helps us to adjust to the reality of approaching death; address “unfinished business” (for example, past conflicts or unexpressed feelings); and focus some of our energy on facing the future.

Emotions of the Dying Person

Since each of us approaches death in our own way, the emotions experienced may vary considerably. There are, however, some feelings that are common as death approaches.

Denial

After receiving a terminal diagnosis, a person may experience denial – of the facts of the illness itself, of the implications of the illness, and of the notion of impending death. Denial allows a person to avoid the painful reality, and can give them time to come to terms with that reality in their own way and at their own pace. Sometimes a person will remain in denial until death occurs. This is often the case for younger individuals, in particular.

Anxiety and Anger

Death presents us with the unknown. When and if a person moves beyond denial to an acknowledgment of approaching death, they will often experience feelings of anxiety and uncertainty. These feelings may remain unchanged, or they may turn into anger. That anger may be due to numerous issues including a loss of control, a feeling of unfairness or of being cheated, and an awareness of possible pain and suffering. Sometimes the anger is not expressed openly, but is directed at loved ones, the medical community, the god of their faith, or themselves. Anger is a normal part of the response to approaching death, though it may not always be experienced.

Guilt

Guilt is another frequently experienced emotion as death approaches. People may look back on events in their lives and feel they acted contrary to their code of ethics, leading to feelings of regret or a fear of punishment. Sometimes feelings of guilt can develop as a result of presumed omissions, oversights or activities earlier in life.

Desire for Normalcy

In the midst of trying to come to terms with reality, a dying person sometimes feels the need to return life to normal. It is overwhelming to think that things will not be the way they have always been. There may be an effort to bargain with God or to create new activities or relationships to make life appear the way it was before illness struck. However long it lasts, this time can bring feelings of frustration, helplessness, or renewed anger. Despite the desire to create some sense of normalcy, the painful reality is still present.

Depression

Before acceptance of approaching death occurs, a person may experience depression. This is really the beginning of acceptance, since one must at least recognize reality in order to be depressed by it. This is a very natural part of the dying process. It is not necessarily a state that needs to be treated, since a person naturally moves through depression as a part of the acknowledgement that life cannot return to normal. For many people, it is not so much depression that is felt, as resignation.

Acceptance

Acceptance of death (and whatever that implies to an individual) is sometimes a quiet event that is not apparent to those around the dying person. While some people come to this sense of calmness and openness long before death actually occurs, often it is during the contemplative last days of life, when a person has turned inward, that acceptance and the accompanying feelings of peacefulness and serenity emerge.

Death is uniquely experienced by each individual, and the feelings and emotional states experienced can vary significantly. What is most consistently true, however, is that the dying person will benefit from having their feelings acknowledged and accepted by those around them.

Sharing the Spiritual Journey of Dying and Death

"Why did this happen to me?"

"What hope do I still have?"

"What will happen to me after death?"

"Is there a purpose to what is happening to me?"

"Has my life counted for anything?"

"How can I find peace with the life I have lived?"

These questions and others are quite normal and are part of the spiritual struggle that often comes with news of a terminal illness, limited life expectancy and approaching death. Associated emotions of fear, guilt, remorse, uncertainty, anger and bewilderment are also a natural part of this spiritual journey. An individual may not experience all of these emotions. The Gilchrist chaplain is available to assist in dealing with thoughts, questions and concerns about spiritual issues.

Initially, patients and family members may voice denial because of the shock associated with the diagnosis. They may express belief in miraculous healing or use religious language to express denial. If they adhere to no particular faith, people may simply voice disbelief in the terminal nature of the diagnosis.

As disease-related changes become evident, it is common for people to become fearful or angry. Patients may voice feelings of anger at family members and at the god of their faith. The expression of anger by patients may most often be viewed as a cry for support. They may follow that anger by bargaining with the god of their faith in the hope of healing or avoiding approaching death. While denial and anger may result in withdrawal, bargaining can produce a sudden warmth and engagement and increased religious practice.

Following this period of bargaining, and usually just as suddenly, a person may withdraw and become introspective. This is natural behavior. The internal spiritual work that the patient or family member is doing can lead to acceptance of the diagnosis and approaching death. This internal work will allow for a focus on spiritual closure in a patient's life.

There are many ways to provide aid and support during this period. For example, you can:

- Be available as a nonjudgmental presence during both conversations and periods of silence;
- Allow your loved one to initiate the ways in which they need support; and
- Offer to contact the Gilchrist chaplain or the individual's own clergy.

Individual clergy can offer the comfort of religious support while Gilchrist's chaplain can provide spiritual support and address related questions. During this period it is extremely important to respect the individual's religious and spiritual preferences. Also be careful not to impose beliefs upon them.

Remember, the best gift family members and friends can offer their loved one is comforting companionship on the spiritual journey.

"While we are apart...we will simply hold hands across time, smile into each other's minds and bask in the warmth of our love."

-Hugh and Gayle Prather

Conversation Needs and Preferences

Every person is truly unique – absolutely one of a kind – in so many ways. The way we look. The way we think and feel. The way we behave. The list goes on and on. It is little surprise, then, that every person has different needs and preferences when it comes to conversation at the end of life.

Some people at the end of life want to talk about their thoughts and feelings. For instance, they may want to discuss with family members plans for after they are gone. Conversely, others may prefer to focus not on conversation but on living until they are gone. The range of needs and preferences is as varied as the unique individuals who have them.

We can best care for and serve them by trying to understand, respect, and meet their needs and preferences.

Saying Goodbye and Giving Permission

People with life-limiting illnesses and their family members sometimes have difficulty figuring out when and how to say goodbye. They fear that such a conversation may upset or somehow damage loved ones. Family members may worry that they are saying goodbye too soon or that in hearing the goodbyes, their loved one may lose hope. People are also afraid that saying goodbye might be interpreted as meaning they are eager for death to occur.

Saying goodbye and giving permission to let go can be important steps to take when a loved one is ready. It can be very difficult to give your loved one permission to let go. A person who is dying can try to hold on – even when this may prolong discomfort – until family members and friends have reassured the person that those who will be left behind will be alright. There are many ways to give permission and say

goodbye. Holding hands with your loved one or, if it will not cause them discomfort, laying next to them can be soothing.

Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden or apologized for. Tears are simply a physical expression of love. Your tears may, in fact, give others permission to release their own pent-up emotions. Tears can sometimes bring a sense of release and relief.

When saying goodbye and giving permission, you may wish to share treasured memories or recount favorite stories. Giving permission to let go and saying goodbye may be as simple as saying, “I know you have to go, and it’s okay.”

It can never be too early to say goodbye. The course of illness is not always predictable. Following a death, we may grieve missed opportunities. What are the things you might regret not having said? What are the things that are important for your loved one to know? You may find it easier to put your thoughts in writing and then use these words to guide your conversation.

Bear in mind that a lifetime of communication patterns may not change as the end of life approaches. If you wish, the Gilchrist chaplain or social worker can assist you with the process of giving permission and saying goodbye. Be gentle with yourself and always remember, the gift of your presence and your love is beyond measure.

Book Resources

Albom, Mitch. *Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson*. Warner: 2000.

Boss, Pauline. *Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief*. Jossey-Bass: 2011.

Byock, Ira. *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life*. Avery: 2012.

Callanan, Maggie and Patricia Kelley. *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. Simon & Shuster: 2012.

Duvall, Kirby J. *Healing Your Grieving Heart When Someone You Care about has Alzheimer's: 100 Practical Ideas for Families, Friends, and Caregivers*. Companion Press: 2011.

Gawande, Atul. *Being Mortal: Medicine and What Matters in the End*. Metropolitan Books: 2014.

Kalanthi, Paul and Abraham Verghese. *When Breath Becomes Air*. Random House: 2016.

Miller, James E. *The Caregiver's Book: Caring for a Loved One, Caring for Yourself*. Augsburg Fortress Publishing: 2008.

Pausch, Randy and Jeffrey Zaslow. *The Last Lecture*. Hachette Books: 2008.

Shefter, Steven. *Preparing to Part: Love, Loss, and Living*. Book Baby: 2021.

Stilwell, Dawn. *Breathe: An Anticipatory Grief Journal*. The Publishing Shop: 2022.

Viorst, Judith. *Necessary Losses: The Loves, Illusions, Dependencies, and Impossible Expectations That All of Us Have to Give Up in Order to Grow*. Fireside Publishers: 2010.

Wolfelt, Alan. *Expected Loss: Coping with Anticipatory Grief (Words of Hope and Healing)*. Companion Press: 2021.

Web Resources

Alzheimer's Association: www.alz.org

American Association of Retired Persons (AARP): www.aarp.org

HopeWell Cancer Support: www.hopewellcancersupport.org

National Alliance for Children's Grief: nacg.org

What's Your Grief? (Grief support): www.whatsyourgrief.com

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Unable are the loved to die.
For love is immortality.

—*Emily Dickinson*

Gilchrist Hospice, in collaboration with Inova

Hospice Care

At Gilchrist Hospice, in collaboration with Inova, we offer seamless compassionate care that focuses on pain and symptom management, emotional and spiritual support, and guidance for patients and their families every step of the way.

For more information on hospice care, call **844-774-0242**.

