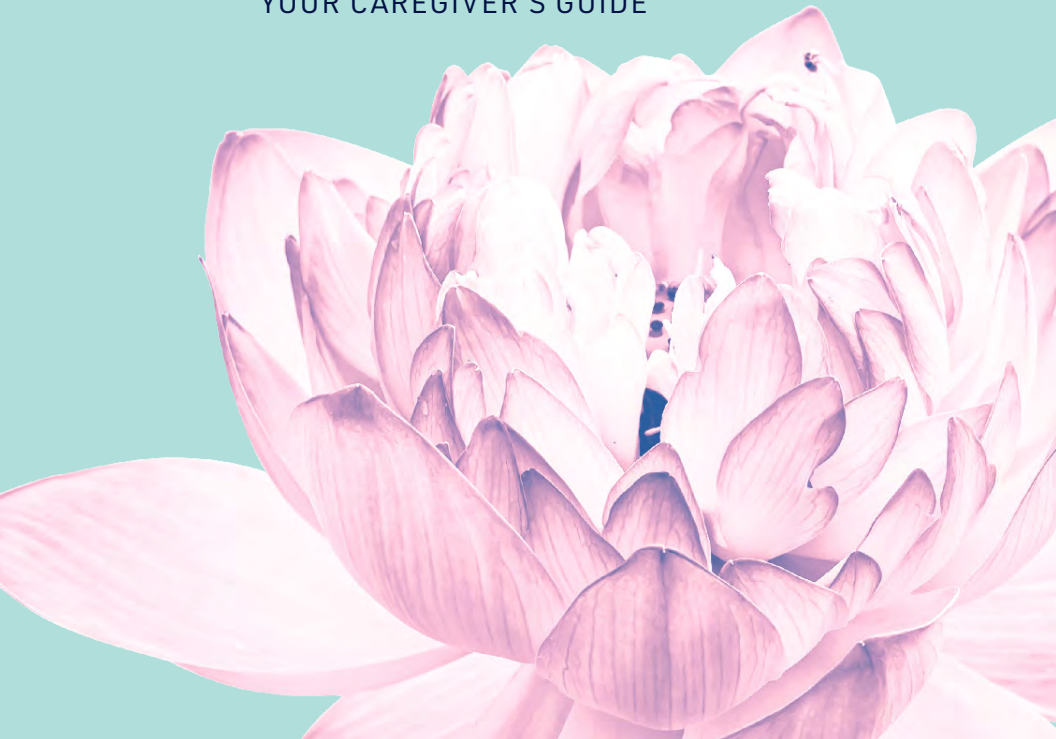




When *the Time* is Near

YOUR CAREGIVER'S GUIDE



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We dedicate this book to all the patients we have been honored to serve and who's families have entrusted us with their care.

KINDFUL HEALTH

Introduction

Although dying is a natural part of life, most of us do not know how to care for someone at the end of life. It is normal for a caregiver to have a wide range of feelings or to be unsure of what to do.

You may feel uncertain, lost or overwhelmed with all the decisions you face and you may not know what to expect. This booklet will help you understand what to expect when caring for someone **in the final days of life.**

Family and friends can all play an important role. However, **you as the caregiver play a vital role.** A caregiver is a guide who listens, feels, empathizes, and gently directs care during a time when it is most needed. At the end of life, it is not so much what you say or do. Just being there can provide a sense of support and comfort.

Each person's death is unique. No one can anticipate what it will be like or when it will happen. We hope this booklet helps to guide the way.

Our goal is to support you by showing you how to respect and honor your loved one by providing you, the caregiver, with a guide to giving high quality comfort care.

Staying positive doesn't mean
you have to be happy all the time.
It means that even on hard days
you know that there are
better ones coming.

ANONYMOUS

Thoughts at the End of Life

Source: Dr. William Lamers

Although death is a topic that many of us find uncomfortable to discuss or even contemplate, some people are curious about what the dying process entails. What are the signs that death is approaching? Does it always happen the same way, or is it different for each of us? Will there be noises that could frighten my loved ones? Is there information to help my family and loved ones know what's happening and that death is near?

Dr. William Lamers, a medical consultant with the Hospice Foundation of America, has written extensively about the signs of approaching death. He begins the list by noting this is a general picture of the dying process, and there will be differences from person to person. Below is a description of the most common physical signs of a body's last moments:

- Withdrawal
- Decreased Appetite
- Changes in Toileting
- Changes in Breathing
- Changes in Body Temperature
- Confusion
- Restlessness and Anxiety

Typically, as death draws near a person goes into a coma that may last from minutes to days before death occurs. Dr Lamers goes on to say that "a person in a coma may still hear what is said even when he or she no longer seems to respond to verbal stimuli. Those who are nearby should always act as if the person is aware of what is going on and is able to hear and understand." As hearing is the last sense to leave, anyone in the room at this time may want to tell favorite stories, sing or play music, pray, or say anything that you don't want left unsaid.

Withdrawal

As death draws near, a person may seem unresponsive or withdrawn. This may be the beginning of “letting go”. Just as you are losing someone you love, the dying person is in the process of losing everyone and everything they love. It is only natural to be withdrawn.

If the person is allowed to express their sorrow, the stage of final acceptance will be easier. If the person is unresponsive, remember hearing remains until the end.

How to Help

- Say your name when you speak. Tell the person what you are going to do before you do it. For example: “Mom, this is Dana. I’m going to raise your bed now.”
- Speak to your loved one in your normal tone of voice.
- Do not say anything you would not say if they were awake... they can still hear you.
- Plan tasks and visits for the times of day when the person seems most alert.
- Hold their hand and say whatever you need to say that will help the person to “let go”.

I’ve learned that people
will forget what you said,
people will forget what you did,
but they will never forget how
you made them feel.

MAYA ANGELOU

Decreased Appetite

Refusing Foods and Fluids

As death approaches, the person may want less and less food and fluids, eventually refusing them altogether. The body is conserving energy that would be used to digest the food for other functions.

Seeing a loved one refuse to eat can be very hard for families to accept but often nothing tastes good to the person. Don't force foods or fluids. Weight loss is normal and it does not mean that the person is hungry or being starved.

How to Help

- Look for signs the person does not want to eat. This might include coughing, biting the spoon, clamping teeth, turning head or spitting food out. Do not force food or drink.
- Liquids may be better than solid foods and some people find thicker liquids easier to swallow.
- There may be times when the smell or a small taste of familiar food is comforting. Make sure to check with the nurse to be sure it is safe if the person asks for food or drink that is unusual.
- Ice chips or crushed up frozen juice are often refreshing in the mouth.
- A person near death may appear thirsty but can't drink water. Frequent mouth care can help. You can use Chapstick or lip balm to soothe dry lips. If oxygen is being used, use a non-petroleum based product.

Changes in Toileting

Decreased Urine Output or Loss of Bladder Control (Incontinence)

Incontinence occurs as fluid intake decreases and as circulation through the kidneys decreases. The urine may be darker than normal. It may also be cloudy or have a strong smell which is normal for this stage. The person may lose bladder and or bowel control as muscles in that area begin to relax. These changes can be embarrassing so ensure that the person is kept clean, dry and comfortable to protect their dignity. If your loved one has a bladder catheter in place, you will notice that the amount of urine will decrease as death draws near.

Constipation

Bowel movements that are hard, painful or irregular are also common. Often this is the effect of pain medicine and reduced fluid intake. This can cause major discomfort at the end of life so it is important that you update the nurse of any changes in bowel movements to ensure appropriate interventions to relieve constipation are maintained.

How to Help

- Check your loved one often to ensure they are clean and dry. Respect their dignity by providing privacy during personal care.
- Bed pads and disposable briefs may help and the nurse or aide can show you how to change these.
- Constant moisture can cause the skin to break down so in addition to keeping your loved one dry, your Kindful nurse may suggest certain creams to protect the skin from breakdown and discomfort.
- To prevent incontinence, the nurse may place a thin tube (catheter) into the bladder. This will prevent “accidents” and keep the skin dry. There may be some discomfort as the catheter is inserted but afterwards the person will barely notice.
- Inform the nurse if your loved one has less than 3 stools/week or has trouble passing stools. Care teams will give laxatives or stool softeners with pain medicine to help.
- Only give treatments that are approved by your Kindful nurse.

Changes in Breathing

Periods of Interrupted Breathing (Apnea)

It is not uncommon for a person to stop breathing for 15-45 seconds. This is called apnea. There may be periods of rapid respiration alternating with periods of shallow or absent breathing. This is called "Cheynes-Stokes" respiration. It is very common and indicates a decrease in circulation to the internal organs and build-up in the body waste products. This is not uncomfortable for the person and is a normal response as the body weakens.

Rattling Breathing or Wet Gurgling

Secretions in the throat or the relaxing of the throat muscles can lead to noisy breathing, sometimes called the "death rattle". Repositioning the person, limiting fluid intake, or using drugs to dry secretions can minimize the noise. Such treatment is aimed at the comfort of the family or caregivers because noisy breathing occurs at a time when the dying person is unaware. The death rattle does not cause discomfort for the dying person. This breathing can continue for hours and often means that death will occur in hours or days.

How to Help

- Inform your Kindful care team if there are changes in breathing. They will determine if oxygen might provide comfort.
- Elevating the head of the bed 30-45 degrees may help bring comfort if saliva gathers in the throat. You may also gently turn the person on their side to help drain it.
- The Kindful nurse may request medicine to help dry the saliva. They may also request medicine such as morphine to provide comfort.
- Often the person may breathe with their mouth open. This combined with less fluid intake can make the mouth very dry so it is important to provide routine mouth care. Moisten the mouth and lips often with swabs and lip balm.

Changes in Body Temperature

Cool Skin

As the body shuts down and the brain starts to lose control of body temperature, circulation diminishes to the arms and the legs and they may feel very cool to the touch. The pulse will become harder to feel. The skin color may change. You may notice the underside of the body becoming much darker in color; knees, ankles and elbows may look blotchy; lips and the skin under the fingernails may turn bluish. Even though the skin is cold to the touch, most dying persons aren't aware of feeling cold.

High Temperature

It is also not unusual for a dying person to have an elevated temperature even as high as 104 degrees as they draw closer to death.

How to Help

- Use light clothing and make sure there is fresh, circulating air.
- A change of position every two hours protects the skin and promotes comfort.
- The person may sweat a lot as the fever drops so change their clothing and sheets as needed to provide comfort.
- Give pain medications such as Tylenol. These are available in pill, suppository and gel form.
- Apply cool moist cloths to the forehead or back of the neck.
- Gentle massage may help increase blood flow but check with your Kindful nurse first because some people may have skin that is too sensitive for massage.

To care for those who once cared for us is one of the highest honors.

TIA WALKER

Confusion

The person may be confused about time, place or who is present in the room. Some of this may be due to changes in metabolism, changes in vision or increased sleeping. They may not recognize family or friends. They may see things no one else can see or talk to people who are not there.

Sometimes our loved ones may let us know that they are ready for death by talking about travel and say things such as, "I want to get my keys; Where's the bus/train?" or "I need to find my suitcase." This is known as "symbolic language" and they could be trying to tell us goodbye. Some people think the medicine is causing the confusion but this is a normal part of the dying process.

How to Help

- Limit visitors to help lessen confusion.
- Have each visitor identify himself. Do not ask, "Do you know who I am?" Tell them who you are "Hi Dad, this is Russ".
- Speak softly, clearly and truthfully when you need to communicate something important.
- Try to orient your loved one to reality with familiar objects and pictures of family, friends, etc.
- Tell them that you are there to take care of them and they are safe.
- Inform your Kindful care team of confusion as they may adjust medicine.
- Let the person describe what they are seeing, feeling or hearing. Do not argue with them as these things are very real to the person.
- Listen carefully as there may be meaningful messages being shared in symbolic language.
- Consider keeping a journal of the things said. This may be a source of comfort to share with other loved ones.

Restlessness

Restlessness sometimes indicates something is still unresolved and unfinished and they can't let go. The care team may be able to help you identify what is happening and help discover a way for your loved one to find release from tension or fear. Sometimes restlessness and anxiety can be a sign of discomfort or pain. Emotional or spiritual concerns may also cause anxiety. A dying person will try to hold on, even though it brings prolonged discomfort, in order to make sure those who are left behind will be alright.

One of the greatest gifts you can give is your ability to release your loved one from concern and give the assurance it's alright to let go whenever he/she is ready.

How to Help

- Inform the care team that your loved one is restless or anxious. They will check for pain or discomfort and ensure the appropriate medications are given as prescribed by the doctor.
- Ask your Kindful social worker or chaplain to discuss spiritual or emotional matters with your loved one.
- Try to help the person **Resolve** issues. Offer to take over unfinished tasks or ask others to help complete tasks to help **Relieve** anxiety.
- Bring comfort in the simple form of touch. Hold hands, stroke hair, etc.
- Keep the person's space quiet by turning off radios, TVs or phones. It may also help to limit visitors.
- Speak to the person in a slow and soothing voice. Give comfort by calmly reading something the person enjoys or play soft music.
- Help your loved one **Remember** the beauty of their life by sharing memories of special holidays, good times or favorite places.

Changes in Energy

Dying loved ones may show sudden, short bursts of energy. They may become surprisingly alert and clear. They may ask to eat when they haven't eaten for days or they may want to get up to visit when they haven't been out of bed for weeks.

Bursts of energy don't always happen in such a dramatic way. They may be more subtle such as the person may awaken more often. It is understandable how this might give false hope that the person is getting better. Sadly, this is not likely and it just may be that the person is building up strength for their last full-body moments in this life.

How to Help

- Help educate other family members about this process. Many times family members see this energy as a sign of improvement and delay plans to spend time with their loved one. This often prevents them from saying their final goodbyes.
- Use this time to share memories and say goodbye. **Remember** the beauty of their life.
- Be together. Be present. Hold hands.
- Enjoy this special time for what it is.

To love a person is to
see all of their magic,
and to remind them of it
when they have forgotten.

ANONYMOUS

The Importance of Goodbye

When and how to say goodbye is a personal choice. There is no right or wrong way to do it but many find that once it is done, it can be a gift. More often than not, those that don't take the opportunity to say goodbye regret it later.

Family and friends may not be sure whether to say goodbye and some worry that it might cause death sooner. Others may want to say goodbye, but do not know what to say. We are not here to hasten death nor prolong life.

How to Help

This time with your loved one is precious so take time while the person is awake to say what you need them to hear. If it is heart-felt then you can not say the "wrong" thing.

You Might Start With

- ▶ "What I love most about you is..."
- ▶ "What I will always remember is..."
- ▶ "What I will miss most about you is..."
- ▶ "What I learned from you..."
- ▶ "What I hold close to my heart..."
- The most important gift you can give your loved one at this time is **Resolution**. Take this time to say, "I'm sorry", to forgive or to let go of past hurts or anger. To resolve is to provide relief for your loved one.
- You may use this time to give thanks.
- Don't be afraid to hold hands. We all need human touch... especially during this time.
- Don't be afraid to shed tears. It is a normal part of saying goodbye and can be a healthy way to show how much you love the person.

An Imprecise Timeline

Determining the timeline for death is an imprecise science but the following list of signs may mean that death will take place soon. This is simply a guide. Some people may not show all of these signs and they may present themselves at different times.



1 to 3 Months


- Sleeps more
- Talks or engages less
- Eats and drinks less
- Withdraws from people and activities

1 to 2 Weeks

- Physical Changes:
 - ▶ Does not eat, drinks little
 - ▶ Body temperature changes
 - ▶ Breathing weak/uneven
 - ▶ Blood pressure drops
 - ▶ Skin color changes
 - ▶ Pulse changes
- Confused about place, time or people
- Talks to others who are not in the room
- Uses symbolic language ("I can't find my keys.")

My caregiver mantra
is to remember
The only control you have
is over the changes you
choose to make.

NANCY L. KRISEMAN



Days to Hours

- Sleeps most of the time
- Is restless or anxious
- Burst of energy
- More changes in skin color
- Weak pulse
- Has a hard time swallowing
- Bigger drop in blood pressure
- More changes in breathing (long pauses between breaths)
- Rattling sounds while breathing
- Less urine or no urine
- Eyelids do not close all the way

Minutes

- Short breaths with longer pauses
- Mouth open
- Does not respond

How to Help

Although as a caregiver, your main focus is your dying loved one, it is also falls to you to help your family and friends through the dying process. By educating them you can help **Relieve** some of the uncertainty and anxiety that is always present at the end of life.

Time of Death

We use science, technology and experience to do our best to predict when death will take place. Despite this, no one can tell when death will occur. Some people die when others are present yet some take their last breath when they are alone. It is important to talk to family, caregivers and friends about what to do if they are present at the time of death.

When a person dies there will be no heartbeat or breathing. There will be no response to voice or touch. The eyes may be partly open and the pupils will not respond to light. The jaw will relax and the mouth will open. Also, there may be loss of bowel and bladder control.

Even if death was expected it can still come as a shock. **At the time of death, nothing needs to be done right away other than calling hospice. There is no need to call 911 or the police.**

Death
ends a life,
not a
relationship.

MITCH ALBOM
TUESDAYS WITH MORRIE

How to Help

- First, contact Kindful so the care team can provide all the necessary services. A nurse will visit and other care team members may help as needed.
- You may want to call a friend or family member to be with you at this time.
- When the Kindful nurse or care team member visits, they may:
 - ▶ Confirm death
 - ▶ Remove any tubes
 - ▶ Contact the doctor and the rest of the Kindful team
 - ▶ Give guidance on what should be done with unused medicine
 - ▶ Arrange to have equipment removed
 - ▶ Call the funeral home
 - ▶ Offer to bathe and prepare the body
 - ▶ Provide support
- Some families prefer to have the funeral home come right away while others wait before calling.
- Some have cultural rituals or honor their loved ones by:
 - ▶ Sharing a ritual from the person's spiritual beliefs
 - ▶ Bathing and dressing the person in special clothes
 - ▶ Lighting a candle or putting flowers in the room
 - ▶ Telling stories
 - ▶ Playing special music
- Let the funeral home know when you are ready for them to come. You can be there when they take the body or wait in another room of the house. The funeral home will help you make memorial plans if you wish or the chaplain can assist you with these decisions.

Don't Forget About Yourself

Caring for your loved one at the end of life is the most amazing blessing you can give. However, it can leave you drained and weary. You have given your mind, body and spirit to caring for another person. Often caregivers juggle other duties like work, family or their own health concerns. Balancing another's care with your own needs can be a big challenge and often results in the negligence of your own needs.

How to Help

- Drink plenty of water. Eat healthy meals at regular times.
- Try an exercise routine. Take a walk outside as this can help reduce stress and boost energy.
- Take deep breaths many times a day as deep breathing can refresh your body and mind.
- Rest when you can by lying down or sit with your feet up in a quiet place for 20 minutes.
- Ask for help. People want to help but often don't know what you need. Keep a list of tasks to be done, such as shopping or walking the dog.
- Contact your Kindful care team. Our trained volunteers can help with errands or sit with your loved one while you take a break.
- Decide if calls or visits will help. Limit visits if you need to give yourself time alone.
- Share your thoughts and feelings with a trusted friend, your spiritual counselor or someone from our care team.
- Find a balance between your loved one's care and your own needs. It is important to take care of yourself.
- Please be gentle with yourself. Take life one moment, one step at a time and contact us if you ever need help. **We are here for you.**

Why Kindful

We Believe

Clinical care at the end of life is just as important as clinical care at beginning of life.

Kindful Care

Providing relief, comfort, compassion, and kindness to you and your loved one.

Kindful People

To deliver Kindful Care, we hire to our traits and values creating teams of like minded “kindful” people to deliver on our Purpose, to Serve Patients and their Families.

♥ Courtesy of Kindful Hospice

Special Thanks to Jeff Whitaker, Physical Therapist and Kindful SVP for his major contribution to this guide. Our hope is that this guide brings peace, comfort, and understanding to many patients, families, and caregivers.



TRANSFORMING

the Care of
Serious Illness

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