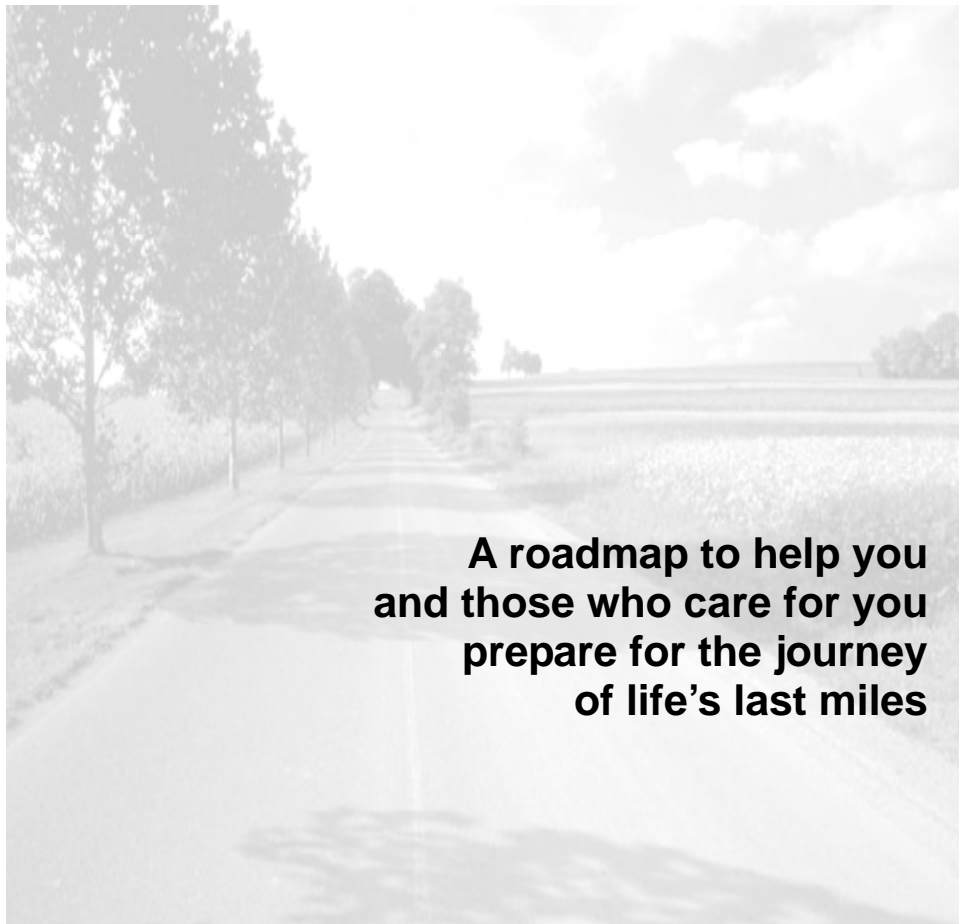




Home Health & Hospice

The Journey



**A roadmap to help you
and those who care for you
prepare for the journey
of life's last miles**



The Journey

Adapted from a poem by
Grace Noll Crowell

*May we come along on this journey, friend,
and be with you in your grief?
We who have seen sorrow such as yours,
can try to understand.*

*May we come in where you are weeping, friend,
and may we take your hand?
We who have seen tears such as yours,
can try to understand.*

*May we come in to care for you, friend,
and comfort and ease your pain?
For we have seen pain and sorrow such as yours,
and can try to understand.*

*So as we walk together,
lean on us where the road is rough,
For we have been down this road before, friend,
And can truly understand.*

You have been told something that has shattered your world – your illness has come to a point where you must start to think about care and comfort, not cure. Your plans, hopes, and dreams must now change. Your path must take an unexpected and perhaps unwanted direction.

Without a chance to prepare, your entire family has been sent on a journey that must seem overwhelming and frightening.

It is our hope that you will allow hospice to travel with you and your family on your private and intense journey. We offer our experience and knowledge to ensure that you are comfortable and your family has the assistance it needs. We will help you find your bearings and gather the strength you need. You do not have to take this journey alone.

Mayo Clinic Health System – Home Health & Hospice



Understanding The Journey

Dying is not an event. It is a process of slowing down and a course of transformation. It involves the whole person – the outer body as well as the inner spirit.

The changes are usually slow. There is a gentle transition as the body and spirit naturally prepare for the last stage of life.

You may notice subtle signs of change early after your doctor tells you that you have a serious illness. Hospice is available whenever you and your doctor feel that the time is right. Many things can bring you comfort at this early stage: medications can relieve pain or other distressing symptoms, emotional and spiritual support can bolster your strength and education can help you feel more prepared for what might lie ahead.

It can be frightening to think about the end of your life, but sometimes knowledge can help dispel fears and uncertainty. A guideline can help you anticipate and get ready for the journey of life's last miles.

It can help if you remember that there is no absolute - each person meets death in his or her own time and own unique way.

There are things that your family and hospice can do to ease the way. Pain and other distressing symptoms can almost always be managed effectively. You can experience a quality to your life.

The following suggestions will help ensure your safety, comfort and dignity.

The Last Few Months



You are fatigued. Your body may feel tired or heavy. Your eyes close frequently and you sleep more often. The body is conserving its energy to sustain your inner core strength.

Your appetite will probably lessen. This is very natural and usually gradual in happening. Food may not taste the same or you may not feel like eating. Solid food, especially meat, takes a lot of energy to chew and digest. Soups, soft foods, and liquids may taste better to you and be easier to eat.

You may find yourself slowly becoming less interested in the world around you. First, you may find yourself caring less about the larger world – newspaper and television become unimportant. Then, visits from neighbors or acquaintances, while appreciated, may become burdensome. Finally, you may want only your closest support people nearby.

Hard work is going on inside you – you try to make sense of what's happening, sort through emotions and feelings, evaluate yourself and your life. Social conversation is a connection to the world and it may feel less important.

Now may be the time to make sure the important words are spoken to those closest to you: "I love you", "Thank you", "Forgive me," "I forgive you," or "Goodbye".

How can those who care for you help?

- ❖ Encourage frequent rests throughout the day.
- ❖ Cut back on the number and length of friends' visits or visit with them in a separate room.
- ❖ Place a sign on your door to limit visitors or time of visits.
- ❖ Offer small amounts of favorite foods; understand that a decrease in appetite is natural and expected; Don't be discouraged or show disappointment if only a small amount is eaten.
- ❖ Remember the importance of touch and closeness.

How can hospice help?

- ❖ Provide all comfort medications and keep in close touch with your personal physician.
- ❖ Provide equipment meant to help conserve energy and promote safety such as a hospital bed, air mattress, wheelchair, walker, shower chair, commode, lift chair, or portable intercom.
- ❖ Lend videotapes about caregiving techniques.
- ❖ Provide personal care and bathing assistance.
- ❖ Provide trained volunteers to assist with household needs and companionship to allow family to tend to other needs or get rest.
- ❖ Provide nutritional counseling.
- ❖ Provide music for relaxation and comfort.
- ❖ Provide spiritual, emotional and/or religious support.
- ❖ Assist with end-of-life planning; financial, legal, or funeral preparation or transitional care arrangements, such as assisted living or nursing home care, if needed.

The Last Few Weeks



Your body now is undergoing many physical changes as it tries to find ways to keep going despite the strain of your illness.

You may now be even less interested in eating or drinking. You may find it difficult to swallow your usual medications.

Urine output gradually lessens and becomes darker in color. Bowels may move less frequently. You will probably not be eating or drinking much, but you will not be hungry. Your body does not need or want food now.

There may be fluctuations in your blood pressure and pulse. Your breathing may change from quite rapid to very slow, with long pauses. There may be a puffing or blowing or moaning with each breath.

Your skin may look different as the heart conserves its blood flow. You may notice paleness or a gray or yellowish hue. Your arms, legs, or bottom may temporarily have a bluish or purple color and look 'blotchy' at times.

Most of the time you will spend sleeping, but you will be easily aroused out of sleep. At times you may be confused or agitated, or have some restlessness or aimless activity with your arms or legs.

Your family may hear you talking to people they cannot see. This time has been described as "having one foot in each world." You may be privileged to see something others are not able to see at this time.

How can those who care for you help?

- ❖ Encourage frequent turning or repositioning in bed.
- ❖ Rub back, arms, legs, and feet with lotion.
- ❖ Offer small sips of liquid or ice chips if desired; try a small glass with a straw cut shorter.
- ❖ Consider discontinuing all but comfort medications.
- ❖ Listen closely to what your loved one tells you about what he or she sees or hears; it can be very comforting.
- ❖ Talk out your feelings of fear, regret, sorrow, gratitude, love; say goodbye.
- ❖ Make at least a preliminary call to a funeral home; feel free to ask if they would come to your home.
- ❖ Sometimes it is easier to make arrangements ahead of time.

How can hospice help?

- ❖ Decide if you desire more support from your clergy, shaman, faith community, or spiritual mentor and let your hospice team know if you do. They can assist you with this.
- ❖ Assess comfort medications; suggest alternate methods of giving medications to keep your loved one as comfortable as possible and teach the family to administer them.
- ❖ Teach the family how to turn, reposition, or help you move to maintain your comfort while ensuring their safety.
- ❖ Watch closely for signs of pressure sores; supply a special mattress and dressings to maximize comfort.
- ❖ Insert a urinary catheter.
- ❖ Provide waterproof pads for the bed.
- ❖ Provide oxygen for respiratory comfort.
- ❖ Offer increased services of the hospice team to support and relieve family.

The Last Few Days



The effort of dealing with illness has drained your body of its reserves. You are very weak and will most likely stay in bed now. You may seem to go into a deep sleep and be unable to respond at this point.

You may show a new or increased restlessness or agitation. Occasionally, there is an ability to rouse from sleep to talk to family right up until the time of death. Experience has shown that even though you may be too weary to respond back to your family, you will be aware of their presence and hear them.

Your pulse will probably increase briefly as the heart tries to maintain your body functions, then it will decrease and your blood pressure will lower. The body temperature may change frequently between fever and chills. Your circulation is slowing and the body pulls in to protect the 'core.' Your hands and feet may feel cool to the touch and there may be increased discoloration or a shift in body fluids (either more or less swelling or edema).

Your breathing may become very irregular and the pauses between breaths may be quite long (apnea). Your family may hear a rattling, congested sound that is caused by air passing over thin fluid in your throat. It will not cause you discomfort or distress.

You may experience a small, brief surge of energy at this point – an alertness, a clarity, a strength to your voice not seen in awhile. It has been said that this is a 'spiritual energy,' a gift, a 'rally' that arrives to help your transition.

How can those who care for you help?

- ❖ Use medications as ordered to maximize comfort.
- ❖ Continue to turn and reposition every few hours.
- ❖ Use blankets (non-electric) to ward off chills.
- ❖ Put the head of the bed up or support as upright as possible with pillows or a wedge to decrease airway congestion; remember your loved one is not choking and there is little discomfort even though the rattling sound is difficult to hear.
- ❖ Use wet mouth swabs to keep the mouth moist and clean; use lip balm to moisten dry lips; offer ice chips.
- ❖ Open a window, blow a fan or apply a wet, cool washcloth to the face to decrease the sensation of shortness of breath.
- ❖ Gather at the bedside; your very presence can assure your loved one that he/she has not been abandoned and is not alone.
- ❖ Use any religious tradition that brings comfort.
- ❖ Continue to talk to and touch your loved one; say you will miss him/her; that you will be alright; that it is Okay to go when the time is right (this release often brings much relief and comfort to your loved one and to you).

How can hospice help?

- ❖ Maximize our services; increase visit frequency if needed.
- ❖ Talk to the physician to inform that death is near.
- ❖ Make sure you have needed medications and supplies.
- ❖ Provide a bedside service of prayer and blessing, if desired.
- ❖ Obtain medicines to control increased oral secretions.

The Last Few Hours



Your blood pressure and pulse will slowly diminish. Your breaths will become more shallow and further apart. There may be a sigh and several last, long breaths as your journey ends.

How can those who care for you help?

Continue to provide comfort medications.

Find comfortable ways to ease the passage into death:

- ❖ Quiet presence
- ❖ Words of endearment
- ❖ Readings
- ❖ Music
- ❖ Favorite songs or hymns
- ❖ Prayers
- ❖ Touch
- ❖ Candles
- ❖ Blessings

It may bring comfort to you to be held or embraced in the arms of someone you love.

How can hospice help?

Be available to support the family, if desired.

After Death Has Occurred

How can those who care for you help?

Don't be disappointed if the death occurs when you are not present; it is a common occurrence – perhaps a last effort to remain private or spare sadness. Look for signs of death: no breath, no heartbeat, no movement, skin cool, eyes staring. Call hospice; the nurse will come. If death occurs in a facility, request facility staff to call hospice.

How can hospice help?

Pronounce the death by checking for vital signs.
Call the physician (the official time of death is when the RN pronounces the patient has died).
Notify other officials, if required.
Call the funeral home.
Offer to dispose of narcotics.
Arrange for the removal of all rental equipment.
Notify all members of the hospice team.
Make arrangements to follow the family for bereavement care for one year.

NOTES

Let Evening Come

By Jane Kenyon

*Let the light of late afternoon
shine through the chinks in the barn,
moving up the bales as the sun moves down.*

*Let the cricket take up chafing
as a woman takes up her needles and her yarn.
Let evening come.*

*Let dew collect on the hoe
abandoned in the long grass.
Let the stars appear
and the moon disclose her silver horn.*

*Let the fox go back to its sandy den.
Let the wind die down.
Let the shed go black inside.
Let the evening come.*

*To the bottle in the ditch,
to the scoop in the oats,
to the air in the lung
Let evening come.*

*Let it come, as it will
and don't be afraid.
God does not leave us comfortless,
So let evening come.*



For additional copies of *The Journey*, contact:
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