



HOSPICE
MINISTRIES, INC.

Final Matters

A guide to help you through the dying experience

FINAL MATTERS

The Dying Experience

Your loved one is dying. Though you knew the end of life would come eventually you might not feel prepared to let your loved one go. But you can be prepared to help make your loved one's last days of life be as comfortable as possible. And understanding what to expect can reduce the anxiety you will feel as the end of life draws near.

The death of a loved one is an overwhelmingly unique experience, and is deeply personal. During this journey you may encounter situations that we have not discussed here. Remember you are not alone in these "Final Matters" as your Hospice Ministries team is always available to offer you guidance, education, and support.



ONE TO THREE MONTHS PRIOR TO DEATH

As one begins to accept their mortality and realizes that death is approaching, they may begin to withdraw from their surroundings. They are beginning the process of separating from the world and those in it. They may decline visits from friends, neighbors, and even family members. They are beginning to contemplate their life and revisit old memories. They may be evaluating how they lived their life and may be sorting through any regrets.

Food becomes less appealing as the body begins to slow down; the body doesn't need the energy from food that it once did. The dying person may be sleeping more now and not engaging in activities they once enjoyed. They no longer need the nourishment from food they once did. The body does a wonderful thing during this time as altered body chemistry produces a mild sense of euphoria. They are neither hungry nor thirsty and are not suffering in any way by not eating. It is an expected part of the journey through the end of life they have begun.

HOW YOU CAN HELP?

LIFE REVIEW

- Allow the patient to reminisce
- Encourage discussion
- Encourage family members and friends to visit
- View photo albums with the patient

CLOSURE

- You may assist the patient with completing projects
- Travel while the patient is able
- Assist in settling unfinished business

ACCEPTANCE

- Early celebration of holidays, anniversary or birthdays or accept they may not want to celebrate
- Make funeral arrangements
- Encourage reconciliation

APPETITE CHANGES

- You may offer small, frequent feedings of desired foods and fluids (every 1-2 hours while awake).
- Position patient with head elevated to assist swallowing.
- Concentrate on providing foods your loved one enjoys, even if they seem less nutritional (i.e., milk shakes, sweets, Popsicle, etc.). Fluids with texture (juice and milk) are easier to swallow than water.
- Do not make the patient feel guilty about not eating.
- Not eating is a natural part of the dying process.
- Consult your hospice nurse regarding nutritional supplements and various feeding techniques.

SLEEP INCREASES

- Plan to be with the person for whom you are caring and schedule visits from others when he/she is most alert.
- Assist and supervise all patient activity to promote safety, (sitting, walking, transferring to chair, feeding, and turning).

ONE TO TWO WEEKS PRIOR TO DEATH

MENTAL CHANGES

This is the time during the journey that one begins to sleep most of the time. Disorientation is common and altered senses of perception can be expected. One may experience delusions, sometimes thinking others are trying to hurt them. They may also have a sense of grandeur, thinking they are invincible.

They may experience hallucinations, sometimes seeing or speaking to people that aren't there. Often times these are people that have passed on before them. Some may see this as the veil being lifted between this life and the next. They may pick at the sheets and their clothing in a state of agitation. Their movements and actions may seem aimless and may make no sense to others. They are moving further away from their starting point in their journey: their life on this earth.

WHAT YOU CAN DO

- Use calm, confident tones when speaking with a confused person to reduce the chance of startling or frightening them.
- When possible, gently re-orient the patient to you and the present, but avoid “testing” the patient by asking him/her pointed questions such as : “Who am I?” “Where they are?,” etc.
- Provide reassurance to the patient if he/she is frightened. Talk in a soothing voice.
- Supervise all activity of a confused or agitated patient. Do not leave patient alone during this time.
- Accept what they tell you about seeing or talking about others – Listen.
- Holding hands, a touch, or a gentle massage can help a person feel connected to those he or she loves.
- Always talk to, not about, the person who is dying. Identify yourself when you come into the room.
- Avoid loud noises and television. Try soft music.
- Create a peaceful atmosphere.
- Have a limited number of people in the room.

PHYSICAL CHANGES

- Difficulty getting out of bed
- Body temperature may lower by a degree or more
- Decrease in blood pressure
- Incontinence of bowel and/or bladder
- Increase in perspiration
- Breathing changes occur, often becoming more rapid and labored
- Congestion (mouth and lung secretions) – may cause a rattling sound and cough
- Sleeping more and responding less
- Complaint of the body being tired or heavy
- Taking in very little fluids (dehydration)
- Body alternating between hot and cold
- Changes in skin color (especially in hands and feet, lips and nail beds)
- Involuntary or reflex movements of the arms or legs
- Loss of appetite or not eating or drinking
- Difficulty in healing wounds and infections
- Swelling in the arms and legs
- Speaking decreases and eventually may stop altogether

WHAT YOU CAN DO

- Ask the patient if he/she is in pain. Use medications as directed. Use pillow between knees or under arm when lying on side for support and to relieve pressure.
- Turn patient every two hours to decrease accumulation of secretions in the lungs and throat and to help avoid skin breakdown.
- Encourage the patient to take deep breaths and cough every 2 to 3 hours when awake.
- Elevate the head of the bed to promote full deep breaths.
- Position a fan to blow gently onto the patient's face.
- Use a cool mist humidifier to help loosen secretions.

- Give fluids if the patient can swallow. This will also help loosen secretions.
- Offer ice chips or small amounts of juice or water. Use a straw since lifting a cup may become difficult.
- Turn the patient to the side and swab the mouth with a moist cloth or swab.
- Keep clean and dry.
- Lip balm or lubricant applied to the lips will help prevent drying. If the patient is on oxygen, do not use petroleum-based products.
- Keep your patient warm with lightweight blankets. Do not use electric blankets or heating pads.
- If warm and perspiring, sponge bathe the patient with lukewarm water to decrease temperature and promote comfort.
- Pad the bed beneath the patient with disposable pads to decrease need for frequent linen changes.
- Talk with your Hospice Ministries' nurse and aide for more hygiene techniques.

DECREASE IN VISION AND CLARITY

WHAT YOU CAN DO

- Continue to reassure the patient of your presence even if you are unsure that he/she hears you.
- Use soft lighting and consider leaving a light turned on near the patient during the night.
- Continue to touch your loved one, particularly when he/she is unable to respond to you, as this will reassure him/her of your presence. Use your discretion if a touch appears to cause agitation.
- Stand near the head of the bed so your loved one can see you better.

A FEW DAYS PRIOR TO DEATH

Your loved one is moving closer to death. Sometimes there is a surge of energy; patients may talk clearly and become more alert for a few hours or a few days. A favorite meal may be requested and eaten when nothing else has been eaten for days. Your loved one may visit with relatives when previously they had not wanted to be with anyone. Though it can be confusing for you to see your loved one with renewed strength, keep in mind this is a normal part of the dying process and your loved one may not actually be getting better. The final surge of energy is often a good time to gather family and close friends to say final goodbyes.

The surge of energy is usually short lived and then the previous signs become more pronounced as death approaches. Breathing becomes more irregular and often slower. “Cheyne-Stokes” breathing, rapid breaths followed by periods of no breaths may occur. Congestion in the airway can increase causing loud, rattled breathing. Lips may become cracked and dry hands and feet may become blotchy and purplish (mottled). This mottling may slowly work its way up the arms and legs. Lips and nail beds are bluish or purple. The person usually becomes unresponsive and may have their eyes open or semi-open but not seeing their surroundings. It is widely believed that hearing is the last sense to go so it is recommended that loved ones sit with and talk to the dying during this time.

WHAT YOU CAN DO.

- Reassure your loved one that you are there.
- Continue speaking to your loved one.
- Express your love, but also let your loved one know that it’s all right to let go.
- Continue the physical support.

When death occurs, the patient’s muscles will relax, breathing will stop, the heart will stop beating, and there will be no pulse. Even when death is expected, you may still experience shock and disbelief. Many people find it comforting to take some time to sit with their loved one and see them at peace. Call your hospice nurse, if you have not already called her, to be with you. She will help you contact the funeral home and coroner.

PREPARING FOR DEATH AT HOME

CONCERNS AND ANSWERS

What can I do to help me make sure I take care of everything at my loved one's death?

Organizing practical matters ahead of time can reduce some of the stress of caregiving and help caregivers concentrate on spending time with their loved one. The following are some practical tips that may help you organize your time and focus your efforts on your loved one.

- Make a list of people your loved one would like to have visit in the final weeks.
- Although the moment of death cannot be planned, it is best to think about who should be present at or around the time of death. Decide whether a clergy member should be at the bedside.
- Make a list of phone numbers of people to call after death occurs and enlist the help of a friend or relative to make those calls.
- Choose a funeral home and notify them that a death is expected in the near future. Most hospices will call the funeral home for you and inform them of the circumstances of the expected death.
- Notify the hospital or hospice staff of cultural and/or religious mourning customs. This may include such things as a list of who should be present before and after the time of death, and any special customs surrounding washing, dressing, or caring for the body after death. Informing the hospital, hospice, or funeral home staff ahead of time can help ensure that they can accommodate the patient's wishes and those cultural practices will be followed.

What should I do when my family member dies at home?

- Call the Hospice Ministries' nurse at our office number.

What hours are the hospice nurses available?

- Our nurses are available 24 hours a day, seven days a week. Office hours are 8 a.m. to 5 p.m. Monday through Friday. After hours, the answering service will have the on-call nurse get in touch with you as soon as possible. The inpatient facility has nurses caring for patients around the clock.

Will the nurse come to our home when the death occurs?

- We want to be there to support you and your family, but this is your decision.

Who notifies the physician?

- The nurse will notify the physician, the same day or the next morning.

What about the coroner?

- The nurse will contact the coroner and provide the needed information. The coroner may or may not come to the home.

What about the funeral home?

- We strongly suggest that arrangements be made with the funeral home in advance. This will make the situation less stressful when the death occurs. However, whether or not arrangements have been made, the nurse will call the funeral home of your choice and give the necessary information.



Dear Caregiver,

As Hospice patients come closer to death, many will stop eating and drinking. This can become very frustrating and alarming to family members who feel that their loved one is suffering and dying more rapidly without food or drink.

Many articles have been written, several studies have been conducted, and the following conclusions have emerged concerning artificial hydration and feeding in the terminally ill.

Dehydration is not painful. Most patients do not feel any hunger or thirst. Keeping the mouth moist with small amounts of water, ice chips or a moist cloth is usually comforting.

Neither intravenous fluids nor tube feeding make a patient live longer. Several studies in fact have shown a shorter survival when these are used.

Tube feedings are associated with complications such as pulling out the tube, use of restraints to keep the patient from pulling out the tube, pneumonia from the feeding going into the lungs; nausea; diarrhea; increased pulmonary secretions, etc. They are also painful to insert and to keep in place.

IVs are also painful to start, and difficult to keep in place. They are associated with swelling of the arms, hands, legs and feet and can cause cough and lung congestion.

As there are generally no benefits from intravenous fluids or tube feedings in the terminally ill, Hospice Ministries advises against their use. However, each patient is different and all situations will be considered individually.

Hospice Ministries' Medical Directors

**They are not dead
who live in the hearts
they leave behind.**

— Tuscarora saying



Gone from My Sight

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then someone at my side says, "There, she is gone!"

"Gone Where?"

Gone from my sight. That is all. She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear her load of loving freight to her destined port.

Her diminished size is in me, not in her. And just at the moment when someone at my side says, "There, she is gone!" there are other eyes watching her coming, and other voices ready to take up the glad shout, "Here she comes!"

And that is dying.

— Henry Van Dyke

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Information lovingly prepared by Hospice Ministries' Nurses.

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