



Hospice Journey[®]

A Guide of Signs, Symptoms, and Caregiving

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HEALTH

This book is a guide to help you through the dying journey—a natural part of life. Many changes can be seen as a body prepares for death. These changes usually begin in the final 1 to 3 months before death. None, one or all of the following signs may be present on your journey. You may see a slow or rapid progression of these signs as the body prepares for death. Just as we are all unique in how we live; we are also unique in how we die.



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Pain Control

When people say they are having pain, it generally means they are hurting somewhere in their body. Pain can usually be controlled well by medications. The person may have side effects such as drowsiness or nausea during the first few days of a new pain medication or an increased dose. But, most side effects usually pass in a few days. Constipation is common with the use of pain medication. See the constipation section of this book to help prevent this side effect.

Non-Verbal Signs of Pain

- Moaning
- Grimacing
- Crying
- Restlessness
- Withdrawal
- Weakness
- Skin pale in color
- Low or high blood pressure
- Slow or fast heart rate
- Problems breathing
- Excessive sweating
- Guarding, lack of mobility

Verbal Signs of Pain

Rank your pain on a scale of 0–10, with 0 being no pain and 10 being the worst pain you can imagine.



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What You Can Do

- If there is pain most of the day, medication scheduled around the clock is more helpful than taking it only as needed.

- Try to stay on top of the pain. Do not wait until the pain gets really bad. Take your pain medicine when pain starts.
- Take your pain medication a half-hour before activities if activity makes pain worse.
- If you are having pain, relax and take deep breaths.
- When you are relaxed your muscles are not tense and pain medication will work better. Change your position, listen to relaxing music, or dim the lights to help you relax.
- Heat or cold may help. Only apply heat or cold for 20 minutes at a time. Allow at least 20 minutes between applications. Never apply ice or heat directly on the skin. Never fall asleep with a heating pad on.
- At times, the pain medication dose and/or frequency may need to be increased. If your pain medicine does not work as well as it used to, talk to your nurse about what you can do for comfort.
- Non-pharmacological interventions
 - Distraction
 - Validate the person's discomfort
 - Alternating rest periods
 - Silk pillowcases
 - Repeated assurances and support
 - Warm compresses
 - Massage
 - Warm blankets
 - Body pillows
 - Assisting with positioning
 - Soft stuffed animal
 - Phone calls to family
 - Relaxation techniques
 - Breathing exercises
 - Aroma therapy
 - Glider rocker
 - Music therapy
 - Warm bath/whirlpool
 - Rehabilitative services
 - Visual imagery
 - Leisure activities
 - Coping skills
 - Offer companionship
 - Pet therapy
 - Use assistive devices as needed such as a walker, wheelchair, etc.

Nutrition and Dehydration

Nutrition is a big part of our lives. Our culture places a lot of importance on meals and the need for nutrition to heal and become stronger. Often feeding and preparing meals for a loved one are ways of showing love, concern, and caring.

One of the hardest things for the caregiver to accept is when the dying person no longer eats or drinks enough to stay alive. As the body changes, not wanting to eat or drink is a natural response. Food may not taste as good. Liquids may be preferred. It is common for hard to digest foods such as meats to be the first foods the person does not want. Next, the person may not want to eat vegetables.

People who are terminally ill often are not hungry. Those who do become hungry usually only need small amounts of food or fluid to satisfy their hunger. Changes that happen with dehydration may produce a natural analgesic (pain relief) effect in the final days of life.

Dehydration also causes:

- Less urine output or less need to use a bed pan, urinal, or commode or fewer episodes of incontinence
- Fewer secretions in the lungs which may relieve coughing and congestion
- Less swelling which may decrease pressure symptoms
- The mouth to be dry—this can be controlled by doing oral care often

What You Can Do

- Allow your loved one to direct their intake of food.
- Do not force food or fluid intake. It is a natural response to not want to eat or drink as the body prepares to die. Weight loss can be expected.
- You may wish to try nutritional supplements.
- Offer 4 to 6 small meals or snacks throughout the day. More frequent, small meals may be more appealing than 3 large meals. Cool, bland, or soft foods may be best.
- Change the times of meals to when the person is pain free and has the most energy. This is often the morning or mid-afternoon. Offer pain and/or nausea medicine one hour before mealtime.
- Cups with lids such as travel mugs allow the weak person to drink without worry of spilling.
- Provide frequent mouth cares. As the body becomes dehydrated, the mouth will get dry. Offer ice chips, use artificial saliva, and apply moisturizer for the lips.
- Toothette swabs are also helpful in keeping the mouth moist.
- Fever can occur as the body becomes dehydrated. First try removing extra blankets and use a lighter covering such as a sheet. Temperature can be checked with a thermometer. A cool washcloth to the forehead or a sponge bath can offer comfort. If the fever still remains, medications may be given.

Constipation

Constipation is common when a person is on pain medications. Usually the following preventive measures will be started at the same time as a pain medication. Besides pain medications, less activity or movement and less food and drink will also increase constipation. Nausea, vomiting, and more pain may be felt when you are constipated.

What You Can Do

- Try to increase fiber intake. Eat more fruits, vegetables, and grains.
- Drink fluids as tolerated.
- Consider drinking a cup of a stimulant such as coffee or one-half to one cup of warm prune juice.
- Try taking a stool softener and/or stimulant.
- Be more active if you are able.

Skin Care

Good skin care can help make the dying person more comfortable. This becomes more important when your loved one has to stay in bed, eats and drinks less, or is no longer able to control bladder or bowel function (incontinent).

What You Can Do

- Daily personal care and hygiene.
- Encourage daily movement and activities as tolerated, even simple motion exercises to the arms and legs.
- Prevent rubbing and friction injuries.
- Use skin barrier creams or ointments. Apply liberally. There is no need to remove all the skin barrier cream or ointment every time.
- Use mineral oil to make removal of cream or ointment easier.
- Protective barrier creams or ointments may prevent fungal or yeast infections.
- Reposition the person every 2 hours for comfort.
- Encourage high protein, high calorie foods as tolerated and desired.
- Pressure relief devices can be used for heels and elbows.
- Keep skin moisturized with a lotion of choice.
- Special padding or cushions can be used for the bed or chair.
- Tell your hospice nurse if any skin irritation or breakdown occurs.

Seizure Precautions

- Take your medication to prevent or treat seizures as instructed by your doctor and hospice nurse.
- Seizures are rarely a severe threat. But they can be when a seizure is immediately followed by another and another.
- You may feel a warning sensation (aura) before a seizure. This will alert you that a seizure is about to happen. Confusion, disorientation, and sleepiness often follow a seizure.
- When a person begins to have feelings of an aura or starts to seize, have the person lie down. Stay away from areas that would result in injury until the seizure stops. If they are in bed, pad side rails with a blanket to prevent injury.
- Do not try to restrain the person when a seizure happens.
- Position the person on their side to allow drainage of secretions and to keep the airway open.
- Do not put anything in the person's mouth.
- Call the hospice nurse for more instruction and help.

Physical Changes

The Last 1 to 2 Weeks of Life

During this time you will see many physical changes. You may see some or all of these changes:

- The heart rate may increase or decrease from the normal. This is the body's way of conserving energy. As the heart gets weaker, it will not pump as strongly as before. The blood pressure may drop.
- Body temperature may go back and forth between hot and cold. The skin may be clammy. The person may sweat more.
- The skin may turn a bluish or purple color (mottling). This may be seen first in the nailbeds, legs, and arms.
- Breathing patterns may change as the body tries to conserve energy. The dying person may breathe faster or slower than usual. The depth of breaths may decrease and become more shallow. An irregular breathing pattern may be seen. Pauses in breathing (apnea) may occur. These pauses may last from a few seconds up to a minute.
- Congestion or a rattling sound may be heard when the dying person breathes. The cough is usually weak and does not always clear this congestion. Often congestion can be helped by turning the person on one side or the other.
- Little to no intake of food and fluids can be expected. Because the dying person is taking in fewer liquids, there is less urine output. He or she may be incontinent of bladder or bowel.
- Confusion or disorientation may occur or be increased. They may see things and/or people that others do not see, and speak to people who are not there. The dying person may become unresponsive sometime before death. The person may have a glassy look in their eyes or they may shed tears.

What You Can Do

- Keep room quiet and peaceful.
- Put on and remove blankets as body temperature changes.
- Keep skin dry and clean. Accept help with bathing your loved one in bed.
- Moisten lips with lip balm.
- Talk to your loved one. Sit and hold their hand. Touch and hearing are the final senses to go.
- Consider getting a hospital bed so the head of the bed can be raised to ease breathing.
- Position your loved one so there is less congestion or noisy breathing. Medications may help with congestion.
- Continue to give medications as directed to help with pain, restlessness or shortness of breath.
- Use disposable diapers or disposable pads for incontinence to protect linen.
- Continue with oral cares. Swab mouth with a toothette moistened with water.
- Being there is one of the most comforting things you can do.

Restlessness or Agitation

A dying person may become agitated and restless. They may be seen “working” with their hands and arms in the air or picking at blankets while they sleep.

At times, the dying person may also talk about leaving or going home. They may talk about deceased family members or friends. Disorientation and confusion may occur before a person dies.

What You Can Do

- Talk to the dying person. They may not be able to respond but they can hear you.
- Hold their hand or give a massage. Touch can be comforting.
- Keep the environment relaxed.
- Consider medications to help with anxiety or treat the underlying cause such as pain or shortness of breath.
- Encourage activities or offer distractions.
- Consider needs such as repositioning, providing for comfort with a warm blanket or sips of water.
- Offer spiritual comforts such as praying, reading or listening to music.
- Welcome visitors, but also be aware your loved one may not tolerate long visits or many visits in one day. Be honest with visitors. Ask them to limit visit time or tell them when your loved one does not want visitors.
- Help your loved one resolve any issues.

As a person accepts that they are dying, they may start to withdraw. They may lose interest in favorite activities, friends, and family. They may spend more time sleeping. While sleeping, a dying person is often reviewing their life.

Signs of Death May Include

- Breathing cannot be seen or heard
- No heartbeat
- Loss of bladder or bowel control
- No response to your voice or touch
- Eyelids slightly open
- Eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

What To Do at the Time of Death

Call Hospice.

Do not call 911 or the ambulance.

The hospice staff will help you confirm that the person has died. They will call the funeral home and the doctor. Although this may sound frightening, the hospice team's goal is to prepare you for what will happen. Your physical and emotional well-being is important to us.

Preparing for When Someone Dies

This checklist will help you keep track of what needs to be done when someone dies. Not all of the items will be needed by everyone. It will be helpful to check off items as they are done. Look into items marked with an asterisk (*) before the death.

Reminder: Most bank accounts and computers will be protected by passwords and pin numbers. Write this information down in advance.

At the Time of Death

- Notify Hospice. They will contact the doctor and funeral home.
- Notify immediate family and close friends.

Within Hours of Death

- Notify the Power of Attorney (POA).
- *Address organ, eye, or tissue donation as needed.
- *Find and review deceased's funeral and burial wishes.
- *Arrange care for children or other dependents.
- *Arrange care for pets.

In the Next Few Days

- Notify family members and friends.
- *Make arrangements with funeral home (cremation, burial, funeral, and/or memorial services)
- *Prepare and arrange for the obituary.
- Have post office hold or forward mail.
- Cancel or rearrange home deliveries.
- Arrange for care or disposal of perishable property (food, plants, etc.)

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Preparing for When Someone Dies

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After the Funeral

- Get death certificates (at least 6 copies for bank accounts and insurance policies).
- Keep records of all payments for funeral and other expenses.
- Tell Social Security and other agencies as needed.
- *Locate safe deposit box(es). Contact bank for safe deposit box procedures.
- *Locate important papers and documents. Some of the items you may need include:
 - Birth and Marriage certificates
 - Social Security Card for dependent children, spouse, and deceased
 - Recent federal tax returns
 - Military records and discharge certificates
 - Wills, legal documents, and trusts
 - Bank accounts, stocks, bonds, and real estate records
 - Life insurance policies

Investigate

- *Social Security Benefits (800) 772-1213 or www.ssa.gov
- *Life insurance
- *Veteran's burial allowance and benefits
- *Union or fraternal organization death benefits
- *Employee benefits including: vacation pay, death benefits, retirement plans, deferred compensation, final wages, and medical reimbursements
- *Refunds on insurance or canceled subscriptions
- *IRA accounts
- *Business, partnership, and investment arrangements

As Needed

- Meet with attorney about estate.
- Meet with CPA for tax and accounting matters.
- Meet with life insurance agent to collect benefits or consider options.
- Deal with fire, theft, liability, and auto insurance on deceased's property.
- Determine value of assets.
- Review credit cards and charge accounts, cancel if needed.
- Do not pay any of the deceased's debts until the attorney discusses this with the family.
- If there is a trust involved, arrange for any allocations and transfers.
- Arrange for final income tax return and estate tax return as needed.

Notes



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