

Patient Education

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Hospice Services

Compassionate Care at the End of Life

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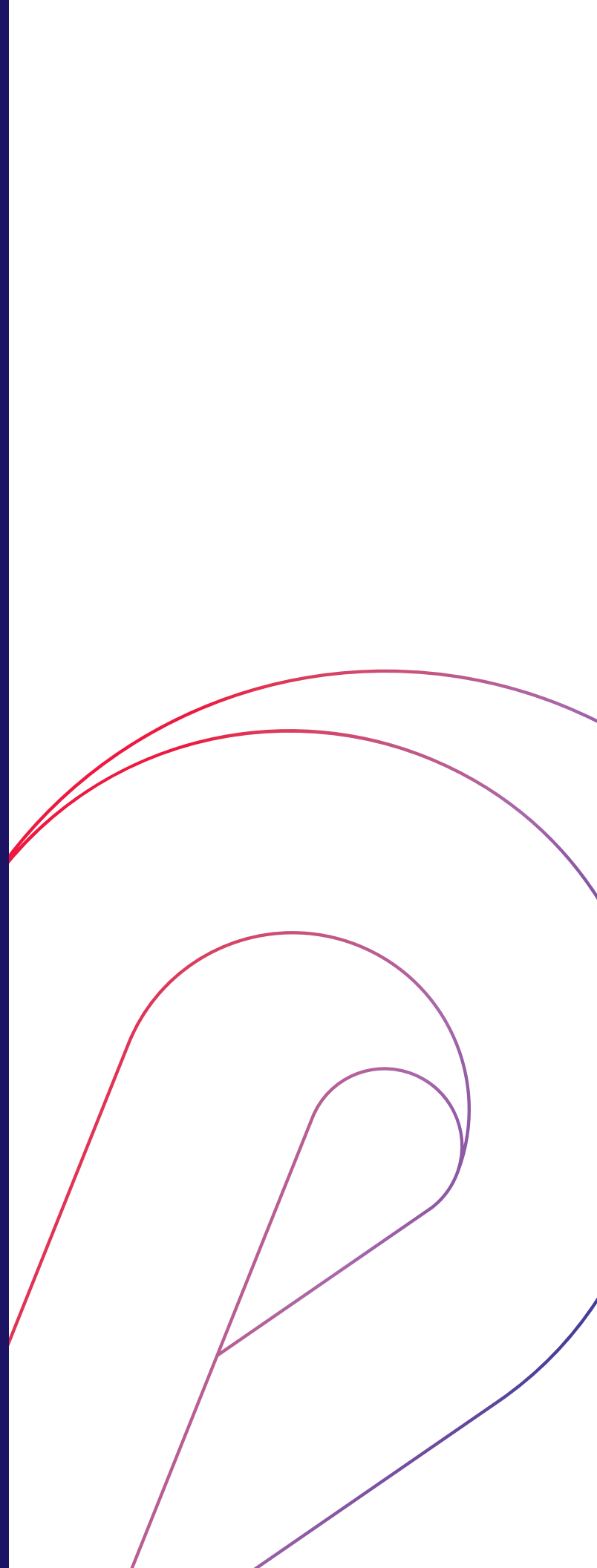
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Intermountain Hospice Services

This booklet provides information and tools to help you understand hospice, learn what care can be provided at the end of life to manage pain and other symptoms, and know what to do when death occurs.

Intermountain Hospice Services aims to provide you with the most compassionate and skilled care possible. Please do not hesitate to ask for help with anything that affects your well-being or that of your family.



Introduction to Hospice



Hospice care focuses on:

- Meeting your needs and supporting your family
- Managing your pain and symptoms
- Giving you comfort and support
- Allowing you and your family to live life to its fullest
- Supporting and educating your caregiver to provide you comfort and dignity
- Preparing you and your family for the end of life

Hospice is a specialized program of compassionate care for people living with a life-limiting illness. Hospice is provided by a team of professionals with expertise in end-of-life care. This care includes pain and symptom management — as well as emotional, social, and spiritual support. Care is usually provided in the home but is also available in long-term care facilities.

Medicare, Medicaid, and most private insurances provide coverage for hospice care.

Who is eligible for hospice care?

Anyone with a terminal illness seeking comfort care (rather than a cure) is eligible for hospice. Your doctor and a hospice doctor must both certify that you have a terminal illness and have 6 months or less to live if the illness runs its normal course. While you are receiving hospice services, your hospice eligibility is re-evaluated regularly.

What is a hospice plan of care?

Your hospice team, along with you and your family, will develop an individualized plan to guide your care in hospice. This plan of care lists the treatments and services needed to meet your goals for pain and symptom control. It also lists services needed to meet any emotional, social, and spiritual needs for you and your family.

What services are covered by hospice?

Your hospice team will provide all medical care and services needed to provide comfort and support related to the terminal illness and related conditions. Services may include the following:

- In-home visits by your hospice team
- Medical or nursing care for physical symptoms
- Intermittent assistance with personal care needs
- Pain and symptom management
- Medications for comfort
- Medical supplies and equipment
- Help and support for the emotional, psychosocial, and spiritual aspects of dying
- Coaching caregivers on end-of-life care and what to expect
- Short-term inpatient care for pain or symptom management
- Inpatient respite care when the caregiver needs a rest
- One year of bereavement support to surviving loved ones and friends including:
 - Bereavement mailings with information and tips on dealing with grief
 - Phone calls to see how you are doing and to provide help with your grief
 - Bereavement education groups



Hospice is always open

Nurses and physicians are available 24 hours a day, 7 days a week. Feel free to call with questions and concerns.

Talk with your team

Make sure you understand the services covered by your hospice benefit.

Who To Call: Hospice Agency

Name:

Phone:

Hospice Nurse

Name:

Phone:

Social Worker

Name:

Phone:

Chaplain

Name:

Phone:



What services are NOT covered?

Services that are not covered by hospice include:

- Treatment that is intended to cure the terminal illness.
- Medications used for a cure rather than comfort.
- Day-to-day non-medical care (such as food, housekeeping, and rent).
- Care from another hospice provider, unless set up by Intermountain Hospice Services.
- Room and board charges for a nursing home or inpatient hospice, unless arranged for short-term inpatient care or respite care.
- Emergency room care, ambulance transportation, or hospital care, unless arranged by Intermountain Hospice Services.
- Healthcare for problems unrelated to the terminal illness. Coverage for these services should come from insurance outside the hospice benefit.

Who is on your hospice team?

Each hospice team member has a specific role as described on the next page. All hospice employees and volunteers have been interviewed, had background checks, and received specialized training to serve you and your loved ones. Your main caregiver, although not a hospice employee, is also a vital part of your team.

Medical Director (Hospice doctor)

- Consults regularly with members of the hospice team regarding your health status and care
- Provides overall guidance and supervision on the plan of care
- Determines initial and ongoing hospice eligibility
- Makes home visits when necessary

Nurse

- Acts as the main contact between team members, including the family and doctors
- Assesses physical and emotional condition
- Assesses and manages pain and other symptoms
- Recommends medication adjustments when necessary
- Makes sure the right medical equipment and supplies are provided
- Provides medical treatments
- Provides training and support for caregivers

Hospice aide

- May be available to help with scheduled personal care activities (bathing, dressing, feeding, and general mobility).

Social worker

- Acts as an advocate for you and your family
- Assesses emotional, social, and psychological needs and works to address them
- Makes referrals for financial assistance and other community resources
- Helps with coping skills and family conflicts
- Provides counseling

Volunteer

- Provides companionship and support
- Gives caregivers a break for short periods of time
- May perform light housekeeping

Chaplain

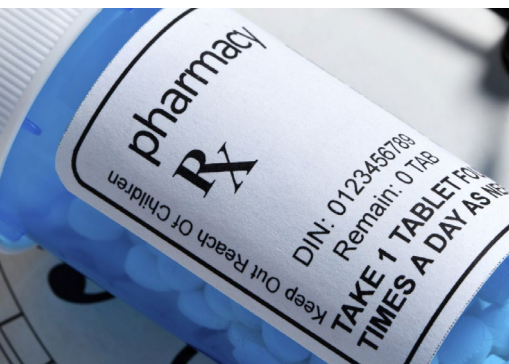
- Supports your spiritual values and beliefs
- Discusses search for meaning in life, the illness, and death
- Provides information, prayers, counseling, and other spiritual support
- Can coordinate between the family and religious leaders
- May assist with funeral arrangements

Attending physician (Personal doctor)

- Determines initial hospice eligibility
- Develops the hospice plan of care with the team
- Approves or initiates changes to the plan of care

Caregiver

- Provides companionship and care
- Gives medications
- Provides daily medical care as trained by hospice staff, as needed
- Communicates with the hospice team about:
 - Changes or new concerns
 - Scheduled doctors' appointments
 - Participates in the development of the plan of care
 - Communicates with family members



The importance of pain management

Pain management makes you feel more comfortable — and also provides these benefits:

- Increases energy
- Lowers stress
- Decreases the severity of many other symptoms

About pain medications

Many people fear they may become addicted to morphine or other opioid pain medications. However, when taken as prescribed, these medications are reliable and safe. Besides reducing pain, opioids can improve breathing and ease uncomfortable feelings of breathlessness.

Managing Pain in Advanced Illness

People with advanced illness are often concerned about pain. They worry that the pain will be more than they can handle, or what the side effects will be. Please share your concerns with your care team. Hospice nurses are trained to help manage pain in the most effective way possible.

Everyone experiences and reacts to pain differently. What may be tolerable for some will be unbearable for others. Successful pain management does not always mean taking away all of the pain — but rather, bringing it down to an acceptable level. The nurse will work with you to set an individual goal for pain relief. You will frequently be asked how intense your pain is on a scale of 0 to 10. This provides a standard way to compare how your pain is being managed, if your goal for pain relief is being met, or if additional interventions are needed.

Pain relief medications

Depending on the severity of your pain, you may start with a medication like acetaminophen (Tylenol) or ibuprofen (Motrin, Advil). If you do not have good pain relief with these non-opioid medications, your doctor will likely prescribe an opioid. Opioids are narcotic medications that are very effective at relieving pain.

Common opioid pain medications used in hospice are:

- Morphine (Roxanol)
- Oxycodone (Percocet)
- Hydromorphone (Dilaudid)
- Dolophine (Methadone)

These medications are started at small doses and gradually increased as needed. The best way to keep your pain managed is to take the medications on a schedule. Do not let your pain become severe by waiting too long between doses. Once pain gets out of control, it could take hours or days to get it controlled again.

Liquid medicines are often used when pills cannot be chewed or swallowed. These medicines can be given with a medicine dropper or a syringe without a needle.

Pain relief without medication

Besides medication, there are other ways to help manage pain. The strategies described below don't replace your medication but may provide additional relief.

- **Relaxation.** Breathe in and out slowly and rhythmically. Focus on the area of discomfort and relax the muscles around that area as you breathe out.
- **Distraction.** Visit with friends, listen to music, play games, read, or watch TV.
- **Cold and heat.** Apply a cold pack or heat pack to the painful area.
- **Repositioning.** Move yourself to a more comfortable position or have someone adjust the bed or pillows.
- **Atmosphere.** Try to reduce annoying sights and sounds. Make your environment as peaceful and pleasant as you can.

CALL the hospice nurse anytime your pain:

- Increases
- Is not relieved with pain medications
- Is intolerable
- Wakes you up
- Prevents you from doing activities

Keep a pain diary

It is helpful to keep a daily pain diary to get an idea of how well your pain is controlled. Share your diary with the nurse. Include the following information:

- Date and time
- Pain level on a scale of 0 to 10, with 10 being the worst possible pain
- Pain medication details
 - Name of medication
 - Amount taken
 - Relief given
 - Side effects
- Things that make the pain worse
- Things that decrease the pain

Pain Medicine Tracker						Intermountain Health	
Use this sheet to track how much pain medicine you take. Have someone you trust help you keep track of how many pain pills you take each day. Do not take any other medicine while you are taking your pain medicine unless your doctor says it's okay. Do not take more medicine than your doctor has prescribed, even if you still have some pain. If you still have a lot of pain—even after taking your pain medicine, tell your doctor. Tell your caregivers to CALL 911 if they notice your breathing slows down or stops, or if they can't wake you up.							
Day, Date	Medicine	Dose, How often it can be taken	Time taken	When next dose can be taken	Pain level		
Monday, 3/5/23	Example: Percocet	Dose: 5 mg (1 pill) every 6 hours, only as needed	2:00 PM	8:00 PM	Before	<input type="checkbox"/> 0	<input type="checkbox"/> 1
		Dose: _____ every _____ hours			After	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 4	<input type="checkbox"/> 5
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 6	<input type="checkbox"/> 7
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 8	<input type="checkbox"/> 9
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 10	<input type="checkbox"/> 11
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 12	<input type="checkbox"/> 13
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 14	<input type="checkbox"/> 15
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 16	<input type="checkbox"/> 17
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 18	<input type="checkbox"/> 19
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 20	<input type="checkbox"/> 21
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 22	<input type="checkbox"/> 23
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 24	<input type="checkbox"/> 25
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 26	<input type="checkbox"/> 27
		Dose: _____ every _____ hours			Before	<input type="checkbox"/> 28	<input type="checkbox"/> 29
		Dose: _____ every _____ hours			After	<input type="checkbox"/> 30	<input type="checkbox"/> 31

Symptom Management

CALL the hospice nurse if you experience any new symptoms or if an existing symptom gets worse.

One of the main goals of hospice is to help lower pain and keep you as comfortable as possible. If you have a symptom that's causing discomfort, discuss it with your hospice team. The team can help determine the cause of the symptom and the best options for relief.

See the following list of symptoms that are common with advanced illness and things you can try to help relieve them.

CONSTIPATION

Causes:

- Pain medication
- Decreased physical activity
- Decreased fluid intake

What can help:

- Avoid constipating foods (such as red meat, bananas, rice, dairy)
- Eat natural laxative foods (such as prune juice, raw fruits, bran muffins)
- Increase activity level
- Increase fluids
- Change medications

When to tell your hospice team:

- Any change in the frequency of bowel movements
- Irregular bowel movements
- Abdominal (belly) discomfort

NAUSEA AND VOMITING

Causes:

- Many causes

What can help:

- Drink liquids, but no food, immediately after vomiting
- Eat small, frequent meals
- Avoid gas-forming foods (such as broccoli, beans, cabbage)
- Avoid fried foods, milk products, or foods with strong smells
- Eat bland foods (such as potatoes, applesauce, sherbet, crackers)
- Medications to control nausea

When to tell your hospice team:

- New or worsening nausea or vomiting

SHORTNESS OF BREATH

Causes:

- Diseases affecting the lungs or heart
- Advanced illnesses

What can help:

- Use pillows to sit up in bed or raise the head of a hospital bed
- Sit in a chair or recliner
- Use a fan
- Keep the room cool
- Take slow, deep breaths through your nose, then breathe out slowly through your mouth
- Oxygen (may or may not help)
- Medications

When to tell your hospice team:

- If shortness of breath keeps you from doing what you want to do
- If breathing difficulty causes fear, anxiety, nervousness, restlessness, or blue lips and fingernails

DECREASED APPETITE

Causes:

- Changes in sense of taste can make foods taste bland, salty, or sour
- Slowed digestion
- Decreased activity

What can help:

- Eat what you want, when you want
- Try small, frequent meals
- Try protein supplements, such as Ensure or instant breakfast mixes
- Take drinks or sips often and clean the mouth frequently

When to tell your hospice team:

- Unable to eat or drink
- Changes in appetite
- Trouble swallowing
- Dry mouth, tongue, or skin
- Confusion or drowsiness

How your caregiver can help

Avoid struggles and disagreements about eating when your loved one has a decreased appetite. Never force food.

SKIN BREAKDOWN

- | | |
|----------------|--|
| Causes: | <ul style="list-style-type: none"> • Immobility • Being bedbound • Poor nutrition • Decreased feeling in extremities |
|----------------|--|

- | | |
|-----------------------|---|
| What can help: | <ul style="list-style-type: none"> • Turn or shift weight every 1 to 2 hours • Change clothes, undergarments, and linens immediately when soiled or wet • Perform range-of-motion exercises daily • Eat healthy meals (if eating) • Protect bony areas by using pillows, cushions, and possibly special bed mattresses • Use a mild soap with warm (not hot) water • Use lotion on dry areas |
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- | | |
|--|--|
| When to tell your hospice team: | <ul style="list-style-type: none"> • Any reddened areas or skin breakdown • Pain |
|--|--|

FATIGUE

- | | |
|----------------|--|
| Causes: | <ul style="list-style-type: none"> • Disease • Emotional state • Pain |
|----------------|--|

- | | |
|-----------------------|---|
| What can help: | <ul style="list-style-type: none"> • Gradually increase activity • Plan, schedule, and prioritize activities for your best times of the day • Eliminate activities that are not important • Allow others to help with activities • Rest and sleep as needed • Keep a regular bedtime • Eat healthy meals (if eating) |
|-----------------------|---|

- | | |
|--|---|
| When to tell your hospice team: | <ul style="list-style-type: none"> • Unable to perform normal activities • No appetite • Sleepiness • Not talking • Depression • Exhaustion • Spiritual and emotional concerns |
|--|---|

ANXIETY, SADNESS, DEPRESSION

- | | |
|----------------|---|
| Causes: | <ul style="list-style-type: none">• Fears and concerns• Loss of independence• Loss of control• Confusion |
|----------------|---|

- | | |
|-----------------------|--|
| What can help: | <ul style="list-style-type: none">• Identifying patterns of anxiety and sadness• Medications• Coping techniques• Counseling with your hospice team• Reduce feelings of isolation by being included in activities• Express as much independence as possible• Write down thoughts and feelings |
|-----------------------|--|

- | | |
|--|--|
| When to tell your hospice team: | <ul style="list-style-type: none">• Any signs of anxiety or sadness• Personality changes• Problems with relationships• Spiritual concerns |
|--|--|

CONFUSION AND DISORIENTATION

- | | |
|----------------|---|
| Causes: | <ul style="list-style-type: none">• Overstimulation• Too many people around you at once• Physical discomforts• Infection |
|----------------|---|

- | | |
|-----------------------|---|
| What can help: | <ul style="list-style-type: none">• Identify confusion and disorientation• Medications• Coping techniques• Speak softly, clearly, and soothingly• Try a simple touch or hug• Create a quiet living space to reduce stimuli• Try not to argue or correct• Have clocks and calendars in plain sight• Try to maintain a schedule |
|-----------------------|---|

- | | |
|--|--|
| When to tell your hospice team: | <ul style="list-style-type: none">• Any signs of confusion or disorientation, especially if new or worsening |
|--|--|



Final Choices

Important conversations

It is important to discuss your wishes with your loved ones and complete any necessary legal documents. The hospice social worker and chaplain can help you.

There are many choices to make at the end of life. Making and expressing your wishes and plans will help your family carry out your last instructions. It can be a great final gift to your family, sparing them needless expense and emotional distress.

Some end-of-life decisions that need to be made include:

- Estate planning
- Advance Directives (healthcare and financial)
- Do Not Resuscitate Orders (DNR)/Provider Order for Life-Sustaining Treatment (POLST)/Physician Orders for Scope of Treatment (POST)
- Organ or body donation
- Burial or cremation
- Cemetery
- Use of professional funeral director services (transport body, contact people for funeral service, obituary, death certificate, prepare the body, provide casket)
- Embalming
- Memorial donations
- Memorial or funeral service

As Death Approaches

Death comes differently for every person, and your death will be unique. However, some changes are common to this final phase of life. This section explains some of these changes and gives ideas for care and comfort. This information may help you anticipate the changes you may see and allow you to go forward with more peace and confidence.

Changes you may see; things you can do

This section describes physical and behavioral changes that are commonly seen in the dying process. You may not see all of these changes, or at least not at the same time. But it may help you to know a little about what you're seeing and experiencing and what you may want to do.

Appetite, ability to eat and drink

You may not need or want much food or liquid. This is a sign of the body's gradual process of shutting down. Right now, eating and drinking aren't helpful.

- Choose when and what to eat or drink. Your caregiver should not insist that you take food or fluids.
- Eat ice chips or take small sips of fluid that can be sucked from a sponge or a moist washcloth.
- To ease dryness:
 - Wipe lips with a cool, moist washcloth.
 - Use an oral moisturizer on your teeth and gums.
 - Apply small amounts of lip balm (like ChapStick or Vaseline).
 - Use a water-based product (like K-Y Jelly) on dry lips and nostrils (if using oxygen therapy).



About changes at the end of life

The changes discussed here show how the body prepares itself for death—the final stage of life.



Sleep

Over time, you will sleep more and more. The sleep may seem deeper and it may be difficult to wake. This change signals a slowing of the body's metabolism.

How your caregiver can help:

- **Note if there are times of the day when your loved one is more alert and has more energy.** Try to plan visits and activities for these times.
- **Realize that your presence matters and is a comfort.** Even if your loved one is asleep or can't carry on a conversation, they know you are near.
- **Talk or read.** Play music or sing quietly. Your loved one may hear your voice and find it soothing.
- **Reach out.** Hold your loved one's hand. Stroke their hair or rub lotion on their hands. As your loved one withdraws, remember that this is simply part of the dying process, not a rejection. Your caring touch can comfort your loved one and express your connection.

Body temperature, skin changes

Your hands, feet, and limbs may become cool to the touch. You may also notice that the skin is splotchy and very pale gray or dusky purple. It may be darker on the underside of the body. These changes are signs that your circulation is slowing down.

How your caregiver can help:

- **Use blankets, socks, and slippers** to keep your loved one warm.
- **Don't use an electric blanket or heating pad.** The heat may be too intense for your loved one's skin.
- **Keep in mind that even though the skin feels cool, your loved one may feel hot and want to take off the blankets.** In this case, don't insist on blankets. Do whatever seems comfortable to your loved one.

Bladder and bowel changes

You may notice fewer bowel movements and less need to urinate. The urine will have a darker color and a stronger smell. This is normal. As you take in less fluid and food, there's less waste. Also, the kidneys may be shutting down. During this time, it's also common to begin to lose bladder and bowel control.

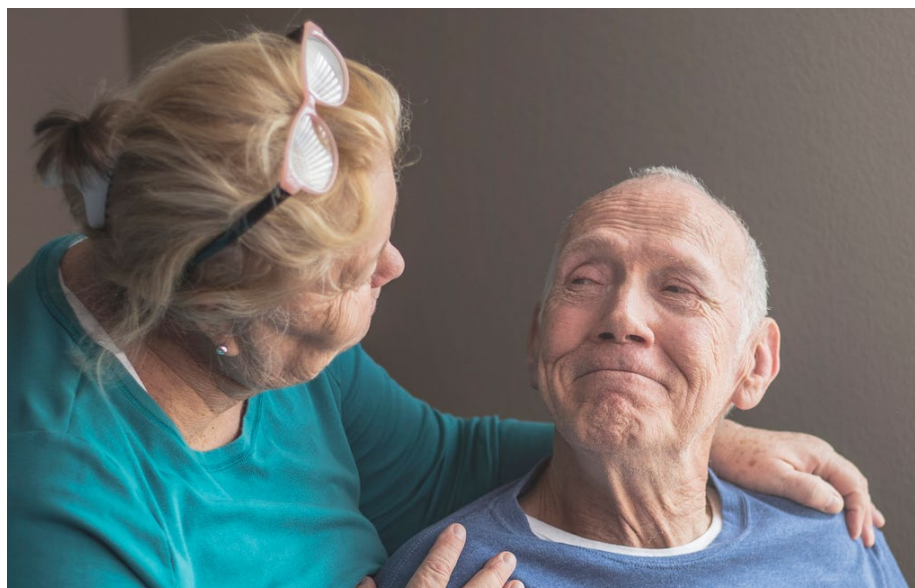
- If necessary, use disposable diapers and bed pads.
- Consider asking the care team about the bladder and bowel changes. They can determine, for example, if a catheter or medication would be helpful.

Awareness and mood

You may become increasingly confused about time, place, and people. (Some people even have trouble recognizing close friends and family members.) At times, you may feel restless or upset — picking at the sheets, changing positions a lot, seeing things that aren't there, and so on. These behaviors are caused by changes in the body during the dying process, such as less oxygen to the brain, less fluid in the body, and lower kidney function. Medications, pain, and infection can cause shifts in mood and awareness.

How your caregiver can help:

- As often as needed and as long as it seems comforting, **remind your loved one of the day, time, and surroundings.** Speak in a gentle, reassuring tone.
- **Don't insist on "correcting" your loved one.** Don't argue or try to reason with them.
- **Sit next to the bed and hold hands with your loved one.** Your close presence can help orient and soothe your loved one.



As Time Becomes Very Short

Advice for the caregiver

- Schedule breaks away from the bedside. Have someone take your place there if you're reluctant to leave your loved one alone.
- Get outside every day, if only for a brief walk. A few minutes of fresh air can soothe and center you.
- Get enough sleep and rest. You may need to leave the hospital or home for a few hours.
- Eat regularly and focus on healthy foods. You need good fuel during this stressful time.
- Find a time and place to cry, complain, shout — to express the intense feelings you may be holding inside. An understanding listener can help.
- Be gentle with yourself. The end of life will come in its own time, in its own way. You're not in control, but you can honor and comfort your loved one by caring for yourself.

In your loved one's final hours, you may notice that the changes described previously are even more pronounced. For example, your loved one will likely sleep more, become colder to the touch, and be more agitated.

Continue the comfort measures that feel right to you. As your loved one's breathing becomes more labored, you may want to raise your loved one's head and body with pillows. Turning the person partly to the side may help to manage secretions.

As your loved one draws very close to death, you may see additional changes:

- **Louder breathing.** Your loved one's breathing may become louder, more ragged, or have a gurgling sound like snoring. This happens because saliva is more dry and thick, and the throat muscles are more relaxed. It's not distressing or painful to the patient.
- **Pale, bluish lips and nail beds.** This is a further sign of slowing circulation.
- **Half-open eyes and mouth.** When near death, some people's eyes remain partly open and look glassy. Their mouths may fall open.
- **Stop-and-start breathing.** Your loved one's breathing pattern may change, and there may be long periods between breaths. This interrupted and irregular breathing is common in the final hours of life.

If you notice any of these things, call your nurse and let them know. They will assist you in these last hours of your loved one's life. Hospice is there for you.

When Death Occurs At Home

Signs that death has occurred:

- No response to touch or voice
- No breathing and no heartbeat
- Eyelids may be slightly open with eyes in a fixed stare
- Jaw is relaxed and the mouth slightly open
- Loss of bowel and bladder control

A guideline for things to do when your loved one dies at home

Within minutes to hours:

- Call hospice. The nurse will come to the house and help you.
- DO NOT CALL 911.
- If you are alone, call a family member or friend to be with you.
- You or the nurse will contact the funeral home of your choice when you are ready.
- Contact loved ones and friends.

Within 1 to 2 days:

- Call and make an appointment with the funeral home to review the arrangements.
- Ask for at least 5 copies of the death certificate. (You may need more for your estate distribution records.)
- Plan the funeral program (date, time, place) and choose pallbearers, speakers, music numbers, a pianist, a presiding religious leader, and so on.
- Arrange burial needs.
- Call the newspaper and ask how to submit an obituary and about the cost.
- Write and submit the obituary. Check to see if the funeral home will help you with it.

Within a week:

- Notify Social Security and your health insurance of the death.

When you are ready:

- Make decisions about the estate, contact an estate/will attorney if needed.
- Notify the bank(s).
- Notify utilities.
- Notify insurance companies (such as auto, life, and home).

To find this booklet and other patient education, go to:
intermountainhealth.org



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