Intermountain Homecare & 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 Homecare & Hospice 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.
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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

Introduction to Hospice

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 eligibility for hospice is reevaluated regularly. This happens after 90 days, then again in 90 days, and every 60 days thereafter. Reevaluation requires your hospice team to visit you and perform a detailed assessment. If you live longer than 6 months on hospice, you can continue to receive hospice services for as long as the doctor recertifies that you are terminally ill. However, if your health improves or the illness goes into remission, the team may determine that hospice is no longer needed. You may also choose to stop receiving hospice care at any time.

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. The plan also lists services needed to meet any emotional, social, and spiritual needs for you and your family.

Your hospice team will visit you regularly to assess how things are going, provide treatments, make changes to the plan of care, and provide guidance and training for the caregiver. (The caregiver — often a family member or loved one — is the person who helps with daily medical care and decisions, as needed.) Following your plan of care, the team will explain what the caregiver can expect as the disease progresses and how to manage situations that arise.
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.
- Continuous home care during periods of crisis.
- 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.

What services are NOT covered?

Services that are not covered by hospice include these:

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

Who is part of your hospice team?

Each hospice team member has a specific role as described below. 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.

**Hospice doctor (Medical Director)**
- Consults regularly with members of the hospice team
- Provides overall guidance and supervision of the plan of care
- Determines initial and ongoing hospice eligibility
- Makes home visits when necessary

**Nurse**
- Acts as primary 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 (bandages, catheters, IVs, and so on)
- Provides training and support for caregivers

**Hospice aide**
- Helps with personal care activities (bathing, dressing, feeding, and general mobility), light housekeeping, and simple meal preparation
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
- Helps with simple meals and light housekeeping

Chaplain
- Supports your spiritual strength (values and beliefs)
- Guides in a search for meaning in life, the illness, and death
- Assists with building lasting legacies
- Provides information, prayers, counseling, and other spiritual support
- Can coordinate between the family and religious leaders
- May assist with funeral arrangements

Personal doctor (Attending Physician)
- 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
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 they worry about the side effects of pain medication. If you share these concerns, it may help to know that hospice nurses are trained to help manage pain in the most effective way possible.

We all experience and react to pain differently. What may be tolerable for some will be unbearable for others. Successful pain management does not always mean taking away 100% of the pain — but rather, decreasing it 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.

The most common opioid pain medications used in hospice are:

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

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.
- **Comfort.** 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.

**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 0–10, with 10 being the worst possible pain.
- Pain medication taken:
  - Name of medication.
  - Amount taken.
  - Relief given.
  - Side effects.
- Things that make the pain worse.
- Things that decrease the pain.

**CALL...**

the hospice nurse anytime your pain:

- increases
- is not relieved with pain medications
- is intolerable
- wakes you up
- prevents you from doing activities
Symptom Management

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 obtaining relief.

Below is a chart listing symptoms that are common with advanced illness and things you can try to help relieve these symptoms.

<table>
<thead>
<tr>
<th>CONSTIPATION</th>
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<tbody>
<tr>
<td>Causes:</td>
</tr>
<tr>
<td>• Pain medication</td>
</tr>
<tr>
<td>• Decreased activity</td>
</tr>
<tr>
<td>• Decreased fluid intake</td>
</tr>
<tr>
<td>What can help:</td>
</tr>
<tr>
<td>• Avoid constipating foods (e.g., red meat, bananas, rice, dairy)</td>
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<tr>
<td>• Eat natural laxative foods (e.g., prune juice, raw fruits, bran muffins)</td>
</tr>
<tr>
<td>• Increase activity level</td>
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<tr>
<td>• Increase fluids</td>
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<tr>
<td>• Medications</td>
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<tr>
<td>When to tell your hospice team:</td>
</tr>
<tr>
<td>• Any change in frequency of bowel movements</td>
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<tr>
<td>• Irregular bowel movements</td>
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<tr>
<td>• Abdominal discomfort</td>
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</tbody>
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<table>
<thead>
<tr>
<th>NAUSEA AND VOMITING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Causes:</td>
</tr>
<tr>
<td>• Multiple factors</td>
</tr>
<tr>
<td>What can help:</td>
</tr>
<tr>
<td>• Drink liquids, but no food, immediately after vomiting</td>
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<tr>
<td>• Eat small frequent meals</td>
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<tr>
<td>• Avoid gas-forming foods (e.g., broccoli, beans, cabbage)</td>
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<tr>
<td>• Avoid fried foods, milk products, or foods with strong smells</td>
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<tr>
<td>• Eat bland foods (e.g., potatoes, applesauce, sherbet, crackers)</td>
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<tr>
<td>• Medications</td>
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<tr>
<td>When to tell your hospice team:</td>
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<tr>
<td>• New or worsening vomiting</td>
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</tbody>
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**SHORTNESS OF BREATH (DYSPNEA)**

**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 you cannot do what you want to do
- If dyspnea causes fear, anxiety, nervousness, restlessness, or bluish discoloration

**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
- Trouble swallowing
- Dry mouth, tongue, or skin
- Confusion or drowsiness

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**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:**
- Immobility
- Bed bound
- Poor nutrition
- Decreased feeling in extremities

**What can help:**
- Turn or shift weight every 1 to 2 hours
- Change clothes, undergarments, and linens immediately when soiled or wet
- Perform daily range of motion exercises
- Eat healthy meals (if eating)
- Protect bony areas by using pillows, cushions, and possibly special bed mattresses
- Use mild soap with warm, not hot, water
- Use lotion on dry areas

**When to tell your hospice team:**
- Any reddened areas or skin breakdown
- Pain

### FATIGUE

**Causes:**
- Disease
- Emotional state

**What can help:**
- 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:**
- Unable to perform normal activities
- No appetite
- Sleepiness
- Not talking
- Depression
- Exhaustion
- Spiritual and emotional concerns
## Anxiety, Sadness, Depression

### Causes:
- Fears and concerns
- Loss of independence
- Confusion

### What can help:
- 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:
- Any signs of anxiety or sadness
- Personality changes
- Problems with relationships
- Spiritual concerns

## Confusion and Disorientation

### Causes:
- Overstimulation
- Too many people at once
- Physical discomforts
- Infection

### What can help:
- 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:
- Any signs of confusion or disorientation, especially if new or worsening
Final Choices

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.

End-of-life decisions:

- Estate planning
- Advance Directives (healthcare and financial)
- Do Not Resuscitate Orders (DNR) / POLST
- 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 body, provide casket)
- Embalming
- Memorial donations
- Memorial or funeral service

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.
As Death Approaches

Death comes differently for every person and your death will be unique. However, there are changes that 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 Chap Stick or Vaseline.
  - Use a water-based product (like K-Y jelly) on dry lips and nostrils — if you are on oxygen therapy.

About changes at the end of life

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

Sleep

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

How your caregiver can help:

• Notice if there are times of the day when he/she 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 grey 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 prevent your loved one from feeling cold.

• 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 as often. 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 can also be a factor.

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.
Tips for your caregiver as time becomes very short

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

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 gurgling. It may sound like snoring. This happens because saliva is more dry and thick now, the throat muscles 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.** 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 very common in the final hours of life.
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 relaxed and mouth slightly open.
- Loss of bowel and bladder control.

Following is 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 arrangements.
- Ask for 5 copies of the death certificate.
- Arrange the funeral program (date, time, place) — pall bearers, speakers, music numbers, pianist, presiding religious leader, etc.
- Arrange burial needs.
- Call the newspaper and ask how to submit an obituary including the cost.
- Write and submit the obituary.

**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 (auto, life, house, etc.).