



**Hospice**  
*Patient Handbook*





## Who we are and what we do

### Hospice Mission

Asante Hospice serves our community by providing quality end-of-life care. We honor our patients' and families' choices through compassionate holistic services.

## What we aspire to be

### Hospice Vision

Asante Hospice is a community-recognized leader in providing excellent hospice and palliative care; we are responsive to the needs of patients, families and community partners.

We offer collaborative, interdisciplinary care by highly skilled and educated team members who are valued for their knowledge, experience and presence.

Our community honors dying as a natural part of life and understands that hospice and palliative care can assist both patients and their loved ones in finding peace, meaning and comfort.

### Asante Vision

To be your trusted health partner for life — every person, every time.

# Contents

## Welcome to Asante Hospice

The hospice benefit.....	1
24-hour on-call system .....	2

## Meet the hospice team

Patient and family .....	3
Hospice physician .....	3
Nurse .....	4
Medical social worker.....	4
Spiritual counselor.....	4
Hospice aide.....	5
Nurse practitioner.....	5
Bereavement coordinator .....	5
Volunteers.....	5

## Hospice bill of rights

Patient rights.....	6
Notice of nondiscrimination .....	8

## Practical matters

Patient responsibilities .....	9
Making decisions about medical treatment.....	10
Getting affairs in order .....	10
Caregiving.....	11
Options for placement .....	12

## Emotional care

Common emotions .....	13
Just for the caregiver .....	15
When there are children in the family .....	17
Grief and bereavement .....	18

## At-home infection prevention

Hand washing .....	19
Home environment .....	19

## Training for symptom management

Pain .....	20
How to breathe better .....	23
Bowel changes .....	24
Nutritional issues.....	24
Nausea .....	25
Mouth issues.....	26
Skin issues .....	27
Pressure injuries.....	28

## The final days

The weeks before death.....	29
One or two days before death .....	31

## When death occurs

When the patient dies .....	33
Drug management.....	34

## Safety and comfort at home

Tips for staying independent.....	36
When a patient falls.....	37
Asante Lifeline .....	37
Equipment safety tips.....	37
Oxygen therapy .....	38
Fire safety .....	39
Preparing for emergencies .....	39

## In conclusion

Important documents.....	42
A final word .....	42
Helping others .....	43

# Asante Hospice

## Asante Hospice

(541) 789-5005 | (800) 888-6579 | [asante.org](http://asante.org)

### Hospice team

Hospice physician

---

Nurse case manager

---

Medical social worker

---

Spiritual counselor

---

Hospice aide

---

Nurse practitioner

---

Bereavement coordinator

---

Volunteer

---

If you speak another language, assistance services are available at no cost.  
Call (541) 789-5322: TTY (541) 789-7104

Si habla otro idioma, tiene a su disposición servicios de asistencia gratuitos.  
Llame al (541) 789-5322: TTY (541) 789-7104



# Welcome to Asante Hospice



Asante Hospice supports terminally ill patients and their families in achieving their end-of-life goals and making the most of each hour and each day. We are here to help you be comfortable, alert and capable of participating in life as fully as possible for as long as possible. The Hospice Interdisciplinary Team comprises professionals from multiple disciplines who give you and your family skilled physical, psychological, emotional and spiritual support throughout your journey.

## The hospice benefit

A person diagnosed with a terminal illness is eligible for coverage under the hospice benefit when the following conditions are met:

- A physician can certify that the patient has a prognosis of six months or less.
- The patient chooses comfort care rather than curative or aggressive medical treatment.
- The patient has a safe place to live, and caregiving is available.

## Medications, supplies and medical equipment

When a patient is admitted to Asante Hospice, a hospice physician or nurse practitioner reviews their medications.

Medications related to comfort and hospice-related illness are paid for by Asante Hospice so long as they are effective and there is no preferred alternative.

Medications that do *not* relate to the patient's life-limiting prognosis or its symptoms are not paid for by Asante Hospice, but they may be covered under Medicare Part D or other insurance.

Neither Asante Hospice nor Medicare pays for ineffective medications or those with a preferred alternative, so the patient or family would be responsible if those medications are continued. Given the changes that occur at the end of life — such as decreased appetite, weight loss, altered metabolism and decline of kidney and liver function — some longtime medications may need to be phased out. The risks and benefits of certain medications change as illness progresses. For example, patients with diabetes, who have focused on tight blood sugar control to prevent complications, are now at greater risk of low blood sugar.

Asante Hospice may make medication recommendations. A hospice physician and a pharmacist will review all medications at least every two weeks to manage symptoms as the patient's situation changes.

The hospice team will discuss durable medical equipment needs upon admission and whenever new needs arise. If part of the treatment plan, items such as a hospital bed, oxygen and commode can be delivered to the patient's home. Expect delivery and pickup during usual business hours. On delivery, you will be shown how to use the equipment safely (*also see [Equipment safety tips on page 37](#)*).

# Welcome to Asante Hospice

## How the hospice benefit is paid

Medicare, Medicaid (the Oregon Health Plan) and most private insurance cover the hospice benefit. The payer determines a set daily reimbursement rate, which covers the following services:

- Hospice physician.
- Nurse.
- Medical social worker.
- Spiritual counselor.
- Medications, supplies and medical equipment related to the terminal illness and that keep the patient comfortable.
- Other individualized services as determined by the Hospice Interdisciplinary Team, such as a hospice aide.

## Levels of care

Depending on the needs of the patient and family, the medical director will determine one of four levels of care:

- Routine home care.
- Acute general inpatient care.
- Respite care.
- Continuous home care.

## Discharge

Occasionally when a patient is stable or improving, we discharge them from hospice until our services are needed again. A patient may also choose to leave the hospice program at any time and for any reason.

## 24-hour on-call system

Regular office hours are 8 a.m. to 5 p.m., Monday through Friday; **(541) 789-5005**.

A hospice nurse is available 24 hours a day, seven days a week, for any problems or questions concerning patient status or care. Call **(541) 789-5005** and ask for a nurse. Give the patient's name and telephone number. If the nurse doesn't call you within 15 minutes, call back and ask again for a nurse. We do not screen calls, so all calls are returned. In the evenings and on weekends and holidays, the answering service will receive your call and will page the on-call nurse, who will call you back. The nurse has access to physician services at all times.

## Reasons to call

- Unexpected change in the patient's condition.
- Injury from a fall.
- Uncontrolled pain.
- Questions about medications.
- Bladder pressure or pain if the patient cannot urinate.
- Bleeding.
- Seizures.
- Difficulty swallowing.
- Uncontrolled agitation or restlessness.
- Problems with oxygen.
- Problems with the bed or commode.
- Problems with an intravenous, or IV, line or pump.
- Clogged catheter.
- Change in the patient's breathing pattern.
- You are frightened or feeling panicked.
- You feel that the patient needs to go to the hospital.
- The patient is dying or has died.

**Always call hospice first in an emergency involving the patient: (541) 789-5005.**

## Meet the hospice team



The Hospice Interdisciplinary Team works with you to meet your physical, emotional and spiritual needs. The unique needs and preferences of the patient, as well as those of the family and caregivers, determine which team members play a role in the patient's care.

Hospice team members make scheduled, intermittent visits. In other words, they do not stay all day or all night, and they do not take the place of a caregiver in the home. The patient's regular doctor, or primary care provider, collaborates with the hospice physician in decisions about medications and treatments.

### Patient and family

The patient and family are the most important part of the hospice team. We will explore with you and your family the goals that are important to you and include them in your plan of care.

### Hospice physician

The hospice physician is a trained specialist in treating pain and managing symptoms holistically. They collaborate with the patient's hospice attending provider and meet at least every two weeks with the Hospice Interdisciplinary Team. This coordination provides ongoing hospice and palliative care to meet each patient's individual care needs. A hospice physician makes home visits for symptom management as needed. One hospice physician serves as the medical director both providing direct care and ensuring that Asante Hospice provides high quality care.

## Meet the hospice team

### Nurse

A professional registered nurse is assigned to every patient to serve as the case manager, coordinating the team and arranging for the treatments and services that the provider orders.

- The nurse visits the patient. How often the nurse visits depends on the patient's needs at the time.
- The nurse assesses the patient; communicates with the patient, caregivers and providers; provides necessary treatments; and arranges for medications and equipment.
- The nurse trains caregivers to care for the patient at home.
- If you need a visit at night, on a weekend or on a day when the nurse case manager is not scheduled, a different nurse may visit. This nurse informs the patient's case manager about the visit.

### Medical social worker

The medical social worker can provide emotional and logistical support for the patient and family:

- Help find available community resources.
- Coordinate with other in-home services.
- Provide information about financial resources that may help meet the costs of a severe illness.
- Provide or arrange for individual or marriage and family support and counseling.
- Help you communicate with your spouse, friends and family.
- Offer information and assistance with advance directives for health care.
- Assist in assessing and, if needed, arranging placement for the patient outside the home.
- Assist in planning final arrangements.
- Give you information about the federal Family and Medical Leave Act.

Like all the team members, the medical social worker calls first to make an appointment with you. If you need to talk with a social worker when a visit is not scheduled, just call Asante Hospice, and we will arrange it.

### Spiritual counselor

A spiritual counselor is assigned to each patient and their caregivers. These skilled professionals are calm, compassionate listeners. Without preaching or imposing, they support you in your own belief system.

Spirituality is about those aspects of life that are not material, such as relationships, meaning and values. People may express their unique spirituality through religion or in more individual ways.

Many emotions, such as fear, anxiety, guilt and despair, may be examples of spiritual distress, which is common at times of change, such as a serious illness.

Here are some ways a spiritual counselor can help:

- Give unbiased, nonjudgmental spiritual or religious support.
- Explore questions about the meaning of life, suffering and death.
- Help find ways to complete a life's work and prepare for death.
- Offer tools such as ritual or guided visualization to move toward forgiveness, integrity, acceptance and peace.
- Contact members of the clergy or the minister of a specific church or faith community and complement that spiritual support.
- Administer sacraments, if desired.
- Assist in planning and carrying out funeral or memorial service arrangements.



## Meet the hospice team

### Hospice aide

Hospice aides are certified nurse assistants with additional hospice training. How often the aide visits is based on the patient's needs. We try to schedule the same aide for each visit.

Hospice aides help in multiple ways:

- Assist with personal care such as bathing, shampooing, dressing and care of the skin and mouth.
- Help the patient change positions in bed, help with transfers (for example, from bed to a chair) and help with walking if safe for the patient.
- Change linens and help with the patient's personal laundry if there are laundry facilities in the home.
- Clean the patient's bathroom after care and tidy up the bedside area.
- Prepare a light meal.
- Train the family to care for the patient.

### Nurse practitioner

The nurse practitioner is another member of the Hospice Interdisciplinary Team who may make home visits or be available as an attending provider. The nurse practitioner is an independently licensed clinician who works under the supervision of the medical director to provide holistic care.

### Bereavement coordinator

The bereavement coordinator is a certified grief counselor who reaches out to grieving families to offer counseling services and support. Be sure to provide the hospice team with contact information for each family member who might welcome this support.

### Volunteers

Asante Hospice volunteers are warm, caring people who give the gift of their time and energy to patients and their families. Volunteers provide practical assistance as well as companionship and understanding. They are screened and complete extensive training in hospice care and services before they make visits.

Volunteer visits last two to four hours, one day a week, usually the same day and time. Evening and weekend volunteers are also available. If you need to cancel a volunteer's visit, please call us as soon as possible, and we will contact the volunteer for you.

Here are some of the ways that volunteers can help:

- Sit with the patient while family members rest or go out.
- Provide companionship and emotional support for the patient and family.
- Assist with running errands such as shopping.
- Call you to check on how you are doing.

Volunteers are not allowed to:

- Provide nursing or personal care, including patient transfers.
- Pick up prescriptions or over-the-counter medications.
- Administer medication — unless it is premeasured and set out in advance by the caregiver; the patient must be able to take the medication with just cueing by the volunteer.

## Hospice bill of rights



### Patient rights

Hospice patients have the right to written notice of their rights and obligations before treatment begins.

#### A right to dignity and respect

- Hospice patients and their caregivers have a right to mutual respect and dignity without fear and prejudice.
- Hospice patients have the right to be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown source and misappropriation of patient property.
- Hospice patients have a right to have their property treated with respect.
- Hospice workers are prohibited from accepting personal gifts and borrowing from patients and their families.
- Relationships with hospice providers are based on honest and ethical standards of conduct.
- Patients and caregivers may voice grievances without fear of discrimination or reprisal.
- Patients and their families will be informed of the procedure they can follow to report complaints about care with the hospice provider.
- To report complaints with Asante, call **(541) 789-5005** and ask to speak with the hospice manager. Office hours are 8 a.m. to 5 p.m., Monday through Friday.
- Hearing-impaired individuals may contact Asante Hospice 24 hours a day through the state TTY exchange device number: **(800) 735-2900**.
- The Oregon Health Authority's hotline is **(800) 542-5186**. Call with patient complaints or questions regarding care. It is available from 8 a.m. to 5 p.m., Monday through Friday.
- For quality-of-care complaints, contact Kepro at **(888) 305-6759**.

## Hospice bill of rights

### A right to make decisions

You have the right to:

- Choose your own attending physician.
- Find out about and formulate advance directives for health care.
- Notice regarding the care that is to be furnished.
- Refuse any and all care, including medical and surgical treatment, if you so desire, and be advised of the consequences of refusing that care.
- Expect that within limits determined by your physician, you and your family will be taught about your illness so that you can help yourself and so your family can understand and help you.
- Participate in the planning of your care and any changes in your care.
- Be given advance notice of any change in your plan of care.
- Refuse services or request a change of caregiver without fear of reprisal or discrimination.
- Request a copy of the Asante Hospice policy governing admission to service and discharge from service.

### A right to privacy

You have the right to:

- Confidentiality of information about your health, your social and financial circumstances and what takes place in your home.
- Have information about you released only as required by law or as authorized by you and as consistent with Asante Hospice's internal policy.
- See your written service record by submitting a written authorization to Asante Hospice.

### Please **SPEAK UP**

**Safety first.** Speak up if you have concerns or questions.

**Pay attention** to your health care. No one knows your needs better than you do.

**Educate** yourself about your treatments, medications and diagnosis.

**Ask** someone you trust to speak up for you if you are unable.

**Know** about your medications. If you don't understand them, ask.

**Use** care providers and agencies that have good references.

**Participate** in your health care decisions.

### A right to financial information

You have the right to:

- Be informed of the extent to which payment may be expected from Medicare, Medicaid or any other payer known to Asante Hospice.
- Be informed of the charges for which you may be liable.
- Receive this information, orally and in writing, within 15 working days of the date that Asante Hospice becomes aware of any changes in charges.
- Have access, upon request, to all bills for service that you have received regardless of whether they are paid out-of-pocket or by another party.
- Be informed of Asante Hospice ownership status and its affiliations with any entities to which you are referred.

## Hospice bill of rights

### A right to high-quality care

You have the right to:

- Receive effective pain management and symptom control for conditions related to the terminal illness.
- Be assured that all Asante Hospice staff members are qualified, through education as well as licensure or certification, to carry out the services for which they are responsible.
- Be told what to do in the case of an emergency, including advice about a home evacuation plan, 911 and 24-hour hospice service availability.

### Notice of nondiscrimination

Asante complies with applicable federal civil rights laws and does not discriminate or exclude people on the basis of race, color, national origin, age, disability, sex, gender, sexual orientation, communicable disease or religion.

This statement is in accordance with the provisions of Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, Section 1557 of the Patient Protection and Affordable Care Act and regulations of the U.S. Department of Health and Human Services issued pursuant to these statutes at Title 45 Code of Federal Regulations Parts 80, 84 and 91.

Asante provides free aids and services to people with disabilities to communicate effectively with us:

- Qualified sign language interpreters or video remote interpreting services.
- Written information in other formats (large print, audio, accessible electronic formats).

Asante also provides free language services to people whose primary language is not English:

- Qualified remote interpreting services.
- Information written in other languages.

If you need these services, ask your health care provider. You may also contact the Resource Management Department or the hospital's house supervisor.

If you believe that Asante has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with:

Asante Corporate Compliance Officer  
2650 Siskiyou Blvd.  
Medford, OR 97504  
**(541) 789-4816**  
TDD or state relay: **(541) 789-7104**

You can also file a civil rights complaint electronically with the U.S. Department of Health and Human Services through its Office for Civil Rights Complaint Portal at [ocrportal.hhs.gov/ocr/portal/lobby.jsf](http://ocrportal.hhs.gov/ocr/portal/lobby.jsf) or by mail or phone at:

U.S. Department of Health  
and Human Services  
200 Independence Ave. SW  
Room 509F, HHH Building  
Washington, DC 20201  
**(800) 368-1019**  
TDD: **(800) 537-7697**

Complaint forms are available at [hhs.gov/ocr/complaints/index.html](http://hhs.gov/ocr/complaints/index.html).

## Practical matters



### Patient responsibilities

As a patient of Asante Hospice, it is important that you participate in the care you receive. This participation includes the following responsibilities that you assume.

You will:

- Remain under the care of a qualified attending provider while receiving hospice services.
- Provide Asante Hospice with a complete and accurate health history.
- Provide Asante Hospice with all requested insurance and financial information.
- Sign the required consents and releases for insurance billing.
- Provide a safe home environment in which care can be given.
- Unload and safely secure firearms during hospice visits.
- Treat Asante Hospice personnel with respect and consideration.
- Abide by Asante policies that restrict the duties its staff may perform.
- Participate with the physician and the hospice team in the development of your plan of care and in any changes to that plan, by asking questions, expressing concerns, making suggestions and giving approval or disapproval.
- Follow to the best of your ability the plan of care, orders from providers and suggestions of the hospice team.
- Take medications as prescribed and report any possible adverse reaction immediately.
- Report to the hospice team any changing or newly occurring physical symptoms.
- Notify the hospice team of changes in residence or phone number.
- Notify Asante Hospice in advance if a visit is to be canceled.
- Advise Asante Hospice administration of any dissatisfaction or problems with care.
- Accept responsibility for any refusal of treatment.

## Practical matters

### Making decisions about medical treatment

#### Who decides about medical treatment?

If you are unable to make decisions and have no written instructions, your provider will ask your closest available relative or friend to help decide what is best for you. That may work, but sometimes there is disagreement about what you would want. That's why it is helpful for you to fill out an advance directive — a legal document that provides directions for your health care if you are unable to speak for yourself or make decisions.

#### What is an advance directive, and who can fill one out?

The Oregon Advance Directive is a preprinted “fill in the blank” form that lets you name a representative to make health care decisions for you when you are unable. This can be any adult relative or friend. It also prompts you to say when you would and would not want certain kinds of treatment. Anyone who is 18 years or older and of sound mind can fill out this form. You do not need a lawyer to authorize it.

#### How can I get more information about an advance directive?

If you already have a completed advance directive, please provide a copy to Asante Hospice so that it can be kept in your health record. If you have questions about any such forms, please talk with the medical social worker.

#### Are there other living wills I can use?

Yes, you can use any available forms — or write your wishes on a piece of paper and then sign and date it — but we recommend completing an Oregon Advance Directive.

#### What is a Physician Orders for Life-Sustaining Treatment form?

Your provider uses the Physician Orders for Life-Sustaining Treatment, or POLST, document to turn your medical decisions into medical orders. It states how much and what kind of life-sustaining medical treatment you want or do not want. This includes such treatments as cardiopulmonary resuscitation and mechanical ventilation.

The bright-pink-edged POLST form must be signed by an authorized health care professional before it can be followed. After being signed, the original POLST form is returned to you to post in your home on the front of your refrigerator or by your front door. The medical social worker can help you start a POLST form.

#### Getting affairs in order

As difficult as it is to think about dying, it is often wisest to address some of these issues early on because it is usually even more difficult to take care of them during a crisis. If you need assistance with any of this documentation, the medical social worker can help (*see Important documents on page 42*).

## Practical matters

### Estate planning

A current will or living trust makes things easier for the patient's loved ones. There will be fewer questions about what the patient's wishes really are. Sometimes it is helpful when the patient makes a list of items to be given to specific people or presents the items to loved ones personally.

### Final arrangements

Planning your loved one's final arrangements may seem like something you want to avoid, but it is less painful to do it now than at the time of death. The biggest task is choosing a mortuary or funeral home. You can ask friends or neighbors for recommendations, or the medical social worker can help you choose one.

Planning ahead allows you to:

- Involve the patient if desired.
- Plan carefully, take your time and be more objective.
- Decide what type of memorial service there will be, if any; who and what will be included; and when and where it will be held.
- Begin setting aside funds to cover the memorial or funeral costs.
- Discuss arrangements with several funeral homes to find the one that best suits your needs.
- Consider options such as burial or cremation.

Once you have selected a mortuary or funeral home, you can begin planning.

- Visit or call the funeral home to make initial arrangements, get a cost estimate and find out about payment plans.
- Plan the service with a clergy member, the funeral director or the hospice spiritual counselor.

- Select clothing and jewelry for the funeral or cremation.
- Plan for the storage or dispersal of cremated remains.
- Arrange for a burial plot and a marker if the patient's wish is to be buried.
- Select pallbearers and invite them to participate. If someone is physically unable, consider an invitation to act as an honorary rather than a literal pallbearer.
- Gather vital information that you will need for the death certificate and an obituary notice.
- Plan for the disposition of flowers.
- Decide which organizations will receive memorial donations.

### Caregiving

#### When you need more help

Sometimes people need help with household chores and personal care. The first step is to determine exactly what you need. The medical social worker can help you decide and can also suggest the appropriate level of care. The social worker also knows about federal, state and local resources that may be available to reduce or cover the costs of care.

If you have long-term-care insurance, the policy may cover part of the costs. Call the insurance company to file a claim before you make changes that would depend on insurance benefits. Medicare and private insurance plans do not cover personal care costs, and Asante Hospice cannot provide 24-hour or shift caregiving. It is your responsibility to provide for personal care for the patient. The social worker can help you explore options.

## Practical matters

### Finding a caregiver

Finding the right caregiver can be a challenge. The medical social worker can help you determine the appropriate level of care for the patient and exactly what assistance you need.

The social worker can also help you decide whether to hire someone privately or through an agency. Caregiving agencies are licensed and bonded and have liability insurance. The agency is responsible for finding a substitute if the regular caregiver cannot come. Hiring a private caregiver does not have these advantages, but it may be less expensive. Hiring privately, however, places responsibility on you as the employer to withhold or pay taxes, Social Security and workers' compensation insurance.

There is a lot you can do to make hiring a caregiver go well, so remember that the social worker is always available to help you.

### Options for placement

No matter how much you want to care for your loved one at home, there may come a time when the weight of caregiving becomes so great that you must consider a move to another setting.

Here are just some of the factors that may lead to this decision:

- **Burdensome incontinence** – when it is difficult for caregivers to keep the patient's skin clean and dry, and the patient is at risk of skin breakdown.
- **Too much heavy lifting** – when the patient can no longer assist in turning and lifting, and the caregiver is not able to safely help.
- **Sleep deprivation** – when the caregiver's sleep is disturbed on a regular basis, and the caregiver is not getting enough sleep.

- **Injured or sick caregiver** – when the caregiver is neglecting their own injury or illness that requires medical attention or rest.
- **Other stress** – when there are other stressors taking an excessive toll on the caregiver.

Making the decision to leave home is hard, especially if promises may have been made that the patient could stay at home. If care needs have changed, however, staying home may no longer be the best choice for the patient or family.

The patient or some family members may find this decision difficult to understand and may have strong feelings about the move. The caregiver may feel guilty. The hospice team will support both patient and caregiver during this time. They can ease the transition by helping arrange the transfer, and Asante Hospice will continue providing care to the patient in the new location. The hospice nurse will continue overseeing the professional nursing management of the patient's care, regardless of the setting.

The financial responsibility for the placement is the patient's. Medicaid (the Oregon Health Plan), Veterans Health Administration assistance and long-term-care insurance may help with payment. Medicare and other private health insurance do not cover the cost of alternative residential care.

Residential facilities provide a range of care levels, so there are multiple options from which to choose:

- Assisted-living facilities.
- Residential care facilities.
- Adult foster homes.
- Memory care units.
- Nursing facilities.

The medical social worker can discuss each option with you and your family and help you decide which one best suits your needs.





## Common emotions

When someone has a life-threatening illness, the patient and family experience a wide range of emotions. These emotions may come at different times for each person involved. Not everyone experiences these emotions or has them in a given order; but because many people do, it may be comforting to know that these reactions are normal and that other people in your situation have similar responses.

One woman compared being incurably ill to being dropped into a foreign land where everything was suddenly strange and unfamiliar. The seriousness of the illness may be new territory for you and your loved ones. Some things may frighten you, but you may also discover moments of great insight and deep love. Many families say that this time together is rich and rewarding. They describe opportunities to learn about themselves and one another, to achieve a deeper understanding of their beliefs and to express feelings for those they care about.

To stay open to these opportunities for growth, you may need to come to terms with some of the more difficult feelings that arise so that they do not dominate your life. Some of these feelings may be new to you or stronger than

ever before. This section explores what others who have taken a journey like yours have felt. You can take from it what feels right and is useful to you and just leave the rest.

## Shock

Shock is a normal reaction to a difficult situation. It is the mind's way of protecting itself until it is strong enough to cope. Shock gives time for an overwhelming concept to sink in. You could feel confused or disoriented.

When we are with someone in shock, we need to be available, listen without judgment, encourage the expression of feelings and repeat information several times.

## Anger

Anger is a natural response to news of a serious illness. You have the right to feel angry and to all of your other strong feelings. Constructive outlets for working through anger can be verbal or nonverbal, including exercise, physical exertion, crafts, art, music, journaling and talking with others.

If such anger is directed at you, recognize it for what it is, acknowledge your own reactions and be as tolerant as possible. Take a break and come back when you are ready.

## Emotional care

### Sadness and grief

When the shock and anger ease, sometimes a great sense of loss settles in. This sorrow can be a reaction to decreased physical ability, financial strain or family upheaval, or it may occur when facing impending loss. For patients it is the sadness of knowing that they will lose their connections to familiar people, places and things. For both patients and caregivers, it is mourning the future that will never be.

It is important to acknowledge these feelings of sorrow. We should not cut off someone's expression of loss or try to jolly them out of sadness. Grief comes with terminal illness and is part of the process of letting go.

Hope diminishes sadness. You may find that over time what you hope for changes, but you can still identify dreams, goals and outcomes you would like to achieve. For example, a patient may hope to remain physically comfortable, see a newborn grandchild or attend a family reunion.

### Anxiety and fear

While some fear is natural, at times it can be all-consuming. Confronting your fears head-on may decrease the amount of fear in your life. It may help to talk about your fears with someone you trust — maybe a member of the hospice team. Some fear may arise from not having information you need. Remember, there is no such thing as a dumb question where your wellbeing is concerned. When you feel uncertain, ask.

### Guilt

Guilt is a big issue for many who are seriously ill. The patient may spend a lot of time thinking about what the illness is doing to their loved ones. They may worry about being a physical and financial burden or about inconveniencing those they care about. Maybe their role before the illness was to look out for everyone else, and now everyone else is looking out for them. Family and friends are also likely to have their own feelings of guilt and regret.

It is important to remind yourself that no one chose this situation — it just is. Caring for the patient lets loved ones show their concern. Guilt may arise, but you can choose not to dwell on it. As a patient, you do not need to apologize for your illness.

The medical social worker and other hospice team members are here to help you; they are available to talk about your feelings and physical well-being at any time.

### Feeling overwhelmed

Medical problems and all the changes they bring about can be hard to take. Each day do what you can and forgive yourself for what you cannot do. Give yourself the same support that you would give your best friend.

Laughter can often make situations a little more tolerable. Spend time with friends and family members who leave your heart lighter after a visit. You have the right to limit time spent with people who do not add to the quality of your life.

## Emotional care

### Loneliness and isolation

A shared load can be lighter. Sometimes an illness yields an opportunity to learn or to teach others to be gracious receivers after a lifetime of giving. Clear communication helps others care for and support you in the way you would like them to.

- Let others know how they can best help you, including being clear about what you would like to do for yourself.
- Be clear about how much information you want about the illness, when you need to talk and when you need a break from serious business.
- When you have something you need to talk about, choose the best time, place and person. Sometimes privacy is hard to come by. You have the right to private conversations with anyone you wish.

### Acceptance and accommodation

Many patients move beyond anger and sadness, acknowledging and accommodating what is happening to their body and preparing to leave it. This is often a quieter time for the patient, with less interest in the outside world. Family members who reach acceptance may be able to give their loved one “permission” to go. One way to give permission might be to say, “I love you more than anything, and I will miss you so much, but I will be OK.”

However you choose to travel this journey, Asante Hospice is there to support you — all the way.

### Just for the caregiver

Caregivers have many important responsibilities including maintaining their own physical, mental and spiritual health. Most people have not cared for someone at end of life before, but with the help of the hospice team we hope you can avoid burnout and feel you have done a good job.

### Physical health

Your loved one’s needs for care are likely to increase over time. It may be more important for you to rest and prioritize other tasks. Ask for help from friends and relatives. If you don’t ask, they may assume you do not want or need their help. Invest in short periods of exercise. This can increase your energy, serve as an outlet for strong feelings and help you rest better.

Even if your loved one is no longer eating regularly, you still need to eat. Keep a stock of high-quality, nutritious foods that need little preparation. Avoid getting in a junk food rut and be aware of excessive smoking or drinking.

Fatigue can rapidly affect your mood and outlook. Sleep is very important and may be difficult, but it is critical you get adequate rest. Avoid caffeine, alcohol and tobacco; all three disrupt your sleep cycle. You may find an afternoon nap refreshing. Sometimes you can rest while the patient is sleeping.

You may also request a volunteer sit with the patient so you can catch up on your sleep, shopping, or anything else you have been putting off. If anxiety is interfering with your ability to rest, ask the medical social worker for suggestions.

### Mental health

You may not be able to eliminate the causes of stress right now, but you can work to manage your stress in healthy ways. Here are some suggestions:

- Set limits on what you will do.
- Work through feelings by writing, exercising or other activities.
- Have a good cry.
- Talk with friends, the medical social worker, a spiritual counselor or private counselor.
- Use relaxation techniques, such as deep breathing, meditation or visualization. The social worker or spiritual counselor can help you.

## Emotional care

- Consider joining a caregivers' support group.
- Have a laugh with a friend or watch a favorite comedy.
- Spend time with a pet.
- Continue your favorite activities as much as possible.

Caregiving does not have to be perfect to be good enough, so avoid judging yourself; you are doing the best you can. You are giving the precious gift of yourself and your time for the patient to be comfortable and respected.

You will be more refreshed and relaxed and will make better decisions if you share caregiving responsibilities. This is not being selfish, this is survival. Your loved one may feel like less of a burden knowing you are getting out occasionally. So, accept offers for breaks from friends, family members and hospice volunteers. Hire help if you can. It is OK to have fun.

When there is a history of a strained relationship with the patient, you may hope the relationship will be repaired with the changes the patient is going through. There is always hope, but people do not change who they are in illness or in dying. We can change how we react to our loved one and that might provide some healing. We can only change ourselves, not others.

Ira Byock, MD, an expert in palliative care, recommends four simple phrases that can help resolve difficulties with love. They can be powerful to say even if you feel there is nothing to forgive:

1. *Please forgive me.*
2. *I forgive you.*
3. *Thank you.*
4. *I love you.*

### Spiritual health

This may be a time when your search for meaning, purpose and connection feels more urgent.

Suggestions include time for prayer, reflection, daydreaming, yoga or listening to music. It can be helpful to visit nature or a place of worship. Recordings of religious services, podcasts, inspirational books or other sources of messages may speak to you. Active options include gardening, taking walks and dancing. The spiritual counselor is available to help you connect with your values and address concerns about your future.

### Burnout

The sooner you address signs of burnout the better. Signs of burnout are different for everyone, but these are common:

- **Physical.** Fatigue or feeling tired despite getting enough rest; frequent illness; or often having accidents.
- **Emotional.** Feeling impatient, irritable, forgetful; not being motivated; no enjoyment or any feelings at all.
- **Loss of coping.** Denying any of the above symptoms; an increase in compulsive behaviors; stopping hobbies, recreation or social contacts.

The hospice team can help you develop a plan to address and recover from these symptoms. Remember, Asante Hospice provides respite volunteers. If needed, we also may be able to arrange a five-day respite in a nursing facility for the patient.

## Emotional care

### When there are children in the family

No matter how hard you try to protect them, children, grandchildren and teenagers are nevertheless affected by a serious illness in the family. They usually need some age-appropriate guidance for coping with the changes that illness brings. Here are some general guidelines that adults can follow to help children cope.

#### Provide accurate information

Children are sensitive and usually know when significant changes are under way. Keeping information from children just makes them feel alone. Use simple language and be as specific as possible. Call the disease by its name, such as “lung cancer,” “diabetes” or “heart disease.” Describe why certain changes are happening and why the patient is using medical equipment. For example, “Uncle Mike has a mask and oxygen tanks in his room to help him breathe better.” When a child asks if the patient is going to die, it is best to be gentle but honest: “Yes, I think he will. He has a very serious illness, and his body is too sick to keep going much longer.”

#### Answer their questions

You cannot always guess what children are wondering or worrying about, but you can always answer their questions. Children whose questions go unanswered will fill in their own responses. Their imaginations often come up with explanations that are much worse than reality, so it is important to answer their questions simply and directly. Children will ask for what they need to know, and their questions will change with age. They need reassurance that people do not die from most illnesses and that the patient’s illness is not the child’s fault.

### Keep their routine

Children need reassurance that they will always be taken care of even if their primary caregiver is sick. If friends or family members have offered to help, suggest that they spend one-on-one time with the children. Frequently, children have been getting less attention due to the illness. Friends and family can also help the children maintain their routine activities, like providing rides to soccer practice or music lessons. Children may need help understanding the changed behavior of the adults around them. Adults are likely to be sad, irritable or distracted due to worry and fatigue. Children need to know that they are not the reason why the adults in their lives are acting differently.

### Let them participate

Children should be allowed to visit, touch and talk with the patient and to participate in any important family gatherings. It is appropriate for adults to display some of their strong feelings in front of the children. Those feelings are part of life. While we do not want to frighten children by acting out of control, showing little or no emotion can also be damaging. If no one seems to be showing their feelings, children might wonder whether the adults really care and will wonder if their own strong emotions are normal. It is also important not to go to children for your own emotional support. That is too much weight for young shoulders. Ask for support from family members, friends or the hospice spiritual counselor or social worker.

Asante Hospice has many books, coloring books and other resources to help children cope with grief and loss. The social worker is always available to talk with you and the children in your family.

## Grief and bereavement

### A natural process

Grief over a death is a natural part of life that people express in their own ways. There is no timetable for grief, and there is no right or wrong way to express it. Grief can come and go and pop up at surprising times. Sometimes important dates like a birthday, an anniversary or a holiday can reawaken or intensify grief.

Grieving takes different forms at different times. Initially, you may feel disbelief and expect to see your loved one even though you know that they are gone. You may feel angry at being “abandoned” by your loved one. You may feel sad and relieved all at once. You may feel regret — for your anger, for surviving your loved one or for things you might have said or done (or did not say or do). All of these feelings and more are normal.

Grief can be overwhelming at first, but it is important that you not neglect your own needs. You may not feel like eating, but you need to eat healthy foods and keep up your strength. You need rest. If you cannot sleep or cannot make yourself get up, tell your provider about your loss and how it is affecting you. Alcohol and mood-altering medications should be avoided at this time. Stay active — get out and take a walk. Find a sympathetic person to talk with about your grief.

### Asante Hospice bereavement services

In times of grief and difficulty, having someone to talk with may make all the difference. One of the most important ways Asante Hospice helps bereaved families and friends is through our support groups. For some people, grief is a private experience that cannot be shared; for others, talking about it and listening helps ease

the pain. Shared bereavement gives us hope of getting through difficult times and learning positive ways to cope with loss.

Our support groups provide education, companionship and emotional support in dealing with grief and adjusting to a new life situation. Each session includes time for an informational presentation, personal sharing and social interaction. This eases the transformation of grief and loss into healing, growth, strength and hope.

Grief support groups are open to the community, and there is no fee to attend, but please call ahead. Asante Hospice will contact the families of our patients about bereavement. Others who are interested in support groups may call our bereavement coordinator at **(541) 789-5005**.

Asante Hospice also offers one-on-one counseling for children and adults with our certified grief counselor. This service is free for one year after the patient’s death. Counseling services are intended for individuals who want to explore their grief-related feelings and emotions. Sessions take place in person or by phone.

### Other resources

Asante Hospice also provides information about other bereavement groups and services in the area. Call us to learn about community resources that are available to serve specific needs, such as those following the death of a child or spouse, a violent death or a suicide. Resources tailored to the special needs of grieving children and teens are also available, and we can make professional referrals to help those experiencing complicated grief.

***There is no way out of the desert except through it.*** — African proverb

## At-home infection prevention



### Use the proper procedure

Lather your hands with soap and water, vigorously rub together all surfaces of your hands for 10 to 15 seconds, then rinse under running water. Dry with a clean towel or paper towels.

Infections can be a major health hazard. An infection is a disease that results when germs invade and grow in the body. Some infections can cause a short illness, whereas others can be very serious. The infection may involve a body part or the whole body.

Notify the nurse if the patient develops any of the following signs or symptoms: fever, pain or tenderness, fatigue, loss of appetite, nausea, vomiting, diarrhea, rash, sore on mucous membranes, redness or swelling of a body part, and discharge or drainage from any area of the body.

Patients and caregivers can help prevent infections by observing the following guidelines.

### Hand washing

Hand washing is the single most significant way to prevent the spread of infection.

- Wash your hands before and after providing care.
- Wash your hands before and after preparing food.
- Wash your hands before and after eating.
- Wash your hands after using the bathroom.
- When possible, provide liquid soap and paper towels for the hospice staff to use.
- Expect staff to wash or sanitize hands before and after touching the patient.

### Home environment

- Each family member should have their own towels, washcloths, toothbrush, drinking glass and other personal-care items.
- Wash cooking and eating utensils with hot soapy water after use.
- Do not leave food sitting out and uncovered. Close all food containers.
- Refrigerate foods that will spoil.
- Keep hot food hot and cold food cold.
- Clean cooking and eating surfaces daily with soap and water or a disinfectant.
- Clean bedrails and bathroom surfaces — bedside commode, sink, toilet, toilet seat and floor — routinely with disinfectant, bathroom cleaner or detergent and water.
- Damp-mop uncarpeted floors at least once a week.
- Soiled bed linens should be changed immediately and washed in hot water and detergent. Heavily saturated or bloody linens may be rinsed in cold water first to minimize stains. Wash separately from other laundry.
- Other specific precautions to prevent infection in a particular situation will be addressed, as needed, by the hospice nurse.

**Always call hospice first in an emergency involving the patient: (541) 789-5005.**

## Training for symptom management



### Pain

Keeping the patient's pain under control is one of the hospice team's most important goals. Not all patients have pain, but it is a significant concern for those who do. The whole team — patient, caregivers, hospice staff and attending provider — work together to keep the patient's comfort a top priority.

Hospice patients can expect:

- A concerned staff committed to pain prevention, monitoring and management.
- That reports of pain will be believed.
- Health professionals who respond quickly to reports of pain.
- To receive information about pain and pain relief measures.
- Multiple approaches to pain management if needed.

Asante Hospice strives to improve the quality of patients' lives by helping them remain comfortable. Being comfortable may even enable the body to better fight disease.

Patients in pain tend to eat less, avoid visitors, move around less and breathe more shallowly. Pain can cause anxiety, fear, insomnia, fatigue and depression, which in turn can make pain

worse. It is important to “stay on top” of pain. The first step in good pain management is to ask the patient to be as accurate as possible when describing any kind of pain. If the pain is described as “burning,” the provider may prescribe a different medication than if the patient describes it as “achy.”

Many people report less pain than they actually feel. This occurs for several reasons. Some assume that they simply must live with pain. Others feel that it is a sign of weakness to admit to having pain. Still others fear addiction or think they need to save the “strong stuff” for later. All pain is real, and only the person experiencing it can say what the pain is like.

Pain is subjective and individual — and it changes. Pain varies with type, site, intensity, time and frequency. We help the patient describe their pain by asking the following questions:

- What hurts?
- Where does it hurt? Does the pain radiate to another location?
- When does it hurt — morning, noon, night, occasionally, frequently, constantly?
- How does it hurt — dull, radiating, squeezing, stabbing, nauseating?



## Training for symptom management

### Pain scale

Mild	Moderate	Severe
<ul style="list-style-type: none"> <li>■ Pain is hardly noticeable — mildly distracting.</li> <li>■ The patient is still able to do most activities.</li> </ul>	<ul style="list-style-type: none"> <li>■ Pain is hard to ignore and is interrupting activities.</li> <li>■ The patient avoids most activities due to pain interference.</li> </ul>	<ul style="list-style-type: none"> <li>■ Pain is the focus of attention.</li> <li>■ Pain makes many activities impossible.</li> <li>■ Pain is as bad as it could be; nothing else matters.</li> </ul>

### Pain scales

When describing pain, it is often useful to use a scale. The patient can describe their pain with pictures, words or numbers. Pain can be rated from 0 (none) to 10 (most) or from minor (1–3), to moderate (4–6), to severe (7–10).

If the patient is unable to speak, the nurse observes them to assess signs of pain and can train you to do the same.

### Pain medications

Mild to moderate pain may be controlled with aspirin, acetaminophen (Tylenol), naproxen (Aleve) or ibuprofen (Advil or Motrin). If the patient is taking any of these medications, tell the nurse. There may be times when they should be avoided.

A stronger medication may be required to manage pain. It is important to know that there is no need to save stronger medicine for “the end.” If the pain gets worse, medications can usually be adjusted to provide continuous pain relief.

Pain medications come in many forms: syrups, liquids, pills, capsules, patches, suppositories, injections and IV mixtures. The hospice team will determine the best route of administration based on the patient’s individual circumstances.

### Adjustment time

Stronger medicines may contain an opioid such as oxycodone, morphine, fentanyl or hydromorphone (Dilaudid). When taken for the first time, these medications may cause drowsiness or nausea for a couple of days, but these symptoms will pass. Sleepiness may also be because of poor sleep due to pain.

Because the nurse needs to know how well the pain medication is working, they will ask the patient to rate the pain using a pain scale; the nurse may then adjust the dose or schedule.

Almost everyone taking opioid medications needs a laxative to prevent constipation. If nausea persists, that too can be controlled with medication.

### Regular schedule

Many of us try to avoid taking medications, but it is better to treat the pain early, before it becomes severe. Once the pain is severe, it is harder to get under control. Most pain medications are prescribed to be given at regular intervals; the next pill is given before the previous one completely wears off, to “stay on top” of the pain. This may even mean waking the patient at night to take medicine if the dose is every four hours. Do let the nurse know if the patient routinely has pain before the next dose of medicine is due.

## Training for symptom management

### *Addiction*

Addiction is the use of substances because of psychological dependence even though they do not improve quality of life. Because hospice uses opioid medications for our patients, we need to know if the patient, family or anyone involved in care has a history of substance use. If so, we will address this with you and the hospice team and will put additional measures in place to ensure your family's comfort and safety.

We believe that these medications are beneficial at the end of life by enabling less pain, less trouble breathing, better sleep, a better quality of life and maybe even an extended life. If anyone around the patient may be at risk of overdose, we recommend asking the provider or pharmacy for naloxone.

### **Other pain relief**

In addition to medication, there are many things you can try to ease the patient's pain.

### *Distraction*

When a person is distracted, their mind does not register pain as intensely. If pain is severe, however, it is hard to focus on anything else. When pain is somewhat controlled, taking one's mind off it may help. Try reading, listening to music, looking at photo albums, watching television or writing letters. Daydreaming, playing with a pet and visiting with friends also work well.

### *Relaxation*

Relaxing is a way to release muscle tension and reduce pain. The medical social worker can teach you ways to relax and may suggest guided imagery or listening to relaxation recordings.

### *Meditation or prayer*

Meditation is a conscious effort to relax the mind and body by tuning out external stimuli and focusing on something else. Mindfulness meditation is paying attention to your breathing and then simply noticing what comes to mind.

For some people, prayer is comforting and reduces pain.

### *Therapeutic touch*

This form of very gentle massage can sometimes relieve pain. Check with the nurse before you try deep massage.

### *Heat*

Applying heat can sometimes be effective for muscle aches, but it requires careful attention. Whether using a heating pad or a gel pack heated in the microwave, always keep the heat low. It is very easy to burn the skin, especially of frail people. Never allow the patient to sleep with a heating pad because even at lower levels prolonged heat can cause damage.

### *Cold*

Applying cold is quite effective for many kinds of pain. Cold can be applied with a flexible frozen gel pack, an ice bag or simply a plastic zip bag filled with crushed ice. It is a good idea to wrap the ice pack in a washcloth or towel before applying. Never put a cold pack directly on the skin. If the cold works but the patient is too chilled, try applying gentle heat to another part of the body at the same time.

### *Breathing*

Patients who are anxious or in pain may not be taking deep breaths. Remind the patient to breathe slowly and deeply to reduce anxiety and pain. The hospice team can teach you deep-breathing exercises.

## Training for symptom management

### How to breathe better

Trouble breathing can result from diseases such as heart and lung disease, anxiety and more. It can feel like shortness of breath or trying to catch your breath. If you must think about your breathing, treat it before it gets uncomfortable.

### What to do if you experience trouble breathing

1. Raise the head of the bed, add pillows or come to a sitting position.
2. Take medication or breathing treatments. (See your medication sheet in your binder for directions.)
3. If on oxygen, check the tubing to make sure there are no kinks or blockages preventing flow.
4. Turn on a fan or open a window to increase air flow.
5. Put a cool damp cloth on your forehead or neck.
6. Belly breathe. **Inhale** through your nose and feel your belly **inflate** like a balloon. **Exhale slowly** through your mouth like you are whistling by pursing your lips. Repeat this cycle five times, and again as needed.
7. Sit with your feet flat on the floor, lean forward and rest your forearms on your knees or a table.



If you have oxygen in the home but have not used it and would like to try it, connect the tubing, apply the cannula to the nose, turn on the machine (concentrator) and use as directed. Place setting on “2L” if you have not received directions yet.

If you have any questions, or need help or support for trouble breathing, please call:  
**Asante Hospice (541) 789-5005 any time, day and night, 24/7.**

## Training for symptom management

### Bowel changes

#### Constipation

Many things can contribute to constipation, or passing stools less often than usual; these include eating less, drinking less fluid, decreasing activity, decreasing muscle tone and especially taking opioid pain medications. Constipation can cause discomfort, loss of appetite, heartburn and nausea.

Even a patient on a liquid diet or eating almost nothing should have regular bowel movements that are more than a smear. Tell the nurse if it has been longer than two or three days since the patient's last bowel movement.

Here are some tips for preventing and treating constipation:

- Most patients who take an opioid daily (except those with an ileostomy) should also take a laxative daily, such as senna (Senokot) or polyethylene glycol (MiraLAX).
- If the patient is constipated, have them try lying on their left side with a warm compress on the belly — and call hospice.
- Some patients can help prevent constipation by exercising; by increasing their fluid, fruit, dried fruit, vegetable, prune juice or fiber intake; or by having a warm drink with meals.

Keep a record of the patient's bowel movements, as needed. The nurse will ask about bowel movements and adjust medications if necessary.

#### Diarrhea

Some disease processes or dietary changes can cause diarrhea, or loose stools. Be sure to tell the nurse if the patient has diarrhea.

Here are some suggestions for addressing it:

- It is important to replace fluids lost through loose bowel movements, but avoid drinks containing caffeine (such as coffee, tea and cola), which stimulate the bowel.
- Hot drinks stimulate the bowel, so keep them tepid.
- Avoid fruits, fruit juices, raw vegetables and most dairy foods; also avoid fried, spicy, highly salted and fatty foods.
- Try clear liquids like broth, tea and Jell-O.
- Also try dry toast, crackers, bananas, applesauce, rice, low-fat yogurt, cottage cheese or baked potatoes (but skip the butter and sour cream).
- Diarrhea stools tend to be very irritating to the skin, so be sure to wipe well and wash thoroughly after each loose stool.

#### Incontinence

Incontinence is the loss of control of bladder or bowel function. This is normal at the end of life. The nurse or hospice aide can discuss with you ideas for managing it.

#### Nutritional issues

Food often symbolizes life and love and caring. When a life is ending, the need for food decreases — but the desire of family and friends to provide it does not subside. Sometimes patients eat when they are not hungry simply to satisfy others. Letting a person who is edging toward death refuse food may be one of the hardest — but kindest — things you can do.

## Training for symptom management

### Eating tips

While the patient still feels like eating, the following suggestions may help.

- Let the patient decide if and what they want to eat or drink.
- Offer small frequent meals throughout the day rather than a few large ones.
- Give the patient plenty of time to eat and stay with the patient to keep them company.
- Offer food when pain and nausea are under control and at the time of day when the patient's energy is highest.
- It is more important for the patient to enjoy the dining experience than to eat nutritious foods.
- If solid food is too difficult, try smooth, soft foods that are easy to swallow, such as pudding, smoothies, yogurt and ice cream.
- Make sure a patient who is eating in bed is sitting up to prevent choking. If choking is a problem even when sitting up, thicker liquids (such as fruit nectars, creamed soups and milkshakes) may be tolerated better than thin ones (such as water, tea and juice).
- Consider keeping a small cooler at the bedside for drinks and snacks. This makes it easy to offer foods often, and the patient does not feel like they are inconveniencing you.
- Straws, medicine droppers, and cups with lids may be useful.

### Loss of appetite

As body systems wind down, so does the ability to digest food. Often tastes change and old favorites are no longer appealing. Solid foods, especially meat, become unappetizing and too difficult to chew and digest. Later the patient may prefer only liquids and at some point not even those.

If you remember only one thing about food and the hospice patient, remember that it is OK not to eat.

### IV fluids and tube feeding

When a patient is naturally declining, intravenous and tube feedings may actually overload the body and cause swelling, discomfort, trouble breathing and increased oral secretions. Instead of making patients feel better, these treatments may make them feel worse.

As difficult as it may be, we must try to honor what the patient's body is telling us. There is some evidence that when a patient stops taking fluids, they may feel less pain and be somewhat more alert. Nature seems to tell us to stop eating when it will benefit us the most. Someone nearing death needs very little fuel, and their body will supply that.

### Nausea

Nausea can greatly diminish quality of life, so controlling it is an important goal of the hospice team. Like other symptoms that may arise, nausea is often best managed by employing several different methods to help control it.

Nausea occurs when an area deep in the brain responds to some kind of irritant. Any number of things can provoke this, but among the most common are disease, medications, motion, constipation and odors. Others include fear, anxiety, chemotherapy, radiation and even talking about nausea. Although everyone responds differently, the following suggestions may be useful in reducing the patient's nausea.

## Training for symptom management

### Foods

- Upon their waking, offer the patient dry soda crackers.
- Before the patient gets up, offer clear liquids until the nausea settles down (broth, weak tea, ginger ale, apple juice, Jell-O or popsicles).
- Ginger in any form can help.
- Provide bland foods and avoid spicy ones. Also avoid foods with strong, distinctive smells.
- Encourage the patient to nibble, eat slowly and have multiple small meals rather than a few large ones.
- Serve cold foods, as they often have less odor.
- Limit liquids at mealtimes. Encourage the patient to take fluids an hour before or an hour after eating and to sip fluids slowly.
- Offer the patient hard candy or fruit-flavored ice — but only to suck on, not to chew.

### Environment

- Keep the air in the room as fresh and cool as possible.
- Remove sources of odors. Even cooking odors that once were pleasurable can now trigger nausea.
- Raise the patient's head with pillows or elevate the head of the bed.
- Keep the patient sitting up for an hour or two after eating if possible.
- Relax as much as possible. Try slow, deep breathing or listening to relaxation recordings (*see Other pain relief on page 22*).

### More help

- Look for a pattern when nausea occurs and report it to the nurse. For example, you notice that nausea occurs after lunch or every evening after taking medicine.
- The provider may prescribe anti-nausea medication, which the nurse can teach you to administer.
- Keep the nurse informed about the patient's nausea and most recent bowel movement.

### Mouth issues

#### Dry mouth

Often during illness, people do not drink as much as they normally would, and the mouth becomes dry. Some treatments and medications can add to this problem. If the patient sleeps with their mouth open, that too causes dry mouth.

Here are some suggestions:

- Hard sour candy like lemon drops helps draw out saliva, as does chewing gum. To prevent choking, these should be used only when the patient is wide awake and not likely to fall asleep.
- Ice chips (flavored or unflavored) and frozen juice bars to suck on can relieve dryness for a while.
- Artificial saliva is available at drug stores and pharmacies and is pleasant tasting. It is sprayed into the mouth.
- A small mist bottle filled with water can also be used. A drop of lemon juice or glycerin may be added.
- Petroleum jelly applied to the lips can help prevent cracking — however, do not use petroleum-based products to lubricate the lips or nose if the patient is using oxygen (*see Oxygen therapy on page 38*).

## Training for symptom management

### Teeth brushing

Ideally, the patient should brush their teeth after meals, using a soft toothbrush and just a little toothpaste. If you are helping a bedbound patient, have them sit up to avoid choking. Place a towel across their chest and provide a small basin or bowl for spitting. If brushing is not possible, the patient may rinse with a little alcohol-free mouthwash.

You can also wipe the gums, tongue and teeth with swabs or “toothettes,” which the nurse can provide. Another way to clean the mouth is to wrap a piece of damp gauze or washcloth around your finger and rub it along the patient’s gums and teeth. Do not try this if the patient is confused or if there is a chance that they may bite you.

### Dentures

Dentures should be cleaned at least once a day by brushing or soaking them with tablets. While the dentures are out, be sure to have the patient rinse their mouth — or you can wipe their gums. When someone loses weight, dentures often no longer fit well. This can cause rubbing on the gums and lead to sores. The dentures may need to be left out.

### Skin issues

#### Bathing

Taking a shower or bath requires a lot of the patient’s energy. At some point, for safety and energy conservation, it may be best for a caregiver or the hospice aide to help the patient bathe. As the patient weakens, a shift to a chair bath at the sink and then a bed bath may be needed.

Here are some general guidelines for helping someone bathe:

- Have all bath supplies on hand to avoid leaving the patient alone.
- Keep the bathroom door closed to make sure the room is warm enough and the patient will not become chilled while wet.
- Ensure privacy by closing blinds and curtains. Explain what you are doing to the patient.
- If moving is painful, give the patient pain medication at least one hour before the bath.
- Avoid soap if possible. Unscented moisturizing cleansing lotions are easier on the skin.
- Rinse the washcloth often.
- Keep the water warm. You may need to change it frequently during a chair bath or bed bath.
- Work from top to bottom, washing the face first and the feet last.
- To avoid chills, uncover only the part of the body that you are washing. Wash and then dry one part of the body at a time.
- Be as gentle as possible to prevent discomfort.
- Ask your nurse about itchy or irritated skin.

## Training for symptom management

### Itchy skin

Itching can be caused by many things, including dry skin, hot baths, dehydration, stress, medications and the disease process. The following suggestions may help relieve itching:

- Provide the patient with cotton pajamas and clothes.
- Prevent the patient from perspiring or becoming too warm. Use the fewest number of blankets that is comfortable.
- Rinse sheets, towels, clothes and pajamas twice when washing to remove all traces of laundry detergent.
- Avoid hot water when bathing the patient. Use the coolest water that is comfortable.
- Avoid soaps when washing. Consider using a cleansing lotion that does not have to be rinsed. If using soap, rinse very well.
- Keep the skin moisturized with lotion.
- You can also talk to the hospice team about oral medications or anti-itch lotions that can help.

### Pressure injuries

Pressure injuries, or bedsores, occur when a patient stays in one position for a long time. Bedsores often appear over bony areas where the skin is between the bone and another surface. Common locations include the heels, tailbone, hips and elbows. But pressure injuries can also develop on the back of the head, the ears, the shoulder blades and along the spine. They do not happen only to bedbound people. For example, someone who spends a lot of time in one position in a chair can develop a sore on the tailbone. Sometimes, despite excellent care, pressure injuries appear.

### Tips

- Have the patient change position at least every two hours during the day and evening and at least every four hours at night. For patients who cannot reposition themselves, the caregiver will need to help.
- Use moisturizing cleansers to avoid chapped skin. Always rinse the skin well when bathing.
- If you see any reddened areas, relieve the pressure to the area. Tell the nurse about any redness that does not go away.
- Use a draw sheet. This is a folded sheet or towel placed across the middle of the bed; when the patient lies down, the part of the body from the knees to the shoulders is on the sheet. With this you can help turn or lift an immobile patient without pulling on the patient or hurting yourself. Ask the nurse or hospice aide to demonstrate the use of a draw sheet.
- If turning is painful, plan the moves so that the patient has had pain medicine at least one hour before being repositioned.
- The nurse may suggest methods to relieve pressure on certain areas or recommend using a special mattress.

*Review **Safety and comfort at home** on pages 36-41 regarding injury prevention and being prepared for the unexpected.*



## The final days



### The weeks before death

Most people are unsure that they will know what to do and whether they will be able to manage in the final days of their loved one's life. This section explores some of the things that may happen and includes suggestions for providing comfort to the patient. Remember that Asante Hospice is always just a phone call away.

#### Appetite

The need and desire for food and fluids naturally begins to decline (*see Nutritional issues on page 24*). We associate food with life — we eat to live. And now the patient may not want or need food and fluids. This may be a difficult time for family and friends.

Let the patient be the guide; they will let you know if food or fluid is desired. If the patient coughs and sputters when taking food or fluid, it may be time to stop trying. Talk to the nurse. Patients who cannot speak will sometimes bite a straw or spoon, clamp their teeth closed or spit out food to let you know they do not want it. Often patients near death

may say they are thirsty yet refuse water; they may be trying to tell you that their mouth is dry. It is important to provide frequent mouth care to maintain comfort in the final days (*see Mouth issues on page 26*).

#### Incontinence

The loss of control of the bladder or bowels can sometimes occur as the muscles in the lower body relax. The overall goal is simply to keep the patient clean, dry and comfortable.

- Adult disposable briefs (these words give the patient more dignity than saying “diapers”) and underpads on the bed may solve the problem. The nurse or hospice aide can train you in their use.
- The nurse may suggest placing a catheter (a tube) into the bladder to keep the patient's skin from being constantly wet. A catheter is uncomfortable only for a few seconds going in; then the patient is generally unaware of it.
- Often the patient will produce much less urine in the final few days, and the color is usually darker than normal.

## The final days

### Withdrawal

Sometimes, even weeks before death, a person begins to withdraw from family and friends and the world at large. As the circle of family and friends becomes very small, it is appropriate and important to limit who visits and the length of the visit. It is even OK to say, “no more visits.”

This is often a time to sort through feelings about oneself and one’s life. Words lose their importance, and tone of voice and gentle touch take on more meaning. Turning inward may start with the patient sleeping more and eventually becoming difficult to awaken. A patient who can no longer be woken up is in a coma.

- Plan activities and visits for times of day when the patient is most alert.
- Because hearing seems to remain intact until the very end, you can continue to reassure the patient by talking in a warm, normal tone of voice about what you are doing, how much you care or things you want the patient to know.
- Tell the patient what you are going to do before you do it. For example, “Pat, I’m going to clean your mouth now.”
- Remember not to say anything in front of the patient that you would not say if they were wide awake.

### Restlessness

Restlessness sometimes occurs as the patient’s circulation begins to slow. As less oxygen gets to the brain, the patient may become restless and fidgety. They may make repeated motions or pick at the sheets or the air. At this point oxygen is usually not helpful.

- You can reassure the patient that you are with them. Speak slowly and calmly in a soothing way.

- Try reading quietly to the patient, playing soft music or massaging the patient’s forehead, hands or feet.
- Do not restrain the patient, but you may need to use bed rails or have someone stay at the bedside (*see Bed rail safety on page 38*).
- Make sure the patient is still getting the usual pain medications. Just because they no longer tell you about pain does not mean the pain is gone.
- Call hospice if restlessness occurs after a medication change.
- The nurse will help assess if a full bladder or bowel may be part of the cause.

### Disorientation

As the body begins to shut down, changes occur that can cause a dying person to be confused. Sometimes it becomes difficult or unimportant for the patient to keep track of time and people.

- If the patient forgets the date or where they are, you may gently remind them — but if correcting the patient is upsetting, don’t do it.
- The calm presence of another person may be comforting and orienting. Conversation may not be needed.
- Some patients seem disoriented to time in another way: sleeping during the day and being awake at night. This may be caused by a fear of dying in one’s sleep when no one will notice. It may seem safer to sleep when there are people around during the day. Or it may just be caused by too many daytime naps.
- Pets may also help keep a patient oriented.
- Keep medications out of reach of a confused patient. Dispensing should be done by a caregiver.
- If the patient experiences sudden disorientation, call the nurse.

### Confusion and hallucinations

Sometimes a patient appears to be hallucinating — seeing people and places that are not visible to anyone else — or the patient may have imaginary conversations. At first you may think that the patient is over- or undermedicated or is simply “out of it.” But if you listen carefully, there may be meaningful messages in what sounds like rambling.

People nearing the end of life often talk about travel, as though they are planning a journey. A patient might ask about the bus schedule, whether the suitcase is packed or if there will be a high tide soon. This can actually be reassuring; it lets you know that your loved one is aware of the transition that is soon to occur.

- Dying people sometimes appear to have one foot in this world and one foot in another. They may talk clearly to people who have already died, often close relatives or friends, and then turn and talk clearly to you.
- Another common theme is seeing a place that those in the room cannot see, or the patient may say that they are “ready to go home.” At first you may want to answer, “You *are* home” — but the patient is probably not talking about the physical house. Instead you may get more response by asking, “Are you ready to leave?”
- It is not helpful to correct the patient. These are normal experiences. Talk calmly and reassuringly so as not to startle or frighten your loved one further.
- If the patient is truly hallucinating (such as seeing bugs on the wall), tell the nurse. Adding or discontinuing medications can often relieve such symptoms.

### Fever

As the body becomes weaker, so does the temperature control mechanism in the brain. Often a patient near death has a slight fever.

- If the fever is not causing discomfort, the patient does not need any medication. A cool washcloth to the forehead and fewer blankets may be soothing.
- If the fever is causing discomfort, tell the nurse, who may suggest acetaminophen (Tylenol). As the medication takes effect, the patient may perspire, and you may need to change their pajamas and sheets if wet.
- If the patient throws off the covers, it is important to remember that they may be too warm even when you feel cool.
- Sometimes a patient is sweaty and clammy even without a fever.

### One or two days before death

#### Energy surge

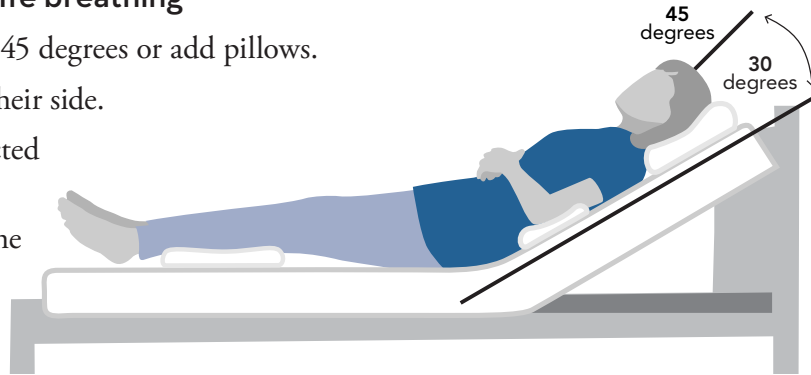
A sudden, unexplained surge of energy is a phenomenon that you may see in a patient who has been weak, disoriented and withdrawn. The patient may become unexpectedly alert and clear, ask to eat for the first time in days or want to get out of bed to visit for the first time in weeks.

- Enjoy this time with your loved one.
- Realize that this may be a sign that death is approaching.

## The final days

### What to try for end-of-life breathing

1. Raise head of bed to 30-45 degrees or add pillows.
2. Position the patient on their side.
3. Use medications as directed in the medication folder.
4. Sometimes your loved one needs you to step away from the bedside for a brief break.



If wet, gurgling breathing is severe and does not improve with positioning, or you need help with other symptoms or support for yourself, please call: Asante Hospice (541) 789-5005 any time, day and night, 24/7.

### Normal end-of-life breathing might:

- Look fast, shallow, slow, uneven or have long pauses.
- Sound noisy. Due to fluid collecting in the back of the throat, the noise it creates can be wet, gurgling and rattling. There might also be normal snoring, grunting or groaning.
- Include a blue color on the face, ears, nose, fingers and toes.

Breathing changes and congestion can come and go and be different for each person. These can be scary to see and hear, but normally do not bother the patient.

Grimacing, uncomfortable sounds or other signs of distress can be treated. See instructions for *What to do if you experience trouble breathing* on page 23 or call hospice.

### Slowing circulation

When death is just hours or a day or so away, a person's circulation slows to the point that their arms and legs feel cool to the touch. The hands and feet may become purplish, and the knees, ankles and elbows may look blotchy or mottled. Parts of the body that the patient is lying on will be darker than the rest. The patient may appear pale and have a bluish cast around the lips and under the fingernails.

- This state does not cause any discomfort to the patient, although it is another sign that death is imminent.
- You may use a warmed blanket — but not an electric blanket — at this time.
- Gently continue to move the patient if it does not cause discomfort.
- Offer very gentle touch or massage.
- This is a time to speak reassuringly to your loved one. You might say that you love and appreciate them, or perhaps give them permission to go.

Always call hospice first in an emergency involving the patient: (541) 789-5005.

## When death occurs



### When the patient dies

When the patient has died, you will see no breathing and feel no heartbeat. There will be no response to your voice or touch. The eyes will be partly open, and the pupils will be large and staring. The jaw will relax, and the mouth will open. Sometimes there will be a loss of bladder and bowel control.

### What to do

**Call Asante Hospice at (541) 789-5005**, as well as the friend or relative whom you have arranged to be with you. Even if you do not want an immediate visit from hospice, please call us to let us know that the patient has died.

**Do not call 911.** This is not an emergency; it is what you have been expecting. The police do not need to be notified. No matter how well prepared you are, death can still be a shock. We encourage you to call us and accept our help. Hospice staff are available 24 hours a day. A team member can remove equipment such as tubes, bathe the patient and prepare the body. If you wish, we can call the patient's primary care provider, as well as the mortuary or funeral home.

Although the mortuary should be notified of the death, you can decide when you would like them to come. There is no hurry. It is not necessary for the body to be removed immediately; the body can remain in the home for up to 24 hours. There may also be an extra charge from the mortuary for coming at night. If you want to keep the body in the home for more than 24 hours, the mortuary will provide you with instructions for caring for the body during this time.

You may want time to sit and say good-bye or for others to arrive. Let the mortuary know when you are ready for them to come. When they arrive, most people leave the room while they move the body, but you may help if you wish — whatever feels right for you. The mortuary will advise you about what to do next.

This is all you have to do right now. Let others help you. Remember to eat. Do not be surprised if you have strong feelings of confusion, fear, numbness, anger, sadness or relief. These are all normal responses. Rest when you can. Now is the time to focus on taking care of yourself.

## When death occurs

### Drug management

Asante Hospice has a specific policy and procedure regarding the management and disposal of controlled drugs.

#### Policy summary

Asante Hospice contracts with pharmacies that label, store and dispose of drugs in accordance with accepted standards of practice, as well as state and federal laws and regulations.

Caregivers are responsible for the proper disposal of unused medications. This is important because drugs that are safe for the patient may severely harm others — even drugs that appear harmless.

#### Drug facts

- Drugs are labeled in accordance with currently accepted professional best practices, which include appropriate use and cautionary instructions, as well as an expiration date.
- Controlled drugs include almost all pain and anxiety medicines used by Asante Hospice. Once they are provided to you, please review these drug disposal policies and procedures.
- Staff are required to ensure that you understand the safe use and disposal of controlled drugs.
- Staff will write in the clinical record that you understand how to safely use and dispose of controlled drugs.
- If there is any misuse or diversion of controlled substances, staff will document and report this to Asante Hospice administration and/or other authorities as appropriate.

### Drug disposal

You are responsible for disposing of medications that the patient no longer needs. When you call Asante Hospice to report that the patient has died, staff will remind you to dispose of any unused medications. We recommend taking them to a local drop-off site (*see **Collection locations for unused drugs** on page 35*).

To reduce the danger of unintentional use, overdose or abuse of medicines that may be especially harmful, the U.S. Food and Drug Administration recommends that certain potentially dangerous medicines be quickly taken to a collection drop-off site or transferred to a Drug Enforcement Administration–authorized collector.

If you are unable to bring the medications to a collection site or are concerned about diversion (the drugs going to someone they shouldn't), you may dispose of medications yourself, using the following steps or with help from a hospice nurse.

- Take medications out of their original containers. Remove labels and scratch off or destroy personal information to ensure patient confidentiality; using a permanent marker or duct tape works well.
- Wearing gloves to protect your hands, fold patches with sticky sides together, then cut them up and dispose as medical waste.
- To reduce appeal to children, animals and drug seekers, medications may be crushed or dissolved with water and mixed with an undesirable material such as coffee grounds, kitty litter, kitchen waste, sawdust or dirt and then placed in a plastic bag. Seal the container well and put it in the trash.
- In some situations it may be necessary to flush controlled substances down the toilet (*see list available at [fda.gov](http://fda.gov); search: **Medicines Recommended for Disposal by Flushing***). Check to make sure they have flushed completely before leaving the toilet unattended.

## When death occurs

### Collection locations for unused drugs

The following public agencies have drug drop-off boxes (may be closed holidays).

Visit [staysafeoregon.com/store-dispose-safely/safe-disposal/](https://staysafeoregon.com/store-dispose-safely/safe-disposal/) or call individual locations for hours.

Location	Drop-off site
Ashland	Ashland Police Department 1155 E. Main St. <b>(541) 482-5211</b>
Central Point	Central Point Police Department 155 S. Second St. <b>(541) 664-5578</b>
	Jackson County Sheriff's Department 5179 Crater Lake Highway <b>(541) 774-6800</b>
Eagle Point	Eagle Point Police Department 17 S. Buchanan Ave. <b>(541) 826-9171</b>
Grants Pass	Grants Pass Department of Public Safety 626 NE 7th St. <b>(541) 450-6260</b>
Jacksonville	Jacksonville Police Department 225 S. Third St. <b>(541) 899-7100</b>
Medford	Jackson County Jail 787 W. 8th St. <b>(541) 774-6850</b>
	Rogue Community Health Pharmacy 19 Myrtle St. <b>(541) 842-7747</b>
Talent	Talent Police Department 604 Talent Ave. <b>(541) 535-1253</b>
White City	Rogue Community Health White City Pharmacy 8385 Division Road <b>(541) 500-0989</b>

Always call hospice first in an emergency involving the patient: **(541) 789-5005**.

## Safety and comfort at home



### Tips for staying independent

Removing potential hazards and making things easier to do can help both patients and caregivers remain independent for as long as possible.

#### Check all rugs, runners and mats

Consider removing rugs and runners from the home, especially if they tend to slide. For those you keep:

- Ensure that they have a slip-resistant backing.
- Apply double-faced adhesive carpet tape or rubber matting to the backs of existing rugs and runners. Rubber matting can be cut to size.
- Check rugs and mats periodically to see if the backing needs to be replaced.

#### Check areas around beds

- Rearrange furniture closer to switches or move lamps close to beds.
- Install night lights.
- Keep a phone within reach.
- Don't smoke in bed or have hot liquids or other heat sources near the bed.
- Electric blankets can be used only on regular beds — not hospital beds — and only for patients who have full sensation and ability.

- Never go to sleep with a heating pad turned on, and check skin frequently for inflammation.

#### Check bathtub and shower areas

- Apply textured strips or appliqués to the floors of tubs and showers.
- Use nonskid mats in the tub or shower and on the bathroom floor.
- If you are unsteady on your feet, use a stool with nonskid tips as a seat while showering or bathing.
- Grab bars can help you get into and out of a tub or shower and can help prevent falls. Check existing bars for strength and stability and repair them if necessary. Towel racks and shower curtain rods are not sturdy enough to be used as grab bars.

#### Check all cords

- Minimize the use of extension cords. Place all cords against a wall, where people cannot trip on them.
- Remove cords from under furniture and carpeting.
- Replace damaged or frayed cords.
- Place heaters away from passageways and flammable materials.



## Safety and comfort at home

### Check entrances and stairs

- Put bright lights over the front and back doors.
- Replace dim and burned-out lights along pathways and halls.
- Put nonskid strips on the outer edge of steps — or paint the edges white.
- Repair handrails and steps.

### When a patient falls

- Staff cannot come to your home to help pick up your loved one.
- Make a list of friends or family members who would be available to help in the event of a fall — and verify that they will be able to assist you.
- Call Asante Hospice at **(541) 789-5005** to tell the nurse about the fall and determine if a visit is needed.
- Consider an emergency alert system, such as Asante Lifeline, that you wear on your wrist or as a necklace at all times to alert responders about a fall or other emergency.
- In certain areas of Jackson and Josephine counties, the fire department may be available to assist with nonemergent transfers, but there may be a fee.

### For more information about Asante Lifeline

- Email [lifeline@asante.org](mailto:lifeline@asante.org).
- Call **(541) 507-2680**.
- For a national representative, call **(800) 242-1306, ext. 4609**, and mention program code OR035.

### Equipment safety tips

#### Canes and crutches

- Wear supportive, flat-soled, nonskid shoes. Avoid high heels and slip-ons.
- Avoid walking on slippery, wet or uneven surfaces.
- Remove throw rugs to enhance safety.
- Make sure the rubber tip on the cane or crutch end fits securely and has no cracks or tears.
- Always look straight ahead while walking with a cane; do not look at your feet.
- Always get up slowly from a sitting position and assess if you feel dizzy or off balance. While standing, breathe slowly. If dizziness persists, sit down and call for assistance.

#### Walker

- When ready to walk, the patient should stand for a few minutes with the walker to balance. If dizziness occurs and does not go away, the patient should sit down and call for assistance.
- Walking surfaces should be dry, clean and well-lit.
- Remove throw rugs to enhance safety.
- When the patient is walking, remind them to look straight ahead, not down.
- The patient should wear supportive, flat-soled, nonskid shoes. Avoid high heels and slip-ons.
- Attach a lightweight bag or basket to the patient's walker for safely transporting small items.

## Safety and comfort at home

### Wheelchair

- Always lock the wheelchair brakes before attempting to rise.
- If the patient is unable to place both feet flat on the floor, they should not lean forward in the wheelchair — a fall could result.
- Prolonged sitting in the wheelchair may cause pressure injuries to develop. Help the patient establish a routine of shifting weight from side to side if possible. The armrest and the seat of the wheelchair may be padded to help cushion and relieve pressure (*see Pressure injuries on page 28*).

### Hospital bed

- Always keep the wheels locked. Unlock them only to move the bed.
- Electric beds may malfunction, or a power failure may cause the bed to remain in one position. Always know how to use the hand crank.
- A bedridden patient should always have a way to summon help. Be sure to provide a bell or other call system.

### Bed rail safety

Most patients can be in bed safely without bed rails. When bed rails are used, perform an ongoing assessment of the patient's physical and mental status; closely monitor high-risk patients.

Consider the reasons why the patient gets out of bed, such as hunger, thirst, going to the bathroom, restlessness and pain. Anticipate and meet these needs by offering food and fluids, scheduling ample toileting and providing calming interventions and pain relief.

- Monitor the patient frequently.
- Use a bed that can be raised and lowered close to the floor to accommodate both patient and caregiver needs.
- Keep the bed in the lowest position with the wheels locked.

- Reduce the gaps between the mattress and the side rails.
- If the patient is at risk of falling out of bed, place mats next to the bed so long as this does not create a tripping risk.

### Oxygen therapy

#### Safety

- Oxygen supports combustion — do not smoke within 5 feet of the user or the oxygen equipment.
- Oxygen is not to be used within 5 feet of a space heater, stove or any open flame, such as a cigarette, candle, fireplace or gas pilot light.
- Keep an all-purpose fire extinguisher in the home.
- Use only water-soluble lubricating jelly in the nose if needed. Do not use products that contain oil or alcohol.
- Never permit oil, grease or other flammable substances to come in contact with the oxygen equipment.
- Oxygen tubing should not be covered by bed linen, clothing or furniture. Be careful of tubing on the floor, as tripping may occur — keep it flat and away from traffic paths.
- Never use oxygen at a higher liter flow than prescribed by the patient's physician; it may be harmful.
- Store oxygen cylinders upright in a safe, well-ventilated place.
- Cylinders should not be stored in cars.
- If a large cylinder is being used, always make certain that it is secured to a stand or wall mount. Smaller cylinders should be mounted to a stand or cart.
- Always verify that the oxygen cylinder valve is fully closed (clockwise) before disconnecting the regulator from the cylinder.

## Safety and comfort at home

- Never attempt to repair or take apart oxygen equipment; always call the medical supply company.
- Notify the nurse or medical supply company when tanks are getting low.

### Maintenance

- Cannulas, masks, and liquid-portable and stationary units should be wiped daily with a clean, damp cloth.
- Humidifiers should be cleaned according to the manufacturer's directions to ensure effective treatment and to reduce the possibility of contamination.
- Some concentrators have an exterior black foam filter that should be cleaned as instructed. Remove the filter, wash it with warm soapy water, rinse, wring out excess water, and wipe dry or allow to air dry for several hours before replacing.

### Fire safety

- Devise an emergency exit plan.
- Install and maintain smoke detectors.
- Some local fire departments or government agencies help citizens acquire and install smoke detectors.
- Check or replace the batteries on a regular basis (such as twice a year, at the beginning of January and June).

### In the event of a fire, remember RACER

**R**emove patient and family from immediate danger. Develop a fire escape plan for your home and determine one safe place outside for all family members to meet.

**A**ctivate — **call 911**. Remember to give your street address.

**C**ontain the fire, if possible, by closing all doors. Ensure your own safety first and do not place yourself in danger.

**E**xtinguish the fire if possible. If not, evacuate the area. Again, do not place yourself in any danger.

**R**elocate to your safe location away from the fire.

### Preparing for emergencies

In the event of a community-wide emergency, Asante Hospice will attempt to contact you according to your level of need. If unable to visit, our staff will make every effort to stay in contact with you. If you need immediate assistance, **call 911**.

To keep informed, tune your radio to 1700 AM or call the Jackson County citizen hotline at **(541) 776-7338**. The hotline operates only during a disaster.

During a disaster, you may be able to stay in your home, but you could be without power or water for days. Local emergency services have developed an effective and cooperative emergency response system. Agencies work together closely to prepare for disasters, but there is no substitute for individual preparedness. Experts recommend that you be prepared to be on your own for at least 72 hours. The following suggestions will help you be ready.

## Safety and comfort at home

### Devise a plan

- Meet with household members and care providers. Discuss the dangers of fire, severe weather, power outages, earthquakes and other emergencies that might occur in your community, then determine your needs for each type of disaster.
- Post emergency numbers in a prominent location and program them in cell phones. Teach children how and when to call for help.
- Learn how to turn off the water, gas and electricity at main valves or switches.
- Learn what to do in case of power outages. Learn how to connect or start a backup power supply for essential medical equipment.
- If you or someone in your household uses a wheelchair, make more than one exit wheelchair-accessible, in case the primary exit becomes blocked.
- Teach those who may need to assist you in an emergency how to operate necessary medical equipment.
- Arrange for a relative or neighbor to check on you in an emergency.
- Plan and practice how to escape from your home in an emergency.
- Consider getting a medical alert system like Asante Lifeline that will allow you to call for help if you are immobilized in an emergency.
- If you live in an apartment, ask the management to identify and mark accessible exits.
- Learn your community's evacuation routes.
- Pick one out-of-state and one local friend or relative for you and your family members to call if you become separated by disaster.
- Pick two meeting places: a place near your home in case of fire and a place outside your neighborhood in case you cannot return home after a disaster.
- Keep family records in a watertight, fireproof container.

### Prepare a disaster supply kit

Assemble all the supplies that you might need in a backpack, duffel bag, rolling suitcase or plastic bin:

- Three-day supply of water: 1 gallon per person per day.
- Three-day supply of nonperishable food and a manual can opener.
- Solar charger for a mobile phone.
- Portable, battery-powered radio or television and extra batteries.
- Flashlight and extra batteries.
- First-aid kit and manual.
- Sanitation and hygiene items (hand sanitizer, moist towelettes, incontinence supplies, toilet paper).
- Whistle.
- Extra clothing, blankets and rain gear.
- A copy of the patient's POLST form.
- Emergency and physician contact information, including names, addresses and telephone numbers.
- Medications and any oxygen concentrator or cylinders.
- Photocopies of identification and credit cards and your complete medication list.
- Cash.
- Special needs items such as prescription medications, eyeglasses, contact lens solution, hearing-aid batteries and denture supplies.
- Tools, a map of the local area and other items to meet your unique family needs, such as supplies for babies, children and pets.

## Safety and comfort at home

### Disaster Registry

The Disaster Registry is a database of names, locations and needs of people who require special assistance during an emergency. This database is available to fire, police and rescue workers.

Sign up for the local Disaster Registry if you or someone for whom you are legally responsible would:

- Need outside help to safely leave your home during a disaster.
- Be in jeopardy if you stayed in your home, without assistance, for three days.
- Need special notification about the need for evacuation, due to impairment.

**Being on the Disaster Registry does not guarantee that you'll get help first in a disaster.** There are so many needs during an emergency that first responders can't help everyone at once. But if your name is in the Disaster Registry, they will know of your need for special assistance. Once an application has been received, it may take three months or more for the information to be made available to rescue workers.

Note that even if you are on the Disaster Registry, you should **call 911** if you find yourself in a life-threatening situation.

### To apply for the Disaster Registry

- Visit [rvcog.org](http://rvcog.org) to download an application or apply online.
- For more information call the Senior & Disability Services of the Rogue Valley Council of Governments at (541) 664-6674.

## In conclusion

### Important documents

It is helpful if you locate and organize the following documents.

- Copy of the will or trust papers
- Prepaid burial plans and cemetery plots
- Birth certificate
- Marriage certificate
- Social Security card
- Citizenship papers
- Medical insurance cards
- Military records
- Information about savings and checking accounts
- List of stocks, bonds, certificates of deposit and other investments
- IRAs, Keoghs, 403(b) and other retirement account information
- Safe deposit box information
- Deeds to the house and other property
- Automobile titles and insurance information
- Homeowners insurance policies
- Long-term care and life insurance policies
- Mortgage and other loan information\*
- Credit card accounts\*
- Copies of utility bills
- Income tax report and records collected for the following year
- Other important papers

\*Note that some loans and credit cards have an insurance benefit that may pay off the balance.

### A final word

We at Asante Hospice thank you for entrusting us to help you with the care of your loved one. It is our privilege to assist at this critical time. We understand the importance of providing you and your family with the right amount of high quality care.

We hope that this handbook serves as a useful guide throughout your hospice experience. It is not meant to be a substitute for direct contact with our staff, however. If you have questions or concerns, please call us at **(541) 789-5005**.

After your hospice experience, you may receive a survey. We encourage you to complete the survey. We appreciate your feedback and use the information to improve the quality of our services.

We hope you and your loved ones felt supported throughout your experience with Asante Hospice. If we met your expectations, please consider sharing a short review on Google by visiting [asante.org/hospicereview/](https://asante.org/hospicereview/).



If you would like to recognize a hospice employee for service or behavior that exceeded your expectations,

go online to: [asante.org/patients-visitors/values-in-action/](https://asante.org/patients-visitors/values-in-action/) or call **(541) 789-5500**.

## In conclusion

### Helping others

You can make a real difference in the lives of people in our community who need hospice or are dealing with grief and loss. Your donation to Asante Hospice helps ensure patients receive comfort care whenever and wherever they need it and can live their remaining days fully in dignity, comfort, and in accordance with their wishes and beliefs. Please consider donating in memory or honor of a loved one.

### You may direct your donation to a specific Asante Hospice priority:

- **Compassion Fund** – Address immediate needs of patients not covered through hospice benefits. Simple items such as a heater in the winter or a fan in the summer can bring comfort to patients.
- **Complementary Therapies Fund** – Complementary therapies such as massage, music and pet therapy are proven to be beneficial alongside treatments and help with symptom control through psychological, emotional, physical and spiritual support.
- **Education Fund for Asante staff** – To provide our community with a comprehensive level of services, professionals must continue their education to become even more knowledgeable and skilled in delivering hospice services.

### There are several ways to make a difference:

#### *Invite others to give in tribute*

Designating Asante as the recipient of gifts, in lieu of flowers, is a meaningful way to honor the life of a loved one, while making a lasting impact on the lives of others. Call Asante Foundation to arrange a memorial designation. Gifts may be directed to Asante Hospice or the area of your choice. The amount of the donation is always confidential.

#### *Plan a gift for the future*

- Make a bequest in your will or trust to Asante Hospice.
- Designate Asante Hospice as a full, partial or contingent beneficiary of your retirement account.
- Name Asante Hospice as a beneficiary of your life insurance policy.

#### *Make a gift today*

Please mail your donation to:

Asante Foundation  
229 N. Bartlett St.  
Medford, OR 97501-9836

To make your gift with a credit card, visit [asantefoundation.org/donate/](http://asantefoundation.org/donate/) and choose “End of Life Services (Hospice & Palliative Care)” as your designation.

If you have any questions about making a donation now or planning one in the future, please call the Asante Foundation office at **(541) 789-5025**.

Asante Foundation is a nonprofit approved by the IRS as a tax-exempt, charitable organization. Asante Foundation Tax ID is 93-6087366.



**Asante Hospice**  
**(541) 789-5005 | (800) 888-6579 | [asante.org](https://asante.org)**

© 2023 Asante. All rights reserved. No part of this publication  
may be reproduced in any form except by prior written permission.  
HOSP326150\_103023