

PATIENT EDUCATION

Hospice Handbook

For patients, caregivers, families, and friends



“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

--Dame Cicely Saunders,
founder of the modern
hospice movement

GUNDERSEN
HEALTH SYSTEM®

Gundersen Lutheran Medical Center, Inc. | Gundersen Clinic, Ltd.
Gundersen Boscobel Area Hospital and Clinics | Gundersen Moundview Hospital and Clinics
Gundersen Palmer Lutheran Hospital and Clinics | Gundersen St. Joseph's Hospital and Clinics | Gundersen Tri-County Hospital and Clinics

Gundersen Hospice

(608) 775-8435 - or
 (800)362-9567 - Ask for Hospice
 Both numbers are answered 24/7

Do not call 911 if emergency relates to patient condition. Only call 911 in weather-related emergencies.

Other helpful phone numbers:



The symbol for Gundersen Hospice is a quilt - **a comforter**.

- Rings stand for our team, patients and families.
- Hearts represent cherished relationships.
- Each draws warmth, comfort, support and strength from all others in this pattern of care

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Hospice care is founded on the ancient practice of giving shelter and rest (hospitality) to sick or weary travelers. Dame Cicely Saunders first applied the term to special care for dying patients at St. Christopher's Hospice in London. Today the respite and relief of hospice are offered wherever we choose or are able to spend our last days, weeks and months. Hospice supports those on the journey of life-ending illness and all who walk beside them.

In hospice, we accept death as the final stage of life. Hospice neither hastens nor postpones death. We focus on the needs of each person and family instead of disease or aging and its effects. Hospice makes the best of the time that remains. We care for the whole person – mind, body and spirit. We listen and offer choices until the very end. We do what each person needs to feel fulfilled and dignified.

While you are in hospice, we make every effort to let you stay in control and enjoy your life. We want you to be alert enough to enjoy people around you and help make choices about your care. We will help manage side effects to keep you as free from pain and other symptoms as we can. Our team provides:

- Expert medical care
- Pain management
- Support and training for your family and caregiver(s)
- Emotional and spiritual support tailored to your needs and wishes

Does accepting hospice care mean I am giving up?

Hospice involves knowing most late-stage disease cannot be cured. It does not mean giving up hope. Even when treatment ends, many find renewed hope in hospice. Focus shifts to helping you achieve comfort and peace of mind - the death with dignity many wish for. With pain and symptoms controlled, you can enjoy life and make the most of each day. Hospice need not be put off until your last few days. Many patients and families say they wish they had chosen hospice sooner.

Who will care for me and where?

It depends on the level of care you need. You may be at home, assisted living, nursing home, or hospital. Your primary caregiver (the main person who cares for you at home) can be a family member or a friend. In other settings, staff will provide your care with our guidance. Your hospice team will train anyone who accepts this responsibility.

We will assist you and your loved ones to express, share and work through feelings and emotions. The doctor of your choice will be in charge of your care. Your primary doctor will provide routine medical support and care. The hospice medical director will coordinate all of your care.

During regular visits, hospice staff will check on how you are doing. They will arrange extra care or services as needed. Hospice staff is on call 24/7. Roles and responsibilities are described on pp. 7-8.

Services and coverage

Hospice services include:

- Care by a team of professionals
- Medicine for pain and symptoms related to your terminal illness (See coverage limits p.3.)
- Hospice-approved medical supplies based on assessed needs
- Medical equipment (wheelchairs, commodes, hospital beds)
- Treatment for pain and other symptom management
- Short-term hospital care when pain or other symptoms are too much to manage at home
- Respite care for family or friends who need a break from demands of daily care

Hospice care is covered by:

- Medicare hospice benefit
- Most private insurance plans
- Managed care (HMOs)
- Medicaid hospice benefit (Wisconsin and Minnesota)

If you are not covered by any of these, we will work with you and your family to provide at least some level of service. We will contact your insurance company to confirm what is covered.

Hospice coverage has some limits. These are **not** covered:

- Treatment intended to cure your terminal illness
- Medicine to manage symptoms not caused by your terminal illness, e.g., allergies
- Service from other sources that is the same as hospice care
- Housing of any kind

Advance care planning

What if you could not speak for yourself? Who would you want to speak for you? What would you want them to know about your health care goals, values and preferences?

Advance care planning (ACP) is a process that helps you:

- Think about your goals and values.
- Reflect on future health care decisions you may need to make.
- Select a person to decide for you if you cannot decide for yourself.
- Make a written plan for the future.
- Talk about what matters most to you.

This conversation is the best way to prepare your health care agent and others to act on your behalf.

What is an advance directive?

It is important to write down your goals, values and preferences. There are many ways to do this. We recommend using a document called an advance directive. The type used most often by our patients is a legal document called a power of attorney for health care. It lets you name a person to make health care decisions for you. He or she will only make decisions if you cannot make them yourself. You may also include specific instructions for care you prefer.

An advance directive may be changed at any time as long as you are capable and you may revoke your advance directive at any time. A copy of your advance directive belongs in your medical record. Keep a copy for yourself. Give copies to your health care agent(s) and anyone close to you who is likely to be present in a medical crisis.

Comfort is our priority

Fear of being in pain worries all hospice patients. Sudden, acute pain can make you upset and anxious. Chronic pain, whether low grade or intense, can exhaust you because it never seems to end. No one expects you to be a “good” patient who never complains. In fact, talking about your pain is best for all concerned. Your comfort is important to your family, friends, and care team.

Going without pain medicine is not a sign of strength. You have enough battles to fight. Let medicine fight pain for you. Save your energy for more important things. No matter what causes your pain, hospice offers options to relieve most, or all, of your pain. We work with you and your doctor to get the relief you need.

Causes of pain

Any disease process can produce pain at some point. Cancer pain occurs when growing tumors press on organs and nerves or attack bones. Even anxiety and lack of sleep can cause pain. When you describe your pain in detail, you help us choose the best way to manage it. We need to know:

- Where it is
- What it feels like (dull ache, sharp stab, prickly, etc.)
- How strong it is (rate your pain 0 to 10)
- How long it lasts

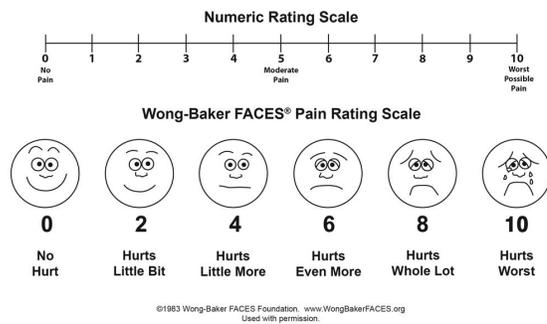
Learning all we can about your pain helps us reduce or end it.

All discomfort is valid, real and personal. Only you know how much you can or are willing to tolerate. Be honest when you talk about pain. Hold nothing back. Without judging, your care team will listen while you explain your pain and goals for relief. We then select medicines and prescribe doses suited to your needs.

Goals may be as simple as:

- A good night's sleep
- Freedom of movement
- Being able to enjoy certain activities

Pain will be discussed during each nursing visit. You will be asked to “rate” your pain on a scale of 0 to 10, with 10 being the worst pain you have ever felt. We will show you scales like these or ask questions.



We may not be able to achieve zero pain (0 = no pain). We will do our best to keep your pain at a level you can tolerate. By talking with you and adjusting your medicine and other factors, we will find that tolerable level together. If you have concerns about pain between visits, you or your caregiver can call and talk with our staff.

Extreme pain (9, 10 or higher) is an emergency. Your nurse will make sure you have medicine on hand for such a crisis. You should also call Hospice right away at (608) 775-8435 or (800) 848-5443.

Dehydration and IV Fluids

Patients nearing the end of life sometimes have trouble drinking enough fluids. This can cause dehydration (dee-hy-DRAY-shun: not enough water in the body). Mixtures of water and sugar or salt can be given through an intravenous (in-trah-VEE-nus) line (IV) into the bloodstream. A nurse can do this. Others can be taught to connect fluid packs to an IV line that has been taped in place.

IV fluids can cause problems if a patient is weak or near end of life.

- There is more chance of infection.
- There may be more mucus in lungs or other breathing issues.
- More fluids can cause vomiting.

Dehydration does not hurt, but it may feel wrong to deny water to a loved one. Even so, taking in less fluid can:

- Reduce breathing problems, vomiting and incontinence.
- Act as a natural anesthetic and make the patient sleepy enough to feel less pain.

Patients rarely feel thirsty when they are not able to drink. Dry mouth is a common complaint. Ice chips, artificial saliva, and lip moisturizers can provide relief.

Eating with advanced disease

Sharing food with family and friends is one way we give comfort and show we care. It can be stressful for others when a loved one does not eat. Even favorite foods may be refused because:

- Food tastes bad or has no taste at all.
- It is hard to chew or swallow.
- Medicine causes nausea or bowel changes.
- Disease may partially block the digestive tract and cause pain.
- Eating may not seem important when it is hard to breathe.
- Sad feelings about having a disease and dying reduce appetite.

Find other ways to show love and caring.

- Give a foot massage.
- Play cards or read to the patient.
- Sometimes just sitting quietly with each other is enough.

When a loved one stops eating, remember:

- Loss of appetite is normal.
- Let the patient choose food and drinks. Give nutritional drinks such as Boost® or Ensure® if the patient asks for them.
- If the patient could comfortably eat, he or she would.
- Not eating or drinking causes dehydration.

IV and tube feeding are usually not helpful for patients with advanced illness. They are expensive and can be uncomfortable. They can cause infections and other problems.

Hospice team roles and responsibilities

The **hospice medical director**:

- Works with your primary provider as an extra support for ongoing medical care.
- Makes home visits on request when your primary provider cannot travel to your home.
- Oversees care coordination with the interdisciplinary team.

Hospice nurses assist with all aspects of your care. They:

- Provide comfort and symptom management.
- Review medicines and confirm their medical necessity.
- Work with facilities to develop a plan of care.

Medical social workers assess family needs and dynamics and:

- Serve as a resource for you and your family.
- Address financial and psychosocial issues.
- Provide information for patient/family decisions.
- Explore other living arrangement options.

Hospice chaplains do not replace your usual spiritual counselor.

Whether or not you profess a certain faith, chaplains can:

- Make sure you, family members and significant others get the support you need.
- Help with life-review and memory-making activities.
- Work with clergy or church members to meet your spiritual needs.

Hospice aides assist you and your nurses in these ways:

- Light housekeeping
- Follow the care plan written for you.
- Help with bathing, personal cares and exercises.
- Provide emotional support.

They cannot provide transportation or care, but **volunteers** can:

- Run errands.
- Assist with meals.
- Provide respite for caregivers.
- Assist with life review.
- Check in periodically with patient and family.

Physical, occupational and speech therapists promote safety, comfort and communication. They help patients be as independent as they can. They teach caregivers and family members how to:

- Perform safe transfers and aid patients moving around at home.
- Assist with daily exercises.
- Help control pain with positioning, equipment and other methods.

Bereavement coordinators offer:

- Grief support to families and care facility staff if needed
- Education to families
- Resources to grieving families and friends
- Support for 13 months after the patient dies or for a period based on needs of the bereaved

Oxygen use at home

Oxygen is a medicine. It must be prescribed by a doctor.

- Do not change the liter flow unless you are told to.
- If you feel your prescribed flow is too low, contact Hospice.
- Keep your equipment clean and dust-free.
- Do not use flammable agents (oil, grease, etc.) near oxygen.
- Avoid open flames, sparks, and gas stove pilot lights.
- Change nasal cannula and tubing as shown by your supplier.
- Do not try to repair equipment. Contact your oxygen supplier.

For the safety of all persons:

- No one should smoke within 10 feet of an oxygen system.
- Post **No Smoking-Oxygen in Use** signs throughout your home.
- Keep an all-purpose, dry chemical fire extinguisher nearby.
- Have working smoke detectors around your home.

When you travel, bring at least 1 extra tank in case you are gone longer than expected.

Pain medicine and other methods

Your nurse will teach you and your caregivers the purpose, correct dose and side effects of each medicine you take. Mild and moderate pain relief products are widely used by hospice patients. Some need no more than aspirin or acetaminophen (Tylenol®) with codeine.

Medicines to control anxiety and relieve depression can help improve outlook on life and pain tolerance. They are often used as sleep aids.

Opioids (OH-pee-oyds) may be prescribed because they:

- Control moderate to severe pain with less risk of bleeding and kidney problems.
- Improve well-being and help manage symptoms.
- Can be taken for an indefinite length of time

- Reduce heart workload to ease shortness of breath and chest pain.
- Reduce anxiety and that “out of breath” feeling.

Research shows opioids do not shorten survival at the end of life.

Morphine: The opioid most often prescribed for hospice patients

Morphine and similar drugs are the mainstay in pain control. Many patients take a long-acting morphine tablet twice a day. If you cannot swallow a tablet, you may wear a skin patch that contains some other long-acting medicine.

You will also have a short-acting medicine for breakthrough pain that may occur between doses of long-acting medicine. Write down times for breakthrough pain and what you take to ease it. This record and your verbal report help your nurse adjust medicines as needed.

Some patients resist starting morphine. They fear it means a turn for the worse. In fact, morphine can mean a turn for the better when you are comfortable and well rested.

Do you worry about having nothing stronger to take if your pain gets worse? Morphine doses can be safely increased. Do not worry about an overdose. Morphine will work now and for the rest of your life.

Other opioids that may be prescribed include:

- Oxycodone
- Fentanyl
- Methadone
- Hydrocodone
- Hydromorphone

All of these are narcotics (nar-KOT-ix). It is against the law to give or sell them to anyone else.

Effective pain management

Take the exact dose your doctor orders. If doses are scheduled, take them on time. Write down the dose and time for each medicine – especially doses taken “as needed” for pain that occurs now and then. You will have fewer side effects and need less pain medicine if you take it on a schedule.

Skipping a dose can make it harder to get pain back under control. **Do not wait for pain to get worse before you take a dose.**

Taking too much at once or more often than prescribed can cause severe side effects and death.

Do not use opioids with alcohol or sedatives unless you discuss this with your doctor or nurse.

Do not drive until you know how these medicines affect you. Even then, be careful when you drive or use any type of machine. Opioids affect judgment and response time.

If you can no longer swallow, your nurse will tell your caregiver how to give your doses.

If pain decreases, do not stop taking pain medicine until you contact your hospice nurse.

Side effects of opioids

Sleepiness and nausea are likely for 2 to 3 days at first. If these persist or get worse, tell your hospice team. If you are sleepy but **still** in pain, call us. Something else may need to be prescribed.

Constipation is common as long as you take opioids. Most people need a daily dose of laxative to keep bowels moving. If you can, exercise and drink more fluid. (See p. 14 for more information about coping with constipation.) Call Hospice if:

- You have not had a bowel movement in 3 days.
- You are straining to pass hard stools.

Many common side effects can be managed with dose changes, switching between opioids and other methods:

- Confusion
- Dry mouth
- Increased pain
- Indigestion or gas
- Nausea / vomiting
- Dizziness
- Headache
- Pain sensitivity (hyperalgesia)
- Itching
- Sedation

- Sweating
- Tiredness
- Sexual dysfunction

Adverse side effects require prompt intervention. Call Hospice if you have any of these symptoms:

- Respiratory depression - Feeling drowsy, slow or shallow breathing, trouble waking up, loud or unusual snoring
- Mental status changes - Confusion, bad dreams, hallucinations, restlessness, agitation, seizures
- Opioid-induced endocrinopathy – Loss of libido, impotence, fatigue, mood changes, loss of muscle mass and strength
- Sleep apnea- Loud snoring, short-term memory loss, impaired concentration, changing length of pauses between breaths, depression, morning headaches
- Trouble passing urine – Pain when you urinate, feeling bloated

If friends or family members have strong feelings about drug addiction, let them know you cannot sleep, visit with them or do other things you enjoy without pain medicine. Let your hospice nurse know this is a concern. He or she can gently guide a conversation on this sometimes difficult topic.

Alternatives to pain medicine

- Warm or cold packs
- Massage
- Guided imagery
- Physical therapy
- Music
- Painting or drawing
- Keeping a journal
- TV or audio books
- Writing poems
- Relaxation techniques
- Essential oils
- Support groups
- Knitting or crocheting
- Distractions such as crosswords, reading, playing cards or sewing

Essential oils may ease pain, nausea and emotional distress. They come from plants grown without chemicals. They help balance your body. Through the sense of smell, these oils trigger parts of the brain that control:

- Mood
- Emotion
- Memory
- Learning

There are many brands of essential oils. Their uses vary. Ask your nurse about those we suggest to hospice patients. Use any oil listed below every 4 to 12 hours. You can inhale its scent right from the bottle - or -

- Put 2 drops on a cotton ball. Tape it to clothes or skin in the upper chest area.
- Place one drop on the bottom of each foot.

Frankincense

- Emotional healing
- Helps you focus
- Quiets the mind
- Aches or pains

Mandarin

- Nausea
- Anxiety
- Sleep
- Digestion

Support Your Healing

- Anxiety
- Tension
- Depression
- Emotional healing

Soothing Relief – Only this oil can be used on skin besides the foot. For muscle aches or pains, rub 3 to 5 drops onto skin without wounds, cuts, scrapes or rash.

Do not use essential oils during 1st and 2nd trimester of pregnancy. Many brands of essential oils are sold in stores and online. At Gundersen Health System, Healing Concepts® essential oils can be purchased at:

- Gundersen Health System La Crosse Campus Gift Shop
- Gundersen Health System Onalaska Campus retail store
- Online at <https://shop.gundersenhealth.org/>

Coping with constipation

Like many pain relief medicines, opioids make your bowels less active. You could have belly pain or a harmful blockage if stools harden and move slower. A severe blockage could injure your bowels.

Increased fiber and fluids help, but diet alone cannot relieve this common side effect. Other medicines are required. As soon as an opioid is prescribed, start taking a stool softener and gentle laxative. Most people need a daily dose of laxative to keep their bowels moving. Call Hospice or the doctor who prescribes your pain medicine if:

- You have not had a bowel movement in 3 days.
- You are straining to pass hard stools.

You may need to be on a bowel program, which may include:

- 1 to 3 tablets of docusate sodium (100 to 300 milligrams) each day, plus
- 2 to 6 tablets of senna 2 times each day.

Start with docusate (DOK-u-sate) and senna unless your health care team suggests a different pair of drugs. Buy them combined or separately.

We advise against high fiber or bulk-forming laxatives (Metamucil™ or Fiberall™) that absorb water and expand. Stools may harden and move slower if you do not drink enough water. Taking these products with too little water can make constipation worse.

If you are already constipated and would like to try a suppository, call Hospice at (608) 775-8435 or (800)362-9567, ext. 58435.

Primary caregiver

A family member or friend may be the main person making sure your daily physical needs are safely met. He or she may do this alone or with help from family, friends, private pay staff or volunteers.

The hospice team supplements and supports the efforts of all who share this responsibility. Your primary caregiver will:

- Monitor medicine you need to relieve pain and other symptoms.
- Make sure equipment and supplies are on hand.
- Tell a hospice team member when needs arise for any of these.
- Pick up medicine, supplies or equipment at the hospice office, pharmacy or equipment vendor.
- Follow the care plan written for you by the hospice team.
- Promptly inform the hospice team about your response to the care plan and changes in your condition.

Caregivers should care for themselves, too. (See pp. 32-35.)

Safety for all: Infection control

Keeping hands clean is the best way to prevent the spread of infection. There is risk each time you or someone caring for you touches:

- Blood
- Urine or stools
- Nose and mouth fluids
- Drainage from an open sore

Wash hands often. **Always** wash them after using the bathroom or bedpan and before you eat. Avoid touching bandages, dressings, or open sores. You may have an infection and not know it. You and all who provide care in your home should:

- Cover nose and mouth with a tissue during each cough or sneeze. Throw used tissue in the trash right away.
- Sneeze into your sleeve if you have no tissue.
- Wash hands with soap and warm water for at least 30 seconds – **or**
- Rub sanitizer gel or foam on both hands for at least 15 seconds.

Staff members often wear gloves. They may also wear masks, gowns, aprons or goggles. Family and friends should wear gloves when exposed to body fluids (e.g., dressing changes, catheter emptying).

Wearing garments to protect more body surface may be wise before handling large amounts.

All persons should wash hands after they provide care **even when gloves have been worn.**

Home safety tips

Be safe where you walk.

- Clear clutter off the floor where you walk from room to room.
- If there are kids or pets at home, be sure toys are picked up.
- Arrange furniture to leave clear pathways.
- Pick up all small, loose rugs (scatter rugs or throw rugs).
- Trim and then tape or tack loose carpet edges.
- Use non-skid wax or no wax at all.
- Put nightlights in hallways.
- Keep cords out of pathways and out from under rugs.
- If you use a walker, carry items in a basket or walker bag.
- If you use a reacher, attach it to your walker with Velcro.

Be safe where you sit.

- Keep a lamp, phone, TV remote and other things you use often beside your favorite chair.
- Your chair should be firm and sturdy with arms but no wheels.
- If you have had a recent hip replacement, sit only in chairs that hit the back of your knee or higher.

Be safe on the stairs.

- Stairs need at least one handrail. Use the rail(s) going up or down.
- Keep stairs well-lit and in good repair.
- Mark top and bottom steps with paint or colored tape.
- Wear sturdy shoes or slippers with hard rubber soles. Do not walk in nylons, socks or cloth slippers.

- Keep clutter off steps. Put a basket nearby for small items. Carry the basket in one hand. Hold the railing with the other.
- Plan your trips up and down. Make fewer trips.

Be safe in your bedroom.

- Have a nightlight near your bed.
- Put your phone, a lamp and a flashlight on the nightstand.
- Pick up all small, loose rugs (scatter rugs or throw rugs).
- Keep closet doors and drawers closed.
- Before you get up, sit for a minute to keep from getting dizzy.
- Make sure pathways are clear of clothes, slippers and blankets.
- Keep clothes you wear often within easy reach.

Be safe in your bathroom.

- Clearly label all medicine.
- Never use out of date medicine. It belongs in a hazardous waste facility, not your sink, drain or toilet. (See pp. 35-36)
- If you pre-measure, keep doses in small bottles or a pill tray.
- Put a nightlight in the bathroom.
- Keep glass objects out of the bathroom.
- Never use a towel rack as a grab bar.
- Only use bathroom rugs with nonskid backing.
- Keep electrical appliances away from sink and tub.
- Use liquid soap and long-handled sponges. Do not pick up things you drop when you shower. Wait until you are done and dried off.

Think about adding these safety features;

- Grab bars by tub and toilet (mounted in wall studs)
- Raised toilet seat (especially after hip replacement)
- Sturdy bench or chair in your bath or shower.
- Safety strips on the bottom and outside of your bathtub.
- Hand-held shower head

Be safe in your kitchen.

- Keep items you use often within easy reach. Put them on the counter or in lower cupboards. Pull them forward in drawers.
- All rugs should have a nonskid backing to prevent slipping.
- Never carry food, dishes or tools while using a walker. Instead:
 - Use a walker bag, basket or wheeled cart.
 - Slide items along the counter.
 - Use a travel mug to carry liquids.
 - Sit to work.
- Unplug appliances when you are not using them.
- Do not overload circuits.

Be safe when you use the stove or oven.

- Keep spray cans away from your stove or oven.
- Mark dials in red to make them easy to read.
- Wear close fitting sleeves so they cannot brush against burners.
- Use front burners whenever possible.
- Open pot lids away from you.
- Turn pot handles in toward the stove to prevent spills.
- Slide pots instead of lifting them when you can.
- Use oven mitts instead of potholders.
- Pull out oven racks instead of reaching in.
- Use proper oven ware.

Be safe on the phone.

- If you have trouble seeing, use a phone with large numbers.
- Keep a list of emergency numbers near the phone.
- Turn up the volume of the ring if you need to.

Be safe outdoors.

- Attach a grab bar by the steps from the garage into the kitchen.
- Take care not to trip on garden tools, hoses, curbs and cracked sidewalks.

Symptom management

Anxiety/uneasy feelings

Anxiety is a feeling or deep sense that things are not right. It is OK to experience it sometimes. Anxiety can help people focus on completing a task or deal with a stressful situation. But it is not okay for people to have strong, extreme and lasting worry and fear about everyday life. If you have trouble with activities of daily living because of your feelings, ask for help to manage anxiety.

- Fear
- Worry
- Confusion
- Tension
- Rapid breathing
- Sleeplessness, disturbing dreams or nightmares
- Racing heartbeat
- Shaking
- Inability to relax or get comfortable
- Sweating
- Problems paying attention or concentrating

What to report to the hospice team:

- Feelings that may be causing anxiety (like a fear of dying or worrying about money)
- Concerns about illness
- Relationship problems with family or friends
- Spiritual concerns
- Signs and symptoms that anxiety is changing or getting worse

What can be done to help relieve anxiety?

The hospice team will try to find its cause. They will talk with you and your primary care provider about treatment options. Things you can do:

- Activities that have helped your anxiety in the past.
- Write down your thoughts and feelings.
- Treat physical problems, such as pain, that can cause anxiety.
- Try relaxing activities like deep breathing or yoga.
- Play soothing music.
- Keep your surroundings calm.

- Limit visitors.
- Massage your arms, back, hands or feet.
- Count backward slowly from 100 to 0.
- Avoid caffeine and alcoholic beverages.
- Exercise.
- Provide reassurance and support.
- Ask for help from family, friends and other care team members.
- Live life one minute at a time.
- Use ordered medications as prescribed.

Delirium

- Sudden mental status change within hours or days
- Mental clouding with less awareness of one's environment
- Confusion about time, place and person

What are the signs?

- Reversal of sleep and awake cycles
- “Sundowning” or confusion that is worse at night
- Mood swings that may change over the course of a day
- Difficulty focusing attention or shifting attention
- Hallucinations (sees, hears or feels things that are not there)
- Agitation and irritability
- Drowsiness and sluggishness
- May be restless and anxious

What to report to the hospice team:

- Any of the signs or behaviors listed above
- Changes in food or fluid intake
- Decrease in urine output
- Change in frequency or type of bowel movements
- Depression

- Wandering
- Withdrawal from people or activities
- Any change in medications the team is unaware of

What can be done?

Delirium is common at the end-of-life. It has many causes. The team will try to find out what is causing the delirium and discuss treatment options with you. As a caregiver you may:

- Keep the patient safe.
- Remind the patient who you are when you assist with caregiving. Tell them what you are going to do. For example, “I am going to help you get out of bed now.”
- Offer support such as “I am right here with you.”
- Try to maintain a routine and structure.
- Avoid asking a lot of questions.
- Provide a quiet, peaceful setting, without TV and loud noises.
- Play the patient’s favorite music
- Keep a nightlight on at night
- If starting a new medication, watch for improvement, worsening or side effects and report to healthcare provider

Dementia

Dementia is a result of diseases that affect how the brain works. The most common cause is Alzheimer’s disease. Symptoms occur gradually over time. Memory loss is usually the first sign. Dementia also affects mental and physical functioning. Dementia does not affect each person the same.

What are the signs and symptoms?

Symptoms fall into five groups. All symptoms cause safety risks.

- Decreased attention span – The person may not be able to do two things at once. Even familiar activities and tasks take longer and may not be done correctly. May stop doing favorite hobbies.

- Difficulty with decision-making and complex projects – Extra time is needed to do planning. Decreasing ability to do a job and care for household upkeep and expenses.
- Memory – Long-term memory is usually better than short-term memory. Forgets where he/she placed items. Repeats questions. May not be able to find his/her way home if walks out the door.
- Language problems – Trouble remembering names of people and objects. Grammar slowly worsens. The person may not be able to use simple words or may use the wrong word to fill in what he/she does not know. It may be hard to know what he/she is trying to say.
- Unaware of what is socially accepted behavior – May not dress for situation and weather. Exhibits decreased empathy and inhibition in what he/she does and says. May have a personality change.

What to report to the hospice team:

- Any signs of the behaviors listed above
- Any signs of unsafe behaviors including hurting self or others
- Needing more help to care for the person with dementia

What can be done?

Family

Respect the person by treating him/her as an adult and remember:

- He/she has limited control of his/her abilities and behaviors.
- He/she believes that their “reality” is what is real.
- All behaviors are communicating something.
- Allow the person as much control as is safe. Give two choices – “Do you want to wear the green shirt or the red shirt?”
- Remind the person of the day, place, and time, until this no longer has meaning to the person.
- Tell what you will do before you do it. “I am going to help you with your shower.” “I will help you take off your shirt.”

- Try to find the meaning behind the behaviors, emotions, and feelings of the person. Being combative during a bath may mean he/she is cold. Pacing may mean he/she has forgotten the location of the bathroom.
- Create a daily routine with small rituals. Include activities he/she can complete. These can include prayers, washing hands, or preparing food. Try to not overtire the person.
- Allow the person to do as much of their own care as possible. This will help maintain their self-esteem.
- Include activities with positive memories that have meaning to the person – hobbies, pictures
- Provide physical closeness, hand holding, if he/she allows.
- Talk in a calm, reassuring, and inviting manner. “Let’s go to the dining room.”
- Safety for you and the person is always comes first!
- When bothersome or unsafe behaviors are exhibited, redirect the person to safer, more enjoyable activities. Know his/her “triggers” and use them to redirect his/her attention. Start to sing a favorite song you know he/she will join you in singing.
- Caring for someone with dementia is physically and emotionally demanding. Take care of yourself and ask for help when needed.

Depression

This range of feelings may include sadness, gloom, numbness, emptiness, helplessness and hopelessness. It occurs often in chronic and terminal illness. Signs and symptoms are often like those of illness. They include:

- Fatigue
- Sadness, depressed mood
- Loss of appetite with weight loss
- No interest or pleasure in daily activities
- Withdrawal from family and friends
- Sleep problems

- Feelings of worthlessness, hopelessness, guilt
- Difficulty focusing and thinking
- Thoughts of death or suicide
- Agitation or slowing down

What to report to the hospice team:

- Any of the symptoms listed above
- A known history of depression
- Any symptoms such as pain, nausea, difficulty breathing
- Change in medications the team may be unaware of

What can be done for depression?

Depression may occur at the end-of-life. There is a wide range of intensity of depression. The team will help you sort out causes of depression. They will discuss treatment options with you. For yourself, you may:

- Optimize physical status with rest and nutrition
- Set small, realistic, achievable goals
- Utilize relaxation techniques
- Consider complementary therapies such as aromatherapy, art and music therapy

Your caregiver may:

- Keep you and your area safe
- Let you know that they will be there
- Allow you to express feelings
- Allow you to control as much as possible related to treatment decisions and activities

Fatigue

Fatigue is a feeling of being tired or exhausted. Even after getting plenty of sleep or rest, people with fatigue feel like they have no energy. They are so tired they cannot do the activities they enjoy. Fatigue is common among hospice patients.

Diagnosing reasons for fatigue may take time. Fatigue can have many causes, including illness, emotions and treatments. Sometimes, fatigue can come with feelings of depression or sadness.

What are the signs of fatigue?

- “Just too tired” to care about or do normal activities or routines
- Lack of appetite or not having energy to eat
- Sleepiness
- Not talking
- Depression

What to report to the hospice team:

- Any signs listed above
- Describe how bad the fatigue is by using a scale from 0 to 10 when 0 = no fatigue and 10 = in bed all day
- What makes the fatigue better or worse
- Spiritual, social or emotional concerns and worries
- Changes in appetite
- Any troubling symptoms that are not controlled, such as nausea, pain or bowel problems
- If you have experienced fatigue before, and what made it better

What can be done to help fatigue?

Because fatigue can have many causes, it may take a number of actions to improve your symptoms. Talk to your hospice team about your fatigue. The team will work with you and your family to find the causes for the fatigue. They will discuss treatments that may work best for you.

Things you may do to help your fatigue:

- Slowly increase activity. Do so a little at a time to save energy.
 - Keep a log of which time of day seems to be your best time.
 - Plan and do activities during your best times of the day.
 - Avoid or delay activities that are not your priority.
 - Change your position. Do not just stay in bed.

- Use sunlight or a light source to help feel more energized.
- Try activities that restore your energy, such as music, meditation or spending time outdoors.
- Allow caregivers to assist you with daily activities such as eating, moving or bathing as needed.
- Talk with family about your energy level and how to help.
- Rest and sleep better.
 - Listen to your body. Rest as needed.
 - Try to keep a regular time to go to bed and to wake up.
 - Avoid things that may prevent sound sleep such as lighting, certain food, drinks or medicine taken too late in the day.
 - Avoid interrupted sleep. Try to get continuous hours of it.
 - Plan rest times or naps in late morning or mid-afternoon.
- Avoid late afternoon sleep. It could affect nighttime sleep.
- Ask if using oxygen when you sleep will help you sleep better.
- Increase food intake.
 - Try nutritious, high protein food.
 - Eat small, frequent meals.
 - Add protein supplements to foods or drinks.
 - Perform frequent mouth care before and after meals.
 - Ask about possible use of medications to stimulate your appetite or relieve fatigue

Nausea and vomiting

Many causes may relate to your illness or treatment. Your team will try to discover the underlying reason in order to offer options.

- Nausea is an unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting.
- Vomiting is the emptying of stomach contents.

What to report to the hospice team:

- Amount and frequency of nausea and vomiting
- Description of vomited fluid
- Altered mental status

What can be done?

The good news is there is much you, your caregiver and hospice team can do. Talk with your team about which options are best for you:

- Record what causes you to feel nauseated or to vomit and what decreases the nausea and/or vomiting
- Sip carbonated drinks that have gone flat
- Drink sports drinks such as Gatorade® (Pedialyte® for children)
- Eat small amounts of salty foods such as crackers and broth
- Provide foods as requested by patient in small frequent amounts. Large meals may be overwhelming.
- Provide frequent mouth care.
- Try sips of water or ice chips before eating again.
- Maintain a comfortable room temperature.
- Increase air flow. Open windows or use a small fan.
- Try alternative therapies such as massage, guided imagery or progressive muscle relaxation.
- Try activities that may distract from nausea, e.g., listen to music, watch TV, do puzzles, sketch, draw, read, or yoga
- Use medications as ordered by your healthcare provider
- Avoid juices such as cranberry, grape and apple.
- Avoid fried foods, milk products, or foods with strong smells.
- Avoid strong odors such as perfume and deodorizers.
- Avoid eating immediately after vomiting.
- Avoid constipation.

Contact your hospice care team if nausea and vomiting continue.

Psychological distress

Uneasy feelings of anxiety or depression in response to physical, spiritual, or emotional demands – or a combination of multiple demands – that result in temporary or permanent harm

What are the signs and symptoms of psychological distress?

- Feelings of anxiety, sadness, anger. Wanting to be alone
- Feeling “out of control” or overwhelmed much of the time
- Difficulty coping with everyday problems
- Unable to talk about ways to solve problems or talk about fears
- Needing the help of others to make decisions
- Trouble sleeping
- Not taking care of self
- Looking sad, frowning. Crying easily.
- Loss of hope or sense of comfort
- Laughing at odd times
- Aches and pain. Feeling that your heart is racing
- Thoughts of suicide or hastening death
- Not wanting to follow the advice of the healthcare team

What to report to the hospice team:

- Any signs of behaviors listed above
- New reckless behavior. Talking or thinking about suicide
- Firearms in home. Hoarding or stockpiling medications
- Seeing images or hearing voices not seen or heard by others
- History of psychiatric illness or history of use of medications taken for depression, anxiety, schizophrenia, dementia, or bipolar disorder
- Lack of interest in self or life in general
- You experience a new problem or a current problem is getting worse and medicine does not seem to work.
- Side effects of medications

What can be done?

Psychological distress is common with terminal diseases, especially if physical symptoms are present. Your healthcare team wants you to be physically comfortable. There is a direct link between how one feels physically and how one feels psychologically and emotionally.

Patients and Family

- Do not feel you are bothering your team by asking questions.
- Asking questions means you care.

Patient

- You may not feel up to talking with many people. You may want to have one person to talk to whom you trust.
- Try to have a daily routine including a regular sleep schedule.
- Eat a balanced diet and exercise as you are able.
- Avoid alcohol and non-prescribed drugs and herbal remedies.
- Ask for and accept help from your team, including family, friends, nurses, physicians, nursing assistants, social workers, or chaplain/spiritual counselor.

Family

- Provide calm, relaxing setting
- Be flexible. The patient may want to talk one day. The next day he/she may need quiet and calm.
- Be willing to be with them without having to “do” something
- If needed, help with medications. Report any medication side effects or changes in behavior.
- Treat the patient with dignity and respect.
- Don't be afraid to ask for help.
- Do not be hard on yourself with comments like “I should have done this or that” or “I should have known that.”
- As much as you can, enjoy this time together. Look for ways to make memories.

Restlessness

This is the inability to rest, relax or concentrate. Extreme restlessness is sometimes called agitation. Restlessness occurs in nearly half of all patients during the last 48 hours of life.

What are the signs?

- Muscle twitching
- Moving around without a known reason
- Pulling at sheets, covers or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

What to report to the hospice team:

- Any of the signs or behaviors listed above
- Unable to give medications by prescribed method
- Things that make restlessness worse, e.g., loud music
- Things that ease restlessness, e.g., soft music
- Concerns you may have as a caregiver to cope
- Need for spiritual support
- Situations that might be unsafe

What can be done?

The team will try to find the reason for the restlessness and talk with you about treatments. Things you can do:

- Give prescribed medications as ordered
- Offer frequent reassurance
- Offer relaxation activities, e.g., play soothing music
- Keep things calm, e.g., decrease the number of visitors
- Read favorite stories, poems, etc. in a calm voice
- Hold the person's hand, give them a gentle massage

- Keep the person safe. Do not leave the person alone while restless. Check often when he or she is calm.
- Understand this may be a sign the patient is close to death. Let other family members know what is happening.

Shortness of breath (dyspnea)

This is a personal experience. It is an uncomfortable feeling of having difficulty breathing. It may be described in these ways:

- I cannot get enough air.
- I cannot catch my breath.
- The room is closing in. There is not enough air in the room.

When should I seek advice about my shortness of breath?

- It stops you from doing what you want to do.
- You or your family feel fearful, anxious, nervous or restless.
- Skin turns bluish on your face, ears, nose, fingers or toes.

What can be done?

The good news is there is much you, your caregiver and hospice team can do. The team will try to find the cause and discuss treatment options with you and your family. Things that may be helpful:

- Sit in a chair or recliner.
- Elevate your head on pillows when lying in bed.
- Sit with your hands on your knees or on the side of the bed leaning over the bedside table.
- Practice pursed lip breathing. Take slow, deep breaths. Breathe in through your nose. Then, breathe out slowly and gently through lips that are “puckered” as if you are whistling.
- Increase air movement. Open a window. Use a fan or air conditioner. Apply a cool cloth to your head or neck.
- Use oxygen as directed by your healthcare provider.
- Take medication as directed by your doctor
- Decrease anxious feelings by keeping your environment quiet.
- Use prayer, medication, calming music or massage to relax.
- Tell the team if shortness of breath is not relieved or gets worse

Travel while you are a hospice patient

It is important to have options for how you want to spend the rest of your life. Some patients are content to remain at home. Others prefer to travel while they can. The choice is up to you and your caregiver.

- Discuss travel plans with your family and attending doctor.
- Inform your hospice team at least 5 business days before you start your trip. The help we give depends on your travel plans

Caring for the caregiver

Love for your family member and satisfaction from helping him or her may be mingle with other feelings. You may resent loss of privacy. Having no control over what happens may frustrate you. It may be hard to accept the decline of the special person you care for. Feelings depend in part on:

- Your prior relationship with that person
- How much responsibility you have as a helper
- Time you need for your work, social and leisure pursuits

Mixed emotions can cause guilt and stress. Your mind, body and spirit can be drained if you do not take care of yourself. You need to maintain your health and find ways to cope with your situation.

Help yourself. Accept your feelings.

They affect the way you view and cope with care-giving. **All** feelings are okay and real – even anger, frustration, and sadness. You cannot resolve guilt and stress until you recognize and accept your emotions. Learn to express feelings to others.

Know when there is too much stress.

These can help you know when you demand too much of yourself.

- Feeling irritable
- Worry
- Being preoccupied
- Feeling gloomy
- Having trouble sleeping
- Diarrhea or constipation
- Being abrupt or crabby to people you care about

Pain, anger and resentment can sicken us if they are not released.

Join a caregiver support group.

This can be a safe place to share information and feelings with support from trained staff. Group members often form strong bonds, become friends and help each other. It is also okay to just attend and listen. Being in a group can help you manage stress and improve skills. Hearing how others cope with the same challenges can help you manage your own. At some point, you learn to accept some problems cannot be solved. Coming to that knowledge among friends is better than struggling alone.

Set realistic goals.

Care-giving is one of many demands on your time. Recognize what you can and cannot do. Set priorities and stick to them. Turn to family, friends, and neighbors. Keep a list of tasks for those who offer to help, such as:

- Taking your children after school one day.
- Taking your care-receiver for a ride.
- Fixing a meal.
- Running an errand.

Communicate with family and friends.

Turning to others can be a mixed blessing. Their visits may make you feel less alone and better able to deal with care-giving. They can give you a break by spending time with your care-receiver. Do not expect others to ask if you need help. It is up to you to do the asking.

Those whose help you need may criticize the care you provide. They may comment on how the house is kept and how the care-receiver is dressed. They react to what they see with little knowledge of the challenge you face each day. They may feel some guilt for failing to be more involved. It may not be easy, but listen calmly and politely to comments from others.

If you and your care-receiver are okay with how things are going, keep doing what meets your needs. Schedule family meetings to keep others informed, involved and (hopefully) more willing to share care giving tasks.

Community resources

Find out more about in-home services or adult day care. Hire a homemaker to cook and clean, or an aide to help your care-receiver bathe, eat, dress, use the bathroom or get around the house. Contact your hospice social worker for more information.

Respite care

You need breaks from time to time. Find someone or ask hospice volunteers to stay with your loved one for a few hours at a time on a regular basis. He or she may enjoy a break from staying home as much as you do. Ask how to arrange for respite care in our hospital.

Maintain your health

Your well-being affects your outlook on life and how well you cope. You need to eat 3 balanced meals a day and:

- Exercise daily.
- Allow yourself leisure time.
- Get enough sleep/rest.

Remember “laughter is the best medicine.”

Laughter is a way to release tension. It can also:

- Reduce pain.
- Improve breathing.
- Elevate mood.

Humor therapy can help us through stressful times. For yourself and your care-receiver:

- Try to see the humor in being a caregiver.
- Write on a card: **Have you laughed with your care-receiver today?** Post it in the bathroom or kitchen.
- Read funny books or jokes.
- Listen to tapes or watch shows and films that make you laugh.
- Share something funny with your care-receiver, a friend, or relative.
- Attend social groups where there is friendship, joy and fun.
- Notice how often you smile. It takes less energy than frowning.

Avoid behavior that hurts you – and get help.

Sometimes we handle stress in ways that cause more harm than relief. Eating or drinking too much, using drugs or smoking will create problems, not solve them. If your choices result in neglect or abuse of the person in your care, you could be breaking the law. **You do not have to go it alone.** Turn to family members, friends, clergy members, professional counselors, or a caregiver support group for help and support.

Build self esteem

Pursue activities and social contacts outside your home. Do what you enjoy. Go to a movie, play a musical instrument, or get together with friends for a card game. It may not be easy to schedule these activities, but the rewards are great for having balance in your life. Taking care of yourself benefits you and your care-receiver. Meeting your own needs will satisfy you. It will give you more strength and vigor for caregiving tasks.

Safe medicine disposal

Dispose of medicine no longer needed by a hospice patient as soon as you can. Storing unused medicine for any length of time is very risky. Small children or pets could be harmed by a single dose of unused medicine. Someone could take it by mistake.

Dispose of unused or out-of-date medicine in secure drop boxes at:

- Gundersen Clinic, La Crosse (in the lobby near the pharmacy)
- East Building Clinic Pharmacy
- Onalaska Clinic Pharmacy
- Cass St Pharmacy

To find other disposal sites or events, ask local police or any pharmacy. You can also call Great Rivers 2-1-1.

To prepare liquids, inhalers, pills capsules and powders:

1. Remove medicine from its container.
2. Put pills or liquid into a leak-proof plastic bag that can be sealed (Ziploc® or other brand).

3. Peel or scratch personal information off labels. Rinse and toss boxes, bottles and vials in your trash.

If you cannot take medicine to a drop box or disposal event:

1. Empty pills or liquids in a plastic bag that can be sealed.
2. Add coffee grounds or kitty litter.
3. Seal and place the bag in your trash.
4. Take personal information off containers. Put them in your trash.

Never put medicine in a sink or drain. Medicine should not be flushed down the toilet unless it is on a special FDA list. (You can see or print this list. Just search this phrase online: fda.gov, drugs you can flush)

How to tell if medicine is out-of-date (expired)

Over-the-counter medicine may not be safe or as strong as when you bought it. The lot number and/or expiration date may look like these:

- EXP 06/17
- LOT 12345 06/17
- EXP 06/17 L12345

This means do not use it after June 2017. Buy a new package. Prescribed medicine can also expire. The label may say:

- Use before 5/30/17
- Discard after 5/30/17
- Use by 5/30/17

Do not use this medicine after May 2017. Have it refilled.

Needles, sharps and other hazardous materials

Gundersen pharmacies accept sealed sharps containers. You can take one to the Gundersen clinic that issued it to you even if no pharmacy is on site. Take other hazardous materials to the nearest public “haz mat” disposal site or “clean sweep” event. Contact your local solid waste department for more information. Wisconsin residents can use the La Crosse County Household Hazardous Waste Facility for free. Minnesota and Iowa residents can use the facility for a fee. Call (608) 785-9999 for hours and other information.

What to do when a loved one dies

Losing a loved one can be overwhelming. Coping with grief alone is a great challenge. At the same time, many “musts” add to your burden. Most cannot be ignored or delayed. This checklist can guide you through the days and demands ahead. Refer to it often as you think about how to honor your loved one and manage his or her assets. Know that you are in our thoughts and hearts at all times.

Perform these tasks right away

- Give Hospice the name of a family member to contact for follow-up.
- Select a funeral home. Hospice will contact the one you choose.
- Contact close family or friends. Ask them to help inform others.
- If the deceased wanted to donate eyes, tissue or organs and was healthy enough, decide whether to arrange for this. Hospice staff can assist and answer questions about what is involved.
- Arrange for care of pets or other animals, if any.
- Secure the home and property of the deceased. Store cash, jewelry, collectibles and other valuables in a safe place.
- Arrange for a funeral or memorial service. Ask a local funeral home to explain options and cost. The list may include:
 - Burial, cremation, mausoleum or columbarium
 - Private or public service
 - Visitation
 - Celebration of Life or other ceremony
 - Choice of site
 - Funeral home
 - Church or chapel
 - Community center, park, or other event space
 - Family home
 - Graveside

- Meet with the funeral director:
 - Bring a photo of your loved one.
 - Bring his or her Social Security number.
 - Discuss service, obituary, flowers and memorial options.
 - Request copies of the death certificate.
 - Ask for a detailed breakdown of all costs and options.

- Was the deceased a veteran? Explore free burial in a national cemetery.

After the funeral or memorial service

You and your family need time to grieve. For many, financial concerns can add stress to your situation. Certain steps are required to receive proceeds from an estate, insurance and other benefits.

- **Death certificate:** You may need as many as 10 to 20 certified copies. Get these from the funeral director.

- **Birth certificate and marriage license:**
Obtain copies from the county and state where the deceased was born and married. County clerks or registers of deeds are likely sources.

- **Social Security benefits:** To apply for benefits, call (800) 772-1213 or go to your local Social Security office. Bring the deceased's SS number, certified death certificate copy, and proof of your relationship (marriage license and/or birth certificate). Benefits should come within 60 days.

- **Veterans benefits:** These might cover part of the funeral costs. Other benefits may apply. Call 800-827-1000 for the nearest VA office address.

- **Insurance benefits:** Contact each company or its nearest named agent to obtain claim forms. Complete and submit these with a certified copy of the death certificate and a copy of insurance policy.

- **Retirement plan and pension benefits:** Call the employee benefits department where the deceased last worked. You must provide certified copies of the death certificate.
- **Will:** Obtain copies. If you are not certain one exists, contact the attorney of the deceased. If there is a will, review it with the attorney and discuss how to settle the estate.

Financial records and account access

Contact banks, insurance agents, accountants, brokers and financial planners. Most require death certificates and other documents before you can access checking, savings, safety deposit box, investments, IRAs and other funds. Search the home of the deceased for bank statements, tax returns, credit card bills, utility bills, mortgage payments and other records of unpaid debt.

- **Deeds and titles:** You need the original or copy of each of these: home and/or business property, mortgage(s), vehicle title(s).
- **Other forms:** Court documents for divorce, property settlements, name changes, prenuptial agreements, adoptions, military service, domestic partnership registration, driver's license, passport, citizenship, etc.
- **Bills:** Make a list of routine bills. Handle them as they arrive. Give unpaid bills to the executor or personal representative for prompt payment.
- **Post Office:** Online or at the counter arrange to have mail forwarded. As needed, stop mail delivery to the home and/or business of the deceased.
- **Other services:** Cancel services no longer needed such as cell phone, landline, Internet, cable TV). Do not cancel utilities. They may be needed.

“Know when there is too much stress” (p. 32) - Caregiver Connection: A Training Manual
Developed by the Aging Consortium of Oklahoma County. Diane Publishing Company. © April
1989. All rights reserved.

All other text in **Caring for the Caregiver** (pp. 32-35) is from Caregiver’s Handbook, published
by The Caregiver Education and Support Services Seniors Counseling and Training Case
Management Services of San Diego County Mental Health Services. Robert Torres-Stanovik,
LCSW, ed. 1990.

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This information is meant to inform and educate our patients. It supports the care you receive
from your health care team. It does not replace medical evaluation, advice, diagnosis or
treatment. Talk to your doctor or health care team before starting any new treatment.
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Gundersen Hospice Patient and Family Bill of Rights

We respect the dignity, beliefs and values of each patient. We use proven best practices without regard to:

Race	Religion	Gender
Color	Economic Status	Sexual Orientation
Culture	Age	Source of Payment
Nation of Birth	Physical Abilities	

As a patient or family/caregiver you have the right to:

- Receive this information before admission to hospice.
- Be told what to do if these rights are violated.
- Assert your rights without fear of any adverse response.
- Have your property and yourself treated with respect.
- Be informed of and understand all services available from Hospice, including:
 - Services covered under the hospice benefit
 - Services for which you may be charged and the amount of those charges
 - Specialized services for unique patient groups, such as children, and limits, if any
 - Contracted services
- Be informed of criteria for being discharged from Hospice.
- Know Gundersen Health System hospice advance care planning policy.

For protection of your privacy, you have the right to:

- Communicate privately with others.
- Confidential treatment of your personal and clinical record information
- Request and receive an exact copy of your clinical record.
- Approve or refuse release of information to any individual outside Hospice except:
 - In case of transfer to another facility
 - As required by law
 - As required by 3rd party payment contract

Your right to be involved in your own care includes these rights:

- Receive effective pain management and symptom control.
- Receive visitors at any hour, including small children.
- Refuse visitors if you are receiving care in a facility.
- Be informed of any significant change in your status.
- Be free of mistreatment, neglect, or verbal, mental, sexual and physical abuse, and misappropriation of your property
- Be free from restraints and seclusion, except as authorized in writing by the attending physician for a specified and limited period of time. This authorization must be documented in the plan of care if you receive care in a facility.
- Be treated with courtesy, respect and full recognition of your dignity and individuality.
- Choose physical and emotional privacy in treatment, living arrangements and the care of personal needs.
- Participate in developing your plan of care.
- Refuse any care or treatments.
- Choose your attending physician for hospice.
- Complete an advance directive your hospice team will honor when providing your care.

You have the right to share any concerns about your care. Your concerns will be:

- Received with respect.
- Answered and resolved in a timely manner.

If you have concerns, complaints, or compliments, please:

- Talk with a member of the hospice team.
- Call Hospice and speak with the Hospice clinical manager.
- Call Gundersen Service Excellence (608) 775-7676.

If you are not satisfied with how Gundersen Hospice resolves your concern, you may file a complaint with the state in which you are receiving care, or with The Joint Commission, which accredits our program.

Wisconsin residents

Call Wisconsin Home Health / Hospice Hotline at (800) 642-6552 or write to:

DHS/Division of Quality Assurance
Bureau of Health Services
Attn: Hospice Complaint Coordinator
819 N. 6th St., Rm 609B
Milwaukee, WI 53203

Website: <https://www.dhs.wisconsin.gov/guide/complaints.htm>

Minnesota residents

Minnesota Adult Abuse Reporting Center

Phone: (844) 880-1574

Website: mn.gov/dhs/adult-protection/

Or, you may contact the state ombudsman for advocacy:

Office of Ombudsman for Long Term Care
Minnesota Board of Aging
P.O. Box 64971
St. Paul, MN 55164-0971
Phone: (651) 431-2555 or (800) 657-3591

The Joint Commission may be contacted toll free at (800) 994-6610. (Press 1 to speak to someone.)

Or, you may mail a written complaint to:

Office of Monitoring – The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, IL 60181

Or, email: patientsafetyreport@jointcommission.org

GUNDERSEN HEALTH SYSTEM®

1900 South Avenue, Mailstop: EB0-002
La Crosse, WI 54601
(608) 775-8435 or (800) 362-9567, ext. 58435
gundersenhealth.org/hospice