

Pain & Symptom Management



Home and Hospice Services

Symptom Management for Patient and Caregivers

When you are sick, it is not uncommon to experience symptoms such as pain, trouble breathing, anxiety or sadness, nausea, vomiting, constipation, restlessness, agitation or other symptoms. Most symptoms can be managed with medication and other interventions.

WHY SYMPTOM MANAGEMENT MATTERS

- When symptoms are not controlled, quality of life is poor
- Poor management of one symptom can cause other symptoms to become worse
- Symptoms that are not managed can cause emotional distress for you or your loved ones
- Caregivers can also experience problems or feel overwhelmed
- Caregivers may have difficulty sleeping, feel very tired, feel confused about how to manage medication or how to provide certain types of care, question their ability as a caregiver, or experience feelings of restlessness, anxiety and depression

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Any questions or concerns you have about symptom management
- Any symptoms you experience
- Any questions or concerns about a medication's effectiveness or side effects

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and help address concerns
- Ask questions and evaluate your needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training to manage symptoms
- Your hospice nurse will provide training on how to safely use and store medications

Call our 24-hour number **(847) 475-3002** with questions or concerns so we can provide timely care.

How Symptoms May Progress as Death Approaches

While each person's experience of symptoms at end of life is unique, there are certain signs and symptoms that are common and can help determine life expectancy. Remember that most people will not experience every symptom listed here. Your hospice nurse can help explain the symptoms below and what they mean. Your nurse will train you on how to manage the symptoms.

DURING THE LAST WEEKS TO MONTHS, SOME PEOPLE EXPERIENCE

- Tiring more easily with physical activity and/or the need to sleep more often
- The need to talk or interact with others less
- Changes in appetite
- New pain or an increase in existing pain

DURING THE LAST DAYS TO WEEKS, SOME PEOPLE EXPERIENCE

- An increasing need to sleep as energy levels and tolerance for activity continue to decrease
- A feeling of heaviness and tiredness in the body
- Low blood pressure and/or a faster or slower pulse
- Irregular breathing
- Congestion
- Increased sweating and/or changes in body odor
- Skin that feels warmer or colder than normal; changes in coloring of the skin
- Little or no desire to eat or drink
- Periods of confusion or feeling restless, anxious or disoriented
- Seeing others who have died, or speaking with them

DURING THE LAST HOURS TO DAYS, SOME PEOPLE EXPERIENCE

- An increase in the intensity of the symptoms experienced in the last days to weeks
- A sudden surge of energy
- Eyes half open, unfocused and/or tearing more
- Increased restlessness or little to no activity
- Further decreases in blood pressure and a weak pulse that is hard to find
- Irregular breathing with breaths that may stop and start
- Gurgling or bubbling sound with breathing
- Abnormally low or high body temperature
- Less urine and stool and changes in the ability to control going to the bathroom
- Bluish or purple coloring of hands, knees, feet; arms and legs abnormally warm or cool to the touch

For additional information, please see the Helpful Tools for End of Life section in your binder.

Pain

Pain is an unpleasant feeling often caused by an injury or illness. Pain is different to everyone, and only the person experiencing pain can fully describe it. Words used to describe pain include aching, burning, gnawing, grabbing, soreness, throbbing or feeling uncomfortable.

WHY PAIN MATTERS

- Pain can cause physical, emotional or spiritual suffering for those experiencing it, as well as their caregivers and loved ones
- Pain can impact the ability to sleep and care for oneself
- Pain can make it hard to enjoy activities and makes the overall quality of life poor

WHAT ARE THE NONVERBAL SIGNS OF PAIN?

- Behavior changes such as pacing, fidgeting, irritation, confusion and agitation
- Making unusual noises like moaning or calling out
- Facial expressions like grimacing or actions like guarding an area of the body
- Faster-than-normal breathing or higher-than-normal blood pressure

WHAT YOU CAN DO IF YOU ARE EXPERIENCING PAIN

- Take pain medications as prescribed by your healthcare provider
- Try relaxing activities including massage, warm baths, listening to music or spending time with pets
- Try distracting activities like watching television, playing games, arts and crafts, or reading
- Use heating pads, warm towels or ice packs on painful areas as ordered by your healthcare provider

WHAT TO REPORT TO THE HOSPICE CARE TEAM

- Any new pain or old pain that is higher than your pain goal number
- Pain medication side effects like sleepiness, dizziness, confusion, itching, vomiting, feeling like you will vomit, difficulty having a bowel movement or not having a bowel movement for three or more days
- Any signs that your treatments for pain are not working as well as they previously had, such as needing to take your pain medication more often

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Work with you to identify and describe your pain and make a pain management goal
- Evaluate your needs and develop a care plan to meet them
- Communicate your concerns to your doctor and to others on your hospice care team
- Train you and your caregivers how to measure pain and manage it
- Train you and your caregivers how to use medications and what side effects to look for

Managing Your Pain

AS A PERSON WITH PAIN YOU HAVE THE RIGHT TO

- Have your reports of pain believed
- A timely response from hospice staff when you report new or worsening pain
- Make decisions about the best way to manage your pain
- Pain medication and treatments, provided by hospice, as ordered by your doctor
- Training on pain management and pain medication side effects

YOU HAVE RESPONSIBILITIES IN MANAGING YOUR PAIN, INCLUDING

- Explaining your pain to the nurse and reporting any new or worsening pain promptly
- Telling the hospice nurse if your pain is not relieved
- Telling the hospice nurse about any worries you have about taking pain medication
- Storing medications safely and calling hospice if you think others are taking your medication
- Asking questions about your treatments and asking for clarification as often as you need it
- Reporting any side effects of pain medication you experience promptly to your hospice nurse

WHAT DOES THE HOSPICE NURSE NEED TO KNOW ABOUT YOUR PAIN?

- How often you have pain
- Where you feel pain and if it spreads anywhere else
- How long your pain lasts
- Your pain scale rating with 0 being no pain and 10 being the worst imaginable pain
- What the pain feels like (stabbing, squeezing, aching, burning, tingling, throbbing, etc.)
- What you do to lessen the pain and what makes it worse
- How pain affects your daily life (sleep, appetite, activities, emotions)

DO YOU HAVE ANY BARRIERS TO MANAGING YOUR PAIN?

- Worries about taking pain medication because of addiction or side effects
- Worries that your pain cannot be relieved
- Believing that pain is normal and/or necessary
- Concerns about burdening others by talking about your pain
- Needing to be “a good patient” and not wanting to ask for too much medication

Side Effects of Pain Medication

Opioid pain medications such as morphine, hydromorphone, oxycodone, fentanyl and methadone are often used in hospice. These medications can provide relief with certain kinds of pain and may also help with trouble breathing. Like most medications, opioids have side effects. Some of the most common side effects are listed below. Your hospice nurse will talk to you about these and any other side effects you may experience with other medications.

CONSTIPATION

- Ask your hospice nurse about a daily laxative if you are taking daily pain medication
- Increase the amount of liquid you consume, if you are comfortable doing so
- Track how often you have a bowel movement, and call your hospice nurse if you do not have a bowel movement for three days, if you are straining when have a bowel movement, if you feel abdominal fullness or if you have only small amounts of watery stool
- If other methods to relieve constipation do not work, laxative suppositories are provided in your comfort pack

SLEEPINESS OR SEDATION

- Sleepiness is typically a short-term side effect that usually wears off after a few days of taking pain medication
- Drinking coffee or caffeinated drinks (if allowed by your doctor) can minimize sleepiness
- Talk to your doctor or hospice nurse about taking non-opioid medication for mild pain

NAUSEA AND VOMITING

- Avoid taking medication on an empty stomach, if you feel comfortable eating
- Other medications can be ordered to prevent nausea and vomiting

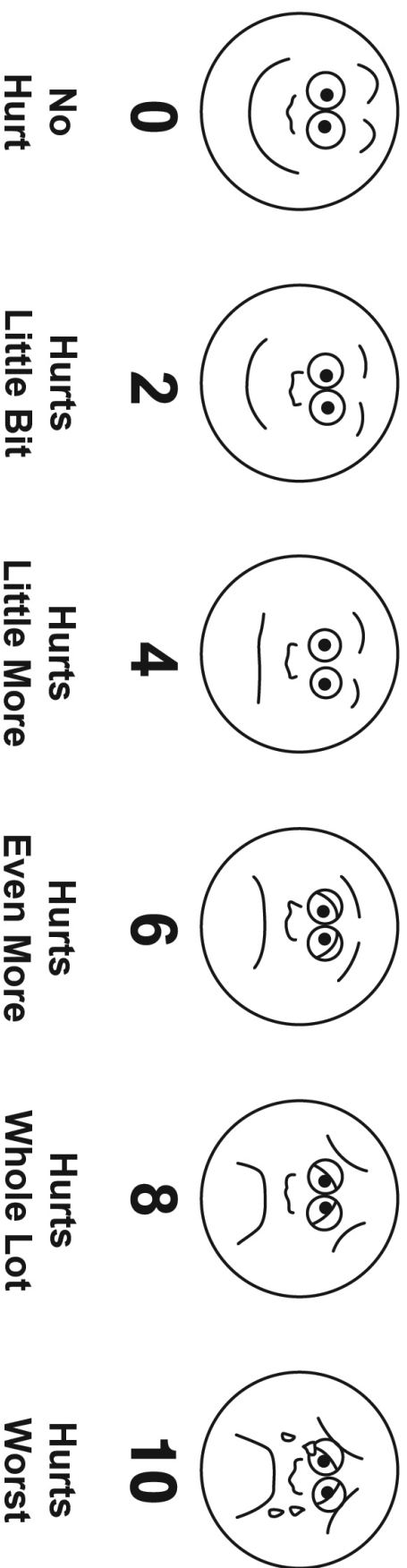
SLOWED BREATHING

- In hospice, slower breathing is often considered beneficial for patients who are short of breath
- Contact hospice if you notice changes in breathing, with sedation, and shaking in hands or body

DIZZINESS

- When taking opioid pain medications, be sure to limit activity, including driving or operating equipment, until you know how they will affect you
- Rise slowly when getting up from a lying or seated position

Wong-Baker FACES® Pain Rating Scale



INSTRUCTIONS FOR USAGE

Explain to the person that each face represents a person who has no pain (hurt), or some pain or a lot of pain.

Face 0 does not hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurts a whole lot. Face 10 hurts as much as you can imagine, although you do not have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain he or she is experiencing.

Trouble Breathing

Trouble breathing, often referred to as shortness of breath, is the feeling that you cannot get enough air and can include chest pain, swelling of hands and feet, or feeling out of breath when walking short distances or at rest. You can have trouble breathing or feel short of breath even when you are getting enough oxygen.

WHY TROUBLE BREATHING MATTERS

- Trouble breathing can be an uncomfortable symptom
- Trouble breathing may cause anxiety
- Trouble breathing can make daily activities more difficult

WHAT CAN HELP

- Relaxation techniques
- Breathing treatments like inhalers and nebulizers
- Oxygen if ordered by your doctor
- Pain medication like morphine or hydromorphone
- Sitting upright
- Sleeping with head of bed elevated
- Fan use and reducing the room temperature
- Other treatments as recommended by your doctor

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Chest discomfort
- Trouble breathing or feeling short of breath
- Feeling of tightness in the chest
- Difficulty swallowing
- Swelling of hands and feet

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and help address concerns
- Ask questions and evaluate your needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training on how to manage trouble breathing
- Provide training on how to safely use and store medications for trouble breathing

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Oxygen Safety

WHY OXYGEN SAFETY MATTERS

Oxygen therapy can be helpful if you have breathing problems; however, oxygen can increase your risk of injuries or fire if not used properly. The information provided here will help you understand how to use oxygen safely at home.

OXYGEN SAFETY PRECAUTIONS

- Never smoke any tobacco products (cigarettes, cigars, pipes), cannabis or e-cigarettes when wearing oxygen or let others smoke these products around you or your oxygen source (concentrator or cylinder)
- Always keep the “NO SMOKING” sign provided to you posted on your front door or window
- Never cook while wearing oxygen; stay at least six feet away from any source of open flame or sparks
- Do not use electrical appliances like heating pads, hair dryers, electric blankets or electric razors while wearing oxygen
- Do not use oil-based lubricants or apply oil-based face or hand lotions, petroleum jelly products or aerosol sprays to your face or body while using oxygen
- Do not use extension cords with oxygen concentrators; always plug the cord directly into the wall outlet
- Never plug the concentrator into an outlet that is being used to power another major appliance
- Always position your concentrator at least 12 inches away from walls and furniture
- Be sure your oxygen cylinders are secured at all times; store portable oxygen cylinders lying down or in a storage rack
- Never store oxygen cylinders in an enclosed space, such as a closet, as oxygen can leak out; a small spark can ignite a fire
- Never place oxygen cylinders or oxygen equipment in the trunk of your car; if your car is rear-ended, oxygen tanks may explode

CLEANING AND MAINTAINING HOME OXYGEN EQUIPMENT

- Replace your nasal cannula or oxygen face mask every two to three weeks or sooner if cracked or discolored

- Clean the concentrator filter according to instructions in the manual provided by your oxygen supplier
- Clean the humidifier bottle at least once a week
- Use only distilled water (or boiled and cooled tap water) in the humidifier bottle
- Use only a cloth dampened with water to clean the surface of your concentrator

TROUBLESHOOTING AND HOME OXYGEN EQUIPMENT

- If you have a problem, first check to see that the power cord is plugged into the wall outlet
- Make sure the oxygen tubing is not kinked, and is properly connected to you and your oxygen source
- If you have questions or concerns about your oxygen equipment, contact the supplier’s 24-hour number for help; this number is usually located on the equipment

EMERGENCY PREPAREDNESS

- Register life-sustaining medical equipment with your utility company and local authorities
- Keep the emergency oxygen tanks provided to you for emergencies only
- Call your oxygen supplier before known potential emergencies (such as severe weather) to ensure that you have an adequate backup supply of oxygen
- Keep the number for your oxygen supplier close by; call immediately if you lose power (electricity)
- Be sure you have smoke detectors in your home and that they are functioning properly at all times
- Make sure your house number can be seen easily from the street and/or alleyway for emergency response teams if needed

Constipation

Constipation happens when you do not have bowel movements regularly and can cause small stool that is difficult to pass.

WHEN CONSTIPATED, YOU MAY HAVE ONE OR MORE OF THESE SIGNS AND SYMPTOMS

- No bowel movement for three days
- Hard stool or diarrhea
- Belly swelling, pain or cramping
- Reflux, burning in the throat or chest, or vomiting
- Bleeding when you have a bowel movement

WHY CONSTIPATION MATTERS

- It is common for constipation to occur due to less activity than normal, drinking less water or fluids, certain medications or poor nutrition, or with illness
- Constipation can be an uncomfortable symptom

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- No bowel movement for three days—please track bowel movements on Event Log
- Small and hard or runny stool
- Upset stomach, heartburn, feeling like you may vomit or actually vomiting
- Need to use fingers to remove stool

WHAT CAN HELP IF YOU HAVE CONSTIPATION

- Fluids such as water, juices, soups, jello, warm liquids including tea, coffee, broth, frozen treat such as popsicles
- Medications
- Other treatments as prescribed by your doctor

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully, ask questions and evaluate your needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Help address concerns
- Provide training to manage symptoms of constipation
- Provide training on how to safely use and store your medication

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Anxiety or Sadness

WHAT ARE SOME COMMON SYMPTOMS OF ANXIETY AND SADNESS

ANXIETY

- Feeling overwhelmed, worried, jittery or confused
- Panic attacks, including racing heart or shortness of breath, hot or cold flashes, sweating, nausea, neck tension or headaches

SADNESS

- Tearfulness
- Feelings of hopelessness, unworthiness or emptiness
- Loss of interest in normal activities
- Thoughts of suicide

COMMON SYMPTOMS OF BOTH ANXIETY AND SADNESS

- Avoiding others (or the opposite) and feeling needy or clingy
- Feelings of fear or anger
- Trouble sleeping



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WHY ANXIETY OR SADNESS MATTERS

- It is common for anxiety or sadness to occur with illness
- Anxiety and sadness affect your quality of life
- Your total comfort and symptom management matter to your hospice team

WHAT YOU CAN DO IF YOU ARE EXPERIENCING ANXIETY OR SADNESS

- Soothing activities such as music, art, reading or meditation
- Medication as prescribed by your doctor
- If you experience shortness of breath, creating air movement, such as a fan, can help
- Use the services of a hospice social worker, chaplain, music therapist, child life specialist or grief counselor

WHAT TO REPORT TO THE HOSPICE CARE TEAM

- Any of the symptoms listed here
- Lack of interest in activities you normally enjoy
- Concern about medication side effects
- Mental health history
- Thoughts of suicide, or harming yourself or others
- Use of over-the-counter medication and herbal remedies

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and address your concerns
- Ask questions and evaluate your needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training to manage symptoms of anxiety or sadness
- Your hospice nurse will train you on medications

Restlessness and Agitation

SIGNS AND SYMPTOMS OF RESTLESSNESS AND AGITATION

- Whether awake or not, the patient may moan or fidget, repeatedly try to pull off oxygen tubing, pull at sheets/blankets/clothing, try to get up from bed, or make faces that show he or she is uncomfortable
- The patient who is awake and able to talk may say things like “I’m scared,” “I need to get up,” or “use the toilet” or “go” without really having a place in mind

WHY IT MATTERS

- It is common to see restlessness and agitation in hospice patients*
- It can be distressing to watch a loved one who is restless and/or agitated
- Restlessness and agitation can result in safety concerns for patient and caregivers

WHAT CAN HELP

- Creating a peaceful environment (limiting visitors, lowering lighting, quieting the room)
- Arranging for someone to sit with the patient to ensure safety
- Offering soothing activities like hand-holding, light touch, soft music, or reading aloud
- Talking with a chaplain or spiritual advisor; meditation or prayer
- Medication to address restlessness and agitation
- Calling the hospice nurse



*Restlessness and agitation often occur or increase as patients near the end of life. Your hospice care team is prepared to help address periods of restlessness and agitation.

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WHAT TO REPORT TO YOUR NURSE OR ANY OTHER MEMBER OF THE HOSPICE CARE TEAM

- New or worsening signs or symptoms of restlessness and agitation
- Concerns about the safety of the patient or caregiver
- Difficulty when attempting to give medication or the patient's refusal to take medication
- Any questions or concerns

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and help address concerns
- Ask questions and evaluate needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training to manage symptoms of restlessness and agitation
- Your hospice nurse will train you on medications
- Offer other care options that may help (such as music therapy, spiritual support or relaxation techniques)

When Agitation Becomes Unsafe

If the patient becomes extremely agitated and cannot calm down on his or her own, medications or devices may be used to prevent the patient from hurting him- or herself or someone else. These medications and devices are called restraints. Restraints are used to prevent patients from harming themselves or others when they are agitated and striking out or pulling at tubes and other medical equipment necessary for their comfort. Restraints are a last resort and should only be used when other methods to calm down have failed.

WHY RESTRAINT USE MATTERS

- Restraints are used to keep the patient safe, but they can cause harm if not used properly
- Restraints may be needed to keep the patient from harming him- or herself, others, pulling out tubes or lines, or falling out of beds or chairs
- Restraints should not be used in place of supervision



TYPES OF RESTRAINTS

- Bed side rails
- Bed or chair alarms
- Medication such as Haldol (haloperidol)
- Mittens

PROBLEMS ASSOCIATED WITH RESTRAINTS

- Physical injuries can occur if patients struggle against restraint devices or if they are not properly applied
- Some patients become agitated with restraints
- Medication used as restraints can have undesirable side effects

WHAT CAN HELP BEFORE USING RESTRAINTS

- Moving the patient to a separate room or quiet space
- Smoothing the patient's bed sheets or using a comfortable chair pad
- Distracting activities such as watching TV, listening to music, reading or talking to the patient
- Encouraging family or caregiver involvement
- Talking to a spiritual advisor or the hospice chaplain or social worker

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Concerns about the patient's safety
- Any problems that arise with the use of restraints
- Concerns about the need to start or stop using restraints

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and help address the patient's concerns
- Ask questions and evaluate the patient's needs and discuss options
- Work with the patient and caregivers to make a plan to help the patient stay calm without restraints
- Communicate issues to the doctor and the hospice team
- Train the patient and caregivers on safe and appropriate restraint options and how to use them, including:
 - Choosing the correct type of restraint to use while keeping the patient safe and comfortable
 - Changing positions every two hours to avoid pressure sores
 - Checking the patient for skin changes or sources of pain
 - Supervising and observing whether restraints are used properly
- When restraints are in use, regularly reassess the need to continue using restraints
- Train the patient and caregivers how to use medications for agitation and watch for side effects

Caring for Your Wound at Home

WHY WOUNDS MATTER

Wounds are breaks in the skin or deep tissue. Breaks in the skin can lead to infection. Sometimes wounds develop as health declines, even with proper care and attention to the condition of your skin.

WHAT YOU CAN DO TO HELP PROTECT AND CARE FOR YOUR WOUND AT HOME

- Washing your hands with soap and water before and after wound dressing can help prevent infection in your wounds
- Using the right dressing treatment as ordered by your doctor or nurse will help protect the wound from germs and infection
- It is important to protect your wound from injury or trauma; try to avoid bumping into things or letting anything other than the dressings ordered touch your wound
- Use double bagging to dispose of old dressings to prevent spread of germs from the wound
- Store dressing supplies in a clean container out of reach for children and pets to prevent contamination
- Monitor your wound for signs of infection; fever, chills, redness, increased pain, swelling around the wound, or strong odors and drainage from the wound may be signs of infection

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Signs of infection or changes in the wound such as fever, chills, increased pain, redness, swelling around the wound, heat at the wound site, or a strong odor or drainage coming from the wound should be reported right away to your home care team or doctor
- Questions or concerns you have about your wound or how to care for your wound

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WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully, ask questions and help you address your concerns
- Communicate your concerns to your doctor and to others on your hospice care team
- Talk to you about how to care for your wound and how to monitor for signs of infection
- Talk to you about any medication, dressing changes or treatments ordered to help you manage your wound
- If you will be changing dressings, the nurse will talk to you about how to follow these dressing change instructions at home:
 1. Prepare your work area. You need a clean surface on which to place wound care dressing supplies.
 2. Gather all needed supplies.
 3. Wash your hands and put on clean gloves.
 4. Remove the old dressing and place it in a plastic trash bag.
 5. Remove dirty gloves and throw them in the trash bag.
 6. Rewash your hands or use a hand sanitizer, then put on new gloves.
 7. Follow the wound care instructions on the back of this page to complete the dressing change.
 8. Remove dirty gloves and throw them and any remaining waste in the trash bag. Tie off this bag and place it in a second trash bag. Tie the second bag off before placing it in the trash.
 9. Rewash your hands.

Nausea

Nausea is a sick, uneasy feeling in your stomach that often comes before you vomit. Nausea can be caused by extreme pain, illness or the stress of coping with illness. Nausea can also be a side effect of medication or treatments for an illness.

WHY NAUSEA MATTERS

- Feeling nauseated or sick to your stomach can make it hard for you to eat and drink
- Not eating or drinking enough fluids can make you lose weight or cause dehydration
- Not eating and drinking can lead to problems with constipation
- Being unable to eat or drink can lead to problems with your skin
- Nausea and vomiting can make it hard for you to take and keep down the medications
- Nausea can make you tired, depressed or anxious
- Nausea can make it hard for you to sleep or rest
- Nausea can affect your quality of life

WHAT CAN HELP

- Eating smaller meals more often (six small meals instead of three big meals each day)
- Avoiding foods that are spicy, greasy, fatty or very sweet
- Sucking on hard candies or popsicles
- Sipping clear juices, water, tea, broth or sports drinks throughout the day to be sure you get enough fluids
- Rinsing your mouth before and after meals, or after vomiting, to help control bad tastes in your mouth



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- Relaxing activities like listening to music, deep breathing, meditation or gentle massage
- A cool cloth on your forehead or the back of your neck
- Medication to control your symptoms

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- What seems to cause the nausea
- If nausea happens after you eat certain foods or take certain medications
- If nausea happens after radiation treatments or chemotherapy
- Whether nausea happens most often when you are awake or asleep; sitting or lying down
- What makes it better, what makes it worse
- How long the nausea lasts when it occurs

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully, ask questions and help address concerns
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training to help you manage symptoms of nausea
- Provide training on how to safely use and store your medications

Changes in Eating and Drinking

As you near the end of life, you may feel less hungry. You may also lose the ability to swallow effectively. You or your loved ones may have to decide whether you would like to receive artificial nutrition or hydration. Artificial nutrition and hydration are treatments prescribed by a doctor that allow a person to receive food and fluids when he or she is no longer able to take them by mouth. Artificial nutrition and hydration can be given through a tube inserted into the vein (IV) or by a tube inserted in the stomach.

WHY CHANGES IN NUTRITION MATTER

- A decrease in hunger and thirst as well as difficulty swallowing are normal at the end of life
- You have the right to refuse artificial nutrition and hydration
- Artificial nutrition at end of life can cause uncomfortable physical symptoms such as bloating, swelling, cramps, diarrhea and trouble breathing
- While it is a concern for some family members and caregivers, eating and drinking less at end of life is part of the natural progression, is not painful and does not worsen a patient's condition



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WHAT YOU CAN DO IF YOU EXPERIENCE A DECREASE IN HUNGER OR THIRST OR DIFFICULTY SWALLOWING

- Eat and drink only as much as is comfortable
- If you have difficulty swallowing, sit up at a 90-degree angle, take small bites or sips and avoid using straws—if you begin coughing, take a rest from eating and drinking
- If your mouth is dry because you do not feel like drinking, keep it moist with sponges and the drink of your choice; clean your mouth frequently
- Review your POLST form and make sure that your wishes regarding artificial nutrition are accurate
- Discuss any concerns you may have with your doctor and spiritual or religious advisor

WHAT TO REPORT TO THE HOSPICE CARE TEAM

- Any new coughing during or immediately after eating or drinking
- Any nausea or vomiting that makes it difficult to eat or drink
- Any bloating, swelling, cramps, runny stool, trouble having a bowel movement or trouble breathing
- If you have a feeding tube or IV tube, report any changes in the tube's length, a clogged tube, leaking or swelling, pain, redness or oozing in the skin around the tube
- Call hospice immediately if your feeding tube or IV tube comes out

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Explain how artificial nutrition may affect you specifically
- Work with you to identify what type of nutrition is best for your quality of life
- Help you review your POLST form to ensure that your wishes for end-of-life nutrition are reflected
- Respect your wishes regarding artificial nutrition and help you explain them to others in your life
- Evaluate your needs and develop a care plan to meet them
- Communicate your concerns to your doctor and to others on your hospice care team
- Train you and your caregivers how to help you receive nutrition
- Teach you and your caregivers how to use medications, fluids and artificial feedings and what side effects to look for

Oral Health

Oral health is the condition of your mouth, teeth, gums and tongue.

WHY ORAL HEALTH MATTERS

- Mouth bacteria can cause problems in other parts of your body
- Medications, diseases and oral health issues can cause oral thrush—bumps in your mouth requiring medication
- Good oral care can prevent breathing or swallowing problems
- Good oral health helps you feel better

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Mouth discomfort (pain, dryness, etc.)
- Bleeding in your mouth
- Presence of mouth bumps or sores
- Trouble swallowing
- Choking on water or food

WHAT CAN HELP

- Brushing your teeth (or dentures) and tongue at least twice a day and flossing between teeth to help decrease germs in the mouth and keep gums healthy*
- Keeping your mouth moist
- Drinking enough water
- Eating or drinking only when awake and upright
- Using medication, as prescribed, to treat mouth sores

WHAT YOUR HOSPICE CARE TEAM WILL DO

- Listen carefully and help address concerns
- Ask questions and evaluate your needs related to oral health
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training on proper oral health

**Oral swabs may be used if a toothbrush cannot be used safely.*

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Urinary Tract Infection (UTI)

The urinary tract is your body's drainage system for removing waste and extra water. Urinary tract infections (UTIs) are often caused by bacteria (germs) and can involve one or more parts of the urinary tract.

WHY UTIs MATTER

- UTIs can cause pain, confusion, fever, chills and weakness
- Most UTIs are not serious, but some can lead to serious health conditions like sepsis (bacteria in your bloodstream) or kidney infections

WHAT YOU CAN DO TO HELP PREVENT UTIs

- Practice good hygiene when washing your genitals and after using the bathroom (women should clean from front to back using a clean area on the cloth or tissue for each wipe)
- Take showers instead of baths
- Change diapers or pads as soon as possible when they are wet or soiled
- Avoid tight-fitting underwear, and wear cotton fabrics
- Drink fluids as tolerated
- Avoid holding your urine or delaying trips to the bathroom
- Urinate and wash your genitals after sexual activity
- Consider probiotics, vitamin C, cranberries or blueberries if approved by your doctor
- Take medication as prescribed; not all UTIs require treatment with medication

WHAT TO REPORT TO YOUR HOSPICE CARE TEAM

- Sudden changes in mental status; feeling less alert or confused
- The urge to urinate (pass water) frequently or immediately
- Burning, pain or trouble emptying your bladder completely when you urinate
- Urine that looks cloudy or bloody or that smells foul
- Bladder spasms, or cramping in your lower belly, feeling sick to your stomach or throwing up
- Weakness, fever, feeling warm, or shaking and having chills
- Pain in the back or sides below your ribs (flank pain)

WHAT YOUR HOSPICE CARE NURSE OR TEAM WILL DO

- Listen carefully, ask questions and help address your concerns
- Communicate your concerns to your doctor and to others on your hospice care team
- Train you and help you understand how to prevent UTIs or care for yourself if you have a UTI
- Train you on the use of medications if ordered by your doctor

Call our 24-hour number **(847) 475-3002** with questions or concerns so we can provide timely care.

Caring for Your Indwelling Urinary Catheter

An indwelling urinary catheter is a tube sometimes placed in the bladder through the urethra (the opening through which urine flows) if you have trouble passing urine or need to manage the flow of urine from your body.

WHY CARING FOR YOUR INDWELLING URINARY CATHETER MATTERS

Knowing how to properly care for an indwelling urinary catheter can help prevent infection from happening.

WHAT YOU CAN DO TO HELP PREVENT INFECTION IF YOU HAVE AN INDWELLING URINARY CATHETER

- Always wash your hands before and after handling the catheter/bag, and whenever you wash your genitals or use the bathroom
- Clean around the catheter opening every day with soap and water
- Clean your rectal area thoroughly after every bowel movement
- Keep your drainage bag lower than your bladder; this prevents the urine in the bag from going back into your bladder
- Empty the drainage bag whenever it is one-half to two-thirds full
- Have your indwelling catheter changed at least every four to six weeks or sooner if needed for medical reasons or catheter problems, or as recommended by your doctor or hospice care team
- Change leg and overnight drainage bags every one to two weeks or as directed
- Avoid switching bags or opening the urine drainage system more often than directed; this helps reduce the possibility of infection
- Wash the collection bag that is not in use (leg or overnight) daily with a vinegar solution (one part vinegar: three parts water)
- When changing from leg bag to overnight bag, clean connecting parts with alcohol (allow to air dry for 10 seconds); re-cap the tip of the bag that is not in use

IF YOU ARE PRACTICING INTERMITTENT CATHETERIZATION, DO THE FOLLOWING

- Wash your hands before and after handling the catheter each time you catheterize
- Clean around the urinary opening every day with soap and water
- If reusing catheters, wash them thoroughly with mild soap and warm water after each use, then rinse and air dry