

# Comfort, Dignity and Peace at End of Life: A Hospice Caregiver's Guide



For assistance or support, call St. Luke's Hospice ANYTIME at **218.249.6100**.

THE PATIENT. ABOVE ALL ELSE.®

 **St. Luke's**  
**Hospice Duluth®**



# Dear Caregiver,

Being a caregiver can be very rewarding. Our goal as a hospice team is to promote comfort, dignity and peace for you and your loved one. We are committed to partnering with you to provide this care.

With this booklet, we offer you some basic training in the care of your loved one. As a team of hospice professionals, we believe our experience can help make things a bit easier for you and your family.

During this time of caring for your loved one, multiple approaches may be needed in order to find what works best for you and your family. We trust your decisions. Not everything works for everyone. Please let us know your needs, as well as what works for you and what does not.

St. Luke's Hospice provides a journal for your use while providing care. Please consider using it for the following:

- Questions to ask at the next nurse visit (don't forget you are welcome to call 218.249.6100 at any time)
- Tracking of "as needed" medications (often referred to as "PRN")
- Special instructions or changes in care
- Visitors' notes

If your loved one is in a care facility, detailed medical information should NOT be included in the journal to protect patient privacy.

Please talk to your hospice staff before purchasing any medications, supplies or equipment. We may be able to cover the cost and have items delivered to you.

We invite you to call St. Luke's Hospice Duluth® at any time with questions or concerns, or if you need support. A hospice nurse is available 24 hours a day, 7 days a week. If you do not receive a return call within 15 minutes, please call again.

Sincerely,  
St. Luke's Hospice Duluth® Team



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One way to promote dignity is to keep your loved one safe. Making safety a priority can help avoid injuries. Encourage your loved one to accept help with activity. Explain your desire to keep him or her safe and at home.

## MOBILITY

- Encourage the use of non-slip shoes, socks or slippers, to avoid slips and falls.
- Be sure clothing fits well (not too loose or too tight).
- If a walker is needed, keep it nearby at all times.
- To prevent falls, help your loved one avoid bending, leaning and reaching.
- Keep walkways and other areas free of clutter and well lit.
- Be mindful of pets as a tripping hazard.
- A medical alert system (bracelet, pendant, etc.) may be helpful. For additional information, ask your hospice social worker.
  - A baby monitor can alert you to movements or calls for help.
  - A bell, doorbell or pan and spoon can be used to call for help, as well.

### What to do if your loved one falls:

- If your loved one is in severe pain, DO NOT move them. Call the Hospice nurse right away.
- If there is not severe pain and everything seems normal, help your loved one back to a chair or bed.
- If you need help lifting or moving your loved one (beyond family or friends), call 911 for a lift assist.
- Do tell your hospice nurse about any falls, even if no injury is evident.

## HANDWASHING

- Washing hands is the best way to prevent infection. Wash with soap and water for at least 15 seconds.
- It is OK to use a hand sanitizer instead of soap and water if hands are not visibly soiled.

## MEDICATION SAFETY

- Keep all medications together in a safe place, out of reach of children and pets.
- Keep narcotics out of reach to prevent accidental use by others. Hospice can provide a locked storage box, if needed.

## OXYGEN SAFETY

- Oxygen is extremely flammable. NEVER use when smoking or near flames (fireplace, candles, stove, etc.).
- DO NOT smoke in the same room where oxygen is present.
- If your loved one does smoke, turn off the oxygen and move the tubing away from your loved one until finished.
- Oxygen tanks should only stand upright if in a rack. If they are not in a rack, lay them on their side.
- Review the additional oxygen safety information in your hospice folder.

**Symptom management is complicated. One symptom is often tied in with others. For example, nausea may be related to pain, constipation or anxiety. Your primary care physician and our hospice medical director are available for consultation and support, as needed. Please discuss any needs with your hospice nurse.**

## **PAIN**

**Comfort is a priority. Whatever the source of pain, your hospice team wishes to work with you and your loved one to keep pain at a level they are satisfied with. Pain control allows for effective rest or activity and can help your loved one to move through some of the hard work associated with facing the end of life.**

- Pain manifests in different ways: physical, emotional, spiritual, financial and social.
  - Your loved one's reporting of their pain is believed regardless of how they appear outwardly.
  - Your loved one may be unable to report pain using words. Visible signs might include frowning, grimacing, groaning, moaning, restlessness, tenseness, crying or sobbing.
  - Options to relieve pain include re-positioning, supporting the affected area, heat, cold, relaxation, massage, music, prayer, meditation, guided imagery, exercise, pet therapy, therapeutic touch, aromatherapy, acupuncture, acupressure, humor and biofeedback.
  - A specific activity can draw the mind away from pain. Options include working on a puzzle, drawing, reading or listening to an audiobook, watching a TV program, or gentle exercises.
  - Pain medication given regularly on a schedule can help regulate comfort. This can also eliminate the need to "play catch-up."
  - Pain medication given as needed allows you to respond to changes in pain that are tied to time of day, activity, etc.
- Some common side effects of narcotic pain medications include constipation, nausea, dizziness, confusion, drowsiness, sedation, itching, vomiting, abdominal pain, headache and dry mouth.
    - A tolerance to the medication may develop after a few days making these side effects go away. Discuss this with your hospice nurse.
    - With any medication, it is important to weigh the benefits of symptom relief against the risks of side effects.
  - Call your hospice nurse if the pain is not being well managed.
  - Emotional pain may reduce the effects of pain medicine. Encourage talking openly about fears. Reach out to your own spiritual support people and/or our hospice social worker or chaplain.





## TROUBLE BREATHING

**The act of breathing is vital to life. When people have trouble breathing, it can be very scary. Your calm approach to helping your loved one breathe easier is a great help toward achieving a more comfortable state.**

- Signals that someone is working hard to breathe might include breathing fast, breathing through pursed lips (like they are trying to whistle or blow out a candle), breathing hard after mild exertion, wheezing, high-pitched squeaking or whistling sounds, wet or gurgling sounds, bluish color of fingernails or around mouth, needing to sit up rather than lie down to breathe, or visibly using chest muscles to help inhale or exhale.
- Encourage your loved one to conserve energy by resting.
- Rearrange the layout at home, so less energy is needed to get through the day.
- Eliminate activities that require effort but do not bring comfort or happiness.
- Change positions. Try elevating the head of the bed or bending slightly forward when sitting up.
- Try to eliminate whatever causes anxiety. When people who have trouble breathing become anxious, breaths become faster and shallower. This can make them feel even more out of breath, the anxiety increases, and a negative cycle begins.
- Use a humidifier or vaporizer to increase humidity if the air is too dry. Clean the humidifier at least weekly.
- If the air is too humid, an air conditioner or dehumidifier may be helpful.
- Keep the environment cool. Open windows or use a fan to increase airflow.
- Go through breathing and relaxation exercises together (see Relaxation section, page 11).

- Medications may help relax the breathing and calm anxiety. Please discuss with your hospice team.
- Oxygen use may be helpful, if it provides comfort. Not all people who are approaching the end of life need to use oxygen. Sometimes the burden outweighs the benefit.

## COUGHING

- Coughing may be relieved by frequent sips of water, warm tea with honey, hard candy or lozenges, humidification, cool mist, or eliminating allergens (feathers, dust, pet dander, etc.).
- Not all coughs should be suppressed. Sometimes coughing can help loosen secretions and help people breathe more comfortably.
- If your loved one's cough is interfering with comfort or rest, be sure to discuss with the hospice nurse. Medications may be available to help.

## AIRWAY SECRETIONS

**Clearer airways can ease your loved one's breathing and improve his or her overall sense of well-being.**

- Moist breathing and difficulty handling oral secretions is common.
- Changes in position may minimize breathing noise and risk of choking. Helping your loved one to lie on their left side or elevating the head of their bed can be especially helpful.
- Encourage coughing to clear airways if your loved one is able.
- Discuss any concerns about secretions with the hospice team. There may be additional interventions or medications that could help improve your loved one's comfort.



## APPETITE AND DECREASING FOOD/FLUID INTAKE

Offering nourishment can be a powerful way to show love. Just one bite, or even the aroma of a meal being prepared, can be very meaningful.

- As diseases progress, it is normal for people to eat and drink less. Your loved one will let you know if food or drinks are needed.
- Weight loss is common and often unavoidable.
- Enjoyment should be the focus of eating and drinking.
- Respect your loved one if they are not hungry or thirsty. Forcing food and drink can cause nausea and anxiety. It also increases the risk of choking or aspiration.
- Food may taste differently from day to day. Ask what is and is not being enjoyed. Respect this and be flexible. It might help to avoid extremes in smell and taste.
- Offering smaller portions of soft foods frequently may be helpful.
- Dehydration is not painful. As the body slows down, it is less able to use nutrients and fluids. People approaching the end of life are often more comfortable without food and drink.
- Give mouth care often. Having a dry mouth is uncomfortable and may eliminate the desire to eat.
- A dietitian is available for consultation. Talk to your hospice nurse to schedule an appointment.

Soothing comfort foods include yogurt, applesauce, ice cream, mashed potatoes, oatmeal, Jell-O, sherbet and baby food.

## DRY AND GENERAL MOUTH CARE

Gentle, regular mouth care provides refreshment. It also ensures that uncomfortable conditions in the mouth or throat are identified and managed. With a natural decline in fluid intake, the mouth will be dry. This is very common and can cause discomfort.

- Offer ice chips and sips of favorite liquids.
- Apply lip balm to the lips and corners of the mouth.
- Prepare soft, moist foods.
- Offer cool foods or drinks.
- Clean the mouth at least two times a day with a soft toothbrush or swab. Remove dentures, if present.
- If there are mouth sores, talk to your loved one about avoiding or minimizing the use of dentures.
- Ask your hospice nurse about mouth swabs, artificial saliva and/or mouthwashes. Avoid mouth washes containing alcohol.
- Rinse the mouth often. A rinse made from ½ teaspoon salt dissolved in 1 cup of water can help soothe mouth sores.
- White patches or redness in the mouth or on the tongue may be oral infections. These may cause discomfort or difficulty swallowing. Consult your nurse with any concerns.
- Discomfort can be relieved with warm salt water rinse (as described above), brushing the tongue and teeth with a soft brush and/or medication.

Some foods may help a dry mouth such as ice chips, frozen fruit pieces, lemon drops, mint candies, and sugar-free gum/candy.

## NAUSEA

**Nausea can be caused by many things. It is important to understand and focus on the causes, as well as the nausea itself.**

- If nausea occurs in the morning, offer something small to eat by keeping a light snack within your loved one's reach.
- If nausea is related to lightheadedness or dehydration, offer something to drink.
- Be mindful of cooking techniques. Using the oven can fill the house with unpleasant smells. Grilling or microwaving can reduce these odors.
- Offer small portions and frequent meals. A full plate may look overwhelming.
- Avoid overly sweet, spicy, fatty or greasy foods.
- Don't offer foods that need to be chewed well.
- Serve food cold or at room temperature to reduce its smell and taste.
- A distraction while eating may help. Consider turning on music or watching television together.
- Incorporate relaxation exercises such as deep breathing (see Relaxation section, page 11).
- After eating, encourage sitting up or reclining with the head and shoulders elevated. Try to avoid lying down for at least two hours after eating.
- Anti-nausea medications may provide relief. Please discuss with your hospice nurse.

### Foods to try:

- Cool, clear beverages such as apple or cranberry juice, broth, popsicles, ginger ale, lemon lime soda or warm peppermint tea. Be sure that the liquids are sipped slowly.
- Lightly seasoned simple foods that are broiled, boiled, steamed or baked.
- Dry, plain foods like crackers.
- Sour foods such as pickles, sour hard candy or lemon sherbet.



## BOWEL AND BLADDER CONTROL

Loss of bowel or bladder control can decrease a person's sense of dignity and self-worth. It can also highlight the continual loss of independence. Requiring help in this private area is very difficult for most people. Your loved one may have an especially hard time receiving help from family members. Remain sensitive to these things, as well as the need for physical comfort and skin protection.

### Incontinence

- Encourage routine attempts to urinate, in the bathroom or on a commode, to help your loved one maintain control.
- Help with gentle, thorough and regular cleansing to prevent irritations, sores or rashes.
- Skin protectants such as Vaseline or A&D ointment can be used on clean skin.
- Avoid using cream or lotion with powder. This combination creates caking on the skin.
- Use washable or disposable pads to protect bedding. Hospice can supply them.
- Limit fluid intake at night.

#### To manage odors, try the following:

- Put charcoal in an open container where pets and children can't reach it.
- Use wintergreen oil in a diffuser.
- Place a peppermint-soaked cotton ball in a bedpan or commode.

## Constipation

Constipation is a common issue related to changes in diet, and decreased fluid intake and activity, as well as a side effect of medications needed for comfort. It is very treatable. Your hospice team will work with you and your loved one to prevent constipation.

- Having a bowel movement every two or three days is normal. Anything longer than that, contact your hospice nurse.
- What has worked to alleviate constipation in the past is okay to try again, but may not work now.
- Increase fluids if able. Hot fluids increase bowel activity. A cup of tea or warm water with lemon first thing in the morning can be a gentle, natural laxative.
- Avoid foods that can cause constipation, such as cheese and eggs.
- Increase daily activity if able.
- Stool softeners, laxatives or a combination of both may be helpful. Your hospice nurse can help adjust the dose and frequency, as well as recommend other medications, if needed.
- Strive to avoid the cycle of constipation: using medications to get bowels moving, getting stools too loose, cutting back on medications, and then experiencing constipation again. Ask your nurse to help you with medication adjustments.

High-fiber foods such as bran, wheat germ, fresh raw fruit and vegetables, purees and juices (especially prune juice) may be helpful.

**NOTE:** High-fiber foods can worsen constipation if your loved one doesn't also increase of fluid intake.

## Diarrhea

**Diarrhea can be very uncomfortable and limit the ability to plan activities or engage with others. It can leave people exhausted. Try to find the cause and discuss with your hospice nurse instead of only focusing on this symptom.**

- Try the B.R.A.T.Y diet: Bananas, Rice, Apple juice, plain Toast and Yogurt.
- Avoid spicy, fried/fatty foods, caffeine, alcohol, fizzy beverages, artificial sweeteners, very hot or cold foods, cabbage and beans.
- Review the recent bowel history. Consider when the last normal, formed bowel movement was. Diarrhea can be a result of constipation. Discuss with your hospice nurse.
- Offer smaller meals more often.
- Add nutmeg to food. This helps to slow the intestines.
- Offer fewer fruits and vegetables.
- Serve foods at room temperature. Hot or cold fluids may increase bowel movements.

## SKIN CARE

**Skin care is for your loved one's comfort. It provides sensory stimulation, as well as a sense of well-being and connection.**

### Protection

- Change your loved one's position at least several times during the day as well as when you are awake at night. Changes in position can prevent stiffness, soreness and even skin breakdown.
- Encourage frequent position changes (side to side, back) and shifting of weight. Even slight position changes can help.
- To prevent dryness, use warm (not hot) water for bathing, with mild soap. Rinse the soap off well. Dry the skin thoroughly. Gently apply lotion or cream.

- Avoid alcohol-based moisturizers, as they can cause dryness.
- Watch for redness of the skin. This may indicate developing pressure sores in areas at risk (where skin covers bony areas). Common pressure areas to keep an eye on include heels, ankles, hips, tailbone, back of head and ears, elbows, and inner knees.
- Check skin folds, underarms and groin creases for cleanliness, rashes and redness.
- Use pillows for support between the knees, behind the back, and against the chest/abdomen to hug when your loved one lays on their side. Elevate heels off the bed with a pillow under the calves (blankets or towels can be used in place of a pillow).
- Frequently massage skin with lotion.

### **Talk to your hospice team about the following:**

- Pressure-reducing mattresses or overlays for bed or chairs.
- Recommended lotions or creams.
- Concerns about any questionable areas or if your loved one complains of sensitivity.

### Bathing

- Clothing can impact a person's dignity and comfort. Shirts or nightgowns can be cut up the back for ease of dressing.
- Bathing can be done in a shower, tub, at the sink or in bed. This is not required daily.
- Scalp care and shampoo can be done in bed.
- Assist with personal hygiene in a way that maintains dignity and safety.
- Hospice home health aides are available to assist with personal hygiene and skin care needs.

## FATIGUE & WEAKNESS

As time goes on, your loved one's energy level and tolerance for activity will decline. This might be discouraging to them. You can help by focusing on the things they can do. It is important to be safe and feel good about accomplishing even small goals.

- Try to balance rest and activity. Plan for spots to sit and rest during walks.
- Pay attention to when your loved one has the most energy. Schedule important activities during these periods of the day.
- Eliminate non-essential activities.
- Adjust activity goals to be realistic and achievable. This can help your loved one feel a sense of purpose and accomplishment, rather than frustration.
- Encourage asking for help if your loved one feels weak or unsteady.
- Gentle exercise can improve circulation and a sense of well-being.
- Physical or occupational therapists can provide training on active or passive exercises that can improve comfort, prevent stiffness, and promote circulation, such as gently bending and extending all moveable body parts.
- Consider accepting the help of a home health aide to reduce your loved one's exertion.
- Personal hygiene and shampooing can be done in bed. Discuss this with your hospice team.

### Ideas for energy conservation:

Wheelchair, walker with a seat, commode, bedpan, or catheter (fewer trips to bathroom)



## SLEEP DEPRIVATION

Exhaustion greatly limits a person's ability to safely perform basic activities or engage with others. Your patience and understanding will make a big difference.

- Encourage the discussion of worries, fears and concerns.
- Promote daytime activities, as able.
- Minimize over-stimulation and stimulants (such as caffeine) during the evening and night hours.
- Avoid late, heavy meals. Consider a small bedtime snack instead.
- Avoid temperature extremes.
- Consider a white noise machine.
- Consider respite care for yourself, as needed.
- Encourage a bedtime routine. This may include bathing, a cup of tea, gratitude list, music, reading, prayer, meditation, deep breathing or relaxation exercises (see Relaxation section, page 11).
- Consider emotional and/or spiritual unrest as a possible cause of sleep deprivation. The hospice social worker or chaplain is available to provide support.



## FEVER

**Toward the end of life, the temperature-regulating center in the body may become less efficient. This can result in fevers. You can improve your loved one's comfort greatly by managing the associated aches and keeping them safe if confusion occurs.**

- Sponge the body with cool, not cold, water.
- Try a fan for comfort.
- Offer fluids often.
- Cover and uncover the body, as needed.
- Cuddling can help reduce chills.
- Some medications can reduce fever. Discuss with your hospice team.

## MEDICATION

**Medication can be a useful tool in helping manage symptoms such as pain, constipation, nausea and anxiety.**

- Many medications have side effects. You and your loved one, together with the help of your hospice team, can weigh the risks and benefits of each medication, and develop a plan that meets your loved one's needs.
- Knowing what side effects to watch for will help you keep your loved one safe. For example, pain medication may make a person sleepy or constipated. By understanding these effects, you will be able to take precautions to prevent harm (fall prevention measures, monitoring bowel movements, etc.).
- It is important for your hospice nurse to know ALL medications being used so the nurse can check for interactions between them. This includes over the counter, herbals, prescriptions and medicated skin care products. Please tell your hospice nurse if you add or change anything.

- Your hospice nurse is able to set up pills in a pill box with a medication schedule for you if desired.
- At some point, it may be helpful to discontinue medications that are not specifically for the purpose of managing symptoms and providing comfort. This can be considered if your loved one has a hard time swallowing and there is no safer way to take the medication. Please discuss with your hospice team.
- Store all medications safely (see Safety section, page 2).
- Please discuss all medication questions and concerns with your hospice nurse.



Your presence and calm support can be a powerful help to your loved one.

## RELAXATION

Promoting peace is a core value in hospice. The following activities may be helpful both in achieving physical rest as well as quieting the mind and soul. Your presence and calm support can be a powerful help to your loved one in this area.

### Deep Breathing Exercise

- Sit or lie in a comfortable position.
- Relax the muscles in your neck and shoulders.
- Breathe in slowly through your nose while counting to two.
- Breathe out slowly and gently through pursed lips while counting to four.
- Repeat slowly several times.

### Visualization and Imagery

- Close your eyes. Breathe deeply.
- Picture yourself in a quiet, peaceful place.
- Imagine how you feel in that place. What are the sounds in that place? What are the smells? Who is with you?
- If other thoughts enter your mind, take a deep breath and try again.

### Progressive Body Relaxation

- Close your eyes. Clench your foot muscles.
- Hold for a few seconds, then release.
- Repeat with the muscles in your calves.
- Work slowly up your body, tensing and relaxing different muscle groups from your abdomen, chest, arms, neck and face.

## Conscious Relaxation

Conscious relaxation can help decrease the fears and anxieties associated with death. To do your own relaxation exercise, try the following:

- Try to match your breathing with theirs, then slow your breath to see if your loved one can follow yours. If possible, try to make the exhalation longer than the inhalation.
- Sit close to the person's head so that your loved one can hear easily. Beginning with the feet and working your way up to the top of the head, tell each body part to relax, including the internal organs. You can use as much detail as you wish.

## Meditation

To comfort both yourself and the person who is dying, memorize a short phrase, scripture verse or other favorite saying. Repeat that phrase in a soothing tone. Here are some examples:

- "God, grant me peace."
- "I am held secure in the arms of love."
- "Soon I will be free."
- "Rest. Breathe. Remember."



## EMOTIONAL CARE

Often, you and your loved one can be comforted by meaningful, even difficult conversations.

### Core Emotional Needs

- To be needed and useful
- To have opportunities to care for self and others
- To have self-esteem boosted
- To give and receive love
- To experience joy and laughter
- To have the option to choose

### Confirmation of Value

It is important for dying people to know two things:

- Their life mattered.
- They touched other people's lives.

### Four Messages<sup>7</sup>

Following are four statements offered to honor and experience what really matters most in our lives every day. None or all may be helpful. These are suggestions only:

- "Please forgive me."
- "I forgive you."
- "Thank you."
- "I love you."
- "Good bye," is sometimes added to this list.



### Comfort Strategies

Encourage life review and reminiscence. Some ideas on how to do this:

- Letters written (or dictated) by the dying person to each of the survivors.
- Audio recordings of conversations with the dying person and among family and friends as they talk and share.
- Letters of love and gratitude written by family and friends given to the loved one.
- Drawings and letters from children placed around the person.
- A guestbook in which visitors write something about the person or their feelings on that particular day.
- Create a journal for visitors to write in.
- Technology may help to connect loved ones who cannot be present. This could include telephone calls, conference calls, FaceTime or CaringBridge.

*Continued on next page.*

- The presence of children can bring a unique perspective. Often children ask honest questions, are able to provide unique emotional comfort, and can help with the smaller tasks of caregiving. This may include<sup>6</sup>:
  - Filling a water glass
  - Bringing flowers to the bedside
  - Drawing pictures
  - Sitting close while watching TV
  - Lighting a candle they have chosen or made
  - Saying a prayer
  - Drawing a picture of their feelings or their memories of the loved one
  - Reading or singing to their loved one
  - Rubbing oil or lotion on the hands or feet of their loved one
  - Looking through photos together
  - Writing a note for their loved one
- Try to be accepting and forgiving of others. People typically do the best they can and are impacted by loss in different ways.
- Communicate with others when you need time alone with your loved one.

## **SPIRITUAL CARE**

**This type of care is about meaning, connectedness and developing closure at the end of life.**

- Meditation, relaxation exercises and guided imagery can promote a sense of well-being and calm.
- Don't be afraid of being with your loved one in silence. Love is a language of the heart that doesn't always need words.
- You could create 'sacred spaces', whether that be in your loved one's room, somewhere in the home or outside in nature. Include a photo, keepsake, memento from a trip, treasures from nature, a candle, etc.
- Use prayer or spiritual readings from your religious practice.
- Connect with your minister, priest, rabbi, spiritual guide or hospice chaplain for support, guidance and assistance with religious rituals such as communion or receiving the sacraments. If a sacrament is desired, reach out early to allow time to schedule.
- Tell stories, use reminiscence and life review to promote connection and meaning.



## ANXIETY & AGITATION

As with pain, anxiety and agitation can be related to physical, emotional, spiritual, or social concerns.

- Provide an environment that your loved one finds peace in. This may be calm and quiet with soft lighting, or filled with socialization, laughter, noise and activity.
- Anxiety might be caused by pain, trouble breathing, a full bladder, or another symptom. Try to take care of what is causing the anxiety.
- Use of relaxation tapes, massage and essential oils may be helpful.
- Encourage slow, deep, rhythmic breathing. Breathe slowly and deeply together.
- Attempt relaxing music or other forms of quiet distraction.
- The quiet presence of someone who provides comfort to your loved one may be valuable.
- Keep your loved one's space calm and reassuring. Speak in a slow and soothing tone of voice. Gentle touch, such as keeping your hand on theirs, may be calming.
- Consider emotional or spiritual unrest as a possible cause of restlessness, anxiety or agitation. The hospice social worker or chaplain is available to provide support.
- An anti-anxiety medication may help. Please discuss with your hospice team.
- See Relaxation section, page 11

## DEPRESSION

Depression can be a very real, sometimes overwhelming companion. Whether it is your loved one who is depressed or someone in a caregiving role, depression blankets one with heaviness, hopelessness, and sadness. It can rob a person of energy, appetite, the ability to experience pleasure or even think clearly. Depression may be treatable even at the end of life.

- Communicate acceptance and affirmation of the person.
- Be willing to be present quietly.
- Help manage cumbersome tasks that may feel overwhelming to the one who is depressed.
- Encourage conversation and reminiscence, if your loved one will tolerate this.
- Periods of soft, soothing music may help unravel some of the 'knots' in the soul.
- Gently reframe negative thoughts with an affirming, realistic lens.
- Consider social worker, chaplain or volunteer visits.
- Being aware of good things in a person's daily life can significantly improve mental, social and physical well-being. Writing them down may help as well.
- An anti-depressant may help. Discuss this and other treatment options with your hospice nurse.

Don't be afraid of being with your loved one in silence. Love is a language of the heart that doesn't always need words.

## MEMORY & CONFUSION

There are a number of physical causes that can create confusion, such as infection, progression of a disease, metabolism changes, as well as medication-related possibilities. Please discuss changes in mental status or confusion with the hospice team.

- Confusion and frustration may be due in part to not recognizing or understanding the physical changes that are occurring, or why they are occurring.
- Remind your loved one who you are and what you are going to be doing. Point out familiar objects.
- Keep a large wall calendar and clock nearby, if you have them. Announce the day and time first thing each morning.
- Circle important dates on the calendar and remind your loved one often of upcoming events, including planned visits by members of your hospice nurse.
- Reviewing photo albums may be helpful.
- For familiarity, you could show your loved one photos of people who are coming to visit. Also, consider photos of family members or friends your loved one has not seen for a while.
- Visitors can be helpful or exhausting. Be sure they know if your loved one is struggling with confusion. If having fewer visitors helps to limit confusion, consider limiting the number of people or length of visits.
- It is not necessary to correct someone who is confused or hallucinating. Let the person tell you what they are seeing. Then, gently tell them what is really going on, if helpful.

- Confusion can be a frightening experience. Do your best to be positive, calm and patient with your loved one, especially in the midst of confusion.
- Discuss any additional concerns with your hospice nurse.



Do your best to be positive, calm and patient with your loved one, especially in the midst of confusion.

# When Death is Near

**Your presence, love and care are most important at this time. Being present is the most valuable thing you can do.**

- Review and discuss with your family and hospice nurse the “Gone From My Sight” booklet provided. It includes common signs and symptoms in the last minutes, days, hours, weeks and months prior to death.
- Signs that death is near may include changes in breathing patterns, including shallow breaths, pauses that become longer and more frequent, mottling (bluish/purplish discoloration of fingers/toes that begins to extend up arms and legs), and decreasing urine output. Dying may take hours or days. These signs may appear and disappear.
- Ask for time alone with your loved one. It can be very healing and help to provide closure.
- You may experience increased visits from friends and family. With consideration of your loved one’s preferences, it is okay to limit the number of people in the room and the length of visits.
- Be honest and open about what is happening.
- Listen to the dying person’s questions, and answer honestly and briefly.
- Take the time to say “good bye.”
- At times, loved ones may need permission to die. Taking time to say it’s okay can be helpful and ease the dying process.
- Remember happy memories.
- Allow your loved one to make as many decisions as possible to lessen their loss of control.
- Let your loved one know that you understand their concerns.
- Try to keep a sense of humor.
- Quiet presence can be very valuable and may include knitting, reading, or doing puzzles.
- Keep your loved one clean, dry and warm.
- Touch, hug and kiss your loved one. Be gentle and slow.
- Keep in mind that even if your loved one doesn’t respond, they may be more aware than you think. When talking in front of him or her, say hello and goodbye as you enter the room. Explain what you are doing when you are providing care.
- Try to arrange for someone to be with your loved one as they near the end. Keep in mind that sometimes a dying person may need privacy to die.
- The dying process itself is not painful. The other conditions your loved one is dealing with may continue to cause pain, if pain has been a problem.
- Do not stop the pain medications that have helped keep your loved one comfortable.
- Do not force foods or fluids. This can be uncomfortable and even unsafe. As death approaches, dehydration occurs naturally and can bring mental changes that lessen awareness of suffering.
- Let your loved one know that they will be deeply missed but not forgotten.
- Some people need privacy at their time of death. Don’t be afraid to step out of the room to take care of your needs for rest, nutrition or hydration, exercise, and staying connected with the ongoing parts of life. If your loved one dies while you are gone, trust that this is the way it was meant to unfold.
- Ask for help from a hospice spiritual care provider.
- It’s okay to lie in bed with your loved one, hold hands and say everything you need to say.

*Continued on next page.*

# When Death is Near

- You may find comfort in tracing the hand of your loved one, and preserving that memento, or snipping a lock of hair.
- Tears are normal, let them come.
- Honor cultural rituals and practices.
- Honor any religious rites.
- At the time of death, call your hospice nurse at 218.249.6100. A nurse will make a visit. This visit can be declined, but a nurse can provide help with arrangements, offer education, give a bath and most importantly, provide support.

## **Help your loved one make peace with any unfinished business:**

- Some people may use this time to say “thank you.”
- Some people may take this time to say “I am sorry.” They may take the time to forgive or let go of past anger.

## **Take time while the person is awake to say or do what you need to. Some people start with:**

- “What I love most about you...”
- “What I will always remember...”
- “What I will miss most about you...”
- “What I learned from you...”
- “What I hold close to my heart is...”





## **REST. BREATHE. REMEMBER.**

The death of a loved one is life-changing and people grieve very differently. You may feel many emotions in the days and months ahead.

Grief has many forms. There is no wrong way to feel or to grieve. You may experience relief, happiness, anger, gratitude or sadness. Allow yourself to experience these emotions as they are a normal part of grief.

It is important to take care of yourself. You did what you could for your loved one.

The hospice bereavement/grief support team is available for you and your family for at least the first year after your loved one's death. Periodic phone calls and mailings are offered during this time. Please feel free to call if you are in need of additional support or assistance in the year following your loved one's death.



# ..... Taking Care of Yourself .....

Being a caregiver can be very rewarding, and challenging. Ask for tips on how to cope. Take care of yourself. You matter. Learn ways to relax and manage stress. Do your best to get regular sleep.

Preparing for end of life is difficult for each individual involved. There is great value in extending understanding and forgiveness to yourself and others.

Take 'time-outs' from caregiving when needed. Know your limits and honor them. Accept offers of help from your hospice home health aide and volunteer services when needed.

Think about specific ways others could help you, so you are ready if asked. Pick a day of the week when helpers could come, so that you can plan for breaks or companionship. You will be better able to provide care to your loved one when you are refreshed.

Please ask for help when you need it. Hospice care is a partnership and we are here to assist and support you.

Thank you for choosing St. Luke's Hospice Duluth. We are honored to walk this path in partnership with you.

## **References**

Symptom Management Algorithms: A Handbook for Palliative Care, Third Edition, by Linda Wrede-Seaman, M.D. 2009. Intellicard, Inc.

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THE PATIENT. ABOVE ALL ELSE.®

 **St. Luke's**  
**Hospice Duluth®**

St. Luke's Hillside Clinic  
220 North 6th Avenue East  
Duluth, MN 55805  
**218.249.6100**  
**[slhduluth.com/hospice](http://slhduluth.com/hospice)**