

GENERAL GUIDELINES FOR CAREGIVING®



HOSPICE

B U F F A L O

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The following guidelines were written to help you care for the hospice patient at home. Please remember that every illness progresses differently, and that every person experiences the process in a unique way. Changes that are mentioned in the following information may or may not be experienced. The goal of this information is to prepare you for what might happen in the future and to guide you.

This information is not all-inclusive. If you have questions or concerns about anything, you may call the hospice patient line 24 hours a day. A nurse, experienced in hospice care, is available to guide you in this difficult time.

ACTIVITY AND SAFETY

- If weakness is a problem, provide assistance in walking. Try to allow as much independence as possible. If the patient is unable to assist, the decision to not move the person may need to be discussed.
- Support the patient on his or her strongest side.
- Use side rails on the bed whenever possible. Side rails provide assistance in changing positions.
- Always lock the wheels on the bed or wheelchair before transferring.
- Help the patient to change positions slowly (for example, when lying to sitting, sitting to standing)
- Remove throw rugs and other moveable objects such as toys and shoes from the floor.
- Wipe up floor spills immediately to avoid slipping.
- Report any equipment in need of repair to the hospice office. Do not use until replaced or repaired.
- Report any falls to the hospice nurse at the time of occurrence.

PERSONAL CARE

- Always wash your hands before and after all care is provided.
- To prevent infection wear gloves when likely to touch body fluids or mucous membranes (vomit, urine, blood, stool).
- Assist with personal care as needed. Encourage as much independence as possible.
- It is important to keep the skin clean and dry, but a daily bath may not be necessary.
- Keep skin soft with lotion to help prevent cracking of the skin.
- Keep sheets as clean and wrinkle free as possible.
- Reposition patient frequently to relieve pressure points. Areas that are prone to pressure are the buttocks, back, hips, elbows, shoulder blades, heels, ankles, the back of the head, and the ears.
- Use a draw sheet to help with turning and repositioning. Ask the nurse for instruction.
- Back rubs and massages are soothing and relaxing. Ask the hospice nurse for instruction.

PERSONAL CARE

- Try to avoid leaving wet clothing or bed linen in contact with the patient. Waterproof, disposable pads are available.
- Let the hospice nurse know about any breaks in the skin or reddened areas. The nurse can show you how to care for these areas.
- Avoid heating pads or electric blankets. They can easily cause burns.
- Despite efforts to prevent pressure sores, they may occur. The hospice nurse will teach you ways to prevent the area from enlarging.
- Keep the patient's nails clean and trimmed.
- Offer mouth care several times per day:
 - Brush teeth with a soft toothbrush and toothpaste. Rinse with water.
 - Special swabs may be used when brushing is not feasible.
 - Report any mouth soreness to your hospice nurse.
 - A water-based lubricant may be used on the lips and nostrils.

NUTRITION

One of the basic ways family members give to one another is by preparing favorite foods. Because of this, you may feel frustrated when this avenue of support is no longer perceived as helpful to the patient.

Many family members express concern that the person will "starve" if he or she is not forced to eat or drink. This is a common concern but, in reality, you will not extend the person's life by forcing him or her to eat and drink. Often, people feel helpless over this issue. **It is natural for a person who is dying to stop eating and drinking.** Listen to the suggestions of your hospice nurse. The nurse will guide you about your family member's need for nutrition. See guidelines to follow:

- **Irregular eating habits are to be expected.** Amounts of food desired often vary. Smaller meals and snacks throughout the day may be better tolerated than three meals. Altering mealtimes and surroundings and taking plenty of time to eat may increase enjoyment. Forcing additional, undesired

amounts of foods will cause discomfort. Usually, the patient is the best judge of appropriate amounts.

- Be sensitive to odors that may be disturbing. Cooking odors may sometimes be unpleasant. Decreasing cooking times by using a micro wave oven may help cut down on cooking odors.
- Taste changes may occur. Sweets, or red meats, may not be tolerated. Flavorful seasonings, marinades, tart foods, and foods served at room temperature may make foods more appealing.
- A high-calorie supplement may be appropriate. Ask your hospice nurse for suggestions.
- If dry mouth is a problem, sweet or tart foods may improve this. Changing food consistencies, or adding sauces, gravies, or dressings to foods will make them easier to swallow. Frequent sips of water, ice chips or hard candy may be comforting. Lip salves will keep the lips moist.

NUTRITION

- Swallowing may be difficult. Changing consistencies and textures of solids and liquids may ease swallowing ability. For example, soft foods such as pudding or jello may be more easily tolerated.
- Please notify the hospice nurse if the patient experiences difficulty swallowing or soreness in the mouth.

BREATHING DIFFICULTIES

- If breathing is a problem, raise the head of the bed or prop with pillows.
- Encourage slow, calm breathing. Sit with the patient, providing calming reassurance.
- Open a window or turn on a fan to promote air circulation over the patient's face.
- Administer medications as directed for relief of respiratory distress.
- If oxygen is being used, make sure it is on and functioning. A portable tank is provided in case of power failure.
- Call the hospice nurse if these measures do not provide relief.

ELIMINATION/BOWEL AND BLADDER CARE

- Always start a combination of stool softener and laxative as recommended as soon as the pain medication is started, and then adjust as necessary. Do not wait until constipation is a problem.
- Avoid bulk-forming laxatives (e.g., Metamucil) in debilitated patients when fluid intake is less than 1.5 to 2 quarts per day, as these form "glue."
- Establish a regular bowel regimen with the assistance of your nurse, and record bowel movements to monitor effectiveness.
- Bowels should move every 1-2 days, even if the amount of food being eaten is small.
- The normal position for defecation is the sitting position. Enhance comfort for ease of defecation; raised toilet seat, commode, pain control.
- If possible, attempts at having a bowel movement should be made 30 to 60 minutes following eating of a meal to take advantage of the movement of the intestines.
- As the amount of fluid taken in decreases, urine formation also decreases. Urine may also become darker and more concentrated.
- If bladder control becomes difficult, you may use adult diapers or absorbent pads. Families are responsible for obtaining these. A catheter may need to be placed if the bladder is full, and the patient is unable to urinate.
- **If the following occur, please contact the hospice R.N.:**
 - **no bowel movement in 3 or more days**
 - **6-8 loose stools per day**
 - **blood in the urine or stool**
 - **no urine output in 12 hours**

PAIN

There are numerous medications and methods to control pain. Your hospice nurse will work with you and your physician to maintain comfort.

Follow these guidelines:

- When medication is being taken to control pain, addiction does not occur.
- Pain can be affected and magnified by anxiety, stress, fear, frustration, fatigue, and depression.
- Pain is unique. Pain is whatever the person who is experiencing it, says it is.
- As a general rule, medications taken by mouth are as effective as injectable medications. The oral (by mouth) route of administration is preferred.
- Pain medications may cause drowsiness for a few days (especially if the patient has not slept in days or weeks due to unrelieved pain).
- Nausea may occur with increases in pain medication. This is a temporary side effect that will subside in a day or two. Ask your nurse about medications that may help.
- Repositioning or gentle massage may relieve tension and add to comfort.
- Relaxation, imagery, or distraction may help ease pain and discomfort.
- Pain medications need to be taken on a scheduled basis around the clock. This is to establish a level of medication in the bloodstream.
- "Breakthrough" medication is given on an as-needed basis.
- Record medications given to help the nurse determine if changes need to be made.

NAUSEA AND VOMITING

- Clear liquids, dry toast, or soda crackers may help diminish nausea. The patient should have nothing to eat or drink for 2 hours after a vomiting episode.
- Ice chips help to keep the mouth moist when unable to swallow fluids. Sipping fluids off a spoon every 10 minutes until nausea subsides may also be helpful.
- Forcing food or fluids may increase discomfort.
- Remove offensive odors, sights, or sounds. A quiet, calm environment is relaxing. Provide good ventilation.
- When food is desired, begin with clear liquids. After that, the foods offered should be bland. Avoid greasy, fried, or fatty foods.
- Encourage small portions, eaten slowly. Offer meals more frequently than three times per day.
- If antiemetics (antinausea medications) are ordered, try them as directed.
- Try to avoid favorite foods when nauseated. The patient may associate them with the nausea feeling and not tolerate them when nausea is resolved.
- Call the hospice nurse if nausea and vomiting last for more than 24 hours or is associated with:
 - abdominal pain
 - constipation
 - blood in vomitus

EMOTIONS

We are told that dying persons may have fears that they do not express. One is that they are a burden to their caregivers; another is that they will experience severe pain. These unexpressed (or expressed) fears often surface in behaviors that confuse caregivers. The following suggestions may be of help.

- Be sensitive to questions or statements that may indicate the person is experiencing these fears. Be reassuring, but honest.
- Anger may result from frustration experienced because of the illness. This is a common emotion that is generally not directed at anyone personally.
- Loss of control over aspects of life (for example, when to eat, sleep, bathe, or move about) sometimes makes the person feel irritable, angry, or sad. Having control, even in small ways, becomes very important. Being flexible helps.
- Sadness and crying are appropriate expressions of grieving. Respond with a willingness to listen and /or a reassuring touch. Discuss with members of the hospice team any concerns you may have.

MENTAL CHANGES

- There may be personality changes as the disease progresses.
- If fear is expressed, try to be reassuring. A simple touch or hug may calm the worst fears.
- Reduce the feelings of isolation by including the patient in activities. Hang a calendar in the room, and have a clock or watch accessible.
- Confusion sometimes occurs. Identify yourself by name before you speak. Speak softly, clearly, and truthfully. A night light may help decrease fear and anxiety.
- Hallucinations or “visions” may occur. Understand that these are experienced as real, and patients may even find comfort in them. Be truthful, yet open to discussing the experience.
- If the patient is experiencing fear or agitation related to the hallucinations, contact the Hospice nurse.
- Sense of hearing may be present, even if the patient appears unconscious. Use a soothing voice, and touch frequently.

MEDICATION: SAFE USE AND DISPOSAL

- Medications should be stored in a safe place out of the reach of children.
- Store medications in a dry, clean area.
- Apply gel medications with gloves to avoid absorption to the person applying it.
- Be sure that you understand the purpose and instructions for each medication.
- Ask your nurse about anything that you do not understand.
- Whenever possible, have the patient sit up before swallowing.
- Moisten the mouth with 1 or 2 sips of water before tablets are taken.

MEDICATION: SAFE USE AND DISPOSAL

- Always check with your nurse to see if medications can be crushed. If it is safe to do so, crush tablets and give them on a spoon in liquid, jelly, applesauce, sherbert or ice cream.
- If the patient is unable to swallow medication, talk with your nurse about giving it in another way; i.e., liquid, suppository, injection.
- When medications are no longer needed, they must be disposed of

in the following manner:

- Caplets, tablets, be flushed down
- Gloves should be patches. Patches sections and flushed
- Liquid medications down the toilet
- Suppositories should water and disposed or toilet.

GENERAL HOME SAFETY

Fire Safety

- Smoke detectors should be present on each level of the home.
- Change batteries every six months (spring and fall)
- Develop family escape plan.
- Have furnace, fireplace and wood stove cleaned and inspected every year.
- Keep kerosene space heaters three feet from walls and furniture.

Electrical Safety

- Run extension cords along walls, not under rugs.
- Replace frayed or broken cords.
- Never overload electrical outlets.
- Keep electrical appliances away from sinks, tub, and shower areas.
- Only use electrical appliances that are listed by a testing laboratory.

Kitchen

- Do not use stove or oven for heat.
- Store cleaning supplies away from food and in original containers.
- Keep all cleaning supplies out of the reach of children.

- Set utensils, foods and other needed items at a convenient height on stable shelves.
- Do not wear loose clothing around the stove.
- Place heavier objects on the ground or low level shelves. If there is inadequate space, install shelves or cupboards at a convenient height.
- Provide a reaching device to prevent the use of unstable chairs or step stools.

Bathroom

- Make sure faucets and towel bars are easy to reach.
- Put non-skid rubber mats inside bathtub.
- Install grab bars on bathroom walls (especially near the toilet and shower).
- Keep water temperature no higher than 105°.
- Place non-skid flooring strips or carpeting to avoid slipping.
- Provide an elevated toilet seat or install a safety frame for ease of use.
- Use the same safety precautions in both downstairs and upstairs bathrooms to lessen the use of stairways.

GENERAL HOME SAFETY

Lighting

- Hallways or stairways should be properly lighted with accessibility to light switches at entrances.
- Switches and lamps should be easy for the person to reach.
- Use translucent light shades or frosted bulbs to reduce glare.

Floors and Hallways

- Remove clutter and low-lying objects like coffee tables which can trip a person or lead to bruising or other injuries if the person walks into them.
- The best modification is to clear the path the person uses the most and provide stable furniture as support. A lack of furniture can be a hazard as it offers no support for a person to use when through a room.

- Use non-skid carpet runners rugs to alleviate slippery floors down carpet edges.

Stairways

- Provide secure non-slip handrails non-skid step edges.
- Repair worn steps and apply contrasting non-skid tape for visibility.

Furniture

- Furniture should provide ample and facilitate ease of rising and
- Provide chairs with armrests
- Adjust the mattress height for getting in and out of bed.

THE SUBTLE CHANGES: PREPARING FOR THE BEGINNING OF THE DISEASE PROGRESSION

When your loved one first entered Hospice, it may have seemed as though nothing had changed. Your loved one may have been going on with his/her daily activities and in some cases, may have seemed a little bit better with the help of medications and assistance from the Hospice staff. Recently though, you may have seen some “changes” in your loved one that have you concerned. Please know that just because these changes are occurring, it does not mean that your loved one’s death is imminent. Noting and talking about these changes is, however, a way to prepare yourself for the next phase of your loved one’s life. Please take a moment to review the following changes that you may be seeing. If there is something on the list that you do not understand, or if there is something that is happening and is not on the list, please talk to your Hospice nurse. If you would like to review this with a nurse, please let us know. It is so very important for us to help alleviate your fears and concerns. That is what we are here to do.

PHYSICAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Decreased Mobility	This could mean that your loved one’s body is beginning to lose energy and/or function. It could be that the disease is progressing.	Assist with activities. Some forms of equipment may be helpful as well as making some adjustments to the home to accommodate the change. There are Home Health Aides that may be able to assist you. It is important to recognize your loved one’s limitations and help him/her remain as active as he/she wishes to be. Your Hospice Team can help you with all of this.
Increased Pain	This could mean that there is disease progression. It could also be a result of not being mobile.	Adjustments to medications can be made by the doctor. You can also try some diversion activity such as music, reading, light massage, etc. It is also helpful to give a full description of the pain to the nurse, as there may be other treatments that would be more effective.

PHYSICAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Increased Sleep	This could mean that there is decreased energy. It could also mean that there is a desire to withdraw from activity. Disease progression also causes the need for more sleep.	Schedule shorter lengths of time for any event. Allow your loved one rest periods between events. If he/she is comfortable on the couch or in a chair, prop up his/her feet. Spend time with your loved one after he/she has rested so both of you get the maximum benefit from your time together.
Decreased Appetite/ Weight Loss	This can result from needing less food because there is decreased energy output.	Encourage your loved one to eat smaller meals if possible. Present one food item at a time. Let your loved one eat his/her favorite foods. As hard as it may be, try not to force your loved one to eat. If you encourage eating and he/she still refuses, it is OK. Your loved one's body knows what it needs and he/she would probably much rather spend time with you.
Difficulty Swallowing	There may be a bad taste or no taste to food because of changes to the taste buds. There may be a feeling of fullness or nausea. Your loved one may just not be hungry.	It can be dangerous to force food or fluid if your loved one is having difficulty swallowing. The Hospice nurse can help you determine what foods, fluids and consistencies are best. Positioning of your loved one is also important. Tell your nurse if there is any problem with swallowing.
Incontinence (not being able to control urination or bowel movements)	Incontinence can be a result of relaxation of the muscles that control elimination, which can be a result of disease progression.	There are many products that can be used to manage incontinence and to maintain the dignity of your loved one. It is also important to protect your loved one's skin. Your nurse can assist you with all of this.

PSYCHOSOCIAL AND SPIRITUAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Increased Desire to be Alone; Withdrawal	Your loved one may be preparing for the physical separation that will happen when he/she dies. Your loved one may need to reflect on his/her life and thus may need time alone. The reality of what lies ahead may be coming into focus and he/she may need time to grasp this.	This is a very difficult part of the process for you and your loved one. Your loved one may be asking you to understand and offer the space that is needed. Let him/her know how you feel and that you are there when needed. The Hospice Team can help you sort out the emotions that you are feeling.
Increased Desire to "Get Affairs in Order"	Your loved one may feel the need to reassign family duties and to feel assured that family and friends will be taken care of in the "right" way.	This can be a very difficult conversation to have because it means that the reality of the situation is out in the open. Your Hospice Team can give you many helpful suggestions on how to get through these conversations. One of the greatest gifts you can give your loved one is the ability to have control over this type of discussion.
Increased Desire to Discuss Spiritual Issues	Your loved one may have a desire to gather information about people's perceptions life after death. This of may be a result of curiosity, fear or a need to confirm beliefs.	There are numerous resources that can assist your loved one in this quest for answers. In the same way, the answers for some may be found in nature. Whatever and wherever the search, this is a significant part of the dying experience. Your religious leader and/or the Hospice chaplain can offer support and suggestions.

PSYCHOSOCIAL AND SPIRITUAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Increased Desire to Do Something or See Someone	Your loved one may tell you about a life long dream or a recent desire to add quality and meaning to his/her life. Your loved one may feel the need to resolve an issue with someone.	If it is possible, every effort should be made to facilitate these desires. Hospice has volunteers who can help. If the person lives far away and travel is not possible, a phone call should be encouraged. This sense of completion may have a positive effect on the way your loved one approaches death.
Talking About Memories	The process of remembering one's life is a way of validating existence. It is also a way of reliving those moments that are held dear. It may be a way for your loved one to assure that he/she will not be forgotten.	There are many ways in which a person can reminisce. You may find that your loved one's desire to talk and remember is very painful, as it is a reminder that time is passing. The emotional feelings that your loved one may experience are very healing, and once again, you have an opportunity to give him/her a great gift. The Hospice Team has many unique ways to assist you and your loved one in creating tangible memories.
Request Assistance with Funeral Plans	Your loved one may feel a "loss of control" with the changes that are happening. He/She may have a desire to regain that control by "designing" the funeral and having input in every way possible.	Talking about the funeral is actually very healthy and may give your loved one a sense of control. There are many things to consider, and to have these things "figured out" in the way that your loved one would like is one less burden on you. Trying to arrange a funeral when your loved one has just died can be very painful and taxing. Your willingness to engage in these conversations gives your loved one the gift of peace. We are here to help you.

MAKING CHANGES: PREPARING FOR END OF LIFE PHASE

You may begin to notice some new significant changes in your loved one's condition. The nurse may describe these changes as "actively dying" or state that your loved one is "making changes."

Even though your loved one is entering into this stage of life, there is no way for any of us to predict when your loved one will die.

Changes may occur physically, emotionally and/or spiritually. All of these changes play a great role in your loved one's remaining time. In some cases, emotional and spiritual changes are more significant than physical ones.

You may feel as though you cannot leave your loved one. We support your need to be with him/her and encourage you to take care of yourself as well. Many caregivers fear that if they leave to spend time with their family, run an errand, or even take a shower, they may return to find that their loved one has died. Communicate with your loved one in ways that you feel comfortable. Try to say what you need to say. Try to do what you need to do.

The following are some of the changes you may see. Your loved one may or may not experience all the things on the list. Our hope is that you will feel comfortable reading over what you may expect, what these changes mean and what you can do for your loved one. We also hope that you will talk to the Hospice Team about questions or concerns you may have. We are here to help you through this time.

PHYSICAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Skin Changes	The common changes in skin are usually related to blood flow. Your loved one may have cool hands and feet, while the rest of the body is warm. You may notice a pale or bluish hue around the lips and nail beds. You may see red or purple circles on the skin (called "mottling"). None of this is painful.	If your loved one feels cool to the touch, place an extra blanket on him/her. If he/she is too warm, put on light clothing. Regulate the room temperature accordingly.

PHYSICAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Changes in Body Temperature	Increases in temperature may be related to disease progression or lack of fluid intake. Decreases in temperature are usually due to decreased blood flow.	Follow the same principles as above. If hands and feet are cool, you can rub them with lotion, which may help to increase circulation and relaxation.
Changes in Level of Consciousness	Your loved one may become less responsive or unresponsive. This can be caused by disease progression or decreased blood flow to the brain. Your loved one may not be able to talk or look at you, but that does not mean he/she cannot hear, feel or understand.	We encourage you to talk and act as if your loved one was awake. Tell him/her who is coming to visit. Hold hands if you feel comfortable and let your loved one know how you feel. Your Hospice Team can help you with these conversations.
Changes in Breathing	Your loved one may have interruptions in his/her breathing for about 10 seconds to a minute (called "apnea"). He/She may take long and deep breaths and breathing may be shallow. You may hear a gurgling sound which is a collection of fluid in the back of the throat. This is dependant upon the disease progression.	Positioning your loved one in a certain way, ordering certain medications prescribed by the doctor and giving your loved one oxygen may help him/her to breathe comfortably. Sometimes a fan may also help. It is important to remain calm and re-assuring. Raise the head of the bed and/or place more pillows behind the back and head - this helps to assure better comfort and better alignment of the airway. Encourage your loved one to sit up and lean forward - this helps to ease the breathing process.
Inability to swallow	As the body begins to "shut down," two functions that are lost are the gag reflex and the ability to swallow. Remember that because your loved one's body is slowing down, there is little or no need for food. This is a natural part of the dying process.	Be sure to keep the mouth and lips moist. There are different ways to do this and your Hospice nurse will help you. Remember that giving fluid to someone is dangerous because the fluid can easily go into the lungs instead of the stomach. If you are unsure about whether your loved one has the ability to swallow, call your Hospice nurse.

PHYSICAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Restlessness and Confusion	Your loved one may be restless for several reasons such as pain, decreased oxygen or fear. Confusion can also be present due to decreased blood flow to the brain or disease progression, and may cause more restlessness.	Be sure that your loved one is positioned comfortably and is not in pain. There are medications that we can give for restlessness as well. It sometimes helps to control the extra stimulation in the room by dimming the lights and toning down noise. Reading to your loved one or playing music may help him/her to relax.
Decreased Urine Output/ No Urine Output	You may notice a decrease in, or lack of, urine output. This may be due to disease progression, lack of blood flow to the kidneys or a lack of fluid intake.	Our main concern is that your loved one's dignity is maintained. The skin may become irritated. Your Hospice nurse can provide you with supplies to keep your loved one dry and protected if he/she is incontinent.
Changes in Blood Pressure and Heartbeat	Changes in vital signs can be related to the body's natural process of shutting down. The pulse may increase or decrease. The blood pressure usually decreases.	Though there are ways that we can help breathing and temperature, it is difficult to control blood pressure and heartbeat. We can help you focus on your loved one and your time together, and pay less attention to numbers.

PSYCHOSOCIAL AND SPIRITUAL CHANGES

WHAT IS HAPPENING	WHAT IT MEANS	WHAT YOU CAN DO
Fear of: <ul style="list-style-type: none"> • Dying • Family well-being • Where they are going • Dying alone • Dying in a specific place 	These fears all fall under the heading of "The Unknown."	Talking with your loved one may ease the fear of dying. If there are specific family members that your loved one is worried about, perhaps they can talk to each other. Ask what your loved one thinks it may be like and what he/she hopes it may be like. The most helpful and loving thing we can do is to listen. Remember to use music and reading if this is something that has a calming effect as well.
Sadness	Your loved one may feel a profound sadness about leaving you and the life that he/she knows. This is natural. Your loved one may not be sure if he/she will be missed or remembered.	One of the ways in which you can help is to create a scrapbook, video or collage of pictures. A collection of favorite things in a decorated box is also an idea. Let your loved one know you are doing this. Your Hospice Team can help you with this project.
Predicting Their Own Death	Your loved one may have a keen sense that his/her body, mind and spirit have aligned and are prepared to move on.	It is best to listen and find out what your loved one needs you to do. If this frightens you, let the Hospice Team know and we can help.
Seeing Spiritual Beings	Your loved one may claim to see a family member, religious figure, or what he/she describes as a light or a place. He/She may just reach up or look up or carry on a conversation with someone. This is a phenomenon that cannot be explained. It is also referred to as "transitioning."	Listen and validate what your loved one is saying and seeing. If you have questions about this, your Hospice Team will be there for you.
Relief	Your loved one may feel relief that that this will soon be over and his/her death will lift your burdens as well. There may be a sense that he/she has lived a full and beautiful life and is "ready."	It may be difficult to know that your loved one is relieved to go. If possible, try to focus on the fact that he/she is at peace.

HOW TO HELP AS THE BODY SLOWS DOWN

As the patient emotionally and physically withdraws from this world, caregivers can suffer from feelings of helplessness. Withdrawal is normal for the patient as he/she becomes less concerned about surroundings. This is a good time for family members to gather together, since they may have some last thoughts or expressions of love to share with the patient.

Some people may need reassurance or approval to “let go,” so giving them permission and reassuring them that you will be OK helps the patient to feel comfortable and supported about letting go.

Tell visitors and other family members not to speak in front of the patient as if he/she wasn't there. Nothing should be said that would upset the patient should he/she overhear it. It is important that if at any time you or your family are unsure of what is happening, you call Hospice. Even if you need a little reassurance or support, that is what we are here for 24 hours a day.

COMMON QUESTIONS ABOUT THE DYING PROCESS

Can my loved one hear and understand?

Sometimes it is difficult to tell if your loved one can hear and understand once he/she becomes unresponsive. We encourage everyone to speak and act as though he/she can hear and understand everything. There have been many instances when loved ones who had not moved in hours or days responded to something that had been said. If someone is not able to be at your loved one's side but wishes to speak with him/her, place the phone to his/her ear. Play some favorite music, sing a song or turn on a favorite TV show. Whatever your loved one enjoyed before may be soothing now.

How do I know my loved one is not in pain?

If and when your loved one can no longer communicate verbally, there are many cues that tell us he/she is not in pain. We look at vital signs, the expression on your loved one's face, the rhythm of his/her breathing and the position of the hands and legs. All of these signs indicate your loved one's comfort level. Your Hospice Team will point these out to you.

Why is my loved one hanging on?

The mind and spirit can play a huge role in the time someone chooses to remain. We may or may not know what your loved one is thinking about or "working through." Your loved one could be:

- worried about someone's well-being
- waiting for you to give permission to leave
- waiting for someone to leave or arrive
- spending last moments with family and friends and not be ready to leave

In essence, your loved one may feel as though he/she still has a purpose here. We know how difficult this "vigil" can be. You want to be there, but it is hard to take off from work or find someone to watch the children. It is hard to try to stay awake. We are here to help you figure these things out.

What if my loved one dies when I am not there?

It is difficult to predict the exact moment of death. There are ways of knowing when death is near, and we can help you see that progression. Sometimes it is easiest to let your loved one decide. You can tell him/her that you are going somewhere and that if he/she wants to leave, you will be OK. This way, you give your loved one the choice, taking the burden off of yourself. Remember that there were many days when you were not together, and yet you knew that you loved each other.

COMMON QUESTIONS ABOUT THE DYING PROCESS

How will I know when my loved one has died?

The Hospice Team will be able to tell you when your loved one has died. In the case that a Team member is not present, you will know your loved one has died when breathing has stopped. Call us as soon as you can so we can help you as soon as possible. A referral for Bereavement Care to Life Transitions Center will be made by your hospice team. You will receive information in the mail for grief support and education groups in the near future.

What will my loved one look like when he/she dies?

At the moment of death, you will not see much difference from how your loved one looked just before. You will notice that breathing has stopped. As time passes, he/she will become paler and the skin will become cooler. His/Her eyes and jaw may or may not close. You may find yourself checking over and over again for breathing. It is normal to think that you see the chest rise or hear breathing. Don't be afraid. Your Hospice nurse will answer any questions you may have.

What do I do when my loved one has died?

Call Hospice if you have not already done so. While you are waiting for a Hospice Team member to arrive, you can do whatever you feel comfortable doing. You can sit with your loved one. You can hold your loved one. It's important to take the time to say goodbye. You can call friends and family. We will be there as soon as possible and will help you from there. **You do not need to call 911 or the police.**

Care of your loved one's body

Once the Hospice nurse has arrived, you will be able to determine when you want your loved one's body to be picked up, if you have not already done so. You may want to bathe your loved one beforehand. The Hospice nurse can do this for you and you may help if you wish. If you do not feel comfortable, that is OK, too. When your loved one's body is picked up, you may have difficulty watching him/her leave the home. We encourage you to share your fears, concerns and sadness with us, your family and friends. Please know that we are here for you.



Thank You

We thank you for the privilege of assisting you
with the care of your loved one.

We salute you for all you have done to surround
your loved one with understanding care, to provide
your loved one with comfort and calm, and to enable
your loved one to leave this world with
a special sense of peace and love.

You have given your loved one the most beautiful and
sensitive gift we humans are capable of, and in giving that gift,
have given yourself a wonderful gift as well.

HOSPICE
B U F F A L O

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