



Hospice  
of Southern Kentucky



# Caregiver Handbook

A training tool to help you care  
for your loved one



270-746-9300

Please call if you need anything, or have questions or concerns.

## **When to Contact Hospice of Southern KY?**

Call your Hospice of Southern Kentucky Care Team FIRST- day or night- if you:

- Are considering calling 9-1-1. PLEASE CALL US FIRST. We can help.
- Feel that your loved one's pain or other symptoms are not controlled.
- Notice a change including: increased pain, agitation, trouble breathing, nausea, or vomiting.
- Have a question about medications, how to provide care, etc.
- Have questions or concerns that can't wait until your nurse visits.
- Have a change of address, or your loved one is traveling a long distance.
- Your loved one dies.

Dear Friend,

We welcome you to Hospice of Southern Kentucky. We are here to help you be as confident as possible, and to support you in the journey ahead.

Your hospice care team will assess the needs of you and your loved one and provide the visits, supplies, medication, and equipment needed. They will train you how to care for your loved one, and support you in becoming a confident caregiver.

This guide has information about how to provide daily care, how to use the supplies and equipment, the expected changes that may occur, and other resources you may find helpful. Use this guide like you would a dictionary... to look up something when you have a question or need guidance. Don't be afraid to write in it! Take notes and jot down questions to ask at the next visit. If at any time you have a concern, or want to ask a question, please call our main line at 270-746-9300—anytime, day or night. Remember, your hospice care team is only a phone call away.

It is our privilege to serve you and your family during this special time.

Sincerely,

Hospice of Southern Kentucky

# Pain Management

## **1. How is pain managed?**

The nurse will assess your loved one to find where they are having pain, what type of pain they have, and how intense the pain feels. Your Hospice Care Team will work to find the medication(s) that will keep your loved one most comfortable. Other relief measures can be tried to increase your loved one's comfort level as well.

## **2. What are the types of pain medication that may be used?**

The doctor and nurse will consider the type and intensity of pain to decide on the right pain medication. Mild pain is usually treated with acetaminophen, aspirin, or ibuprofen. Moderate to severe pain may need a stronger pain medication such as morphine or oxycodone. Pain that involves the nerves and bones may need additional medications.

## **3. What are opioid medicines?**

Opioids are medicines used to control moderate to severe pain. Opioids work by blocking the pain and help to provide comfort and relief. The most common opioids are morphine and oxycodone.

## **4. Will my loved one become addicted to pain medication if they take it regularly?**

Hospice patients who are prescribed medications and opioids will not become addicted and should not be a concern. Medications will be prescribed at low dosages and increased as the pain increases. Patients may form a tolerance to pain as their pain increases, but this is not considered an addiction. True addiction happens when the medications are misused and are not used to control pain.

# Pain Management

## **5. What if my loved one continues to have pain?**

Please notify the Hospice Care Team any time, day or night, if your loved one's pain worsens or if the current medication is no longer working. You may have been given a Comfort PAK which has extra medications that can be used in addition to the prescribed medicine. There are several things that can be done to prevent side effects. For example, a doctor can prescribe laxatives or a stool softener for patients on opioids to prevent constipation.

## **6. Will my loved one be drowsy all the time?**

If an opioid pain medication is given for the first time, or if the dose is increased because of increased pain, they may be drowsy for the first two or three days. The body will then adjust and the drowsiness will subside.

## **7. If my loved one takes strong pain medication now, will it still work if the pain worsens?**

There is no limit to the amount of strong pain medication that may be given. Your nurse will consult with your physician to obtain increases in pain medication when needed. The pain level and frequency of the pain will determine the strength of the medication needed.

## **8. If my loved one can no longer speak, how do I know if they are in pain?**

Patients who are unable to speak often demonstrate pain and discomfort in alternate ways such as restlessness, agitation, moving around a lot, and facial grimacing. Don't hesitate to provide prescribed pain medication if your loved one is demonstrating these symptoms.

# What you can do for pain:

- Give the medications as directed.
- Don't skip any long-acting dose of medication without permission by the nurse.
- Give the short-acting dose as directed (known as PRN or breakthrough dose) if your loved one is having pain. You may give the short-acting dose at the same time as the long-acting dose if your loved one is having pain. If the pain continues, call Hospice of Southern Kentucky at 270-746-9300 at any time, day or night.
- If activity causes pain, give your loved one a dose of short-acting medication about 15 to 30 minutes before doing the activity.
- Keep records of the pain medication given. This information is important to the doctor and nurse in making medication adjustments.
- Ask your nurse about other pain relief.

## Notify the nurse if your loved one:

- Has an increase or change in severity of pain.
- Has needed more than three doses of breakthrough pain medication in a 24-hour period.
- Regularly has pain before the next dose of medication is due.
- Is having any unpleasant side effects such as confusion, nausea, vomiting, restlessness, inability to urinate, rash or itchiness, allergic reaction (shortness of breath, hives).

### *Alternative methods to help with pain*

*Massage, Aromatherapy, Relaxation Exercises, Deep Breathing & Music Therapy*

# Symptom Management

## *Shortness of Breath*

Your loved one may say that they can't get enough air or catch their breath. Their breathing rate may increase or become labored, causing anxiousness and restlessness. Shortness of breath can occur for a variety of reasons and can be treated with medication. Sometimes an opioid medication, like morphine, is used to relax breathing.

### **How You Can Help**

- Keep the room cool. Use a small fan blowing gently in your loved one's direction.
- Elevate the chest and head with pillows. A hospital bed may be ordered to help.
- Instruct your loved one to sit upright, leaning forward with arms on the side rails or elevated on pillows. This position helps the chest to expand.
- Instruct your loved one to breathe in through the nose, and breathe out slowly through pursed lips so that the exhalation is extended.
- Frequent mini-meals may help. Full meals often make breathing harder.
- Give your loved one loose, light clothing to wear.
- Arrange the home so that your loved one does not have to exert a lot of energy. If possible, put a chair bedside or move the commode close to the bed.
- Administer medications as instructed by the nurse.

### **Notify the nurse immediately if shortness of breath:**

- Is present for the first time.
- Is worse in spite of medications and the above suggestions.

# Symptom Management

## *Nausea and Vomiting*

There are many reasons why your loved one could be experiencing nausea, vomiting, or dry heaves such as severe pain, side effects of medicine, constipation, severe anxiety, or coughing spells.

### **Nausea Prevention Tools**

- Give small amounts of dry food, such as toast or crackers, when they wake up.
- Eliminate foods, tastes, and smells that nauseate them.
- Avoid serving fried, fatty, spicy or citrus foods.
- Avoid giving pain medications on an empty stomach.
- After eating, have them rest in a sitting or semi-reclined position.
- Keep a written record of when they need anti-nausea medication so you can keep your nurse updated.

### **What to do When Vomiting Has Occurred**

- Prevent choking by turning your loved one on their side.
- Place damp, cool cloths on the forehead and neck.
- Help them rinse their mouth and brush their teeth.
- Have them avoid eating and drinking for one or two hours after vomiting.
- Give them small amounts of clear liquids such as broth, clear juices, popsicles, gelatin or sports drinks.
- Rest the digestive tract up to 24 hours, then try bland soft food like cereal or pudding.

### **Notify the nurse immediately if:**

- Your loved one is vomiting repeatedly. The nurse may recommend anti-nausea/vomiting medication.
- The vomited material looks like coffee grounds or has blood in it.
- Your loved one cannot take the anti-nausea/vomiting medication.
- The current anti-nausea/vomiting medication is not helping.
- Your loved one is becoming weak, dizzy or thirsty.



# Symptom Management

## *Sore/Dry Mouth*

Your loved one may develop a sore or dry mouth that can be painful and make eating difficult.

### **How You Can Help**

- Apply lip balm to dry lips
- Cut food into small pieces to reduce the amount of chewing needed
- Remove loose dentures that may be irritating the gums
- Check the tongue, sides of cheeks and roof of mouth for white patches, sores, bruising, or red pinpoint dots
- Avoid hot, spicy, hard, or coarse foods
- Try cold juices (apple, pear or peach) or foods that are soft like ice cream or yogurt
- Use a soft toothbrush or foam mouth swabs for mouth care

### **Notify the nurse if your loved one:**

- Has white patches, sores, bruising, or bright red pinpoint dots in the mouth
- Is unable to eat or drink because of soreness or discomfort

# Symptom Management

## *Constipation*

Constipation can happen when a loved one is eating/drinking less, moving less, or taking medication.

### **How You Can Help**

- Try to include fruits at meal times/Offer a glass of prune juice
- Increase fluids if possible, especially warm drinks to stimulate the bowel
- Use stool softener or laxatives as directed

### **Notify the nurse if your loved one:**

- Has not had a bowel movement for two days
- Has any stomach discomfort or runny stool
- Is having difficulty taking laxatives

## *Diarrhea*

### **How You Can Help**

- Use gloves when cleaning the skin around the rectal area
- Apply a moisture barrier protective cream to protect the skin from irritation
- Avoid dairy products, solid foods, sugar and stimulants such as caffeine or nicotine
- Try "The Big Four"- bananas, white rice, unsweetened applesauce, dry toast
- Try using an adult brief to avoid accidents

### **Notify the nurse if your loved one:**

- Has more than three loose bowel movements in a day
- Has blood in the bowel movement
- Has severe cramping or a fever
- Begins passing small amounts of liquid stool after being constipated

# Symptom Management

## *Confusion*

### **How You Can Help**

- Speak quietly and in short sentences
- Keep the noise level down and limit the number of people in the room
- Do not try to correct your loved one, as this may lead to arguing and increase their distress. Try asking questions instead, such as "What's going on?" and "Tell me what you see." Try to be supportive and accept their train of thought
- Spend time sitting quietly with your loved one
- Leave a small light on in the room at night

### **Notify the nurse if:**

- Confusion has appeared for the first time or has increased
- Your loved one is becoming restless with repetitive movements such as trying to get in and out of a bed/chair or they are picking at the air
- Confusion has placed your loved one at risk for falls or injury

## *Difficulty Sleeping*

### **How You Can Help**

- Offer a light bedtime snack such as cereal and milk, cottage cheese, or cheese and crackers
- Limit naps during the day
- Administer pain medicine as directed to ensure comfort at bedtime
- In chronic cases, sleeping medicine can be administered

### **Notify the nurse if your loved one:**

- Is not sleeping at night, has difficulty falling asleep or staying asleep.

# Symptom Management

## *Skin Breakdown*

Your loved one may begin to spend more time in bed due to increased fatigue. As a result, there is an increased risk for skin breakdown. Skin is compromised due to decreased circulation and dryness, but preventative measures can be used to minimize or avoid skin breakdown.

### **How You Can Help**

- Encourage your loved one to change positions every hour when sitting in a chair. Your loved one can shift from one hip to the other, or alternate a pillow under each buttock to relieve pressure.
- Encourage your loved one to change positions every three to four hours while in bed. Help reposition him or her if they are too weak to turn themselves.
- When your loved one is lying on their back, place pillows under the lower legs to lift the heels off the bed.
- When your loved one is lying on their side, place pillows between the knees and ankles.
- Apply lotion to elbows, knees and hips as long as the skin is not red
- Keep urine and feces off the skin by applying a moisture barrier protective cream.
- Your nurse can also contact the physician if further treatment is needed.
- If a dressing is needed, follow directions as given by the nurse.

### **Notify the nurse if your loved one:**

- Has any red or discolored areas that don't go away in 15-20 minutes once the pressure is off the area.
- Has any cracked, blistered or broken areas of skin.
- Has any rashes that don't respond to moisture barrier protective cream.
- If you need instruction on repositioning or you need assistance.

# Symptom Management

## *Depression*

Depression is difficult to identify because the symptoms can overlap with disease symptoms.

### **Signs and Symptoms of Depression in a Hospice Patient**

- Sleep interruption (not related to pain or discomfort)
- Persistent pattern of too little or too much sleep
- Feelings of hopelessness, helplessness or desperation
- Recurring thoughts of suicide
- Anxiety and irritability
- Difficulty concentrating or making decisions
- Sadness or crying more often; increased sensitivity

### **How You Can Help**

- Listen, without judging, when your loved one shares feelings of being discouraged, hopeless, sad or suicidal.
- Ask them if they feel depressed.
- Make sure they do not have access to firearms or other items that could cause harm.
- Administer anti-depressant medication, if ordered, as long as your loved one is able to swallow.

### **Notify the hospice team if your loved one:**

- Develops mood, sleep or outlook changes.
- Begins talking about not being able to cope with things, making statements like, "I wish I could end it all," or asking you to give them enough medication to end things sooner.
- If you feel there is an immediate concern or you need additional support.
- Does not gain relief from anti-depressant medication. The nurse will consult the physician about a dosage or medication change.

# Food & Hydration

Decreased interest in food and water is one of nature's ways of allowing a person to pass away more comfortably and peacefully. As the need for food and fluid decreases, you and your loved one may face difficult spiritual and emotional decisions. Below are some common phrases heard by the Hospice Team and things to remember as a caregiver.

***"My family is afraid I'm starving to death."***

The body cannot process food in the final stages of terminal illness. Weight loss, weakness, and skin color changes may occur. Be sure to offer but don't force your loved one to eat or drink. Instead, focus on their comfort and offer support.

***"I feel guilty because my family feels like I'm giving up."***

Sharing food is important in many cultures and caregivers often feel helpless when their loved one cannot eat. Low food intake doesn't cause hunger or discomfort. The body's need for food decreases with a terminal illness and eating more may cause discomfort.

***"I don't have an appetite."***

Remember not to force your loved one to eat or drink. Try to keep the mouth and lips moist with sips of water or lip balm and provide frequent mouth care to ensure no sores develop. You can also ask the nurse if any medications may be affecting appetite.

***"I am hungry but I fill up fast."***

Digestion will slow and food may stay in the stomach longer, so normal sized meals may not be tolerated. Try offering small amounts of food throughout the day.

# How to be an Effective Caregiver

Caring for someone at the end of their life can be a privilege, a blessing and an honor. This is a selfless time, and caregiving is a gift that rewards both the caregiver and the patient. There is a sense of intimacy when serving your loved one at their most vulnerable time. These experiences, although difficult at times, can be meaningful in unexpected ways.

The caregiving role may be something you've done most of your life or it may be a new experience. Regardless of your experience level, caring for a loved one with an incurable illness brings responsibilities and demands that may seem overwhelming at times.

Remember, you are not alone. Your Hospice Care Team is here to support you in your role as caregiver. We are here to help you learn how to care for your loved one, support you with information and resources, and help you work through any caregiving challenges. There are times when difficult decisions need to be made, and our team members are always available to help.

## **Take Care of Your Health**

Get regular checkups and practice good preventive health care. By taking good care of yourself, you are indirectly taking care of your loved one. Discuss your needs, feelings, fears and concerns with your resource coordinator. They are knowledgeable about the services offered by Hospice of Southern Kentucky and other community resources available. They can help you consider all your options so you can make informed decisions. Your social worker is also a skilled listener, counselor and may be able to help you problem solve a situation.

# How to be an Effective Caregiver

## Understand Your Feelings

The following are some feelings that you may experience and ways to deal with them. You are not alone. A member of the Hospice Care team is always available at any time to talk with you.

### ***Feeling Overwhelmed***

As a caregiver, it is normal to find yourself facing situations over which you have no control. This can be frightening and stressful. Plan as best you can and trust that things will be resolved.

- Try not to make important decisions when you are upset. Give yourself time to calm down, even if you have to leave the room. Take deep, calming breaths and then reconsider the decision.
- Make a list and check things off as you complete them. This can help give you a feeling of accomplishment and control.
- Learn to say 'no'. Determine what your limits are, and let others know what you can and cannot do. This is not a form of selfishness, but an expression of self-love.
- Talk to someone you can trust to give you unbiased feedback.

### ***Feeling Anger***

You may be angry that your loved one is ill and can't participate in activities. You may resent their dependence on you or the lack of understanding or assistance from others. You may feel angry over lack of personal time to do things for yourself. It is important to express your anger in an appropriate way before it gets worse.

Denying or repressing feelings of anger can result in resentment or a short temper. Discuss your feelings from your perspective. (For example: "When you say you're going to help me and don't show up, I feel like you don't care.") If your anger is based on frustration, it may help to beat a pillow, scream in your car, work in the garden, exercise or write down your feelings in a journal.



# How to be an Effective Caregiver

## ***Feeling Fear***

Your loved one may have symptoms you are not familiar with, or you may have questions about what to do or what to expect as the disease progresses. This may be frightening. Identify your fears and write them down. When you have the opportunity, address these with your nurse or other team members.

Discuss your feelings of fear or anxiety with your resource coordinator. They can teach you techniques to help lessen the intensity of these feelings. Sometimes talking it over with someone else may be all you need.

## ***Feeling Guilt***

Guilt can come unexpectedly. It may result from conflicts in relationships or second-guessing decisions made about health care. Something innocently said by your loved one may trigger guilt. You may overreact to a situation and feel guilty about your reaction. If you've made a mistake or overreacted, apologize and forgive yourself.

## **Caregiver Burnout**

It is common for people to feel overwhelmed when caring for a loved one. Below are some warning signs that may indicate that you need extra help or support. If you begin to experience some of the following symptoms, please discuss them with your social worker.

- Withdrawal from friends and family
- Loss of interest in activities you once enjoyed
- Feeling blue, irritable, hopeless or helpless
- Changes in appetite, weight or both
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to hurt yourself or your loved one
- Emotional and physical exhaustion

# How to be an Effective Caregiver

## Anticipatory Grief

When a loved one is dying you have time to prepare, but you may experience symptoms of grief before the death has occurred. The intensity of the symptoms may vary, and they may come and go. Not everyone experiences anticipatory grief or all of its symptoms.

Symptoms can include:

- Depression and crying
- Extreme concern for the dying person
- Sense of helplessness or denial
- Fear of continued uncertainty
- Health issues such as fatigue, sleep loss and weight loss or gain

## What You Can Do

- Acknowledge the joys and pleasures still available
- Talk with a trusted friend or your hospice team
- Give yourself permission to cry
- Spend time on a hobby
- Write your thoughts in a journal

## Spiritual Care

Hospice Support Advocates are emotional and spiritual guides that strive to fulfill the spiritual needs and desires of patients, caregivers and families. They can help individuals reconnect or maintain relationships with religious communities, and affirm the ultimate value of each and every life and assist with any unresolved issues.

Our Support Advocates provide support by creating a spirit of loving care and inner peace. Dealing with spirituality at the end of life may include finding strength to face one's death or the death of a loved one, or making meaning out of the life remaining. Hospice Support Advocates go on this journey with patients and caregivers, regardless of religious affiliation and without imposing any particular religious perspective.

# End of Life Signs & Symptoms

There are some common signs that usually appear to prepare the body for this transition. This process can take days to weeks, unless death comes suddenly from an event such as a heart attack or stroke. **Now is a good time to spend extra time with your loved one, sharing your memories, thoughts and love.** It is important to have time to say goodbye.

## Increasing Weakness

This is often the earliest sign that your loved one is nearing the end of life. Their legs will become weak, and they may be unable to rise from a chair, get out of bed or walk to the toilet or bedside commode. Someone should be nearby at all times. It helps to think ahead and plan for how you will provide this increased care.

### **How You Can Help**

- Notify your nurse when you notice this change. Equipment such as a hospital bed, wheelchair or bedside commode can be ordered.
- Ask for help from your family and friends if they are available.
- Discuss the changing situation with the resource coordinator to review options for care when your loved one is bed-bound.

## Increasing Sleep

Sleeping increases until the person sleeps more than they are awake. They are usually capable of being aroused and may have short periods of being alert.

### **How You Can Help**

- Let your loved one sleep as much as they want.
- Make the most of the time when they are awake, and give personal care and medications at this time.
- Make sure to wake your loved one to give them their regularly scheduled pain medications so pain control is maintained.

# End of Life Signs & Symptoms

## Change in Bowel & Bladder Function

Bowel movements become less frequent and the amount of urine decreases. Darker urine is expected as your loved one drinks less. They may become unable to control their bladder or bowels at this time.

### **How You Can Help**

- Use disposable bed pads and disposable briefs.
- As long as your loved one can swallow, it is important to continue medications to prevent constipation.
- Clean the skin thoroughly after each passage of urine or stool and apply a moisture barrier to protect the skin.
- Discuss a urinary catheter with the nurse.

## Restlessness

Restlessness may occur. It may be due to the changes in the body, lower oxygen levels to the brain, emotional issues or spiritual concerns. Your loved one may toss and turn, try to get out of bed, talk rapidly or pull at the bed covers.

### **How You Can Help**

- Speak quietly.
- Keep the lights dim.
- Try playing soft music, giving a back rub or reading aloud.
- Notify your nurse. Medications can be administered to calm and relax your loved one.

# End of Life Signs & Symptoms

## Emotional & Spiritual Signs

When your loved one gets close to the final stage of dying, they may give hints in behavior or words that the time is close. Your loved one may:

- become less interested in what is going on around them.
- use expressions of speech that indicate they realize the end is close, such as “I am not going to win this ball game” or “I am going home soon.”
- “see” or “talk” with people who have already died.
- reach out for things that cannot be seen.

## **How You Can Help**

- Be accepting of what your loved one says or does. Do not try to correct them. Ask gently what they are doing or seeing, and listen carefully.
- Listen for unspoken needs, such as, “Do they need to be reassured that you will be okay without them?”, “Are they needing your forgiveness for anything?”, “Do you need to forgive them for anything?” or “Is there someone they would like to see for the last time?”
- Express your love and appreciation for them.

# When Death is Near

Your Hospice Care Team members will review what may be expected to happen in your specific case.

## **Saying Goodbye and Giving Permission**

Giving permission to your loved one to let go can be hard. They may try to hold on, waiting to be sure loved ones will be all right. Your ability to release them from this concern and give them assurance that it is okay to let go is a gift you can give to your loved one.

Saying goodbye can be done in many ways. Touching your loved one can be comforting to you both. Tell your loved one that you love them. If they are unable to respond, answer for them, "And I believe you love me, too." Forgive your loved one or apologize for past acts or words. If they are unable to respond, answer for them, "I believe you forgive me, too." Recall favorite memories, say "thank you for...", and tell them goodbye. Crying is a normal and natural response to saying goodbye.

If your loved one is no longer able to communicate, review their advance directive to familiarize yourself with how they would like to be cared for at the end of life. The guide on the next two pages is provided to help with the understanding of some of the changes that you may start to see.

# When Death is Near

## Signs & Symptoms of Approaching Death

This guide helps to understand and anticipate the changes that may occur as a person nears death. Please remember these changes may not always occur, or occur in any certain order. Discuss any questions with your hospice nurse. Our goal is to keep your loved one as comfortable as possible.

### ***Breathing***

Your loved one may begin breathing with their mouth open and the breathing rate may become faster or slower, deeper or labored. You may hear a "rattling" sound in the back of the throat with each breath. They can still get air but they may be too weak to clear their throat. There may be periods of no breathing for 5-15 seconds or a brief pause in breathing. This is known as apnea and is not painful.

To help:

- Use mouth swabs dipped in ice water on your loved one's gums, teeth and tongue
- Elevate the head of the bed or position them on their side
- Notify the nurse if the rattling sound is not relieved. A medication may be given to decrease the accumulation of secretions ("wet" breathing). Generally, suctioning the patient's lungs is avoided because it usually increases agitation.
- Rattled breathing will signal that death is very near. Anyone who has expressed the desire to be with your loved one at the time of death should stay near.

# When Death is Near

## ***Circulation***

Your loved one's arms/legs may cool as circulation decreases, look pale or mottled, or become blue or purple in color, as do the lips and nail beds. This is not painful and is natural as circulation slows down. Be sure to turn your loved one as instructed and massage areas of the body on which your loved one was previously lying.

## ***Confusion***

The time may come when your loved one does not know the time of day or recognize people, places, or objects. They may not be able to speak clearly. You can gently remind them of these things but try not to appear distressed. Stand where they can see you while you speak and encourage your loved one to speak slowly.

## ***Dreams***

It is not unusual for patients to talk about contact with loved ones who have died or to have "visualizations" about going on a long trip. Recognize that this is quite a normal experience and encourage them to share it with you.

## ***Eyes***

Your loved one's eyes may become dry/crusty and the body may create tears to compensate for the dryness. A comatose person's eyes may stay partially or completely open. To help, use a warm moist washcloth to gently cleanse the eyes. You may try to close the person's eyes, but they will likely open again.



# When Death is Near

## ***Fatigue***

Your loved one may become more tired and begin sleeping more than they are awake. The deep sleep is called "coma". Even if they are not able to respond, you can talk to your loved one and reassure them you are near. They probably hear and understand you, even if they cannot respond.

## ***Fever***

Some may experience a high fever as the temperature regulator in the brain begins to fail prior to death. Your loved one may sweat heavily and the chest/abdomen may be warm while the legs and arms are cool. Be sure to change clothes and sheets if they become damp. If your loved one is hot, gently sponge their skin with lukewarm water. Notify the nurse if your loved one's temperature is above 100.5 degrees so appropriate medication can be given.

## ***Unresponsive***

Your loved one may become unresponsive, meaning they do not respond to touch or words. At this time, take turns with family and friends at the bedside. Be sure to turn your loved one every 3 or 4 hours and position with pillows for comfort. Keep in mind the sense of hearing remains until the end.

## ***Muscles & Restlessness***

Muscle twitching may occur from imbalances in the blood and your loved one may move about in the bed, pull at the sheets/blankets, or reach out and pick at the air. The muscle twitches are usually not painful but restlessness can be an indicator of pain. Notify your nurse and medications may be adjusted to help.

# Call Hospice of Southern Kentucky at the Time of Death- 270-746-9300

Remember, you are not alone. If you think your loved one has passed away, please call Hospice of Southern Kentucky any time, day or night at 270-746-9300. The nurse will ask you your name, the patient's name and the time of death. If your loved one passes away at home, a team member will be sent to the home.

Signs that your loved one has passed away include:

- no breathing, no heartbeat
- total loss of bowel or bladder control
- no response to stimulation
- eyelids slightly open
- eyes fixed
- mouth slightly open and jaw is relaxed

The Hospice Care staff member will:

- confirm that your loved one has passed away.
- advise the Hospice Care Team and the patient's physician of the patient's death.
- provide emotional support to the family and caregivers.
- assist in calling the funeral home as needed.
- review appropriate disposal of medications.

Members of the Hospice Care Team may call and visit to offer support to the family.

The home medical equipment company will call to schedule a time to pick up equipment.

A member from our Bereavement Program will call in a few weeks to see how you are coping with your loss and let you know about the services that are provided to support you.

# My Notes & Questions

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