



# The End-Of-Life Journey

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**What Family & Caregivers Can Expect**

**1.800.233.1708 | [www.hospice.org](http://www.hospice.org)**

Belleville Location 618-235-1703 • Marion Location 618-997-3030



*Hospice of Southern Illinois is your  
community not-for-profit hospice.*

*There comes a time...  
to ask how hospice can help.*

*February 2018*

# To The Caregiver

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**One of the most important rules for the caregiver is to take care of yourself too.**

You have an extremely stressful, exhausting, and emotionally taxing job. You must make sure you take care of yourself while taking care of the patient.

**Eat Right** – the patient may not have an appetite or may not want to eat “good, well-balanced” meals – but you should.

**Get Some Rest** – if you become worn down and exhausted, you won’t be in any condition to care for the patient. Have others take a night or two with the patient.

Sleep when the patient sleeps. Nap when the patient naps. But, no matter what, try to get the rest you need.

**Take a Break** – sometimes you just need to get away. Even if it’s only for a couple of hours, do it. You are working very hard and under extreme conditions. You deserve a little “down-time” too!

**Respite Care** - a social worker is available to explain and coordinate options for respite care. This is helpful when needing a short break from caregiving, planning vacations, medical emergencies for caregivers, etc. If more caregiving assistance is needed overall, the social worker can educate you about your options for obtaining extra help.

# **Possible Symptoms Experienced by the Patient While Receiving Hospice Care**

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*Anxiety and/or Sadness*

*Restlessness and/or Agitation*

*Trouble Breathing*

*Pain*

*Constipation or other Bowel Changes*

Your team of hospice professionals is formally trained to carefully listen to your concerns and to assist with providing comfort and care to you and the patient.

It is important that you communicate your questions and concerns to the hospice team and they, in turn, should clearly explain all instructions and aspects of the patient's care to you.

No question is too small to ask. Medical information and technical terms can be confusing and are often difficult to understand.

Your hospice team is made up of caring professionals who are pleased to assist you and the patient with understanding what to expect, what symptoms might occur, what medications might control symptoms, and the possible side effects of those medications.

***Our goal is to help you understand what to expect during the patient's time in hospice care.***

# Signs of Declining Condition

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## **A decreased interest in eating and drinking may occur.**

It is okay not to eat. The digestive process takes a great deal of energy; energy that the patient does not have. The refusal of food may be an indication that the disease is advancing, things are changing, and the patient is preparing to die. Nutrition (food) and hydration (fluids) are not always beneficial to the patient when their terminal illness is progressing.

### **What You Can Do:**

- Offer, but do not force, food or fluids. Forcing food or fluids on the patient who is no longer able to swallow, or has no appetite, can lead to aspiration (going into his/her lungs). It can also lead to nausea and vomiting.
- Do not give food or fluid to an unresponsive patient.
- Sips of fluids, ice chips, or popsicles may be helpful.
- Offer small, frequent meals or snacks. Offer the patient their favorite foods.
- Ask the patient what food or fluid sounds good to them and get it for them.
- Provide frequent oral care with a toothbrush or with toothettes (mouth swabs).
- Keep lips moistened with lubricating balm and clean mouth with toothettes. Do not use petroleum-based lip products if the patient is on oxygen, as petroleum is flammable.
- Other \_\_\_\_\_

**Urinary output may decrease in amount and frequency.**

Urine may be very dark in color (often tea-colored), and may have a strong odor.

**What You Can Do:**

- Offer, but don't force, fluids.
- Keep the patient's private areas clean and dry to prevent infection.
- If the patient is unable to urinate, or is nonverbal and suddenly becomes restless, notify the hospice nurse at 1-800-233-1708 immediately.
- Other \_\_\_\_\_

**Loss of bowel and bladder control may occur.**

The patient doesn't always realize they have lost control of their bladder and/or bowels.

**What You Can Do:**

- Check for loss of bowel or bladder control (incontinence) often if you have noticed the patient hasn't gone to the bathroom for a long period of time.
- Provide emotional support, as this can be embarrassing to the patient when it occurs, especially if it is because he/she is too weak to get to the bathroom.
- Keep the patient's private areas clean and dry. Change bed pads and linens as needed if they are soiled.
- Protect the patient's mattress from getting soiled by applying a waterproof mattress pad.
- Keep room odor neutralizers/deodorizers close by to decrease odor.
- Other \_\_\_\_\_

## **There may be a reduced level of alertness.**

As the body weakens, the patient may sleep more and begin to withdraw from his/her surroundings. With this withdrawal, the patient may communicate less with words.

### **What You Can Do:**

- Notify the nurse if this occurs, as this may be an expected result of the medication the patient is taking. The hospice nurse will assess to determine if there are signs of decline in condition of the patient.
- Remind the patient who you are and of any others present in room.
- Use a calm and reassuring tone when speaking to the patient.
- Reassure the patient that he/she is not alone and he/she will be cared for.
- Hold the patient's hand.
- Reassure the patient that you are doing well and are taking care of yourself.
- Other \_\_\_\_\_

## **Mental confusion, disorientation or “strange dreams” may occur.**

The patient may “talk to people” about places and things of which you have no knowledge and cannot see. It is not unusual for the dying person to see and talk with people who have already died.

These signs are frequently experienced by the dying person due to the progression of the disease process, disease-related low oxygen levels, expected side effects of comfort medications, etc.

### **What You Can Do:**

- Don't try to stop the patient if you see him/her picking at the sheets and the air. This is very common among the dying.
- Reassure the patient that he is not alone and will be cared for.
- Remind the patient who you are and who is present in the room.
- Try not to correct the patient's “confused talking” since this may cause an increase in anxiety and agitation. Instead, ask the patient to describe what he/she is seeing or hearing.
- Quietly listen if the patient talks about wanting to “go home.” They may not be talking about a physical address.
- Other \_\_\_\_\_

## **Anxiety, agitation and restlessness may occur or increase as the time of death draws near.**

There can be many causes for these symptoms, and they may be physical, emotional, and/or spiritual in nature. The patient may have told you that he/she is ready to die, but the “body” may resist what the “spirit” is willing to accept. As a result, it is not unusual for the dying person to get anxious or restless, for what appears to be “no reason.”

The patient may demonstrate periods of great strength or try to get out of bed, even if he/she has been very weak or bedbound for a period of time. The patient may have a sudden “surge” of energy and become more alert and talkative. He/she may even have an increase in appetite and eat more than he/she has eaten before.

### **What You Can Do:**

- Reassure the patient that you are there and he/she is not alone.
- Speak to the patient in a calm, reassuring voice.
- Play music that the patient found soothing and comforting when he/she was healthier and more alert.
- Protect the patient from falling out of bed by keeping side rails up (in home setting) or placing the bed against a wall.
- Changing the patient’s position in bed may help. He/she may be restless from lying in an uncomfortable position.
- Check for wet or soiled linens and provide personal care if needed.
- You may give the patient permission to die if you feel comfortable doing this. If you don’t feel comfortable saying those words, you can tell the patient that you understand if he/she “has to go” or that it’s okay to “do what you need to do.”
- If appropriate, you may want to tell the patient if other people are due to arrive to visit.
- Give medications ordered to decrease anxiety and/or restlessness.
- You may need to have a sitter stay with the patient, if safety concerns are identified, and you are unable to sit with the patient.
- Call the hospice nurse at 1-800-233-1708 if symptoms seem unmanageable and you become concerned or frightened.
- Other \_\_\_\_\_

**Vision and hearing may become somewhat impaired and speech may be difficult to understand.**

It is not unusual for bright lights or loud noises to bother a dying person. Hearing may become more sensitive. It is important to remember that even an unresponsive person has the ability to hear. The patient’s eyes may be open but not seeing. Eyes may be watery and tears may be present. A “fixed” stare is an expected occurrence.

**What You Can Do:**

- Speak clearly, but no more loudly than usual.
- Keep the room as light as the patient prefers, even at night.
- A small lamp or night light can be comforting.
- Remember bright lights or sunlight may cause discomfort.
- Carry on all conversations with the patient as you normally would.
- Discuss “sensitive” information away from the patient’s bedside, if you think it may be upsetting to him/her.
- Other \_\_\_\_\_

## **During the dying process, the blood flow to the skin is decreased and causes a number of changes.**

The lips, hands (especially nail beds), feet, and knee areas may become bluish in color. The pulse may be difficult to feel and the blood pressure may be difficult to hear. The pulse can also be pounding and rapid at times.

The body temperature may change between hot and cold. There can be increased perspiration or sweating, often with clamminess. The main focus is to ensure the patient is kept comfortable and dry.

### **What You Can Do:**

- If the patient is warm to touch, you may apply cool washcloths to the forehead and armpit area for comfort.
- Apply blankets (not electric) if the patient is cold.
- Remove covers if the patient is hot.
- If the patient's skin is moist and clammy, you may wipe his/her skin with cool washcloths, apply clean pajamas/gown, and change bed pads and linens as needed.
- Keep lips moistened with lubricating balm and clean mouth with toothettes. Do not use petroleum-based lip products if the patient is on oxygen, as petroleum is flammable.
- Other \_\_\_\_\_

## **Breathing may become irregular and there may be notable periods where the patient is not breathing.**

The dying person may seem to be working hard to breathe but are exhibiting normal changes. As the time of death draws nearer, breathing may become more shallow and irregular. The patient may experience periods of not breathing, which is known as “apnea.”

### **What You Can Do:**

- Raise the head of the bed if the patient is able to tolerate it without discomfort.
- A small electric fan placed at the head of the bed may help.
- Changing the patient’s position in bed may provide comfort.
- At this point, oxygen provides little or no benefit since all the body systems are slowing down. Oxygen is drying to the nasal passages and can be removed if it is not contributing to the comfort of the patient.
- Give the medication that has been ordered to decrease labored breathing and shortness of breath.
- Other \_\_\_\_\_

**As the patient becomes less responsive, they will often breathe with their mouth open. Secretions may collect in the back of the throat and cause a “rattling” or “gurgling” sound. Rarely will the patient be aware of this occurring, but often it is very stressful for the caregivers to hear these sounds.**

Secretions collect at the back of the throat and since the muscles are weak and relaxed, the patient will no longer be able to swallow them. The noises heard during breathing are caused by air moving past those secretions.

Suctioning the secretions will not benefit the patient, since most of the fluid is in the lungs and is too hard to reach by suctioning. Suctioning causes discomfort and triggers the production of more secretions.

### **What You Can Do:**

- Keep the patient off of his/her back. Turn him/her from side-to-side, while placing a washcloth on the pillow to absorb any secretions that may drain from the mouth.
- Keep lips moistened with lubricating balm and clean mouth with toothettes. Do not use petroleum-based lip products if the patient is on oxygen, as petroleum is flammable.
- Give the medication that has been ordered to decrease and dry up secretions.
- Call the hospice nurse at 1-800-233-1708 if the patient is becoming congested, if you are concerned, or the patient is distressed.
- Other \_\_\_\_\_

# What Not To Do

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- **Do NOT** leave the patient alone in the home if there has been an expressed safety risk due to his/her declining condition.
- **Do NOT** be afraid to touch the patient.
- **Do NOT** stop giving pain or comfort medications. If you are afraid of giving medications, for any reason, call the nurse and express your concerns.
- **Do NOT** try to force food or fluids. As the body shuts down, it does not require fluids or nourishment. Forcing food or fluids can cause choking or aspiration.
- **Do NOT** think IV fluids will automatically help the patient “feel better.” IV fluid appropriateness is evaluated by the Medical Director on a case-by-case basis. IV fluids given during the dying process can cause unwanted swelling and signs of fluid overload.
- **Do NOT** call 911. *Try not to panic. We are here to help you through these changes.* Call the hospice nurse at **1-800-233-1708** and assistance will be given to you.
- Other \_\_\_\_\_

***While in hospice care, these are some examples of when to call the hospice nurse: 1-800-233-1708***

- If the patient's breathing becomes labored or he/she looks distressed.
- If the patient becomes very anxious or restless.
- If the patient experiences an increase in pain, if current pain medications aren't effective, or if they aren't lasting long enough.
- If the patient suddenly becomes unresponsive or there is a change in alertness.
- If the patient is unable to take their medications the way they have been ordered.
- If the patient cannot urinate and is uncomfortable.
- If you have any questions or concerns.
- If you become anxious and nervous and just need to talk to someone.
- If the patient falls, whether he/she is injured or not.
- If you feel the need to call 911 or ambulance – DO call the hospice nurse instead, and assistance and instructions will be given to you. The patient's comfort is our concern.
- When the patient dies.
- Other \_\_\_\_\_

How will I know death has occurred?

- The patient's breathing stops (You may notice one or two long, spaced-out breaths as the lungs release air).
- The patient's color may be "ashen" or "gray" and his/her skin may be cool to touch.
- The patient's heartbeat stops.
- The patient cannot be awakened, no matter what you have tried.
- The patient's eyelids may be partially open with the eyes in a fixed stare (although this may have already been occurring as the patient's condition has declined).
- The patient will probably have lost control of his/her bowel and bladder.

## **What should I do when my loved one dies?**

- Notify the hospice nurse at 1-800-233-1708. You will reach the office during work hours, and an answering service after hours and on weekends. *Give them your name, the patient's name, the phone number where you are, and whether the patient is on the Orange Team or the Blue Team.*
- Tell the office/operator the patient has died. The hospice nurse will be notified and should return the call within 15 minutes.
- If the nurse does not call back within 15 minutes of the call, call **1-800-233-1708** again and explain that you have not heard back from the nurse. Another employee will be reached to help you.
- You also may tell the office/answering service if you need a social worker to come provide support in person or over the phone.
- A Hospice of Southern Illinois employee will notify you of an expected time of arrival.
- If you are home alone at the time of the patient's death, you may wish to call a neighbor, friend, or another person to be with you.
- Please be mindful of keeping the phone line open, as the nurse may be trying to return your call.

## **What will the hospice nurse do?**

- Upon arrival, the nurse will verify the patient's death. The official time of death will be the time the nurse confirms there are no signs of life.
- The nurse will then call the coroner, physician, and funeral home and will provide personal care to the patient as needed.
- The nurse is responsible for notifying the pharmacy, the equipment company, and any other entities that require notification of the patient's death.
- The nurse will inform you of the way to dispose of any unused medications.
- The nurse will assist you with any other calls as needed.

# Timeline for Signs of Approaching Death

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*It is important to remember that these are only possible timelines. Every person is unique. Not every person will experience all of these signs and there is no particular order in which these events occur.*

## **One to Three Months**

- May experience decreased interest in eating and drinking
- May withdraw from surroundings
- May sleep more
- May have less energy

## **One to Two Weeks**

### ***Mental Changes***

- May experience “strange dreams,” confusion, or disorientation
- May experience increased anxiety, restlessness, or agitation

### ***Physical Changes***

- May experience a decrease in blood pressure
- Heart rate may increase or decrease
- May experience impairment in vision, hearing, and speech
- May have increased sweating
- May experience body temperature changes
- May experience changes in breathing
- May take in very little food or liquids
- May feel very tired and weak

## **Days to Hours**

- All of above signs will intensify
- May have an unexpected “surge” of energy
- May pick at sheets or air
- May see or talk with deceased persons
- May lose bowel and bladder control
- May have decreased urine output, and/or dark urine color
- May have a weak pulse
- May have watery, half-open eyes with fixed stare
- May have shallow, irregular breathing with periods of no breathing
- May have rattling or gurgling sounds related to secretions in back of throat
- May have bluish color to lips, hands, feet, and knees

# Does Hospice Care End with My Love One's Death?

*No, it does not. We are here to support you. Please know that if you ever feel the need to talk with someone about your feelings, please call 1-800-233-1708.*

## **What to expect:**

- Within a week of the patient's death, you will receive information containing helpful resources and expected grief reactions.
- About a month following the patient's death, you will receive a call from a Bereavement Counselor. The counselor will offer to schedule a visit with you, to see how you are doing and to provide support.
- The Bereavement Counselor can also provide you with information about additional resources. If you do not feel a visit is necessary, the information can be mailed to you for review.
- For 13 months following the patient's death, you will receive mailings, phone calls, and/or visits to see how you are doing.
- These contacts are usually made at 1 week and 1 month, as well as on the patient's birthday and the anniversary of his/her death. These times can be particularly challenging after a death.

*You continue to be in our thoughts.*

*This booklet was compiled by the employees of*  
**Hospice of Southern Illinois.**

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*Your Community Not-For-Profit Hospice*

Our mission is to enhance the quality of life for individuals and their loved ones touched by a terminal illness.



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ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-233-1708

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## **Belleville Location**

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## **Marion Location**

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