



The End-Of-Life Journey

What Family & Caregivers Can Expect

1.800.233.1708 | www.hospice.org

Belleville Location 618-235-1703 • Marion Location 618-997-3030
Edwardsville Location Hospice Home 618-659-7900



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

*This booklet was compiled by the staff of
Hospice of Southern Illinois*

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Your Community Not-For-Profit Hospice*

To The Caregiver

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 as well as your loved one.

Eat Right – your loved one 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 your loved one. Have other family members or friends take a night or two with the patient. Sleep when the patient sleeps. But 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 time too!

Signs of Declining Condition

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 your loved one does not have. The refusal of food may be an indication that the patient is ready to die.

What You Can Do:

- Offer but do not force food or fluids.
- Sips of fluids, ice chips, or popsicles may be helpful.
- Do not give food or fluid to an unresponsive patient.
- Moisten lips with a lubricant, such as petroleum jelly, and clean mouth with toothettes.
- Other _____

Urinary output may decrease in amount and frequency.

Urine may be very dark in color.

What You Can Do:

- Nothing, unless the patient expresses a need to urinate and cannot or the patient becomes restless and cannot communicate with you - notify the hospice nurse at **1-800-233-1708** if this occurs.
- Other _____

Loss of bowel and bladder control may occur.

What You Can Do:

- Keep patient clean and dry, change pads and linens as needed.
- Protect the mattress with a waterproof mattress pad.
- Other _____

There may be a reduced level of alertness.

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

What You Can Do:

- Call the patient by name and remind him where he is.
- Remind patient who you are and of any others present in room.
- Use calm and reassuring tone.
- Reassure the patient that he is not alone and he will be cared for.
- Hold the patient's hand.
- Reassure patient that you are doing well.
- Other _____

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

Your loved one may “talk to people” and about places and things of which you have no knowledge. It is not unusual for the dying person to see and talk with loved ones who have already died. Picking at the sheets and air are not uncommon. These signs are frequently experienced by the dying person. They are normally not frightening to either the patient or loved one.

What You Can Do:

- Call the patient by name and remind him where he is.
- Reassure him that he is not alone and will be cared for.
- Remind him who you are and who is present in the room.
- It may be best to go along with the patient’s confused talking and not to disagree with him since this may cause an increase in anxiety and agitation.
- Other _____

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

There can be many causes for these symptoms, both physical and emotional. Your loved one may have told you that he is ready to die, but yet, the “body” may resist what the “spirit” is willing to accept. Again, a reminder to you, it is not unusual for the dying person to appear to hallucinate, to pick at the sheets or air or even to try to get out of bed. Your loved one may have a sudden “surge” of energy and become more alert and talkative. He may even have an increase in appetite and eat more than he has in a long time.

What You Can Do:

- Reassure him that he is not alone.
- Reassure him in a calm voice that you are there.
- Soft music may be soothing and calming.
- Protect him from falling out of bed by keeping side rails up or placing the bed against a wall.
- Changing positions may help.
- Check for wet or soiled linens.
- You may give him permission to die if you feel comfortable doing this.
- If appropriate, you may let the patient know if loved ones are on their way.
- Give medications as ordered for symptoms.
- 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 to bother the dying person. Hearing may become more sensitive. It is important to remember that even an unresponsive person has the ability to hear. The eyes may be open but not seeing. The eyes may be watery and tears may be present.

What You Can Do:

- Speak clearly, but no more loudly than usual.
- Keep the room as light as the patient wishes, even at night.
- A small lamp or night light can be comforting.
- Remember bright lights or sunlight may be uncomfortable.
- Carry on all conversations with the patient as you normally would.
- Discuss “sensitive” information away from the patient’s bedside.
- Other _____

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

The lips, hands, feet, and knee areas may become bluish in color. The skin next to the bed may darken. The pulse may be difficult to feel and the blood pressure may be difficult to hear. The body temperature may change between hot and cold. There can be increased perspiration or sweating, often with clamminess. The mechanism in the brain that regulates body temperature may no longer be working.

What You Can Do:

- Sponge the patient with a cool washcloth if this promotes comfort.
- Provide covers (not electric) if the patient is cold.
- Remove covers if the patient is hot.
- Keep the patient dry, change pads and linens as needed.
- Moisten lips with a lubricant, such as petroleum jelly and clean mouth with toothettes.
- Other _____

Breathing may become irregular with periods of no breathing.

The dying person may seem to be working hard to breathe. As the time of death draws nearer, breathing may become more difficult to see and more mechanical in nature. “Moaning” may be heard, but usually does not mean pain. It is the sound of air passing over relaxed vocal cords.

What You Can Do:

- Raise the head of the bed if patient wishes.
- A small electric fan placed at the head of the bed may help.
- Changing positions may provide comfort.
- At this point, oxygen is of little or no help since all the body systems are slowing down.
- Other _____

Secretions may collect in the back of the throat and rattle or gurgle as your loved one breathes through the mouth.

This does not appear to be uncomfortable to the patient. It is usually more distressful for the caregivers. Saliva collects at the back of the throat and since the muscles are weak and relaxed, the patient is no longer able to swallow.

What You Can Do:

- Turning the patient on his side may help as secretions may drain from the mouth.
- Moisten lips with a lubricant, such as petroleum jelly and clean mouth with toothettes.
- Call the hospice nurse at **1-800-233-1708** if secretions become excessive or if you or the patient is distressed by it.
- Other _____

What Not To Do

- Do NOT leave your loved one alone.
- Do NOT be afraid to touch your loved one.
- Do NOT stop giving pain medication.
- Do NOT try to force food or fluids. As the body shuts down, it does not require nourishment. Forcing fluids or starting IV's can cause increased discomfort.
- Do NOT call 911. (Call the hospice nurse at **1-800-233-1708** and assistance will be given to you.)
- Other _____

When to call the hospice nurse: 1-800-233-1708

- If breathing becomes difficult.
- If the patient becomes very anxious or restless.
- If the patient experiences an increase in pain.
- If the patient suddenly becomes unresponsive or there is a change in alertness.
- If the patient is unable to take medications.
- 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 you feel the need to call 911 or ambulance – **DO NOT.**
(Call the hospice nurse instead and assistance and instructions will be given to you. Your loved one's comfort is our concern.)
- When the patient dies.
- Other _____

How will I know death has occurred?

- Breathing stops. (There may be one or two long spaced breaths as the lungs release the last air.)
- Heartbeat stops.
- The patient cannot be awakened.
- The eyelids may be partially open with the eyes in a fixed stare.
- The mouth may fall open slightly, as the jaw relaxes.
- The patient may lose control of bowel and bladder.

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 arrives at the home.
- The nurse will then call the coroner, physician, and funeral home and will bathe your loved one as needed.
- The nurse will dispose of any unused medications and will need you or another person present to witness the disposal of the medications.
- The nurse will assist you with any other calls as needed.

What should I do when my loved one dies?

- Notify the hospice nurse at **1-800-233-1708**. You will get the office during work hours and an answering service after hours. Give them your name, the patient's name, the phone number where you are and the team color. Tell the operator the patient has died. The hospice nurse will be paged and should return your call within 15 minutes.
- If the nurse does not call back soon, call **1-800-233-1708** again and explain that you have not heard from the nurse. A nurse will be reached to help you. The nurse will give you an approximate time of arrival.
- If you are alone you may wish to call a neighbor, friend, or family member to be with you.
- Remember not to tie up the phone line as the nurse may be trying to return your call.

Timeline for Signs of Approaching Death

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 little food or liquids
- May feel very tired and weak

Days or Hours

- All of above signs will intensify
- May have “surge” of energy
- May pick at sheets or air
- May see or talk with deceased loved ones
- May lose bowel and bladder control
- May have decreased urine output, and/or dark urine color
- Weak pulse
- Eyes watery; half open
- Slow, irregular breathing with periods of no breathing
- Rattling or gurgling of secretions in back of throat
- Lips, hands, feet, and knees may be bluish in color

Does Hospice Care End With My Love One's Death?

NO

- Within a week you will receive a card and information on normal grief reactions.
- About a month following your loved one's death, you will receive a call from a Bereavement Coordinator. A time to visit with you will be scheduled, if you would like.
- The Bereavement Coordinator will provide you with additional information at the visit. If you do not feel a visit is needed, the information will be mailed to you.
- For 12 months following your loved one's death, you will receive mailings and/or phone calls to inquire as to how you are doing. These contacts are usually made at 1 week, 1 month, 3 months, 6 months, and 1 year.
- If you ever feel the need to talk with someone about your feelings, please call **1-800-233-1708** and someone will be reached to talk with you.

Please know that you continue to be in our thoughts and prayers.

Other Resources for Caregivers on the Web Are:

www.aarp.org/health

AARP – American Association of Retired Persons

www.nfcares.org

National Family Caregivers Association

www.caregiving.org

National Alliance for Caregiving

www.stoppain.org

Beth Israel Medical Center



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305 South Illinois Street
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Marion Location

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