

# The Journey to Light



*A resource for patients and families*

Saint Luke's Health System Hospice  
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# INTRODUCTION

*For everything there is a season and a time  
for every matter under Heaven; a time to be  
born and a time to die.*

## ***Ecclesiastes 3:1***



We know that death and life are one; that dying, as living, is a stage of life. Death will come to each one of us, in its own time, in its own way.

These pages are written to help you understand and face one of your most difficult life experiences...that of experiencing the dying process of someone you love. The presence and care you provide to your loved one can aid both of you physically and emotionally.

As you accompany your loved one through one of the most frightful but healing journeys of life, it is important that you respond to the signs and symptoms of approaching death with warmth, gentleness, caring and love. This allows the flame of your loved one's life to dim, flicker and finally extinguish with peace and dignity.

## **PAIN**

Physical pain is experienced by some patients. The appropriate nursing and medical goal is to control the pain while keeping your loved one as alert as possible.

Although pain cannot always be controlled completely, it can be kept at a minimal level. Only the patient knows the severity or extent of the pain. Therefore, it is important for your loved one to be honest about the pain. Many people report less pain than they are really having for fear of addiction, or they think that they must save the strong medicines for when the pain becomes unbearable. Some patients may even feel that pain is a part of their spiritual journey. Feelings regarding pain control need to be openly discussed with your loved one and health care providers in order to achieve optimum pain control and maximum comfort.

As death nears, pain usually decreases and your loved one may become very sleepy or lose consciousness. With the relaxation of the tear ducts, they may have tearing, usually one eye at a time.

Feel free to do anything your loved one requests that will increase comfort or decrease pain. Some comfort measures other than medication include back rubs, hand or foot massage, turning, repositioning and mouth care. Do not be afraid to touch or hold your loved one. If you have concerns please talk with the hospice staff.

## **NUTRITION**

One of the most difficult changes for you, as a family, is your loved one's loss of appetite and decreased desire to eat. Loss of appetite is a natural body process that helps the body save its energy for other uses. Food and fluids are essential when the focus is on living but are not essential for a comfortable death. We eat to sustain life, it is a natural process as the body prepares to die, that eating is slowly discontinued. Digestion slows naturally, as do other body processes. The body also conserves fluids which decreases the need for fluid intake. This extra fluid may be seen as swelling in the hands, abdomen and feet. The only uncomfortable symptoms of dehydration are a dry mouth or a sense of thirst – both of which can be alleviated with good mouth care and ice chips or sips of water. Keeping the mouth and lips moist and clean will increase comfort and decrease or relieve thirst. However, if your loved one desires food or drink, every effort should be made to provide nutritional intake by offering small frequent meals, fluids, or ice chips.

## **ELIMINATION**

Along with a decrease in food and fluids, there is a normal decrease in urine output. The urine will gradually appear darker in color and less volume. As the muscles of the body relax there may be a loss of control of bladder and bowels. This is natural and should be attended to promptly; do not hesitate to ask for assistance in this matter.

## **BREATHING PATTERNS**

Breathing may become irregular as death nears. The rate of respirations may increase resulting in a reddened face. Respirations, however, usually decrease to a very slow rate and the color of the face and skin may become ashen or bluish-gray. There can be puffing, a blowing of the lips on exhaling, or actual stopping of the rhythmic breathing only to resume again. There is a decrease in the swallowing reflex, which results in an increase in saliva in the throat. Congestion accompanied by a rattling sound may occur in the lungs and throat. There may also be medications that can help relieve or control the congestion. These breathing problems can sometimes be relieved by position changes or raising the head.

This is a part of the normal dying process, but our feelings may be of alarm and anxiety because it does not seem natural to us; remember, your loved one is on their final journey. You may wish to hold their hand and speak to them gently.

## **SKIN AND TEMPERATURE CHANGE**

Skin color may change to an ashen or bluish-grey color due to decreased circulation. You may notice it first in the nail beds, kneecaps and feet. Sometimes the skin may turn a pale yellow or have a waxy appearance. The skin may feel cool, or may be hot and feverish. There may be increased perspiration, often with clamminess. As death nears, the hands and feet may become bluish-purple and the trunk, arms, and legs may appear blotchy. Your loved one may feel more comfortable with just a light blanket as cover.

## **REST, SLEEP, AND MENTAL STATUS CHANGES**

The dying experience may result in a change in your loved one's sleep pattern. Some people have difficulty sleeping at night because they fear they may not awaken in the morning. Napping throughout the day is common and may result in a loss of the sense of time. Also, lack of proper rest may result in intermittent confusion. Your loved one may talk about past people or events, or talk to people who have already died. This may include visions of people or places, and is often a way of moving smoothly into their new life. Your loved one may not recognize close friends or family. He or she may display increased restlessness, confusion or agitation, and may pick at the bedding. As part of the dying process, your loved one may have very vivid dreams, which they perceive as real. Allow them to share these dreams without attempting to bring he/she back to reality, this may cause increased restlessness or frustration. Listen to the concerns and wishes of your loved one. Identify yourself by name before you speak rather than asking them to guess who you are. Speak softly, clearly and truthfully when you need to communicate something. Do not talk about your loved one in his/her presence. Speak to your loved one directly as you normally would, even though there may be no response. Your presence will be comforting.

*What we have once enjoyed, we can never lose. All that we love deeply becomes a part of us.*

Helen Keller

## **THE DYING PERSON'S BILL OF RIGHTS**

**I have the right** to be treated as a living human being until I die.

**I have the right** to maintain a sense of hopefulness however changing its focus may be.

**I have the right** to be cared for by those who can maintain a sense of hopefulness, however changing this might be.

**I have the right** to express my feelings and emotions about my approaching death in my own way.

**I have the right** to participate in decisions concerning my care.

**I have the right** to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

**I have the right** not to die alone.

**I have the right** to be free from pain.

**I have the right** to have my questions answered honestly.

**I have the right** not to be deceived.

**I have the right** to receive help from and for my family in accepting my death.

**I have the right** to die in peace and dignity.

**I have the right** to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.

**I have the right** to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.

**I have the right** to expect that the sanctity of the human body will be respected after death.

# TIPS FOR TALKING TO CHILDREN ABOUT DEATH AND DYING

1. Create an environment that allows the child to openly express their thoughts and feelings, letting them know that feelings never are judged to be right or wrong.
2. Allow the child to express grief in whatever manner is comfortable for the child. Accept anger, selfishness, denial, and guilt. Offer comfort and encouragement. Don't hide your grief from your child. Be open and honest.
3. Answer all "why" questions ... the child will supply a cause even if you do not. Avoid the use of images of death such as "a deep sleep" or "a very long trip" lest the child become afraid of these things.
4. Reassure them directly, as well as indirectly, through use of soothing tones and touching, that they will not be left alone or abandoned.
5. Do not tell children that God wants good people.
6. When discussing heaven, remember that this is an abstraction that children may not understand or may internalize very differently.
7. Allow the child and encourage them to share memories about their loved one. You can ask them questions like: What was the best time you ever spent together? What did you learn from him/her? What was your favorite thing about him/her? How are you like him/her?
8. You can expect to see behavior changes such as trouble sleeping, loss of appetite, or struggling in school. Sometimes he/she may not seem to have even noticed. They will often deal with their grief in 'small doses.'
9. Children will deal with grief through various ways, such as playing sports, drawing, writing or listening to music.
10. Accept whatever feelings they express and continue to support and reassure them.
11. Children and adults need a lot of listeners. They need to tell and re-tell their story.
12. Review with them what to expect at the funeral and burial.

# Family/Caregiver Guide

## 1 – 3 MONTHS PRIOR TO ANTICIPATED DEATH

<b>Patient Symptoms</b>	<b>Comfort Suggestions</b>
Withdrawal/ Life processing	Touch and quiet physical presence. Talk about shared times and important events. Discuss advance directives, do not resuscitate, religious rites and funeral planning.
Increased sleep and reminiscing	Tell your loved one how they have affected and enriched your life. Laughter and tears are important.
Decreased food intake	Liquid and soft foods. A decreased appetite is expected and normal.
Decreased taste	Provide frequent small meals or snacks and/or mouth care before eating. Use syringe, or eye dropper for fluids. Serve lukewarm or cold, not hot. Use mouth moisture sprays or mouth swabs to keep the mouth moist. Lipcare sticks, or Vaseline to the lips, or a water based lubricant (ex. KY Jelly) if your loved one is using oxygen.

## 1 TO 2 WEEKS PRIOR TO ANTICIPATED DEATH

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### Patient Symptoms

### Comfort Suggestions

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Loss of sense of time	Orient your loved one if he/she will accept the information.
Reverse days and nights Increase in confusion, Restlessness, agitation and dreams.	Your loved one should have someone in the house with them 24 hours a day. You should also rest during the day, if possible. Use a calm and reassuring voice. Talk to the hospice team about any further suggestions.
Increased pain	Give pain medications if needed on schedule. Consult the nurse or doctor.
May not recognize family and friends	Talk to your loved one in a soothing voice, tell them who you are.
Temperature (increased or decreased), increased perspiration, skin color changes	Give a warm water sponge bath.
Skin itching	Corn starch added to bath water, lotion, or prescription anti-itch medications are available.
Breathing increases or decreases.	Oxygen may be prescribed by doctor. Elevate head of bed.
Congestion in lungs	Elevate upper body and head to 30 degree angle. Medications are also available to manage the increased secretions.
Edema	Position changes every 2-4 hours. Gentle massage.

## 1 TO 2 DAYS TO HOURS BEFORE ANTICIPATED DEATH

<b>Patient Symptoms</b>	<b>Comfort Suggestions</b>
Short surge of energy	Help your loved one accomplish whatever they want to do, if possible.
Difficulty swallowing	Switch to suppository, gels or under the tongue routes of medication. Offer frequent mouth care.
Loud rattling breathing	Try position changes, head elevation. Medication recommended by doctor and hospice nurse.
Circulation fails/ drenching sweat	Light bed coverings and gentle bathing.
Loss of ability to move	Reposition to provide optimum comfort. Reposition with pillows on side and over bony joints, raise head of bed. An air mattress can be ordered for the bed.
Loss of sensation and loss of vision	Gentle, firm touch. Soft lighting at all times. Talk to your loved one with your face close to theirs.
Decreased hearing	Talk in normal voice tones. Tell your loved one what you are going to do to them to prevent startling.
Urine and stool incontinence	Use adults diapers or Chux, catheter if necessary. Protect skin under diaper using protective skin creams (i.e. zinc oxide, Vaseline.)



## ***GARDENING IN THE SOUL***

*I want to plant a garden  
wherever I go --  
to sow the seeds of grace and care  
to bloom in arid soil of  
gloom and despair.*

*To plant the tender shoots  
of a listening heart and ear –  
to bring a smile, or a tear  
fragrant petals of hope  
and trust and good cheer.*

*I will plant  
the silent presence that  
goes beyond words;  
the breath of love  
that blooms and blooms and blooms.*

*Let us all our seeds  
and gifts do take  
to sow them in the wind  
for God to spread and plant.*

*For in the Garden  
we surely were meant to dwell  
amidst the flowers  
of those we knew and  
loved so well.*

**JUDE HIGHBERGER**

## **WITHDRAWAL/DIGNITY/SPIRITUALITY**

As death draws near and your loved one acknowledges the reality of his/her impending death he/she may begin to turn away from the outside world and withdraw into themselves. This means separating oneself from the environment and relationships, including those of loved ones. This withdrawal or separation does not mean you are being rejected or no longer loved, but is an acknowledgement of the finality of one's life here on earth. This withdrawal allows time for internal processing or review of one's life. Communication with loved ones is lessened and sleep increases. Words begin to lose importance. Now is the time when simply touching, wiping a brow, holding a hand, and your silent presence is comforting and felt by your loved one.

The process of dying often results in a person reflecting upon their relationship to things larger than self: faith in God, causes, principles, art, history, higher forces, values, or the supernatural. Facing the loss of self, family and known reality results in your loved one struggling to find meaning and hope. You may ask yourself, "What really matters for my loved one who will soon no longer be among the living?" Health care providers, chaplains and you as family can remain present to discover your loved one's story and struggles. Having your loved one to tell their life story is a wonderful healing experience. A sense of reconciliation, forgiveness, and peace then follows. This compassionate presence converts the dying experience into a triumph of love and human community. Remembering to share laughter as well as tears is an important part of this process.



## **GIVING PERMISSION TO DIE**

Giving your loved one permission to die, your final gift of love, takes courage and may be painful and exhausting. You have been privileged to have shared in your loved one's life. Sometimes, in the midst of your greatest suffering lies some joy; the most wonderful gift one person can give to another is that of accompanying their loved one to the end of their journey.

The terminally ill usually know when they are dying. Try to provide an environment where you can discuss issues surrounding death. Your loved one may cling to life because they fear death, they fear the family won't be able to go on without them, or they have unfinished business. Allow your loved one to discuss these concerns in a way that is comfortable and meaningful.

Family members find it difficult to allow their loved ones to die. Discuss the dying process with your chaplain or health care providers. This will assist you and your loved one to alleviate some of the fears associated with the dying process, complete unfinished business and communicate to your loved one that they have your permission to die.

Saying good-bye is difficult, but it will help you and your loved one reach some closure in your relationship; it will also allow your loved one to let go of this life. It may be helpful to lie beside your loved one and hold him/her, or to hold their hand and say everything you need to say.

It may be as simple as "I love You," or "I thank you for...". Tears are a normal and natural part of saying "good-bye." Tears do not need to be apologized for or hidden from your loved one. Tears express your love and help you let go.

Instead of feeling there is no future for you or your loved one, make the most of the time you have left. Do not focus solely on death and dying, but also on life and living.

## JUST FOR YOU..... THE CAREGIVER

**To be able to take care of another, you must first take care of yourself.**

### **Tips on taking care of yourself...**

- Love yourself at least as well as you love the one you are caring for.
- Get enough rest, perhaps naps during the day. Conserve your energy.
- Exercise. Even a short walk helps and will give you energy.
- Eat well. Choose a variety of foods. Drink plenty of water.
- Reduce stress. Think about what has helped in the past.
- Take breaks. Relax and think of other things.
- Pay attention to what your body is telling you. Is it tired, stressed, tense?
- Nurture your spiritual side. Pursue those things that are uplifting to you.
- Pamper yourself. This is not an act of selfishness, but will ultimately help you provide even better care.
- Allow others to help you. It will not only help you, it is good for them. It is important to recognize the limits of your own strength and endurance.
- Set limits. It is OK to say 'NO'



### **Tips on helping loved ones...**

- Allow them to talk. Listen without judgment and with only occasional comments.
- Acknowledge and validate their feelings and let them express their feelings in many ways.
- Avoid taking negative feelings personally.
- Let them have control over their situation as much as possible.
- Include them in decision making and discussions.
- Let them do as much as they want to and have the energy for, no matter how slow, painful or difficult it seems to you.
- Don't underestimate their pains, symptoms and fear. They are real and valid.
- Avoid judging.
- Talk about subjects you used to discuss together, the times you shared. Laugh.

*Experience gleaned from years of work with patients and families has shown us that often the best patient care provided is that given by family and friends. Regardless of how capable and efficient a professional's care may be, the presence and touch of a person who has a close relationship with the patient will provide the greatest gift.*

The hospice staff and chaplains are available to you for support at any time.

Remember ~ **Grief is not an illness**, it is what happens to us when our loved ones die. No two people grieve alike.

Bereavement support groups are available through Saint Luke's Hospice. For information regarding this group and when they meet please call Saint Luke's Nurseline at (816)932-6220.

## HOW WILL YOU KNOW WHEN DEATH OCCURS

Even though you may be prepared for the dying process, you may not be prepared for the actual moment of death. This is very normal. It might be of assistance to have a family discussion on what to do at the time of death.

Signs of death include no breathing, no heartbeat and no response.

After death has occurred, the body does not have to be moved until you are ready. You may touch the body or assist the nurse in bathing and dressing your loved one, if so desired.

Your loving presence has assisted the nursing staff in giving your loved one comfort and care, enabling him/her to leave this world with a special sense of peace and love. It has been our privilege to assist you in this time.

## WHAT TO DO WHEN DEATH OCCURS AT HOME

1. **Call the hospice office** if your hospice nurse is not already present. They will come and will call the doctor, funeral home and anyone else you would like to have notified.
2. Your loved one does not have to be transported to the hospital to be pronounced dead. **Do Not call 911 or the police.**
3. You may want to call your minister to come to the home at the time of death if this will comfort you and your family.
4. Hospice staff will notify the funeral home of the death. Funeral directors usually make an appointment with you for a later time that day or the next day to discuss funeral arrangements. A recent picture of your loved one is helpful to the funeral director when preparing the body. If your loved one wears dentures, send them with the body. The funeral home will contact the doctor to have the death certificate signed.
5. You may assist the nurse in bathing and dressing your loved one, if so desired.

## To Do's

### **Funeral Preparations**

1. Choose a funeral home.
2. Know your loved one's wishes for a burial plan.
3. Locate any pre-arranged funeral plan.
4. Locate a Marriage License.
5. Locate Birth Certificates.
6. Locate Social Security Cards.
7. Driver's License/Photo ID
8. Locate disability papers.
9. Locate Driver's License or Picture ID
10. Most families need extra copies of the death certificate for insurance, pension, veteran's benefits, etc. when settling the person's estate. Arrange with your funeral director to order 10 – 15 extra copies from the state when he sends in the original certificates.

### **Legal Matters**

1. Locate Tax Returns.
2. Locate W2 for the previous 2 years.
3. Locate Bank Statements.
4. Locate Wills/Trusts.
5. Locate the Deed to your home.
6. List Credit Cards and charge accounts that need to be canceled.
7. Locate automobile titles.
8. Make arrangements for disposition of personal property not specified in the will.
9. List and location of insurance policies and numbers.

## **Veteran's Benefits**

1. If your loved one served in the military, be sure to ask for a Military headstone. It should be furnished and free of charge.
2. Locate Discharge papers from the Armed Services. If you cannot find a copy, contact National Personnel Records Center, 9700 Page Boulevard, St. Louis, MO 63132-5200 (Send it to the attention of the branch in which the deceased served). You can also go online to [www.va.gov](http://www.va.gov) and search "Records." BE PREPARED that it could take up to 6 months for a reply.
3. The government has set up State Cemeteries that are free for Veterans. There is one located in Lexington, MO and one in Fort Leavenworth and Fort Scott, KS.
4. There is also a VA Burial Allowance. Most veterans are also eligible for a burial flag.

\*This is not a complete list of benefits. Please contact the VA for further benefits/services and with any questions.

***Veteran's Administration Toll-Free Phone Number 1-800-827-1000***

**“The span between life and death can be as quick and sudden as a puff of wind that blows out a candle. But the candle does not suffer after the darkness comes. It is the person left in the dark room who gropes and stumbles.”**

**~Helen Duke Fike~**

*We dedicate this book to our patients and families with heartfelt thanks for all you have shared with us. It has been an honor and privilege to have been able to serve your family.*

*The Staff and Volunteers of Saint Luke's Health System Hospice*

## *There She Comes*

*I am standing on the sea shore*

*A ship spreads her white sails to the  
morning breeze and starts for the ocean.*

*She is an object of beauty and I stand watching her.*

*Till at last she fades on the horizon  
and someone says: "She is Gone."*

*Gone Where? Gone from my sight, that is all.*

*The loss of sight is in me, not in her;*

*And just at the moment when someone says, "She is gone."*

*There are other voices who are watching her coming.*

*Other voices take up the glad shout; "There she comes!"*

*And that is dying.*

Harry Scott Holland