



TRAVELING THE JOURNEY





serenity prayer

*God, Grant me the serenity
to accept the things I cannot change,
the courage to change the things I can,
and the wisdom to know the difference.*





INTRODUCTION

Hospice of the Sacred Heart is proud to offer this practical pamphlet for the caregivers and family members caring for a seriously or terminally ill loved one. Sometimes fear of the unknown can be terrifying. But just a little knowledge of what to expect during the final days will help to make the last part of the journey a little easier.

By this time you are well acquainted with your hospice team, and certainly you may have already experienced many ups and downs throughout your family member's illness. Your doctors have kept you informed and guided you along, yet still preparing for the final days is never easy. You may be asking questions like: "What should I expect, and when?" "Will there be pain?" "How will I know the time is near?" All are normal and frequently asked, and it's our hope that this pamphlet will help to ease the pain of uncertainty and help prepare for the last portion of the journey.

As with all experiences in life, sometimes it's not *what* we go through, but *how* we go through it. Our heartfelt hope is to normalize the dying process as best as we can for you and your family, while still maintaining the sense of comfort, hope and sacredness. Your hospice team will strive to walk the journey with you, offering our commitment, expertise, experience and compassion at every step along the way. It is our mission to help you prepare as best as possible for the sacred mystery of death.





COPING WITH THE FINAL HOURS, DAYS AND WEEKS OF A TERMINAL ILLNESS

As a patient enters the final stages of an advanced illness, the goals of care change from aggressive active treatment to comprehensive pain and symptom management. In addition to the physical aspects of the dying process, we give special attention to the emotional, spiritual and social aspects of the illness and its effect on the patient, family and caregivers. Remember that all illnesses progress differently, so we learn to expect the unexpected. Also, each family member deals with death differently, so allow everyone to absorb the new reality in small portions, and over time.

However, there are a variety of symptoms that we can anticipate, and becoming familiar with these symptoms will help us to better prepare for the final hours, days and weeks. As an illness advances, the body begins to slow down and this “shutting down” process is associated with predictable signs and symptoms. Let’s spend some time reviewing a few important symptoms and how to recognize and treat them.





There is a sacredness in tears.

*They are not the mark
of weakness, but of power.*

*They speak more eloquently
than ten thousand tongues.*

*They are messengers
of overwhelming grief ...
and unspeakable love.*

— WASHINGTON IRVING





*"When you are sorrowful
look again in your heart,
and you shall see that
in truth you are weeping
for that which has been
your delight."*

— KAHLIL GIBRAN

LOSS OF ENERGY

Advanced illness often is associated with profound fatigue and can interfere with the body's ability to produce energy. Fatigue and loss of energy are often associated with the dying process to a much greater extent than a healthy person. Patients begin to tire easily, sleep more and move around less. But remember all of this is a new normal for the patient with an advanced illness. As the liver and kidneys "shut down," the patient accumulates toxic substances in the blood, all of which contribute to increasing fatigue and progression of disease.

COMFORT GOALS OF CARE

- Try not to make an accusation that patient is "giving up". Remember that the patient has no control over this process.
- Allow the patient to "set the pace". Time activities as bathing, eating and visiting between rest periods.
- Place everything in room within easy reach of patient, including commode, bedside stand, radio, etc.
- Allow patient to eat as slowly as he chooses; always in small portions. Remember that eating can cause significant fatigue.
- Often, as the disease progresses, medications will be discontinued as they may become more of a burden than a benefit.





Body

BREATHING

As many illnesses advance, breathing can be affected and cause much distress both for patients and their caregivers. Many illnesses including congestive heart failure, cancer, emphysema and even dementia can be associated with breathlessness. Not being able to breathe is an urgent symptom, but can always be treated with prompt use of appropriate medication, again as guided by your hospice team. Breathing may become rapid and labored, and the patient may become restless and agitated as less oxygen gets to the brain. Remember you can depend on your hospice team to provide prompt medical intervention and we will prepare for this event if it were to occur.



*"The entire cosmos
is in our body. Life and
death are merely
the coming and going
of the real human body."*

— MASTER TAISEN
DESHIMAKU

COMFORT GOALS OF CARE

- Moving air is helpful; open a window or turn on a fan.
- Oxygen is often used for comfort. Remember though, it does not prolong life.
- Keep head of bed up as patient tolerates; use pillows to reposition.
- Remember fluids can make breathing worse; decrease fluids.
- Avoid oral suctioning.
- Medication can be used to improve breathing such as Morphine, Dilaudid, Ativan and/or Haldol.
- Scopolamine, Robinul or Atropine drops help to decrease secretions. Your hospice team will guide you carefully through all the treatment options.





FOOD AND FLUIDS

As an illness progresses, the desire for food and fluids decreases along with a lessened appetite. Swallowing becomes difficult, especially with dementia and Alzheimer's disease. As the bowel begins to "shut down," patients may experience nausea, vomiting and/or pain. Some disorders such as colon cancer can cause bowel obstruction, and often times strong pain medications may contribute to constipation. Weight loss is quite common and often signals the end stage of the illness. Remember that all the above items are part of the *normal* dying process, but can be easily treated by our experienced and compassionate team. It helps to realize that patients don't intentionally stop eating ... it's just the body's way of slowing down at the end of an advanced illness. Try to trust the body's natural process of knowing when to stop eating and drinking.

As patients drink less, dehydration begins to occur. Although this may be difficult to accept, this is a natural process and not associated with pain. Less urine may actually be a benefit with less need to get out of bed and less risk of skin breakdown. Also less fluids mean less fluid accumulation in the lungs, and breathing will be easier. Remember that IV fluids *do not* extend life and tube feeding can cause aspiration pneumonia, vomiting and nausea. Sometimes these procedures prolong the dying process, and impact negatively on the quality of life.

COMFORT GOALS OF CARE

- Offer fluids to sip as tolerated, especially ice chips, popsicles. Let the patient be your guide.
- For dry lips and mouth, offer mouth care frequently with oral swabs or sponges.
- Clean mouth and teeth with a toothette or soft toothbrush. Avoid alcohol mouthwash. Watch for red areas or white patches in mouth or on tongue. Use Vaseline or A&D ointment on lips.
- Offer food in small portions, such as milkshakes, soups, pudding, juices or cut-up fruit (if not choking).
- Remember that thickened foods cause less choking, so offer sherbet, pudding or applesauce as opposed to water or juices (especially in patients with dementia).
- Many medications exist to treat vomiting, nausea, diarrhea and constipation, all guided by your hospice team.





BODY WASTES

Often times as the body begins the process of “shutting down” the bowels and kidneys work more slowly or sometimes stop working altogether. This of course is another sign of the dying process, and is expected — so do not be alarmed. Pain, constipation, diarrhea or nausea may occur, but can be treated promptly and effectively. We at Hospice of the Sacred Heart will do all possible to prevent discomfort well before it occurs.

Urine output may decrease, and actually is helpful in that less energy is used getting out of bed and there is less chance of skin breakdown. Urine becomes darker and often a catheter is suggested for patient comfort and safety. Bowel movements come less frequently or sometimes the patient may lose control of urine and stool. Again we will guide you through these sometimes difficult times and be there for you and your loved one.



*“We cannot
prolong our lives,
but we should not
hasten our deaths.”*

— LIEH-TZU

COMFORT GOALS OF CARE

- Place urinary catheter into bladder to drain urine safely, comfortably and cleanly.
- Use of incontinence pads or protective hospice cream.
- Keep groin, back, buttocks clean and dry.
- Moisturizers, massage and music may all be helpful.
- Stool softeners and laxatives are continued since constipation can occur, especially with use of strong pain medications.
- Reposition often to relieve pressure.





PAIN

As patients enter the last stages of a serious or advanced illness, they often worry about uncontrolled pain and symptoms. This can be a stressor for caregivers and family as well. Although many illnesses including cancer, dementia, congestive heart failure and others are associated with pain, we at Hospice of the Sacred Heart make optimal pain and symptom management our #1 priority. We have many years of experience and expertise in using the right medicine, for the right pain, at the right time. Our goal is to provide comfort and care throughout all legs of the journey. Our board-certified hospice physicians are well-versed in pain management and will work closely with all involved in the patients' care. And remember, there is never a need to worry about addiction in patients with advanced disease as addiction is truly a social problem, *not* one of patients who require medications for adequate pain management.

Often patients treated for pain will become sedate, although this improves after a few days. Our hospice motto is to “start with a low dose and increase the dose slowly” — always keeping the comfort of the patient in mind. We also remind you that even unconscious patients may experience pain, so we always treat for pain as may be evidenced by grimacing, moaning or agitated behavior.

COMFORT GOALS OF CARE

- Stay ahead of pain by using medications on a regular basis.
- Medications such as Morphine, Dilaudid, Duragesic, Percocet or Vicodin are frequently used — but remember we have years of experience in using these drugs, and always proceed safely, keeping patients' comfort optimal.
- Medicine for constipation is used in conjunction with strong pain meds.
- If your loved one appears to be in pain, call us anytime. The patient's comfort is our mission.
- Consider pre-medicating prior to bathing, turning, or repositioning.





CIRCULATION

In the last hours of life, as the body begins to “shut down,” blood flow and breathing slow down and is expected. With less oxygen throughout the body, blood pressure begins to fall, heart rate increases and hand and feet begin to cool. Often the ears, lips, fingers and feet become bluish and there may be periods of time up to 30 seconds that the patient may not breathe — all this is a normal part of the dying process. Mottling is caused by pooling of blood in the extremities, feet and knees, and is recognized by marbled purple-blue shading. This tells us that death may be near.



*“The day which
we fear as our last
is but the birthday
of eternity.”*

— SENECA

COMFORT GOALS OF CARE

- These are normal signs and are expected.
- Don't panic. Your hospice team is ready and capable to guide you on this difficult part of the journey.
- Your hospice team is prepared and has the expertise to explain what to expect next. Again, there is no right way to act. You need to find the way that's right for you and your family.
- Remember this may occur slowly over hours to days or sometimes more quickly.
- Sometimes just being there with your loved one is more important than feeling you have to do something.
- We may notify family members who the patient wanted to be present for the “vigil”.





footprints in the sand

One night I dreamed I was walking along the beach with the Lord. Scenes from my life flashed across the sky.

In each scene I noticed footprints in the sand. Sometimes there were two sets of footprints, other times there was one only.

"You promised me Lord, that if I followed you, you would walk with me always. But I have noticed that during the most trying periods of my life there has only been one set of footprints in the sand. Why, when I needed you most, have you not been there for me?"

The Lord replied, "The years when you have seen only one set of footprints, is when I carried you."

— UNKNOWN AUTHOR



Mind

BEHAVIOR CHANGES

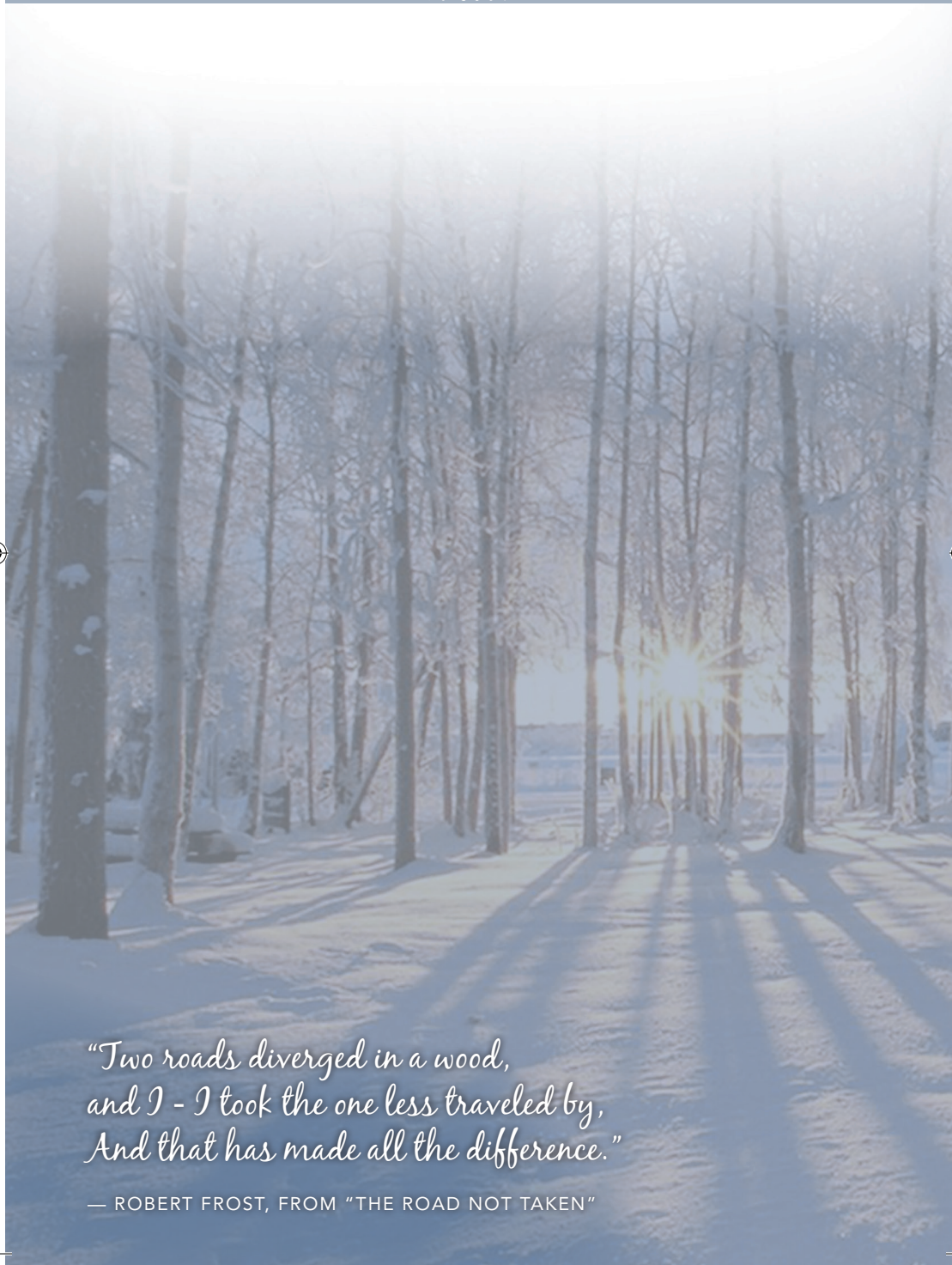
Patients often exhibit changes in their behavior which they do not have control over. This change in their mental status can be caused by a tumor, brain swelling, infection or even medications — so we always try to find the cause and treat it appropriately. Other times this change is just a result of the disease itself — hallucinations, wandering, confusion, aggressiveness or even withdrawal can be seen.

Not only patients with cancer experience changes in behavior, but also those who suffer with dementia, ALS, COPD, congestive heart failure or strokes can be affected as well.

Our team will work closely with you and your loved one to treat the cause or treat the symptoms of behavior changes promptly. We have a number of medications that are effective and safe to use for these symptoms.

COMFORT GOALS OF CARE

- Remember that each patient will have a unique process of dying — no two experiences will be the same.
- Be attentive to changes such as agitation, restlessness, hallucinations or confusion and report them to your hospice staff promptly.
- Haldol is a safe and effective medication for behavioral changes and is frequently used in the hospice setting.
- Always treat pain promptly and continuously.
- Involve social worker and pastoral care as indicated. Other causes for behavioral change may be discovered.
- Limit visitors, provide a calm environment, and reorient gently.



*"Two roads diverged in a wood,
and I - I took the one less traveled by,
And that has made all the difference."*

— ROBERT FROST, FROM "THE ROAD NOT TAKEN"





Spirit

WHAT TO EXPECT IN THE LAST HOURS

Often the last hours of life are filled with symptoms that predict that death may be expected within hours to days. As the body starts the final “shutting down” process, there are expected and normal findings that we need to be prepared for — don’t panic, as your hospice team will continue to guide you through the entire journey. Remember just being at the bedside is more important than feeling you have to do something. Often times this is the opportunity, as noted by the renowned hospice specialist Ira Byock, to say “I forgive you, please forgive me, thank you, I love you, good bye.”

COMFORT GOALS OF CARE

- Patient may lapse into a coma and be unresponsive.
- Feel free to talk to patient and to hold their hand.
- Medications may need to be decreased or discontinued.
- Medications for pain may need to be given subcutaneously.
- Near death awareness or hallucinations are common.
- Many other things to observe have already been mentioned above.



THE SPIRITUAL NATURE OF THE JOURNEY



*"For a brief moment,
the flowers flutter
like jewelled insects
and dance on the
crystal waters:
then, as they slip
away on the laughing
stream, they seem
to say: 'Goodbye,
springtime!
We are leaving
for eternity!'"*

— MASTER OKAKURA
KAKUZO

Many patients find it comforting to have the leader of their religious affiliation present prior to or at the time of death, if possible. We at Hospice of the Sacred Heart have a full-time chaplain available to you and your family if other arrangements have not already been made. But remember that spiritual is not the same as religious, and many patients will not necessarily want a priest or rabbi or minister. But connecting to something larger than oneself is part of the human condition and needs to be supported and nurtured. So we encourage you to support the religious or spiritual experience that the patient may find comforting or meaningful.

Remember that we never know the actual hour of death — it always comes in its own way, at its own time. Your hospice team will guide you and the other family and caregivers every step on the journey. Our mission continues to be providing comfort, care, hope and choice right through the vigil. Also keep in mind, that sometimes patients choose to die alone, even though we hope to be at the bedside at the exact time of death. Give your loved ones the privacy and the flexibility to die as he/she wishes.

We also help with funerals and memorial services as requested or desired.



BEREAVEMENT

Bereavement is the natural grieving process in response to a loss. Everyone goes through the grieving process differently, so you need to find your own way. But even after the death of your loved one, we at Hospice of the Sacred Heart will continue the journey with you and your family. Our social workers are specially trained to assist you with bereavement and more difficult situations are directed by our experienced and compassionate bereavement counselors. We work closely with your physician as may be indicated. We also have semi-annual memorial services and regular bereavement support groups.



*"Death leaves a heartache
no one can heal,
love leaves a memory
no one can steal."*

— FROM A
HEADSTONE
IN IRELAND

COMFORT GOALS OF CARE

- Make an appointment to talk with our counselors as indicated. There is no fee.
- Allow yourself time to grieve — it's a process.
- Visit one of our support groups.
- Surround yourself with positive people.
- Try to stay active, exercise, and visit the doctor regularly.
- Take a walk, garden, visit the beach — this reminds us of the cycle of living and dying.
- Take solace in your personal religious or spiritual practices.





*Hope looks for the good in people
instead of harping on the worst.*

*Hope opens doors
where despair closes them.*

*Hope draws its power from a deep trust in
God and the basic goodness
of human nature.*

*Hope 'lights a candle'
instead of 'cursing the darkness.'*

*Hope regards problems,
small or large, as opportunities.*

*Hope sets big goals and is not frustrated
by repeated difficulties or setbacks.*

*Hope pushes ahead
when it would be easy to quit.*

*Hope puts up with modest gains,
realizing that 'the longest journey
starts with one step.'*

— FATHER JAMES KELLER







SUGGESTED READINGS

- “Dying Well;
Peace & Possibilities at the End of Life”
BY IRA BYOCK
- “A Grief Observed”
BY C.S. LEWIS
- “The Year Of Magical Thinking”
BY JOAN DIDION
- “Paula”
BY ISABELLE ALLENDE

SUGGESTED WEBSITE

- www.hospicesacredheart.org



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