

HOSPICE: A GUIDE TO CARING



DOING WHAT'S BEST.®

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Caregiving can be one of the most fulfilling and life-defining opportunities you will ever experience. Caregiving enables you to make a real difference in your loved one's life and in your own.

Hospice is dedicated to providing supportive care to its patients and their families. This book contains practical information to help you, but it cannot answer all of your questions.

Do not hesitate to call hospice when you need information that's not in this booklet, or just when you need to talk with someone who understands the highs and lows that caregivers experience each day.

We remind you that we are here for you when you need help – 24 hours a day, seven days a week.

Even if you believe your loved one to be in a medical emergency, we ask that you call hospice to help you first. We alone understand the very special needs of end-of-life patients.

With warm regards,

The hospice staff

PART I: PATIENT CARE



BATHING



Attention to personal grooming really lifts a person's spirits. Shaving and hair styling can be done at bath time too.

Daily bathing is important to every patient. Good skin care improves circulation and increases comfort

If the patient is in pain, give him or her pain medication at least 20 minutes before bath time. Then follow these steps:

1. If the patient is in a hospital bed, raise the bed to a comfortable working height.
2. Assemble your equipment before starting:
 - Two basins of warm water: one for soapy water, one for clear rinse water
 - Washcloths
 - Towels
 - Soap
 - Lotion
 - Shaving supplies
 - Comb and/or brush
3. Expose one part of the body at a time, as you are bathing it. Begin with the face. Wash with warm water and pat dry. Then, working from head to feet, soap an area of skin, rinse well and pat dry. Discard the water after washing the feet.
4. With fresh water, wash genitals and buttocks, working from front to back. Dry thoroughly.
5. Dry all skin folds and crevices thoroughly to prevent chapping.
6. Apply lotion to pressure areas and massage gently. Apply lotion to patient's back and give him or her a back rub.

If the patient is unable to tolerate a complete bath due to pain or fatigue, give him or her a partial bath. Wash the face, hands, back and genitals daily.

MOUTH CARE



A clean, moist mouth feels comfortable and reduces the possibility of irritation, infection and mouth odor.

Brush teeth twice each day

1. Assemble a soft bristle brush with a small amount of toothpaste, a small basin or bowl, a glass of lukewarm water, and a straw if the patient cannot sit up to drink.
2. Help the patient to a sitting position if possible, or turn the patient's head to the side towards you.
3. Brush in a downward direction on the upper teeth and upward on the lower teeth.
4. Help the patient rinse with water and spit into the basin.

Daily denture care

1. Spread a clean washcloth or paper towel in the sink or bowl before filling it with a few inches of water. The cloth or towel will protect the dentures if you drop them while cleaning.
2. With the dentures out, help the patient rinse his or her mouth with water or mild mouthwash.
3. Brush dentures inside and outside with a denture brush.
4. After brushing, soak the dentures in water or denture solution.

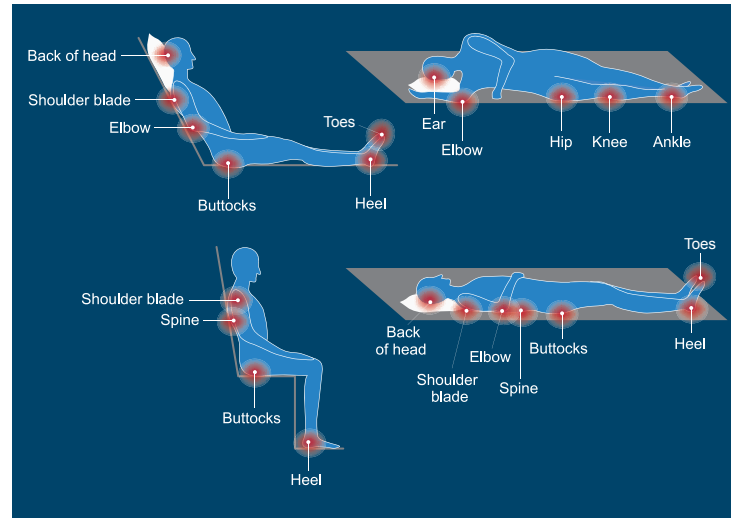
PREVENTING BEDSORES



It is important to keep the patient's skin in good condition. When a person is confined to bed or chair, skin can break down in areas where there is pressure. Pressure sores or bedsores are painful and difficult to treat.



Bedsores are extremely common in patients who have been immobilized by a serious illness. If your loved one develops reddened or sore areas on his or her skin, you should not feel that your caregiving is at fault.



Dots show the sites where bedsores commonly develop.

Prepare the patient's bed and chair for maximum comfort:

1. Use a pad over the patient's mattress to reduce pressure on bony areas. If the patient spends significant time in a chair, use a cushion to protect pressure points while sitting.
2. Don't use rubber or plastic underpads on the bed: they trap moisture and prevent air circulation. These conditions cause the skin to break down.
3. Keep the bottom bedsheet tightly tucked in and free of wrinkles.
4. Use a small flat sheet under the patient to help move him or her more easily. Grasp and lift the edges of the sheet with both hands to slide or gently roll the patient into position.
5. Sprinkle cornstarch lightly over fresh sheets to reduce friction and help prevent irritation.

Take special care with the patient's skin:

- Change the patient's position frequently, using pillows for support. If movement causes the patient pain, wait at least 20 minutes after giving pain medication to change position.
- Use heel and elbow protector pads to reduce pressure on those areas.
- Check the patient's skin daily during the bath. Report any reddened areas to hospice staff at their next visit.
- Use lotion to massage all bony or sensitive areas and around any reddened areas.
- If the patient sits in a hospital bed or wheelchair, ensure that she does not slip into a slouching position. Slouching also causes pressure and sores.

TOILETING



One of the greatest threats to any patient's dignity is the loss of bowel and/or bladder control. Toileting problems can cause embarrassment, anxiety and discomfort. To help protect the patient's dignity, make a special effort to maximize privacy and focus on comfort.

Using the bedside commode

A patient who is too weak to walk to the bathroom but is able to maintain a normal toileting position can use a bedside commode. Hospice staff can assist you in obtaining one.

1. Wash your hands.
2. Move the commode near the bed or chair. Put toilet tissue within reach.
3. Help the patient move safely from the bed or chair to the commode. Help remove clothing, if necessary.
4. Ask the patient to call you when finished or if he or she needs help. Allow privacy, but stay where you can hear the patient call.
5. When the patient calls, put on protective gloves and assist as needed. Discard gloves.
6. Help the patient adjust clothing and wash hands. Return the patient to the bed or chair.
7. Put on a clean pair of gloves. Remove the pan from the commode and empty it into the toilet. Rinse the pan well and empty rinse water into the toilet.
8. Discard the gloves and wash your hands.

Bedpans and urinals are for patients who are bedbound but can still control their bowel and bladder functions. The bedpan and the urinal should be emptied and washed out immediately after use to prevent spills and odors.

Using the bedpan

1. Wash your hands and put on gloves.
2. Place the bedpan and toilet tissue within reach.
3. Help the patient roll to the side, facing away from you.
4. Place the bedpan on the bed, firmly against the patient's buttocks.
5. Hold the pan in place as the patient rolls back onto it.
6. Raise the head of the bed, if it is adjustable, so the patient is sitting comfortably on the bedpan. Cover the patient's lap with the sheet. Allow privacy, but stay where you can hear the patient call.
7. When called, lower the head of the bed. Hold the bedpan securely as the patient rolls onto his or her side away from you. Clean the patient as needed, wiping from front to back.
8. Remove the pan and empty it into the toilet. Rinse the pan well. Empty the rinse water into the toilet.
9. Remove and discard your gloves, wash your hands, help the patient wash his or her hands.

Using a urinal

Put on disposable gloves. Ask the patient to put the urinal between his legs or spread his legs if he is unable to.

1. Make sure the penis is inside the opening at the top of the urinal. If the patient is unable to hold his penis in place, help him to do so.
2. Position the urinal and hold it upright (if the patient cannot do so himself) while the patient urinates.
3. When the patient is done, carefully remove the urinal.
4. Gently wipe between the legs with a damp washcloth and dry thoroughly.
5. Empty the urinal into the toilet and rinse it thoroughly.
6. Remove and discard your gloves, wash your hands, help the patient wash his hands.

Changing adult incontinence briefs

Use incontinence briefs when the patient has lost bowel and bladder control. Skin can become irritated and break down unless kept clean and dry. Frequent changing is necessary.

If the patient is lying on a moisture-proof pad, change this also.

A member of your hospice team will demonstrate and teach you the best way to change the brief. The technique may differ, depending on the patient's size and mobility.

1. Place the following items within easy reach:
 - Toilet paper
 - Pan of warm water
 - Soap
 - Washcloth
 - Towels
 - Disposable gloves
 - Clean brief
 - Plastic bag for discarding used briefs and gloves
2. Put on disposable gloves.
3. Place a waterproof pad under the patient's buttocks to protect the bed. Undo the tape on both sides of the brief the patient is wearing.
4. Discard the gloves and wash your hands.

5. Turn the patient's body away from you. Bend his upper knee toward his chest.
6. Pull down the front of the brief and fold or roll it up to cover the soiled area.
7. Clean the patient's skin. Wipe between the legs with toilet paper. Use the washcloth with soap and water, cleaning from front to back. Dry the patient with the towel. This is a good time to check the patient's skin for sores. Use medication if instructed by the hospice team.
8. Open the new brief all the way, with the plastic side toward the bed. Tuck half of it as far as possible under the patient.
9. Roll the patient toward you.
10. Go around to the other side of the bed.
11. Remove the dirty brief.
12. Clean between the legs on the other side as described above.
13. Pull the other half of the clean brief out from under the patient.
14. Roll the patient on his or her back and fasten the tapes on both sides of the brief.
15. Discard the dirty brief, pad and gloves in a plastic bag. Knot the top of the bag.
16. Wash and dry your hands.

NUTRITION



Hospice patients often experience loss of or decrease in appetite. We support a patient's choice in any treatments, including food. While food has always been a way to show love and caring, we encourage family to show love and caring in other ways at this time.

In the early phases of a terminal illness, encouraging your loved one to eat and drink can contribute to his or her well-being. But later on, encouraging or forcing food and fluids on the patient may actually result in physical and emotional distress to your loved one.

Late in a terminal illness, food is of little importance to a patient's life expectancy. This concept may be difficult for family members to accept, since our society puts high value on giving food and water as signs of love and compassion.

Family members frequently ask if artificial feeding should be given when a patient is no longer able or willing to eat. Research shows that dehydration can actually help a patient feel more comfortable because it decreases nausea and vomiting, urinary output, and other secretions. In addition, dehydration may have a euphoric effect and may result in increased sedation, which may contribute to the patient's comfort during his or her final days.

If your loved one is willing and able to eat, these tips may help you...

- Serve small frequent meals or snacks.
- Allow the patient to eat as much or as little as he or she wants.
- Serve your loved one's favorite foods.
- Add a high-protein supplement, such as a prepared instant breakfast drink.
- Serve food cold or at room temperature to decrease its smell. Food odors cause nausea for some patients.

If your loved one has lost the desire to eat and drink, remember...

- Don't force your loved one to eat.
- Don't view the patient's inability to eat as your failure.
- Don't allow the patient's appetite to become the focus of your care.

MEDICATION SAFETY



Medications, when taken properly, can enhance the quality of the patient's life. When taken incorrectly, medications can put comfort, health – and even life – at risk. Follow instructions to use medication safely.

PREVENTING FALLS



Any fall can be catastrophic to an elderly or ill person. Fortunately, most patient falls can be prevented with careful attention to the home environment and patient care.

Prevent falls by making the environment safe

- Remove scatter rugs from floors.
- Tack down carpet edges.
- Keep pets from underfoot.
- Keep oxygen tubing from trailing around the patient's feet.
- Keep rooms uncluttered.
- Move lightweight furniture out of walking areas.
- Keep frequently needed items within easy reach.
- Keep a low light or night light on after dark.

Hospice patients become increasingly weak and unsteady, placing them at risk for falls. If your loved one falls, keep him or her comfortable and call hospice immediately. A nurse will come to help.

Prevent falls with safe patient care

- The patient should wear sturdy, slip-proof shoes when walking.
- When transferring or walking with the patient, support his or her weak side.
- When moving the patient in or out of a wheelchair, keep the chair's brake on.
- Never leave a confused patient sitting alone in a chair, wheelchair or on the toilet.
- Do not allow the patient to lean forward when walking with a cane or walker.
- Keep the hospital bed in the low-height position with both side rails up while the patient is in it.

SAFE TRANSFER



Getting ready...

- Make sure the patient is wearing footwear that won't slip, and clothing that will not cause him or her to trip.
- Ensure that any tubing or other equipment will not impede the move.
- Explain to the patient how you plan to move him or her.
- If you are using a wheelchair, lock the wheels and swing the footrests to the side.
- Place the chair close to the patient. If one side of the patient's body is weaker than the other, place the chair on the stronger side. Always have the patient move towards the stronger side.

As a caregiver, you may have to help the patient move from the bed to a chair or to another room. It is important to do so safely to prevent injury to the patient or to yourself.

PREVENTING INFECTION



Practicing good personal hygiene is critical in preventing the spread of infection and disease. Hand washing is a vital part of preventing the spread of infection.



“Standard precautions” are a method for infection control. This method treats human blood and other body fluids with caution, as if they have the potential for spreading infectious diseases. Along with hand washing, you should always wear gloves when there is a chance of directly touching any body fluids or anything soiled by body fluids.

PAIN MANAGEMENT



The right combination of medications can keep a patient comfortable and able to enjoy a quality of life not possible for someone who is constantly battling pain.

Uncontrolled pain is often a patient's greatest fear when he or she becomes ill. Pain can affect the patient in many ways: it can keep him or her from being active, from sleeping well, from eating and from enjoying family and friends. Today, combinations of pain medications can control even severe pain. Patients who take narcotics for pain relief do not become addicts.

- Always give the pain medications exactly as ordered.
- Give the pain medication on a regular schedule.
- Use "breakthrough" (in-between) doses of medicine, if ordered, between the regularly scheduled doses as needed.
- Don't hesitate to report unrelieved pain to the hospice team.
- Report any and all side effects of the medication.
- Make sure you have an adequate supply of medicine.
- Do not stop or decrease pain medications suddenly once the pain is under control.
- Keep all medicines out of the reach of children.

Finding the problem

Our staff must have accurate information about the nature of the pain in order to ensure that your loved one receives the correct medication for pain control. The nurse needs to know:

- Is the pain localized (in just one area of the body), or does the patient describe it as "all over"?
- Is the pain dull, throbbing or sharp? What words does the patient use to describe it?
- Do certain activities or conditions (walking, eating, reading, for example) increase the pain?

EASING SYMPTOMS



During his or her illness, your loved one may experience some uncomfortable symptoms. With help from the hospice staff, we can control most symptoms to dramatically improve the quality of your loved one's life.

Dry mouth

- If the patient can swallow, give him or her frequent small amounts of water.
- Wrap a piece of gauze around ice chips for the patient to suck on.
- Leave a toothette in a glass of ice water at the bedside.
- Provide frequent mouth care using a soft toothbrush, toothette or cotton applicator.

Nausea and vomiting

- Discuss the symptom with your hospice team; they may prescribe medication.
- Encourage the patient to eat small meals throughout the day.
- Serve dry foods such as crackers or toast.
- Avoid serving fried or heavily spiced food.

Constipation

- Use medication such as a stool softener or laxative, as directed.
- Offer additional fluids if the patient can tolerate them.
- Add fresh fruits, whole grain breads and cereals for a high fiber diet.
- Try solutions that have eased the patient's constipation in the past (such as prunes or warm fluids).
- Inform the hospice team.

Urinary incontinence

- Use incontinence pads or briefs to keep the patient's skin dry.
- A urinary catheter is a solution for some patients. Discuss this with the hospice nurse.

Leaky Foley catheter

- Place a blue absorbent pad under the patient with the blue side facing away.
- Apply an incontinence pad.
- Check the catheter for bends or kinks.
- Call hospice if the patient complains of abdominal pain or the urge to urinate.

Sleeplessness

- Encourage activity or exercise during the day, if possible for the patient.
- Reduce anxiety with relaxation techniques (see page 46).
- Give the patient sleep medication, as prescribed.

Anxiety or depression

- Use antidepressant medication as prescribed.
- Give the patient opportunities to discuss his or her feelings and fears.
- Relieve any physical discomforts.

Pressure ulcers (bedsores)

- Turn the patient to a different position every two hours.
- Protect pressure point areas: Place padding between knees; keep heels off the mattress.
- Keep the skin dry and clean.
- Report skin irritation to the hospice team.
- Use extreme caution with heating pads or hot water bottles.

If you are unable to control your loved one's uncomfortable or difficult symptoms, call McLaren Hospice for help immediately, rather than 911. Our unique focus is on meeting the special medical needs of end-of-life patients.

CARING FOR YOU, THE CAREGIVER



The responsibility of caring for a family member at home can be overwhelming. You'll have physical and emotional demands placed on you day and night. It's important now to take care of your own health and wellbeing, too.

- Remember to eat balanced meals.
- Get adequate rest.
- Plan times when you can get out of the house.
- Let friends and family members help. They may not know how to offer but it is important that you learn to ask for and accept help now.

People of faith draw comfort and support from their “faith family”

In times of crisis, many families and patients may return to or renew their faith.

Hospice offers non-denominational support through a hospice chaplain that can assist you in exploring your spiritual needs.

They will provide resources or contacts to faith groups to assist you in your spiritual journey at your request.

Please share your needs with your hospice nurse

- Request a hospice patient support volunteer to come and sit with your loved one so you can have some necessary time away. Our hospice volunteers are eager to lend a hand by running errands or visiting with you or your loved one. Again, don't hesitate to call us for help.

Try relaxation techniques

1. Select a quiet environment.
2. Get in a comfortable sitting or reclining position.
3. Close your eyes and pay attention to your breathing.
4. Think about nothing but your breath flowing in and out.
5. After a few minutes begin to systematically tighten and relax each muscle in your body, beginning with your toes and working up to the top of your head.
6. When you have finished, remain for a moment and visualize a place you've been that was physically and mentally relaxing. Try to remember that relaxing feeling again, and let it seep into your body. Feel the peace and calm and imagine your whole body is refreshed.
7. After a few minutes, slowly open your eyes and stretch. Repeat this technique whenever you feel stressed.

A MESSAGE FROM YOUR LOVED ONE



When someone you care about is seriously ill, it's difficult to know what to say or do. These requests from a patient's point of view may help you, your family and friends communicate with your loved one.

- Don't avoid me. Continue to be my friend.
- Please overlook my appearance.
- Please include me in decision making. I've been robbed of many things, but give me a chance to make decisions for my family and myself.
- Help my family. Offer to do errands or offer to come and stay with me to give them a break.
- Sometimes I need to talk about difficult subjects. Find out by asking me, "Do you feel like talking about it?"
- Don't feel like we always have to talk. Sitting quietly is a wonderful gift.
- Hold my hand even if I don't seem to respond.
- Don't force me to eat.
- Remember, even if my eyes are closed or I am in a comatose state I can still hear you. Talk quietly to me but don't require me to respond.
- Reminisce with me. Laugh when I laugh; cry with me when I cry.
- Let me know you will be all right.

*Tell me that you love me. Don't turn away
I know you cannot help change the inevitable.
The shadow of darkness draws closer.
It does not frighten me half so much
as people turning away in helplessness,
instead of sharing their love as a parting gift*

—DR. WILLIAM ADELSON

Spiritual care

People of faith draw comfort and support from their “faith family”

In times of crisis, many families and patients may return to or renew their faith.

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They will provide resources or contacts to faith groups to assist you in your spiritual journey at your request.

Please share your needs with your hospice nurse.

“I will never leave you or forsake you”

HEBREWS 13:5

SURVIVOR’S CHECKLIST



It is helpful to have a list of things that need to be done after the death of your loved one. Making that list now will help you stay on track later, at a time when it may be difficult to do so.

Apply for Benefits

- Most funeral directors can assist you in obtaining copies of the death certificate and to apply for certain death benefits. Additional copies are available from the county health department. You may need several copies to process benefits and to make other necessary changes.
 - Record the death certificate at the county courthouse for possible tax reductions.
 - Notify Social Security at (800) 772-1213 or www.socialsecurity.gov
 - Notify and process claims for life insurance.
 - Process veteran's claims through (800) 827-1000 or www.va.gov
 - Check with credit unions, trade unions, credit card companies, auto clubs, or other member organizations for possible pensions or additional benefits.
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Change titles and ownerships

- Immediately change or cancel all credit cards that are in your loved one's name.
- Change automobile title and auto insurance policies to the survivor's name.
- Notify your bank of the death. If you share a joint account with your loved one, you may find it helpful to keep both names on the checking and savings accounts for up to one year after the death.
- Change deeds, utilities, stocks, bonds and other investments to the survivor's name.
- Notify the driver's license bureau.

Arrangements for mail and residence

- If your loved one lived alone, notify the post office. Request that the mail be forwarded to you or to the executor of the will.
- If your loved one rented, notify the landlord. Set up a time to remove all belongings.

Things to do for yourself

- Make a list of family and friends to notify of your loved one's death.
- Make a list of people you wish to thank for gifts or other acts of kindness.
- Make changes in your own will. Update any advance directives that include your loved one's name.
- Consult an attorney if you need help settling your loved one's estate.

Other things to do



If you need further assistance, your hospice counselor will be glad to help.

PART II: ABOUT GRIEF



THE GRIEF PROCESS



Your bereavement process is emotionally complicated and it begins now, even before your loved one dies. Grieving is natural and normal in the face of impending loss.

Grieving is not just feeling sad. It is a total physiological reaction to the reality of your loved one's dying.

You might sense it as a rumbling in your stomach or a burning in your heart. It may cause you to become more forgetful because you are preoccupied with your loved one. You may feel as if grief has a grip on you, your family, and your circle of friends. At times it may be tough to breathe.

It is important that at the same time you take care of your loved one, you also take care of yourself. Try to get enough sleep. Eat as well as you know how. Find ways to get some exercise. Get out and take some breaks to refresh and enliven yourself.

Only if you take care of yourself will you have the physical and spiritual strength to care for your loved one. You want to offer him or her every chance to live each day to the fullest.

At times the experience of grief can cause difficulties between you and loved one, or you and other members of the family. Recognize that grief is a very individual experience and each person must go about it in his or her own way. Sometimes others won't respond the same way you would. Have patience with each of them and with yourself. Everyone will have to cope with grief as best they can, including your loved one who is dying.

Grief is not easy. It will help you to know that you have been as loving, kind and gentle as you possibly could have been. Even in the midst of grief, you will be able to experience the joy, the beauty and the goodness of the life you share with your loved one.

McLaren Hospice will be here for you for the next year, offering you individual grief counseling, grief support groups to help you learn what to expect when you are newly bereaved, then ongoing support groups to help you get through the first year or longer. We will also offer you occasional workshops and services of remembrance where you can share your experience with others who are also grieving.



A hospice bereavement counselor is always available to help you through this difficult time. Don't hesitate to call if you need bereavement services.

CHILDREN IN HOSPICE FAMILIES



The death of a loved one is probably the most traumatic event anyone can encounter. Our approach to patient care includes guidance and counseling for children, to help them cope with feelings of grief, loss and fear.

McLaren Hospice counsels children and also helps the adults in the family find the right words to talk with their children about death and grief.

After your loved one's death, we continue our contact with families, offering additional counseling to all family members as they work through grief and healing.

A children's grief camp is offered every summer. Please ask a hospice staff member for additional information.



How to talk about death with a child

- Speak in concrete terms. Avoid confusing phrases such as “passed,” “lost,” or “the angels took her.” These terms leave the child – especially a young child – confused about what is really happening. And we know that the imaginations of young children can grow a simple misconception into a greater emotional problem.
- Be as loving, as calm and as frank as possible. But don't try to mask your own emotion. You could say, for example, “You know that Grandma has been sick for a long time. Now her body is so sick that it is going to stop working soon. When that happens Grandma will die. This is a sad time for us because we love her and we're going to miss her.”
- Some children will ask questions while others may need some time to process what they have just heard. Accept the child's silence after such very bad news. In every case, assure the child that you are there to talk when he or she is ready, that it's okay to ask questions, and that expressing sadness is normal and expected.
- By being “real” and speaking from your heart, and allowing your own emotions to show, you can help your child to understand this very complex human experience.

YOUR FINAL GIFTS OF CARING



Your care of your dying loved one is the most tender gift you will ever have to offer. In caregiving, you, as well as your loved one, are receiving something extraordinary. This chapter prepares you for the final caregiving gifts.

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean.

She is an object of beauty and strength. I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then someone at my side says:
“There, she is gone!”
“Gone where?”

Gone from my sight. That is all. She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear her load of living freight to her destined port.

Her diminished size is in me, not in her.

And just at the moment when someone at my side says: “There, she is gone!” there are other eyes watching her coming, and other voices ready to take up the glad shout: “Here she comes!”

And that is dying.

“GONE FROM MY SIGHT”
—HENRY VAN DYKE

Our goal is to help our patients and families prepare for the final days. We offer the following signs of impending death to help you understand what may happen. But no matter how well informed you may be, you may still have questions. Please remember to call your hospice team when you need help or information.

Body temperature

- The patient may become increasingly cold, especially the arms, hands, and legs. Skin may look blue or blotchy because the body is decreasing circulation of blood to the limbs and reserving it for the vital organs. Keep the patient warm with a blanket, not an electric blanket or heating pad.
- The patient may run a fever because of the decreased blood circulation. A cool sponge bath may be comforting.

Sleeping

- The patient may spend more and more time sleeping and may be difficult to arouse. Eyes may stay open during sleep. Sit with your loved one and hold his or her hand; do not shake him or her. Speak to the patient even though he or she may not respond. Never assume the patient can't hear; hearing is the last sense to leave.

Bladder and bowel functions

- You may note a decrease in the amount of the patient's urine and it may appear unusually dark in color. Bowel and bladder function may be lost. Use incontinence briefs now.

Confusion

- The patient may be confused about the time, place and persons surrounding him. Continue to identify yourself and speak directly to the patient.
- The patient may tell of seeing a place or a person not visible to anyone else. Don't argue or challenge, simply accept and validate. Respond with gentle inquiries. It is fine to be honest about not being able to see what the patient sees.

Breathing

- Breathing may be noisy if mucous collects in the throat. Gently turn his or her head to the side and let gravity drain the secretions. Check with the hospice team before suctioning or using oxygen.
- Breathing patterns may change with periods of very rapid breathing or periods of up to a minute with no breath at all. The patient may be more comfortable with his or her head slightly elevated.

Restlessness

- Restlessness and repetitive motions such as pulling at bed linen or clothing are common. Do not restrain the patient. Continue to speak calmly.

Lack of appetite

- Appetite for food and drink may cease. Do not force eating and drinking. Provide ice chips and use sponge toothettes for mouth care.

Withdrawal or surge of energy

- The patient may speak less or not at all. He or she may turn to face the wall or sleep in a fetal position. This is not a slight against family but preparation for detaching from surroundings and relationships.
- It is not uncommon for someone near the end of life to “wake up” and talk clearly, ask for a favorite meal and actually have an improvement in symptoms for a few hours or even a few days.

Holding on

- A dying patient may try to hold on if he doesn't sense your approval. Some patients wait until certain people arrive; others wait until they are alone. Give him or her permission to let go.

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