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PREPARING FOR END-OF-LIFE

Each of us face many choices throughout our lives. Some are easy, some are very difficult. However, we have little choice in the matter of death. Death will occur to all of us but each person will approach his/her own death in his/her own unique and personal way. This booklet will help serve as a guide for those who are experiencing death or experiencing the death of a loved one.

Use this booklet as a general guideline, remembering that nothing is set; all of us are unique. Often this is a slow process and it is very difficult to predict just when death will come. This is a time when you will feel very emotional; it is natural for you to be upset and sad. It is very difficult to watch as your loved one is dying and to know that you must give them up. Not knowing what to expect can add to the stress. Take your time with this information and ask questions when needed.

Palliative care focuses on quality of life. It allows a more natural approach to death with a focus on the patient’s physical, emotional and spiritual needs. As stated in the What is Palliative Care booklet, palliative care allows you to live life to the fullest with good symptom control.
SYMPTOM CONTROL

PAIN
Medications that may help include:
• Over-the-counter pain relievers
• Anti-inflammatory medications
• Narcotics, such as morphine, to decrease pain

Other treatments include:
• Palliative radiation — to decrease pain by shrinking the tumor
• Palliative surgery — to remove a growth
• A nerve block — to help deaden or block the pain
• Integrative therapies
  Massage therapy
  Therapeutic Touch—Healing Touch—Pranic Healing
  Aromatherapy
  Guided Imagery/Stress management
  Relaxation breathing
  Art and Music for enjoyment and relaxation

BREATHING
Medications that may be given to ease breathing include morphine, which may be used in different forms (pills and IV).

Other treatments include:
• Oxygen by a mask or by nasal cannula
• Breathing treatments
• Medications to control increased congestion
• Anti-anxiety medications to improve a patient’s breathing pattern
NAUSEA
- Medications may need to be adjusted if possible
- Other medications may be offered that treat the nausea
- Food may need to be served in smaller portions
- Aromatherapy may be utilized for nausea

DRY MOUTH
- Routine mouth care is needed
- Offer small sips of water or ice chips to suck on
- Apply ointment to the lips
- Swabbing the inside of the mouth with swabs from the nursing staff

BEDSORE
- Frequent changes in position (if patient is able to tolerate)
- Proper padding
- Special mattress or air pad
- Good skin care — cleaning the skin with a warm wash cloth, applying lotion to dry and bony areas

CONSTIPATION
- Laxatives and stool softeners should be ordered, especially if patient is on pain medications
- Diet changes may also be considered if the patient is able to tolerate meals
- May need to increase fluids, if the patient’s condition allows
DROWSINESS
- Medication dosages may need to be changed, but sometimes medication changes may not make a difference (see SIGNS AND SYMPTOMS OF APPROACHING DEATH below). It may take a few days for the body to adjust to the medications and the drowsiness to lessen.

RESTLESSNESS
- Medications may be given
- Keep lights dim and out of the patient’s eyes
- Hold their hand and do not be afraid to touch them
- Massage sometimes helps to promote comfort

SIGNS AND SYMPTOMS OF APPROACHING DEATH
A person undergoes changes as they approach death. These changes can begin as much as one to three months prior to death. Following are things that often, but not always, happen.

WITHDRAWAL
This is the beginning of separation. The person may be spending an increasing amount of time sleeping. He/she may appear to be uncommunicative or unresponsive, and at times, be difficult to awaken. This normal change is due in part to changes in the metabolism of the body. It may also indicate preparation for release, a detaching from surroundings and relationships, and a beginning of “letting go.”
• Sit with your loved one, hold his/her hand
• Do not shake him/her or speak loudly
• Speak softly and naturally
• Speak to him/her directly as you normally would, even though there may be no response
• Never assume the person cannot hear; hearing is the last of the senses to be lost

FLUID AND FOOD INTAKE DECREASE
There is a gradual decrease in appetite and thirst. The person may want little or no food and fluid.
• Do not try to force food or drink into the person (doing this only makes the person more uncomfortable)
• Small chips of ice or frozen juice may be given in small amounts by spoon or straw (ask your nurse for guidance)
• Moistened toothettes may help keep the mouth and lips moist and comfortable

CONFUSION
The person may seem to be confused about the time, place and identity of people surrounding him/her, including close and familiar people.
• Identify yourself by name before you speak
• Speak softly, clearly and truthfully
• Explain what you are doing
• Explain why you are doing it
CHANGES IN VITAL SIGNS
• Blood pressure — May become low and the pulse rate may change between fast and slow
• Body temperature — May fluctuate between fever and cold. He/she may run a temperature as high as 104 degrees. He/she may sweat or feel clammy.
• Antibiotics may be used if it provides comfort for the patient. Tylenol pills or suppository may be given.
• Cool and moist wash cloths applied to the skin and forehead to increase comfort
• Color changes — The skin may become flushed or pale. The hands and feet may become purplish in color, blotchy and cold to touch. The underside of the body may become darker and the skin become purplish or bluish, this is called mottling. It is a normal indication that circulation of blood is decreasing to the body’s extremities and is being reserved for the most vital organs.

BREATHING CHANGE
The person’s regular breathing pattern may change. The person may have periods of very shallow breaths, or no breathing for five–30 seconds, even up to a full minute. The person may also experience periods of rapid pant-like breathing. These breathing changes are very common and are not uncomfortable.
• Elevating the head of the bed or turning the person to his/her side may be helpful.
MOANING
It is common for a person to make a moaning sound as they breathe out or as they move. This does not mean your loved one is in pain.

CONGESTION
It is common to hear gurgling sounds or the “death rattle” noise coming from his/her chest — these sounds may be very loud and may come and go. This normal change is due to the decrease of fluid intake and the inability to cough up normal secretions and causes no discomfort.
• Gently turn the patient’s head to the side and allow gravity to drain the secretions
• Positioning can affect the congestion
• Gently wipe the mouth with a moist cloth
• Medication(s) can be used to prevent further secretions
• Deep suctioning is not done but secretions may be suctioned from the mouth by the nurse

TERMINAL RESTLESSNESS
It is common to see restless and repetitive motions such as pulling at bed linen or clothing.
• Do not interfere with or try to restrain such motions — provide a calming effect
• Speak in a quiet and natural way and begin to lightly massage the forehead
• Read to the person, or play some soothing music
• Telling the person that it is OK to “let go” may help him/her to relax
GLASSY EYES
The eyes may not close totally and may appear glossy. Natural tears/eye drops may provide comfort.

INCONTINENCE
It is common to have the person lose control of urine and/or stool as the muscles in that area begin to relax. Discuss with the nurse what can be done to protect the bed and keep your loved one clean and comforable.

URINE DECREASE
Urine output normally decreases and may become “tea” colored. This is due to the decrease in kidney function.

SURGE OF ENERGY
The person may talk clearly and become alert when they had previously been disoriented and confused.

VISION-LIKE EXPERIENCES
The person may speak or claim to have spoken to persons who have already died, or see places not visible to you. This does not indicate a hallucination or a drug reaction. Do not contradict, explain away, belittle, or argue about what the person claims to have seen or heard. Affirm his/her experiences. These experiences are normal and common. This may also be a time when the person needs to discuss his/her spiritual needs. Spiritual closure is just as vitally important as physical, mental, or emotional closure. You may want to have someone they feel
comfortable with to come and see them or ask to have a chaplain visit.

UNUSUAL COMMUNICATION
The person may make an unusual statement or request, such as preparing to go on a trip, wanting to pack or getting dressed. This may mean that the person is ready to say “good-bye” and is “checking” to see if you are ready to let him/her go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you need to say.

SAYING GOOD-BYE
Giving permission to your loved one to let go without making him/her feel guilty for leaving can be difficult. A dying person may try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are left behind will be all right. Therefore, your ability to release the dying person from this concern and reassure him/her that it’s alright to let go is one of the greatest gifts you can give your loved one at this time. When the person is ready to die and you are able to let go, it is time to say “good-bye.” Saying “good-bye” is your final gift of love.

It may be helpful to lie in bed with the person and hold him/her, or to hold hands and then say everything you need to say. It may be as simple as saying, “I love you.” It may include recounting favorite memories, places and activities you shared. It may include saying “I’m sorry for …,” or “I’m thankful for ….”
Tears are a normal and natural part of saying “good-bye.” They do not need to be hidden from your loved one or apologized for. Tears express your love and help you let go.

*How will you know when death occurred?*

Although you may be prepared for the death process, you may not be prepared for the actual death moment. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the death moment. The signs of death include such things as:

- No breathing
- No heartbeat
- Release of bowel and bladder
- No response
- Slightly opened eyelids
- Enlarged pupils
- Eyes fixed on a certain spot
- No blinking
- Relaxed jaw and slightly opened mouth

A nurse will come to assist you when needed or desired. The nurse can also help with notifying the physician. The funeral director will be notified after the family has finished viewing; if you need more time to allow for more family to arrive please inform the nurse so he/she may make arrangements. Let the nurse know if you or the family want to participate in preparing the body, such as bathing, or dressing, or taking a lock of hair. If you have any questions, do not hesitate to call the nurse.
THANK YOU
We thank you for the privilege of helping you care for your loved one. We salute you for all you have done to surround your loved one with understanding and care, to provide your loved one with comfort and calmness, and to enable your loved one to leave this world with a special sense of peace and love.

You have given your loved one the most precious and beautiful gift that humans are capable of, and in doing so, given yourself a wonderful gift as well.