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Hospice

Providing physical, emotional, spiritual, and psychological care to the veteran during the final stages of life are an important part of the healthcare given by the George E. Wahlen Department of Veterans Affairs Medical Center. Death is part of life, and the Salt Lake VA wants to meet the needs of patients and families as they prepare for and experience death. The George E. Wahlen Department of Veterans Affairs Medical Center has assembled teams of doctors, nurses, pharmacists, social workers, chaplains, volunteers, and others who have the skills to provide quality, end-of-life care to the dying patient and their family.

Our staff will provide guidance to you and your family to meet your wishes and your needs. You will decide which services might be useful. You will let us know what you want us to do. We will support you in your decision-making and will respond as best we can.

*** There may be medical terms used in this pamphlet that you are not familiar with. Please refer to the Glossary in the back to clarify unknown words.**

Advance Directives

A social worker can assist you in completing your advance directives.

As a VA patient, and as part of your treatment care plan, you will be given the opportunity to complete Advance Medical Directives. These directives are legal documents that allow you to give directions for your future medical care. They are valuable tools that can free your family of the responsibility and stress of having to make difficult decisions for you. They also give direction to your healthcare providers. It is your right to accept or refuse specific treatments. Advance Directives ensure that right. They are used only if you become unable to make your choices known. The VA Advance Directives consist of three forms:

1. **The Living Will:** These are written instructions that explain your wishes for healthcare if you become unable to communicate them as a result of a terminal condition. Terminal condition refers to conditions “where death is imminent as well as debilitating conditions from which there is no reasonable hope for recovery, (e.g., a coma);”

2. **Treatment Preference Form:** This form includes any comments, restrictions, or additional instructions you may wish to make; (example: tube feedings, IV hydration, mechanical ventilation).
3. **Durable power of attorney for health care** (sometimes called a “healthcare proxy”): This document allows you to appoint a healthcare agent* (and an alternate). This appointment takes effect only if you are unable to make or communicate your own health care decisions. Agents are expected to follow the decisions made by you in the living will and treatment preference form.

Advance Directives need not be notarized. However, two witnesses need to witness the signature.

The witnesses need to be:

- a. Unrelated by blood or marriage;
- b. Of legal age (18);
- c. Persons who will not benefit financially from your death; and
- d. Not employed by the Department of Veterans Affairs with the exception of social workers, volunteers, clerks and clergy.

**This is different from someone who has durable power-of-attorney for legal or financial matters.*

Withholding/Withdrawal of Life Sustaining Treatment

We care for very ill people in our intensive care units (ICU). Sometimes, a patient's condition may become so poor that death may be near. Physicians, nurses, and others involved in the patient's care meet with the patient and/or his family. Many choices in caring for this very ill patient are discussed. We consider the patient's feelings about "quality of life." Living wills, life support, and other medical treatments are also considered.

When curative treatment is not available, the ICU team focuses on comfort measures. Our goal is to provide quality patient care. This includes meeting the patient's physical, emotional, and spiritual needs during the dying process. We give medications to relieve pain and suffering. We provide a supportive and loving environment to our patients and families during this difficult time. We provide an environment where a person may die with dignity and peace, surrounded by those who love and care about them.

Nutrition and Fluids

Your loved one may want little or no food and fluid. Loss of appetite is common and there are many reasons. Allow your family member to take in what he/she feels will help him/her be comfortable. You can help by not forcing your loved one to eat as this may cause him/her more discomfort. If he/she has been on a special diet in the past, you may provide any food that he/she is able to take in as long as the medical team approves. Family members are often concerned when their loved one is not getting fluids through his/her vein when in the hospital. Intravenous fluids can actually increase discomfort for a person who is dying by increasing secretions, swelling, diarrhea, nausea, and vomiting. Nutrition through a feeding tube or a vein may not be routinely provided. For complaints of dry mouth or thirst, if a person is able to swallow, small amounts of oral fluid can be provided. Swabbing the mouth can be helpful to keep the mouth and lips moist. The goal is to make your loved one as comfortable as possible in the final stages of life.

Physical Signs and Symptoms of the Dying Process

Sleeping

People in the process of dying may spend a lot of time sleeping. Increased sleeping may be a response to changes in the body's metabolism or it may be a way of coping with the situation. This is a normal response and family members should not force someone to stay awake. Family can be supportive by being available when their loved one is awake and by trying to coordinate visitors according to the dying person's wishes. If your loved one becomes unresponsive, or unable to communicate, remember that the sense of hearing may not go away during the dying process, and he/she may be able to hear.

Bowel and Urine Changes

During the dying process, a person may need less to eat and drink. This will affect their urine and bowel routines. As a person gradually decreases their intake, their bowel movements will be more infrequent and their urine may become darker and

decrease in amount. Unless there is discomfort associated with these changes, there is no need to be concerned. It is also common for a person to lose control of their urine or bowels as the muscles begin to relax. Nursing help may be needed at home to keep your loved one clean and dry. If a home health nurse has not been set up, you can contact the hospice coordinators (see Directory of Resources, page 23) or your physician to set up home care. If you would rather provide this care yourself, but need some advice, you can call the hospice coordinators or contact your social worker. They will put you in touch with a nurse who can help.

Restlessness/Confusion

As the body metabolism continues to change and the brain receives less oxygen, you may notice a restlessness or confusion. Pulling at the bed linens, having visions of people or things which are not physically present, or other similar actions are not uncommon. You can help by speaking in a natural tone that does not draw attention to this behavior, playing soothing music, giving gentle massage, or simply holding your loved ones hand. It may also

help to identify yourself by name, and to speak clearly and truthfully when you need to communicate something important for the person's comfort, such as taking pain medication. Keeping a light on in the room is a comfort if he/she wakes suddenly and is disoriented.

Breathing Changes

It is not uncommon for secretions to collect in the back of a person's throat. This is the result of a decreased ability to cough up saliva. You can help by turning the person's head to the side and allowing gravity to drain secretions. It is also helpful to elevate the head, gently wipe the mouth with a moist cloth, and/or use a cool mist humidifier to increase moisture in the room. It is important to remember that the sound of this congestion, which can be alarming, does not necessarily indicate the onset of severe or new pain. You may also notice that the breathing pattern changes. This is a normal part of the dying process. There may be periods of 10 to 30 seconds when there is no breathing.

Body Temperature

A person's hands, arms, feet and legs may become increasingly cool to the touch. Color of his/her skin may also change. This is normal. It shows that the circulation of blood is decreasing in the arms and legs and is being reserved for the vital organs. You can help by putting a blanket over the person or turning up the thermostat, close windows to avoid drafts. Some patients may prefer to have a fan in the room. Do not use electric blankets or heating pads; excess heat can not always be felt and can cause burns.

Symptom Management

The key to successful management of symptoms is good communication with your healthcare team. Be honest and open about your symptoms. It may be helpful to keep a record of what is happening to show your physician or nurse. For most problems, there is more than one solution. If you are given a medication or treatment to do, and it does not work, let the team know so something else can be tried. If you know of something that worked in the past, don't be afraid to make a suggestion.

Pain

Many people will experience pain. Although pain may be expected there are medications that can help. Pain medication can be given in several forms: pills, liquid, IV (through your vein), suppositories, and patches applied to the skin. It is important to remember that patients should not be concerned about addiction or building up a tolerance to the medication.

If tolerance occurs, which can happen, the medical team will adjust the medication. Just as with many medications, if pain decreases, it will be important to slowly decrease the medication over a few days. People with chronic pain usually prefer a long lasting pain medication. These medications, either in pill or patch form, are taken less frequently and the medication is released slowly over a 12 hour to three-day period. If this method of pain control is chosen, be sure to have medication for “break through” pain available. If you are taking any kind of pain medication, it is important to be taking medication to prevent constipation.

There are also ways to manage pain besides medication. These include: relaxation techniques, music, distraction (movies or other activities), massage, heat/cold and special mattresses. Talk to your physician or nurse to develop a plan for managing your pain.

Nausea/Vomiting

Nausea and vomiting may be related to the disease process or to the treatment being given. Treating nausea and/or vomiting may include a

change in diet, removing odors, or taking medications. There are many medications available that can be taken before a treatment or procedure to prevent nausea. Ask to see a dietitian if a change in diet may be helpful. Talk to your physician or nurse to develop a plan for managing nausea.

Constipation/Diarrhea

A change in bowel pattern may be related to the disease, treatment, or pain medication. There are many ways you can change your diet to prevent these problems. Ask to see a dietitian for suggestions. Even with diet changes, many people need medication to help maintain an acceptable bowel pattern. Talk to your physician or nurse to develop a plan for managing these problems. Both constipation and diarrhea can cause significant health problems. Please communicate your needs.

Sedation

Sedation or drowsiness can be caused by medications, or may be related to the dying process. If this side effect is acceptable to the patient there is no need to do anything. Family members may be

concerned or frustrated, but need to listen to what their loved one wants. If a patient does not want to be sedated or wants to be alert for a specific event, there are medications available to decrease sedation. Pain or nausea medication can also be readjusted to decrease the effects of sedation. There may be times of the day when a person is more alert; activities can be planned taking this into account.

Emotional Signs and Symptoms

(For Patient's Family & Friends)

Decreased Socialization

A person nearing death may only want to “socialize” with close family members or friends. They may only want one person to be with them as death approaches. The decrease in socialization can be a sign one is nearing death. This withdrawing from social contact allows the patient to choose whom he/she needs by his/her side as he/she makes the transition from life to death. Ask your loved one if visitors are wanted. Ask who he/she wants to see and when. Above all, respect the wishes of your loved one. If you are not a part of the “inner circle” at the end, it does not mean you are not loved or important. It can mean that you have fulfilled your task with him/her. If you are part of the final “inner circle” of support, there are things you can do to comfort the patient. You can affirm the person in their process of dying, support them, and give them permission to die.

Unusual Communication

The person may make a statement, gesture or request that seems “out of character.” The communication may indicate he or she is ready to say “Goodbye.” It may also be a way of “testing” family or friends about their readiness to let the person die. Accept such moments as a beautiful gift when they are offered. This can be a time to kiss, hug, hold, and cry and to say whatever you need to say. This process can make real the feelings of everyone concerned.

Giving Permission

Giving permission to your loved one to let go can be difficult. Sometimes he/she feels guilty for leaving or that you might have a need for them to live longer. Patients often have concerns that those left behind will be all right. Your ability to release the dying person from these concerns and give him/her assurance is important. It is one of the greatest gifts you have to give your loved one at this time.

Saying Good-bye

When the person is ready to die and you are able to let go it is time to say “Goodbye.” Saying, “goodbye” may be your final gift of love to the dying person. It achieves closure. It may be helpful to lie in bed with the person and hold him/her. Or you may take their hand saying whatever you need to say. It may be as simple as saying, “I love you.” It may include recounting favorite memories, places, and activities you’ve shared. You may want to say, “I’m sorry for whatever pain or difficulties I’ve caused in our relationship.” Finally, it may be comforting to say, “Thank you for.....”

Withdrawal

The dying person may seem unresponsive, withdrawn, or somewhat comatose. Withdrawal can be another indication the patient is preparing for death. He/she is detaching from surroundings and relationships and beginning to let go. Since hearing remains to the end of life, it is appropriate to continue to speak to your loved one. Using a

normal tone of voice you can identify yourself by name, hold his/her hand, and then say whatever you need to say that will help the person “let go.”

Unusual Experience

The person may speak or claim to have spoken to persons who have already died. He/she may claim to see or have seen places not visible to you. This may not indicate a hallucination or a drug reaction. It may indicate the person is beginning to detach from this life.

It may be best not to contradict, explain away, belittle, or argue about what the person claims to have seen or heard. Although you cannot see or hear what the person reports, it does not mean it is not real to your loved one. Affirm his or her experiences. These experiences are normal and common. If they frighten your loved one, explain to him or her that they are normal. Tears are a normal and natural part of saying “Goodbye.” Tears do not need to be hidden from your loved one or apologized for. They express your love and help you to let go.

Spirituality at the End-of-Life

(For Patient's Family & Friends)

Many people who are dying may have spiritual concerns. Below are questions people ask at the end of life:

- a. Why is there so much illness and suffering in the world? Why is this happening to me?
- b. Is there a God? If so, what is God like?
- c. Is there a “next life,” after this one? Where will I go?
- d. What have I accomplished with my life?
- e. Is there anyone that I need to forgive? Does someone need to forgive me?
- f. Who will look after the people I love when I die?
- g. Am I loved? Will I be “alone” when I die?
- h. Will I die with dignity and peace?

Spirituality is a very individual matter. We cannot experience our loved ones spiritual journey. We can help by being willing to talk when they are ready.

Spirituality may center on belonging to a religious group. This may be a traditional religious group. Other groups may provide meaning, direction, and worship opportunity. You may want to invite your religious community to provide support.

VA Chaplains are available to supplement that support. Chaplains also provide comfort when those persons are not available. Spirituality is a private experience for some people. Some may choose meditation or prayer. Others may commune with nature or follow a 12 Step Program. Other people may not believe there is a God.

Whatever their beliefs, a dying person may try to make sense of life. Dying persons wonder what life has meant or can mean. They wonder if a guide will help them cross from this life to the next.

You can accompany your loved one just so far. Then you must face your limitations and “let go.” That is not an act of failure or betrayal. It is simply an admission that our paths must separate. Death is a sad experience because of your loss. If death comes in the hospital, staff or a Chaplain will be there as needed. We will do our best to support your loved ones.

When Death Has Occurred...

(For Patient's Family & Friends)

If you suspect that death has occurred, there is no need to call 911. You can call the VA and ask for your physician, or the physician “on call”. It may be easier if you make plans for this event before it happens. Identify which mortuary you plan to use, have a list of friends and relatives that want to be notified, and if you are alone, you may want to call someone to be with you. It is not unusual to want to spend some time with your loved one before calling the mortuary, this is perfectly acceptable.

Signs of Death Include:

1. No breathing.
2. No heart beat.
3. No response to shaking or shouting.
4. Eyelids slightly open.
5. Eyes fixed on a certain spot.
6. Jaw relaxed and mouth slightly open.
7. Release of bowel or bladder control.

VA Burial Benefits for Veterans

- U.S. Flag
- VA Headstone
- Burial at any veterans or military cemetery or military section of a private cemetery. The Utah Veterans Memorial Park Cemetery located near Camp Williams in Bluffdale, Utah, is available for veterans and the veterans' family members. This is the only veterans state-operated cemetery in Utah.
- Presidential Memorial Certificate

For additional information, please contact Decedent Affairs at 582-1565, ext. 1432.

Bereavement Services

George E. Wahlen Department of Veterans Affairs Medical Center has a list of grief support groups in the community for families of veterans. Bereavement resources are available through the Palliative Care Program. George E. Wahlen Department of Veterans Affairs Medical Center holds remembrance services three times a year in honor of veterans who have died. The family of the veteran will receive an invitation regarding the date, time and location of the service, for which their loved ones will be honored.

Directory of Resources

There are many resources available to patients and their families.

George E. Wahlen Department of Veterans
Affairs Medical Center(801) 582-1565
or 1-800-613 4012

Your Physician _____

Nurse Liaison _____

Social Worker _____

Dietitian _____

Pastor/Clergy _____

Family and Community Liaison ext. 1432
(after business hours or week-ends) . . ext. 1900

Hospital Chaplain ext. 1587, 1588 or 1589

Ethics Committee Ext. 1814

Hospital Outpatient Pharmacist ext. 1221

Hospital Library ext. 1209

The following are available at the library:

Video on Advance Directives:

Title: “The Decision is Yours”

There is a wide range of brochures available in the library about grieving, advance care planning and a large number of diseases. Many books are also available that may be of interest to you or your family at this time. The library also has access to the Internet. You can find many support groups through the Internet.

Community Resources

- Information and Referral Services 211 or
(801) 978-3333
- Alzheimer’s Association 1-800- 371-6694
- American Cancer Society
Utah Area Office (801) 483-1500
- American Diabetes Association
of Utah (801) 363-3024
- American Lung Association
of Utah (801) 484-4456
- National Kidney Foundation of Utah
(located in Provo) 1-801-226-5111
- Parkinson Disease Association
Information & Referral Center .. (801) 585-2354
- Utah AIDS Foundation (801) 487-2323

National Resources

- Alzheimer's Association 1-800-272-3900
- American Cancer Society 1-800-227-2345
www.cancer.org
www.ACSCSN.org (chat room)
- National Cancer Institute 1-800-4-CANCER
- American Diabetes Association 1-800-888-1734
- American Lung Association 1-212-315-8700
To be referred automatically to
your state organization . . . 1-800-LUNG-USA
- National Kidney Foundation, Inc. . . 1-800-622-9010
- Parkinson's Disease Foundation 1-800-457-6676

Glossary

Advanced Directives: This legal document gives a physician instructions concerning desired medical treatment in the event a person becomes terminally ill and also loses the ability to communicate his or her wishes at the time. See also Living Will.

Affirm: To positively confirm an idea or thought.

Affirmation: To make a positive statement about a relationship.

Anemia: Having too few red blood cells. Symptoms of anemia include feeling tired, weak, and short of breath.

Anorexia: Poor appetite.

Benign: A term used to describe a tumor that is not cancerous.

Bone Marrow: The inner, spongy tissue of bones where blood cells are made.

Break through pain: Pain that occurs due to excessive activity or infrequent procedures that require increased pain medication for a specific length of time.

Cancer: A general name for more than 100 diseases in which abnormal cells grow out of control; a malignant tumor.

Caregiver: A caregiver is a person who directly provides some form of service, assistance, or support to another.

Central Venous Catheter: A special thin, flexible tube placed in a large vein. It remains there for as long as it is needed to deliver and withdraw fluids.

Chemotherapy: The use of drugs to treat cancer. There are times when these medications may be recommended for symptom management

Clinical Trials: Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent or treat cancer.

Colony-stimulating factors: Medication that stimulates the production of blood cells. Treatment with CSF's can help the blood-forming tissue recover from the effects of chemotherapy and radiation therapy.

Comfort Measures: All medical treatment is given with the goal of providing comfort. When no other treatment is possible, comfort is always provided.

Decedent: A decedent is a person who has died. The term is used frequently in the course of estate settlement.

Durable Power of Attorney for Healthcare: Individual designated to make healthcare decisions for the patient when he/she can no longer do it.

Edema: An increased amount of fluid in the body tissues, usually in the arms or legs.

Guardian: A guardian is a person appointed by the court to control and manage another person's affairs and/or property. Most typically, a guardian is appointed to manage the affairs of an adult who is incapable of looking after his or her own affairs.

Hospice: Medical care provided to terminally ill people and their families, that emphasizes pain management and controlling symptoms, rather than seeking a cure or prolonging life.

Living Will: This legal document gives a physician instructions concerning desired medical treatment in the event a person becomes terminally ill and also loses the ability to communicate his or her wishes at the time. See also Advanced Directives.

Malignant: Used to describe a cancerous tumor.

Metabolism: This is the process where the body takes in nutrients and at a cellular level converts these nutrients to energy.

Metastasis: When cancer cells break away from their original site and spread to other parts of the body.

Palliative Care: Treatment to relieve, rather than cure, symptoms caused by cancer and other diseases. See also Hospice, Comfort Care.

Platelets: Special blood cells that help stop bleeding.

Radiation Therapy: Cancer treatment with radiation or high-energy rays.

Red blood cells: Cells that supply oxygen to tissues throughout the body.

Remission: The partial or complete disappearance of signs or symptoms of disease.

Spirituality: The quality which gives your life meaning and direction; your experience with the sacred. It may or may not have its roots in traditional religion and worship of God or a higher power.

Stomatitis: Sores on the lining of the mouth.

Symptom Management: Medically taking care of side effects related to disease or treatment of disease.

Tumor: An abnormal growth of cells or tissues. Tumors may be benign (noncancerous) or malignant (cancerous).

White blood cells: The blood cells that fight infection.



NOTES

