

# Hospice 101 Aide Inservice

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## What is Hospice?

Hospice is a special kind of care for people who are dying that treats the physical, emotional and spiritual needs of the patient. Hospice concentrates on quality of life and making the patients final days as pain and symptom free as possible. Over 50% of hospice have cancer, other common reasons a patient is on hospice are heart disease, lung disease, end stage Alzheimer's, AIDS, kidney disease and CVA. Any patient that has a life expectancy of 6 months or less and is declining aggressive treatment is eligible for hospice. A patient or family member can "REVOKE" or change their mind about being a hospice patient at any time. If a hospice patient or their family tells you that they have changed their mind notify hospice immediately so that we can call the hospice and let them know. Hospice is supportive care it does not hasten a death or prolong life.

## Do not resuscitate—DNR

A DNR order means that the patient does not want CPR when he or she stops breathing or has cardiac arrest. A patient or their family can "REVOKE" or change their mind about a DNR at any time and request resuscitation. It is not required to have a DNR order to be on hospice. Please be sure to inquire about DNR status when starting a hospice case. Most patients on hospice will have a DNR.

## What to do when a hospice patient dies?

- If there is no DNR order start CPR and call 911
- After 911 arrives and takes over –call the agency.
- If there is a DNR order-
- Be supportive to the family
- Call the hospice and a nurse will come to the home and pronounce the patient and take care of final arrangements with the family.

While you are waiting for the hospice nurse-

Allow the family time to grieve. Straighten up the bed linens and lower the head of the bed, wash the patients face if needed. Other family may be coming to view the body at then home so make the area as pleasant as possible. Clear away unneeded supplies etc. NEVER COVER THE PATIENTS FACE unless the family requests it. DO NOT leave before the hospice nurse arrives unless instructed to by the staffing coordinator.

## Signs and symptoms of the dying patient

**Lack of Appetite-** The dying patient may not want food or fluids, this a natural part of the dying process, do not force fluids or food on a patient that does not want them. The patient may "aspirate" or choke on the food or fluid causing pneumonia or other complications. Many dying patients have dysphagia or inability to swallow. If a patient requests food and fluid and is able to swallow allow then to eat and drink what they can tolerate. Family members will often have anxiety when their loved one stops eating and drinking be supportive to the family.

**Increased sleeping and drowsiness-** Dying patients will spend a lot more time asleep and may be difficult to awaken. There may also be periods when the patients is wide awake, encourage the family to visit when the patient is awake.

**Decreased urine output-** The dying patient may have decreased urination and may not have regular bowel movements.

**Nausea and vomiting-** Nausea is the uncomfortable feeling in your stomach which may or may not lead to vomiting. If your client is nauseous ask the family if they have medication to relieve it. The medication may be a suppository, a pill or topical cream. Vomiting is the throwing up of stomach content's, it is not the same as coughing up drainage from the lungs and throat. Common causes of nausea and vomiting are chronic pain, intestinal blockage, and fatigue. Patients also may have these symptoms as a result of medication they are taking.

#### **What should you do when a patient is vomiting?**

- Raise the head of the bed or keep the client in a sitting position
- If the client is not responsive or can not sit up, roll them on their side, do not leave the client unattended.
- Apply a cool wet cloth to the forehead
- Avoid fatty foods and those with a strong odor
- Offer fluids as tolerated, ice chips, ice pops, Jell-O, Gatorade ginger ale and other
- Encourage fluids to be sipped slowly through a straw
- NEVER FORCE A CLIENT TO EAT OR DRINK
- If the client starts running a fever or has a new cough or congestion after vomiting
- Notify the nurse ASAP. These are signs that your client has aspirated food or fluid into their lungs and will need medical intervention

**Constipation-** Dying patients are prone to constipation due to immobility and as a result of taking pain medication. Medications can be effective in treating constipation. Notify the nurse and family if the client has had no bowel movement in 3 days.

**Diarrhea-** Diarrhea is loose watery stools more then 3 times a day. Common causes are intolerance to certain foods, disease process, anxiety, effects of medications and viruses.

What can I do?

- Increase fluids if tolerated
- Offer small frequent meals instead of 3 large meals
- Record bowel movements and report to the nurse
- Keep the anal area clean and dry

#### **Dehydration- in Hospice Care**

Dehydration is not painful, studies suggest that dehydration may be a natural analgesic (pain killer) in dying patients. It is a natural process at the end of life and there is evidence that patients do not die sooner than those on artificial hydration ( IV's). In fact hydrating a dying patient can cause other problems such as fluid overload, placing an undue burden on the body. It is very difficult for family members to watch their loved ones not taking food and fluids, be supportive of their feelings. The nurse or hospice team can help with the family if needed. Signs and symptoms of dehydration are decreased urine output, less congestion, fever, decrease in swelling, poor skin turgor ( skin is dry and has poor elasticity ), and dry mouth. Frequent mouth and skin care are needed

#### **Mouth care for a sore mouth**

- Use a soft toothbrush and flavored toothpaste, if the mouth is too sore soft swabs or toothettes may be used
- Dilute mouthwash- regular mouthwash may be to strong and cause pain
- Leave dentures out until the pain is better

- A prescription pain reliever for the mouth can be ordered by hospice
- Keep lips moist using chap-stick type lip balm

### **Skin Care-**

Bathing can be a very tiring process for a dying patient. Patients will often only need sponge bath with mild soap and water with good peri care alternating with a full bed bath. A dying patient's skin is usually dry and fragile, do not rub skin wash gently and pat dry. NEVER LEAVE A WEAK PATIENT UNATTENDED IN THE TUB OR SHOWER.

### **Turning and Positioning-**

A patient who is confined to bed and can not turn himself should be positioned every 2-3 hours. If your client has severe pain and is comfortable, this may be delayed.

Use a draw sheet under the patient for positioning, do not pull the patient across the sheets, to prevent skin BURN from friction. Look for RED areas or skin breakdown and report it ASAP. Massaging skin with lotion will keep skin moist and help prevent breakdown. Use a light circular motion and do not RUB.

### **Breathing Difficulty-**

Dying patients often become short of breath or have increased congestion in their airways. This may be due to the disease process or a sign that death is near. The patient may start to breathe rapidly and turn a bluish color. You may notice noisy breathing or wheezing.

### **What to do –**

- Remain calm
- Elevate the patients head – NEVER LEAVE THE PATIENT FLAT
- If the patient has , turn it on or increase the liter flow if the patient is already on oxygen.
- The patient probably has medication to ease their breathing, ask the family if the patient has medication.
- Notify the hospice nurse

### **Oxygen Therapy-**

Do not smoke, use matches, lighters or gas stoves near oxygen

Oxygen may be delivered via a mask or nasal cannula. The prongs of the nasal cannula must be in the patient's nose to deliver oxygen to the patient, a mask must fit snugly on the face but not be too tight, this can be adjusted using the elastic strap on the mask

The nurse will let you know the regular flow rate for the oxygen. Home patients generally have an oxygen concentrator in the home that pugs into the wall, you will notice one or two sponge like filters on the sides or back of the machine. These filters pop out easily and need to be washed with warm water to remove dust at least every other day or whenever they are dirty. Dirty filters will clog the flow of oxygen to the patient. There should also be a water bottle (humidifier) on the front of the machine with 2 markings on the bottle the water level must remain between these lines. To fill the water, unscrew the bottle from the cap and fill with tap water and replace. If the power goes out there should be a portable green

oxygen tank available to use until the power is restored. Be sure to locate the tank BEFORE there is an emergency and know how to use it. If you do not know how, call the office and the nurse will teach you. There is no need for the humidifier bottle to be used on a portable tank. If the power is out over one hour call the office and hospice so that

alternate arrangements for oxygen can be made. Depending on the size of the tank and liter flow the tanks should last from 4- 8 hours.

### **The oxygen is not flowing though the tube – what to do**

Place the end of the cannula into a glass of water if there are no bubbles there is no flow of oxygen—check the water bottle if there are no rapid bubbles in the bottle, the problem is after the bottle. If there is no bubbling in the bottle, check that the connection to the machine is tight. The water bottle also has a screw type lid make sure it is tight. If the bottle is bubbling check the tubing, be sure it is tight on the water bottle, and follow the tubing to the patient looking for chair legs etc.that may be on the tubing cutting off the flow. If there is still no flow, change the tubing if there is a spare. If all else fails call the hospice nurse for assistance.

### **Itching-**

Itching is a common complaint for hospice patients due to disease process, dry skin, medications. What to do –

- Bathe with warm– not hot—water
- Add baking soda or bath oil to water
- Wash gently DO NOT RUB
- Keep room cool
- Give fluids as tolerated
- Use loose clothing
- Apply skin cream
- Ask family of patient has medication for itching, this may be an oral medication or a cream
- Notify the hospice nurse if itching persists

### **Active dying process**

When a patient is “actively dying” you will notice many changes these may or may not include:

- Blue or purple color of the feet and hands which can extend to the arms and legs, these areas will also feel cool or cold to the touch
- The patient will probably sleep most of the time and you may be unable to arouse the patient.
- Be aware that the patient can probably hear what is said during this time. It is helpful and comforting to touch the patient and speak to him during this time.

Breathing will become irregular and may be noisy and congested. The patient may stop breathing for several seconds, this is called apnea. Apnea may increase as the process goes on. Fluid may accumulate in the back of the throat due to inability to cough up secretions or clear the throat.

Vital signs will change, you may not even be able to hear the blood pressure. The pulse will become irregular and radial and pedal pulses may be difficult to count as circulation worsens. The pulse may become rapid or slow and the blood pressure is usually very low. The patient may suddenly run a fever.

Urine output may become less and urine may be dark and foul smelling.

**\*\*\*Notify the hospice nurse when these symptoms appear.\*\*\***

### **Observations to report to the supervising nurse**

*Observe client closely for the following and report observations promptly and accurately:*

- **Abdomen**—distended, hard, rigid, painful or tender
- **Accidents or Incidents**—time, witnesses, observation of injury, (bruises & abrasions) cause or suspected cause of
- **All Symptoms**—complained of by the client (This includes symptoms observed not complained of)
- **Appetite**—loss of appetite, failure to eat a meal (May be diabetic), eating of additional foods while on restricted diet. Report any difficulty the client may have swallowing, chewing or feeding himself.
- **Bath**- failure to give bath. Refusal of client to receive bath or other routine nursing service for which you are responsible
- **Bowel**—diarrhea, stool of unusual color (clay, black with blood), hard formed stool. Failure to defecate or variation from normal established bowel habits
- **Breath**—peculiar odor, such as unpleasant, foul, sweet, fruity, or smells of alcohol
- **Change in General Appearance**—weak depressed, apathetic, apprehensive, hysterical
- **Change in Respirations**—difficulty breathing (dyspnea), rapid respiration, gasping, inability to breathe except when sitting or standing erect, painful breathing
- **Change in Skin Color**—sudden pallor, flushing, cyanosis or blotching
- **Change in Vital Signs**—temperature, pulse and respirations
- **Chills**—time and duration, severity of chill (violent or shivering). Take temperature 30 minutes after chill is completed.
- **Convulsions**—time duration, whether intermittent or continuous, mild or violent
- **Cough**—exhausting, harsh, tight, dry, hacking, painful or wheezing. If productive, report quantity, color (rusty, green, bloody), thick or mucoid
- **Crying**—describe type of crying, e.g., fretful, sharp, whining or moaning. Report reason for crying, if known.
- **Delirium**—report if it is continuous or intermittent. Observe if there is a rambling of ideas or one persistent idea – coma or unconscious state, failure to respond
- **Discharge**—report any unusual body discharge. Describe location and types e.g., bloody, pus, or clear.
- **Dizziness**—loss of balance, complaints of dizziness or faintness
- **Eyes**—unusual observations such as blood shot, dull, yellowish color, anxious look in eyes, inflammation, watery and tearing, sensitivity to light, twitching lids, pupils contracted, dilated or unequal, constant involuntary movement of eyeballs or fixed look.
- **Mental Disturbance**—anxiety, tension, stress—may be revealed in a combination of symptoms such as rapid breathing with occasional deep sighing and restlessness, trembling, increase perspiration, itching, “White as a sheet”, “Hot under the collar”, “Covered with goose flesh”, failure to answer questions, rambling conversation, shaky voice
- **Nausea or Vomiting**—report self-induced vomiting, projectile (with force projection) vomiting. Describe color (bloody, coffee ground color, greenish), consistency (liquid or undigested food)
- **Oral Hygiene**—Report lost or broken dentures or bridgework, mouth sores, tenderness, bleeding gums.
- **Physical Activities**—report failure of ambulatory client to get out of bed and/or refusal to walk and exercise.
- **Skin Condition**—dry skin, scales, rashes, hives, blotching, boils, itching, reddened areas, bruises, abrasions, bedsores, or open raw areas.
- **Sleep**—moaning while sleeping, restless, inability to sleep or sleeps at short intervals.
- **Swelling (Edema)**—location: generalized or local as legs and feet, color changing accompanying swelling.
- **Urine**—unusual odor, color, cloudy or bloody, change in output, failure to void, catheter drainage system not open or daring an adequate of urine

## Health aide helpful reminders

1. Always check with facility nurse prior to seeing patient to see how your patient is doing or anything you need to know.
2. Check the Health Aide Care Plan in the Hospice Chart at the facility. This will tell you if it is their shower day, hoyer lift, etc.
3. Then provide care to the patient. If the facility has already given the patient a shower, then you will give a complete bed bath or what the patient would prefer if able to voice to you.
4. If you come during meal time, offer to feed or assist your patient with meal. This will allow you to see how well they are eating.
5. Complete Aide visit form: In the Comment section/Note be sure to note if/when patient last voided. (EX: NO VOID DURING VISIT or VOIDED X1).
6. Reporting: Once you have completed your Aide Visit Note you need to find a facility nurse and report off to them about your patient and have he/she sign off on aide visit form underneath your signature
7. During your visit, if any changes are going on with your patient, or patient refusing care. YOU MUST NOTIFY YOUR CASE MANAGER AND ALSO DOCUMENT ON AIDE VISIT NOTE.

## Important issues and decisions

Sometimes people with terminal illnesses have to make decisions about how much treatment they want to have and how long they want to prolong life. Family members may have to make these decisions when the individual is too ill to decide. We must respect and support these decisions even if we do not agree with them—adults have the right to make these decisions.

### Life-sustaining therapies

A life-sustaining treatment is anything used to maintain one or more physical functions in a terminally ill person. This includes machines that breathe for the person, usually called respirators or ventilators. It also includes feeding someone by artificial means, such as through the veins or through a tube into the stomach. Therapies like this keep a person alive when they can no longer eat or drink or breathe without this kind of assistance.

### Withholding and withdrawing treatment

Sometimes a terminally ill person (or the family) may decide to let a doctor start a treatment that will keep the person alive. Then, after a time, it might become obvious that the therapy is not meeting the goals of care, or is doing more harm than it is good. For example, feeding someone through the veins or through a stomach tube can cause swelling, choking, difficulty breathing, discomfort, restlessness, nausea, constipation, and increased pain. If the

life sustaining treatment is causing this kind of discomfort for a terminally ill person, the person and/or his family may decide that they want to stop the therapy and let the illness take its natural course toward death.

Stopping a life-sustaining therapy is legally and ethically acceptable. It is also acceptable not to start the therapy at all if the terminally ill person and/or his family decide that the treatment is not in the person's best interests. The benefits of treatment should be compared to the burdens of treatment when making these decisions.

### Do not resuscitate

An order for "do not resuscitate" (DNR) means the person does not want cardiopulmonary resuscitation (CPR) performed if their heart stops and they stop breathing. It does not affect anything else about their care. An individual with a DNR order may still want every other kind of life sustaining treatment, such as tube feeding.

## **Advance directives**

Advance directives are any oral or written instructions that a person has given about future medical care. These instructions are to be used if the person becomes unable to speak for himself.

There are two kinds of advance directives: a living will and a medical power of attorney. A living will states the person's medical treatment wishes in writing. A medical power of attorney (or durable power of attorney for healthcare) appoints someone to make decisions about medical care when the person cannot make

them. If there is no living will or medical power of attorney, the spouse, children, or parents of an individual will make medical decisions when the person cannot make them. This person is called a surrogate. The surrogate is supposed to make healthcare decisions that the terminally ill person would have made, if possible, and to act in the person's best interests.

Every state has different rules about advance directives. Federal law requires healthcare facilities and agencies that receive Medicaid or Medicare funds to inform residents and patients of their right to issue advance directives.

## **Two ways to view the end of life**

### **Curing**

The "medical model" of dying says there comes a time when all possible treatments have been tried and there is nothing left to do that will prevent death. In this view, we must "give up" fighting against death when we have no other choice.

When doctors, nurses, and direct caregivers think this way, they might quit giving good care to a dying person because they feel there is nothing more that can be done. They feel that they have lost control because they can't "fix" the problem, and may feel helpless and guilty. These feelings can lead them to avoid the dying person. People at the end of life can sense this in their caregivers, and they may fear being abandoned. This fear increases their loneliness and discomfort.

### **Caring**

The "caring model" of dying says the end of life is an important period of dying of an individual's life. During this final phase, curing the problem is no longer possible, and the focus shifts to caring for the person. When caregivers think this way, they concentrate on the many things they can do to make a dying person comfortable, to improve the quality of the dying person's life, and to provide opportunities for the person to meet his or her final life goals.

When caregivers focus on caring, they shift their energies from whether the person will die to how they will die. Helping to relieve pain and other symptoms, giving emotional and spiritual support, and providing family time are all things that caregivers can do to care for a dying person.

### **The rights of a dying person**

1. An individual has the right to decide how to spend the final phase of his or her life.
2. A dying person has the right to refuse treatment (including food and water) and to decide how much treatment to have.
3. A dying person has the right to relief from pain and suffering, as much as is medically and legally possible.

### **The goals of end-of-life care**

Each individual should decide what his or her goals are for the final phase of life. Caregivers can help people identify and achieve these goals. The goals may include things like:

1. The individual's personal goals and desires, such as personal choices about living, continued personal growth, and things he or she wants to accomplish.
2. Relief from pain and other uncomfortable symptoms.
3. Relief from emotional and spiritual distress.
4. Enrichment of personal and family relationships.
5. Transition of individual and family toward death.

### **Your role in caring for someone at the end of life**

You should remember two important concepts when caring for someone who is terminally ill:

#### **Acceptance**

The first thing you must do when caring for someone who is at the end of life is to accept the person and the choices they make about how to live and how to die. You must accept their religious beliefs, the values of their cultural and ethnic background, and their wishes about what they want to do and whom they want to see. You must accept the person without judging his or her decisions. Your job is to listen, encourage, and support the decisions he or she makes.

If you find that it is impossible for you to support a dying person because you feel strongly that their decisions or beliefs are wrong, you must tell your supervisor about it. Sometimes it is necessary for the supervisor to transfer your responsibilities for the dying person to another caregiver. A terminally ill person will probably know when a caregiver disagrees with his or her choices, and this can cause the person to feel afraid, abandoned, or defensive. In this case, it is best for someone else to care for the person if possible.

#### **Relief of suffering through effective care**

Good care can relieve much of the pain and discomfort that a person may experience during a terminal illness. You should always be checking to see if the person is uncomfortable, and finding ways to improve the comfort level. Some things you can do include:

- Position pillows comfortably.
- Moisten lips and mouth.

- Rub lotions on the skin.
- Position body comfortably.
- Provide good oral care.
- Watch for skin breakdown; give skin care.

Pain is not the only symptom that should be relieved. Nausea, constipation, anxiety, depression, difficulty breathing, and other symptoms should be reported to your supervisor so they can be treated with medications and other therapies.

When a person is dying, the need and the desire for food and water decrease. You should not force food or water on someone who doesn't want it. Remember that competent adults have the right to refuse any treatment, including food and water. Often a terminally ill person will have a craving for a particular food, but when it is brought to them, they will take only one or two bites and say they are finished. The best thing to do is get them the food they want if at all possible, but don't force them to eat it. One bite may satisfy the craving.

A dying person may not want to drink anything, but the lips, mouth and throat might get dry. You can relieve this discomfort with small sips of liquid, ice chips, hard candy, and oral hygiene. You should not force someone to drink more than they want.

Don't be worried about "starving" someone to death if they are dying from a terminal illness. The illness is causing death; death is not caused by the decrease in food and water. If the person is allowing the natural processes of death to occur, they will only want enough food and water to be comfortable. Giving food and water only when it is wanted can allow chemical processes to occur in the body that actually decrease pain and discomfort. Forcing food and water on a dying person can greatly increase pain and suffering and cause a more difficult death.