TRAIN FOR SUCCESS INC.
DEATH AND DYING 2Hr

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PURPOSE

The purpose of this course is to review some of the decisions that some individuals face as they approach the end of their lives, review type of assistance or caregiver help they need, whether to receive care within an institution/ facility treatment setting or whether to receive care within their home. Review of the role of the family and the assistance / emotional support that the caregiver requires as well as resources that are available in the community. Excellent course to educate and reinforce the knowledge of nurses; ARNP, RN, LPN, CNA/ HHA and Therapists who are working in the Health care environment, as well as other individuals /students who would like to work within the Health care or Hospice setting.

OBJECTIVES

After successful completion of this course the students will be able to:

1. Discuss end of life care support and resources that are available
2. Discuss some of the decisions that some individuals face as they approach the end of their lives
3. Discuss the type of assistance or caregiver help needed
4. Describe comfortable clothing options
5. Discuss end stage illness and various nutritional approach
6. Discuss medication management and Hospice care setting.

DEATH AND DYING

APPROACHING END OF LIFE

When individuals approach the end of their lives, they often face decisions and tasks that involve a wide range of choices such as:

Type of assistance or caregiver help they need

Whether to receive care within their home

Whether to receive care within an institution/ facility treatment setting.

END-OF-LIFE DECISIONS

End of life decisions are frequently most challenging for terminally ill individuals and their loved ones and also those who are involved in their care.

The dying person may make choices about:

End of life medical decisions

How to spend the limited time

Where to spend the limited time (At home with family or home care/ hospice care)

How to deal with any unfinished business

Religious preparations

Time to reflect on the meaning of life

Psychological factors – dealing with unfinished issues or asking someone to forgive any wrong doing of the past

FAMILY INVOLVEMENT

The dying person often have to make end of life choices, medical decisions, choices about family involvement; who should be involved and the degree of family involvement as well as what family members should be involved in specific areas of care such as who should be involved in making legal decisions about wills, durable powers of attorney and/or advanced directives.

RESPONSIBLE FOR MAKING DECISIONS FOR THE DYING PERSON

For the dying person, the relief of suffering, his/ her beliefs and values are very important. Therefore family members who are involved in making decisions for them need to know and understand their loved ones values and wishes, so that their wishes will be honored.

Some helpful tips include making a list of:

- Emergency contacts
- Medications that are ordered
- When the medications should be taken
- Physicians who are involved in their care and their contact information (telephone number)
- Home healthcare agencies/ Hospice care
- Financial advisors / Lawyers

- Other individuals who can help when additional help is needed

SUPPORT

Death and dying often brings increased stress for the dying person, the family, significant other/ loved ones and the care-givers; nurses, CNA and others involved in their care. Psychologists can be of help; they are trained and can assess mental functioning, pain and mood. The Psychologists can also treat anxiety, depression, as well as other mental health problems, they can advocate for appropriate medical care and they can provide end of life counseling to the dying and their caregivers, families and others involved in their care.

Click on link for detail:

DEATH & DYING AMONG VARIOUS AGE GROUPS

END-STAGE ILLNESS AND NUTRITION

Ask for a nutritional consultation for help as needed. In the last weeks of life the body is shutting down and the individual may want less food. At this time, it is best to offer small amounts of the food that the individual enjoys (if able to take by mouth). Chewing food does require energy, therefore the dying person may prefer pudding, milkshakes or ice cream.

MEAL DELIVERY AND OTHER MEAL PROGRAMS

There are some meal programs that are available to assist, such as: home delivered meals programs and other meals programs.

You may contact: (click on links)

Meals on Wheels,

National Eldercare Locator

State or Area Agency on Aging

Other options also include contacting the grocery stores and find out if they prepare food orders for home delivery or for pick-up.

Patients with end-stage illness often experience various symptomatic problems which affect their ability to eat, such as:

TASTE ALTERATIONS

Ageusia - is the loss of taste functions of the tongue/ the inability to detect saltiness, sourness, sweetness, bitterness, and umami; meaning pleasant/savory taste. Other alterations may include hypogeusia; a partial loss of taste and/ or dysgeusia; a distortion or alteration of taste.

Some suggestions to offer the patients may include:

- Drinking and/ or rinsing mouth with ginger ale, carbonated water, or tea after every meal to get rid of bad taste
- Experimenting with new foods and flavors
- Using condiments on meat, chicken and fish.

CHEWING PROBLEMS

Some suggestions to offer the patients may include:

- Moisten foods

- Trying baby foods; spice to taste or add to broths and soups
- Modifying food consistency, changing from soft to ground consistency to pureed depending on the severity of problem
- Include in meal plan: cooked and cold cereals, stews, soups, eggs, custards, puddings, and liquids
- Mash, chop, or strain cooked fruits and vegetables

DRY MOUTH

Some suggestions to offer the patients may include:

- Increasing fluid intake
- Encourage patients to frequently rinse mouth with salt water. Avoid the commercial mouth wash due to the alcohol content which leads to dryness.
- Use of a humidifier
- Using moistened mouth swabs

SWALLOW DYSFUNCTION (DYSPHAGIA)

Some suggestions to offer the patients may include:

- Modify food consistencies - See chewing problems mentioned earlier
- Encourage high-calorie supplements
- Thicken liquids are often better tolerated than thin liquids. May add mashed banana or ice cream to milk or milk shake to make it thicker.
- Encourage liquid multivitamin.

EARLY SATIETY OR BLOATING

Some suggestions to offer the patients may include:

- Eating small, frequent meals
- Eat slowly
- Sitting upright while eating
- Eating easily digestible foods
- Avoid fatty foods
- Avoid gas forming vegetables
- Drink fluids between meals rather than with meals

CONSTIPATION

Some suggestions to offer the patients may include:

- Drinking plenty of fluids
- Drinking a glass of prune juice or hot liquid in the morning or evening to stimulate the bowel function
- Increasing bulk or fiber in diet if not contraindicated.

DIARRHEA

Some suggestions to offer the patients may include:

- Avoid foods that may cause cramps such as fatty foods, spicy foods, carbonated drink, gum, foods or drink with caffeine
- Decrease the amount of fiber in diet
- Give liquids/ fluids between meals rather than with meals
- Avoid foods containing lactose, if patient has lactase deficiency

Considerations: Potassium depletion

Potassium can be depleted with large fluid losses. If a patient has frequent diarrhea, large volume fluid losses, encourage increase fluid & potassium intake if this is not contraindicated.

Some foods which are high in potassium include:

Bananas,

Oranges,

Orange Juice,

Apricots,

Tomato Sauce,

Tomato Juice,

Watermelon,

Potatoes,

Meat,

Milk,

Kidney Beans,

Wheat Germ,

Peanut Butter,

Yogurt,

Molasses,

Raisins.

PAIN

Some suggestions to offer the patients may include:

Pain needs to be adequately managed / controlled prior to any thought of nutritional therapy.

PATIENT WITH COLOSTOMY

Some suggestions to offer the patients may include:

- Chewing foods thoroughly
- Avoid swallowing air while chewing food
- Avoid foods that may produce odors such as fish, eggs and onions
- Avoid foods that may cause irritation such as popcorn, nuts, seeds and skins from fruits and vegetables and coconut
- Avoid foods that forms gas such as: beans, cabbage, green peppers, Brussels sprouts, cucumbers, peas, onions, corn, cauliflower and broccoli.

COMFORTABLE CLOTHING OPTIONS

Clothing should always look great and make the individual feel the best.

Clothing options should include:

- Colors that the person likes and is coordinated well
- Comfortable clothing
- Clothing with zippers, snaps, buttons located in the front are much easier to open and close

- Skirts or slacks that have elastic waistbands or capable of tying at the waistbands as these are easier to put on and take off

- Non-skid shoes.

HOSPICE CARE

Hospice care is a healthcare option for patients and families who are experiencing/ facing a terminal illness. Hospice focuses on caring, not curing and most frequently Hospice care is provided in the patient's home.

Hospice care may also be provided in:

- Hospice care centers,
- hospitals,
- nursing homes and
- Other long-term care facilities.

HOSPICE CARE SERVICES

Hospice services means items and services furnished to a patient and family by a hospice, or by others under arrangements with such a program, in a place of temporary or permanent residence used as the patient's home for the purpose of maintaining the patient at home; or, if the patient needs short-term institutionalization, the services shall be furnished in cooperation with those contracted institutions or in the hospice inpatient facility.

HOSPICE CARE TEAM

Hospice care team is defined as an interdisciplinary team of qualified professionals and volunteers who, in consultation with the patient, the patient's family, and the patient's primary / attending physician, collectively make assessments, coordinate, and provide the appropriate palliative and supportive care to the hospice patient and the family.

The multi-disciplinary team includes, but not limited to:

- Physicians/ patient' s personal physician,
- Hospice physician (or medical director),
- nurses,
- hospice aides/ Home health aides,
- social workers,
- bereavement counselors
- Clergy /Chaplain
- volunteers
- Physical, Speech, and occupational therapists, if needed.

Some of the responsibilities of the interdisciplinary hospice team include:

- Assist to manage the patient's pain and symptoms,
- Provide the patient with needed medications, medical supplies, and/or equipment,
- Assists the patient and family with the emotional, psychosocial and spiritual aspects of dying,
- Educate the family/ caregiver regarding how to care for the patient,
- Schedule Home Health Aide /certified Nursing Assistants to provide personal health care services to the patient,
- Provides short-term inpatient care available when pain and/or symptoms become too difficult to manage at home,

- Makes short-term inpatient care available when the caregiver needs some respite time,
- Develops a care plan that meets each patient's individual needs,
- Provides special services such as speech, physical and occupational therapy when needed
- Provides bereavement care / counseling to surviving family and friends.

The hospice interdisciplinary team provides care to patients in their own home or in a home-like environment regardless of the age of the patient and address issues that are most important to the patients need and want at the end of their life while focusing on maintaining the individual's quality of life. The hospice care staff makes regular visits to assess the patient, provide additional care and/or other services that the patient may require. Hospice staff is always on-call 24 hours a day, seven days a week.

Hospice care is covered by:

- Medicare,
- Medicaid,
- Most private insurance plans, and
- Other managed care organizations.

MEDICATION MANAGEMENT

HOSPICE CARE ENVIRONMENT

CONDITION OF PARTICIPATION (§418.106)

Drugs and biologicals, medical supplies, and durable medical equipment.

Standard: Managing drugs and biologicals

The hospice must ensure that the interdisciplinary group confers with an individual with education and training in drug management as defined in hospice policies and procedures and State law, who is an employee of or under contract with the hospice to ensure that drugs and biologicals meet each patient's needs.

Hospices must confer with an individual with education and training in drug management, and use acceptable standards of practice for hospice patients to select the most appropriate drugs to meet a particular patient’s need. Conferences may take

place in person or through other means of communication for example teleconference, FAX, electronically etc.

The hospice should also be able to explain drug choices to those providing patient care, the patient or representative, the family, and any authority having jurisdiction, as necessary.

Individuals with education and training in drug management may include: licensed pharmacists; physicians who are board certified in palliative medicine; RNs who are certified in palliative care; and physicians, RNs and nurse practitioners who complete a specific hospice or palliative care drug management course, and other individuals as allowed by State law.

The hospice must be able to demonstrate that the individual has specific education and training in drug management.

A hospice that provides inpatient care directly in its own facility must provide pharmacy services under the direction of a qualified licensed pharmacist who is an employee of or under contract with the hospice.

The provided pharmacist services must include:

- Evaluation of a patient's response to medication therapy,
- Identification of potential adverse drug reactions, and
- Recommended appropriate corrective action.

Standard: Ordering of drugs

Only a physician as defined by Section 1861(r)(1) of the Act, or a nurse practitioner in accordance with the plan of care and State law, may order drugs for the patient.

If the drug order is verbal or given by or through electronic transmission:

(i) It must be given only to a licensed nurse, nurse practitioner (where appropriate), pharmacist, or physician; and

(ii) The individual receiving the order must record and sign it immediately and have the prescribing person sign it in accordance with State and Federal regulations.

Standard: Dispensing of drugs and biologicals

The hospice must:

(1) Obtain drugs and biologicals from community or institutional pharmacists or stock drugs and biologicals itself.

(2) The hospice that provides inpatient care directly in its own facility must:

(i) Have a written policy in place that promotes dispensing accuracy; and

(ii) Maintain current and accurate records of the receipt and disposition of all controlled drugs.

A biological is any medicinal preparation made from living organisms and their products including, but not limited to, serums, vaccines, antigens, and antitoxins.

Standard: Administration of drugs and biologicals

(1) The interdisciplinary group, as part of the review of the plan of care, must determine the ability of the patient and/or family to safely self-administer drugs and biologicals to the patient in his or her home.

(2) Patients receiving care in a hospice that provides inpatient care directly in its own facility may only be administered medications by the following individuals:

(i) A licensed nurse, physician, or other health care professional in accordance with their scope of practice and State law;

(ii) An employee who has completed a State-approved training program in medication administration; and

(iii) The patient, upon approval by the interdisciplinary group.

The patient's individualized written plan of care should identify if the patient and/or family are self-administering drugs and biologicals. If the patient and/or family are not capable of safely administering drugs and biologicals in the home, the hospice must address this issue in the patient's plan of care.

Standard: Labeling, disposing, and storing of drugs and biologicals

(1) ***Labeling***

Drugs and biologicals must be labeled in accordance with currently accepted professional practice and must include appropriate usage and cautionary instructions, as well as an expiration date (if applicable).

(2) ***Disposing***

(i) Safe use and disposal of controlled drugs in the patient's home. The hospice must have written policies and procedures for the management and disposal of controlled drugs in the patient's home. At the time when controlled drugs are first ordered the hospice must:

(A) Provide a copy of the hospice written policies and procedures on the management and disposal of controlled drugs to the patient or patient representative and family;

(B) Discuss the hospice policies and procedures for managing the safe use and disposal of controlled drugs with the patient or representative and the family in a language and manner that they understand to ensure that these parties are educated regarding the safe use and disposal of controlled drugs; and

(C) Document in the patient's clinical record that the written policies and procedures for managing controlled drugs was provided and discussed.

(ii) Disposal of controlled drugs in hospices that provide inpatient care directly. The hospice that provides inpatient care directly in its own facility must dispose of controlled drugs in compliance with the hospice policy and in accordance with State and Federal requirements. The hospice must maintain current and accurate records of the receipt and disposition of all controlled drugs.

Storing

The hospice that provides inpatient care directly in its own facility must comply with the following additional requirements;

(i) All drugs and biologicals must be stored in secure areas. All controlled drugs listed in Schedules II, III, IV, and V of the Comprehensive Drug Abuse Prevention and Control Act of 1976 must be stored in locked compartments within such secure storage areas. Only personnel authorized to administer controlled drugs may have access to the locked compartments; and

(ii) Discrepancies in the acquisition, storage, dispensing, administration, disposal, or return of controlled drugs must be investigated immediately by the pharmacist and hospice administrator and where required reported to the appropriate State authority. A written account of the investigation must be made available to State and Federal officials if required by law or regulation.

Standard: Use and maintenance of equipment and supplies

(1) The hospice must ensure that manufacturer recommendations for performing routine and preventive maintenance on durable medical equipment are followed. The equipment must be safe and work as intended for use in the patient's environment. Where a manufacturer recommendation for a piece of equipment does not exist, the hospice must ensure that repair and routine maintenance policies are developed. The hospice may use persons under contract to ensure the maintenance and repair of durable medical equipment.

(2) The hospice must ensure that the patient, where appropriate, as well as the family and/or other caregiver(s), receive instruction in the safe use of durable medical equipment and supplies. The hospice may use persons under contract to ensure patient and family instruction. The patient, family, and/or caregiver must be able to demonstrate the appropriate use of durable medical equipment to the satisfaction of the hospice staff.

(3) Hospices may only contract for durable medical equipment services with a durable medical equipment supplier that meets the Medicare DMEPOS Supplier Quality and Accreditation Standards at 42 CFR 424.57.

MEDICATION INDICATIONS FOR USE

An indication is a valid reason to use a certain medication, test, procedure, or surgery. The opposite of an indication is a contraindication; a reason to withhold a certain medication or medical treatment etc. due to the harm that it would cause the patient.

All medications have an indication for use. Most of the indications for use are related to the desired actions of the medication. If you do not know the indication for use of a medication that your patient is taking, use a reference such as a drug guide or ask your supervisor or a Pharmacist.

Some medications are not allowed to be used or they are contraindicated for some patients. Therefore, the medication should not be given to the patient. Other medications may only be used with some patients when they are used with extreme caution and with frequent monitoring.

A very common contraindication is an allergy or sensitivity to the medicines. Always check the patient's medical record for allergies and ask the patient before you assist. Sometimes you will observe NKA on the patient's medical record /chart; this indicates that the patient has no known allergies. Sometimes you may observe NKDA- this means no known drug allergies.

ALLERGY

Allergy involves hypersensitivity or an exaggerated response of the immune system, often to common substances such as medication, pollen or foods. A rash or a life threatening reaction such as Anaphylaxis can occur if the patient takes a medication that he/ she is allergic to.

Some types of Allergies include:

- Food allergies e.g. peanuts, peanut butter, shellfish
- Drug allergies
- Latex allergies e.g. latex gloves
- Seasonal allergies
- Animal allergy

Some signs of Allergic reactions include:

- Itching , Hives
- Redness of the skin
- Dyspnea, Shortness of Breath (SOB)
- Problems with breathing
- Throat swelling
- Loss of consciousness
- Irregular heart beat /rhythm
  Decrease in the blood pressure (BP)
  Abdominal discomfort / cramps
- Nausea and / or vomiting
- Death

Anaphylaxis

Anaphylaxis is a severe, whole-body *allergic reaction* to a chemical or substance that has become an allergen. An allergen is a substance that can cause an allergic reaction. Some drugs such as, Penicillin, aspirin, x-ray dye, morphine and others may cause an anaphylactic-like reaction when the patient is first exposed to them. Anaphylaxis is an emergency situation that requires medical attention immediately. Call 911 immediately.

Symptoms will develop very quickly, often within seconds or minutes. They may include:

- Difficulty breathing
- Facial swelling
- Redness of the skin
- Itchy /hives
- Light headed / dizziness
- Loss of consciousness
- Swelling of the face and eyes
- Chest tightness/ discomfort
- Palpitations
- High pitched abnormal breathing sounds
- Wheezing
- Coughing
- Speech becomes slurred
- Difficulty swallowing
- Swelling of the tongue
- Restlessness / anxiety
- Diarrhea

- Abdominal pain
- Nausea or vomiting
- Death

Medication interactions

Some medications may interact with other medications, various herbs, foods, supplements and drink for example; alcohol. Medication interactions can cause the medication that the patient is taking, to be less effective, or cause unexpected side effects, or cause an increase action of a particular medication. Some drugs interaction can be very harmful to the patient. Always read the medication label for every prescription and nonprescription medications.

Take the time to learn about the medication interactions. You will reduce the risk of potentially harmful medication interactions and / or side effects.

Medication interactions fall into three categories:

Drug to drug interactions
Drug to drug interaction occur whenever two or more medications react with each other. This drug-drug interaction may cause the patient to experience an undesired side effect / reaction, for example, patient who takes a blood thinner e.g. Coumadin and then takes aspirin for a headache will increase the risk of bleeding.

Drug to food/beverage interactions
Drug to food / beverage interactions result from medications reacting with the food or drink. For example, having alcohol with some medications may cause the patient to feel sleepy or slow his/ her reaction.

Drug to condition interactions
Drug to condition interactions may occur when the patient has an existing medical condition / disease that makes some medications potentially harmful. For example, patients with high blood pressure may experience an undesired reaction if he/she takes a cough or decongestant medication.

ADVERSE REACTIONS / SIDE EFFECTS

Side effects

A side effect is also known as an adverse effect, adverse event, or undesirable secondary effect when a medication or treatment goes beyond the desired effect and causes or leads to a problem (an undesirable secondary effect). Some side effects are not life threatening but others can be life threatening.

Side effects vary for each patient, and depend on different factors such as;

- the patient's general health,
- age,
- the stage of their disease,
- weight and
- Gender.

Adverse drug reactions

Adverse drug reactions are serious and they can also lead to death. Some medications also have toxic effects. Learn about the possible adverse drug reactions, side effects and the toxic effects of all the medications that your patient is taking so that you can report them.

DOSAGES/ DOSES

All medications have prescribed amount or dosage ranges for the adults and for children. Older patients are at greater risk for adverse drug events because of the metabolic changes and decreased medication clearance that is associated with the aging process. Some adult dosages may be lowered for the older patient because they are more susceptible to adverse medication reactions, side effects, over dose and even toxicity. Adolescents can take the adult dosages. Children are given medications with a dose that is based on their body weight.

Toxicity

Toxicity is the degree to which a substance /a toxin can cause harm to humans or animals.

- Acute toxicity involves the harmful effects in an individual or organism through short-term exposure.

- Subchronic toxicity is the ability of a toxic substance to cause effects for more than one year but less than the lifetime of the exposed organism.

- Chronic toxicity is the ability of a mixture of substances or a substance to cause harmful effects over an extended time period, usually upon continuous or repeated exposure, that can sometimes last for the entire lifetime of the exposed organism/ individual.

Toxicology is the study of adverse and/or toxic effects of drugs/medications and other chemical agents. It involves both drugs used in the treatment of diseases as well as chemicals that may cause environmental, household or industrial hazards.

Medication Routes and Forms

Route of medication administration refers to the path by which the medication is taken into the body. Medications are made in various forms and for administration by different routes. Some routes may be unsafe or ineffective. This can be due to the patient's health conditions, such as unable to swallow, dehydration or other factors. Some medications can be administered by more than one route, for example Tylenol is available in tablet form, suppository and also in liquid etc. The tablet may be taken by mouth in tablet or liquid form; however, a child might not be able to take the tablet and able to take the liquid and/ or a suppository may need to be given by a nurse per rectum if the patient is unable to take the medication by mouth. The medication order has to state the form and the route that the physician wants the patient to take.

Route of administration will vary depending on:

- The property of the medication,
- Its action of the medication,
- The desired effect,
- The patient's physical wellbeing,
- The patient's mental status,
- The patient's age.

Routes of medication administration include:

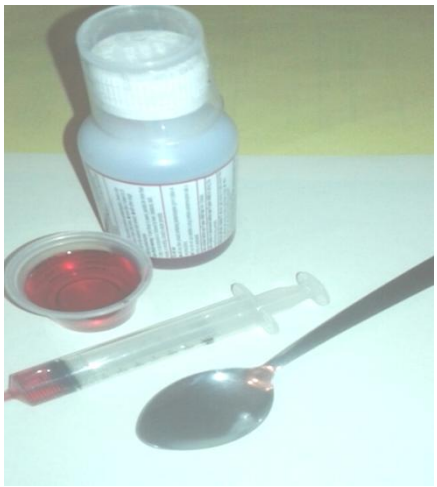
• oral route (by mouth)
• sublingual route (under tongue)
• buccal route (inside the cheek)
• otic (ear)
• ophthalmic (eye)
• topical (applied on the skin)
• nasal route (nose)
• vaginal route (vagina)
• rectal (by rectum)
• inhalation (by inhaling)
• nasogastric tube (tube in the nose to the stomach)
. gastrostomy tube (tube in the stomach)
• intramuscular (into the muscle)
• subcutaneous (under skin)
• intradermal (in the skin)
• intravenous (into the vein via an I.V)
• transdermal (through the skin e.g. a patch on the skin)

Forms of medications

Medications are made in various forms meaning that they are available in more than one form. Therefore a tablet cannot be given if the order says liquid.

Different forms of medications include:

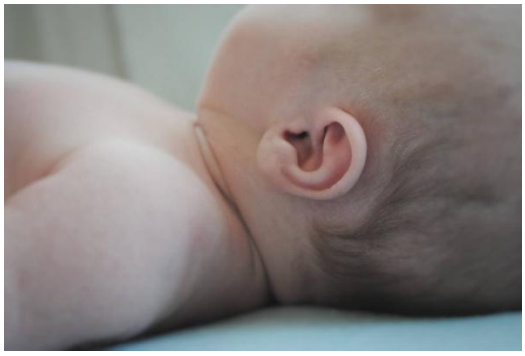
- capsule (regular and sustained release)
- tablet
- suppositories (rectal and vaginal)
- elixir
- syrup
- cream
- oral suspension
- tincture
- paste
- ointment
- drop (ears and eye)
- Intravenous /IV solutions and suspension
- metered dose inhaler



Some Route and Form considerations

When a patient is very ill or has a problem such as difficulty with swallowing, the following things can be done:

- Crush the pill and put it into applesauce or open the capsule and put it into applesauce. Some medications **cannot be crushed**. Some of these medications include time release capsules, sublingual medications, some coated tablets and other medications that may upset the stomach. Check with the Pharmacist or supervisor to find out if a medication can be crushed or what that medication can be mixed with.
- Use the liquid form of the medication. Using a liquid form can also help patients who have trouble swallowing or using the tablets and/or the capsules. At other times the nurse may have to administer the medication by I.V.



MEDICATION DELIVERY CONSIDERATIONS

Age is one factor that you must consider when giving medications;

- For an infant you may use a dropper, syringe or nipple for liquid oral medication.
- For the toddler you may use a cup or spoon for oral liquid medication.
- For the preschool and School Age children, they may be able to take tablets and capsules.
- For adolescents, they are allowed to take adult dosages, forms and routes of Medications.

TYPES OF LIFE SUSTAINING CARE

There are many types of life-sustaining care that is usually taken into consideration when considering a living will.

Some of these include:

1. Do Not Resuscitate (DNR) orders; instruction not to use Cardio Pulmonary Resuscitation (CPR) if breathing or heartbeat stops.

2. Use of life-sustaining equipment such as:

    - Dialysis machines
    - Ventilators
    - Respirators.

3. Artificial Nutrition and Hydration and nutrition such as feeding tube
4. Organ donation and tissue donation and
5. Comfort care, palliative / Hospice care.

PALLIATIVE CARE

The patient may still receive pain medication, nutrition, antibiotics, radiation therapy, and other intervention as the goal of treatment is focused on comfort rather than cure.

With palliative care, the primary focus is helping the patients remain comfortable. The patients can also change their mind and request resuming more aggressive treatments. However, any change in the type of treatment that the patients want to receive needs to be added to the patient's living will.

Health Care Advance Directives

THE PATIENT'S RIGHT TO DECIDE

This is a very important topic to discuss as individuals are being asked to participate in making decisions about end of life wishes and care. Every competent adult has the right to make decisions regarding his or her own health, which includes the right to choose or refuse medical treatment.

When an individual becomes unable to make decisions due to a physical or mental change, such as being in a coma or other conditions or disease such as Alzheimer's disease, they are considered incapacitated.

Only the patient's primary physician can determine if they are incapacitated. To make sure that an incapacitated person's decisions about health care will still be respected, the Florida legislature enacted legislation pertaining to health care advance directives (Chapter 765, Florida Statutes). Check your state for the specific legislature. See also the attached resources.

The law recognizes the rights of a competent adult to make an advance directive which will:

- Instruct his or her physician to provide, withdraw or withhold life-prolonging procedures
- Designate another individual to make treatment decisions if the person becomes unable to make his or her own decisions and /or
- Indicate the desire to make an anatomical donation after death.

Also, the law states that the individuals do not have to be incapacitated to elect a health care surrogate to make their decisions.

By law hospitals, long term health care facilities; nursing homes, home health agencies, hospices, health maintenance organizations (HMOs) are required to provide their patients with written information concerning health care advance directives.

ADVANCE DIRECTIVES

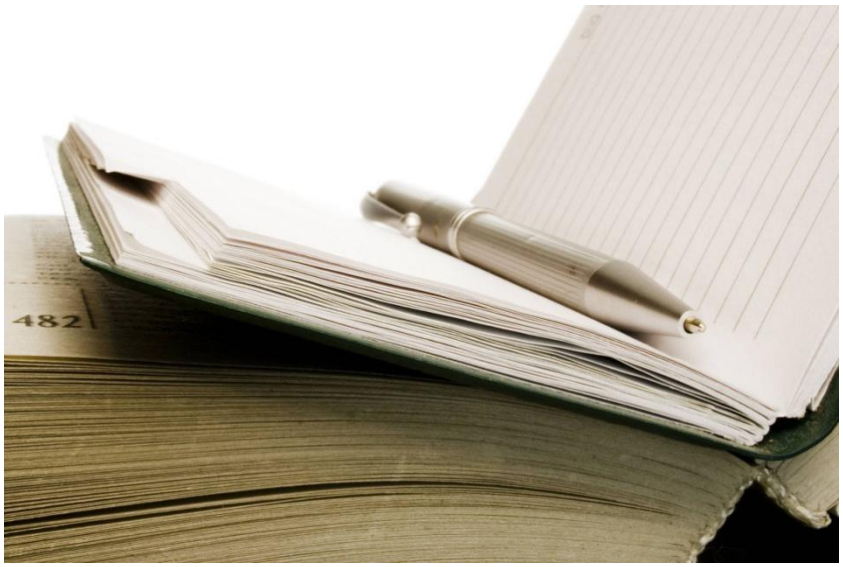
An Advance Directive is a written or oral statement about how individuals want medical decisions made in the event that they are not able to make them themselves and/or it can express the individuals' wish to make an anatomical donation after death. Communicating wishes about end of life wishes or care will ensure that patients with terminal illnesses face the end of their lives with dignity.

Some individuals make advance directives when they are diagnosed with a life-threatening illness. Others put their wishes into writing while they are healthy, sometimes as apart of their estate planning.

Three types of advance directives are:

- A Living Will
- A Health Care Surrogate Designation
- An Anatomical Donation

Some individuals may choose to complete one, two, or all three of these forms; to best serve their needs.

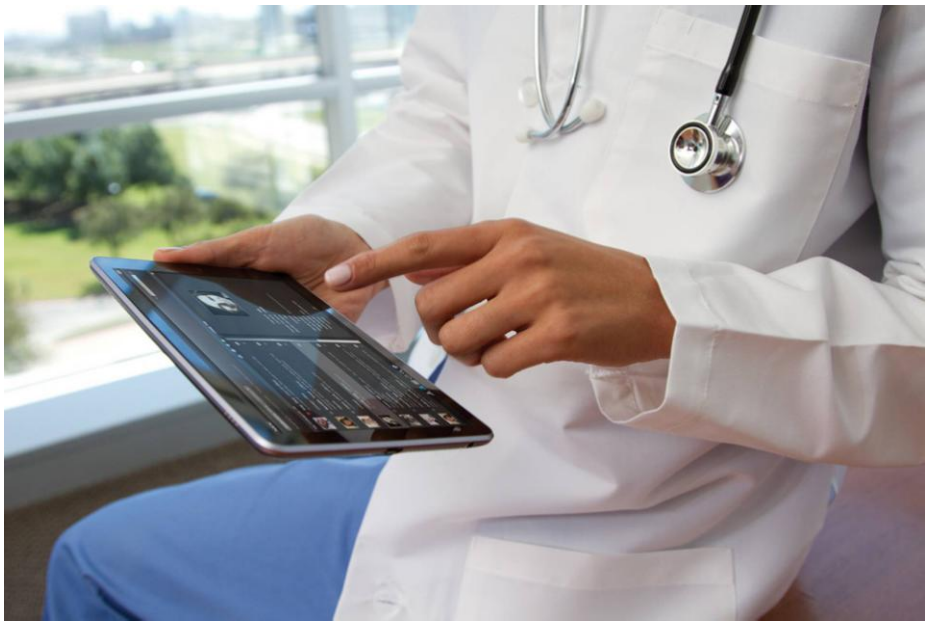


LIVING WILL

A Living will is a written or oral statement of the kind of medical care the resident/ patient or individual want or do not want if they become unable to make their own decisions. It is referred to as a “living will” because it becomes effective while the individuals are still living. Each individual may wish to speak to their attorney or health care provider to be certain they have completed the living will in a way that their wishes will be understood.

HEALTH CARE SURROGATE DESIGNATION

A Health Care Surrogate Designation is a document which has the name of another person as the representative to make medical decisions for the patient if he /she is unable to make the decisions themselves. The patient /individual may include instructions about any treatment that they want or do not want. The patient can also designate an alternate surrogate.



ANATOMICAL DONATION

An Anatomical Donation is a document that indicates the individuals' wish to donate all or part of their body; at death. This donation can be an organ and tissue donation to people in need, or donation of their body for training of health care workers.

The individuals can indicate their choice to be an organ donor by designating it on their driver's license or on their state identification card; this may be done at the driver's license office. The individuals may also sign a uniform donor form or expressing their wish in a living will.

The individual may wish to complete any one or a combination of the three types of advance directives depending on the individual's needs. Within the state of Florida, there is no legal requirement to complete an advance directive. However, if the individual does not make an advance directive, decisions about his/ her health care or an anatomical donation may be made for them by:

- A court-appointed guardian,
- A spouse (wife or husband),
- Their adult child,
- Their parent,
- Their adult sibling,
- An adult relative or
- A close friend.

Sometimes the person making decisions for the patient/ resident may or may not be aware of their wishes. When an advance directive is made and is reviewed or discussed with the significant person in their lives, it will better ensure that the patients' wishes will be carried out the way they desired it to be done.

The advance directive procedures are simple and do not require an attorney; however the individual may choose to consult one. An advance directive completed in another state, as described in that state's law, can be honored in Florida.

WITNESSES

An advance directive, a written document or an oral statement, needs to be witnessed by two individuals. At least one of the witnesses cannot be a blood relative or a spouse. Many states including Florida law provides a sample of each of the following forms: a living will, a health care surrogate, and an anatomical donation.

CANCEL OR CHANGE AN ADVANCE DIRECTIVES?

An individual may change or cancel an advance directive at any time. Changes should be written, signed and dated. Changes may also be by oral statement, physical destruction of the advance directive or by writing a new advance directive.

If the individual has a driver's license or state identification card that indicates that he/ she is an organ donor, but he/ she no longer want this designation, the individual should contact the nearest driver's license office to cancel the donor designation and a new license or card will be issued to them.

When the individual choose to have an advance directive:

If the patient/ individual designate a health care surrogate and an alternate surrogate it is best to ask them if they agree to take this responsibility and also to review / discuss how matters should be handled,

It is also best to give them a copy of the document,

The patients/ individuals should make sure that their health care provider, attorney, and the significant people in their lives know that they have an advance directive and where it is located. Giving them a copy will also be helpful.

The patients/ individuals can set up a file where they can keep a copy of their advance directive as well as other important papers. Some individuals may keep original papers in a bank safety deposit box.

The patients/ individuals may keep a card or note in their wallet, purse / bag that states that they have an advance directive and where it is located; so that it will be found when needed.

WHEN CHANGES ARE MADE

When the patients/ individuals have made changes to their advance directive, they need to make sure that their health care provider, attorney and the significant persons in their lives have the updated copy.

58A-2.015 SPIRITUAL COUNSELING SERVICES

The hospice shall employ a clergy-person or pastoral counselor to provide spiritual counseling. The clergy-person or pastoral counselor shall have a degree in ministry from a college, university or divinity school; or shall have completed a clinical pastoral education program with an emphasis in health care ministry; or shall have completed formal training and is recognized as qualified to perform pastoral services in his or her religion or belief system.

The clergy-person or pastoral counselor shall also have completed a hospice training program sponsored by the employing hospice. Duties shall be enumerated in a job description, including job qualifications, which shall be kept in an administrative file.

The clergy-person or pastoral counselor shall assist the administrator in developing, documenting and implementing policies and procedures regulating the delivery of such services.

The hospice shall ensure, by employment or contractual arrangement, that there are sufficient clergy-persons or pastoral counselors to provide spiritual support to the patient population of the hospice and the patients' families.

The hospice and its agents shall not impose the dictates of any value or belief system on its patients and their families.

58A-2.016 COUNSELING AND SOCIAL SERVICES

The hospice shall employ a social worker who has a degree in social work or a degree in a related field with experience in social work, and who has completed a hospice training program sponsored by the employing hospice. Duties shall be enumerated in a job description, including job qualifications, which shall be kept in an administrative file.

Therapeutic counseling services, if provided, must be provided by a social worker, marriage and family therapist, mental health counselor, or other mental health professional who is licensed by or authorized under the laws of the state of Florida to provide such services.

The social worker shall assist the administrator in developing, documenting and implementing policies and procedures regulating the delivery of such services.

The hospice shall ensure, by employment or contractual arrangement, that there are sufficient social workers and other mental health professionals to meet the social, emotional and mental health needs of the patients and families being served by the hospice. Check with your state for requirements.

58A-2.018 BEREAVEMENT SERVICES

The hospice shall provide bereavement counseling and services to the families of hospice patients for a minimum of one (1) year following the patient's death. The formal and informal supportive services which comprise bereavement counseling shall be supervised or provided by professional staff as described in Rules 58A-2.015 and 58A-

2.016, F.A.C.

The administrator shall ensure the development, documentation and implementation of policies and procedures regulating the delivery of bereavement counseling and services.

The bereavement program shall provide educational and spiritual materials and individual and group support services for the patient's family after the patient's death. check with your state for requirements.

END OF LIFE CARE RESOURCES

(Click on links)

Promoting Excellence in End-of-Life Care
Web site dedicated to long-term changes to improve health care for dying persons and their families through technical assistance to innovative demonstration projects addressing particular challenges to existing models of hospice and palliative care.

National Palliative Care Research Center (NPCRC)
NPCRC is a national initiative committed to stimulating, developing, and funding palliative care research directed at improving care for patients with serious illness and their families.

Phone: 212-241-5388

Center to Advance Palliative Care
The Center to Advance Palliative Care (CAPC) is a resource to hospitals and other healthcare settings interested in developing palliative care programs. CAPC is a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine.

AMDA Foundation
The AMDA Foundation, an independent not-for-profit organization, serves as the research arm of AMDA. The Foundation's mission is: The AMDA Foundation advances excellence in patient care through research and its translation into long term care practice to support the members and mission of the American Medical Directors Association (AMDA). The Foundation also takes an active role in outreach to residents, fellows and young career physicians with an interest in long term care. The Foundation sponsors the following programs and services: * The Long Term Care Research Network is a group of community-based medical directors that conduct outcomes research. All AMDA members are eligible and encouraged to join. * The AMDA Futures Program is an intensive learning experience designed to expose residents and fellows to the numerous career opportunities in long term care and support their attendance at the AMDA Annual Symposium. * The AMDA Foundation/Pfizer Quality Improvement Awards supports innovative projects in the areas of education, quality improvement, and research that will make a distinct impact on the quality of long term care.

Phone: 410-992-3134

Pallimed

Health and Human Services
The U.S. Department of Health and Human Services home page.

Centers for Medicare & Medicaid Services
Welcome to the CMS, the federal agency that administers the Medicare, Medicaid and Child Health Programs.

Library of Congress

Grief, Healing, Spirituality

The Center for Jewish End of Life Care
The Center is dedicated to facilitating conversations about the physical, emotional and spiritual needs of Jewish people affected by any advanced and terminal illness.

The Healthcare Chaplaincy
The HealthCare Chaplaincy is a multifaith community of professionals committed to the advancement of pastoral care, education and research. We are dedicated to the spiritual care of all persons who are suffering in body, mind and spirit.

Growth House, Inc.
A non-profit organization working with grief, bereavement, hospice, and end-of-life issues.

International Resources

International Observatory on End of Life Care
A team of social scientists and clinicians based at Lancaster University (UK) collaborates with colleagues all around the world in an effort to provide research evidence to impact the global development of hospice and palliative care.
Phone: +44 1524 592513

International Association of Hospice and Palliative Care
1515 Holcombe Blvd, Box 112 C/O MD Anderson Cancer Center Houston, TX 77030-4009 Our mission is to increase the availability and access to high quality hospice and palliative care for patients and families throughout the world. We do this by promoting communication, facilitating and providing education, and by becoming an information resource for patients, professionals, health care providers and policy makers around the world. Our vision is to help alleviate the physical and psychosocial suffering associated with progressive, incurable illness throughout the world. IAHPC is a not for profit organization. Where applicable, donations to IAHPC from individuals, companies or sponsors are tax deductible.

Phone: 713-339-9041

Other

The Anatomy Gifts Registry
AGR's donor program and no-cost cremation service has been an extremely valuable resource for Social Workers, Chaplains, Hospice Staff and the grieving families they serve. National, 24 hour hotline.

Phone: 800-300-5433

American Health Quality Association
The American Health Quality Association represents Quality Improvement organizations (QIOs) and professionals working to improve the quality of health care in communities across America.

Gift From Within- PTSD Resources for Survivors & Caregivers
Gift From WIthin is also listed on the Deployment Health Clinical Center website and other websites for those either suffering from trauma and caregiving. Gift From Within, an international nonprofit organization is dedicated to those who suffer post-traumatic stress disorder (PTSD), those at risk for PTSD, and those who care for traumatized individuals. Educational materials include videotapes, books and articles for both clinicians and those experiencing PTSD. Gift From Within was founded by Frank Ochberg, M.D., an expert in PTSD. Dr. Ochberg is the former Associate Director of the National Institute of Mental Health and one of the team members who wrote the medical definition for Post Traumatic Stress Disorder. He was the editor of the first treatment text in America for PTSD. The Gateway to PTSD Information (www.ptsdinfo.org) is a gateway to four nonprofit sites that offer PTSD information and resources. Four national and international organizations are here to help, with articles, references, web-links, mini-courses, 800 phone access and e-mail pen-pal resources. This site is listed on the U.S. Department of Health and Human Services website, under their mental health disorders topic. Gift From Within- PTSD Resources for Survivors and Caregivers l6 Cobb Hill Road Camden, ME 04843 USA 207 236-8858 ph 207 236-2818 fax

Phone: 207-236-8858

American Alliance of Cancer Pain Initiatives
The American Alliance of Cancer Pain Initiatives is dedicated to promoting cancer pain relief nationwide by supporting the efforts of State Cancer Pain Initiatives. Cancer Pain Initiatives are voluntary, grassroots organizations composed of nurses, physicians, pharmacists, social workers, psychologists, and representatives of clergy, higher education, and government. Initiatives and their participants provide education and advocacy to healthcare providers, cancer patients and their families.

TAKE EXAM

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