

Advance Care Planning`

Your Personal Health Care Choices

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The Dilemma

- ❖ Who should make decisions for persons who cannot speak for themselves or make their wishes known or have irreversible conditions and what should they decide?
 - ✓ Their family and physicians must guess the patient's wishes for treatment.
 - ✓ This can be emotionally trying for all involved. If there are several children, they may not all agree.
 - ✓ Indecision and confusion may last for days or even weeks.
 - ✓ There is a better way - ***Advance Care Planning*** and the use of ***Advance Directives***

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What is Advance Care Planning?

❖ Advance Care Planning is:

- ✓ A process for directing treatment at a time in the future when you can no longer make your wishes known
- ✓ Ideally initiated while you are of sound mind and not under stress
- ✓ A dialogue between patient, family, and health care providers
- ✓ A process that may conclude with legal documentation known as advance directives

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Why Should You Participate in Advance Care Planning?

- ❖ To discover your beliefs and values about life, death, and health care choices.
- ❖ To inform others of your beliefs, values, and wishes.
- ❖ To document your health care choices.
- ❖ To decrease conflict and court battles.
- ❖ To ensure your wishes are respected.

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Advance Care Planning

❖ 5 Step Process:

- ✓ Exploration of beliefs and values
- ✓ Knowledge of health care choices
- ✓ Discussion with family and physician
- ✓ Completion of Advance Directives
- ✓ Informing others of my choices

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Step #1: Explore Beliefs & Values

- ❖ We all want to live, but we all understand that sooner or later, we all die.
- ❖ Curing illness is the primary goal of medicine, but many *medical treatments given to patients with terminal or irreversible conditions often cause suffering that may outweigh the benefit of being kept alive.*
- ❖ **Ask yourself, "If I become terminally or irreversibly ill, how much value do I place on extending my life as opposed to the quality of my life?"**

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Step #1: Explore Beliefs & Values

- ❖ These are difficult questions that may be frightening to some and yet when faced, the answers can bring peace of mind.
- ❖ These questions are best faced with careful consideration and not in a crisis situation!
- ❖ In order to answer such questions, we recommend consideration of the burdens of treatment versus the benefit that the treatment will provide.

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Step #1: Explore Beliefs & Values

- ❖ Consider what basic life qualities are important to you.
For example:
 - ✓ How important is your independence and ability to feed, walk, and otherwise care for yourself?
 - Some individuals who are chronically dependent as a result of illness prefer comfort care only to life sustaining treatment should they become critically ill.
 - ✓ How important to you is it that you be able to recognize or respond to your loved ones?
 - Some individuals would prefer not to be kept alive if they were comatose or otherwise unable to interact with their loved ones because of sickness.

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Step #1: Explore Beliefs & Values

- ❖ Personally consider which burdens of treatment you would be willing to bear in order to live a life acceptable to you. For Example:
 - ✓ Would you want to be kept alive by a mechanical breathing machine, knowing that you could not talk, would be restrained, and might be uncomfortable as a result of the machine?
 - ✓ If you were no longer able to swallow, would you wish to have a tube surgically placed in your stomach? Would it matter to you if you no longer recognized your family because of dementia or coma?
 - ✓ Would you wish to be transferred to the hospital for intensive medical treatment if your doctor found you to be terminally or irreversibly ill, or might you prefer to be kept comfortable?

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Step #2: Know Your Health Care Choices

- ❖ There are three basic choices concerning the level or intensity of your treatment:
 - ✓ Palliative Treatment, often called "Comfort Treatment Only"
 - ✓ Limited Life Sustaining Treatment
 - ✓ Intensive Life Sustaining Treatment
- ❖ Make your choices based upon the benefits and burdens of treatment.

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Step #2: Know Your Health Care Choices

❖ Palliative or “Comfort Treatment Only”

- ✓ The goal of this type of treatment is to keep you comfortable and to allow a peaceful death. You will be kept pain free and your dignity will be maintained at all times. Only medications needed to maintain your comfort will be provided. Tests will not be ordered unless needed to help manage your comfort medications. Intravenous lines are only started if needed for comfort. You will be moved to the hospital only if your doctors and nurses are unable to keep you comfortable in your home.

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Step #2: Palliative or Comfort Treatment Only



This treatment addresses the major elements of suffering including physical, mental, social, and spiritual. For example, relief of pain, shortness of breath, and nausea are major goals.

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Step #2: Palliative or Comfort Treatment Only



Palliative treatment is often provided by a Hospice organization.

Hospice organizations focus on total patient comfort, the care of the patient and family as a unit, and provides grief and bereavement support.

Palliative or hospice treatment may be provided in the nursing home, home, or hospital if needed.

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Step #2: Know Your Health Care Choices

❖ Life Sustaining Treatment:

- ✓ Texas law defines life sustaining treatment as "a treatment that, based on reasonable medical judgment, sustains the life of the patient and without which the patient will die. The term includes both life sustaining medications and artificial life support such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration."
- ✓ Life sustaining treatments may be either limited in specific ways based upon your medical condition and values or may be intensive and unlimited.

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Step #2: Know Your Health Care Choices

Limited Life Sustaining Treatment

- ❖ Depending upon your condition and your values you may:
 - ✓ Be transferred to the hospital or remain at your home
 - ✓ Have a trial of appropriate life sustaining drugs, such as antibiotics for infection, either by mouth or by intravenous route
 - ✓ "Artificial Life Support" such as cardiopulmonary resuscitation (CPR), breathing machines, blood transfusions, or "Feeding Tubes" are generally not given for this level of treatment. If they are used, it is for a short period of time to determine whether or not they are medically effective, or effective in meeting your values. This is sometimes called a "time limited trial."

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Step #2: Antibiotics and Other Limited Life Sustaining Treatments



- ❖ Benefits
 - ✓ Treats infection or other life threatening condition
- ❖ Burdens
 - ✓ May require IV access
 - ✓ May cause unpleasant side effects
 - ✓ May require restraints
- ❖ Effectiveness
 - ✓ Varies with underlying condition and treatment used

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Step #2: Know Your Health Care Choices

❖ Intensive Life Sustaining Treatment

- ✓ Transfer to the hospital with possible admission to the ICU if medically appropriate.
- ✓ Intravenous therapies, mechanical breathing machines, artificial nutrition and hydration (ANH), surgery, blood transfusions, dialysis and cardiopulmonary resuscitation (CPR) may be used as appropriate for your particular condition.

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Step #2: Artificial Nutrition and Hydration - “Feeding Tubes”



- ❖ Benefits
 - ✓ Provides fluids and nutrients
 - ✓ Potentially life-sustaining in some conditions
- ❖ Burdens
 - ✓ Invasive and painful
 - ✓ Aspiration of formula into the lungs
 - ✓ Patients with tubes are usually restrained
- ❖ Effectiveness
 - ✓ Ineffective in the setting of dementia and cancer.
 - ✓ Does not prevent aspiration

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Step #2: Breathing Machines



- ❖ Benefits
 - ✓ Life-sustaining
- ❖ Burdens
 - ✓ Invasive and painful due to tube in throat
 - ✓ Side effects include agitation requiring sedation or restraint, inability to talk
 - ✓ Requires ICU treatment and restricted family access
- ❖ Effectiveness
 - ✓ Varies with underlying condition

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Step #2: Kidney Dialysis



- ❖ Benefits
 - ✓ Cleans blood
 - ✓ Life-sustaining
- ❖ Burdens
 - ✓ Time consuming
 - ✓ Requires transfer to dialysis center by ambulance
 - ✓ Invasive and painful
 - ✓ Side effects such as fatigue, weakness, and nausea
- ❖ Effectiveness
 - ✓ Varies with underlying condition

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Step #2: CPR - Cardiopulmonary Resuscitation



- ❖ Benefits
 - ✓ May revive breathing or a heart that has stopped
- ❖ Burdens
 - ✓ Injury common
 - ✓ Invasive and painful - tubes, IV lines, electric shock, ICU
- ❖ Effectiveness
 - ✓ Less than 15 - 20% effective in restarting heart
 - ✓ **Less than 1 out of 100 patients survive to hospital discharge and those patients have high risk for permanent brain injury**

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Step #3: Discussion with Family, Physician, or other advisers

- ❖ **This step is essential.**
- ❖ It may be very difficult for some people.
- ❖ Discuss with your family and physician.
- ❖ You may also want to discuss with your spiritual adviser or attorney.
- ❖ Ask your family and physician to respect your health care choices.

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Step #4: Complete Advance Directives

- ❖ Three important types of Advance Directives under Texas law:
 - ✓ Directive to Physicians and Family
 - ✓ Medical Power of Attorney
 - ✓ Out-of-Hospital DNR

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Step #4: Completion of Advance Directives

- ❖ What is an Advance Directive?
 - ✓ An Advance Directive is a legal document, ideally completed by the patient when of sound mind, allowing the patient to direct future treatment at a time when the patient is otherwise unable to make their wishes known.
 - ✓ With an Advance Directive you may appoint a "surrogate decision maker" and/or direct specific treatment decisions.
 - ✓ An Advance Directive should be the final step in the process of Advance Care Planning.

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Step #4: Completion of Advance Directives

- ❖ What is a Surrogate Decision Maker, Health Care Agent, or Spokesperson?
 - ✓ These terms refer to a person designated to make decisions for you if you are no longer able to make decisions for yourself. You may legally designate this person either on a Directive to Physicians and Family (Living Will) or on a Medical Power of Attorney. Your surrogate or health care agent is instructed by law to make decisions as you would make them for yourself. If you fail to choose a surrogate, state law provides a list of individuals who may make decisions for you.

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Step #4: Completion of Advance Directives

- ❖ What is a terminal condition?
 - ✓ According to state law, a terminal condition means an "incurable condition caused by injury, disease, or illness that according to reasonable medical judgment, will produce death within six months, even with available life-sustaining treatment provided in accordance with the prevailing standard of medical care."

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Step #4: Completion of Advance Directives

❖ What is an irreversible condition?

- ✓ According to state law, an irreversible condition means a "condition, injury, or illness:
 - 1) that may be treated but is never cured or eliminated;
 - 2) that leaves a person unable to care for or make decisions for the person's own self; and
 - 3) that, without life-sustaining treatment provided in accordance with the prevailing standard of care is fatal."

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Step #4: Directive to Physicians and Family or Surrogates

- ❖ Commonly called a "Living Will"
- ❖ Records your choices in writing
- ❖ Directs the medical care you want to receive or reject in the setting of either a terminal or irreversible condition
- ❖ Becomes effective only when
- ❖ your doctor certifies in writing that you have a terminal or irreversible condition and you are not able to communicate or otherwise make your wishes known

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Step #4: Medical Power Of

Attorney (formerly called a "Durable Power of Attorney for Health Care)

- ❖ Allows you to appoint a spokesperson (surrogate or health care agent) to make all health care decisions, whether or not you have a terminal or irreversible condition
- ❖ **Becomes effective when you become unable to communicate or otherwise make your wishes known**
- ❖ Your spokesperson is required by law to make decisions in agreement with your values and preferences, thus your spokesperson should be included in discussions related to the creation of this type of document

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Step # 4: Out-of-Hospital DNR Directive

- ❖ DNR means Do-Not-Resuscitate
- ❖ No attempt will be made to restart your heart or breathing when you die - note that it does not mean do not treat for other problems
- ❖ Allows a person to refuse CPR (cardiopulmonary resuscitation) outside of the hospital setting
- ❖ Health care providers and emergency personnel will not perform CPR
- ❖ The only type of advance directive which requires your physician's signature on the document

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Step #5: Inform Others of My Choices

- ❖ Keep the original copy of your Advance Directives.
- ❖ Provide signed copies to:
 - ✓ your official spokesperson
 - ✓ your family members
 - ✓ your healthcare providers: physicians, clinics, hospitals, nursing homes, dialysis centers, hospice services, etc.

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Key Points to Take Home

- ❖ As long as you are able, you and your physician will make decisions together.
- ❖ Advance Care Planning relieves you and your family of additional emotional distress.
- ❖ Advance Directives are the legal documentation of your beliefs and values.
- ❖ You always have the right to cancel or change your Advance Directives.

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