Death & Dying, Advance Directives

People with terminal illness and their families are asked to take part in decisions about end-of-life care. This sheet provides patients with an outline for thinking about these issues and some guidelines for discussion with their doctors, families, and loved ones. It is also designed to help patients understand the medical, legal, and personal choices they may face in the future.

WHAT RIGHTS DO PATIENTS HAVE REGARDING THEIR MEDICAL TREATMENT?

- Patients are entitled to complete information about their illness and how it may affect their lives. They have the right to share or withhold that information from others.
- People with cancer should also be informed about any procedures and treatments that are planned, the benefits and risks, and any alternatives that may be available. Patients may be asked to sign an "informed consent" form which includes this information. Before signing such a form, patients should read it carefully. Patients should ask the caregiver any questions they might have.
- Patients have the right to make decisions about their own treatment. These decisions may change over time. In the face of worsening disease, some patients may want to try every available drug or treatment in the hope that something will be effective. Other patients may choose not to try aggressive medical treatment. Many patients turn to family members, friends, or caregivers for advice. It is the patient's decision how much or how little treatment to have. Sometimes a patient is unable to make this decision due to severe illness or a change in mental condition. That is why it is important for people with cancer or other terminal illnesses to make their wishes known to friends and family.

WHAT IS END-OF-LIFE CARE? WHAT ARE ADVANCE DIRECTIVES?

- End-of-life care is a general term that refers to the medical and mental care given in the advanced or terminal stages of illness. Advance directives are the legal documents, such as:
  - A living will.
  - Durable power of attorney.
  - Health care proxy.

These documents allow people to convey their decisions about end-of-life care. Advance directives are a way for patients to communicate their wishes to family, friends, and health care professionals. Advance directives are a way to avoid confusion later should patients become unable to communicate.

- Ideally, the process of discussing and writing advance directives should be discussed over time rather than making these decisions all at once.
- Advance directives can be modified as a patient's situation changes.
- Patients can change their minds at any time even after advance directives have been signed.

WHY IS IT IMPORTANT TO WRITE A WILL?

- A will is important so that patients can give instructions about distribution of their money and property when they die. Patients can name a trusted family member, friend, or professional to handle their personal affairs (called an Executor).
- It is advisable to seek the expert advice of a lawyer in drawing up a will. Decisions about taxes, beneficiaries and asset distribution will be legally binding. This process can relieve a patient's family and friends of an enormous burden in case of disputes or questions about allocation of the patient's assets.

WHAT IS A LIVING WILL?

A living will is a set of instructions documenting a person's wishes about medical care intended to sustain life. It is used if a patient becomes:

- Terminally ill.
- Incapacitated.
- Unable to communicate.
- Unable to make decisions.

Everyone has the right to accept or refuse medical care. A living will protects the patient's rights and removes

the burden from family, friends and/or physicians in making difficult end-of-life decisions.

LIFE-SUSTAINING CARE THAT SHOULD BE CONSIDERED WHEN DRAFTING A LIVING WILL.

These include:

- The use or non-use of life-sustaining equipment (dialysis machines, ventilators, and respirators).
- "Do not resuscitate" (DNR) orders. These are instructions not to use CPR if breathing or heartbeat stops.
- Artificial hydration and nutrition (tube feeding).
- Withholding of food and fluids.
- Comfort (*palliative*) care:
  - It is important to understand that a decision not to receive "aggressive medical treatment" is not the same as "withholding all medical care". A patient can still receive antibiotics, nutrition, pain medication, radiation therapy, and other interventions when the goal of treatment becomes comfort rather than cure. This is called palliative care. It's primary focus is helping the patient remain as comfortable as possible. Patients can change their minds and ask to resume more aggressive treatment. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.
- Organ and tissue donation:
  - Once a living will has been drawn up, patients may want to talk about their decisions with the people who matter most to them. They may want to explain the values underlying their decisions. Most states require that the document be witnessed. It is advisable to make copies of the document. Place the original in a safe, accessible place. Give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found.

WHAT IS A HEALTH CARE PROXY AND DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

- A health care proxy is an agent (a person) appointed to make a patient's medical decisions if the patient is unable to do so. Generally, people choose someone they know well and trust to represent their preferences when they can no longer do so. Patients should be sure to ask this person for agreement to act as their agent. An agent may have to exercise judgment in the event of a medical decision for which the patient's wishes are not known.
- The durable power of attorney for health care is the legal document that names a patient's health care proxy. Once written, it should be:
  - Signed
  - Dated
  - Witnessed
  - Notarized
  - Copied
  - Incorporated into the patient's medical record.
- Patients may also want to appoint someone to manage their financial affairs if they can not. This is called a durable power of attorney for finances. It is a separate legal document from the durable power of attorney for health care. Patients may choose the same person or someone different from their health care proxy to act as their agent in financial matters.

MAKE SURE YOU:

- Understand these instructions.
- Will watch your condition.
- Will get help right away if you are not doing well or get worse.

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