

▶ Talking with Your Family and Healthcare Agent

Even if you're not dealing with a life-limiting illness, an accident or injury could occur at any time. That's why it's such a good idea to talk through end-of-life decisions before a crisis arises. An advance directive is a document that gives your doctors and family guidance in how to care for you when you cannot speak for yourself or make your wishes known to them.

Unless we're living with illness, we tend to avoid the subject or think it doesn't pertain to us. But imagine that you are young and healthy one minute, and the next minute there's a car accident and you're on life support. Suddenly, a doctor is asking your family to make hard decisions. Talking with your family now lets them know what you would want done.

Here are some things to ask yourself and then discuss with your family ahead of time:

- ▶ Do you want to be kept alive on machines as long as possible, or to be allowed to die as gently as possible?

Answering questions like this is not easy, and the "right" answer will depend on your exact medical condition at the time. That's why you appoint a healthcare agent, so someone who knows you well is on your side making these decisions when you cannot make them yourself. When talking with your healthcare agent about the responsibilities of their role, can bring clarity out of chaos.

Here are some things to discuss ahead of time:

- ▶ Would you be available to talk to doctors to understand the treatment options available to me?
- ▶ Would you be able to visit me often enough to understand my condition?
- ▶ Can you ask tough questions of doctors and caregivers and make decisions based on the wishes expressed in my advance directive?

It's important to tell your family and healthcare agent about your treatment goals when you are not expected to recover.

- ▶ What things would be important to you at the end of your life?
Being free from pain; being with family; being able to care for yourself; being at peace with your God; resolving conflicts
Not being a burden to your family, physical, emotional, or financial burden
- ▶ What are your feelings about donating your organs to save a life?

 Talking with Your Doctor

If you are living with serious illness or are simply planning ahead for your own or a loved one's future, having a frank discussion with your doctor is a good idea. Putting things into words, getting more information, and asking questions can help you get the kind of care you want.

ARTIFICIAL NUTRITION AND HYDRATION

- ▷ What is meant by artificial nutrition and hydration (ANH)?
- ▷ When is it needed?
- ▷ Is artificial nutrition and hydration effective?
- ▷ Is there a standard of care for the use of ANH in patients with irreversible or terminal illness?
- ▷ If I or a loved one does not have terminal cancer but instead has dementia (Alzheimer's) or some other brain injury leading to swallowing problems, will ANH help?
- ▷ What if I or my loved one doesn't have dementia or cancer but is just frail, elderly, has trouble swallowing and lives in a nursing home? Will placing a "feeding tube" help?
- ▷ Even if I or a loved one has dementia, cancer, or some other terminal or irreversible condition, doesn't nutrition and hydration make the patient feel better? Won't I or my loved one be hungry and thirsty?
- ▷ Will I or my loved one suffer if adequate nutrition and fluids aren't provided?
- ▷ Is artificial nutrition and hydration ever helpful for terminally or irreversibly ill patients?
- ▷ What are the ethical issues involved?

CARDIOPULMONARY RESUSCITATION (CPR)

- ▷ What is Attempted CPR?
- ▷ Does Attempted CPR work?

Talking with Your Doctor

- ▷ What are the circumstances of patients for whom Attempted CPR increases suffering and is not likely to work?
- ▷ In patients for whom Attempted CPR is not likely to work, what do doctors recommend?
- ▷ What is an AND order (*Allow Natural Death*)?
- ▷ How does an AND order affect other decisions about life-sustaining treatments?
- ▷ What are DNR orders (*Do Not Resuscitate*)?
- ▷ Do DNR orders apply outside the hospital, such as in the nursing home?
- ▷ Isn't there more to a decision about CPR and AND than statistics about results of treatment?
- ▷ What are the ethical issues involved?

HOSPICE

- ▷ What is hospice?
- ▷ Aren't hospice and palliative care the same?
- ▷ Am I giving up on myself or my loved one if I choose hospice care?
- ▷ What might I expect from hospice?
- ▷ Does hospice shorten life?
- ▷ Does hospice cost extra?
- ▷ How do I know when hospice is the right thing to do?
- ▷ Where can I get more information about hospice?

MANAGING PAIN IN SERIOUS ILLNESS AND AT LIFE'S END

- ▷ Are there deficiencies in pain management for seriously ill hospitalized patients?
- ▷ Where can I get help with pain management?

Talking with Your Doctor

- ▷ Is this what patients want when facing serious illness? Is this what patients want if they might be at the end of life?
- ▷ What are some of the ways that pain can be treated in a medical or care-giving setting?
- ▷ What are opioids? Aren't opioids bad for a patient? Don't they cause addiction and do more harm than good?

PALLIATIVE CARE

- ▷ What is palliative care?
- ▷ What are the goals of palliative care?
- ▷ Who is eligible for palliative care?
- ▷ What services are provided through palliative care consultation?
- ▷ How may I access palliative care services?

SEVERE BRAIN INJURIES

- ▷ What are the causes of severe brain injuries?
- ▷ What is a coma?
- ▷ If I or my loved one is in a coma, does that mean they are brain dead?
- ▷ How is a coma treated?
- ▷ How long does a coma last? Can my loved one ever recover from a coma?
- ▷ What is brain death?
- ▷ How can the doctors say my loved one is brain dead when I see them breathing and their heart is still beating?
- ▷ Is there any treatment to reverse brain death? Who makes a decision to stop such treatments?

Talking with Your Doctor

- ▷ If the doctors determine that my loved one is in the vegetative state, what do they mean?
- ▷ How long does the vegetative state last? Is there any treatment to reverse the vegetative state and make it go away?
- ▷ The doctors say my loved one is in the minimally conscious state. What does that mean?
- ▷ How do doctors know what type of brain problem my loved one has?
- ▷ How do doctors know if there is any chance of recovery?
- ▷ “Meaningful recovery” sounds like a loaded term. Who is to say what is “meaningful”?

AUTOPSY & ORGAN DONATION

- ▷ What is an autopsy?
- ▷ Why should an autopsy be done? Why is it important to families? To society?
- ▷ Will the autopsy affect funeral plans?
- ▷ How do I get an autopsy done?
- ▷ Is there a charge for the autopsy?
- ▷ How do I find out the results of the autopsy?
- ▷ What is involved in organ donation? What happens to the body?