Advance Directives:

Increase Patient Awareness and Participation in End of Life Issues

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What’s the Problem with Dying in America?

- $$$
- The Miracle of Modern Medicine
- Only 25-30% of Americans have advance directives
- Emotional and Ethical costs
What is the Solution?

Advance Care Planning Helps
Maintain a Sense of Wellness
...and is a Gift to You and to Those You Love

By Nancy Newman, Director, Patient Support and Advocacy and Cynthia Shimizu, LCSW

Advance care planning is for all of us, not just for people who have cancer. It’s for all adults, ages 18 and older, who want to maintain a sense of wellness and dignity throughout their life. Advance care planning applies to you—whether you’re currently healthy or receiving medical treatment for a serious illness. Having an advance care plan is like having a roadmap your doctors and loved ones can use to honor your wishes. If in the future, you’re not able to make or communicate your own decisions.

As adults, we’re often faced with a variety of health care situations that require us to make decisions about what to do. Some decisions are relatively easy to make, like which over-the-counter medications to take, or whether we should have an elective surgery. Other decisions are more difficult, so we weigh the benefits and burdens of each choice and opt for what fits our values and lifestyle. Sometimes, we’re not able to make a decision at all.

Just for a moment, imagine yourself in the following heartbreak circumstances:

- You’re 24 years old with a massive head injury from a car accident.
- You’re 58 years old in the end stage of a serious medical condition.
- You’re 86 years old with an advanced stage of dementia, like Alzheimer’s disease.
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At some point in each of these situations, you would probably lose your ability to make decisions. Medically, this is a serious problem for two reasons:

1. Communication: You may not be able to communicate any decisions.
2. Decisions: Some decisions may not be able to make decisions with someone who has a serious illness. In some cases, communication may be necessary to share the decision making with someone who can make decisions on your behalf.

By talking with your family and loved ones, you can help ensure that your wishes are respected and followed.
What’s the Problem at Moffitt?

- Based on random chart audits of 109 established Moffitt Radiation Oncology patients in January 2016, only 23.35% had an advance directive and 22.7% in chart
- Lack of educational resources
- Who, when, where?
- Having the difficult conversation
Advance Care Planning: It’s Your Choice!

Moffitt Cancer Center recognizes the importance of knowing and honoring your wishes.

Who needs it?
- All adults over the age of 18
- Moffitt employees, patients, families and caregivers

What is an Advance Directive?
- A legal document
- Allows you to have control over your life choices
- Gives you the opportunity to choose your own end-of-life care decisions

Where can I get it?
- From your nurse, social worker or clinic while you are at Moffitt Cancer Center

Why do I need it?
- Communicates your wishes to family and loved ones
- Allows you to plan ahead
- Relieves stress and burden

In Florida, the most common advance directive forms are the Designation of Health Care Surrogate and the Living Will. These forms are legal documents, but do not require an attorney to complete.

- **Health Care Surrogate**
  This document identifies the trusted person you want to make health care decisions for you when you are unable to make them. This document does not need to be notarized, but it does need two witnesses to your signature.

- **Living Will**
  This document describes your health care wishes if your health condition cannot be cured and getting better is not possible. This document does not need to be notarized, but it does need two witnesses to your signature.

We can help you through this process. Contact your treatment team to let them know if you’d like assistance with creating and completing an Advance Directive. You can reach the Social Work Office at 813-745-8407 to make an appointment.

Produced by the Patient Education Department. Reviewed by Patient & Family Advisors.

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Start the Conversation

My family knows my wishes does yours?

I have mine do you have yours?
What Do Our Nurses Think?

- Only 33% had some knowledge of AD
- 72.15% felt only somewhat comfortable discussing AD
- 16.5% felt dissatisfied with education about AD
- 16.5% felt it was difficult or very difficult to fill out AD
What Do Our Patients Think?

- Question 1: knowledge of advance directives
- Question 2: willingness to complete AD
- Question 3: how satisfied with education
- Question 4: difficulty of completing AD
Survey Results

• June 2016: 30.76% no knowledge or some knowledge, 26.15% had AD, 19% not willing, 32.29% somewhat dissatisfied or not at all satisfied with education, 38.45% easy or very easy to fill out

• August 2016: 48% no knowledge or some knowledge, 39.2% had AD, 7.2% not willing, 3% somewhat dissatisfied or not at all satisfied with education, 40.8% easy or very easy to fill out
Surveys Continued

November 2016:

• 39.16% no knowledge or some knowledge
• 33.82% had AD
• 8.9% not willing
• 4.45% somewhat dissatisfied or not at all satisfied
• 33.82% easy or very easy to fill out
Did We Make a Difference?

• Chart audits in December 2016 showed of 110 patients 56.36% had AD and 30.9% is in the chart. Difference of 33.01% more patients had AD and 8.2% more AD in chart

• Surveys of nurses in January 2017 showed 99.6% felt very knowledgeable about AD, 91.63% were satisfied with education, 58.31% are very comfortable discussing AD and 100% felt it’s easy or very easy to fill out AD
Culture Change

• Healthcare technology is advancing

• Death is universal and inescapable

• Uncertainty about end of life care is avoidable

• Nurses and providers need to be able to have the difficult conversations

• Education of staff and patients works!
Resources


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Norals, T. E., & Smith, T. J. (2015). Advance care planning discussions: why they should happen, why they don't, and how we can facilitate the process. *Oncology, 29(8), 567-567.* Chicago


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Jeong, Dr. Sarah. (July 2014). The Majority of Hospitalized elderly people at high risk of dying have thought about end-of-life care, though documentation of preference in medial records may be lacking. *Evidence Based Nursing, volume 17*, number 3.