Making Choices and Communicating with your Healthcare Advocate
Presented by: Susan Reynolds, MSW, LICSW
University of Washington Medical Center
Huntington’s Disease Center of Excellence
The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2017 HDSA Convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.
Presenter Disclosures

Susan Reynolds

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list
Health Care Decision Making

• It is important to know that as adults, 18 years of age and older, and of sound mind, we have the right to put our decisions about our health care in writing to guide our medical care team.

• Let’s start with some definitions so we are talking the same language.

• Medical Provider – Medical Doctor (MD), Advanced Registered Nurse Practitioner (ARNP), Physician’s Assistant (PA) – Primary medical provider for your health care.

• Agent, Proxy, Health Care Advocate (HCA) – An individual or individuals chosen by you to act as you if you become unable to make your own decisions.

• Advance Directives -Durable Power of Attorney for Healthcare (DPOA-HC).
Health Care Decision Making

• Legal document that allows individual to appoint an Agent, HCA to make medical decisions if individual is unable to do so
• Needs to be in effect prior to the individual losing capacity to make their own health decisions
• Witnessed by one or two individuals unrelated, and/or notarized
• Durable means it remains in effect even if individual loses capacity for decision making
• Health Care Directive AKA Living Will – written document that states an individual’s wishes when the individual is in a permanently unconscious condition documented by two doctors or diagnosed in writing by the attending doctor to be in a terminal condition, and the application of life-sustaining treatment would serve only to artificially prolong process of dying
Health Care Decision Making

• Mental Health Advance Directive – written document that expresses an individual’s instructions/preferences, or appoints an agent to make decisions on behalf of the individual about mental health treatment that is consistent with the provisions of the State mental health AD

• Physician Order for Life Sustaining Treatment (POLST) -POLST is an order signed by your physician that states your wishes for resuscitation (AKA CPR or do not resuscitate(DNR). It may also include wishes for other types of intervention measures

• AD can be completed by an individual independent from an attorney depending on your state law, and most states require one or two witnesses and/or notary signature
Conversations with Health Care Advocate

• Communicating about health care wishes is an ongoing process
• Important factors to consider:
• Choose someone in your family or friend community whom you believe will be willing to honor and follow your wishes as your health care advocate (HCA)
• Set aside time to begin the conversation with this person as well as family members about what your values and what you want in place at end of life
• Remember, this is not a one time conversation and is important to start the conversation sooner than later
• Inform your medical providers, family and others in your circle as to what your wishes are for healthcare
Conversations with Health Care Advocate

- The literature suggests that approximately only 1/3 of adults have some type of AD
- Ensure that your AD are scanned into your medical records where you receive care
- Ensure that your HCA has a copy of your wishes

- Case Example of communicating with family and HCA
Health Care Advocate

- It is important to remember to review your AD with your HCA regularly; as well as any time there is a significant change in your health
- Be sure to keep your HCA and medical provider up to date with communication and updated changes: This is probably the area for most concern as individual wishes may change, however, they may not always get communicated and documented
- If your wishes are not in writing your State law will determine the order of how decision making around your health care is carried out
- **Case example of issues that can arise when wishes are not communicated in writing**
Limits of Advance Directives

• There are a variety of types of AD: General documents obtained online, provided by medical clinics, hospitals, customized documents drawn up by attorneys. Your completed forms need to be kept updated. Otherwise, if there is more than one document, the most recent will supersede the earlier documents
• Many individuals work with attorneys on their documents to customize and address areas of importance for end of life care
• One of the biggest challenges can exist when there is disagreement between family members about your wishes
• It is very important to talk with your family and medical provider if you anticipate there may be disagreement between family members
Limits of Advance Directives

- There may be medical issues that arise during an acute health crisis or at end of life that are not specifically addressed in your AD
- Legal challenges to Advance Directives
- **Case example of complicated grief that can arise when AD not in place or not followed**
Summary

• Recommendations:
• Begin the conversation about your goals and wishes early and while you are able with family, medical care team and HCA
• Advance planning is an ongoing process of communicating, not a one time conversation
• Regularly review your wishes with your HCA
• Make sure you document and provide the documentation and any changes to your health care providers, family and HCA
• Start your planning now, it is never too early
References

- Conversations Before the Crisis: The Intersection of Family, Faith and Policy in Advance Care Planning; National Hospice and Palliative Care Organization
- Information About your Health Care; University of Washington Medical Center UW Medicine
- Myths and Facts about Heath Care Advance Directives; American Bar Association Commission on Law and Aging
- Selecting Your Healthcare Agent; National Hospice and Palliative Care Organization
- We’re Bad at Death. Can We Talk?; The New York Times