

SESSION # 1

Advance Directives/Advance Care Planning

Prayer

O God, who knit us together in our mother's wombs, we rejoice in your gift of life and in your sustaining presence which has brought us to this place. God of all our days, we often act as if our earthly life will never end. Help us to accept our mortality and consider our dying and death in the light of your love and the love we share with those we love most. Help us to think deeply about these issues so we can make informed decisions that are not driven by ignorance or fear but by the assurance of your presence in this life and the next. Finally, keep us mindful that our dying is a journey that will lead us back to you, the Source and Ground of our being. We ask these things in the name of Jesus, who destroyed the power of death through his death and resurrection. Amen.

Reading – Ps 139:1-18, 23-24

Advance Directives/Advance Care Planning

Advance directives are documents that you can use that will let others know what your wishes are in the event that you cannot speak about them for yourself. They take effect **ONLY** when you are unable to make your own health care decisions. The greatest gift that you can give to your loved ones is letting them know what your wishes are as to how you want to be treated and the kind of care you want/wish to receive as your earthly life nears its end.

Scenario

Two possible scenarios:

An 84-year-old man is brought into the Emergency Room by an ambulance. He had been found unresponsive by his caretaker. It is unknown how long he had been unresponsive. It is determined that he has had a stroke. This is the second stroke he has suffered. His old medical record was retrieved from Medical Records and a Health Care Proxy form was found. The person named as his Health Care Agent was called and she immediately came in. She told the ER doctor that after his first stroke, he told his family that he did not want to be kept alive if he suffered another stroke that was more debilitating than his first stroke, which had left him in a wheelchair and unable to take care of himself. So, he had completed a health care proxy, naming her as his Agent.

Two days later his attending physician said it was likely that he would not regain the ability to communicate. Communication had been the one function that he could still accomplish after his first stroke. The Agent informed his attending physician that she did not want him hooked up to any machinery and wanted to allow nature to take its course.

The attending physician was not in agreement with the Agent's decision and asked for a consultation with the hospital ethics committee. The co-chair of the Ethics Committee talked with the Agent and read the proxy form. She then let the doctor know that he needed to follow the directions of the Agent. He still disagreed and withdrew from the case. The patient's primary doctor was called and he took over the care of the patient. The patient was moved to a private room and kept comfortable. What he was able to take in by mouth, he was given. He was not in any pain and for the most part, rested comfortably. The family took up residence in the room and stayed around the clock with him. They read to him, talked about life together and laughed and cried together. Their clergyperson came and anointed him and offered communion to the family, which they were grateful to receive. Three days after his stroke, he stopped responding to his family, took in no nutrition and appeared to be at peace, with no pain. Two days later, he died, with his family surrounding him.

Another patient, also in his mid-80s, was brought into the ER about the same time, having suffered a series of strokes. His family was called and when they came to the ER, the doctor informed them that their loved one would not be able to communicate with the family at this time and would likely be confined mostly to bed but, perhaps, to a wheelchair, having lost the ability to sit up on his own or walk. The family was asked if there were any advance directives. They responded that they never wanted to talk about the possibility that any of them might die, so, no, there were no advance directives. The patient was transferred to the Intensive Care Unit. Two weeks later he had to be placed on a respirator because he became too weak to breathe on his own. He was also provided with artificial nutrition and hydration. The patient was able to open his eyes but did not seem to know his family. Once he was stabilized, he was transported to a long term care facility, where he lived for 18 months. He never appeared to recognize or respond to his family or staff and continued to receive artificial nutrition. The costs for his care were borne by Medicare and his family. He finally succumbed to an infection.

Discussion

Which of these two scenarios would you prefer? Or is there another scenario that you would prefer? There is no "right" or "wrong" answer. What is important is what YOU want and how you want to be treated when you are no longer able to make health care decisions for yourself.

The time to let others know what your wishes are is now, while you are able to discuss your wishes and communicate them clearly. So, it is important to have these discussions and be sure to include what is important to you for your life to have meaning and also how you might see it years from now.

Think about and discuss the following questions:

- What is a meaningful life for you?
- What does “living” mean for you?
- Are there things that you **MUST** be able to do in order for your life to have meaning? For example:
 - Must you be able to communicate?
 - Must you be able to take care of your bodily functions by yourself?
 - Must you be able to interact with family and other loved ones?

- What is **MOST** important to you? For example:
 - Spending time with family and loved ones?
 - Seeing your children or grandchildren grow up?
 - Going to church and taking walks in the woods?

- Do you want everything done to keep you alive, no matter what the quality of your life is?
- Where is God in your decisions about the kind of medical care you wish to receive when you are critically ill or at the end of your life?
- Do you think that God would want you connected to machinery that was keeping your body functioning even if you were unable to move or respond and had no hope of improvement or recovery?
- Do you want your organs/tissue to be used for organ donation, if viable?
- Are there family considerations that might affect your wishes about medical treatment if you become very ill?
- Another factor to consider is that there may be ways for you to continue to live a fruitful and meaningful life even if you cannot speak, walk, eat, breathe or take care of your bodily functions by yourself. You may be able to use a motorized wheelchair, other technology, and home care services to help you live life to the fullest. It is important to think about these issues in the broader context of your whole life.

Information

[This section is being provided so that the group leaders can use it during the discussion. Once people have spent about half of the session talking about the above questions, you can begin to provide this information. It may be helpful to have this information copied and distributed to the attendees so that they have it for future reference. Please have Health Care Proxy/Agent forms available that are for your particular State (you can download a form that is accepted in your State at <http://www.caringinfo.org/stateaddownload>) for people to either complete during the session or take home with them to complete with their family. You may want to follow up at the beginning of the second session to see how many of them

completed their HCP form and encourage them to complete them and bring a copy to the church to keep in case needed.]

There are several different ways you can have these conversations. One of the best ways is with all of your family present at the same time, since it will be helpful for everyone to hear directly from you what your wishes are. These are not easy conversations and many children (even adult children) will not want to discuss this. You might consider sitting around the kitchen or dining room table with those who are closest to you. Over coffee or tea, and after offering a prayer, start talking about what the important aspects of your life are – talk about the questions above, or use one of the tools that are available on-line. There are also several different forms that you can use, which are available on-line. (Resources are given at the end of the section.) They may also be available at your doctor's office.

A Health Care Proxy/Durable Power of Attorney for Health Care is the form that addresses the widest range of situations, yet it does not need to include any specific wishes (except in New York and Missouri where there must be specific wording about use of nutrition and hydration). This form allows you to select an individual (and a secondary person) to make healthcare decisions for you when you can no longer make them for yourself. The person you select should be prepared to make the decision that YOU want made, not what they want for you. If they are not willing to abide by your wishes, you should consider appointing someone else. Hopefully, you and the individual(s) you selected will have ongoing discussions over the years as you age and your priorities shift and medical technology evolves. Here's an example as to why conversations should be ongoing:

Susie is asked and agrees to be the Health Care Agent for her friend, Jean. Jean, when asking Susie to be her Agent, tells Susie that she wants to stay alive as long as possible, that she is afraid of death and wants everything done to keep her alive. Susie agrees to honor Jean's wishes. Jean gives Susie a copy of her completed Form, which Susie keeps with her other important papers. Jean also gives a copy to her doctor and her children, and puts one with her will and other papers.

About a year later, Jean's uncle is in the intensive care unit, and is connected to a number of life sustaining/supporting machines. After several weeks, he finally dies from an infection. Shortly after the funeral, Jean calls Susie and says, "After watching my uncle go through this, I don't want that. Do not keep me alive if there is not the strong possibility that I will be able to return to a somewhat normal life. Do not let them give me artificial nutrition and hydration or put me on a respirator for a long period of time. If I am not going to return to life as I know it, then I don't want to be kept alive by machinery. Do you understand and will you agree to that, Susie?" Susie responded in the affirmative. Subsequent conversations helped them both understand even better what Jean wanted and didn't want done for her.

Because of their ongoing dialogue, it is clear what Jean expects Susie to do should something happen to her. In some states, had there been a Living Will, Jean would have had to redo it to reflect the change in her wishes. In other states, a Living Will could be used *only* to forgo life-sustaining treatments, so Jean's original wish to have 'everything done' could not have been part of a living will in the first place. Jean did not need to revise her documents since she had a HCP and not a Living Will.

Most Health Care Proxies/Durable Power of Attorney for Health Care forms don't require a lawyer, nor do they need to be notarized in most states. Be sure to check the form and follow the directions for your state so that you can ensure that your wishes will be followed.

Living Wills (LW) provide for specific interventions in specific situations and may not cover what actually happens to you. There are one page LW forms that you can use and there are several page LWs that you can sign that may or may not cover what happens to you. (You will find links to the forms in the resource section. Please note that LW vary from state to state, so be sure to check out what is an appropriate use of a LW in your state) Here's an example of when a living will may not be the best form to use, depending on the state in which you reside:

A woman was diagnosed with breast cancer. At the time of diagnosis and her initial surgery, she completed a one-page living will and checked off that she wanted to be resuscitated. This form remained in her chart and several years later, when she was dying, the doctor asked the daughter to sign a Do Not Resuscitate (DNR) order because her mother's cancer had advanced and the odds of surviving a cardiac arrest and CPR were minimal and a resuscitation attempt might cause her mother great suffering. The daughter, knowing that her mother had said on her living will that she wanted to be resuscitated, felt that she could not agree to a DNR because her mother had expressly stated that she wanted to be resuscitated. Chances are, if the mother and daughter had ongoing conversations as her illness progressed, the daughter would have been able to make that decision knowing that her mother's wishes had changed as her prognosis changed. It is also possible that the patient had forgotten that she had signed the LW since it had been several years between her initial diagnosis and her current hospitalization.

Surrogate Decision Making/Substituted Judgment is allowed in some states, particularly if there has not been a health care proxy/durable power of attorney for health care form completed. In this scenario, the person tries to determine, based on knowing you, how you would want your treatment to proceed. The surrogate uses your life history and known preferences, values, goals and objectives in order to make the best decision he or she can make, taking "you" into account and not their own preferences for your care decisions.

The law of a given state may establish categories of eligible surrogates and may prioritize among them. Usually spouses are the first eligible category, followed by adult

children, siblings, etc. If there are multiple family members in a category, such as adult children, they may disagree about what should be done for the patient. Because a state may resolve this issue through a ‘majority rules’ provision, advance discussion among family members is desirable. But this, in turn, argues again for the creation of a written advance directive, preferably a Health Care Proxy/Durable Power of Attorney for Health Care, followed by the kind of family discussion suggested earlier.

Do Not Resuscitate/Do Not Intubate Orders (DNR/DNI)/Allow Natural Death (AND)

Do Not Resuscitate (DNR) orders are physician orders often written in hospitals when a patient’s medical condition warrants them and/or or when the patient requests that resuscitation not be performed. A DNR Order in the medical record precludes the use of resuscitative measures including chest compressions, artificial respiration, defibrillation, and cardioactive medications in the event of cardiopulmonary arrest—if a patient’s heart stops or he/she stops breathing. In other words, a “code” is not called and attempts to resuscitate are not begun.

Some states have created Do-Not-Resuscitate Orders that are legally recognized as another form of Advance Directive. These orders typically extend beyond the hospital into settings such as hospice care, nursing homes, and even the patient’s home. They alert emergency personnel not to attempt resuscitation if the patient suffers an arrest.

It is also possible for a physician in the hospital to write a Do-Not-Intubate Order, in which a patient who experiences breathing difficulties (sometimes a sign of an impending cardiac arrest) will not have a breathing tube inserted down his or her throat. Typically, in the hospital this Order also means that if the patient suffers a full cardiopulmonary arrest, no ‘code’ will be called and resuscitation will not be attempted.

Some states have instituted a Do-Not-Intubate Order as another kind of Advance Directive. In contrast to standard hospital practice, in the event of a full arrest these orders sometimes permit, or even require, a modified form of resuscitation that may include all of the ‘code’ elements *except* the use of a breathing tube. Most clinicians believe this “partial” resuscitation is ineffective and advise against its use. Also, many states have not authorized official DNI Orders. You may check your state health laws to find out whether or not your state has this form of advance directive. You will find the link in the reference section.

The Allow Natural Death (AND) form started in Texas where they believe that when one signs a paper to “not” do something, one is allowing the natural progression of the illness to occur. To not “code” the person is allowing nature to take its course. AND has been receiving very positive feedback especially since, to the patient/family member who is signing it, it feels like they are doing something positive by allowing death to take its natural course without human intervention.

Some hospitals do not actually ask patients or family members to “sign” a DNR, but take their oral consent as agreement.

When a person is in hospice care, an out-of-hospital DNR Order (typically a form provided by the state) is signed, usually by the patient and the physician, so that death is allowed to happen without emergency interventions as a natural result of the

progression of the illness. There will be more information about hospice DNRs in a later session.

Foregoing Life-Sustaining Interventions

Patients may choose to forego treatment with or without an advance directive in place. It is the choice of the patient and/or family member to have life-sustaining interventions withheld or withdraw interventions previously started (if allowed by state law). Types of interventions that may be foregone include, but are not limited to: placement in intensive care units; cardio-pulmonary resuscitation; intubation and ventilation (being put on a respirator to assist with breathing); any drug therapy regimen; dialysis; blood transfusions; intravenous fluids and feedings; radiation; chemotherapy; surgery. Patients may continue or begin to receive adequate pain medication so that the patient is as free from pain and anxiety as possible. This choice may be reversed at any time. Courts have ruled that competent patients may forego life-sustaining interventions.

It is important for the patient and family members to understand that death will probably follow this refusal of life-sustaining interventions. At the same time, it is worth remembering that the real 'cause' of death is not the refusal of these interventions, but rather the underlying illness. Family members may find comfort in this fact.

Organ Donation

In the late 1960s, the Uniform Anatomical Gift Act became public policy in the US. It has encouraged individuals to donate one's organs or tissues after one's death so that someone else might benefit from the transplanted organs and/or tissues. In the mid 1980s, in an attempt to increase donations, families became the focus for consent and laws were passed that required "the" question be asked of all families. The need for organs is very real and the chance for someone to continue to live, even as someone else dies, can be a real "gift" to that person and their family.

Decisions about organ donation after a diagnosis of brain death can be heart wrenching for families. Often the cause of the total brain failure has been a sudden accident, injury, or body "malfunction." As a result, just when the family is only starting to deal with the pain of their loved one's death, they are also being asked to give the "gift of life" to someone else – usually a stranger – who may be a match. Because time is of the essence (viable organs need to be removed as soon as possible in order for the recipient to have the best chance of survival), family members may feel pushed to make the decision. This possibility is why it is important for you to have this conversation with your family. Your wishes concerning donating organs or tissues can make their decision that much easier once they know how you want your body treated when your life ends.

Role of Clergy and Congregations in Assisting Congregants

Clergy can be of assistance to their congregation by being willing to talk openly and honestly about our living and our dying. Clergy can assist families with discussions about what their congregant's priorities and wishes are concerning how they want their body treated as they near the end-of-life.

Clergy can encourage families to have discussions about what their congregant's priorities and wishes are. They can also offer to participate in those discussions. Parish nurses and lay ministers, such as Stephen Ministers, might also encourage or facilitate these conversations.

Clergy can develop a parish file containing copies of congregants' advance directives. If needed, the advance directives can be retrieved from the parish office and brought to the hospital by the pastor, parish nurse, or lay minister.

Clergy can be advocates for their congregants if they know what their congregant's wishes are. Clergy can provide "clear and convincing" evidence (in states that require this legal standard) – so it is important that clergy keep notes of any conversations they have with congregants where the congregant expresses his or her wishes.

Clergy can also assist their congregants by suggesting that the entire family be a part of any discussions about what the person might want so that when the person is ill and/or dying, the whole family understands what the wishes of the patient are. If there is a Health Care Agent, clergy may gently remind all family members that the patient has designated that person as the patient's decision maker and spokesperson.

Clergy can be helpful when the Health Care Agent/Surrogate has to make the decisions by reminding that Agent/Surrogate that the decision they are making is not about their own wishes, but the wishes of the patient.

Closing Prayer

Faithful God, we are grateful to learn of the many ways we can describe our wishes for how we want to be treated at the end of our lives and for the peace that making use of these options can provide us and our loved ones. Take us by the hand and help us move from fear and anxiety to relief and hope as we prayerfully consider our options and make our desires known to our loved ones and our physicians. Finally, open our hearts and minds to consider donating our organs to people who need them, so that we can give the gift of life and health to others when our earthly lives come to an end. We ask these things in Jesus' name, who gave his life for our sake. Amen.

Resources:

Websites for state Health Care Proxy and Living Will forms

This website will enable you to download a form that is acceptable for your specific state. <http://www.caringinfo.org/stateaddownload>

Websites for other advance care planning documents:

Caring Conversations

Center for Practical Bioethics

<http://www.practicalbioethics.org/cpb.aspx?pgID=986>

Finding your Way

Sacramento Health Care Decisions

<http://www.sachealthdecisions.org/finding.html>

Five Wishes

<http://www.agingwithdignity.org/5wishes.html>

Respecting Choices

An advance care planning system from Gundersen Lutheran Medical Foundation

<http://www.respectingchoices.org/>

Ethical Wills

Offers a way to leave your legacy by writing down your values and beliefs.

www.ethicalwill.com

Information about Organ Donation:

<http://www.organdonor.gov/>

<http://www.donatelife.net/>

<http://www.organtransplants.org/>

Books:

Jacobs, Martha R. *A Clergy Guide to End-of-life Issues*, Cleveland: The Pilgrim Press, 2010.