



Starting the Conversation: Advance Care Planning

The topic for this presentation is, "Starting the Conversation: Advance Care Planning." You may be wondering what advance care planning is all about. Very simply, advance care planning is the opportunity to clearly document in writing your wishes for medical care and treatment interventions in the event you are unable to speak for yourself. This presentation focuses on assuring that by completing advance directives, your voice and values are honored in the event you are medically unable to advocate for yourself. You can think of it as a gift you give yourself and your family to ensure that decisions about your care are consistent with your wishes and preferences. The process of advance care planning involves several steps, and we are going to review those steps in this presentation.

We will begin the discussion with the challenges in talking about advance care planning and the importance of making your wishes known.

If you have never completed an advance directive, you are not alone. Although most Americans agree with documenting their wishes, the Center for Disease Control estimates that 70% of us have not completed an advance directive.

Why have so many not completed one? There are several possible reasons. One of the main reasons we avoid completing an advance directive is that we don't understand its purpose. Many people may connect advance directives with "pulling the plug" so to speak; however, the truth is that this document allows you to make your medical wishes clear, whatever they are. If you are in an accident or become very ill and you want every medical treatment possible, you can state that in your advance directive. It's not just for people who don't want aggressive medical treatments.

Another misunderstanding about advance directives is that they are only for people that are very ill or old. This just isn't true. We all know you can't predict an accident or the start of a sudden illness that could leave you unable to speak for yourself no matter what your age.

Another reason we may not have completed one is that many of us don't like to think that we will ever need such a plan. We just plain don't want to think about not being able to speak for ourselves. We don't like thinking about our own mortality or of those we love. We are often scared or resistant to having discussions about end of life with our family or friends. Actually, such discussions often relieve tension by allowing us to discuss our thoughts and fears.

Considering the following questions can help you identify possible barriers that may prevent you from discussing advance care planning. Are you unsure what advance care planning is and wonder why this topic is important? Are you uncomfortable discussing death or



find yourself resistant to even thinking about it? Are you unclear about the need or benefits of advance care planning? Take a few moments to think about these questions and if any may be preventing you from making your wishes known.

Why is it important to talk about advance care planning? First and foremost, the aim of advance care planning is to keep your “voice” heard so that people know what is important to you, even when you are too sick to speak for yourself.

Let’s imagine for a moment that you have been in an accident and can’t speak. Imagine that you are so injured you might die. The doctors providing your care may have to make decisions about what lengths they will go to keep you alive. What should they do? Who can they ask? Does your family know whether to agree to artificial means of keeping you alive? Would family members be able to agree on decisions for your care?

With situations like this in mind, there are several benefits to advance care planning. First, you continue to have a say in your medical care, even when you can’t speak for yourself. Second, you will have the peace of mind in knowing that you are more likely to receive the medical treatment you want and not receive treatment you don’t want. Finally, your family and friends won’t have the undue burden of having to make decisions without knowing your wishes.

Without advance care planning, family or significant others may find themselves in the position of having to make very difficult decisions without knowing what you would have wanted. Having a plan in place relieves family members from wondering if they "did the right thing" on your behalf. A plan also avoids a situation where family members are divided on decisions about your care. When a family is experiencing all the feelings that go along with the critical illness of a loved one, everyone’s emotions can be elevated. When difficult decisions must be made about your care, it can cause conflict between family members. You may prevent these conflicts by making your wishes about your health care treatments clear. This will free your loved ones to be there to support each other and you.

Talking about end-of-life issues while you are healthy and before a crisis allows for honest discussion, reflection, and planning with those you care about. It can help to strengthen your relationships with family and friends. Sharing your wishes with others can be a rich and rewarding experience and can bring you closer.

Talking about these issues before a crisis can also help a family cope with moving on after you are gone knowing that they supported your wishes and are not left to question if they did the right thing. and could potentially make end of life grieving far more painful than it already may be.



Lastly, talking about these issues may help you discover important information about your values, hopes and fears and may help your loved ones understand you better.

Let's move on to explain some of the terms used in advance care planning. To begin, we will define the term "advance directives." An advance directive is an umbrella term that simply means that a person has chosen to pre-plan their own medical care should that person be unable to make their wishes known. We will discuss two forms of advance directives called living will and health care proxy. While each state may have slightly different documents, they all have some form of both advance directives.

Let's begin by describing the living will. The living will is an advance directive that provides direction for health care when one is unable to make their own health care decisions. The living informs the medical team, your family and loved ones, about the procedures or treatment you would want provided and under what circumstances or conditions you would want these interventions. The living will is often an end-of-life document clearly stating your wishes for treatment and comfort.

The second advance directive document we will discuss is called the health care proxy or health care agent and is also known as a medical power of attorney. This document or directive names a person that you authorize to make health care decisions for you if you are unable to make those decisions yourself due to your medical condition. It is very important that you discuss your wishes with the person you are thinking of designating as your health care agent so that they are clear about their role and your wishes. Once you appoint them, provide that person with a copy of the completed health care proxy form and confirm they are willing and prepared to take on this role.

Now let's explore how to begin the process of creating an advance directive.

Knowledge is power so it is important to talk to your doctor or other health care providers to understand under what circumstances the documents will be called upon and what medical treatments you will want provided.

You will want to learn about life-sustaining treatments so that you can be clear about all the medical intervention options and decisions. There are specific medical actions that keep a person alive when their body can't function on its own. You may want to accept these treatments if they will return you to normal functioning or improve your condition.

Some people may decide they may not want to prolong their life if they are faced with a serious life-limiting condition. These life sustaining treatments could include cardiopulmonary resuscitation to restore your heart's ability to function, inserting a tube to help you breathe, or to



provide artificial nutrition or hydration. Ask your doctor to explain what each treatment is, when you would need it, and the pros and cons of these treatments. Also, it may be important for you to ask your doctor about pain management and what can be done to maximize your comfort.

After talking to your doctor, take the time to reflect on what is important to you. It is important to do your own “emotional homework” before you try to talk about your wishes to your loved ones. What questions do you need to consider prior to completing your living will?

Let’s take some time now to consider some of the ideas you might consider when completing these advance directive documents. What are your values and views on what makes life worth living? For example, is it most important for you to prolong life as long as possible even if it requires using artificial means? Are you most concerned with ensuring you are kept comfortable? Do you feel that under certain conditions you would not want to be kept alive by artificial means?

Consider what aspects of life give it the most meaning for you. For example, how important is it for you to be independent with everyday tasks and to recognize your loved ones? Suppose you have advanced Alzheimer’s disease, and you no longer recognize loved ones and are not able to feed or dress yourself. Would you want CPR if your heart stopped or a feeding tube if you were no longer able to swallow?

Consider how your religious or spiritual beliefs affect your attitudes toward end-of-life care. For example, some people believe that every means necessary should be used to sustain life, while others reject any medical treatment relying only on their spiritual beliefs or a higher power to heal.

You may wish to take some time to reflect on these matters before completing your living will. Another aspect of completing the advance directive is to decide who to select to be your health care agent or the health care proxy. It may be a family member or close friend who understands your wishes. It is important to select someone you can trust to speak up for you and be clear about your wishes, even if others may be unhappy with your choices. You may also appoint a backup to make decisions if your primary health care agent is unable to. Make sure these people are comfortable with making health care decisions that reflect your wishes. Be aware that most states laws do not allow your doctor or any other professional caregiver to be your health care agent.

Next let’s discuss how to prepare your advance directive. To prepare an advance directive some individuals choose to seek legal and/or medical assistance, however this is generally not required. In most cases, you do not need to contact an attorney or medical



professional, however talking with your doctor prior to completion can be of benefit to you in learning about specific treatment choices.

Once you are confident that you understand the choices, you can start making out the advance directive of your choice. Some states have just one form that combines the health care proxy and living will. Please be sure to choose the advance directive for your particular state. Advance directives are state specific, and most forms will not be honored in a different state. You can find your specific states forms at the web site: www.caringinfo.org

After you have secured your particular state's form you then complete the form and sign and date with witnesses' present. The witnesses will also sign and date the form(s). The witnesses cannot be the person or persons designated to assist with health care decisions.

If you decide that you would like assistance with completing the advance directive forms, you certainly can use an attorney. Your advance directives are official when you sign and date them in the presence of witnesses that will also sign and date the form. Again, it is not required to have an attorney to complete these forms. It is merely an option based on your preference.

It is important to remember that when completing the health care proxy form that the person signing as a witness cannot be the person designated to make decisions as the form becomes null and void. It is considered a conflict of interest for the person to act as your health care agent and to witness the signing of the form. Your doctor can assist with helping you understand the form, but they also cannot act as a witness. The Veteran in your life can complete advance directives through the VA doctors and social workers; just let them know at the next appointment and they will assist.

Next, we will review the specific aspects of the living will form and how to complete it. The living will form consists of an opening statement which includes your name and a statement that confirms you are of sound mind and have the ability to make decisions regarding your health care in the event you are unable to state those decisions due to a medical condition. The living will is an end-of-life document outlining your preferences for care, treatment, and pain relief. There are several sections to address in the living will and we will explore those now.

The first section of the living addresses life sustaining treatments. What are life sustaining treatments? These are treatments or procedures meant to prolong life, often by artificial means. In this section of the living will you have options to identify which treatments or procedures that you do not want provided to you in the event that there is no reasonable expectation for recovery. There is also an option you may select if you want to prolong your life as long as possible. This means that there are no limitations for treatment and care.



The second section of the living addresses pain. This section on pain relief provides for maximum pain relief and comfort. This allows your medical team to treat any signs or symptoms of discomfort during your end-of-life journey.

The third and last portion of the living addresses your wishes for organ donation. Organ donation is a highly personal choice, and this section allows you to make choices ranging from no organ donation through options to donate any and all parts for any purpose.

The health care proxy form is the next form we will talk about completing. Remember, this is the form that allows you to select someone to make health care decisions for you if you are unable to make those decisions for yourself.

The health care proxy form begins with a statement, "I hereby appoint," and you would provide the name, home address, and telephone number of the person selected to be the primary health care agent, or the person to make decisions for you. The health care proxy only takes effect if you become unable to make your own health care decisions and only if your medical condition is very serious and it is expected that you will not recover to your previous state of health and functioning.

These advance directive forms can be obtained at the website www.caringinfo.org. Forms can also be obtained through any community hospital, doctor's office, or area Office for the Aging near you. The Veteran can obtain forms and assistance through his or her local VA Hospital.

Next, let's explore some ideas about how to talk to others about your wishes. It is best to talk to your doctor or health care providers about your wishes before you have a health care crisis. Let your doctor know that you are completing your advance directives and you would like his or her input. As mentioned before, ask your doctor to explain treatments and procedures that may be confusing to you. It is very important to have a direct conversation to make sure your doctor understands your wishes and is willing to follow your directives.

Now, let's turn to discussing your wishes with family and other loved ones. As we mentioned earlier, it is sometimes hard to talk about end-of-life issues with loved ones. Remember, it's up to you to take the initiative to express your wishes.

Once you have introduced the subject, it's important to share your wishes with your loved ones. Start with the person you want to make health care decisions for you. Make sure that person is willing to take on that role. Ask them directly. "Will you respect my wishes even if they are different than what they used to be and if you don't agree with my choices? Will you be my advocate to make sure what I want is done, even if you would not make the same choice



yourself?" It is very important that you make sure your health care agent knows what treatments you want and in what circumstances.

Let your family and loved ones know who you have appointed as your health care agent and explain why. Explain your wishes to your family and loved ones and why you are now putting them in writing. Share your values, spiritual beliefs, views about what makes life worth living, and your attitudes toward death. Talking with your family about your wishes gives them the opportunity to ask questions and talk about any concerns they might have.

Communicate with family members, especially if you think they may not agree with your decisions. Make your wishes clear and let them know who you have chosen to make decisions about your medical care. Give them a copy of your advance directive.

Once you complete your advance directive you may be wondering what to do with it next. How will anyone know it exists? The first thing is to make sure that those closest to you in your life know that this document exists and to provide a copy to any health care agent you have selected. A copy should be provided to your physician and any or all specialists that may be involved in your care.

Depending upon your medical status you may choose to place a copy on your refrigerator because most emergency response personnel are trained to look at the refrigerator upon entering the home specifically to see if there is an advance directive available. Be sure that more than one person knows where to find your advance directive in the case of an emergency situation.

What if you change your mind about the advance directive? If you create an advance directive, take the time to review it from time to time. You could do this at specific time intervals, such as yearly, on your birthday, or anytime your health status changes. Ask yourself if there is anything you'd like to change or add. You should also review whether the person you appointed as your health care agent is still willing and able to fill this role and if it is still the person you want to make health care decisions for you.

If you have changed your mind about having an advance directive, you can always revoke it. If you desire to change your health care agent or make specific changes to treatment preferences, you can simply create a new advance directive to have placed into your medical chart. The advance directive with the most recent date is the one that will be followed.

The decision to plan for your medical care in advance is a personal one. It is best to start advance care planning before you have a medical crisis, so you have the opportunity to consider what is important to you.



Remember, you can't assume your loved ones know your wishes or that you know theirs. Conversations about health care decisions and end of life issues can be difficult, but there are also many benefits. Your wishes for treatments and procedures, or the decision not to have specific treatments or procedures will only be known to others if you have shared these decisions with those you love. You can put your decisions in writing using an advance directive and this ensures that your wishes will be honored.

The forms can be obtained at the website: www.caringinfo.org . Forms can also be obtained through any community hospital, doctor's office, or area Office for the Aging near you. Veterans can obtain forms and assistance through his or her local VA Hospital.

We hope that this discussion has helped you to understand the importance of advance directives. We hope that it has helped you better understand how to put these powerful and personal decisions in your hands. You deserve to have your wishes followed. You not only are caring for yourself but are giving your loved ones the gift of your direction, so they are free to support you with the confidence they have honored your wishes.