

**What You  
Need to Know  
About Advance Care Planning**

**(Living Wills & Healthcare Surrogates)**



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Project GRACE is pleased to present ***What You Need to Know About Advance Care Planning*** as a resource to assist you with the frequently asked questions about medical decision making. For more information about advance care planning or to download additional copies of this information booklet, visit the Project GRACE website at [www.projectgrace.org](http://www.projectgrace.org) or contact us at 727-536-7364.

### **What is Advance Care Planning?**

Advance Care Planning (ACP) is a thoughtful process of planning for future medical care should you become unable to make your own decisions due to a life-limiting illness or injury. It involves education, reflection, communication and documentation. It is a valuable tool for families as they face difficult decisions about caring for you in your final phase of life. Studies show that families that engage in the ACP process have less stress, confusion and guilt about their decisions.

***Advance Care Planning is a gift to you and those you love.***

### **10 Steps to Good Advance Care Planning**

1. **Understand** the process (terminology, living wills, healthcare surrogates, legalities, current health status, available tools)
2. **Explore** your values, beliefs, cultural perspectives and goals for care
3. **Appoint a healthcare surrogate** to make decisions for you when you are too sick or hurt to speak for yourself
4. **Make informed choices** about medical treatment options (understanding the benefits and burdens of CPR, breathing machines, feeding tubes, antibiotics)
5. **Discuss** your wishes with your surrogate, family, doctor, spiritual advisor and anyone else who may be involved in your care
6. **Document** your wishes in a living will (advance directive)
7. **Execute your document:** Sign and date the document and have it witnessed
8. **Follow-up** with doctors, lawyers and faith professionals if needed to provide additional information or guidance
9. Make at least **10 copies to share** with your doctor, family, and surrogate. Remember to keep a few on hand for admission to a hospital or other healthcare facility ( a photo copy is as legal as the original)
10. **Review and update** your documents periodically, especially after major life events



### **What is a Living Will?**

A living will is a legal document that allows you to make health care choices for the future, if you can no longer speak for yourself. A living will is **ONLY** followed when you have reached the end stage of an illness or condition and the medical treatment would only prolong your natural dying.



### **Why does Project GRACE have an Advance Care Plan instead of a Living Will?**

The Project GRACE Advance Care Plan Document combines the living will with the Designation of Healthcare Surrogate form. This means you only need to have one document witnessed.

### **Why should I have an Advance Care Plan?**

Having an Advance Care Plan while you are well, helps to ensure that your wishes are honored, should you become unable to speak for yourself.

### **Why does the Project GRACE Advance Care Plan document identify four conditions for choices of care?**

Physicians with extensive experience in end of life care have identified these four conditions as the most common situations in which the continuation of treatments that attempt to prolong life are of no benefit and often prevent giving good comfort care. If you choose "No", it means you have chosen to let death take its course naturally without medical interference.

### **Why is there a place for "Other Choices"?**

Many individuals may wish to add details or personal instructions about their choices or even exceptions to the choices provided in the Advance Care Plan document. For example, Jehovah's Witnesses may ask that blood products be withheld under all circumstances. Also, instructions such as "I want maximal pain medications, even if it hastens my death," "I do not want to be placed in a nursing home," or "I want to die at home" can be added to this section.

### **When does my Advance Care Plan take affect?**

Your living will **only** applies when you lose capacity to make health care decisions and there is little or no chance of recovery. In the state of Florida, the patient's physician along with another physician must determine your condition cannot be made any better before life-prolonging procedures may be withheld or withdrawn. Your requests to withhold treatments in your living will do not apply when there is reasonable chance of cure or improvement.

### **Does an Advance Care Plan encourage my death?**

**NO.** You are not signing an agreement that says that you wish to die. You are making a choice for the future, about medical treatment (breathing machines, tube feeding, CPR, surgery, antibiotics, etc.) that you do and do not want, when there is little or no hope for recovery.

*The Advance Care Plan becomes active **ONLY WHEN** you cannot tell your doctor and loved ones what your choices are about medical treatments.*

### **How should I choose my Healthcare Surrogate?**

This is a very important question. Your Healthcare Surrogate will speak for you when you are unable to speak for yourself. You must choose your Healthcare Surrogate carefully, and then share your choices for medical treatment near the end of life with that person. You want to be sure that your Healthcare Surrogate is easily accessible by the medical team, and is a person that you can count on to honor and communicate your personal wishes even if they do not agree with them. Most people choose a close relative or friend who knows them best.

### **Why would I not want a feeding tube with artificial feedings at the end-of-life when I can no longer eat? Wouldn't I "starve to death"?**



A feeding tube is a small tube placed through the nose and into the stomach to deliver artificial liquid feedings. A more permanent form of feeding tube that is placed through the wall of the abdomen and the stomach is called a gastric tube. Putting in a gastric tube is a surgical procedure. In most cases, people stop eating and drinking because the dying body no longer has a need to do so. People who are permanently unconscious, in a vegetative state, or

who have end-stage dementia (permanent, severe confusion) lose all feeling of thirst or hunger. There is no medical evidence that not using a feeding tube with artificial feedings leads to a more painful death. In fact, the research says just the opposite. Artificial feedings through a tube may prolong dying and make it more uncomfortable.

### **What about fluids given by the vein?**

Fluids delivered through a small plastic tube inserted into a vein consist of sterile water and sugar. When the body prepares itself to die, intravenous fluids are not necessary and may cause discomfort. In patients who have any awareness, sips of water or ice chips, lubricated lips and good mouth care are enough to relieve a dry mouth and to provide comfort.

*It is legally and ethically appropriate to discontinue medical treatments that are no longer beneficial. It is the underlying disease, not the act of withdrawing treatment, which causes death.*

### **When should I prepare an Advance Care Plan?**

**The sooner, the better** for all persons over the age of 18 years. No one can know when an accident or disease may make one unable to state his or her personal choices.



### **What if I change my mind?**

Advance Care Plans are never final until capacity to make decisions is lost. Everyone has the right to change their document at any time. Simply complete a new document and provide your doctors with the updated version. To avoid confusion, it is wise to destroy out-dated documents.

### **Do I need to have my document notarized or witnessed by a lawyer?**

If you are a Florida resident, it is not necessary to notarize your Advance Care Plan document or have a lawyer involved to complete the document. It is required that the document signatures be witnessed by any two competent adults, other than your designated surrogate and one witness should not be your spouse or a blood relative. It is best to have someone witness the document signatures who is neither your heir, your family member nor your health care provider.

### **How often should I revise my Advance Care Plan document?**

Advances in medical science happen all the time, and the laws about Advance Care Plans can change within the state and across the nation. It is wise to discuss your plan with your primary doctor every few years or whenever you have questions.

***Review your document after major life events like marriage/divorce, birth/death, retirement, or major illness.***

### **What do I do with my Advance Care Plan document after I complete the form?**

After your Advance Care Plan document is completed, make certain you have signed and dated the form. Always keep your original document along with your other important legal papers. Provide your hospital with a copy of your Advance Care Plan Document each and every time you are admitted to the hospital. In addition, we recommend that you provide a copy to any doctor who participates in your care. You should discuss your choices and goals for care in detail with your designated health care surrogate and those who care for you.

### **How can I make sure that my wishes are followed?**

Your Advance Care Plan should be part of your medical record. It should be readily available to doctors and other health care providers. It is important to include your Healthcare Surrogate and your family in your planning, keeping them informed of your wishes, and provide them with a copy of your Advance Care Plan.

### **I have several doctors. With whom should I discuss my Advance Care Plan document?**

Dependent upon your illnesses, any or all of your doctors may be involved in your care if you reach a condition in which your Advance Care Plan is needed. Treatment recommendations and decisions are often made through agreement of several doctors. You should discuss and give copies of your Advance Care Plan to all of your physicians, especially your primary care physician.

### **Are there conditions when my expressed wishes may not be honored?**

Yes. Even though your Advance Care Plan is a legal document, your physicians and surrogates are ultimately responsible for interpreting and carrying out your choices for you when you are no longer able to communicate your choices. These decisions are sometimes difficult and require judgment. When there is a question, they must serve you according to the spirit of your instructions. It is the legal responsibility of your physicians and health care providers to honor the choices of the dying for end-of-life care. The clearer your Advance Care Plan is, and the better you communicate its contents to your physicians and surrogates, the more likely they are to be able to follow your exact wishes. For example, when a condition involves some but very little chance of recovery, or when a treatment involves significant risk or added suffering with low potential for benefit, your surrogate will be required to make value judgments on your behalf after full medical advice from your physicians.



### **In the past, why have doctors had difficulty following Advance Directives?**

Many living wills ask doctors not to perform "heroic measures" or "use artificial means of treatment." These and other vague statements, such as "terminal condition" or "if death is expected", have no clear meaning. Some documents ask doctors to certify that there is no hope for improvement. These terms and phrases prompt doctors to do more medical procedures, not less. Withholding ineffective medical

technology and allowing a natural death is a slowly evolving concept in American medical care and is contrary to the way many doctors have trained and practiced for many years. It is often possible to give "palliative", or comfort care, at the same time as continuing treatments that are intended to cure illness. A change from ineffective "curative" care efforts to comfort or "palliative" care is sometimes best for you. Recognition that you are unavoidably nearing death and switching the emphasis of your care to "comfort" care, however, can be the greatest gift that doctors and families can give to you.

**A clearly written Advance Care Plan and personal discussion with your doctor and family is your best assurance that your wishes will be followed.**

### Why would anyone want "No CPR?" Isn't that a form of suicide?

No. The success rate of cardiopulmonary resuscitation (CPR) is much less than people think.

- For individuals over 60 years of age, the success rate of CPR in hospitalized patients is 10 to 15%.
- For victims of heart arrest outside a hospital, CPR is successful only 3 to 5% of the time.

For a dying individual, cardiac arrest with no attempt at resuscitation (which is typically painless, like going to sleep or passing out), is usually the most merciful method of dying. By saying that one **does not want CPR when death is near**, one says that, "when my time comes I do not want to prevent the natural way of dying."



*Many patients dying from cancer, terminal heart or lung disease, or with Alzheimer's disease, or individuals who are healthy but have reached an advanced age, may not want doctors to prevent them from dying a natural, peaceful death. Their choices may include a "Do Not Resuscitate" (DNRO) order.*

### If I have an Advance Care Plan, does that automatically mean that I won't be resuscitated if my heart and lungs stop?

**NO.** Medical personnel will ALWAYS attempt resuscitation UNLESS you have been identified as being in a condition that YOU have listed in your Advance Care Plan that you have chosen not to be resuscitated for.

All decisions regarding CPR should always be discussed by you with your physician. If you do not want CPR, you should ask your doctor for a "Do Not Resuscitate" (DNRO) order to be entered in your hospital medical record. Currently, in the State of Florida, a separate form (DH Form 1896) must be signed by you (or your health care surrogate, if you are unable to sign), and by your physician. That form must be with you at all times to ensure that CPR will not be performed in a non-hospital situation.

### Where can I get the Florida Do Not Resuscitate Order Form (DH Form 1896)?

Your physician should be able to provide you with the form, or you may contact Project GRACE to obtain one. Remember, you must also have your doctor sign the form to prevent unwanted CPR outside of the hospital.

### Will my living will be honored if I become ill in another state?

Most states will honor another state's advance directive. Every state has its own laws governing living wills, healthcare surrogates and DNR orders. To be safe, it is important that you check the laws of states where you spend time.

No advance directive can be all-inclusive or long enough to provide for all situations. Discussions about death and end-of-life issues are often avoided in American culture. However, an open, detailed “kitchen table” discussion with your family and physicians is the best way to ensure that your choices will be understood and honored.

### **My Advance Care Planning “To Do” List**

- I learned about the advance care planning process
- I have given thought to my personal values, religious beliefs and cultural perspectives about end-of-life issues
- I chose someone to speak for me
- I considered the kind of care and medical treatments that I want and don’t want
- I shared my wishes with my:
  - family
  - doctor
  - healthcare surrogate
  - spiritual advisor
  - attorney
- I completed my living will or advance care plan document
- I signed and dated my document in front of two witnesses who have also signed and dated the document
- I followed up with my doctor to get my questions answered
- I made copies to share with my family, doctors and healthcare surrogate
- I plan to review and update my document regularly

***Mark your calendar, National Healthcare Decisions Day is every April 16th!***



***Helping Families  
Create, Communicate and Honor  
Medical Care Wishes***

This document has been prepared as a general information document for the residents of the State of Florida. While prepared in conjunction with healthcare professionals and attorneys, it is general information and does not encompass specific advice. Because laws and regulations are subject to change and vary from state to state, this information should not take the place of legal counsel. If you have specific questions regarding your situation, we urge you to obtain competent medical or legal advice.