# MAKING CHOICES

A Publication of the Neighbors-Helping-Neighbors Program
Spanish Lakes Country Club Village
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*[This document is issued by the SLCCV Neighbors-Helping-Neighbors Program. It uses the text, with permission, from a great publication with the same title prepared by the Florida Department of Elder Affairs. That document is now out of print. They hope to be able to reprint in the future and, if they do, we would urge you to acquire a copy. In the meantime we believe the messages in the original document are important and potentially useful to the residents of Spanish Lakes Country Club Village.]*

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## LIFE PLANNING PERSPECTIVE

The most important aspects of life planning and end-of-life preparation should begin well before we enter the final stages of our lives. In fact, life planning should begin while we have good health and are considered to be of sound mind. Unless we carefully and deliberately plan and express our wishes in writing and in the appropriate legal format, there is no guarantee that our wishes will be correctly interpreted and honored.

As we get older, there are two important things we must do. First, give ample consideration as to the way we want our assets managed if we should become sick or incapacitated and are no longer able to manage ourselves. Who do we know and trust who will act in our best interest? We must also consider the way we want our assets distributed upon our death. Secondly, give ample consideration to the way we want our health managed if we are not able to manage it ourselves. What kind of medical care or services do we want to receive and what services would we refuse?

Defining our wishes and communicating them to our family and loved ones is of vital importance when addressing end-of-life issues. Although the decision making process may be difficult emotionally, taking thorough and thoughtful actions now could ensure clarity later.

**Common Life Planning Mistakes**

- Not keeping records up-to-date and current.
- Not sharing the location of vital records/documents.
- Letting emotions rule your decisions
- Not getting legal affairs in order (e.g. property titles)
- Naming inexperienced or irresponsible executors.
- Waiting too late to begin the planning process.

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# LAST WILL & TESTAMENT

Over our lifetimes we will inevitably accumulate property and possessions. A will is a document that directs how your property will be passed on at the time of your death. It also designates a person to be responsible for assembling the property, paying debts and taxes, and distributing what is left. A person who dies without a will dies intestate. Consequently, their property passes as designated by the laws of intestacy, regardless of the wishes of the deceased. It is a good idea to make a will, even if you have very little property or possessions, to ensure that your things are passed on according to your wishes.

Examples of property include stocks, bonds, certificates of deposit and real estate. Most people wish to pass their possessions on to their children and/or family members.

Proper estate planning will enable you to reduce estate taxes and, thereby, pass on more of your estate to your loved ones. It is important that you execute a will and specify who you want to receive what items.

Ask yourself: “How can I protect my assets, but at the same time make sure I do not violate laws or rules that may affect my receiving long-term care?” Consult with an attorney specializing in elder law for an answer to this question and other related “asset protection” questions. In seeking professional help, make sure that the person you select is knowledgeable of Medicaid rules and regulations.

# BEYOND A LAST WILL & TESTAMENT

## *(Terms To Understand)*

**Advance Directive-** A general term that refers to oral or written instructions given by a person expressing wishes about future medical care in the event they are unable to speak for themselves. Advance directives can be changed or modified by the author.

A competent adult has the right of self-determination regarding decisions concerning their health, including the right to refuse medical treatment. Without an advance directive in place, there is no guarantee your wishes will be honored. A person's intent may be communicated in the following three ways: a living will, a health care surrogate, and/or a durable power of attorney. A brief description of each of these directives is provided below.

**Living Will-** A document that formalizes an individual's wishes regarding the medical care that is to be used or withheld if he or she becomes incapacitated or unable to make his/her own decisions.

Many living wills include "do not resuscitate orders" (DNRO) that spell out under what circumstances an individual does no want to be revived. Most information about DNROs is included in this publication.

**Health Care Surrogate-** An individual you select to make decisions for you when you are no longer able to make them yourself. Your surrogate will be responsible for communicating your wishes to your doctor. In order to change or revoke the designation of a surrogate, you must provide a signed, dated acknowledgement of your wishes.

Advance Directives Generally Must Be:
- In writing.
- Signed by the person making the will.
- Compliant with state laws.
- Witnessed

**Durable Power of Attorney-** A document that can delegate the authority to make health, financial, and/or legal decisions on a person's behalf. Unlike a general power of attorney, a durable power of attorney continues to be effective when a person becomes incapacitated. The durable power of attorney must be in writing and must show the person's intent to give specified power if the person is incapacitated. The durable power of attorney must specifically state that the designated person is authorized to make health care decisions.

If you choose not to write an advance directive, be sure all of your family and friends clearly understand what you wish to have done if you are incapacitated. This common understanding among family and friends will help prevent confusion as to the interpretation of your wishes.

Ask yourself: "Do I need an attorney to complete my end-of-life documents?" Consulting with an attorney is recommended. Although an attorney is not required to fill out advance directive forms, there are specific legal requirements that vary from document to document and from state-to-state. Failure to follow these specific requirements may invalidate an entire document and could result in one's wishes not being observed. An attorney, licensed in Florida, can ensure that your forms are in proper order. To find a licensed attorney, contact that Florida Bar Lawyer Referral Service at 1-800-342-8011 or visit www.flabar.org. If you cannot afford an attorney, you may contact your local legal aid office.

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## COMMUNICATING END-OF-LIFE CHOICES TO FAMILY AND LOVED ONES:

### *"Isn't It Time We Talk About It?"*

Kathy Brandt, M.S., and Karen Lo, M.S., R.N.

We are all parents, adults, children, spouses or partners, siblings, nieces, nephews, grandchildren or grandparents. No matter what our role, we have responsibilities to family. One of the most difficult obligations is the role of health care surrogate. In Florida, if a person becomes in capacitated and cannot communicate health care wishes or decisions, a health care surrogate can make those decisions. What happens if someone has not selected a surrogate? The responsibility for medical decision-making would fall to family members. This means that you could automatically become a relative's proxy should something happen to them. Would you know their wishes? Likewise, one of your relatives could become your proxy if something happened to you. Would they know your wishes?

If advance care planning is not done, wonderful relationships may become strained for those left to decide medical treatments for someone with an acute or chronic illness, or those at the end-of-life. This is why advance care planning and advance directives are so important. Yet, most adults do not have an advance directive that states their preference regarding the use of medical treatments to prolong life. Many adults are reluctant to even talk about it.

Conversations about end-of-life issues are not easy to start. Many people think that they do not need to worry about these issues. However, there are countless tragic situations in which family members are fearful of making decisions about the care of someone who did not communicate their own wishes clearly.

Ask yourself: “How can I ensure that my wishes are honored if something happens to me?”

You should talk with family members and let them know your wishes regarding how much emergency or life-preserving care you want, should you become incapacitated. Those wishes should be formalized in advance directives. You should also consult with an attorney for assistance in developing a will (last will and testament) or a trust agreement to protect and distribute your assets in accordance with your wishes upon death.

The following are tips to start a conversation about end-of-life preferences:

## Explore Personal Beliefs

Ease into the discussion by talking about personal values. If you know someone’s values, it will be easier to make decisions for them if you are ever appointed their surrogate. This might also help to clarify their feelings prior to talking specifically about medical care options. You might consider some of the following questions:

- What would help you live well at the end-of life?
- What do you want to accomplish before you die?
- How will you prepare for your own death?
- What would you want said for your eulogy?
- What legacy from your life do you hope to leave to others?
- What would help you cope with facing your death or the death of a loved one?
- Do you have any relationships that need attention, care and/or reconciliation?

## Explore Preferences

Some people know what they do not want, rather than what they do want. If you do not know the answer to a medical question, you can always ask your physician or call your local hospice. You might consider some of the following questions:

- Who would be most able to provide comfort to you?
- Where do you want to spend the last days of your life?
- What kind(s) of medical care do you want as the end-of-life approaches?
- Are there specific medical procedures that you want to learn more about before making care decisions?
- Are there some procedures you definitely do not want?
- Have you discussed these issues with anyone?

* Have you completed any advance directives such as a living will? If so, where is it?

* Are there any issues related to dignity or quality of life at the end-of-life that you want to explore with your family or physician?

After having these conversations, it is important to decide whether or not you feel comfortable putting your wishes in writing. Many people find the idea of writing down their preferences in a living will confusing and intimidating. Although options exist that do not require your options in writing, written statements more effectively formalize your decisions. Living wills are written statements in which an individual expresses his/her desires for end-of-life care. They preserve the individual's right to accept or decline care—even when he/she may be incapacitated. Legal counsel is not required to complete and execute an advance directive.

## Conclusion

We cannot plan when or how we will die. However, we can take steps now to ensure that our wishes are honored at the end-of-life. Let it be a time of peace, where the greatest burden to your loved ones is saying goodbye – and not determining how you will die.

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# STRATEGIES FOR ADVANCE CARE PLANNING

Gail Austin Cooney, M.D., and William L. Allen, J.D.

Deciding to have an advance directive is only the first of several key decisions about end-of-life care. Once a person makes this decision, a number of questions arise about the best approach to take. However, the best approach may vary from one individual to another. This article identifies the benefits as well as the potential problems with various approaches. This information is intended to help you determine which avenue is best suited to your situation.

### 1. Having Only A Living Will.

***Advantage:***

Some people have felt that if they could be sufficiently clear about their choices of treatment limitations in a living will, they would not need a surrogate decision-maker. In one case a man reported that he deliberately chose this strategy, so that his wife would not have the emotional burden of making decisions or the responsibility for carrying out his choices about limitations or refusals of treatment.

***Disadvantages:***

Most living wills cannot adequately foresee all of the clinical circumstances that may arise; therefore, some decisions may need to be made that the patient could not have foreseen or directly addressed in prior instructions. Therefore, what is expressed in a living will often needs to be augmented by a decision-maker chosen by the patient who will be able to interpret what is in the living will or explain what the patient would have wanted under the circumstances.

## 2. Having Only A Health Care Surrogate Decision-Maker.

***Advantages:***

Some groups advise that the best way to prevent a living will from being interpreted in a way that results in an outcome contrary to your intention is to not write one at all. This strategy tries to prevent that misinterpretation by simply naming someone who knows what you want and who will express those decisions for you, without having a document that may be ambiguous and therefore used by others to challenge what your surrogate says you would want.

***Disadvantage:***

Although the risk of the above scenario cannot be ruled out, a written living will can also be an important source of formal support for what your surrogate says you would want when someone challenges his or her account of what you would have chosen. If your surrogate is challenged by someone who says, "How can you demonstrate that what you have chosen is what the patient would have wanted?" Written documentation of your choices can be used to show consistency.

## 3. Having A Combination Of Living Will And Health Care Surrogate Decision-Maker.

***Advantages:***

The key to making this option work for you is to make sure your surrogate has read your living will and asked you questions to clarify any remaining questions. If you have both a living will and a surrogate, a challenger will find that it is his word against yours and your surrogate's, instead of his word against your surrogate's word alone.

***Disadvantage*:**

If your surrogate hesitates to follow your choices as expressed in the living will, it makes it very difficult for the physician to withdraw treatment that you refused in writing.

## 4. Adding a "Values History."

A "values history" is an idea derived from the term "medical history". Just as your medical record, augmented by your physician's elicitation of new information during each encounter with you, provides a history of your health status that guides medical diagnosis and recommendations for testing and treatment, so a values history is an attempt to elicit your values, feelings, choices, and biographical details that may shed light on what decision you would make if you ever lost the capacity to decide for yourself. A values history, either as part of or separate from an advance directive, can help your surrogate and your care providers determine what you would be likely to decide, based on a broad expression of what has been and is important to you. A key component of a values history is your own expression of what constitutes an acceptable quality of life for you. This can help your physicians and surrogate know that if proposed treatments cannot restore you to a quality of life you find acceptable, you would refuse such treatment.

To help you develop a values history consider the following:

- Overall attitude toward life and health
- Personal relationships
- Thoughts about independence and self-sufficiency
- Living environment
- Religious background and beliefs
- Relationships with doctors and other health caregivers
- Thoughts about illness, dying and death
- Finances
- Funeral plans

## 5. Relying On The Proxy Decision-Maker Instead Of Naming A Surrogate Decision-Maker.

***Advantage:***

If choosing one member of your family to be your surrogate will hurt the feelings of others, it may be tempting to simply avoid choosing, especially if the list of proxy decision-makers specified in statute will turn out to be the same person you would have chosen, anyway.

Health care decisions may be made for the patient – if the patient has no advance directive or designated surrogate – by any of the following individuals, in the follow order of priority:

- Judicially appointed guardian
- Patient's spouse
- Adult child of the patient
- Adult sibling of the patient
- Adult relative of the patient
- Close friend of the patient

(See section 765.401, Florida Statutes.)

***Disadvantages:***

The problem with this is that a proxy's decision may be more easily challenged than a specified surrogate's. By naming a surrogate, you are giving that person the legal presumption (in Florida) that his/her determination of what you would want is correct. Anyone challenging what your surrogate says will have the burden of showing that person is wrong. By naming a surrogate, you place your decision-maker in a much stronger position to prevail against anyone who might decide to challenge him or her.

## 6. Including "Choice Of Settings" Language.

One strategy that may help you improve the probability that you will have your choices honored is to specify in your advance directive (living will and/or surrogate) your choice of the setting in which you want to spend your last days. You may want to rank order several options to allow for trials of certain types of treatment that require hospitalization, but specifying that if there is not sufficient improvement, you choose to be moved to your home, or if that is not possible, to a residential hospice or a nursing facility near your home and family or friends.

You may also want to add a statement that once the conditions of your living will are met, you wish to be moved to your home or choice of facilities, even if such a move could increase the risk to your health status.

Decisions on which of these approaches to advance care planning best suits you require careful reflection. But don’t stop with reflection. Follow up by implementing the approach you choose, and talk with your physician(s) and your loved ones about what you have chosen. This process can minimize a host of problems later.

# EMERGENCY MEDICAL SERVICES & THE DO NOT RESUSCITATE ORDER

Freida Travis and Jessica Swanson

The emergency medical services (EMS) system delivers rapid out-of-hospital medical care for victims suffering from sudden illness or injury. Over the last 30 years, new developments in medical technology and new treatments have improved the ability of EMS providers to mobilize care and sustain life in emergency situations. Emergency medical technicians (EMT) and paramedics complete comprehensive coursework and are trained to perform highly technical life-saving measures using sophisticated equipment. Standard levels of care have evolved from closed chest cardiac compressions to definitive techniques using equipment such as automated external defibrillators, in many instances reversing sudden death outside the hospital.

Until very recently, there were few provisions in emergency medicine for withholding care from patients who would not benefit from advances in medical technology and training – specifically, those who suffer from an end-stage condition, terminal illness or persistent vegetative state, where advanced life-saving measures can be painful, intrusive and futile. As nearly as 1990, the growing awareness over end-of-life issues and the desire to honor a patient’s wish not to be resuscitated, prompted the Florida Department of Health, Bureau of Emergency Medical Services to examine ways to validate a document that would allow EMS providers to honor a patient’s last wishes.

In 1992, the first legislation addressing pre-hospital Do Not Resuscitate Orders (DNRO) was enacted. The 2000 Do Not Resuscitate Order legislation authorized changes to the form, and also provided protection from civil liability for criminal prosecution to virtually every licensed health care facility honoring the DNRO. Since that time, the Bureau has consulted with health care providers, consumers and other state agencies. In February 2000, a revised, yellow DNRO form was redesigned for simplicity and portability.

## The “Do Not Resuscitate Order”

A Do Not Resuscitate Order is a specific, physician-directed document that says that the individual does not wish to be resuscitated in the event of cardiac or pulmonary arrest. It is usually written for someone who is terminally ill, suffering from an end-stage condition or in a persistent, vegetative state. According to the DNRO, Form 1896, cardiopulmonary resuscitation includes artificial ventilation, cardiac compression, endotracheal intubation and defibrillation.

The development of the DNRO was critical to EMT’s and paramedics. When an EMT or paramedic arrived on the scene they needed to respond immediately by providing care to the patient in cardiac or respiratory arrest, unless presented with clear proof of the patient’s wish no to be resuscitated. This situation could become volatile and occasionally led to conflict when family members disagreed with the EMT’s decision to attempt resuscitation. Many health care facilities would use their own forms, and doctors would write, “Do Not Resuscitate” in a patient’s chart. However, it a patient was transferred or transported to another facility, their wishes may or may not have been honored.

EMS needed a readily accessible, standardized document that would meet the needs of the patient, but that would also be recognized statewide by EMS providers as legal and binding, protecting them from potential civil and criminal liability for honoring the DNRO document.

The revisions in 2000 were made to the DNRO in an attempt to alleviate public and professional concerns that do-not-resuscitate orders were confusing, hard to access and could not be used when transporting a patient between health-care settings. To assess the extent of these problems and to identify possible solutions, the state held workshops to collect input on how the DNRO should look and how it could be incorporated throughout the continuum of care.

The outcome of these workshops resulted in a form that was easy to identify, met the needs to the patient, and was portable between health care settings. Consequently, the DNRO is intended to be used as a tool to record the patient’s wishes, reduce conflict on scene and allow EMS personnel to provide compassionate and appropriate care.

## The DNRO “Yellow Form”

The DNRO is often referred to as the “yellow form” because it must be either the original on binary-yellow paper, or a copy made onto similar colored-yellow paper. It must be signed by the individual or the individual’s health care representative and by a Florida licensed physician. According to Chapter 64E-2.031, Florida Administrative Code, any previous version of the Department of Health Do Not Resuscitate Order will be honored, and there is no need to sign a new form. The Florida DNRO is only valid in Florida, and it can be revoked, either orally or in writing, at any time by the patient or patient’s health care representative.

## Patient Identification Device

At the bottom of the DNRO there is a patient identification device that was included and may be removed from the form by cutting on the perforated lines, completed and may be laminated. To use the Patient Identification Device, the person or the person's health care representative and a Florida licensed physician must sign the device. If laminated, the device can be worn around the neck, on the writs, or attached to bedding, clothing or somewhere else where it can be easily seen. The Patient Identification Device was designed for portability between settings.

The device is a card, and does not have to be completed with the DNRO, Form 1896, for the form to be valid. Once completed and removed from the form, the Patient Identification Device is equally valid to the DNRO, Form 1896. The Patient Identification Device should not be carried as a walled card. Emergency medical technicians and paramedics are unlikely to have the time before they attempt resuscitation to search a wallet of someone in cardiac or pulmonary arrest. If using the device, it is best to keep it displayed or easily accessible at all times. It also protects the health care professional, from criminal prosecution or civil liability for the withdrawal or withholding of cardio-pulmonary resuscitation. The significance of portability means that having one form signed, whether it is the original copy, and keeping a copy with you will protect your wishes if you are transferred between health care settings.

## Calling 9-1-1

When a person signs a DNRO it is a critical time in his or her life. He or she has made a personal choice, hopefully with the support of family, caregivers and health care workers, including hospice professionals and volunteers. Even if prepared, managing death is difficult and may not occur instantly. The person may experience a wide range of symptoms, including shortness of breath, pain, seizure or other problems. When this happens, those caring for the patient may be unsure of what to do, scared, or just want the support of a health care professional. This is the time at which many decide to call 9-1-1, the emergency services telephone number.

Any family member, caregiver or health care provider can call 9-1-1 at any time to attend to the patient with a DNRO. The DNRO only means that in the event of cardiac or pulmonary arrest, EMS will not attempt resuscitation. A person will still be treated for pain and provided "comfort care." It is clear that a DNRO does not mean "do not treat for pain," "do not offer comfort care measures like oxygen" or if there is a reversible medical problem, "do not treat or transport to another facility." The State of Florida is undertaking an educational effort to prepare emergency medical technicians and paramedics to better respond to calls involving a DNRO so that they are prepared to treat and comfort patients and families at the end-of-life.

Emergency Medical Services personnel are there for the family and act as a resource in a difficult time, providing comfort care or transport to another facility if the need arises. If 9-1-1 is called, it is important to communicate a brief description to the dispatch operator and explain the situation. For example, "My family member has a DNRO form, but is convulsing and I don't know what to do." When the emergency medical technician or paramedic arrives, as much information as possible should be shared with them so they will be able to provide the most effective and efficient care.

It is important to have the DNRO available immediately, so that they will not delay treatment while someone searches through files or drawers for the proper documents. Make clear the wishes of the patient, specifically that they do not want to be in pain or what type of comfort or care they need or request. The emergency responding EMS professional is there to answer any questions or concerns about treatment and care.

## Resources

When deciding to complete a Do Not Resuscitate Order, it may be best to speak with your physician, local clergy, or a social worker about your wishes. You should also inform your family members or caregivers about your wish not to be resuscitated. It is important to reiterate that a Do No Resuscitate Order does not mean do not treat, and the provision of comfort care measures, such as oxygen or medicines are available through emergency medical services.

If you have questions about the DNRO, Form 1896, contact your local EMS provider, your physician, local attorney or senior center program. You can also call (850) 245-4440, ext. 2735 or write to:

Bureau of Emergency
Medical Services
4052 Bald Cypress Way
Bin C 18
Tallahassee, Florida
32399-1738

or visit Bureau of EMS's web page at http://www.doh.state.fl.us/demo/EMS/default.htm

Florida is a very diverse state, and many people have requested translations of the DNRO in their native language. Unfortunately, the Bureau of EMS does not provide translations of the form. There are some health care agencies in Florida that do translate, but to date only into Spanish. Emergency medical services providers cannot honor this translation, and it should be used only for informational purposes. If the patient or patient's health care surrogate signs a Spanish version they should also sign the Department of Health English version 1896 and keep the forms together. This ensures that a responding EMT or paramedic can read and honor the English, Department of Health version, while also assuring that the patient fully comprehends the document.

## DNRO Conclusion

Emergency medical services providers throughout the state are working in their communities to provide leadership and resources for people at end-of-life. The DNRO is one tool people can use to help ensure that their wishes not to be resuscitated will be honored. The DNRO was redesigned to be easy to understand, locate and transfer between health care settings. EMS will work in partnership with the community and health care facilities to provide medically appropriate and compassionate care, improving the quality of end-of-life care.

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# END-OF-LIFE PREPARATIONS AND HOSPICE CARE

Hospice care is a special way in which family members and others provide comfort and support to terminally ill loved ones during the final months of their lives. Rather than engage in painful struggles to keep patients alive, this time is used as a period of social, emotional, and spiritual healing. The objective of hospice care is to improve patients' quality of life by making them as comfortable as possible.

Hospice care strives to manage a patient's pain while keeping them coherent and alert. It also emphasizes care and counseling of both the patient and his/her family. Although consent and certification from a doctor is necessary for admittance to hospice care, it is often a more cost effective choice then traditional hospital care.

Should your loved one reach a point where death appears to be inevitable, it is important to discuss their wishes with them.

With advances in today's medical care, a person's life can be extended through the use of life support systems; however, the remaining quality of life may be unacceptable. Often patients with terminal illnesses would rather spend their remaining time in the comfort of their home, close to family and friends.

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# BEREAVEMENT AND FINAL ARRANGEMENTS

The loss of a loved one, whether they lived to be over 100 years old or died much sooner, is a sad, painful, and deeply personal experience. While bereavement is a time of reflection and healing, it is also a time when many critical decisions must be made. These decisions range from the choice of funeral and burial arrangements, to assets protection and accounting, as well as securing your own future care needs. Unless life care and end-of-life issues have been planned well in advance, a decision made out of highly charged emotions may prove to be problematic.

Be careful. Do not be pressured to make decisions on the spot or too quickly. Do not be afraid to get second and third opinions, compare prices and services, and always seek information from independent sources.

Sadly, your period of bereavement can be an opportunity for dishonest persons to try to take advantage of you. During this time, dishonesty can take many forms including attempts to deny benefits or claims due, overcharging for services rendered, or withholding important information that could affect the decisions and choices you make. Pay careful attention when making arrangements and consult with loved ones when you have concerns.

Listen carefully to those individuals who have no vested interest or potential gain in the outcomes of your decisions. While grieving, remember that your loved one cared about you and would be concerned about your financial and physical well being long after he or she is gone.

Try to take comfort in the times and memories you shared. It is okay to laugh, cry, and talk about your loved one as though he/she were still with you and remember all of these reactions are a normal part of grieving.

Confused about funeral and burial services? "Funerals: A Consumer Guide" is a publication produced by the Federal Trade Commission. It will assist you in asking the right questions and help you understand your rights as a consumer when making final arrangements. To request a copy, write to:

Funerals: A Consumer Guide
Public Reference
Federal Trade Commission
Washington, DC 20580.

Now that you know more about why advance directives are important, it's time to get started. Here are two resources to help you as you begin to make these decisions:

National Hospice & Palliative Care
Organization
www.nhpco.org
1-800-658-8898

Aging with Dignity
www.agingwithdignity.org
1-888-5-WISHES
(1-888-594-7437)

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