



Making Choices

Beginning to Plan for End-of-Life Care

Sponsored by the

Florida Department of Elder Affairs in collaboration
with the Florida Partnership for End-of-Life Care



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Terry White, Secretary
Florida Department of Elder Affairs

Jeb Bush, Governor

4040 Esplanade Way
Tallahassee, Florida 32399-7000
850/414-2000 * FAX 850/414-2004 * TTY 850/414-2001

Internet address: <http://elderaffairs.state.fl.us>
(Spanish) <http://elderaffairs.state.fl.us/doea/ancianos.html>

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Message from Governor Bush



Floridians are living longer today than at any point in our history. And thanks to advances in technology, we are living a better quality of life. With these advances often come difficult decisions about end-of-life care, and the effect it will have on our families and loved ones. By talking with family members and planning for our care, we can ease the burden of making some of life's most difficult decisions. Florida is taking the lead in helping caregivers and individuals prepare for these challenging choices. In an effort to continue helping our most vulnerable citizens, I encourage all Floridians to begin discussing end-of-life care with your family and loved ones.

Message from Secretary White



One of our goals at the Department of Elder Affairs is to educate Floridians about every aspect of the aging process. We have learned that education about future choices is most helpful when it occurs long before it is needed. With this philosophy in mind, advanced planning allows for preparation of medical, legal and spiritual decisions. Having a conversation with your family and friends about your preferences in end-of-life care offers the best opportunity for making choices.

Acknowledgments

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Professionalism**

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Florida Bioethics Network

Statewide Network of 23 Community Coalitions

The members of the Florida Partnership would like to acknowledge the encouragement and support of numerous individuals including State Senator Ron Klein from Boca Raton, Florida.

The vision of the Department of Elder Affairs is “to lead the nation in providing older persons with information, choices and opportunities.” The mission of the Florida Partnership is “to ensure that all Floridians have access to quality end-of-life education and information”.

If you have any questions about the information provided or would like to contribute, call the Department of Elder Affairs at 1-850-414-2000 or the Florida Partnership office at 1-850-878-2632.

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End-of-Life Choices: Introduction to this Booklet

Ray Moseley, Ph.D., and Linda Macdonald, M.S.

The following series of articles covers many of the crucial issues involved in end-of-life care. These articles provide a good starting place to begin thinking about the choices we may have to make about the care at the end-of-life for ourselves and our loved ones.

This volume begins with three articles, by Gail Clooney, William Allen, Kathy Brant and Karen Lo, which address the possible choices we are faced with in end-of-life care planning. These choices include the decision about whether to have an advance directive and what type may be best for you. These articles also discuss the difficulty with, and importance of, talking to loved ones about your end-of-life decisions.

Next, Ken Goodman discusses a very common and often very significant confusion in end-of-life decision-making, namely the confusion between “withholding” and “withdrawing” life prolonging medical treatments.

The problems surrounding a person’s decision to not want to be resuscitated in the event of cardiac arrest are addressed in two articles. The article by Ray Moseley discusses the issues with the Do

Not Resuscitate Order in the hospital setting, and the article by Freida Travis and Jessica Swanson discusses the Florida’s response to the problem of transportable Do Not Resuscitate Orders, which allows Emergency Medical Services to honor a person’s refusal of resuscitation in the event of cardiac arrest at home.

The final set of articles address the issues involved with care of the whole person at the end-of-life and the care of that person’s family and loved ones. Kathy Brandt discusses the importance of understanding the grief process. William Allen discusses the necessity of effective pain management. Samira Beckwith discusses the role of hospice in effective end-of-life care and answers important questions about economic access to hospice care. She also dispels the numerous myths about hospice care.

These articles are not designed to be a complete resource guide to end-of-life care but rather offer an important starting point for those who are beginning to think about and plan for end-of-life care for themselves or for their loved ones.

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 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. In this article, we have tried to identify the benefits as well as the potential problems with various approaches. We hope this information will help you determine which approach is best suited to your situation.



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

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

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 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.

A living will might have made a difference in the recent St. Petersburg case of Terri Schiavo who has spent 11 years in a persistent vegetative state since collapsing from a cardiac arrest at age 26. Her parents’ claim that their daughter would want to continue life support could be refuted or supported by her own words in print rather than simply her husband’s assertions that she would not want treatment.

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

Values History

To help you develop a values history, the Health Sciences Ethics Program of the University of New Mexico has developed a form that is not copyrighted. This document provides questions to help you clarify your feelings and identify your thoughts on such topics as:

- 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

For more information or to obtain a copy, write to:

Health Sciences Ethics Program
University of New Mexico
Nursing/Pharmacy Bldg., Room 368
Albuquerque, NM 87131
Or e-mail requests to pierson@unm.edu
Cost per hard copy: \$3.00
(payable to Health Sciences Ethics Program).

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 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 are 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.

Values history separate from your living will legal document:

The conventional wisdom on this option has been that the values history is an autobiographical narrative that is not appropriate for inclusion in a formal legal document like a living will. It is true that the process of reflection and expression of the personal values that might be relevant might be too general to be useful in a living will. However, some of the end results of the process of expressing one's personal values on end-of-life questions may not be useful and appropriate to be integrated into one's living will.

Values history as part of the legal document:

Although the length and the narrative elements and generality of some aspects of a values history may not lend themselves well to a formal advance directive intended to be a legal document, there is no good reason why the outcomes of a values history process

cannot be incorporated into one's living will. In particular, one's own personal definition of the minimally

acceptable quality of life or levels of existence that one would find unacceptable can be specified in the living will to provide further guidance to one's decision-makers and could clearly be intended to convey the full force of your legal intent.

“Deciding to have an advance directive is only the first of several decisions about end-of-life care.”

5. Relying on the proxy decision-maker instead of naming a surrogate decision-maker.

Advantages

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 following 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 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 wished to be moved to your home or choice of facilities, even if such a move could increase the risk to your health status.

Reflection on which of these approaches to advance care planning best suits you requires careful reflection. But don't stop with the 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.

Advance Care Planning: Communicating End-of-Life Choices to Your Physician

Gail Austin Cooney, M.D.

Advance care planning is a journey. Like preparing for most journeys, it begins with individual reflection about one's goals. In this case, it is reflection about the goals of your health care as you near the end of your life. Advance care planning identifies care which you do,



and do not, wish to receive in various situations. This is commonly called a “living will” or “instructional directive.” Advance care planning also identifies those people whom you want to make health care decisions for you if you are unable to communicate your choices. This is your “health care surrogate.”

Ideally, advance care planning is a process of structured discussion and documentation, woven into your routine health care, with regular updates and revisions. It is designed to

ensure that your unique wishes will be respected, even if you are unable to participate in the decision-making. When the journey of advance care planning is successful, it fosters a sense of control and peace of mind, for both you and your loved ones. The process of clarifying and documenting your end-of-life health care goals may involve many people, but it is critical that one of these people should be your physician.

Why should I talk with my physician?

Why is the physician's involvement so important? Your physician has the legal and professional responsibility to ensure that your wishes are carried out. Your physician will be the one at your bedside, determining the actual medical orders. But unless you personally make your physician aware of your choices in advance, your goals of care may never be known in time to affect your medical care. Like vaccinations and regular check ups, advance care planning is good preventive medicine because it avoids future confusion and conflict and ensures that you will receive the health care that you want.

When should I talk to my physician?

Communicating your advance care plans with your physician is the best way to maintain control over your own

health care, even if you become unable to make your choices known. When is the right time to have this discussion? Many people feel they must wait until their physician brings up the topic. Do not wait! The best time to review your goals of care is *now*, when there appears to be no need for the discussion: when your health is good or at least stable. This is a time when both physicians and patients often fail to think about advance care planning, but it is the easiest time to objectively look at your personal goals and choices. It also ensures that, when urgent decisions need to be made, your values and goals are already defined and known. It relieves your family of the burden of making difficult decisions without knowing what you would have chosen to do.

How do I get started?

Let your physician know ahead of time that you want to review your advance care plan at your next appointment. That way, the physician will be able to schedule enough time for a thoughtful discussion. Bring your health care surrogate with you to this appointment. A joint meeting between the patient, physician, and surrogate can create a common understanding of your goals. This can be invaluable if you become incapacitated and your surrogate and physician are later faced with the need to collaborate about a plan of care for you.

What do I say?

Start by telling your physician that you want to have a frank and realistic discussion. You want your physician to feel comfortable asking you questions. Your physician should come away from this appointment with a working knowledge of your goals for health care. The physician needs an understanding that can be converted

into appropriate medical care.

Next, review your living will. This instructional directive records your wishes regarding various

types of medical

treatments so that your desires can be understood and respected. Under Florida law, a living will, goes into effect, when the person becomes incapacitated, and has designated and meets one or more of three possible criteria, Terminal Illness, Persistent Vegetative State (PVS) or End-Stage Condition. A person must designate one or more of these three criteria in their living will, that they want met prior to the implementation of the instructions in their living will. Patients, surrogates, and physicians may differ in their interpretation of the term “terminally ill,” as well as the other criteria. You should be aware of the legal definitions of these criteria, and be sure to discuss your individual definitions of “terminally ill” or the other criteria if different than the legal definitions with your physician. You should also discuss and your feelings

“When the journey of advance care planning is successful, it fosters a sense of control and peace of mind, for both you and your loved ones.”

about end-of-life care with your physician, so that he or she can correctly carry out your living will. Your living will may also address “heroic measures” or “life support.” Talk with your physician about those things that make your life “worth living” and what kinds of treatments you want or do not want. Physicians often have a much broader experience of the range of clinical situations to which your living will may apply. Help them to understand how you would weigh the pros and cons for recovery in different situations. You may want to revise the instructions in your living will in light of this discussion with your physician.

Involve your surrogate in the discussion. Your surrogate should be someone whom you trust and who is willing to represent your wishes in making medical decisions. Remember, your surrogate decision-maker does not need to be a family member or significant other. Sometimes, the decisions required are too difficult for people that close to you. They may be overly influenced by their attachment or by the burdens of care. A surrogate acts as you would act, without regard to his or her own personal goals or beliefs. By having your surrogate present during the discussions with your physician, you ensure that the two will be better equipped to make the choices that you would make in a difficult end-of-life decision.



During your discussion, be sensitive to issues of individual conscience. Sometimes, physicians may make personal moral choices that are different from yours. This does not necessarily make one choice right or wrong. It merely reflects the different goals that we each have for our own health care. Be sure that your physician will not have difficulty following your living will because of his or her own personal feelings about the end-of-life. Florida Statutes ensures that your wishes take priority and allows your physician to involve other physicians in your care, if he or she cannot fully support your choices. Listen to their concerns but remember that your decisions about your health care are what ultimately matter.

Continue the Conversation

Be sure to continue the dialogue during subsequent visits, especially as your situation changes. Your physician can enter clarifications or changes into your medical record or you may want to revise your living will. By repeating your commitment to the goals of care established in your advance directive, you reassure your physician that these decisions are important to you. This also serves to remind your surrogate and your physician that these are accurate and up-to-date documents that reflect changes in your health and in your life.

Just Do It!

Although discussions regarding end-of-life care can be difficult ones, it is important to take the initiative and outline your wishes to ensure that you receive the care and treatment you desire. A friend once asked me how to be *certain* that her living will would be respected at the end of her life. My advice was for her to tell everyone what she wanted. And to keep telling them, month after month and year after year! And that the most important person to tell was her physician! This same advice applies to anyone who wants to maintain control of his or her health care, even up to the end-of-life.

Communicating End-of-Life Choices to Family and Loved Ones: Isn't It Time We Talk About It?

Kathy Brandt, MS, and
Karen Lo, MS, R.N.

We are all parents, adult 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 incapacitated and cannot communicate health care wishes/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 preferences regarding the use of medical treatments to prolong life. Many adults are reluctant to even talk about it.



The Hospice of the Florida Suncoast, in partnership with many local organizations, participated in a statewide effort in 2000, to encourage everyone to discuss advance care planning and communicate wishes to friends and families through conversations, and by completing advance directives. The "Isn't It Time We Talk About It?" campaign focuses on the importance of these discussions.

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. 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?

Conversations are important, and need to happen whether or not someone actually has an advance directive.

Many people find the idea of writing down their preferences in a living will confusing and intimidating. Living wills are written statements in which an individual expresses his or her desires for end-of-life care. They

“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.”

preserve the individual's right to accept or decline care — even when he or she may be incapacitated. You do not need a lawyer to complete and execute an advance directive.

Three Types of Advance Directives

Living will – A living will provides written directions regarding life-prolonging procedures to provide guidance and instructions when a person is no longer able to communicate in a life-threatening situation.

Health care surrogate — A health care surrogate is an individual you select to make medical decisions for you when you are no longer able to make them yourself.

Durable power of attorney — A durable power of attorney is a document that can delegate the authority to make health, financial and/or legal decisions on a person's behalf. It goes into effect when a person is unable for himself or herself. The power of attorney must specifically state that the designated person is authorized to make health care decisions. ***The power of attorney must be in writing and must show the person's intent to give specified power if the person is incapacitated.*** You, your family and loved ones, your physician, your lawyer and/or your clergy should have copies of your advance directives.

We cannot plan when or how we will die. However, we can 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. Is it not time *you* talk about end-of-life planning with your friends, family, and health care providers?

If you or someone you know needs further information about advance directives, please refer to the "Resources for End-of-Life Choices" at the back of this booklet.

The Moral and Legal Equivalency Between Withholding and Withdrawing of Treatment

Kenneth W. Goodman, Ph.D.

Rights are slippery things. They are difficult to identify, difficult to agree on, and difficult to protect. Worse, we toss them around in conversation like poker chips or sacks of beans:

- Right to life,
- Right to health care, or
- Right to die.

The point of a right, or entitlement, is that it seeks to ensure some benefit or to protect us from some harm. One right that most everyone correctly agrees on is the right to bodily integrity or the right to control access to one's body — fundamentally, the right to say “no” to unwanted touching.

Based on the powerful concept of self-determination or autonomy, this is also the right to refuse unwanted medical treatment. Now, there are two times one might refuse a medical intervention: either before it has begun or after it has begun. This has led over the years to some confusion about the difference, if any, between withholding treatment and withdrawing it.

Well, is there a difference? What kind of difference is it? How does this question matter in discussions of end-of-life care?

For some people, there is a psychological or emotional difference between withholding and withdrawing life-sustaining treatment: “If we never

start we will not feel like we are giving up.” More importantly, some people have the feeling that the act of withdrawing a tube or turning off a machine is an action that somehow makes them responsible for a death. This is despite the fact that what causes death in such cases is the underlying disease or malady.

Additionally, some religions distinguish between withholding and withdrawing. It is sometimes thought that the act of removing life support expedites the dying process and is therefore inappropriate, whereas not starting an intervention may be permissible. This has led to cases in which it was judged unacceptable to terminate treatment until a nutrition or ventilation tube needed to be cleaned. Once the tube was removed for that “necessary” purpose it was judged permissible not to reinsert it.

In other faiths, the act of removing life support may be seen as eliminating a spiritually unnecessary burden.

Is the withdrawing/withholding distinction of any *ethical* use? Here it is hard to see why it should be, or how it could be in those cases in which the withdrawal was requested by the patient (perhaps in a living will) or through a surrogate. To see why most philosophers and others contend there is no useful ethical difference between withdrawing and withholding, we

should return to the importance of the right to refuse treatment.

Recall that people may (and probably should) say “no” to forms of physical contact they find objectionable or undesirable. This right to refuse would be hollow if it did not apply even when the stakes are high. So, a right to refuse is not a right only when offered a cup of tea. It is also a right to refuse cancer treatment, cardiopulmonary resuscitation or brain surgery. These are serious interventions. They might be life saving; indeed, they often are. But if “no means no” in the hospital, there is no sense in which it makes any difference whether the action being refused has commenced or not.

In other words, the right to refuse treatment should be respected whether the treatment has been started or not.

It can be quite difficult to decide if a particular treatment is worthwhile. Reasonable people differ on questions related to dignity, hope, and futility. Individual variations are rich and intimate, and require consultations with family members, doctors, nurses, clergy, and friends. Given the same set of facts, the same diagnosis, the same prognosis, two different patients might take two different paths. This is the essence of free choice.

It is also worth observing that in some cases, and contrary to expectations, patients sometimes do better when certain interventions are ceased. For

instance, a growing body of evidence suggests that artificial nutrition through feeding tubes might actually cause patients to die sooner by aspiration.

The right to refuse treatment is not simple, no matter whether the refusal is before or after a treatment starts. To refuse treatment, especially life-sustaining treatment, a patient must fulfill three requirements. He or she

- Must be adequately informed of the consequences of the refusal, as well as alternatives to it.
- Must be capacitated, or competent to understand and appreciate the information.
- Must be making the decision voluntarily, without coercion or undue influence.

Of course, these requirements are just the requirements of informed or valid consent, except that here we are asking them to serve as the criteria for valid refusal. These criteria do not make the refusal of life-sustaining treatment

easier — rather, they order it and give it ethical credibility. They also serve to underscore the

lesson we have drawn so far, namely, that there is not a useful ethical distinction to be found between withdrawing and withholding of treatment. For if a patient met these criteria and therefore was informed, capacitated and not coerced, there would be no reason to force him or her to endure an unwanted intervention, even if it happened to have been started already. That we would have to withdraw it instead of withhold it is

“Rights are slippery things.”

seen to have no ethical traction whatsoever.

In addition to all these ethical reasons for not making too much of the difference between withdrawing and withholding treatment, there is a very practical one (with ethical upshots). It is this. If it was harder or more difficult to stop a treatment than never to commence it, we should fear the loss of all those instances in which the health care team, including the patient, undertook an intervention for a trial period, to see if the results were satisfactory. If you are going to make it more difficult for me to say “no” after a treatment has started, then I might be less likely to allow it to be started in the first place. Surely this would be a therapeutic loss.

At its best, applied ethics guides decisions so as to make them better, not easier or happier. It will still be sad when the patient dies. But not nearly as sad as it will be when the patient dies after a period in which we have ignored or overruled her valid refusal.

What is more, by showing that the difference between withdrawing and withholding is not ethically significant, we have grounded our intuitions, simplified the decision process and maybe even improved the chance of a good outcome! It is a measure of the utility of bioethics in end-of-life care: practical, straightforward and respectful of the rights we sometimes struggle very hard to enjoy.

“Do Not Resuscitate Orders”: Do They Have to Pose a Dilemma?

Ray Moseley, Ph.D.

Should a physician resuscitate a patient if the heart has stopped beating? The answer to this question seems to be obvious. If you ask most people, whether they would want their heart restarted if it stopped, the overwhelming answer would be “Yes, of course.” And this answer makes sense. However, the answer is not so obvious for patients who are suffering serious life-ending disease, or from patients who are actually in the dying process. For these patients the relative benefits of resuscitation, versus the burdens associated with resuscitation are much more debatable, and where a host of difficult and often confusing issues for patients and physicians arise.

In thinking about the issue of resuscitation, the first thing to note is that nothing significant happens with patient care in a hospital without a specific physician order. Most physician orders are concerned with which treatments and medications a patient will receive. A physician order not to provide a specific treatment is the exception. It is also contrary to the prevailing medical model of emphasizing cure and medical intervention. Medical education emphasizes active medical intervention when faced with a patient who is seriously ill. The very idea that medicine might offer no curative treatment to a seriously ill patient is difficult for both physicians and patients to accept. Thus, if no

resuscitation attempt is to be made a specific physician order in the patient’s medical record is required. Without that Do Not Resuscitate Order (DNRO) the hospital staff will resuscitate automatically in the event of a cardiac arrest.

The question then becomes, when should a physician write a DNRO? There are at least four acceptable reasons this order might be written. The first is that in a discussion between a physician and the competent patient, the patient decides that given his/her medical situation, in the event of a cardiac arrest, the burdens associated with a resuscitation attempt simply out-weigh the possible benefits of resuscitation. The second reason is that the incapacitated patient has an Advance Medical Directive that says that the patient does not want to be resuscitated, given the patient’s current medical condition. The third reason is when the wishes of a currently incapacitated patient, to not be resuscitated, are expressed to the physician by the patient’s surrogate or proxy. Finally, a physician may write a DNRO, if that physician believes that any resuscitation attempt would be “medically futile.”

A DNRO based on the patient’s informed decision resulting from a conversation between a capacitated patient and the patient’s physician is the least problematic. What should

the patient know before making this decision and agreeing to a DNRO? The physician should give clear understandable information about the medical procedures that take place during resuscitation. The patient should understand the likelihood of a “successful” resuscitation, and the likely medical/physical condition that would be experienced after resuscitation. Discussion should occur about the possibility and desirability of further resuscitation attempts, if the initial attempt is successful but is followed by another cardiac arrest. The patient should also understand whether resuscitation, if attempted, affects the long-term prognosis.

A clear and open discussion between a patient and physician about resuscitation is, of course, difficult under even the best circumstances. When a patient is incapacitated, making the decision about whether to resuscitate becomes an even greater challenge. This is because in this circumstance the physician must rely on the patient’s written wishes or the patient’s surrogate or proxy for guidance. If the patient had previously discussed resuscitation with their physician, or if she clearly documented her resuscitation wishes in an Advance Medical Directive (Living Will), or if the patient’s wishes were specifically made known to the surrogate or proxy, then the physician would have confidence in the appropriateness of writing a DNRO. However, even under these “best” circumstances, the physician and/or surrogate/proxy may have uncertainty since the patient might not have anticipated exactly the medical condition being currently experienced,

or had a clear understanding of what is involved in resuscitation. (A surrogate decision-maker is somebody the patient had specifically named to be the decision-maker in the event of patient incapacity. A proxy decision-maker is recognized from the hierarchy list in state law, usually a close relative, as the person to make the decisions for the incapacitated patient.)

This problem becomes even worse when a currently incapacitated patient fails to specifically mention the resuscitation issue in his Advance Medical Directive, or make his specific wishes known to the surrogate/proxy. In this case the physician must decide if the general non-treatment wishes of a patient as expressed in his Advance Medical Directive and/or to the surrogate/proxy is sufficient evidence to justify the writing of a DNRO. This judgment call can be very uncomfortable for the physician who wants to respect the patient’s decision-making autonomy.

Another difficult circumstance arises when a physician concludes that resuscitation will simply not achieve any medical goal for the patient and thus conclude that resuscitation would be medically futile. The physician could then write a DNRO based on the medical futility of resuscitation. The simple idea behind this decision is that a physician should not be obligated to provide a medical treatment that will not work. Furthermore, patients would not want to be subjected to treatments that offer no benefit. The problem with “medical futility” is that it is often defined in terms of the personal values of physicians and patients. Most of

these decisions come down to what burdens one thinks is acceptable for relatively small and often unknown chance of transitory or limited benefits, and this assessment varies greatly between different people.

Because this is often a subjective “value”

decision, the consensus in medical law and medical ethics is that these issues should be determined by the

patient’s own values, not the values of a physician or even of next of kin. Physician decisions about the medical futility of resuscitation should be reserved for only medical situations where a resuscitation attempt clearly will not succeed in restarting the heart. Even in this limited circumstance the patient or the surrogate/proxy should be consulted and informed if the physician is going to write a DNRO.

Even if resuscitation is correctly determined to be medically futile, it does not mean that other medical treatments would also automatically be medically futile. Indeed, some might be quite effective, or at least offer some prospects for improvement for the patient. Whether to accept other treatments should be considered jointly by the patient and physician and independently from the DNRO.

One of the most serious confusions over the DNROs is caused by these multiple sources for the same physician order: A DNRO on a patient’s medical record may be confused with a patient’s Advance Medical Directive.

Medical/nursing staff might see that a patient has a DNRO and presume that it indicates that the patient also has an Advance Directive indicating the patient desires only comfort care.

Others might assume that anyone who would refuse

resuscitation would also refuse all other curative medical interventions. This view is partly held

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because many health care professionals see that medical intervention must be an “all or nothing” response to a patient’s medical situation. In other words, if you are going to try and save a patient, then one should do every possible medical treatment to do so. This “all or nothing” view, of course, may easily be false. A patient might want relatively aggressive medical treatment to extend his current quality of life, while refusing the possibility of a resuscitation attempt which if attempted would only leave him with a diminished quality of life.

In summary, if your physician asks about the possibility of a DNRO, you should talk in detail with him or her about the benefits and burdens of a resuscitation attempt. Your physician should be willing to discuss the likelihood of a successful resuscitation in the event of a cardiac arrest, your possible medical condition after resuscitation, and the impact on your eventual prognosis. In addition to this information, if you want to include the resuscitation issue in your Advance Medical Directive, you should talk with

your physician about how to make those instructions as clear as possible. Equally important you should share your views about resuscitation with whoever will make health care decisions for you if you become incapacitated. Make sure that they are willing to respect your wishes. If you have not yet identified a specific surrogate to make decisions for you if you become incapacitated, it is a good idea to do so. These steps will go a long way in helping insure that your decisions about resuscitation will be honored, and that confusion over these decisions will be minimized.

Emergency Medical Services and 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 early 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 Department of Health, Bureau of Emergency Medical Services to examine ways to validate a docu-

ment 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

The development of the DNRO was critical to EMT's and paramedics. When an EMT or paramedic arrived on scene they needed to respond immediately by providing immediate care to the patient in cardiac or respiratory arrest, unless presented with clear proof of the patient's wish not 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, if 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 of 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 canary-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.

FLORIDA DO NOT RESUSCITATE ORDER
(Please use ink)

Patient's Full Legal Name _____ (Date) _____
(Print or Type Name)

PATIENT'S STATEMENT

Based upon informed consent, I, the undersigned, hereby direct that CPR be withheld or withdrawn. (If not signed by patient, check applicable box):

Surrogate Proxy (both as defined in Chapter 765, F.S.)
 Court appointed guardian Durable power of attorney (pursuant to Chapter 709, F.S.)

(Applicable Signature) (Print or Type Name)

PHYSICIAN'S STATEMENT

I, the undersigned, a physician licensed pursuant to Chapter 458 or 459, F.S., am the physician of the patient named above. I hereby direct the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation) from the patient in the event of the patient's cardiac or respiratory arrest.

(Signature of Physician) (Date) Telephone Number (Emergency) _____

(Print or Type Name) (Physician's Medical License Number) _____

Pursuant to s. 401.45, F.S., a copy or original of this DNRO may be honored by hospital emergency services, nursing homes, assisted living facilities, home health agencies, hospices, adult family-care and emergency medical services.

DH Form 1896, Revised February 2000

EMERGENCY STATEMENT

I, the undersigned, a physician licensed pursuant to Chapter 458 or 459, F.S., am the physician of the patient named above. I hereby direct the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation) from the patient in the event of the patient's cardiac or respiratory arrest.

(Signature of Physician) (Date) Telephone Number (Emergency) _____

(Print or Type Name) (Physician's Medical License Number) _____

Pursuant to s. 401.45, F.S., a copy or original of this DNRO may be honored by hospital emergency services, nursing homes, assisted living facilities, home health agencies, hospices, adult family-care and emergency medical services.

(Applicable Signature) (Print or Type Name)

NOTE: This form shall be printed on yellow paper (64E-2.031, Florida Administrative Code)

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 the 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 wrist, 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 wallet 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.

Portability

The yellow DNRO form was redesigned also with portability in mind, allowing one document to walk through many different health care settings. According to Florida Statutes, the DNRO may now be honored in most health care settings, including hospices, adult family care homes, assisted living facilities, emergency departments, nursing homes, home health agencies and hospitals. It also protects the health care professional, from criminal prosecution or civil liability for the withdrawal or with-

holding of cardiopulmonary resuscitation. The significance of portability means that having one form signed, whether it is the original or a copy, and keeping a copy with you will protect your wishes if you are transferred between health care settings.

Do Not Resuscitate Orders, Living Wills and Advance Directives

The DNRO is different from a living will or other type of advance directive.

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.

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.

When the emergency medical technicians and/or paramedics arrive, 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 Not 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. 2731 or 2742) or write to the

Bureau of Emergency Medical Services, 4052 Bald Cypress Way, Bin C 18, Tallahassee, Florida 32399-1738 or visit the Bureau of EMS's web page at <http://www.doh.state.fl.us>. 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 if 9-1-1 is called the responding EMT or paramedic can read and honor the English, Department of Health version, while also assuring that the patient fully comprehends the document.

Conclusion

Emergency medical services providers throughout the state are working in their communities to provide leadership and resources for people at the 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.

Understanding Grief To Help Yourself and Others

Kathy Brandt, M.S.

Grief most often occurs when a loved one dies. However, people also grieve other losses. Losing a pet, home, or job, having a child move away, losing a child through miscarriage or adoption, experiencing a divorce or breakup — all can cause intense grieving. While more than half of all American adults will experience the death of someone they know this year, few people understand grief, where to find help, and how to support a grieving person.

Grief is a normal emotional, spiritual, social and physical reaction to a significant loss of any kind. Grief is a life-changing journey that is often something a person adjusts to and moves through, rather than gets over. The difference is significant. Getting over grief implies that the symptoms will cease, and the person will feel the same as before. This is an unrealistic expectation. While we can expect the pain to decrease, we never “get over” a significant loss. A more realistic expectation is learning how to adapt.

Each person adjusts to loss differently. One person might need to be isolated for a period of time, while someone else might prefer to be around people. A person may actively grieve the loss for weeks, months or years. We must recognize that people need to grieve in

their own ways, and we can provide support, even providing the opportunity for healing and personal growth.

How to Help

The most important thing to do is to keep in touch through a simple word, touch on the arm, or card in the mail so that the person does not feel isolated. Many times people who are grieving find that friends forget to call during the days and weeks after a funeral. Often the ability to focus and

accomplish simple tasks disappears. Ask how you can help by doing chores, shopping or other activities that might be beyond their current capabilities.

A common fear people have when reaching out to a grieving person is “I’m afraid I’ll say the wrong thing.” Simply providing an opportunity for the grieving person to talk can help. You might say:

- I am sorry for your loss.
- I cannot imagine how you feel.
- I do not know what to say.
- How is your life different?
- What is the hardest time for you?
- Is there anything I can do for you today?

Helping remember the deceased can be beneficial. Talking about the deceased shows that you care and have not forgotten the loss. Ask the person to tell stories about the deceased or



share a memory about the person. Looking at photos and videos allows the chance to review life experiences.

Remember, the grieving person may simply need you to listen with compassion. Do not feel you need to “fix” the person. Quietly spending time with a person in their grief can be a valuable gift.

If a person seems embarrassed or appears to be choking back tears, it may be helpful to mention that crying provides healthy relief and reflects the significance of their loss. Attempting to distract the bereaved through forced cheerfulness discounts the person’s feelings.

Grief can be a long and sometimes isolating journey. As we age, our grief from previous losses is remembered. For people who have had multiple losses over a short time, the grief can intensify with each loss, so it may be helpful to acknowledge all of the losses when comforting the grieving person.

Over time, look for opportunities to include the grieving person in social activities. Perhaps start with individual activities and gradually work up to larger group activities. You can offer to take the person on a ride, to the movies, for a walk, out to lunch, anything to help the person ease back into the world.

Holidays, birthdays and anniversaries are always difficult times. A card in the mail, phone call or planned activity to remember the deceased are ways to acknowledge the life that was lost and grief that is felt. The anniversary of the death can often bring about the need

Typical Grief Responses

Physical:

- Hollowness in stomach
- Weakness
- Muscle tension
- Tightness in the chest
- Lack of energy or strength
- Heart palpitations
- Dry mouth
- Stomach problems
- Over sensitivity to noise
- Changes of sexual desire
- Breathlessness
- Weight gain or loss
- Exhaustion
- Changes in sleep patterns
- Vulnerability to illness

Spiritual:

- Changes in spiritual belief
- Ambivalence
- Anger directed at God
- Questioning
- Increased reliance on spiritual hope
- Yearning
- Change in interest in the after life
- Guilt
- Need for forgiveness

Emotional:

- Numbness
- Anger
- Hopelessness
- Relief
- Guilt
- Shame
- Sadness
- Loneliness
- Abandonment
- Yearning
- Helplessness
- Ambivalence
- Anxiety
- Loss of control
- Loss of interest in pleasurable activities
- Depression
- Despair
- Inability to focus

Social:

- Decreased interest in social events
- Fear of being alone
- Desire to be alone with memories
- Change in level of involvement with friends
- Lack of interest in holiday celebrations

to talk about the deceased and process the grief again. It can be helpful to memorialize the deceased at this time.

Finding Help

Often people who are grieving do not know where to find help. It is important to know about the resources available in your community. Bereavement groups are a good way to get peer support. Bereavement groups help people to understand that what they are experiencing is normal, through listening to others share their feelings. AARP, the American Cancer Society, churches and synagogues, hospices and other community organizations have ongoing bereavement groups that are facilitated by trained professionals.

Many people find that attending bereavement groups with people who experienced a similar type of loss is helpful. There are specialized bereavement groups for nearly everyone. For those who are uncomfortable with bereavement groups or who need individual counseling there are mental health professionals in most communities who are trained grief and bereavement specialists. Every hospice has trained counselors who can help with the grieving process, and many offer services to anyone in the community, even if hospice did not care for the deceased.

Community clergy members are another resource and can offer spiritual and emotional counseling to people during the grieving process. Many people question their relationship with God and the spiritual meaning of life and death. For more information, call your local hospice.

Palliative Care: Will You Ever Need or Want It?

Kathy Brandt, M.S.

Palliative care is often misunderstood, yet it is possible you might want to receive palliative care at some point. So what is it and who can receive it?

Palliative care focuses on the relief of physical, emotional and spiritual distress. It is most often equated with pain and symptom management and relief of suffering. To give a simple example of palliative care — when you take a decongestant to relieve a head cold, it will not cure the cold, but it relieves the symptoms. That is palliative care. The goal is not curing the cold; it is eliminating the symptoms that you are experiencing.

Most palliative care is done for those in the last years of life — when a disease or condition can not be cured. However, aggressive palliative care can alleviate the symptoms. Palliative care can help to minimize suffering from pain, nausea, shortness of breath, wounds, confusion, anxiety and other signs and symptoms from debilitating illnesses. By concentrating on relief from suffering, people can spend time with loved ones and remain engaged in living. Improving quality of life is the goal of palliative care.

Since quality of life is influenced by many factors including non-physical symptoms, holistic palliative care focuses on the entire person including emotional and spiritual needs. Many people with an advanced illness have anxiety, become depressed, feel angry or question their spirituality. Palliative care counselors and chaplains are trained to help support the patient to work through feelings and adapt to their illness and circumstances. With good palliative care, people can often accept their illness or condition and enjoy some quality of life.

Ideally palliative care is provided by an interdisciplinary team, which includes physicians, nurses, social workers and counselors, chaplains, home health aides and volunteers. The team's job is to work together to focus on the physical, emotional and spiritual needs of the patient and family. Care is provided in a patient's home (which can also be a nursing facility, senior living community or hospice residence) or at the hospital prior to discharge. This is the hospice model of palliative care.

Hospices in the United States have been providing palliative care for more than twenty-five years.



And while all hospice care is palliative in nature — seeking to improve quality of life by controlling symptoms — not all palliative care is the same as hospice care.

Some palliative care teams or clinics are medically driven, with care focused primarily on the physical symptoms. While this is certainly necessary, this approach sometimes discounts the tremendous emotional and spiritual burdens usually associated with advanced illness.

Since palliative care focuses on symptom management and relief, good palliative care can often help to prevent or reduce the number of times someone has to go to a hospital. For patients with chronic conditions, such as heart or lung disease this is particularly important. If there is a sudden onset of symptoms, people often have to go to the hospital if their physician is unavailable or the symptoms are too severe.

Good palliative care is pro-active — it focuses on managing current symptoms and preventing new ones. This is done by teaching patients and their care givers simple things to reduce the chances that symptoms will get severe. For example, certain things can be done to make it easier for patients with lung disease to breathe. Putting a fan in the room to increase air circulation, lowering the air temperature, making

sure the patient doesn't feel claustrophobic and teaching the caregiver ways to reduce anxiety can help to reduce the severity of breathing difficulty. Helping to reduce the stress of the family caregiver can be just as important in calming the patient. These tips are taught and reinforced through visits to the patient's home. Nurses also ensure that patients and caregivers understand the medications prescribed and how and when to take them.

Recently many hospices and other healthcare providers started looking to expand the availability of palliative care and services to people in the last years of life. Some hospices are starting separate services for people in the last years of life who may benefit from good palliative care to control symptoms.

“To give a simple example of palliative care — when you take a decongestant to relieve a head cold, it will not cure the cold, but it relieves the symptoms.”

Since this expanded hospice model is new, each community may have different services available. For example some palliative care teams include an advanced registered nurse practitioner (ARNP), palliative care physicians and support from the hospice interdisciplinary team of social workers/counselors, chaplains, home health aides and volunteers. With this model the team works with the patient's current physician and the patient and family caregivers to identify what services are needed and desired. The ARNP is the primary “care manager” coordinating services among team members to be

sure all needs are met. Hospices may offer different “pre-hospice” palliative services, call your local hospice for more information.

Some hospitals and nursing facilities are also providing palliative care to their patients to ensure symptoms are controlled. Some have palliative care clinics and others have a palliative care nurse and physician who are brought in to consult with other physicians to help with symptom management. Community partnerships between hospices, hospitals and nursing facilities, in cooperation with physicians, can ensure that patients and families receive excellent care across care settings. This new focus on palliative care can only improve the quality of life for those experiencing symptoms from chronic or life-limiting illnesses.

Hospice care in the United States was originally designed to provide care to cancer patients in the last six months of life. Over the past twenty years as hospice services have evolved to care for all people with a life-limiting illness, the current Medicare Hospice Benefit model of hospice care no longer meets all the needs of patients with chronic illnesses. Patients and families are often unable to access care until the last days or weeks of care, therefore missing the benefits of the palliative care team.

Services beyond the traditional hospice services offered in the last six months of life are not currently part of the Medicare or Medicaid benefits and are not covered by insurance policies. Programs may use a sliding fee scale, to determine how much is owed to the

hospice for the services. This enables people with limited resources to access care.

Several demonstration projects are underway to determine if these services can actually save Medicare money by managing patient’s symptoms without hospitalization. If these work, perhaps palliative care will become a staple of the Medicare Benefit, helping to ensure that people receive quality, holistic care which not only relieves symptoms but also helps to support the patient and family who are living with a chronic or life-limiting illness.

Like other aspects of medical care, palliative medicine for people in the last years of life is a complex medical specialty. Until recently, most health and human service professionals received little training in palliative care. Most hospices provide extensive training to staff to ensure that they are experts at the art and science of palliative care.

National training programs have been developed to teach physicians and nurses the principles of palliative care. These focus the full experience of advanced illness, including physical, emotional and spiritual care to alleviate suffering and enhance the end-of-life experience. As the practice of palliative care evolves, palliative care programs will become more prominent in your community. If you or a loved one has a chronic or life-limiting illness, ask your physician about palliative care. We also encourage you to call your local hospice and ask them what services are available.

Relief from suffering is a basic human right. Most symptoms can be relieved with good palliative care. Together we can ensure that some of our most vulnerable citizens receive the care they need, when they need it. Hopefully the Medicare Hospice Benefit will expand to include palliative care for anyone who needs it. For more information about palliative care, call your local hospice or talk to your physician.

Pain Management at the End-of-Life

William L. Allen, J.D.

The story of Elizabeth Bouvia, although it took place in the 1980s, is still relevant today. Ms. Bouvia was a 28-year-old quadriplegic from cerebral palsy with severe chronic pain from arthritis. After numerous hospital stays and no relief from unremitting pain, she decided to refuse nutrition and hydration. The hospital rejected her decision and sought court authorization to force feed her. Eventually, she was granted the right to decline nutrition and hydration, even if she died as a result.

As an afterthought, someone provided her with a thorough assessment of her pain. Following this process, physicians dramatically improved management of her pain, and she decided to resume nutrition and hydration.

Providing adequate pain control at the end-of-life might appear simple. It might seem that even though modern medicine cannot extend life indefinitely, at least we should enable people to die without pain. Yet as many as half of patients in the dying process do not have their pain adequately controlled. Some of the reasons are surprising.

The Need for Pain Assessment

Probably the simplest reason pain is not adequately controlled is it is not appropriately assessed. It is impossible to treat an unrecognized condition.

Unlike other physical symptoms that usually lead to tests or other procedures to discover the nature of the underlying problem,

pain is subjective, with no objective measurement. Pain is too often treated as a mere symptom of the real underlying disease, and therefore, given inadequate attention.

To remedy this situation, pain assessment and control require trust and dialogue in the relationship between the patient and the healthcare provider. Patients have a responsibility to disclose their pain. Providers must believe the patient's description of his or her pain and to be persistent in relieving it.

Pain can have severe psychological and physiological effects. Uncontrolled pain can even rob a patient of the will to live, as in the example of Ms. Bouvia. From this perspective, pain is not merely a symptom, it is a devastating disorder in its own right with serious consequences for the patient's

“Success is often seen as enduring pain, as well: “No pain, no gain”. Giving in to pain may be seen as a sign of weakness and a lack of determination to succeed.”

well being. Medicine was once impotent to do much toward curing serious diseases, so it was more focused on relieving suffering. Dramatic advances in medicine have cultivated a corresponding decrease in focusing on relief of suffering as a primary goal. Thus, recognized accomplishments in medicine seem to target advances that promise cures rather than manage pain.

Fear of Addiction Unwarranted

One of the top reasons for undertreatment of pain is fear of drug addiction. Although it is certainly possible for persons to become addicted to narcotics when these substances are abused, such drugs do not create addictions or addicts when appropriately used to control pain.

These drugs can be successfully used to treat serious pain even for short periods without withdrawal syndromes by tapering the dosage as the level of pain subsides. There is a crucial distinction between addiction and drug dependence. Persons with serious chronic pain may depend on narcotic pain medications to control constant pain, but this is different from addic-



tion. Persons with diabetes require daily shots of insulin, but we would never assert that they are “addicted”. Especially in the context of patients at the end-of-life, concern about creating a life-long drug addiction is unwarranted.

Addressing Side Effects: Sedation and Respiratory Depression

Another concern about using narcotic pain medications is the side effect of sedation. There are ways to counteract these side effects by taking a prescribed stimulant at the same time. In this way, a dose sufficient to eliminate the pain may be taken without sacrificing alertness. Fear of respiratory depression also contributes to undertreatment of pain. Although it can occur as a side effect of narcotic medications, the fear of its causing death is exaggerated. As tolerance to the analgesic effect increases, so does tolerance to the respiratory depression effect. Thus, as the dosage is increased to treat pain, the respiratory depression does not increase at a harmful rate. Of course, if an overdose is given, the effect of respiratory depression could be fatal, but this does not occur when the drug is appropriately administered to match the pain and to account for the increased tolerance. What determines an overdose is not a particular amount, but the suddenness of a large increase. There is no inherent upper limit to the dosage that can be sustained without respiratory depression.

In many cases, patients can control the increases necessary to take care of their pain by using a pump designed to

increase the dosage by a set amount at regular intervals. These are safe because they require a patient to push the pump, so that if a patient's dosage were increased too quickly, the patient would fall asleep and be unable to self-administer more medication before it could reach a harmful level.

Cultural Attitudes Affecting Pain Management

Cultural and religious factors can also contribute to the lack of aggressive evaluation and treatment of pain. Patients may decide to not disclose their pain or decide to refuse treatment for it. Pain may be regarded as divine punishment, and some persons may feel they deserve their pain. These factors can also affect the aggressiveness providers use to deal with patients' pain. Providers sometimes feel that some patients are perceived to have brought their condition on themselves, such as in smokers with lung cancer or those with HIV. This response can affect their attitudes in how aggressively they attempt to address the patient's pain. Pain is often associated with bravery and heroism. Since bearing pain may be seen as a reflection of character and inner strength, motivation to assess and treat pain effectively may be undermined. Success is often seen as enduring pain, as well: "No pain, no gain". Giving in to pain may be seen as a sign of weakness and a lack of determination to succeed.

An Institutional Focus on Pain Management

Recent efforts have improved this situation. The Joint Commission for

Accreditation of Health Care Organizations, which accredits most hospitals and other health facilities, now evaluates whether health care facilities are adequately addressing the pain management needs of their patients. The new attention to pain management will help to overcome the cultural and regulatory barriers, but such entrenched factors are not changed overnight. Public demand for better pain management will expedite such changes. Momentum is building. Add your voice.

Florida Hospices: Comfort, Care and Compassion When It Is Needed Most

Samira K. Beckwith A.C.S.W., C.H.E.

What would you think if someone told you about a new program available to help families and caregivers who are dealing with the serious illness of a loved one? This service, which is completely covered by Medicare, involves a time-honored philosophy which puts the comfort of the patient first, honors each person's dignity, respects each individual's wishes, and promotes peace of mind and quality of life for the entire family.

Furthermore, it combines state-of-the-art medical care with emotional and spiritual reassurance and also provides practical assistance and companionship. You might think, "I wish I knew about this kind of program." Indeed, many hospice patients and families say, "We wish someone would have told us about hospice sooner."

As you may have guessed, this is not a new program at all. In fact, the hospice concept first came to our shores over 30 years ago, during a time when great numbers of cancer patients suffered needlessly. In those days, the medical community simply sent dying patients home and told them that there was nothing more that could be done to help them. In actuality, there was a lot



more that could be done, and is being done, every day by hospices across the country.

The United States spends more money per person on health care than any other nation, yet ranks only 37th in access and quality of care. A disproportionate amount of money is spent delivering hopeless treatments that often disregard the final wishes of patients and leave them feeling abandoned as they spend their final days suffering from pain and other distressing symptoms.

Hospice Is Unique

Hospice is the only health care program that has been specifically created to serve the special needs and circumstances of people facing life-limiting illnesses.

- Hospice care has been extraordinarily successful because it:
Relieves pain and suffering for the patient, caregiver, and other family members.
- Respects the unique physical, emotional, and spiritual needs of each person.
- Recognizes the critical importance of a coordinated team of experts to help people access a variety of settings including

home, outpatient clinics, hospitals, nursing homes, and doctor's offices.

- Is cost efficient.

Nowhere is the hospice philosophy more enthusiastically provided than in Florida. Florida hospices have been serving residents for 30 years and have led the nation in providing access and quality of care. They have also been involved in numerous pilot programs further elevating the level of care available.

Each year, more than one half of all Americans will be personally affected by the illness and death of a friend or family member. In addition to the grief they experience from their loss, many will also feel frustrated by today's complex and impersonal health care system. The current system generally ignores the fundamental relationship between body, mind, and spirit. This view reduces illness to a biological function and treats the body as machinery to be fixed.

Why Hospice Is Needed

Twentieth century medicine has blessed us with a remarkable extension of the human life span through the development of miraculous life-saving technologies and unimaginable breakthroughs. Its continued mechanistic approach to health, however, prevents it from providing compassionate care

to the millions of aging Americans living with chronic illness. Eighty million Americans are suffering with chronic diseases such as cancer, heart diseases, lung diseases, dementia, and HIV. It is likely that these long-term illnesses will at some point claim their lives. Living with these diseases also usually means living with increasing disabilities over a longer period of time, adding to the burdens of caregivers, and stressing the resources of the existing system that is not designed for patients who require longer term care.

The same people who are slowly aging are also slowly dying. Before hospice

came to the US, people often died from diseases with a predictive course over a shorter period of time. Today, dying is no longer measured in a weeks or months, but is often a process

that involves the progression of disease and disability over years. This reality is why hospices have become leaders in providing palliative care — care aimed at relieving pain and suffering.

How will these 80 million Americans die? Nationally, in 1999, 50 percent died in hospitals, 25 percent died in nursing homes and 25 percent died at home. Ninety percent of Americans prefer to spend their final days at home surrounded by individuals who

“Hospice care is most effective when the team is given several months to prepare the patient and family for the ultimate outcome. Yet, half of all hospice patients die within less than one month after admission.”

mean the most to them. Despite this, few people died in their preferred manner. Fortunately, the picture is brighter in Florida. In our state, nearly 40 percent had the benefit of hospice care — unfortunately, some had it only for a short time.

Too many people with chronic medical conditions are dying in hospitals and nursing homes. These systems are not adequately prepared to address people's complex needs although many are now providing palliative care and are developing relationships with hospices.

Hospice in Florida

Florida hospices continue to set national standards for end-of-life care, including being the first to offer “complimentary therapies,” such as art, music, massage and aromatherapy for a person's comfort and peace of mind. By operating as an inter-active team, the patient's physician or a hospice physician, nurses, pharmacists, counselors, social workers, chaplains, personal care aides, volunteers and therapists work together offering patients and families a comprehensive package of comfort and compassion.

But, hospice today is experiencing its own expansion issues. With medical advances, it is more difficult to predict the course of diseases. Also, diseases are more complex. And, to further complicate matters, today's caregivers are often more frail and elderly.

Often, individuals are referred far too late. People need hospice's comfort, compassion and caring much earlier than they often get it. Hospice care is

most effective when the team is given several months to prepare the patient and family for the ultimate outcome. Yet, half of all hospice patients die within less than one month after admission. Of that group, 20 percent die within one week. While the patient's physical pain, anxiety and restlessness can be alleviated in a few weeks, little time is provided for meeting the emotional, spiritual and financial needs of both the patient and the family. More time allows the patient and family to say goodbye as they learn to cope with their grief.

There are many reasons people are not referred to a hospice program in a timely manner:

- Sometimes physicians hesitate to openly discuss the prognosis.
- Physicians are often unprepared to deal with a dying patient because medical schools train them to “cure” their patients.
- Others may try to avoid the sense or feeling of failure or “giving up hope.”
- Family members may not want to avoid what is happening to their loved one and may persuade the physician not to “break the bad news” to the patient.
- Sometimes the patient himself may express feelings of fear or be in a state of denial and may offer signals that he or she is not ready to hear the truth, even though it may be known on a deeper level.

Changed Views About Death

Society is now looking at death and dying in a different light. There is no

question that twentieth century medical advances have been miraculous, but some are wondering if some medical procedures are futile and if all costly prescriptions are actually increasing the quality of life for people facing life-limiting illnesses. The pendulum is beginning to swing back to the center as people realize that an increase in *quantity* of life does not necessarily equate to an increase in *quality* of life.

Individuals today are beginning to take a more active role by making informed choices about their care. More and more people are turning away from end-of-life medical programs which only prolong dying, opting instead for the traditional comfort and support found in palliative care, which is being viewed as medicine that combines a high technology approach with a compassionate nature. Of course, this is nothing new to the pioneers of the hospice movement, without whose vision, end-of-life palliative care would not exist. As long as medical advances continue to become available, hospice professionals will continue to blend them with the comfort, care and compassion, *which is hospice*.

The hospice of tomorrow will provide care to patients and families at any stage of disease, not just the end stage. Newly diagnosed patients will have immediate assistance with symptom management, decision-making, counseling, care planning and palliative care consultation. The hospice of tomorrow will also reach out to those affected by loss, regardless of the cause, including violent crime, suicide or other catastrophic events.

By broadening their range of services, hospices continue their mission of compassionately supporting the evolving needs of people in the community.

Medicare Hospice Benefit: Everything You Need to Know

Samira K. Beckwith L.C.S.W., C.H.E.

It happened again just the other day, during a presentation to a community group about hospice care. The room was initially silent... but as I explained all the care and services people are entitled to under the Medicare and Medicaid Hospice Benefit, the questions and comments started flying. “This must be one of the best kept secrets!” one woman exclaimed, “Why didn’t anyone tell us?”

It is not a secret! In fact, the Medicare/Medicaid Hospice Benefit was first offered in 1983. What is astounding, though, is the fact that not enough people get the benefits. Everyday, we hear horror stories in the media about both the cost and quality of care, as

well as people not having their choices for care respected. In this environment of increasing co-payments and reduced coverage, the Medicare Hospice Benefit is truly an underutilized benefit for people living with a life-limiting illness.

For people facing serious illness, it is imperative to know that both the appropriate care and the funding needed are available to help them. It is just a matter of spreading the word and correcting the misunderstandings that exist. Patients and families can benefit from all of the comfort, care and compassion, offered by Hospice, while knowing that all of the related expenses are covered under this special Hospice Benefit.

What is the Hospice Benefit under Medicare and Medicaid?

The Hospice Benefit under Medicare and Medicaid provides for the complete package of physical, emotional, spiritual and practical care that the hospice community is so well known for. All treatment related to the primary diagnosis is covered, including the following:

Physical Care

Physicians & Nurses
Inpatient hospitalization
Medical supplies & equipment
Medications & IV therapy
Speech & physical therapy
Dietary & occupational therapy

Emotional & Spiritual Care

Counselors
Chaplains
Coordinate community resources
Healthcare system advocacy
Healthcare system advocacy
Bereavement support

Practical Care

Personal Care Aides
Specially trained volunteers
Inpatient respite care
Light housekeeping
Assistance with paperwork
Caregiver education

Additionally, Medicare and Medicaid pays hospice directly for services that are provided. Patients do not have to process complicated paperwork or bills and there are not any co-payments or deductibles. Also, many hospices offer therapies such as massage, pet, aroma, music and art.

The heartbreaking part is, that because of the misunderstandings about the Hospice Benefit, too many families are not pursuing hospice care because they assume that they would not be able to pay for it or they think that it means giving up hope. **When in fact, many of the services included in the Hospice Benefit, including medications and medical supplies, are not covered through any other health care provider, facility or home health agency.** Physicians across Florida are realizing that there is a direct relationship between the time spent in a hospice program and increased quality of life that patients and families can experience together. Patients can peacefully enjoy the company of friends and family while having time to handle unfinished details. Caregivers can receive greatly needed support and family members can begin preparing for the grief and bereavement process.

As the community group discussion continued, several key questions were posed. By the end of the presentation, a new understanding about several end-of-life care issues came to light. The following questions highlight the key points of that discussion:

Would my physician still be involved with my care if I elected the Medicare Hospice Benefit?

Yes! Choosing this benefit does not affect the individual relationship between the patient and the attending physician. In fact, your physician is encouraged to be an active part of the hospice care team. Your doctor participates in the establishment of the

plan of care and works with the hospice team in everyday matters. Hospice physicians, who are experts in palliative or “comfort” medicine, are also available to consult on matters of specialized pain and symptom control at the patient’s or physician’s request.

Does this benefit affect my regular Medicare or Medicaid benefits?

No. In fact, the two benefits work concurrently. As mentioned before, the Hospice Medicare Benefit covers all of the treatments and services associated with your life-limiting diagnosis. In the case where there is an unrelated medical need, your regular Medicare or Medicaid coverage remains in effect. It would act in the same manner as it always has, with the same deductibles and co-payments that you are accustomed to.

Would I receive the same coverage from another health care provider such as a hospital facility or home health agency?

No. The Medicare / Medicaid Hospice Benefit is unique. Your Medicare-certified hospice can provide comfort and compassion in the comfort of your own home or other place of residence such as an assisted living facility or nursing home. Under the Hospice Benefit, hospice continues to provide care to you and your family as you move from setting to setting. Some examples include those in the chart on the next page.

Examples of coverage and types of care	Hospice	Hospital	Home Health
Payment for prescription medications at home to control pain and other symptoms.	YES	NO	NO
Services are provided even if the patient is not homebound.	YES	NO	NO
Inpatient respite care for a period of relief for care givers.	YES	NO	NO
Continuous nursing care at home during periods of medical crises.	YES	NO	NO
Inpatient care provided for pain control or symptom management without a deductible or co-payment.	YES	NO	NO
Payment of consulting physician fees without deductible or co-payment.	YES	NO	NO
Coverage of durable medical equipment and medical supplies without a deductible or co-payment.	YES	NO	NO
Counseling services at home for patient and family with no deductible or co-payment.	YES	NO	NO
Homemakers.	YES	NO	NO
Bereavement counseling and support groups.	YES	NO	NO
Volunteers with specialized training.	YES	NO	NO
Nurses, social workers and chaplains available On-call 24 hours a day, 7 days a week for patients and families.	YES	NO	NO

Who is eligible for the Hospice Benefit?

Hospice care is available to any patient whose focus of care has shifted from “cure” to “comfort”. Furthermore, many people do not realize that this includes people with a variety of diseases such as: Alzheimer’s, cardiac diseases, neurological disorders, renal or liver disease, AIDS, pulmonary disease, and of course, cancer. Anyone under the care of a Medicare-certified hospice can elect the benefit simply by completing an election statement. The

physician indicates that, the end-of-life may come in six months or so if the disease follows an average course.

What happens if the six-month time limit passes?

As we all know, it is virtually impossible to accurately predict a person’s life expectancy, no matter what the physical condition. Physicians can offer educated guesses based on research and experience, but quite often the human spirit defies the odds and survives well beyond expectations.

In fact, many people experience a physical improvement after beginning hospice because their pain and symptoms are under control and they have begun receiving the emotional and spiritual support that may have been missing. Fortunately, it is reassuring to know that there is no penalty to either patients or physicians if a person outlives their predicted life expectancy. As long as the plan of care is palliative in nature, focused on comfort care and the patient continues to qualify for the Medicare benefit periods, the patient will continue to be covered. Patients have been cared for by hospice for years and still meet the criteria.



What are the benefit periods?

The benefit periods are structured into two 90-day periods followed by an UNLIMITED number of 60-day periods. There are times, in fact, when a person can enjoy hospice care for several years.

What happens if I get better?

Time and time again, we are pleasantly surprised when a serious illness takes a turn for the better. Sometimes, people under the care of hospice improve to the point that they no longer qualify for the Medicare Hospice Benefit. When this happens, the patient is “discharged” from hospice care and goes back to being covered solely by their regular Medicare benefit. If needed, a person can re-enter hospice care by re-electing the Hospice Benefit

at a later date and receive all of the same treatments and benefits with the same convenience they were previously accustomed to.

In closing, it is widely known that hospice is the only model of care that effectively and compassionately treats the whole person... mind, body and soul, while at the same time, supporting the caregiver and family members. Experts, such as the American Medical Association and others, agree that patients and families who spend more time in a hospice program at the end-of-life, experience a higher quality of life during that time, than those who do not have full access to hospice care. The Medicare/Medic-

aid Hospice Benefit makes this possible for anyone who qualifies for Medicare or Medicaid and whose course of treatment focuses on comfort, rather than cure. Furthermore, many people do not realize that hospices also provide care to people with private insurance. The ultimate winners are, of course, the growing number of people and their families who are living with serious illness, because they now know that this is no longer a secret.

A special man once told me, “Now that I have hospice care, I’m at peace, and I’m ready to go... but that doesn’t mean that I’m getting on the next bus.” We cared for him for 8 months and when he did “go” the journey was less difficult because he truly lived each day as fully as possible.

Myths About Hospice

Samira K. Beckwith L.C.S.W., C.H.E.

Referrals to hospice are often not made because of the many myths and misunderstandings about hospice which exist on the part of both the patient and physician.

MYTH: *Only terminal cancer patients are eligible for hospice care.*

FACT: While this was true years ago, today, people in the late stage of other diseases, such as Alzheimer's disease, Parkinson's disease, Multiple Sclerosis, ALS (Lou Gehrig's disease), AIDS, respiratory diseases, cardiac diseases, and liver and kidney diseases can benefit from hospice. No matter what the illness, if the focus of the person's care is palliative (comfort) in nature and the patient is in the end stages of the disease, the patient will most likely be approved for admission into a hospice program.

MYTH: *Only individuals over the age of 65 are eligible for hospice care.*

FACT: Hospice is appropriate for any person of any age with any disease that meets the requirements. Unfortunately, today's physicians are seeing an increase in cases of serious disease in young people. While it can be heart wrenching to come to terms that a child may die, it is just as unfair to put a young person through end-less hopeless procedures. Several hospices in Florida have been leaders in the development of special pediatric programs, which provides palliative care

to children while helping the family deal with the illness and eventual loss.

MYTH: *Hospice can only be called in during the final week of life.*

FACT: One of the most common myths involves a confusing Federal government "timeline" which regulates hospice admissions of Medicare or Medicaid patients. The guideline that

Hospice also helps to care for caregivers.

- Nearly 26 million Americans spend an average of 18 hours a week taking care of frail relatives or friends suffering from progressive chronic medical conditions.
- Approximately 73 percent of these caregivers are women who devote between 4 and 10 years caring for their loved one.
- 31 percent of these individuals experience significant physical, emotional and spiritual stress, and can have a 63 percent higher mortality risk than persons not involved in care giving.

physicians must consider when referring their patient to hospice is that “the prognosis may be six months or less *if the disease follows its expected course.*” This is often misunderstood, keeping untold numbers of deserving patients from the hospice care they are entitled to receive.

The reality is that many individuals, once under the special program of hospice care, actually notice a physical improvement and remain in the hospice program for much longer than six months. This happens after the physical pain is relieved and the emotional and spiritual concerns are addressed. There are many reasons some patients live longer than expected. The human spirit is unique and physicians often have difficulty predicting specific prognosis timeframes, which often prevent patients from access to timely care. Since it is so difficult to predict timeframes, another approach would be for the physician to ask the question, “Would I be surprised if the patient died during the next year?” This can be an appropriate way to think about the special needs of each person and allow more families to take advantage of all that hospice has to offer.

MYTH: *Hospice is mostly about dying and giving up hope.*

FACT: The opposite is true. Hospice is about making the most of life each day.

Most of us do not know how much time we have here on earth. The terminally ill have a better idea that the end of their life is approaching. It is during this time that miracles can happen.

Individuals have said that they did not truly begin to live until their disease reminded them how precious every moment was. Outlooks change, roles switch and priorities shift when people realize that their time is limited. Hospice professionals help patients and families sort through all of these challenges.

They can also help families understand the complex health care system and ensure that all available community resources are provided. Many caregivers have said that it was such a relief to have had the hospice advo-



cates on their side. Both patient and caregivers often look forward to the hospice team home visits. Families recognize that hospice is about living,

not dying. That is why so many families and caregivers say that they wish they had known about hospice sooner.

MYTH: *Hospice is the same as any other home health agency.*

FACT: While it is true that hospice care is often provided in the home, that is where the similarity ends. The complete range of services that hospice offers and the team approach to care truly puts it in a class of its own.

MYTH: *Hospice requires that I use a hospice physician, instead of my own.*

FACT: Hospice understands and respects the bond between an individual and his/her own physician. Hospice encourages physicians to continue being involved with the care of their patient. In fact, the physician is viewed as an integral part of the care team. Hospice physicians can offer assistance as needed on a case-by-case basis. Since they are experts in palliative medicine, they are often consulted so that the patient has the best of both worlds.

MYTH: *I would never be able to afford high quality hospice care.*

FACT: Fortunately, there are many options for people who are concerned about their ability to pay for hospice care. Individuals who are entitled to Medicare or Medicaid can take advantage of a separate Hospice Medicare benefit that covers all of the costs associated with the life-limiting illness. This includes nursing, counseling and personal care aide visits, as well as home medical equipment, prescriptions and volunteer support. Also, for

those who are not Medicare or Medicaid eligible, more and more private insurance companies are adding hospice coverage to their policies. Finally, at Florida hospices, families are not denied services simply because of an inability to pay. Organizations offset un-reimbursed care so that they can focus on their true mission, regardless of financial issues.

Hospice also helps to care for caregivers.

- Nearly 26 million Americans spend an average of 18 hours a week taking care of frail relatives or friends suffering from progressive chronic medical conditions.
- Approximately 73 percent of these caregivers are women who devote between 4 and 10 years caring for their loved one.
- 31 percent of these individuals experience significant physical, emotional and spiritual stress, and can have a 63 percent higher mortality risk than persons not involved in care giving.

End-of-Life Decisions: Some Final Thoughts

William Allen, J.D.

We are beginning to hear or read about the critical illnesses of public figures with who are not expected to live. However, we more frequently learn of their illnesses only after their deaths. A remarkable exception was the news coverage of James Michener's decision to discontinue kidney dialysis at age 90. Such an announcement illustrates a fact of contemporary life: Death can involve decisions we either make for ourselves or have others make for us.

Of course, death is something we cannot simply choose to avoid. The timing of death, as well as the circumstances and quality of life we endure as it approaches, are becoming matters of choice. Life sustaining technology has blurred the transition between life and death, forcing us to distinguish between physiological functions, like breathing, that sustain life and our perceptions of the quality, value, and dignity of life. Our anxiety about the blurring distinction between life and death crystallized in the cases of Karen Ann Quinlan in the '70s and Nancy Cruzan in the '80s. Both were young accident victims in permanent vegetative

states, whose families were forced to go to court to have life support withdrawn.

In the '90s, however, this fact of life became so clear that news coverage of the deaths of public figures like Richard Nixon and Jackie Onassis reported that they left instructions about their choices to limit medical treatment at the end-of-life.

Effects of Technology

Prior to the development of dialysis machines, ventilators, feeding tubes, cardiopulmonary resuscitation, and other medical technologies, death may not have been welcomed, but at least individuals were not often required to make decisions about it. Death just happened and there was not much anyone could do to delay it. Being

To our grandparents, death was a more accepted part of the life cycle. Family members were cared for in the home, surrounded by friends and loved ones. With the advances of modern medicine, society allowed the medicalization of the end-of-life. Now, blending this traditional approach with the highest quality medical care ensures the patient's needs are met. The underlying belief is that the end-of-life should be as special as the beginning of life, and that it, too, is a family event.

—Samira Beckwith

confronted with this new phenomenon of choices about dying is not something most people have welcomed.

Facing death is hard enough when we can no longer evade its approach. It seems even more onerous, somehow, that we must dwell on it far enough in advance to make crucial decisions about the terms of encountering and enduring it.

It is not only decisions about our *own* deaths we wish to avoid, but most people want to avoid being a surrogate decision-maker for someone else.

No one wants to hear their loved ones talk about dying, much less assume the responsibility of actually implementing their choices.

That is why Michener's announcement before his death was so striking. Richard Nixon's and Jackie Onassis's choices about their deaths were more abstract when we learned about them after they were already gone.

Michener's decision to stop dialysis, and the recognition that he was still alive and aware of his approaching death, produced a concrete existential echo in our own psyches that was impossible to ignore.

Having this type of choice thrust upon our era is ironic because it results from the development and widely used life-sustaining technologies. When such measures can restore a life that would otherwise be lost, we welcome them. However, it dawns on us that having

such technology also forces upon us hard choices about when to use them or when to stop using them, as Michener did.

The Importance of Making Decisions

One wonders, when Michener chose to begin dialysis, if he anticipated what it would be like to decide to stop it. Accepting a life sustaining medical procedure often seems preferable to its alternative. Eventually, however, such measures may no longer offer an acceptable quality of life.



We may try to avoid such difficult choices by refusing to consider them. After all, federal and Florida law prohibit anyone from being forced to sign a living will or to appoint a surrogate decision-maker. We cannot be forced to refuse medically appropriate treatment. In reality, however, since implementation of life sustaining procedures

has become standard, they are usually applied unless specifically refused by a competent patient. Thus, especially in the case of patients who are incapable of making their own decisions about care, failure to refuse treatment is essentially a choice for treatment. Not to decide against treatment is, in effect, to decide for it.

Many of us do have definite preferences about such choices. Some want to exhaust every sliver, while others have a horror of the dying process

being prolonged. In facing the difficulty of anticipating death, many have found the process of actually making their choices about quality of life to be a liberating or enlightening experience.

Yet we need not embrace death with indifference to make choices about how and when it occurs. We may even “rage against the dying of the light,” as Dylan Thomas urged, but still choose the setting and terms of the inevitable surrender. At first glance it may seem contradictory to say, “I do not want to die, but I do refuse life sustaining treatment.” In reality, however, it is simply saying, “Although I want to live, the quality of life that life support can bring is not worth the burdens it forces me to endure.”

Confronting Mortality

Confronting our own mortality is nothing new to the human condition. Life-sustaining devices and the inevitable choices about using them have, however, conjured up a new confrontation with our mortality. In the end, such choices are not only about dying; they are about living, too. Since we have spent most of our lives distracting ourselves from the reality of death, we are not generally prepared to decide how to live as we approach death.

Therefore, reflection on how we wish to live during the time we are dying is well worth doing. Moreover, discussion of our choices with those we entrust to carry out our decisions (if we are unable) is crucial.

As a society, we can profit from the poignant example of James Michener and others who have struggled with

such decisions. We have not yet developed adequate symbols and rituals to help us through this new rite of passage. Nor do we have an adequate sense of making these hard decisions in spite of our reluctance. We need to recognize that in carrying out others' decisions to forego life support, we perform a noble service for them, rather than shrinking from the role as if we had been asked to be the hooded executioner.

Contributors

Florida Hospice and Palliative Care

– Overall coordination of the grant project, formation of a statewide coalition of end-of-life care leaders, development and maintaining community coalitions and activities of coalitions, palliative care initiative, development of educational materials and professional education and training.

Samira Beckwith, L.C.S.W., C.H.E, Principal Investigator for the project, is also President and CEO of Hope Hospice.

Susanne F. Homant, M.B.A., Executive Director for Florida Hospice and Palliative Care, Inc.

Robyn Chase, Project Coordinator

Florida Department of Elder Affairs

– Establishment of culturally sensitive end-of-life materials, development of related educational programs for the public and professionals, regulatory initiatives and education particularly in the area of advance directives, distribution of advance directives and information, and awareness survey on end-of-life care issues.

Linda Macdonald, M.S., Office of General Counsel. She is responsible for the coordination of the Department's end-of-life care activities including policy development, hospice rule writing and legislatively mandated workgroups. She is a member of the National Advisory Committee for "Transforming Caregiving at Life's End".

Horacio Soberon-Ferrer, Ph.D., Research Director

Florida Department of Health

– Involved with regulatory initiatives and education particularly in the area of DNRO and end-of-life education for EMS personnel, training and educational programs, development of educational materials for the public and professionals, professional education and training, distribution of advance directives and information.

Freida Travis is the Administrator for the Operations Sections within the Bureau of Emergency Medical Services. She is a certified emergency medical technician and has 25 years of experience with the Bureau of EMS in a variety of positions. Ms. Travis served as an advisor to the End-of-Life Care Panel created in 1998.

Jessica Swanson, M.S.W., is a Systems Analyst for the Bureau of Emergency Medical Services. She completed her Masters in Social Work at Florida State University and

earned her Certificate of Gerontology from the Pepper Institute on Aging and Public Policy.

Florida Agency for Health Care Administration

– Involved with regulatory initiatives and end-of-life care public education.

Anne Menard, M.S.W., is the Supervisor of Home Care and Hospice Programs, Bureau of Health Facility Compliance and responsible for grant activities.

University of Florida

Program of Law, Ethics, and Medical Professionalism

– Assists with regulatory initiatives, coordination of professional education for lawyers and clergy, ethics training and education, development of educational materials for the public and professionals.

William L. Allen, J.D., M.Div., is the Co-Investigator for the project. He serves on the Shands Hospital Ethic's Committee, the Health Science Centers Human Subjects Institutional Review.

Ray Moseley, Ph.D., is Director of the Medical Humanities Program (M.H.P.) in the College of Medicine at the University of Florida and is an Associate Professor in the Department of Community Health and Family Medicine. He specializes in ethical and legal issues in end-of-life care.

University of Florida, College of Pharmacy

– Involved with Pain management initiatives.

David Brushwood, R.Ph., J.D., is a professor of Pharmacy Health Care Administration at the University of Florida College of Pharmacy. He serves as co-principal investigator on an NIH grant, Conquering Pain: Enabling Dialogue Through CD-ROM/WEB. His participation in the Florida Partnership will result in the creation of a statewide network of clinical pharmacist pain management specialists.

University of Miami, Ethics Programs

– Public information and ethics training and education, professional education and training.

Kenneth W. Goodman, Ph.D., is the Director of the University of Miami Ethics Program and co-director of the statewide Florida Bioethics Network. He was an advisor to the Panel for the Study of End-of-Life Care which crafted changes to key parts of Florida's advance directive law. Recent articles written have addressed living wills, end-of-life legislation, and the use of computers to predict mortality.

Rallying Points Regional Resources Center

Kathy Brandt, M.S., Director of The Hospice of the Florida Suncoast Rallying Points Regional Resources Center, an initiative of The Robert Wood Johnson Foundations

Last Acts Campaign. She serves on the board of the Florida Counsel on Aging and is an active member of Florida Hospices and Palliative Care, Inc.

Hospice of Palm Beach County

Gail Austin Cooney, M.D., has been the Medical Director of Hospice of Palm Beach County since 1997. She graduated from the Mayo Medical School in 1978 and trained in Internal Medicine and Neurology at Emory University. She is a member of the Board of Directors of Hospice of Palm Beach County and the Area Agency on Aging. She is an active participant in the Omega Project, focusing on educating health care professionals to better care for older people.

The Hospice of the Florida Suncoast

Karen Lo, M.S., B.A., R.N., curriculum specialist, trainer and consultant at The Hospice of the Florida Suncoast and with K-Lo Training & Associates, Inc.

Resources for End-of-Life Choices

American Association of Retired Persons (AARP)
National Office
601 E St., North West
Washington, DC 20049
Phone: 1-800-424-3410
Website Address: www.aarp.org/

American Association of Retired Persons (AARP)
Florida Office
200 West College Avenue
Tallahassee, Florida 32301
Phone: (850) 222-7344
Website Address: www.aarp.org/endoflife

Aging with Dignity
P.O. Box 11180
Tallahassee, Florida 32302-3180
Phone: (850) 681-2010; toll free 1-888-594-7437
Website Address: www.agingwithdignity.org

Americans for Better Care of the Dying
Phone: (202) 895-9485
Website Address: www.abcd-caring.org

Florida Department of Business and Professional Regulation
Board of Funeral Directors and Embalmers
Tallahassee, Florida
Phone: (850) 488-8690
Website Address: www.myflorida.com

Florida Bioethics Network
P.O. Box 016960 (M-825)
Miami, Florida 33101
Phone: (305) 243-5723
Website Address: www.med.ufl.edu/chfm/ethics/fbn/

Florida Department of Health (DNRO Form- English version)
Bureau of Emergency Medical Services
4052 Bald Cypress Way, Bin C 18
Tallahassee, Florida 32399-1738
Phone: (850) 245-4440
Website Address: www.doh.state.fl.us

Florida Funeral Directors Association
150 South Monroe Street
Tallahassee, Florida 32301
Phone: (850) 224-1969
Website Address: www.ffda.org

Florida Hospices and Palliative Care, Inc.
1616- D Metropolitan Circle
Tallahassee, Florida 32303
(850) 878-2632
Website Address: www.floridahospices.org

Partnership for Caring
Phone: Toll free – 1-800-989-9455; (202) 296-8071
Website Address: www.partnershipforcaring.org

Project GRACE (Guidelines for Resuscitation and Care at End-of-Life)
1311 North Westshore Blvd., Suite 107
Tampa, Florida 33607
Phone: (813) 281-2324; Toll-Free 1-877-99-GRACE
Website Address: www.P-Grace.org

United States Department of Health and Human Services
Administration on Aging
330 Independence Avenue, SW
Washington, DC 20201
Telephone:

- (800) 677-1116 (Eldercare Locator - to find services for an older person in his or her locality)
- (202) 401-4541 (Office of the Assistant Secretary for Aging) (Congressional and Media Inquiries)
- Federal Relay Services - 1-800-877-8339 - toll free relay service to call AoA and other federal agencies from TTY devices— useful for persons with hearing impairments (off-site)

Website Address: www.aoa.gov/

*Florida Partnership for End-Of-Life Care
Advisory Committee (Founding Members)*

Bill Allen, J.D., M.Div., Director
Program in Bioethics, Law, and Medical Professionalism
University of Florida College of Medicine
P.O. Box 100222
Gainesville, FL 32610-0222
Phone: (352) 848-1109

Samira K. Beckwith, L.C.S.W., C.H.E., President & C.E.O.
Hope Hospice & Palliative Care
9470 HealthPark Circle
Fort Myers, FL 33908
Phone: (941) 489-9140

David B. Brushwood, R.Ph., J.D.
Pharmacy-HealthCare Administration
University of Florida - P.O. Box 100496
Gainesville, FL 32610-0496
Phone: (352) 392-2472

Ken Goodman, Ph.D., Director
University of Miami Ethics Program
P.O. Box 016960 (M-825)
Miami, FL 33101
Phone: (305) 243-5723

Linda Macdonald, M.S.
Department of Elder Affairs
4040 Esplanade Way, Suite 315L
Tallahassee, FL 32399-7000
Phone: (850) 414-2000

Anne Menard, M.S.W., AHCA Administrator
Agency for Health Care Administration
2727 Mahan Drive, Building 1
Tallahassee, FL 32308
Phone: (850) 414-6010

Ray Moseley, Ph.D., Program in Bioethics, Law, and Medical Professionalism
University of Florida College of Medicine
P.O. Box 100222
Gainesville, FL 32610-0222
Phone: (352) 392-4321

Horacio Soberon-Ferrer, Ph.D., Director of Research and Planning
Department of Elder Affairs
4040 Esplanade Way, Suite 280L
Tallahassee, FL 32399-7000
Phone: (850) 414-2000

Jessica Swanson, M.S.W.
Department of Health
4052 Bald Cypress Way, BIN C18
Tallahassee, FL 32399-1738
Phone: (850) 245-4440

Freida B. Travis, Program Administrator
Bureau of Emergency Medical Services
Department of Health
4052 Bald Cypress Way, BIN C18
Tallahassee, FL 32399-1738
Phone: (850) 245-4440

For More Information, Please Contact:

Florida Department of Elder Affairs
4040 Esplanade Way
Tallahassee, FL 32399-7000
850/414-2000

Internet address: <http://elderaffairs.state.fl.us/>