



## **Acute and Critical Care Choices Guide to Advance Directives**

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This resource has been developed with the following objectives:

- To provide critical care nurses with information about the legal, ethical, and transcultural principles that guide the preparation of advance directives in the United States
- To help nurses access specific advance directive documents and materials for patient education

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# Acute and Critical Care Choices a Guide to Advance Directives

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## Historical Perspectives

Before the mid-1960s, the model for medical treatment decision making was paternalistic, predicated upon the Hippocratic statement, “the physician is the one who command; the patient the one who obeys.”<sup>1</sup> The doctrine of informed consent began to shift this paradigm by transferring the decision making to the patient, while the physician recommended treatment options. The model for medical treatment decision making shifted to one of patient autonomy.

What happens when a person loses the capacity to make autonomous treatment decisions? The case of Nancy Cruzan illustrates this dilemma.<sup>2</sup> Nancy was in a persistent vegetative state after a serious automobile accident. She was dependent, lived in a long-term care facility, and received tube feedings for many years. On the basis of their belief that Nancy would not want to continue to live under these circumstances, her parents requested that the feeding tube be removed and that Nancy be allowed to die. The Missouri Supreme Court stated that no one could exercise Nancy’s right to refuse treatment without “clear and convincing evidence” of her wishes. After a long and arduous struggle with the healthcare system and the courts, Nancy’s family and attorney were able to present the sufficient evidence. The feeding was stopped and Nancy was allowed to die.<sup>2</sup>

In 1994, the Michigan Supreme Court followed the precedent set in Missouri when deliberating the case of Michael Martin. Michael had numerous conversations with his wife about his fear of becoming disabled. He sustained serious injuries in an automobile accident that rendered him unable to make decisions, talk, or walk. He received tube feedings and was fully dependent on others for his care. His wife requested that the feeding tube be withdrawn, but the court found that there was no “clear, direct, weighty and convincing” evidence to support this action.”<sup>3</sup>

In 2001, the California State Court applied the “clear and convincing evidence” standard in the case of Robert Wendland, a 36-year-old auto accident victim who was minimally responsive, received tube feedings, and lived in a nursing home for 2

years. His wife requested withdrawal of the feeding tube on the basis of his previous statements that he would not want to “live like a vegetable.” The court ruled that “family members had no right to stop life support for an incapacitated patient simply because he had said that he would not want to live a vegetable.”<sup>4</sup> A more recent case involved Terri Schiavo, a young woman who had been in a persistent vegetative state for 15 years after a cardiac arrest, and who was the subject of a dispute between her husband and her parents about continuing tube feedings.<sup>1</sup>

Cases such as these help to explain why individuals have become increasingly concerned about protecting autonomous decision making, particularly in circumstances in which they may lack decision-making capacity.

### **Legal Principles**

It is a well-accepted legal principle that adults with decision-making capacity have the right to consent to or refuse medical treatment—even if the refusal results in death. Since the 1990 Supreme Court’s decision in *Cruzan v Commissioner*,<sup>2</sup> the Patient Self-Determination Act (PSDA) was established. This federal law affirms the rights of adults to make treatment decisions, including the right to refuse treatment. It further protects this right in situations in which the person loses decision-making capacity through the preparation of an advance directive.<sup>5</sup>

The PSDA encourages adults to prepare advance directives. It also requires hospitals, nursing homes, health maintenance organizations, and hospices that participate in Medicare and Medicaid programs to do the following:

- inquire if a patient has advance directives,
- offer information about advance directives, and
- include the advance directives in the medical record.

The PSDA does not require that a patient has advance directives, nor can a healthcare facility or third-party payer refuse to treat a patient who does not have advance directives or use completion of a directive as any type of incentive (ie, provide a reduced insurance premium for completion of advance directives).

All 50 states and the District of Columbia have enacted legislation to comply with the PSDA; however, each state assumes responsibility for determining laws related to advance directives. State-specific advance directives information and sample forms can be obtained at [www.partnershipforcaring.org](http://www.partnershipforcaring.org).

### **What Are Advance Directives?**

Advance directives are a written statement, made in advance by an adult (ie, 18 years of age or older), that appoints someone to make healthcare decisions if a person becomes unable to make decisions and unable to communicate his or her wishes, and/or provides instructions that describe the kind of care a person would want or not want under particular conditions. Physicians, other members of the healthcare team, and family members use these documents to ensure that a person's preferences are honored.

Advance directives do not need to be written or signed by an attorney. Most states require 2 witnesses to the document; many states mandate that the witnesses cannot be the person's relatives, heirs, or healthcare provider. A person can change his or her advance directives at any time or even revoke the document completely. The change or revocation may be made in any way that the person is able to communicate. A third party cannot complete, change, or revoke the directive of another.

### **Types of Advance Directives**

The 2 major types of advance directives are the Living Will and a Medical Power of Attorney. Both documents are executed only if the person lacks decision-making capacity and is unable to make personal treatment decisions. In some states, a person can give directions about organ and tissue donation within the context of these documents.

### *Living Will*

A Living Will is a document that expresses wishes about medical treatment at the end of life. It takes effect only in situations of terminal illness or permanent unconsciousness. Some states have a statutory Living Will document. For example, the state of Iowa created a “Declaration Relating to the Use of Life-Sustaining Procedures.” All states except 3 (Massachusetts, Michigan, and New York) have statutes that provide for Living Wills. <sup>6</sup>

### *Medical Power of Attorney*

A Medical Power of Attorney, also referred to in some states as “Durable Power of Attorney for Healthcare” or “Patient Advocate Designation,” differs from a Living Will in 2 important ways:

1. The Medical Power of Attorney allows a person to name a partner, also called an advocate, proxy, or surrogate, who legally expresses the patient’s wishes about medical treatment when the patient is incapacitated.
2. The Medical Power of Attorney becomes activated in any situation in which a person is unable to make decisions—whether the circumstances are terminal or not.

All states except Alabama have statutes that recognize some form of healthcare proxy. Most address all healthcare decisions, but some are limited to terminal conditions. <sup>6</sup>

There are a number of combined acts that include Living Wills, Medical Power of Attorney and, sometimes, emergency medical services acts. Unfortunately, there is little uniformity among state laws.

Most states accept out-of-state directives or have laws regarding reciprocity. If a person has residences in 2 states, it is advisable to complete documents for each state in which the person resides.

## **Uniform Health Care Decisions Act**

State legislation has often been fragmented and sometimes inconsistent. Statutes enacted within a state and between states often conflict. In an increasingly mobile society, where advance directives given in one state must frequently be implemented in another, a need for greater uniformity has been identified.

In 1993, the National Conference of Commissioners on Uniform State Law adapted a model comprehensive act, the Uniform Health Care Decisions Act (UHCDA). The goal was to avoid inconsistencies within a state's laws and to provide improved mechanisms for making and implementing advance directives.<sup>7</sup> By the time this act was approved, most states had advance directive legislation in place and did not pursue incorporating the UHCDA. The UHCDA is currently in effect in several states, including but not limited to California, Delaware, Hawaii, and Wyoming.

Final, approved copies of the UHCDA in printed pamphlet or computer diskette form and copies of all uniform and model acts and other printed matter issued by the Conference may also be obtained from:

National Conference of Commissioners on Uniform State Laws  
676 North St. Clair Street, Suite 1700  
Chicago, ILL 60611  
(312) 915-0195

The UHCDA supersedes the Commissioners' Model Health Care Consent Act (1982), the Uniform Rights of the Terminally Ill Act (1985), and the Uniform Rights of the Terminally Ill Act (1989). States that enact the UHCDA should repeal these or other similar acts.<sup>8, 9</sup>

## **Emergency Medical Response (911)**

Advance directives do not take effect in 911 emergency situations. All 911 responders are legally bound to exercise every life-support measure possible unless

there is a legally valid, state-recognized do-not-resuscitate (DNR) order completed and presented to the 911 responders. Not all states have DNR statutes; furthermore, most DNR statutes only address situations of cardiac or respiratory arrest (ie, clinical death) and do not address situations of hemodynamic instability or respiratory compromise. Once the patient is in the hospital, 911 procedures are no longer in place and advance directives can take effect.

### **Personal and Financial Decisions**

Advance directives have nothing to do with financial planning. A regular will is a document that instructs how personal finances and belongings should be distributed at the time of death. A Medical Power of Attorney can be used to assign responsibility for financial affairs.

## ADVANCE DIRECTIVES

	<b>Living Will</b>	<b>Medical Power of Attorney</b>
<b>Description</b>	Expresses wishes about medical treatment at the end of life; it takes effect only in situations of terminal illness or permanent unconsciousness	Appoints someone to make healthcare decisions if a person becomes unable to make decisions and unable to communicate his or her wishes  Provides instructions that describe the kind of care a person would want or not want under particular conditions
<b>How wishes are expressed</b>	Written statement about medical treatment preferences	Through the designated healthcare partner and written statement about the medical treatment preferences
<b>Legally binding</b>	Depends on Statue	Yes
<b>Healthcare partner</b>	No	Yes
<b>When advance directives take effect</b>	Only when the patient is terminal or permanently unconscious and unable to make medial decisions for themselves	In the event an individual is unable to make medical decisions (eg, because of Alzheimer’s disease, severe stroke, and coma)
<b>Duration</b>	Indefinite	Indefinite
<b>Changeable</b>	Yes	Yes
<b>Witness</b>	Two required	Two required to sign, or a Notary
<b>Notary</b>	No	Notary or 2 witness
<b>Attorney</b>	Not needed	Not needed

## Key Points

- ❖ Patients with decision-making capacity have the right to choose or refuse treatment—even if the choice results in the patient’s death.
- ❖ The PSDA supports the use of advance directives as a way to protect this right in the event that a person loses decision-making capacity.
- ❖ Each state has legislation governing advance directives. Nurses must be familiar with the laws of their state. The Web site [www.partnershipforcaring.org](http://www.partnershipforcaring.org) provides state-specific information and sample documents. Some states have adopted the UHCDA as a model.
- ❖ There are 2 primary types of advance directives: Living Will and Medical Power of Attorney.
  - A Living Will indicates a person’s treatment preferences only in circumstances of terminal illness or permanent unconsciousness.
  - A Medical Power of Attorney allows a person to name a proxy who would serve as the decision maker if the patient loses his or her decision-making capacity. It also provides a mechanism for indicating treatment preferences and is not limited to circumstances of terminal illness or permanent unconsciousness.
- ❖ A Medical Power of Attorney does not address emergency medical response situations or personal and financial decision making.

## **Use of Advance Directives**

To date, despite the demand for autonomous decision making by patients, few Americans have prepared advance directives. Although no recent nationally representative studies exist about completion of advance directives, data from previous population-specific investigations suggest that fewer than 25% of Americans have advance directives.<sup>1,10</sup> There are many reasons for this phenomenon, including the following:

- lack of knowledge about the document and its use,
- perceived complexity of the process and documents,
- fear that care will be limited without knowledge and/or consent,
- denial of morbidity and mortality, and
- spiritual and cultural values and beliefs.

Most people assume that families and healthcare providers will make the “right” decisions for them if they lose their decision-making capacity. However, studies show that families and providers are not able to accurately predict patients’ decisions.<sup>11-14</sup>

### *Barriers*

Healthcare providers can play a central role in assisting individuals to complete advance directives. Unfortunately, many providers lack basic knowledge about the documents, have little training on how to counsel individuals about preparing advance directives, and may not appreciate the value of the documents in practice. Some providers believe that advance directives are not necessary for young, healthy patients. However, cases such as Nancy Cruzan and Michael Martin, which provided the impetus for advance directives legislation, show that death does not discriminate. Facilitating discussions about advance directives takes time that may not be directly compensated, and lack of compensation for providing the service has been identified as a barrier. In addition, because physicians do not accept death as an appropriate outcome of care, they are reluctant to discuss a plan of care that would not be medically aggressive.<sup>1,15</sup>

### *Limitations*

Advance directives are not the perfect answer to decision making for incapacitated patients. These documents have limitations, including the following:

- the use of broad language,
- failure to incorporate patients' values and beliefs,
- complex terminology that is misunderstood by patients and advocates,
- not addressing the complex and infinite array of treatment choices and scenarios, and
- not being physically available when needed.<sup>1</sup>

However, failure to engage in dialogues about advance planning and to honor decisions that have been articulated by patients in their directives can result in people living and dying under unacceptable conditions.<sup>16,17</sup> Conversely, explicit advance directives can positively affect end-of-life care.<sup>18</sup>

### *Pediatric Advance Directives*

Few policies exist for pediatric advance directives. The opportunity to write advance directives is frequently not offered. Parents of children with potentially life-limiting conditions are not always present when a life-threatening event occurs. Often, children and adolescents with serious illnesses have acquired a good understanding of their disease process and the implication of treatment and therapies. It is important to respect the rights and wishes of minors and involve them in making key therapeutic decisions.

### *How to Develop Advance Directives With Patients*

To develop patient-centered advance directives, it is important to include the patient, his or her family members, and, preferably, the healthcare provider in a dialogue about advance care planning. Consequently, the planning of end-of-life care becomes less document-driven and decision-focused, and more patient- and relationship-focused.<sup>19</sup> The dialogue provides education about the process, but

most importantly provides an opportunity for the patient to talk about values, beliefs, and treatment preferences. These treatment preferences can be further addressed by the healthcare provider, who may be able to provide a perspective on the medical benefits and burdens of the therapies and how the treatments may affect the patient's quality of living and dying. "Advance directives work best when they record, not replace, as series of face to face discussions" in which the following takes place:<sup>19</sup>

- The patient is educated about the process and options.
- The patient is helped to make informed choices.
- There is a mutual understanding of the patient's values, beliefs, and preferences.<sup>19-23</sup>

### **Key Points**

- ❖ There are many potential patient, family, and provider barriers to preparing advance directives.
  
- ❖ Education, advocacy, and dialogue can reduce these barriers.
  
- ❖ Value-based, patient-centered directives can be a useful tool in ensuring that treatment is consistent with patients' wishes, allowing them to live and die in a manner that is consistent with personal values and beliefs.

### **Values**

When discussing advance directives, patients must explore their individual values. Values are core beliefs regarding what is right and fair in terms of our actions and our interactions with others, and what individuals believe to be of worth and importance in their lives.<sup>24</sup>

The patient's values will guide him or her in making healthcare choices. The following 3 types of values should be considered in this situation:

1. Personal values, which form the basis for behavior and include both moral and nonmoral beliefs
2. Cultural values, which are indigenous to a culture or people versus an individual
3. Professional values, which are derived from the individual's professional group

Healthcare professionals' responsibility is to create an open environment where patients are allowed to educate us about their individual values. Values emerge in conversation as part of the creative process, and thereby patients can explore their basic life values, quality-of-life values, and healthcare and medical values.

### **Ethical Principles**

Ethical principles can be defined as "fundamental truths (laws, doctrines, motivating forces upon which decisions can be based."<sup>25</sup> The following ethical principles are related to completing advance directives.

#### *Autonomy*

Autonomy (self-determination) is the fundamental principle that ensures patients the freedom of choice to determine what happens to their person, as long as those decisions produce no harm to others. This principle is grounded in respect for persons, that is, each individual is treated as a person of moral worth and moral agency.<sup>26</sup> "Autonomy implies that people have an inherent right to make treatment decision and should be active participant in their own care."<sup>27</sup>

On the basis of the principle of autonomy, healthcare professionals should respect patients' and clients' choices concerning their lives and not let their own values or morals influence treatment decisions.<sup>28</sup> To support informed decision making, healthcare professionals must give patients access to all the information relevant to a particular decision.<sup>27</sup> It is important to provide technically accurate information that discusses all alternatives, benefits, and burdens so patients can make an informed

decision about their healthcare. If patients are denied this information, their autonomy and dignity are compromised. Thus, veracity (truth telling) is an important moral principle to consider when patients are completing their advance directives.<sup>27</sup> Healthcare providers must clarify patients' questions, fears, and choices regarding healthcare and take into consideration their cultural, religious, and ethnic backgrounds.

### *Beneficence*

Beneficence is the fundamental principle that requires healthcare professionals to ensure that their activities provide benefit for patients. This principle has the following 4 elements<sup>26</sup>:

1. One should not inflict harm or evil (nonmaleficence)
2. One should prevent harm
3. One should remove harm
4. One should do or promote good

Nonmaleficence is a principle element associated with the maxim, *primum non nocere*, "above all, do no harm," which is implied in the Hippocratic Oath, "...I will never use it [treatment] to injure or wrong them."

### **Cultural Perspectives in Completing Advance Directives**

Healthcare professionals often harbor certain assumptions when discussing advance directives. The following assumptions are based on European-American cultural beliefs:

1. The patient wants to make autonomous decisions.
2. The patient expects full disclosure for informed decision making.
3. The patient trusts healthcare professionals.
4. The patient should not suffer.
5. The patient is future oriented.

Healthcare professionals must consider a patient's cultural background when providing healthcare. Health and illness are culturally constructed concepts that frame people's responses to diagnosis and treatment.<sup>27</sup>

Individualism is the concept of self-reliance and mutual independence, which has its roots in American culture. Some cultures do not place high value on this concept; in these cultures, the family is considered to be the smallest unit of identity and decision making cannot be assessed outside this fundamental social unit.<sup>26</sup> In this framework, it then becomes the family's responsibility to make medical decisions, and conflict can arise when completing advance directives because individualism is interpreted as implying detachment from family, religion, spirituality, and/or culture.<sup>28</sup>

In the American medical system, complete disclosure on diagnosis and prognosis is considered essential in good clinical care and is supported by laws. Some cultures do not value this concept; in fact, they prefer that family members communicate directly with healthcare team regarding diagnosis and treatment. In these cultures, the family is expected to filter the news regarding the illness, and avoid burdening the vulnerable patient with the truth. They view blunt, but truthful, communication as extremely rude and disrespectful.<sup>26</sup> In many cultures, discussing death with the patient is thought to hasten death or cause greater emotional and physical harm.

Some people believe that illness and suffering are the will of God. Others feel that harmony with the natural cycles of life and death are the most important, thus, controlling or manipulating death is inappropriate and unnatural. Some believe that if one talks about illness or death it will happen.

Individuals' social and political history may also influence how they make decisions regarding their healthcare. Individuals who may have experienced discrimination, abuse, or exploitive tactics of a government may be reluctant to prepare a legal document referring to their incapacity, such as advance directive. In some cultures, a verbal agreement is binding and a written document may suggest mistrust of a person's promise and is seen as dishonoring the signee.

Some cultural groups see physicians as authority figures with specialist knowledge, who should make the decision for the patients.

When addressing advance directives, healthcare providers must assess the patient's and family members' values and attitudes. Also, healthcare providers should explore the patient's basic beliefs regarding health, illness, death, and his or her perspective on end-of-life decision making. The assessment should also include the family members' and clinicians' role in providing care and making healthcare decision.<sup>27</sup>

Healthcare professionals must consider a patient's culture, ethnicity, and religious and socioeconomic background when providing healthcare. Mechanisms must be in place to accommodate the range of cultural beliefs, to respect family integrity, and to honor individual conceptualization of appropriate life orientation.<sup>30</sup>

### **Nurses as Advocates: Helping Patients to Make Treatment Preferences Known**

"The American Association of Critical-Care Nurses is dedicated to creating a healthcare system driven by the needs of patients and families where critical care nurses make their optimal contribution."<sup>31</sup> This optimal contribution includes, in part, being an advocate for patients and families, and ensuring that the care provided is consistent with the patient's values, beliefs, and treatment preferences.

Unfortunately, when decisions need to be made in the intensive care unit about withdrawal or withholding of treatment, studies suggest that less than 5% of patients are able to participate in the decision-making process.<sup>32</sup>

How can you, as a critical care nurse, be an advocate for patients and families regarding advance medical directives?

- Become informed
  - One of the major reasons people do not have advance directives is a lack of information and understanding. People look to their healthcare providers to discuss advance care

planning and to provide accurate, understandable information.

- Set an example
  - Having your own advance directives communicates to patients and their families that you value the document. Going through the process yourself will also enhance your understanding of and sensitivity to the issues.
- Start at home
  - Completing advance directives is a gift you can give yourself and your family. Having discussions about treatment preferences and documenting preferences in a clear and convincing document can help ensure that you and your family members receive care that is consistent with your values, beliefs, and preferences. It can also reduce future conflict and potential legal disputes.
- Normalize the process for patients and families
  - Inquiring about advance directives when a patient is admitted to the hospital can be uncomfortable for the nurse, patient, and family because for many it may imply that the outcome may not be good.
  - It is helpful to preface the inquiry about advance directives by saying, “We want to make certain that the care we provide is the type of care and treatment that you want. Is there anything that you would like to share with us about your treatment preferences? In the event that you become too sick to talk about and make treatment decisions, do you have a document (advance directives, living will, durable power of attorney for healthcare) that would tell us who you want to make decisions and what you would want them to decide for you?”

- Encourage patients to talk with providers and family members about goals, values, beliefs, and treatment preferences while they are able.
- Advocate for advance directives education in your hospital and community
  - There are many resources for advance directives education, as well as documents that meet your state legal requirements. Several resources can be found in the “Resources” section of this program.

The appendices contain information related to advance directives, as well as tools nurses may find useful in providing advance directives education:

- Talking Point to Help Patients Complete Advance Directives (Appendix A)
- Frequently Asked Questions About Advance Directives (Appendix B)
- Discovering Your Beliefs (Appendix C)
- Choosing and Talking to Your Healthcare Partner (Appendix D)
- What It Means to Be a Healthcare Partner (Appendix E)
- Talking With Physicians, Nurses, Lawyers, or Clergy About Advance Directives (Appendix F)
- Common Medical Situations and How Advance Directives Work (Appendix G)
- Additional Resources (Appendix H)

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## **Appendix A - Talking Points to Help Patients Complete Advance**

### **Directives**

- 1 Completing advance directives is one of the kindest things you can do for your family members. If they have to direct your medical care with physicians, nurses, and other medical staff, they will know that they are carrying out your wishes.**
- 2 Completing advance directives helps you maintain control of your own healthcare in any anticipated or unanticipated medical situation in which you are unable to make decisions and speak for yourself. You can maintain a voice in your own care either through your healthcare partner (Medical Power of Attorney) or through a Living Will.**
- 3 Completing advance directives may give you an opportunity to deepen your relationship with your loved ones, because you will need to discuss your values and the quality of life you want to preserve. These conversations are a powerful way to share your love for each another.**
- 4 Simply telling a family member or a friend how you feel about healthcare treatments may not ensure that your choices will be carried out. Your friends and family can help protect your choices if you discuss them and then complete a Medical Power of Attorney or a Living Will.**
- 5 Your doctor may not know what medical treatments you want and what treatments you would rather refuse.**

- 6 Legally, you are guaranteed the right to make decisions about your medical care, including life support. Without a written statement, however, you could lose the opportunity to direct your own medical care.**
- 7 Advance directives allow you to avoid lengthy and unpleasant court battles over maintaining or withdrawing life support. Your written wishes, along with discussions about preferences for care with family or friends, will greatly increase the chances that you get the care you want and prevent treatments you do not want.**
- 8 If you do not have someone to name as your healthcare partner, a Living Will can still help guide your doctor and loved ones about your wishes if you ever become terminally ill or permanently unconscious.**
- 9 People often take the time to plan for financial matters with a will and estate planning, and healthcare matters are equally important. Just like financial planning, healthcare planning maintains your control and reassures you about the future.**
- 10 Completing a Living Will or Medical Power of Attorney will raise your awareness of important beliefs and values that you have about your quality of life. As you review these beliefs and values, you will be better able to plan your future in satisfying ways. You and your loved ones will also become familiar with common medical procedures and treatments. It will make these treatments less overwhelming if the time ever comes to face them.**

## **Appendix B - Frequently Asked Questions About Advance Directives**

Patients, families, and the community may commonly ask the following questions. The questions are about a Living Will and Medical Power of Attorney, your healthcare partner, medical conditions and treatments, religious issues, and other aspects of completing advance directives.

### **Issues About the Documents**

**Q. What’s the difference between a Living Will and regular will?**

A. A regular will is a plan for disposing your assets and property after you die. A Living Will, on the other hand, has nothing to do with your financial affairs; it is a statement that you write about your wishes regarding critical care treatment, for example, feeding tubes, cardiopulmonary resuscitation, or ventilator. A Living Will takes effect only if you are terminally ill or in a permanently unconscious state and unable to make decisions for yourself.

**Q. What is the difference between a Living Will and a Medical Power of Attorney?**

A. In a Living Will you write down your specific wishes about withholding life-sustaining treatments to help guide your physician. A Living Will takes effect only if you are terminally ill or permanently unconscious. The Living Will speaks for you when you cannot make your own decisions.

In a Medical Power of Attorney document, you name a person—a healthcare partner (sometimes called an “attorney-in-fact” or “agent”)—to communicate your wishes if you are no longer able to make decisions for yourself. This person is legally appointed by you to speak for you in medical situations. An advantage of a Medical Power of Attorney is that it can cover a situation that you have not anticipated in a Living Will. Also, a Medical Power of Attorney is more flexible and comprehensive document. It includes all healthcare situations when you cannot make decisions for yourself, whether or not you are terminally ill.

**Q. Do I need both a Living Will and a Medical Power of Attorney?**

A. No. If you have someone to name as your healthcare partner, a Medical Power of Attorney provides the more complete protection because it has space for specific wishes in addition to appointing someone. If you do not have someone to serve as your partner, you should complete a Living Will.

**Q. Do I have to go to an attorney to fill out the Living Will and Medical Power of Attorney?**

A. No, you do not need an attorney to complete advance directives.

**Q. When does a Medical Power of Attorney go into effect?**

A. A Medical Power of Attorney takes effect only if you are unable to make decisions for yourself. Unlike a Living Will, you do not have to be in a terminal or permanently unconscious condition for it to take effect.

**Q. If I call 911, will my healthcare partner still be able to make decisions for me?**

A. Neither a Living Will nor a Medical Power of Attorney takes effect in 911 emergency situations. All 911 medical personnel are legally bound to use any and all life-support measures possible until the patient is released to a hospital or other medical care facility.

**Note: There is an Emergency Medical Services Prehospital Do Not Resuscitate (DNR) form available, which must be signed by you and your physician. A prehospital DNR order instructs paramedics not to resuscitate you at home or in any other location outside a hospital, including a nursing home or hospice. However, if you call 911 and have only advance directives, paramedics will be required to try to resuscitate you.**

**Q. Who can witness my Living Will or Medical Power of Attorney?**

A. The requirements are slightly different for the 2 documents. A Medical Power of Attorney requires 2 witnesses or a Notary Public. A Living Will requires 2 witnesses. For both documents, witnesses may be any adult except a healthcare provider, an employee of healthcare provider, or the operator or employee of a community care facility or residential care facility for the elderly.

**Q. Can issues about organ donation and transplantation be specified in my advance directives?**

A. Only a Medical Power of Attorney document has provisions for tissue and/or organ donation. You can include any instructions you want regarding donating your organs or tissues for transplantation or medical research.

**Q. Can a child have a Living Will or a Medical Power of Attorney?**

A. No. A child's legal guardian has the right to make healthcare decisions for him or her until 18 years of age. But it is still important to discuss medical preferences with minors.

**Q. What happens if I fill out a Living Will or a Medical Power of Attorney and then change my mind?**

A. You can change your Living Will or Medical Power of Attorney as often as you like, or you can revoke both documents completely. Even if you are in the hospital, you can change the document verbally. It will be noted in your medical record, and you can write a new document when you are able.

Be sure to distribute copies of the new form to the appropriate people. The Medical Power of Attorney remains sensitive to your changing wishes as long as you talk with your healthcare partner about the treatments you want or do not want.

**Q. What if I have 2 homes? I spend half of the year in one state and the other half in another.**

A. Each state has its own law regarding reciprocity, so you will need to check whether your advance directives would be honored in the other state. It is also a good idea to appoint alternate healthcare partners in each place to ensure that there will always be someone available to act as your spokesperson if you ever cannot make decisions for yourself. The safest path is to complete the forms in each of the states you reside.

**Q. Will my Living Will or Medical Power of Attorney be valid if I move to another state?**

A. It is best to complete advance directives in your new home state. Until you complete a new document, carrying a wallet card will at least alert medical professionals that you have advance directives.

**Q. Will my Living Will or Medical Power of Attorney be valid if I'm traveling out of state?**

A. In general, yes. You can take steps to ensure that in an emergency situation, the attending medical staff knows that your advance directives exist. Your wallet card can alert the medical team to your advance directives. You should also make sure that your healthcare partner, physician, and family members have copies of the document.

**Q. Where should I keep my advance directives?**

A. Your advance directives should be easily available to your doctors and others. Don't keep your document a secret or it can't protect your choices. Make sure your healthcare partner, loved ones, and doctors have copies of your advance directives.

### **Choosing a Healthcare Partner**

**Q. Who can be my healthcare partner?**

- A. Any family member, a member of the clergy, or a friend. Your healthcare partner may not be (1) your treating physician or (2) an operator or employee of a healthcare facility, unless they are related to you by blood, marriage, or adoption.

Primary physicians and medical staff are barred from being healthcare partners because of potential conflict of interest. However, it is important to discuss your Medical Power of Attorney with members of your medical team.

**Q. If I choose a friend as my healthcare partner in my Medical Power of Attorney, can my family supersede my wishes?**

- A. No, your healthcare partner has the legal power to speak for you.

**Q. What if my healthcare partner dies before I do?**

- A. It is a good idea to appoint alternate healthcare partners to act as backups if your primary healthcare partner is unavailable. You need to revise the form if your healthcare partner dies.

**Q. What if I don't have anyone to name as my healthcare partner in my Medical Power of Attorney?**

- A. If you do not have a family member, friend, colleague, or spiritual advisor to be your healthcare partner, completing a Living Will is your best option. However, even if you do not have a partner, it is important that you discuss your wishes with your doctors and anyone else close to you.

**Q. Does it make sense to name a healthcare partner if he or she lives out of state?**

- A. Your healthcare partner will be most effective in person. Therefore, you should choose someone who will be able to be by your side in an emergency or other medical situation. If you must choose someone who lives out of state, this person can communicate your wishes to your physician over the telephone or in writing. Remember to distribute copies of your Medical Power of Attorney not only to your partner, but also to your physician and medical team so the document may be found quickly.

### **Why You Need Advance Directives**

**Q. I know what I want regarding life support, so why is there a need to do anything else about it?**

- A. Because a time may come when you cannot make or communicate those decisions for yourself. Expressing your wishes in a legally binding document is the best way to

ensure that your preferences will be followed. Importantly, the forms also help your family and loved ones if you ever need critical care treatment. Your advance directives provide a guide for making decisions within the medical system. A directive helps avoid anguish among family or friends, arising from their uncertainties about your wishes.

**Q. Why do I need a Medical Power of Attorney if I already told my child my wishes about life support? I know what I want and it's taken care of.**

A. This is a popular misconception. Telling a family member about your wishes may not be enough to ensure that those wishes will be honored. Your physician may not be able to rely on an oral agreement as a guide, especially if family members disagree regarding treatment. By completing the form, you are providing your partner with a powerful tool with which to instruct and guide your doctors about the care you want or don't want.

**Q. Does asking someone to be my healthcare partner for my Medical Power of Attorney place a terrible burden on that person?**

A. By completing a Medical Power of Attorney, you may be burdening family and friends for a few hours to discuss your care with you. However, you are relieving them of the long-term emotional burden of having to guess what care you might have wanted. By handing them your advance directives, you are giving them a powerful tool to guide physicians and nurses.

**Q. Why should I give my power to think to someone else?**

A. Actually, advance directives do just the opposite—by preserving your own thoughts and preferences in legal documents so that other people won't exercise their own beliefs over yours. By completing a Medical Power of Attorney you maintain control over your own healthcare choices. Your partner is merely carrying out your instructions and acting as your voice. And remember, your partner would only carry out your instructions in medical situations in which you were so ill that you could no longer decide for yourself.

### **Concerns About Your Wishes Being Carried Out**

**Q. How can I be sure my healthcare partner will carry out my wishes in my Medical Power of Attorney?**

A. Spend time talking to your partner about your feelings, choices, and the quality of life you want to maintain.

- Q. How can I be sure that my physician will honor my wishes in my advance directives, even if it conflicts with his or her own values or religious beliefs?**
- A. The Living Will and the Medical Power of Attorney legally bar physicians from making decisions contrary to your wishes. If a physician personally opposes your wishes, he or she has 2 choices: the physician must either follow your directive or remove himself or herself from your case. It is important to talk to your physician about your choices. Whichever form you complete, make sure it is added to your medical record. Otherwise, the medical team will not know about it. If you complete a Medical Power of Attorney, make sure your partner has a copy and understands that he or she should use it to ensure that your wishes become known.
- Q. Are there any decisions my healthcare partner can't make?**
- A. Each state's Medical Power of Attorney does place some limitations on your healthcare partner's authority.
- Q. If I'm admitted to the emergency department in a comatose state, how will the hospital know that I have advance directives?**
- A. You should carry your wallet card, which notifies medical professionals about your documents and, if you have completed a Medical Power of Attorney, identifies your healthcare partner.
- Q. Should I talk to my children about a Living Will or Medical Power of Attorney?**
- A. Yes, your children may also want to complete a Living Will or Medical Power of Attorney for themselves.

### **Medical Conditions and Treatments**

- Q. What is CPR and how successful is it?**
- A. CPR is cardiopulmonary resuscitation—a variety of techniques to restart your breathing and heartbeat, including forceful chest compressions, mouth-to-mouth breathing, and electric shocks. If you are generally healthy and active, you have a good chance of survival. However, hospitalized people with chronic disease or other illnesses have a poorer chance of survival.
- Q. If I survive CPR, what condition will I be in?**
- A. That depends. When breathing stops, oxygen doesn't reach a person's brain. If this goes on for some time, it can result in severe brain damage and other complications. You should discuss CPR and the quality of life you wish to maintain with your physician or a nurse.

**Q. How do I know a coma is really irreversible? I have heard that people can wake up from comas.**

A. People can wake up from comas and often do following an accident, surgery, or other incident. Therefore, physicians must conduct a series of tests for brain damage and examine a patient over several weeks or months before concluding that a coma is irreversible.

**Q. If I refuse life-support treatment, will I still be treated for pain?**

A. All patients should receive pain treatment and “comfort care” regardless of their decision about life support. Physicians and nurses give comfort care in many forms to ensure that critically ill or dying patients are as pain-free as possible. Comfort care includes offering pain medication, hygiene temperature control, management of nausea, and massage.

**Q. Is Alzheimer’s disease classified as a terminal illness?**

A. Alzheimer’s disease is an irreversible condition, but it is rarely terminal. Patients with Alzheimer’s disease may lose most, if not all, of the functions that allow them to care for themselves and relate to their loved ones, for example, memory loss and inability to feed themselves, wash themselves, dress themselves. However, it is not the disease that causes death; rather, a patient with Alzheimer’s disease usually dies of something else, such as an infection in the lungs, a stroke, or a heart attack.

**Q. Would hospitals really put someone in their 90s who has a severe stroke on life support?**

A. Yes, they do. If you wish otherwise, it is up to you to direct your physician while you can still make decisions. You may choose to try life support temporarily to see if it works, or refuse it altogether. Whatever you choose, talking about that choice with family, friends, and your physician, and then completing advance directives can protect your wishes.

### **Religious Issues**

**Q. What do religious traditions have to say about advance directives?**

A. Different traditions have different guidelines about end-of-life issues, but most support the idea of a legal document to express a person’s wishes. In fact, advance tradition is respected, rather than that of the medical system. You can also ask your clergy member about your religion’s “position statement” on these issues.

**Q. Can I use my Living Will or Medical Power of Attorney form to request that someone pray for me?**

A. Yes, for both documents, you can write down any treatments or preferences you wish in the “comments” section of the form and/or on additional pages.

## **Appendix C - Discovering Your Beliefs About Critical Care Choices**

It may not be easy to think about future healthcare decisions and critical care choices; however, taking the time to consider your feelings on these issues will help you make better decisions, which will serve both you and your family. The following worksheets and questionnaires can help you discover your feelings about a wide range of medical treatments.

You can go through the worksheets and questionnaires by yourself, keeping your answers private, or you can share these exercises with a close family member, friend, physician, or clergy member. You may want to complete all the exercises or just some of them. In different ways, each activity helps you ask yourself about medical treatments and the quality of life you wish to maintain. There are no right or wrong answers.

### **What Would I Do, If This Happened To Me?**

You can read these stories to help explore different issues about quality of life. Then, think about the medical treatments you would want under similar circumstances and the treatments you would prefer to refuse.

This is a story about a patient with Alzheimer's disease.

Mrs. H. is a 72-year-old widow with heart problems. She lives alone, and her 2 adult daughters live out of town. Five years ago, after reading an article in *Reader's Digest*, she told her daughters that if she ever ended up with dementia (a form of senility or forgetfulness), she would not want to live like that. The topic was not discussed in further detail after that time.

A year later, during one of their visits, her daughters found Mrs. H. forgetful and slightly disheveled. Her memory continued to get worse, and over time she lost the ability to care for herself. After an extensive medical and psychological evaluation, she was diagnosed as having senile dementia of the Alzheimer's type. Her children arranged nursing home placement so that she could receive assistance with her daily activities and hygiene.

Several months ago Mrs. H. seemed to lose interest in eating. The nursing home asked her children whether their mother would want a feeding tube to provide hydration and nutrition—without it she would die. The daughters felt conflicted about the decision. On the one hand, they wanted to respect their mother's previously stated wishes. She was almost a different person now, not caring about her previous interests, nor having any memory of family. On the other hand, their mother seemed to enjoy herself in the nursing home, obtaining pleasure in befriending the nursing home's cat and appreciating the daughters' monthly visits even though she did not recognize either of them. It seemed that the feeding

tube may be in her best interests, but the daughters also remembered their mother’s earlier statement about not wanting to prolong life if she experienced dementia.<sup>1</sup>

This example points out various stages of Alzheimer’s disease. Consider the following stages and ask yourself what types of medical treatment you would want. Would you want life support on a long-term basis—such as a machine to help you breathe and a tube for feeding—if a medical crisis arose or if your physical condition were expected to deteriorate steadily?

### Illustrative Stages of Alzheimer’s Disease

		<b>Long-term life support</b>
1	Your are able to bathe, groom, and dress yourself. You go outside, but once in a while you get lost and disoriented during grocery shopping. On occasion, you are unable to recognize your family.	Yes   No
2	You are only able to do daily activities of bathing and grooming with supervision. On numerous occasions you have turned on the gas and forgotten it’s on. Periodically, you are able to recognize family or visitors, but mostly you cannot do this. You have accidentally destroyed some of your personal property by dropping items.	Yes   No
3	You are bedridden. You cannot bathe or groom yourself and you seldom recognize family members. You cannot communicate your need to use the toilet, so you must use diapers. You have little appetite. But, you still smile when you stroke the cat.	Yes   No
4	You are bedridden and rely on a nurse for all your bodily functions and hygiene. You do not respond to touch or to familiar voices.	Yes   No

This is a story about a patient in a coma:

Mr. F. is in his 60s. He has always been healthy and fit, running 2 miles in the morning and biking in the afternoons. A few years ago, one of Mr. F.’s friends was in an automobile accident and taken to the hospital. The friend was in a coma, and during that time needed a ventilator to help him breathe and a tube for feeding. Mr. F.’s friend was in a coma for 2 weeks; he went through some physical and occupational rehabilitation and eventually

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<sup>1</sup> We are grateful to Robert A. Pearlman, MD, Director of Northwest Ethics Center for Veterans Health Care at the Seattle V.A. Medical Center, for bringing this case study to our attention and allowing us to adapt it for this Guide.

recovered fully. After this incident, Mr. F. mentioned to his wife that if he was ever in a coma he would want the doctors to be very confident that he would never come out of it before he was taken off “those machines.”

A year ago Mr. F. was in a serious accident on his bicycle. Unconscious, he was rushed to the hospital with head injuries. After careful observation and testing for 2 days, his physicians could not be sure how much brain damage he had sustained. Mr. F. remained in a coma, supported by a ventilator and feeding tube. The physicians continued testing for 3 weeks and then told Mr. F.’s wife that he most likely was in an irreversible coma and had considerable brain damage, but they couldn’t be certain. They also told her that if Mr. F. came out of the coma they couldn’t be sure what state he’d be in or if he’d ever return to his active lifestyle again. The physicians couldn’t tell Mrs. F. how long Mr. F. would remain in a coma, saying it could be weeks, months, or years.

Mrs. F. continued to visit her husband every day. When Mrs. F. held her husband’s hand, he would seem to respond to her touch. He also opened and closed his eyes. He did not respond to her voice.

Mrs. F. was confused and the doctors could not predict what would happen. She knew a life without exercise and full mental capacities would not be any life for her husband. But, she also remembered the time when she and her husband discussed their friend’s accident, coma, and full recovery. Mrs. F. did not know what to do.

The example of Mr. and Mrs. F. points out the difficulties in predicting outcomes for a person in a coma. Consider the following situations. If an additional medical crisis arose, would you want physicians to intervene in order to prolong your life?

### **Illustrative Stages of a Coma**

		<b>Want additional measures to prolong life?</b>
1.	You have been in a coma for a week. You randomly respond to touch by squeezing another person’s hand. You are not responsive to any verbal instructions.	Yes No
2.	You have been in a coma for a month. You randomly respond to touch by squeezing another person’s hand. You are not responsive to anyone’s voice. Your arms and legs are abnormally stiff and stretched out.	Yes No
3.	You have been in a coma for a year. Your limbs do not respond to any stimulation—by touch, by voice, or even to pin pricks. Your physical condition has been declining steadily for a year.	Yes No

Think about these situations as you complete your Medical Power of Attorney or your Living Will.

**What Kind of Life Do You Prefer?**

People differ in their feelings about quality and longevity of life. Some people would like to live as long as possible, regardless of the quality of life; others want to preserve a certain quality of life even if it means a shorter time alive.

Think about these options and your own feelings. Where do you fall on the scale below?

I want to live as long as possible, regardless of how poor the quality of my life gets.       -  -  -  -  -  -  -  -  -  -       I want to preserve a good quality of life even if it means a shorter time for me to live.

Thoughts that occurred to you as you answered this question:

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**Healthcare Values Checklist**

In this exercise, you will find a number of statements about values. Circle agree, disagree, or depends after each statement. You may want to write notes, questions, or additional thoughts in the spaces provided. You can skip items if you wish.

				<b>Notes to yourself or explanations</b>
I want to make my own decisions about healthcare.	Agree	Disagree	Depends	_____
I want my physicians to make decisions about my healthcare.	Agree	Disagree	Depends	_____
I want my family to make decisions about my healthcare.	Agree	Disagree	Depends	_____
I want to preserve my dignity, even when I can no longer speak for myself.	Agree	Disagree	Depends	_____
If I could not think clearly or recognize people I know, I would not want aggressive medical treatments just to stay alive.	Agree	Disagree	Depends	_____
If I could not think clearly or recognize people I know, I would still want life-support treatment in a medical crisis.	Agree	Disagree	Depends	_____
I want to try aggressive treatment before giving up.	Agree	Disagree	Depends	_____
				<b>Notes to yourself or explanations</b>

I want my religious beliefs and traditions followed in all medical situations.	Agree	Disagree	Depends	_____ _____
I want to die at home and not in the hospital.	Agree	Disagree	Depends	_____ _____
It does not matter to me where I die.	Agree	Disagree	Depends	_____ _____
I do not want my family to be financially burdened because of my medical treatments.	Agree	Disagree	Depends	_____ _____
I want to tie up all loose ends now, in terms of my choices for medical care.	Agree	Disagree	Depends	_____ _____
I don't want to be dependent on anyone to carry out my day-to-day functions (such as feeding, going to the bathroom, and personal grooming).	Agree	Disagree	Depends	_____ _____
I want a comfortable dying process.	Agree	Disagree	Depends	_____ _____
I want to be with loved ones at death.	Agree	Disagree	Depends	_____ _____
I want to donate my organs for transplantation.	Agree	Disagree	Depends	_____ _____
				<b>Notes to yourself or explanations</b>

<p>I want to donate my body organs for medical education and research</p>	<p>Agree</p>	<p>Disagree</p>	<p>Depends</p>	<hr/> <hr/>
<p>I don't want to be dependent on any technology, such as machines or complex procedures, in order to prolong my life if I am inevitably dying.</p>	<p>Agree</p>	<p>Disagree</p>	<p>Depends</p>	<hr/> <hr/>

Review your answers. These value statements point to some of the issues you will want to think about when you prepare your Living Will or Medical Power of Attorney. Of course, all your answers will help guide your healthcare partner (named in Medical Power of Attorney), your doctor, and your family.

**Medical Directive Worksheet**

The worksheet on the following page can help you identify your wishes in various health and treatment situations. Use the Key in the upper left corner to record how you feel about each situation and treatment.

**NOTE: Use this worksheet to begin discussions with your family, physician, and/or healthcare partner.**

## Medical Directive

You may want to attach this form to your Medical Power of Attorney or Living Will.

**Key:** **Y...** Yes; I want the procedure  
**N...** No; I do not want the procedure  
**U...** Undecided; I am not sure  
**T...** Try; I want to try the procedure but have it stopped if no clear improvement is shown

	Situation A	Situation B	Situation C	Situation D
	If I am in my current state of health and then develop a life-threatening but reversible illness:	If I am aware but have brain damage that makes me unable to recognize people, speak meaningfully, or live independently, and I do not have a terminal illness:	If I am in a coma and have a small but uncertain chance of regaining awareness and higher mental functioning:	If I am in an irreversible coma and have no known hope of recovering awareness or higher mental functioning:
<b>Treatments</b>				
Antibiotics				
Pain medication				
Chemotherapy				
Artificial nutrition and hydration (tube feeding)				
Mechanical breathing				
Kidney dialysis				
Cardiopulmonary resuscitation (CPR)				
Other _____				

## **Appendix D - Choosing and Talking To Your Healthcare Partner**

### **Common Medical Situations and How Advance Directives Work**

This section contains real-life stories from families, physicians, and nurses. Their first-hand experiences can help you understand how advance directives can protect you and your loved ones. Discover the perspectives of people who become critically ill, their families, and medical caregivers.

After reading about each personal experience, take a moment to imagine yourself in a similar situation. What would you want done? Sometimes you may think of yourself as the patient. Other times you may put yourself in the shoes of the family. These thoughts will help clarify your own goals for medical treatment, if you ever become unable to speak for yourself.

### **The Family's Perspective**

#### **A. A heart attack strikes a mother, and there are no advance directives**

“My 78-year-old mom had a heart attack. The cardiologist was someone we had never met. Mom was in the hospital and she was very sick; she wasn't improving, and she had trouble with fluid in her lungs. The cardiologist went in to see her and asked her if she would want healthcare staff to use a ventilator to help her breathe, if that became necessary in order to keep her alive. She said “no.” But mom wasn't really alert then; she might have shaken her head, but anyone could see that she didn't understand anything.

“Honestly, it was a toss-up to what mom wanted, even though the doctor thought he knew. Fortunately, mom recovered that time. But the experience really shook us, both mom and me. We talked about what kind of treatments she would want, if a similar thing happened again. She filled out a Medical Power of Attorney, naming me as her partner. Two years later, mom had a severe stroke and could not make decisions for herself. This time the doctors and nurses came right to me for advice about mom's wishes. She was very sick and would have needed a ventilator to keep going. But I knew she didn't want that, and the hospital never put her on machines. Having the Medical Power of Attorney made all the difference. Mom died in the way that she wanted to. (Chicago, Illinois)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

- your family or friends
- your doctor or other medical caregiver
- clergy
- lawyer
- a nurse-advisor

## **B. A father requests a trial period of treatment**

“My dad’s ailing health came as a surprise. After my mom died, dad’s Crohn’s disease, an intestinal disorder, flared up and could not be controlled by medication. He was dehydrated and seriously ill. He had 2 surgeries and 2 bouts with pneumonia. He was 80 years old and quite frail. Following the second surgery, he was in the intensive care unit.

“The doctors and nurses asked us if dad had an advance directive, because he was incoherent. No one could communicate with him. They asked us, ‘What does he want?’ We said, ‘He has a Medical Power of Attorney. He always told us that he wanted to have CPR or any other life support, at least once to see if it works.’ That was our guideline. We used it in this situation, thinking dad would want to at least try a treatment to see if it worked before giving up.

“The doctor said dad needed to be on a ventilator to help his breathing, so we said okay. But we agreed on a 2-week trial to see if he would get better and not need artificial breathing. At the end, dad hadn’t improved, and we withdrew the ventilator—but, of course, kept giving him comfort and pain medications. Dad died the next day.

“When we told the doctor that dad had an advance directive, we could see the sigh of relief. His shoulders relaxed. We talked about Dad’s preferences, and the doctor actually said, ‘Thank goodness you all discussed this already.’ And having discussed dad’s choices earlier gave us time to process it all and not get into a conflict like some families do.”  
(Dubuque, Iowa)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

- your family or friends
- your doctor or other medical caregiver
- clergy
- lawyer
- a nurse-advisor

## **C. A Patient With Alzheimer’s Disease Gets Treated for Cancer**

“My wife is in her 70s and has Alzheimer’s disease. I saw the warning signs for over a year. She started to forget things. She couldn’t follow the directions to work our microwave; she had to stop driving because she got lost. As it progressed, she lost her appetite, couldn’t cook, and started to dress herself in 2 or 3 shirts at a time. She would talk to me about our kids and then all of a sudden babble in gibberish. When I finally couldn’t manage her myself anymore, I found a good nursing home for her.

“Unfortunately, 2 months after she went into the home, her doctors told me that she had breast cancer. Before she became sick, we had filled out a Medical Power of Attorney. She always told me, ‘I want to stay alive unless the doctors tell us there’s no chance I can survive.’ So, I used her words and her advance directive as my guide. When we learned of the cancer, the doctors told me that a lumpectomy plus chemotherapy to kill the cancer cells could allow her to live several more years. I told them to go ahead because I knew my wife wanted to live and the situation wasn’t terminal. The doctors went ahead with the treatment. It was hard on everyone, especially because my wife couldn’t understand what was happening to her. She was uncomfortable and I was by her side the whole time. But she got better, physically speaking. I’m thankful we talked about what she wanted. It’s still hard, but at least I know I’m doing what she wants.” (Abilene, Texas)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

- your family or friends
- your doctor or other medical caregiver
- clergy
- lawyer
- a nurse-advisor

#### **D. An Uncle Expresses His Convictions About Quality of Life**

“Two years ago, my uncle told my aunt that if he was ever so sick that he couldn’t play cards or go on walks, or play with his grandchildren, he didn’t want to live. No nursing homes, no life-support treatment. My aunt is one of these really organized types. She carried their Medical Power of Attorney forms with her all the time in a zip-lock baggy in her purse.

“My uncle, who had diabetes and kidney trouble, was 78 when he became acutely ill with pneumonia. My aunt told his doctors about his Medical Power of Attorney and explained, with confidence, that he did not want antibiotics or oxygen; that was his choice. The doctor agreed that the condition was grave, but he continued to prescribe antibiotics to fight the pneumonia. My uncle wasn’t improving—he had a terrible time breathing and he was in a tremendous amount of pain from all the tubes in his arms. His kidneys also began to fail.

“My aunt was in agony for 2 days—seeing her husband suffer and dealing with a doctor who just would not listen to her. Finally, she decided to take her frustration to her minister and she asked whether he could do anything about the situation. My aunt’s minister explained the circumstances to the hospital Chaplain, who then requested a consultation from the hospital ethics committee.

“After discussions with the original physician, the ethics committee urged that the care of my uncle be transferred to another doctor. This new doctor talked with the family, and my aunt explained my uncle’s preferences about heroic measures. The doctor agreed to withdraw the antibiotics and oxygen.

“During my uncle’s final days, my aunt was by his side, as were his children and their minister. They helped bathe him, comb his hair, hold his hand, and stroke his arm. Sometimes their minister would visit him 2 or 3 times a day. He died within a week. And as we watched him die, we saw that it was a peaceful, kind death. He had his family and minister beside him, and they didn’t feel guilty because they knew they were following through with his wishes.” (San Jose, California)

If you were in this situation, what would you want done? As the patient? As family?

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- lawyer
- a nurse-advisor

### **E. A Young Man’s Accident Leaves His Family Confused About What to Do**

“My brother had a painting business. He and some friends painted houses each summer to earn money during college. But several years ago he fell off a ladder onto a cement driveway 3 floors below. When we got to the hospital, the doctors told us that he was in a coma and had suffered a severe head injury. He required a ventilator to help him breathe and fluids and nutrition through tubes. We kept asking, ‘Will he come out of it? Does he have brain damage?’ The doctors did a lot of tests and watched him for more than 2 months, but they all confirmed that his condition was not improving. He would more than likely need life-support systems forever, or he would die.

“We were devastated and didn’t know what to do. We didn’t want to see him live that way, but we didn’t want him to die either. He didn’t have a Living Will or anything else like that; he was 19. Our family never talked about this stuff and we didn’t even really understand what a Living Will was until this happened. The hardest part was not knowing what he wanted. It would have been easier for us to say, ‘Let him die peacefully,’ if he had talked about these issues. The doctors finally transferred him to a skilled nursing facility. He stayed

on a ventilator and got artificial feeding for nearly 3 years before he died.” (Kansas City, Missouri)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

- your family or friends
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- clergy
- lawyer
- a nurse-advisor

#### **F. A Son With AIDS Shows the Value of Advance Directives**

“My son Rick, 32, recently died from AIDS. His experience shows the importance of completing a Medical Power of Attorney, to dictate end-of-life wishes. Rick had been HIV-positive for 6 years, and had been on a variety of medications to help strengthen his immune system.

“In his last bout with the disease, he arrived at the hospital with severe pneumonia. He was in a weak condition and susceptible to a number of other opportunistic infections. He developed histoplasmosis, a brain infection, which caused him to drift in and out of consciousness. He was disoriented much of the time, and within a few weeks, he was frequently delirious.

“Shortly after Rick found out that he was HIV positive, he completed a Medical Power of Attorney asking his long-time companion, Geoffrey, to serve as his healthcare partner. Many people in the gay community have seen their friends die, and they often have a very clear picture of what they want and do not want in terms of medical treatments. Most do not want heroic measures that are physically agonizing and do little except give the patient a few more days to live.

“When it became clear that Rick had only a short while to live, Geoffrey followed Rick’s preferences by checking him out of the hospital and allowing Rick to die in their apartment. Although Rick was not aware during his last days, he did receive pain medication and was surrounded by the company of his loving family and friends.” (New York City, New York)

If you were in this situation, what would you want done? As the patient? As family?

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- a nurse-advisor

## The Physician's Perspective

### G. Advance Directives Help Patients Get Desired Care, Even When Wishes Change

“One of my patients used to divide his time between here and a home in California. While still healthy, he completed a Medical Power of Attorney naming his wife as partner. They had pretty thorough discussions about treatments like CPR (cardiopulmonary resuscitation), and he wanted to get the whole works—if he became incapacitated. His wife understood his wishes.

“Then Carl’s health began to go downhill. He developed emphysema, which meant that he often had to struggle to breathe. His mobility suffered. Then, on a visit here, an oncologist and I diagnosed him as having “oat cell” lung cancer—that’s almost always fatal and progresses quickly. Carl wanted to die here in Nebraska with hospice help.

“Just as important, Carl began to change his wishes about aggressive care in a critical situation. Fortunately, a Medical Power of Attorney allows this. All Carl had to do was make sure his wife stayed aware of his changing wishes, which she did.

“When he had trouble breathing toward the end, his family decided to take him to the emergency department. There, the physicians said, ‘We’ll make it easier for him to breathe.’ But Carl’s wife, his healthcare partner, asked the physician: ‘Are you talking about putting a tube in his throat? Did you know he has an advance directive?’ Carl’s wife told the doctors not to put him on the ventilator, but to do everything they could to reduce his suffering.

“As she told me later, the physician was relieved to learn of the advance directive, which gave her the power to say ‘no tubes.’ It changed the direction of discussions and the course of Carl’s treatment. They gave him oxygen; he had pneumonia so they gave him antibiotics, too. He died peacefully within a few weeks at home. By having a Medical Power of Attorney and continued discussions about changing care wishes, Carl’s wife knew what to ask in an emergency situation and what treatment Carl really wanted. She was prepared and physicians were able to accept her instructions.” (Lincoln, Nebraska)

If you were in this situation, what would you want done? As the patient? As family?

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- clergy
- lawyer
- a nurse-advisor

## **H. A Stroke Victim “Speaks” Through His Living Will**

“I recently treated a 79-year-old man who previously had been in good health. However, 2 strokes left his right arm and leg paralyzed and also affected his ability to swallow, so we put a feeding tube in his throat. He kept pulling it out. He couldn’t communicate verbally or by writing so we didn’t know if he was pulling the feeding tube out on purpose or not. Because he kept pulling it out we were faced with the situation of maybe placing a feeding tube through his abdomen into his stomach.

“His quality of life seemed poor. He was bed-ridden and living in a nursing home. After several months, another doctor and I agreed that he was near death. We consulted his Living Will and discussed his condition and his stated preferences with his family. We agreed to remove the feeding tube and let nature take its course. The document allowed his family to get through this difficult time without feeling guilty.

“When I look at and talk to families going through situations like this, the families are always in emotional turmoil, especially if guilt takes over. An advance directive is helpful to the patient, the family, and the physician, saving everyone a lot of pain.” (Huntington, West Virginia)

If you were in this situation, what would you want done? As the patient? As family?

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- lawyer
- a nurse-advisor

## **I. Family Conflict Leads to Confusion and Anger**

“We had a man in the intensive care unit who was very sick after his heart surgery. His lungs and kidneys were not functioning well, and he needed artificial nutrition and hydration. We had to explain the patient’s condition to his 2 family member—his daughter and his new wife. There was a terrible animosity between them, and they didn’t agree about the treatment. We were trying to decide what to do, whether to use the ventilator and place a feeding tube in his stomach, and everyone was asking us what to do, but they were arguing. It was very stressful, and an advance directive could have expressed the patient’s wishes.

“Neither family member had taken the time to talk to the patient beforehand about what he would have wanted, so no one knew what to do. Everyone felt guilty and angry. I had to watch the family fight it out, and it was a month before they agreed to avoid aggressive treatment.” (Raleigh, North Carolina)

If you were in this situation, what would you want done? As the patient? As family?

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- clergy
- lawyer
- a nurse-advisor

#### **J. Aggressive Treatment Produces a Prolonged and Ugly Death.**

“We treated a lady in her mid-70s who had a massive infection and multisystem organ failure (several of her organs were not functioning), and who went into shock from the overwhelming infection. We started pumping in fluids through her intravenous catheter so she wouldn’t die. We also explained to her family what was happening so they would understand. She had 5 kids, all by her side. They said, ‘We want everything done.’ So we kept giving her lots of fluids and she started to blow up like a balloon. She also began bleeding. She was bruised everywhere from the treatment and bleeding to the point that she bore no resemblance to her former self.

“Then one of her daughters said, ‘Oh, maybe we shouldn’t have done all that.’ Then the disagreements started among the family. What a mess. The mother ended up dying and looking nothing like herself. There was no advance directive. It would have made such a difference if she’d had one. We would have known what treatment the patient wanted. But more importantly, her children would have known what she wanted and they would not have felt so guilty about possibly not trying everything—which didn’t do any good. It was a sad situation.” (Canton, Ohio)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

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- clergy
- lawyer
- a nurse-advisor

## **The Nurse's Perspective**

### **K. Without Written Instructions, Decisions About Critical Care Remain Uncertain**

“A few years ago, I treated a patient who was from out of town, just vacationing here. He had a severe heart attack and was at the point where he was ready to code (his heart stops). I ushered the wife and grandchildren out of the room, and I heard them say, ‘He doesn’t want any life support.’

“He didn’t have an order or an advance directive telling us not to give any treatment, but the family said he didn’t want it. I called the physician and we weren’t sure what to do. It’s very hard to know without an advance directive to guide us. After lengthy discussions, we decided to take the patient off life support. But it could have gone the other way with a different physician. You can’t be sure without the document as a guide.” (Orlando, Florida)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

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- clergy
- lawyer
- a nurse-advisor

### **L. With No Previous Discussions, an Elderly Man Remains in a Vegetative State**

“I remember an elderly man in his late 80s who experienced short periods where his heart would stop (asystole) after heart surgery. He had internal bleeding. He looked like he would not improve, because his brain was not getting adequate oxygen due to his heart condition. His condition could deteriorate into a case of persistent vegetative state. Our staff was working with his family to explain his condition. All but one member of his family wanted everything done—a feeding tube, ventilator, pacemaker, the whole works. They weren’t ready to let him go and saw us as adversarial because we were presenting other options.

“Unfortunately, the patient had no advance directive. We finally took the case to the hospital ethics committee, and they recommended that we leave him on life support and periodically review his condition and discuss his status with the family. He’s still not aware of anything and on life support now—a year following his surgery. The family insisted on aggressive treatment early on, but they are in turmoil about what to do now. Just think how much easier everyone’s life would have been if the patient had expressed his own preferences in an advance directive.” (Ames, Iowa)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

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- a nurse-advisor

#### **M. Difficult Decisions, But No Regrets When the Healthcare Partner Is Prepared**

“My parents both had Medical Powers of Attorney. We had talked about their choices and each appointed me as healthcare partner, because I’m a nurse and they trusted me as their daughter and as a professional. When my father suffered a massive stroke last year, I knew he didn’t want anything done. Naturally, I was torn. I felt like his guard dog. The nurse in me said, ‘suction him (keep his lungs free of secretions), put him on the ventilator or he’ll get pneumonia.’ But the daughter and healthcare partner in me said, ‘so he’ll get pneumonia. Dad doesn’t want to be fed through a tube in his stomach. He doesn’t want a tube down his throat and a machine breathing for him.’

“It was hard but I told the doctors what dad wanted, and there was no aggressive treatment started. He died peacefully a few days later. That was a difficult decision, but I haven’t regretted it. I knew I was being true to what my dad wanted.” (Bakersfield, California)

If you were in this situation, what would you want done? As the patient? As family?

Check here if you want to discuss this story with:

- your family or friends
- your doctor or other medical caregiver
- clergy
- lawyer
- a nurse-advisor

## Appendix E - What It Means to Be a Healthcare Partner

Most people agree that maintaining control over one's healthcare is important, both for our own dignity and for the peace of mind of our families. However, critical care situations may arise in which a person is unable to make decisions for himself or herself. This inability may result from, for example, a severe stroke, an accident that causes a coma, or Alzheimer's disease. How will others know if the person would want tube feedings, ventilator support, or other medical support—and for how long and with what quality of life? Families can be torn apart in trying to decide whether to continue or to stop treatment.

Advance directives are documents that allow people to express their healthcare instructions in advance, protecting their choices and guiding physicians and family members. These documents are used only in situations in which people are incapacitated and cannot make healthcare decisions for themselves. Advance directives give legal protection to people's choices, allowing physicians to avoid heroic measures to sustain life when the quality of life would be unacceptable to the patient. Advance directives also inform family members about a person's healthcare preferences, easing the burden of uncertainties and guilt about making such decisions.

There are 2 types of advance directives: a Living Will and a Medical Power of Attorney. The Medical Power of Attorney is the more comprehensive and flexible document. It can be used in all medical situations in which a person cannot make decisions for himself or herself. Importantly, an individual who completes a Medical Power of Attorney names a healthcare partner to express his or her preferences, in addition to written instructions in the document. That means that if situations arise that are not specifically mentioned in the Medical Power of Attorney, the healthcare partner can step in and make those decisions in accordance with what he or she understands the patient's choices would be.

A person who completes a Medical Power of Attorney, the *signer* (called the "principal"), appoints a healthcare partner (called an "attorney-in-fact" or an "agent"). If you have been named as a healthcare partner, you are the appointed spokesperson and are invested with legal authority (conferred by State Law) to ensure that the signer's wishes and decisions about medical treatments are carried out. Without your participation, the physicians will not have guidance about the patient's preferences.

Your loved one or friend has chosen you as a healthcare partner because he or she trusts you to make difficult critical care decisions. Completing a Medical Power of Attorney draws you and the signer into a special relationship. Of course, the signer will consider his or her feelings about pain, life-support systems, and other medical issues. The signer may also want to weigh the effect of asking you to express his or her wishes, if the need ever arises. It helps both you and the signer to recognize the significance of the assignment you agree to fulfill. Therefore, it is important that the two of you have talked fully about the signer's preferences about medical treatments. It is also important that you talk with the signer about preferences concerning quality of life—the degree of physical and mental health that makes it worthwhile to try to prolong life.

## **How Can I Help the Person Who Has Chosen Me To Be a Healthcare Partner?**

Your role as healthcare partner has 3 parts:

1. To learn what medical treatments the signer would want or not want, and discuss the signer's values about quality of life
2. To help the signer complete and distribute the Medical Power of Attorney document
3. To express the signer's choices to physicians—in situations in which the signer has lost the ability to decide and communicate such choices

Let's go through the three parts of serving as a healthcare partner.

### **Part 1: Understand the Signer's Medical Preferences and Personal Values**

No one can predict all the different medical circumstances that could arise, but you can talk with the signer as he or she goes through the process of thinking about and completing a Medical Power of Attorney. You will learn about his or her feelings about the most common types of life support, and you will discover the quality of life that the signer feels would justify those means, or make such medical treatments unacceptable.

As a healthcare partner, you can help **now**, before a critical care situation arises, by doing the following:

- Urge the signer to arrange a scheduled time with you to discuss the advance directives.
- Encourage discussion about the signer's values.
- Try these sample questions to stimulate conversation:
  1. What quality of life is important for you to maintain?
  2. Have you read anything or seen anything on television and thought, "I don't want to be like that"?
  3. When would a situation be hopeless for you?
  4. Can we go over your values worksheets together?
  5. Are there any treatments you would want to try before refusing? Can we discuss some of the most common critical care treatments?
  6. Are there religious or spiritual issues I should know about?
- Discuss real-life medical cases with the signer to get a fuller understanding of the his or her preferences. Let the signer ask the question, "What if this happened to me?"
- Offer emotional support and understanding for these difficult decisions about medical care.
- Remind the signer that by making these decisions he or she is lightening the burden on you and on family and close friends. If a critical care situation arises, you will know what the signer wants and will be able to carry out his or her wishes.

### **Part 2: Complete and Distribute the Medical Power of Attorney Document**

- Help the signer complete the Medical Power of Attorney form. You do not need a lawyer for this process. A form that meets California legal requirements and easy-to-follow instructions is included.
- Discuss how to distribute the document to the appropriate people, including physicians, health insurance administrators, and yourself as healthcare partner. It is important to ensure that these people have access to the form.
- Put your own copy of the Medical Power of Attorney in an easily accessible place where you can find it quickly. You will need to have it if a critical care situation arises for the signer.

### **Part 3: Communicate the Signer's Preferences If a Critical Care Situation Arises**

Now that the signer has completed a Medical Power of Attorney naming you as the healthcare partner, you are able to carry out the signer's wishes if a critical care situation should arise. Remember, you are needed as the signer's spokesperson only when the signer has lost the ability to make decisions and communicate them. In such a situation, you can help the signer by taking the following actions:

- Alert the medical team about the signer's Medical Power of Attorney and hand physicians a copy of the document.
- Be forthright about your job as the signer's partner. Tell the medical team to give you all the information regarding the signer's condition and treatment options. This is your right and responsibility as the signer's legal spokesperson.
- Ask physicians and nurses to describe the options and choices for treatment.
- Instruct medical staff about which treatments the signer wants, does not want, or wants for a trial period.
- Communicate with the signer's other loved ones about the situation and treatment options. Share the signer's preferences—as expressed in the Medical Power of Attorney and to you as a healthcare provider.

## Are There Things I Can't Do As a Healthcare Partner?

Refer to the following chart to understand what decisions you can and cannot make legally in the State of California as the healthcare partner.

### Qualifications and Role of a Healthcare Partner

<b>Qualifications</b>	<b>Authority</b>	<b>Limitations</b>
<p>Must be over 18 years of age</p> <p>May not be the signer's primary physician, nurse, or other healthcare provider, unless this person is a relative of the signer by blood, marriage, or adoption.</p> <p>May not be an employee or operator of a nursing home, unless this person is a relative of the signer by blood, marriage, or adoption.</p>	<p>Must follow the signer's wishes regarding healthcare treatments as they appear on the signer's Medical Power of Attorney, or as the signer has specified in discussions.</p> <p>Unless otherwise specified in the signer's Medical Power of Attorney, may make decisions after the signer's death about autopsy disposition of the body, or organ donation.</p> <p>May consult with the signer's physician either in person or over the telephone in carrying out the signer's wishes.</p>	<p>May not make healthcare decisions for the signer that are contrary to the signer's instructions and/or desires as stated in the signer's Medical Power of Attorney or in discussions.</p> <p>May not make or consent to any decisions for the signer about commitment to a mental health facility, psychosurgery, sterilization, abortion, or ECT (electroconvulsive therapy).</p> <p>May not authorize any decision for the signer that are contrary to law.</p>

## **Appendix F - Talking With Physicians, Nurses, Lawyers, or Clergy About Advance Directives**

There are a number of people you may want to consult while you are completing your Living Will or Medical Power of Attorney. Professionals such as physicians, nurses, lawyers, or clergy members can help you through the process of completing an advance directive by providing support, answering your questions, and, most importantly, understanding the choices you have made.

### **Physicians**

#### **What Some Physicians Have to Say About Advance Directives**

*“I try to bring up the topic of advance directives during office visits. Most of my patients are older and don’t know what advance directives are, how easy they are to get, and what to put in them. I tell them that the most important thing for them to do is to talk to me and to their families about what kind of life they want to maintain. I try to give them examples—such as if they had cancer or Alzheimer’s disease, or if they were in a coma—and ask them to tell me what quality of life would be acceptable to them. It’s helpful to them and to me. We both gain peace of mind, knowing that if anything ever happened where they needed life support or any other critical care treatment, and they were unable to make decisions, I would know what they wanted. That is a big relief for everyone.”* (Richmond, Virginia)

*“I feel it is very important to discuss issues about life support. I always encourage patients to complete an advance directive. My dilemmas are when these topics are not discussed with me or with their families. I try to tell my patients that it’s useful for me to have their document but they should not keep their choices a secret. They need to tell everyone they care about so we are all prepared. And then their choices will be protected.”* (San Jose, California)

#### **Questions For Your Physician**

- What is the procedure for ensuring that my Living Will or Medical Power of Attorney is put in my permanent medical record? Where else should it be placed?
- What medical issues do you think are relevant to my Living Will or Medical Power of Attorney? Can we discuss any special considerations for my chronic condition?
- Can you explain exactly what happens when a person is on a ventilator?
- What about artificial feeding? How is that accomplished?
- Please explain about CPR and how successful it is under various circumstances. I’d like to learn more about different critical care treatments and how they work.
- How do you treat patients in pain?

- Does a patient experience pain once life support is withdrawn?
- How will you know if my situation is terminal?
- Do you know what quality of life I want to maintain if I'm ever in need of machines to prolong my life?
- How do you feel about my choices?
- Would you feel comfortable carrying out my wishes?
- Do physicians really honor advance directives?

### **What If You Don't Have a Primary Physician or You See Several Physicians as Part of an HMO?**

- Make an appointment with one of the physicians you see to begin discussing your choices.
- If you are not comfortable with this physician, ask for 2 referrals so you can find someone with whom you will feel comfortable.
- If you receive care from several different physicians and/or cannot find a physician within the HMO with whom you want to discuss your advance directives, discuss your choices with your family, nurses, clergy member, or anyone else with whom you feel comfortable. Then be sure to send copies of your Medical Power of Attorney or Living Will to your physician(s).
- Most HMOs have permanent medical charts for their patients. Each time you see a physician, even if you see many different physicians at different times, your chart is sent to him or her. Regardless of whether you establish a long-term relationship with a physician, call your HMO to make sure your advance directives are placed in your permanent medical chart.
- You should also give a copy of your advance directives to family or friends who are likely to go with you, if you are admitted to the intensive care unit or emergency department. Then they will be prepared to show your directives to the attending physicians.
- At all times, carry your wallet card that shows that you have a Living Will or Medical Power of Attorney.

## **Nurses**

### **What Some Nurses Have to Say About Advance Directives**

*“I used to work in home care for a local hospital. I would listen to the family’s concerns and think to myself, ‘Maybe this is the time to talk to them about their family member’s choices and an advance directive.’ I’ve never been shy about bringing up the topic. I like hearing from the family what the patient would have wanted. It’s my responsibility as a nurse.”*  
(McKeesport, Pennsylvania)

*As a critical care nurse I watch my patients’ quality of life change. I see the same situation played out over and over again: an incapacitated patient is put on some kind of life support and the family wonders what to do next. That’s when you have to step in and raise questions about the patient’s wishes. If nothing has been written down, family members often disagree, and the medical team must reconcile differing recollections and points of view. That can be very frustrating to everyone involved.”* (Chicago, Illinois)

### **Questions for Nurses**

- Does the patient experience pain when life support is withdrawn?
- What kind of comfort can nurses give me if I’m on life support? What comfort can they give me if life support is withdrawn?
- Who will talk to my family and my healthcare partner about my condition?
- Do physicians really honor advance directives?
- How do you feel about advance directives? Why?

## **Lawyers**

### **What Some Lawyers Have to Say About Advance Directives**

*“By allowing for advance directives, the 50 State legislatures have given people the important and valuable right to make their wishes about end-of-life care known. I always encourage my clients to complete advance directive documents. I tell them that the first step in the process is to discuss important issues like serious illness and death with family members or close friends. If people take their responsibility of self-determination seriously and complete advance directives, their choices can be protected.”* (Dubuque, Iowa)

*Often, when I work with clients on their financial will and estate planning , I suggest that they look into a Medical Power of Attorney as well. Advance healthcare planning is an important component of end-of-life planning and one that should not be overlooked. If my clients can plan the care they would want in advance, just as they do with their finances and property, then they can protect themselves from potential problems or family battles later.”*  
(Cleveland, Ohio)

### **Questions for Your Lawyer**

- What is the difference between a will and a Living Will (The Natural Death Act Declaration)?
- What is the difference between a Living Will (The Natural Death Act Declaration) and a Medical Power of Attorney (Durable Power of Attorney for Health Care Decisions)?
- What could be the impact of prolonged, intensive care on the size or value of my estate?
- If I sign a Medical Power of Attorney (Durable Power of Attorney for Health Care Decisions), what can my healthcare partner legally do?
- Is there anything my healthcare partner legally cannot do?
- What will be the legal impact of my Living Will (The Natural Death Act Declaration)? Will it be different if I complete a Medical Power of Attorney (Durable Power of Attorney for Health Care Decisions)?

Note: Talking to a lawyer is not necessary for these documents to be legally valid, but you may want to consult one if you have specific concerns.

## **Clergy**

### **What Some Clergy Members Have to Say About Advance Directives**

*“Christians should seriously consider completing advance directives because we have a responsibility to take care of our bodies. We are created in the image of God (Genesis 1:26-27) and we are endowed with free will and choice. It is important to exercise these God-given abilities in a responsible way, particularly when it comes to our health. When we complete advance directives, we decide for ourselves, diminishing or eliminating guilt or anxiety for family members at a time of serious illness.”* (Protestant Minister)

*“People come to me in the eleventh hour when there is little time for discussion and when decisions must be made. These kinds of decisions should not come at the last moment but rather when people are alive and clear-headed. I try to tell my congregants that it is when they are healthy that the family must open up to each other and have honest conversations. Tragically, without family discussions and advance directive documents, I see families fighting over which sibling loves papa best, and whether the child who would ‘turn off the switch’ is the callous one or whether the one who refuses to act is the compassionate one. These situations are surely the furthest from the will of the dying and not in the interest of the family. Now is the time to rehearse for that which is inevitable.”* (Jewish Rabbi)

*“As Catholics we believe that our life is a gift from God over which we have limited power. We have been called to protect and cherish human life and not destroy it. Saint Paul asks us,*

*‘Do you not know that you are the temple of god and that the spirit of god dwells in you?’  
Our response is our gift to God.*

*“By the same token, we are not morally bound to prolong our lives by means which will inflict serious financial, physical, or emotional hardships on ourselves or our loved ones. Therefore, there is no need to prolong the dying process by every means available to medical science. A person may appoint a family member or friend as attorney-in-fact in an advance directive to see to it that extraordinary means are not used.” (Catholic Priest)*

### **Questions for Your Clergy Member**

- What is our religion’s stance on the medical treatments I am addressing in my advance directives?
- What is your opinion about the choices and values I’m addressing in my advance directives?
- I’m a little unsure about some of the issues in advance directives. Do you have any advice for me?
- Does our religion have a position statement on advance directives?
- How would you feel if I indicated in my advance directives that I would like you to pray with me and my family?

## Appendix G - Common Medical Situations and How Advance Directives Work

### Choosing and Talking to Your Healthcare Partner

When you think about who you rely on for your healthcare, you probably think of physicians, nurses, and other healthcare professionals. But there's another member you should add to your medical team—your healthcare partner. Your healthcare partner could be the most important member of your team because he or she can make sure that the other members of your team follow your wishes if you are unable to make decisions for yourself.

To complete a Medical Power of Attorney, you need to name a healthcare partner. The chart below summarizes the qualifications, authority, and limitations of a healthcare partner, according to California law:

#### Qualifications and Role of a Healthcare Partner

Qualifications	Authority	Limitations
<p>Must be over 18 years of age</p> <p>May not be your primary physician, nurse or other healthcare provider, unless this person is related to you by blood, marriage, or adoption.</p> <p>May not be an employee or operator of a nursing home, unless this person is related to you by blood, marriage, or adoption.</p>	<p>Must follow your wishes regarding healthcare treatments as they appear on your Medical Power of Attorney, or as you have specified in discussions.</p> <p>Unless otherwise specified in your Medical Power of Attorney, may make decisions after your death about autopsy disposition of the body, or organ donation.</p> <p>May consult with the signer's physician either in person or over the telephone in carrying out your wishes.</p>	<p>May not make healthcare decisions for you that are contrary to your instructions and/or desires as stated in the signer's Medical Power of Attorney or in discussions.</p> <p>May not make or consent to any decisions for you about commitment to a mental health facility, psychosurgery, sterilization, abortion, or electroconvulsive therapy.</p> <p>May not authorize any decisions for you that are contrary to law.</p>

## Choosing Your Healthcare Partner

You might choose any of the following as a healthcare partner:

1. Your spouse or domestic partner
2. An adult child
3. A parent
4. A brother or sister
5. Another relative
6. A close friend
7. A physician or nurse (other than your own)
8. A clergy member

There are several issues that are important in selecting an individual, or a few individuals, with whom to talk about possibly serving as your healthcare partner. As you consider your options, think about the following:

- Who will feel comfortable talking to me now about my critical care choices or about death?
- Who has a strong enough personality to insist on what I have said I want in my advance directives?
- Who will not be disturbed by what I have said I want in my Medical Power of Attorney?
- Who understands and respects my values, even though we might feel differently about some things?
- Who will carry out my choices exactly as I have specified them?
- Who can best use his or her judgment for situations that I haven't thought about and still decide on what I would have wanted?

Use the space below to list your possible healthcare partners:

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If you come up with more than one name as a potential partner, choose one person to be your primary healthcare partner and up to 2 others to be your alternate healthcare partners. Having alternates is optional, but it is a good idea in case your primary partner is not available when needed.

**Note: If you still have not come up with a healthcare partner who is comfortable for you, think it over for a few days. At that point, if you still can't decide on a partner, you may want to complete a Living Will, which doesn't require a healthcare partner.**

## **When and How to Talk With Your Healthcare Partner**

When and how to talk to your partner—or with other loved ones—about your care choices will take some planning. You probably know the best time to bring up an important subject and the best setting. You may want to talk one-on-one with your partner at a prearranged time, or you may prefer a discussion with family members or friends during a holiday gathering or other occasion.

You may want to consider these additional points:

- ▶ Set an appointment or date for your discussion ahead of time. Find an occasion that is quiet and not restricted by time constraints or other demands. Let your healthcare partner know that you would like to talk in a relaxed environment, free of the distraction or stress of other activities.
- ▶ At the beginning of the conversation, reassure the other person(s) that your health has not changed. You are just as healthy as you've been and this conversation is not prompted by bad medical news from your doctor. The more positive you are, the more likely it is that your partner and/or family will understand that signing these documents is an opportunity for you to maintain control and independence about your future care.
- ▶ Consider having more than one meeting with your partner and/or family, and encourage them to have an ongoing dialogue with you. Remember, just as it took you time to reach your decisions, it may take time for your partner(s) to be comfortable with your ideas.
- ▶ Let your partner and/or family know that you have studied the issues carefully and that signing a Medical Power of Attorney is something you really want to do. Underscore the importance of these documents by explaining the consequences of not signing them.
- ▶ Ask your partner and others in your family to support your decisions by simply recognizing them. Even if others do not agree with your specific choices, let them know that you're comforted by the fact that you've made these decisions ahead of time so that others won't have to anguish over them.

## Opening Sentences

Sometimes, starting a conversation itself is the hardest part of the process. The following sentences may help you begin discussing care choices with your healthcare partner or with other family members or friends:

“I want to spend some time together so we can talk about something that is very important to me. But, before I do, I want you to know that my health hasn’t changed. I’m just as healthy as I’ve been. In fact, my current health is part of the reason I want to talk to you now about what would happen if I ever go really sick...”

“Let’s talk now about what would happen if I was ever so sick I couldn’t make choices and tell you what I wanted for my healthcare. With all the decisions that might need to be made, I worry that the family could be left with a terrible burden; the last thing I would ever want would be confusion or disagreements about what I would want...”

“I know it’s hard for all of us to talk about my death or the possibility of my ever getting so sick that I couldn’t make decisions for myself. But we need to talk now so I can know that you and my doctor will know my wishes and be able to follow them...”

“I’ve been learning about Living Wills and Medical Powers of Attorney for the last few weeks, and it’s really started me thinking. I had some vague ideas about these documents, but I really didn’t understand how they worked. And I certainly didn’t know how important they are in helping me maintain control of my care. It’s very comforting to know that they are available and recognized by the medical profession—and that they are legal documents, just like a regular will...”

“I have always known what I would want if I ever had to be on a machine to stay alive. But, I never knew there were legal documents available to ensure that my choices are actually followed by my doctor. That reassures me...”

“I recently completed a Medical Power of Attorney and chose (NAME) as my healthcare partner in case I can’t make decisions for myself because of an illness or accident. I chose (NAME) to relieve all of you of the anguish of making care decisions for me if I’m ever unable to speak for myself. (NAME) and I have spent time together talking and sharing my ideas and choices about the specific types of medical care I want and those that I don’t want. I’m confident that if (NAME) ever has to make a decision regarding my treatment, it will be my decision that is being expressed to my doctor...”

## **Suggested Questions for Talking to Your Healthcare Partner**

You may also want to use the questions below to help guide your conversations with your healthcare partner or with others:

1. Do you want to read my values worksheet? It will give you an idea about what I want for my future healthcare.
2. Do you understand what kinds of treatments I do and do not want?
3. Do you understand how I feel about life and my health, even if I haven't given you directions about specific treatments?
4. How do you feel about being my healthcare partner? What, if anything, concerns or bothers you about it?
5. If a time comes when you need to express my choices, how are you going to tell my family, my doctor, and my clergy member what I want?
6. How are we going to talk about my healthcare wishes as I get older, in case I change my mind?
7. Do you think you can tell the doctors what I want, even if you don't agree with my choices?
8. If there's disagreement between what I want and recommendations by family or doctors, do you feel comfortable standing up for my wishes?

**NOTE: You may want to review the following before meeting with your healthcare partner:**

- ▶ **Your Values Worksheets.**
- ▶ **Descriptions of medical treatments.**

After your conversations with your healthcare partner, both of you should plan to complete the worksheets on the following pages. You and your partner will be answering the same questions. The purpose of the exercise is to see how well you and your healthcare partner have communicated about your healthcare wishes. You want your healthcare partner to be able to put himself or herself in your shoes and make the same choices that you would in a difficult medical situation.

### **Questionnaire to Be Filled Out by You**

**Instructions: Imagine that you are the patient in each of the following cases. Think about what you would want and choose the option that comes closest to your preference. Your healthcare partner is reading the same cases and trying to answer the questions just as you would. When you have completed all the questions, compare answers with your healthcare partner. Discuss any differences in your answers so that you both clearly understand your wishes.**

1. Ms. H., a 79-year-old woman, has a history of chronic heart disease. Over the past 9 years, she has been hospitalized on 5 separate occasions for a series of small heart attacks. Recently, she was rushed to an intensive care unit with a massive heart attack. She is in critical condition, but has been stabilized with many medications and the use of a ventilator to help her breathe. Even though she is currently stable, her physicians are worried about her heart stopping because of the extensive damage she has suffered over the years. Physicians need to know whether to attempt cardiopulmonary resuscitation (CPR), if her heart fails. Ms. H. is not strong enough to make decisions or communicate with her medical team. If you were Ms. H., what would you want?
  - (a) Ask for CPR
  - (b) Refuse CPR
  - (c) Something else (explain)
  
2. Following a car accident, Ms. D. is rushed to the hospital with severe head and spine injuries and multiple internal injuries. In the emergency department, there is a flurry of activity to stabilize her. Medical staff perform life-saving surgery to stop her internal bleeding. The surgeons find that Ms. D.'s liver suffered major damage and she lost a lot of blood during the operation. She remains in a coma, completely unresponsive to voice or touch. Physicians have determined that she has permanent brain damage, although they do not know the extent. Her physical condition continues to worsen 4 weeks after the accident. Physicians ask whether they should keep Ms. D. on a ventilator and tube feeding, or withdraw this life support. If you were Ms. D., what would you want done?
  - (a) Stay on life-support machines indefinitely
  - (b) Withdraw life support
  - (c) Continue on life support for a short period, but withdraw if consciousness is not regained.
  - (d) Something else (explain):
  
3. Mr. B., an 84-year-old man, has advanced Alzheimer's disease and is unable to make any decisions for himself, including medical decisions. Mr. B. does not recognize his wife, who takes care of his needs for bathing and grooming. Mr. B. has had diabetes for many years and recently developed an infection in his right leg that does not respond to medication. His physicians explain to his wife that the leg has gangrene and must be removed below the knee. If Mr. B.'s leg is not amputated, he will die within a few weeks. If you were Mr. B., what would you want done?
  - (a) Have the surgery to amputate the leg
  - (b) Do not have the surgery to amputate the leg
  - (c) Something else (explain):

4. Mr. G. is elderly and has suffered 2 heart attacks. The most recent one left him quite frail. He is on a number of different medications to stabilize his condition. He is bedridden and uncommunicative most of the time and has few interests besides occasionally watching TV. His physician has recently diagnosed Mr. G. with colon cancer; aggressive treatment could extend Mr. G's life. His physician has tried to get Mr. G. to express an opinion about the medical options, but he is so disoriented and weak that he is unable to make a decision. If you were Mr. G., what would you want done?
  - (a) No treatment for cancer, let the disease take its course
  - (b) Treatment for cancer, that could include surgery, chemotherapy, and/or radiation
  - (c) Something else (explain):
  
5. Mrs. K. had a severe stroke, and fell and broke her hip. She is conscious but has extensive brain damage and is unable to speak or recognize any family members. The physicians are doubtful about her ability to regain speech or recognition, but they feel she could learn to walk again if she had surgery to repair her hip and rehabilitation. If you were Mrs. K., what would you want done?
  - (a) Go ahead with the hip surgery
  - (b) Tell the doctors not to do the hip surgery
  - (c) Something else (explain)

Now go back and compare your answers with those that your healthcare partner indicated. If you didn't always agree, be sure to discuss why you chose different answers. Your healthcare partner should thoroughly understand your choices and should also be willing to voice those choices even if he or she would not make the same decisions personally.

### **Questionnaire to Be Filled Out by Your Healthcare Partner**

**Instructions: Imagine that you are the person who is signing a Medical Power of Attorney document. This person (the signer) has asked you to be his or her healthcare partner. In each of the following cases, select the option that comes closest to the one that you feel the other person (the signer) would choose. That person is reading the same cases. When you have completed all the items, compare your answers. Discuss any differences in your answers so that you clearly understand the signer's wishes.**

**What you might want for yourself in each of these cases does not matter. What is important is that you know the wishes of the person (the signer) who is asking you to act as his or her healthcare partner.**

1. Ms. H., 79 years old, has a history of chronic heart disease. Over the past nine years, she has been hospitalized on five separate occasions for a series of small heart

attacks. Recently, she was rushed to an Intensive Care Unit (ICU) with a massive heart attack. She is in critical condition, but has been stabilized with many medications and the use of a ventilator to help her breathe. Even though she is currently stable, her physicians are worried about her heart stopping because of the extensive damage she has suffered over the years. Physicians need to know whether or not to attempt cardiopulmonary resuscitation (CPR), if her heart fails. Ms. H. is not strong enough to make decisions or communicate with her medical team. If you were Ms. H., what would you want?

- (a) Ask for cardiopulmonary resuscitation (CPR)
- (b) Refuse cardiopulmonary resuscitation (CPR)
- (c) Something else (explain)

2. Following a car accident, Ms. D. is rushed to the hospital with severe head and spine injuries and multiple internal injuries. In the emergency department, there is a flurry of activity to stabilize her. Medical staff perform life-saving surgery to stop her internal bleeding. The surgeons find that Ms. D.'s liver suffered major damage and she lost a lot of blood during the operation. She remains in a coma, completely unresponsive to voice or touch. Physicians have determined that she has permanent brain damage, although they do not know the extent. Her physical condition continues to worsen 4 weeks after the accident. Physicians ask whether they should keep Ms. D. on a ventilator and tube feeding, or withdraw this life-support. If you were Ms. D., what would you want done?

- a. Stay on life-support machines indefinitely
- b. Withdraw life support
- c. Continue on life support for a short period, but withdraw if consciousness is not regained.
- d. Something else (explain):

3. Mr. B., an 84-year-old man, has advanced Alzheimer's disease and is unable to make any decisions for himself, including medical decisions. Mr. B. does not recognize his wife, who takes care of his needs for bathing and grooming. Mr. B. has had diabetes for many years and recently developed an infection in his right leg that does not respond to medication. His physicians explain to his wife that the leg has gangrene and must be removed below the knee. If Mr. B.'s leg is not amputated, he will die within a few weeks. If you were Mr. B., what would you want done?

- a. Have the surgery to amputate the leg
- b. Do not have the surgery to amputate the leg
- c. Something else (explain):

4. Mr. G. is elderly and has suffered 2 heart attacks. The most recent one left him quite frail. He is on a number of different medications to stabilize his condition. He is bedridden and uncommunicative most of the time and has few interests besides occasionally watching TV. His physician has recently diagnosed Mr. G. with colon

cancer; aggressive treatment could extend Mr. G's life. His physician has tried to get Mr. G. to express an opinion about the medical options, but he is so disoriented and weak that he is unable to make a decision. If you were Mr. G., what would you want done?

- a. No treatment for cancer, let the disease take its course
  - b. Treatment for cancer, that could include surgery, chemotherapy, and/or radiation
  - c. Something else (explain):
5. Mrs. K. had a severe stroke, and fell and broke her hip. She is conscious but has extensive brain damage and is unable to speak or recognize any family members. The physicians are doubtful about her ability to regain speech or recognition, but they feel she could learn to walk again if she had surgery to repair her hip and rehabilitation. If you were Mrs. K., what would you want done?
- (d) Go ahead with the hip surgery
  - (e) Tell the doctors not to do the hip surgery
  - (f) Something else (explain)

Now go back and compare your answers with the signer. If you didn't always agree, be sure to discuss why your choices differed. As the healthcare partner, you should thoroughly understand the choices of the person completing the advance directive. You should also be willing to express those choices to a doctor, even if you don't personally have the same choices about your own care.

## **Appendix H - Resources**

### **Durable Power of Attorney for Health Care Kit. California Health Decisions.**

This brochure explains how to complete Durable Power of Attorney for Healthcare form and includes a wallet card indicating that the individual has completed a directive.

717-647-4920

### **Fidelity, Wisdom and Love: Patients & Proxies in Partnership. Division of Medical Ethics, Weill Medical College of Cornell University.**

This new resource includes a workbook that is a step-by-step guide on how to choose a proxy decision maker and an interactive section describing 4 health scenarios, as well as a 12-minute videotape.

[www.isp-1.hartforddirect.com/fwl](http://www.isp-1.hartforddirect.com/fwl)

### **Five Wishes**

A Living Will that includes personal, emotional, and spiritual wishes of seriously ill persons. Valid in 33 states and District of Columbia.

<http://www.agingwithdignity.org>

**Let Me Decide: The Health and Personal Care Directive That Speaks for You When You Can't. Dr. William Malloy and Virginal Mepham**

A book that addresses decision making and healthcare directives with easy-to-follow explanations of treatment and pull-out forms. Available at [www.amazon.com](http://www.amazon.com) and most book stores.

**My Voice—My Choice. Oakwood Healthcare System, Dearborn MI**

This advance directive is a values-based Power of Attorney for Healthcare with statement of treatment preferences (meets Living Will criteria). It contains activities and worksheets to guide a person through the process. Includes a wallet card indicating that the individual has completed a directive. Also has a self-instructional videotape available. Meets legal requirements for the state of Michigan and most states that recognize Power of Attorney for Healthcare and/or Living Will.

<http://www.oakwood.org>

**Caring Connections**

National Hospice and Palliative care Organization website which has resources on advanced directives and provides free state-specific advance directive documents and instructions.

<http://www.partnershipforcaring.org>

