

ADVANCE DIRECTIVES FOR A NATURAL END OF LIFE

James S. Cole, General Counsel, Missouri Right to Life

I. INTRODUCTION

This presentation will focus on how pro-life people may use the legal tool of a health-care power of attorney containing advance directives in order to maximize the chances that they can live and die by pro-life principles.

One misconception of the pro-life movement's aims should be corrected at the outset. Some think that pro-lifers want to keep patients alive using any and all means available for as long as medical technology allows. That is nonsense. No pro-life group takes that position. Pro-lifers are people, too. *Of course* there comes a time to end further efforts and let a person die.

What Missouri Right to Life finds troublesome are actions that push people into death before nature would otherwise have them die.

Until then a person, no matter how impaired, can live in dignity by bearing sorrow and suffering and by using the time of approaching death to make his or her peace with family and friends, and for religious people, with God.

II. PRINCIPLES

In the early 1990's, Missouri Right to Life adopted a formal policy on euthanasia issues that includes the following language:

Missouri Right to Life does not oppose allowing people to die when they are actually dying. We do, however, oppose causing the death of non-dying people. Furthermore, we do object when public policy defines nutrition and hydration as medical treatment which can be removed from persons who are not dying when that removal results in their death.

There is and should remain in the law a basic difference between allowing a dying patient to die and causing a patient to die by dehydration, starvation, lack of basic medical care or any positive act, including lethal injection or overdose.

For the most part, Missouri law expresses similar principles. In 1988, the Supreme Court of Missouri acknowledged the strong policy of the people of Missouri in favor of life in the Nancy Cruzan case. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. banc 1988).¹ In that case, the parents of Nancy Cruzan pressed for termination of her nutrition and hydration by naso-gastric tube because she was unresponsive some four years after a one-car accident. Although unresponsive, the evidence showed that she was not dying. In its ruling, the Missouri Supreme Court essentially held that when a patient is too impaired to make decisions, the patient may not be deprived of nutrition and hydration when such deprivation will lead to death, unless the patient, anticipating such a condition, directed that deprivation for himself or herself. *Cruzan*, 760 S.W.2d at 425-426. To protect against abuse, the patient's previous wishes are to be proved by "clear and convincing evidence," *id.*, a substantially higher burden of proof than the "preponderance of the evidence" standard that is usually used in civil (non-criminal) trials.

By recognizing that a person has a right to refuse invasive procedures on his or her own body, the Missouri Supreme Court acknowledged the concept of "patient autonomy."² *Cruzan*, 760 S.W.2d at 416-17. If the courts and the Legislature will continue to honor that legal principle fairly, then "patient autonomy" offers pro-life people the opportunity to protect themselves from those who seek to accelerate the death under "quality of life" or "futility" theories.

1. The Missouri Supreme Court's decision was upheld as in accord with the federal constitution in *Cruzan v. Mo. Dept. of Health*, 497 U.S. 261 (1990), but that was a narrow decision regarding the constitutionality of requiring "clear and convincing" proof that Nancy Cruzan actually desired to die rather than live. The United States Supreme Court had jurisdiction only over that narrow federal question. The substantive principles of law governing her case were state-law principles for the Missouri Supreme Court to decide.

2. Christians will recognize that Biblical teachings reject unlimited personal autonomy. "We do not live to ourselves, and we do not die to ourselves. If we live, we live to the Lord, and if we die, we die to the Lord; so then, whether we live or whether we die, we are the Lord's." Romans 14:7-9. However, the *Cruzan* decision allows for Christians to utilize *legal* autonomy so that they may "live to the Lord" and maximize their legal protection from unethical principles that others may want to impose in end-of-life situations.

Unfortunately, medical and societal attitudes are swinging around more and more to “quality of life” and “futility” paradigms. Quality of life is measured by one’s ability to enjoy experiences. The concept of an inherent dignity of a person, no matter how impaired, is rejected. If a patient is perceived as being unconscious or as suffering ongoing pain and discomfort, then quality of life is lacking. The related concept of “futility” assumes that when a treatment will not substantially cure a condition when life gets uncomfortable, the treatment is “futile.” More and more, the medical profession deems “futile” treatments to be wrong.³

Add to these considerations intense pressure from insurance companies and government to reduce medical costs, and the result is that avoiding “futile” treatment becomes a civic duty. Those family members who object to withholding treatments are seen as adversaries, perhaps religious zealots, to be won over or bullied into submission to the decision to end a patient’s life.

These philosophies dehumanize people who are coming to the end of their lives.

Dying and death have been depersonalised, dehumanised, medicalised, technologized, professionalised, institutionalised and certainly de-spiritualised. For the dying person this can result in what psychoanalyst and the late Dr Jay Katz, a Yale law professor, called “intense pre-mortem loneliness” to which asking for euthanasia can be a response. (M. Somerville, If you have the 'why' of living, you can find the 'how,' reviewing Harvey Max Chochinov, *Dignity Therapy*, available online at <https://www.mercatornet.com/features/view/if-you-have-the-why-of-living-you-can-find-the-how/19920>.)

3. For examples, see Nancy Valko, Futility Policies and the Duty to Die, *Voices*, vol. XVIII, no. 1 (Lent/Easter 2003), available online at <https://nancyvalkowwf.wordpress.com/2015/08/06/2003-voices-futility-policies-and-the-duty-to-die> (accessed May 20, 2017); Wesley J. Smith, Medical Futility on the March, *First Things online*, (April 23, 2006), available online at <https://www.firstthings.com/blogs/firstthoughts/2006/04/medical-futility-on-the-march> (accessed May 20, 2017); and on the other side, Peter A. Clark, S.J., Ph.D. and Catherine M. Mikus, Time for a Formalized Medical Futility Policy, *Health Progress* (July-August 2000), pp. 24-32, available online at <https://www.chausa.org/publications/health-progress/article/july-august-2000/time-for-a-formalized-medical-futility-policy> (accessed May 20, 2017). See generally, Wesley J. Smith, *Forced Exit: Euthanasia, Assisted Suicide and the New Duty to Die* (Times Books, 1997) and Wesley J. Smith, *Culture of Death: The Assault on Medical Ethics in America* (Encounter Books, 2000).

Father Tadeusz Pacholczyk, Ph.D., has also described a sense of worthlessness and concerns regarding pain, suffering, and isolation that the quality of life and futility paradigms engender. They often underlie requests for euthanasia and assisted suicide.

[E]uthanasia and assisted suicide are little more than ways of short-circuiting our human interrelatedness and interconnectedness, To end our lives well, on the other hand, is to be open to receiving loving assistance from others, and to accept the measure of suffering that may come our way, thereby humanizing, rather than demonizing, the frailties of sickness and aging. By reaching out to one another at the end of life, in our moments of fear, loneliness and suffering, we elevate this important journey that each of us must make, with death coming in God's providential time as a completion of His work in us. (Rev. Tadeusz Pacholczyk, Ph.D., Euthanasia--Broken Memories, Broken Bonds, available online at https://www.ncbcenter.org/files/3914/6984/9809/MSOB053_Euthanasia_-_Broken_Memories_Broken_Bonds.pdf.)

Nancy Valko, a pro-life nurse in St. Louis who has spoken and written on many life-related issues, has written from her personal experience:

Death is not something to get over with as soon as possible. As some people with terminal illness have told me, they hated being treated as if they were already dead when they were still alive. They wanted to hear jokes, be with family and friends, go to church, etc. And since hearing is thought to be the last sense to go, I interacted with my dying patients in comas just as I did with my conscious patients.

The process of coming to terms with death can be difficult at times but it also can be a meaningful time to review a life with all its joys and sorrows as well as a time for family and friends to show love, support and even healing. (Nancy Valko, Living with Living Wills, available online at <https://nancyvalko.com/2015/11/22/living-with-living-wills/>)

In the face of pressures to forgo treatments, those who agree with the pro-life policies of Missouri Right to Life will want to consider using the tools provided by the law in support of patient autonomy in order to maximize their decisions to receive appropriate care and treatment – again, not maximum care and treatment, but appropriate care and treatment – so that death is not intentionally accelerated but comes naturally. “Advance directives” can serve as evidence to

supply the necessary proof of what a now-incapacitated patient intended for treatment when he or she was still competent.

III. MISSOURI HEALTH-CARE DURABLE POWERS OF ATTORNEY WITH ADVANCEDIRECTIVES

A. GENERAL EXPLANATION

Individuals may exercise their autonomy over end-of-life decisions by appointing someone in a "durable power of attorney for health care" (DPAHC) to serve as their health-care agent to make decisions about their health care when they can no longer express them. In Missouri, a patient binds the health-care agent to a legal duty to follow those directions by putting advance directives into the DPAHC.⁴ See §§ 404.800-404.872, RSMo. The agent must agree to accept that responsibility, of course. § 404.705.4. While he or she serves as the agent, there is a legal obligation to follow the directives of the DPAHC to the best of his or her ability, disregarding any disadvantage to self that accrues. § 404.714.1. This duty is a fiduciary duty, the highest duty to another person known to our law. *Id.*

Missouri law directs that DPAHC's go into effect when the patient is "incapacitated and will continue to be incapacitated for the period of time during which treatment decisions will be required." § 404.825. A proper DPAHC with advance directives provides clear and convincing evidence of a patient's wishes when the patient cannot do so.

B. LIMITATIONS OF DPAHC's

It is important to know the limitations of the "advance directive" portions of many HDCPA forms. Here are the most important ones.

4. The author needs to make a disclaimer here. He is not acting as an attorney for any individual in this paper but only as a commentator offering thoughts to fellow pro-lifers. He does not intend to offer legal advice, and no one should take this article as such.

1. Forms That Include Checklists of Conditions to Forgo are Somewhat Misleading.

Many DPAHC forms present a checklist of types of treatment that one can choose not to have when the time comes. Below is a checklist that the Missouri Bar's DPAHC form contains.

If I am persistently unconscious or there is no reasonable expectation of my recovery from a seriously incapacitating or terminal illness or condition, I direct that all of the life-prolonging procedures that I have initialed below be withheld or withdrawn.

_____ artificially supplied nutrition and hydration (including tube feeding of food and water)
Initials

_____ surgery or other invasive procedures
Initials

_____ heart-lung resuscitation (CPR)
Initials

_____ antibiotics
Initials

_____ dialysis
Initials

_____ mechanical ventilator(respirator)
Initials

_____ chemotherapy
Initials

_____ radiation therapy
Initials

_____ other procedures specified by me (insert) _____
Initials

_____ all other "life-prolonging" medical or surgical procedures that are merely intended to keep me alive without reasonable hope of improving my condition or curing my illness or injury
Initials

However, if my physician believes that any life-prolonging procedure may lead to a recovery significant to me as communicated by me or my Agent to my physician, then I direct my physician to try the treatment for a reasonable period of time. If it does not cause my condition to improve, I direct the treatment to be withdrawn even if it shortens my life. I also direct that I be given medical treatment to relieve pain or to provide comfort, even if such treatment might shorten my life, suppress my appetite or my breathing, or be habit-forming.

Proposing such lists is somewhat misleading, because a person cannot forecast all the different illnesses, conditions, prognoses, and proposed treatments that can eventuate in the future. This means that "informed consent" that the law usually requires for making decisions on medical treatments is necessarily lacking when it comes to considering a laundry list of

treatments. *Cruzan*, 720 S.W.2d at 717. A person simply does not know what conditions will actually afflict her in the future, nor can anyone forecast the medical breakthroughs that create new treatment options for such conditions. That is why a good health-care agent is needed who will assess the situation and make decisions in the patient's stead in light of actual circumstances. The choice of the health-care agent is far more important, in this writer's opinion, than the particular treatments that one might forecast for the future.

2. Checklists Cannot Help But Be Overly-Broad

Because the impairments that can afflict people are quite numerous (for example, think of all the different cancers that people contract), and each can affect individuals in different ways, checklists cannot possibly capture with reasonable definiteness what specific treatments people will prefer in the future. For example, the Missouri Bar's list above includes "surgery or other invasive procedure." This item can cover anything from minor removals of cysts to complex heart surgery. Many people would say the minor surgeries would be fine no matter what, even if they are thought to be persistently unconscious. However, the item as listed suggests an all-or-nothing choice. Another all-too-loose item is "antibiotics," which could include ordinary flu medicines as well as massive doses of medicines for serious internal infections. All "antibiotics" covers a far broader range of medicines than most people probably intend.

Another item in the Missouri Bar's list above would deny permission for any treatment that keeps a person alive without reasonable hope of making the person better or curing the illness or injury. That catch-all is way too broad; its flexibility is suitable for cold-eyed insurance companies but not for giving careful attention to what may actually be unduly burdensome in treatment. It is fallacious as well, for it incorporates an assumption that unless a procedure can actually cure something, it may be dispensed with. People don't stop to think that such an

erroneous principle can be used to end their lives if they are persistently unconscious and also have chronic diseases that will never be "made better" or "cured," such as diabetes, asthma, and others that are not life-threatening in themselves. If their lives are not deemed to meet someone's quality of life standards, then treatment of the chronic conditions that they may have had long before they became unconscious could be withdrawn so that their lives may be ended. This is not apparent when one first reads the form.

The examples may be multiplied, but the truth is that such broad categories are unavoidable in such a laundry list of conditions. A more specific checklist of the treatments that may actually confront people will assuredly be lengthy, and unless several pages are devoted to it, such a list simply will be inadequate to the purpose.

3. People Change Their Minds

Giving directions far in advance does not take into account that people change their minds about many things as they pass through life. Studies indicate that many people alter their attitudes about end-of-life decisions.⁵ Not only does ordinary experience change one's views, it is also true that confronting a situation "for real" is different than thinking about it in the abstract. It is easy to say "I would not like to live like that," when one's mind visualizes good health compared to impaired health. It is much harder to say, "I would not like to live like that," when one has already entered into an impairment and the only alternative is a casket. Moreover, one can predict that few people will make changes to their DPAHC as their attitudes evolve; until a crisis is upon them, they may not even realize that they think differently than they used to.

5. Jerome Groopman, MD & Pamela Hartzband, MD, Why do patients often deviate from their advance directives? *Physician* (September 24, 2012), available online at <http://www.kevinmd.com/blog/2012/09/patients-deviate-advance-directives.html> (accessed May 22, 2017); Defective directives? Struggling with end-of-life care, *American Medical News* (January 9, 2009), available online at

4. Diagnoses of Mental States are Uncertain Judgment Calls

The diagnoses of “persistent unconsciousness,” “persistent vegetative state,” “no reasonable expectation of . . . recovery from a seriously incapacitating or terminal illness or condition,” and the like, lack definiteness. They are labels without much content, much as “neurasthenia” was a century ago. Furthermore, at best they are diagnostic judgment calls. Judgment calls are sometimes wrong. Experience has shown that some people who were thought to be in an irremediable “vegetative state” a quarter century ago may actually have been perfectly conscious but in a “locked in” state that prevented communication with the outside world.

The story of Martin Pistorius represents a rather dramatic example.⁶ At the age of 12, Martin was diagnosed with a form of meningitis, and within weeks he sank into a coma. His doctors told his parents that he was as good as a vegetable, and they should take him home and let him die. His parents refused. They spent long hours that turned into long years feeding him and providing for his needs. In four years, Rodney's brain recovered sufficiently so that he regained full consciousness. But he did not recover the ability to move, so it was another long eight years before he was able to let others know that he was awake and alert. After that realization struck home, he eventually learned, with assistance, how to communicate via a computer keyboard and how to operate a wheelchair. He is married and has authored a book about his experience, *Ghost Boy: My Escape From A Life Locked Inside My Own Body*.

Other stories of such survivors may be found online. Nancy Valko has written about several that she has observed personally. See her blog, available at www.nancyvalko.com.

6. Man Awakens After 12 Years in a 'Vegetative State,' Says 'I Was Aware of Everything,' *Life News*, Jan. 12, 2015, available online at <http://www.lifenews.com/2015/01/12/man-awakens-after-12-years-in-a-vegetative->

state-says-i-was-aware-of-everything/ (accessed May 21, 2017). His story was also carried by national news outlets such as National Public Radio. Locked-In Man, *Invisibilia*, January 15, 2015, transcript available online at <http://www.npr.org/2015/01/09/375928581/locked-man> (accessed May 21, 2017).

5. Quality of Life Concerns.

Most of the DPAHC forms that are presented by secular organizations assume a quality-of-life philosophy, in which the value of life as a gift is downplayed. This is illustrated by the thought, "I wouldn't want to live like *that*." However, if it is a choice of living like *that* and not living *at all*, people's perspectives often changes, as mentioned above. This philosophy leads to discrimination against impaired people, too.

IV. NOT REFUSING CARE DOES NOT OBLIGATE A PERSON
TO RECEIVE IT LATER PAST APPROPRIATE LIMITS

Some people may think that a failure to refuse artificially-supplied nutrition and hydration (ANH) on an DPAHC form means that ANH will never be terminated, no matter the condition they are in. That is not true. In Missouri, if a person does not authorize the withholding or withdrawal of ANH in an DPAHC, that is not the same as requiring that ANH be provided in all circumstances. Missouri law makes it explicit that artificially supplied nutrition and hydration is not required when, in the medical judgment of the attending physician, the patient cannot tolerate it. § 404.820.1. The same principle governs any treatment: if it does not provide a medical benefit, including stabilizing a patient's condition, then it is not good medical practice to provide it, and it may be terminated. § 404.822.

One important detail to keep in mind about nutrition and hydration: Missouri law does not allow withholding of food and water with the intent to cause death when the patient can ingest them without tubes, e.g. by spoon feeding. § 404.820.2.

V. QUALITY-OF-LIFE PHILOSOPHY IN MANY DPAHC FORMS

A. NON-RELIGIOUS CONSIDERATIONS

It is easy to find DPAHC forms offered by sources that are not pro-life, and they all seem to contain a checklist similar to the Missouri Bar's form. For the reasons given above, such forms

are inadequate for the task of assuring sound end-of-life treatment. None of them acknowledges the need, even when a patient is apparently impaired, for human contact and concern. As noted above, people who recover from seeming comas report that they could hear everything but could not communicate because no muscles would respond to their commands.

Rather, the majority of forms available online, including the form offered by The Missouri Bar, assume that no concerns are relevant other than quality-of-life feelings. Durable powers of attorney for health care that are prepared by many private attorneys seem to treat end-of-life concerns in the same way. They dehumanize the journey into death, not recognizing the deep human need for care and concern by other persons and the need to find meaning in one's life.

Father Pacholczyk has put it well:

When we suffer alongside our loved ones, we become aware of the abiding inner truth that a part of ourselves suffers and dies whenever another who is near to us suffers and dies. Our solidarity with them in their struggles and sorrows invariably leads us to a deeper communion with them in our shared humanity, and leads us to more fully participate in the mysterious and enduring graces of a good death. (Rev. Tadeusz Pacholczyk, *Facing Death in Solidarity and Hope*, available online at https://www.ncbcenter.org/files/7914/6982/1077/MSOB057_Facing_Death_in_Solidarity_and_Hope.pdf.)

B. RELIGIOUS CONSIDERATIONS

Religious believers may consider spiritual concerns to be paramount over bodily comfort or discomfort. One online DPAHC form from a secular organization, the “Five Wishes” form, mentions prayer and spirituality in passing but overwhelmingly focuses on quality of life considerations. In that form, the first two Wishes name a person to serve as health care agent and gives a checklist of treatments to accept or reject, while the last three address quality of life matters and how a person wants to be remembered after death. Among the many items in the

third and fourth wishes to cross out if not wanted are, “I wish to have warm baths often. I wish to be kept fresh and clean at all times,” “I wish to have my favorite music played when possible until the time of my death,” and “I wish to have pictures of my loved ones in my room, near my bed.” Who is going to cross such things out? They are not bad in themselves, but the number of them and the space devoted to them in the form reinforce a presumption, in this writer's opinion, that the purpose of end-of-life care is primarily to arrange one's quality of life before the final good-bye.

Only two of the eighteen items in the third and fourth Wishes relate to what religious believers may want (prayers at the bedside and by members of the faith community), and only one of the dozen items in the fifth mentions that death is not the end of the person. No mention is made of the possible importance of retaining the ability to engage in whatever level of prayer is possible for a person, in addition to having friends pray for the patient, reconciling in person (if possible) with other people in the patient's life, having pictures of holy people or saints nearby (in churches that venerate saints), or receiving Holy Communion and especially the last Sacraments (for members of churches that offer sacraments).

For believers, a time to prepare for the journey through death to eternal life is precious, whatever the quality of life might be during the preparation time. A good DPAHC will not presume that quality of life matters more than anything else at the end. Furthermore, there are good public policy reasons not to make quality of life concerns in such forms paramount over respect for human life itself, as was mentioned in Part II above. It bears repeating that "the state's interest is not in quality of life. . . . Were quality of life at issue, persons with all manner of handicaps might find the state seeking to terminate their lives. Instead, the state's interest is in life; that interest is unqualified." *Cruzan*, 760 S.W.2d at 420.

VI. PRO-LIFE DPAHC FORMS

A pro-life person may choose to use a form that better reflects his or her pro-life principles than the forms described above. Missouri Right to Life has posted a new DPAHC for downloading, with a separate Instructions document and related materials. The chief advantage of MRL's new form is that it stresses principles for one's health care agent to follow instead of describing categories of care to choose or reject from a checklist in advance. It also offers guidance to the health care agent on how to weigh benefits and burdens of treatment in light of these principles, in order to make sound decisions for the patient's welfare.

Forms from other pro-life organizations are available, too. The National Right to Life Committee sponsors a "Will to Live" on NRLC's web site, www.nrlc.com. It is a decent DPAHC that provides some pro-life extra's that one would not expect to find, such as declining any treatments that use tissue or products derived from the remains of an aborted unborn child and any organs or tissues from a person whose death was hastened by the removal of the organs. (Will to Live, p. 2.) Food and water are declared to be basic necessities, not treatments. (*Id.* p. 1.) If one insists on naming specific treatments to forgo despite this writer's reservations above, one may add one's own specific treatments to be forgone in the event that death is expected within a week, or another set of specific treatments to be forgone if death is expected within 90 days. (*Id.* p. 2.) There is finally a section offering a place for writing specific treatments to be accepted or forgone, and the conditions thereof, if one has directions that do not fit in the other sections of the document. (*Id.* p. 3.) NRLC cautions patients to be very sparing but also very precise in the use of these sections to indicate specific treatment decisions. (Will to Live, instructions, p. i.)

For Catholics, the Missouri Catholic Conference offers an DPAHC on its web site that

follows Catholic teaching on end-of-life issues, available at www.mocatholic.org/wp-content/uploads/2012/10/endoflifeguide.pdf. The form does not provide for dispensing with specific treatments, but sets forth principles on which treatment decisions ought to be made. It does not give detailed guidance on applying the principles; rather, it refers people to the National Catholic Bioethics Center hotline or to local priests.

The Patients Rights' Council, www.patientsrightscouncil.org, whose president, Rita Marker, has been indefatigable for over 30 years in the struggle against euthanasia in this country, offers a Protective Medical Decisions Document (PMDD) that would be fine to use, in this writer's opinion, except for one thing: key terms such as “appropriate” and “beneficial,” are defined as “the meanings . . . which I have discussed with my agent.” (The PMDD form is available for a small fee from the PRC at P. O. Box 760, Steubenville, OH 43952. PRC stays current on end-of-life issues, and its information is excellent.) The purpose of defining terms according to discussions with the health-care agent is described as ensuring that control over health-care decisions remain under the control of the health-care agent, not institutions. (PMDD Questions and Answers, discussion about whether to add special provisions, p. 2.). In this writer's opinion, using privately-shared meanings puts too much of a burden on the health-care agent to remember or keep good records about the content of conversations that may be many years in the past by the time the PMDD needs to be used. If a reader wants to use the form anyway, legal counsel may insert into it definitions of the key terms, using language drawn from PRC's pro-life information about DPAHC's.

In the event that a fill-in-the-blank form of DPAHC is not used and an attorney will draft one for a person, this writer recommends that the document begin with a statement of principles that the person wants to see applied to future health decisions. The wording may vary from

person to person, but the concepts set forth in *Cruzan* or in one of the pro-life forms mentioned above would provide a foundation for it. Religious believers may want to spend some time in discussions with their clergy (and for Catholics, also in studying the relevant official documents of the Catholic Church), to translate their religious beliefs into principles for their health-care agents to follow. A list of non-religious resources, together with religious resources (non-Catholic and Catholic), to consult on end-of-life issues is being posted on MRL's web site.

In documents drafted by their attorneys, pro-life people should not surrender their pro-life principles. Neither should religious believers surrender their beliefs about what God wants in the manner of leaving this life. A good lawyer will accommodate the pro-life and/or religious beliefs of clients and will not discourage them when he or she drafts an DPAHC document. Clients should not be shy to have such language added to their DPAHC's after they clarify for themselves the principles that should govern treatment decisions at the end of their lives.

VII. THE PROCESS FOR HEALTH-CARE AGENTS TO FOLLOW IN MAKING HEALTH CARE DECISIONS FOR THEIR PRINCIPALS

When one finds a good DPAHC form, one will also need to recruit a good person as a health-care agent. The health-care agent should be educated on how to carry out the responsibilities contained in the DPAHC. These steps are probably the most important part of the whole process of assuring one's wishes for end-of-life treatments are carried out.

Before anything else, when a patient is admitted to a health facility or is treated for the first time by a physician, the patient or the health care agent should tell the doctor or facility that the patient does not have a "living will" but has an advance directive. A copy should then and there be delivered to the facility or doctor with the request that it be included in the patient's medical record. If a health care provider or facility has been provided a copy of the DPAHC before treatment begins, it is not in a good position to refuse to follow it later. If the facility will

not honor it for reasons of conscience, then under § 404.830.3, it must allow the transfer of the patient to another facility that will honor it.

If the need arises for the health care agent to decide on whether to accept or forgo treatment, the agent should follow the decision-making process outlined below. As the agent does so, he or she must keep in mind that he or she is to focus solely on how the factors involved in the decision-making process affect the patient, not society at large, the family, himself or herself, or other persons than the patient. Burdens and benefits as they apply to third persons are nowhere mentioned in the law as part of the agent's responsibility to consider. The relevant Missouri statute provides, "An attorney in fact . . . shall exercise the powers conferred [in the durable power of attorney] according to the principal's instructions, in the principal's best interest, [and] in good faith, . . ." § 404.710.5 (emphasis supplied). A related provision declares, "A person who is appointed an attorney in fact under a power of attorney, . . . who undertakes to exercise the authority conferred in the power of attorney, has a fiduciary obligation to exercise the powers conferred in the best interests of the principal, . . ." § 404.714.1. The fiduciary obligations of the health care agent are not owed to anyone else except the patient.

The health care durable power of attorney statute was enacted in 1991, after the Missouri Supreme Court's decision in *Cruzan v. Harmon* in 1988. The statute accords with principles announced in the *Cruzan* decision, in which the Court indicated that the proper role of anyone clothed with authority to make the patient's decisions includes consideration of the benefits and burdens of treatment to the patient as a matter of medical effect, not quality of life criteria. The length of time a feeding tube had been used for Nancy Cruzan indicated it was not medically burdensome; it did not have adverse medical effects. As the Court concluded, "The issue is . . . whether feeding and providing liquid to Nancy is a burden to her. . . . [W]e do not believe the

care provided by artificial hydration and nutrition is oppressively burdensome to Nancy in this case.” *Id.*, 760 S.W.2d at 423-24. The Court also observed that the probability she would never recover was not a valid medical item to consider as a burden. Such an argument “is but a thinly veiled statement that her life in its present form is not worth living. Yet a diminished quality of life does not support a decision to cause death.” *Id.*, 760 S.W.2d at 422.

The Missouri statute reflects these principles of *Cruzan*; in no way does the statute abrogate them. The Durable Power of Attorney for Health Care statute indicates at least two limitations on a health care agent's authority to withdraw or withhold treatment when death would result. First, section 404.820.2 explicitly states that no health care agent, with the intent to cause death, may authorize the withdrawal of nutrition and hydration that the patient may ingest by natural means. Second, the agent is instructed under section 404.822 to consider the diagnosis and prognosis of the patient and the benefits and burdens of the proposed treatment before determining what to do. Such an analysis would not be necessary if the agent was free to ignore those factors in determining life or death for the patient.

When a health care agent needs to decide on a proposed treatment, then, the following procedure is recommended:

- (1) Obtain as much information from the medical professionals as is possible on the patient's current condition (diagnosis) and its probable progression (prognosis).
- (2) Obtain as much information as possible on what exactly the treatment is expected to do for the patient in medical terms: reduce fever and/or infection? heal skin lesions? kill cancer cells with chemicals and/or radiation?
- (3) Also obtain information on side effects, risks, and burdens: Will the treatment cause other problems (e.g., severe nausea, headaches, mental confusion)? Are there risks of

further injury from the treatment (e.g., gagging, infection from surgery, allergic reactions)? Is the treatment itself traumatic enough to incur the risk of heart failure or other causes of death (e.g., joint replacement surgery)?

- (4) Does the treatment itself accelerate death? It is unethical, and probably a criminal act, to decide to withhold or withdraw treatment with the direct intent to cause death. *See, e.g.,* §404.820.2. However, if pain control or other palliative measures have the secondary effect of reducing a patient's strength such that hastening death is an unavoidable consequence of treating the discomfort, criminal intent is lacking that justifies prosecution of a crime.
- (5) Armed with the information obtained as outlined above, and after reviewing the directives of the patient in the DPAHC, the agent will then make his or her judgment call about what the appropriate treatment decision should be. There is nothing wrong with the agent consulting others (clergy, medical professionals) for further advice.
- (6) One can foresee that a health-care agent may need to fight energetically for adherence to the pro-life directives of an DPAHC. Medical administrators may argue with the agent about “futility” and quality of life considerations that are not legitimate. The health care agent will be greatly assisted by having the patient's directives in writing, because then he or she can point to the document and say he or she is bound to follow the principles stated therein. Having the DPAHC to rely upon will make the agent less exposed to criticism by medical personnel and bolster his or her confidence that the right thing is being done.

CONCLUSION

Not only is thinking and planning about death emotionally uncomfortable, it gets

complicated when advance directives and health-care powers of attorney are to be considered. The writer hopes that this paper provides useful information that will help pro-life people to live, and then to die, with the true dignity of knowing that they have honored the sacredness of all human life, including their own.