HONORING LIFE NEAR THE END OF LIFE

In recent years, end-of-life care has become an important subject. The "medical aid in dying" movement is advancing a nation-wide attack on the lives of seriously ill people. Bills have been filed in the last two sessions of the Missouri General Assembly to approve it here.

Now, I'd rather think of a lot of things besides death, and I bet you would, too. We joke about it. Woody Allen once said, "It's not that I'm afraid to die. I just don't want to be there when it happens."

We laugh, but we should not avoid the subject of death. Rather, we should plan for it. Protecting life enhances our true dignity far better than hastening death.

Nancy Valko, a retired R.N. from St. Louis with long experience caring for people in the ICU, has some wise advice for us. "Death is not something to get over with as soon as possible. . . . The process of coming to terms with death can be difficult at times but it can also 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."

These are not small things.

How do we ensure that our pro-life principles will be carried out when we are unconscious or incapable of communication? How do we express in the present our wishes for treatment (or non-treatment) in the future when we don't know what our future impairments may be or what new medical advances will have been attained by then?

That is where a durable power of attorney for health care comes in. When properly completed under the law, it allows you to to give authentic guidance on how you would apply your pro-life principles to your actual future health situation.

This involves a two-stage process. First is the medical side. In a recent book, To Die Well, a veteran neurosurgeon, Stephen E. Doran, M.D., writes:

> Essential to medical decision-making at the end of life is an understanding of the medical conditions present: What is the diagnosis? What is the prognosis? What is the effectiveness of the proposed treatment? What are the side effects associated with the treatment? What are the alternative treatments? What would happen if treatment were withheld or withdrawn?

Once you or your agent knows the medical situation, the second stage of the decision process is to determine the moral situation. The question is not whether life itself is a good. Pro-lifers know that life in itself is always good. What actually must be answered is whether the proposed treatment does enough good in addressing your medical problems to outweigh any serious burdens, such as substantial pain, that the treatment may cause as well. The answers may depend on subjective factors, such as ability to endure a certain amount of pain. Armed with a pro-life durable power of attorney, your health care agent can give the best responses available he/she can to carry out your pro-life principles. Your agent will be there to make the final call representing you, not anyone else.

There are some misconceptions about durable powers of attorney and advance directives that I should clear up at this point.

Some people assume that a decision made early on to either accept or forgo treatment is binding forever. They think that accepting treatment early on binds a patient to accept it always. Not so. Conditions change, and the benefits and burdens of treatment change, too.

Some people use the concept of "quality of life" and "death with dignity" to justify non-treatment. They say that a patient should have a minimum "quality of life" in order to keep being treated. "Quality of life" and "death with dignity" are very subjective judgments that involves non-medical assumptions about the worth of life. No one improves his or her quality of life or dignity by being turned into a corpse.

Similarly, some people appeal to "futility" in weighing benefits and burdens. These concepts make life conditional on exterior conditions. Life is good no matter what. Medical decisions are not legitimately conditioned on whether *life* is "futile," but on whether a *proposed treatment or non-treatment* is futile because it won't improve or maintain a medical condition to a greater degree than the burdens that it may deepen or create. The two are very different things.

The manner of protecting oneself from the application of anti-life principles begins with "informed consent." "Informed consent" is required for any non-emergency medical procedure. Advance directives in durable powers of attorney allow you to state the principles that guide you in deciding whether you should give informed consent for medical procedures. That way, your agent can decide in your place.

You will want to consider very carefully whether it is wise to tie the hands of your health-care agent with

directives that are not carefully crafted. Many advance directive forms on the Internet contain columns of vague and over-broad categories of care that you may initial or check off if you do not want to receive them when you are incapacitated. Examples of such categories include "antibiotics," "surgery or other invasive procedures," "procedures that are merely intended to keep me alive without reasonable hope of improving my condition or curing my illness or injury."

Here are some serious problems that are presented by the checklist approach:

1. It is Almost Impossible to Give Informed Consent in Advance via a Checklist of Conditions. Informed consent requires knowledge of the medical problem that is actually faced (diagnosis), what the end result will be if treated or untreated (prognosis), what treatment is recommended, and what side effects or risks to health are presented by the recommended treatment. It is almost impossible to know any of these things ahead of time. You cannot know what conditions you will face in the future and what medical treatments are going to be available then. Your "consent" or "refusal" will not be *informed*.

2. Checklists Cannot Help But Be Overly-Broad. Because the impairments that can afflict people are quite numerous and each can affect individuals in different ways, the broad descriptions of treatments presented in checklists (e.g., “antibiotics” or "surgery") are almost always going to include treatments that most people will want as well as treatments they may not want. You will probably want to receive antibiotics if you catch the flu while you're not yet recovered from an otherwise worse condition. Same if you need surgery or other invasive treatment for an accidental broken bone if you're still recovering from a stroke. If you're "too old" for such treatment in some doctor's mind, then having a durable power of attorney and advance directive is a necessity.

3. People Change Their Minds. Giving directions about treatments 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 treatments over time. It is one thing to be 25 years old saying, "I don't want to live like that," and another thing to say it at 75 years old when actually faced with life-threatening conditions. People have a great drive to live when dying becomes a real possibility in their mind.

4. The Absence of a Cure Does Not Indicate That a Treatment is Futile or Should be Discontinued. Sometimes a cure is not feasible, but long-term stability and even some recovery short of an absolute "cure" is. To call treatment futile because no cure will result will consign, for example, many diabetics to a much shorter lifetime than they will enjoy from a regimen of insulin, even though the insulin is not a cure.

5. Diagnoses of Mental States are Uncertain and Often Erroneous Judgment Calls. The diagnoses of “persistent unconsciousness,” “persistent vegetative state,” and the like lack scientific precision and well-defined indications. At best they are diagnostic judgment calls--judgment calls that are often wrong, especially when made within a short time after an injury. Using technology that has been developed in the last twenty years, scientists have learned that approximately 40% of patients formerly deemed in a "vegetative state" in the 1980s and 1990s were actually conscious. It was communication, not consciousness, that was their problem. It is shocking how many people were forced to die by starvation or otherwise! New therapies have been developed to treat the problem of communication and the neurological damage of trauma to the head.

CONCLUSION

Advance Directives and Durable Powers of Attorney are no longer meant just to withhold or withdraw treatments that are recommended by doctors. They serve an important pro-life goal of providing legal protection to patients whose doctors want to discontinue necessary care even if that care is very reasonable and in accord with the patients' wishes. Pro-life persons should review such documents and sign a pro-life version of them in order to protect themselves from the pressures to end treatment that may well be applied to them in the future. MRL offers one such DPA here.