

DIFFICULT DECISIONS IN HEALTH CARE

One Woman's Journey

For nearly two years, a two-page document, "The Health Care Treatment Directive and the Durable Power of Attorney for Health Care Decisions" sat on the corner of my desk at work, significant because I keep my desk clear except for the project on which I am immediately working.

I struggled with the document for two reasons: first, certain phrases were too loose, too undefined, such as "significant recovery," "reasonable period of time," and "acceptable quality of life"; second, it seemed I needed medical facts before I could fill it out appropriately.

During this sojourn with my advance directive, I called friends at Midwest Bioethics Center several times and from these discussions realized that clarifying terms such as "acceptable quality of life" was something only I could do, that what was acceptable to me might not be acceptable to someone else, and vice versa. My friends at the Center were telling me that I had to start looking concretely at what may happen near the end of *my* life, and decide now how I wanted to live in that period. I found this a daunting task.

Wearing my attorney's hat, I sought clarification in court decisions, including the 1976 Karen Ann Quinlan case (Quinlan 1976), in which Mr. Quinlan, together with his family, sought to remove the respirator from his daughter who was in a chronic, persistent, vegetative condition. Karen Quinlan had no awareness of anything or anyone around her and could never be restored to cognitive or sapient life. I knew I did not want to live like that.

— by *Marcia K. Walsh* —

I read the Nancy Beth Cruzan case in which the Cruzan family was asking that artificially administered food and water be taken from Nancy Cruzan. Nancy was oblivious to her environment except for reflexive responses to sound and perhaps painful stimuli. Her highest cognitive brain function was exhibited by her grimacing perhaps in recognition of ordinarily painful stimuli. She could not swallow sufficiently to satisfy her needs. She was not dead and was not terminally ill, but she could live another thirty years in a persistent vegetative state. I did not want to be kept alive artificially, even if, like hers, my condition was not terminal.

In the Hilda Peter case (Peter 1987), I read about a sixty-five-year-old woman in a persistent vegetative state, without hope of recovery, but whose physical condition was good and who could survive for many years if tube feeding and hydration were continued. Prior to becoming incompetent, Ms. Peter had given her friend a written durable power of attorney in which she had expressed that she did not want to be kept alive by a feeding tube if she were in a persistent vegetative state. I, too, would see no point to living like that.

I read the Claire C. Conroy case (Conroy 1983), the case of an eighty-four-year-old woman in a nursing home, who had severe organic brain syndrome as well as other serious ailments. She could not swallow sufficient quantities of food and water to live without the help of a nasogastric tube. Severe contractions of her lower legs kept her in a semi-fetal position. She followed movements with her eyes, used her hands to scratch herself, was able to move her head, neck, arms, and hands voluntarily. She smiled when she was massaged or her hair was combed and moaned when she was fed. She had necrotic ulcers on her foot and diabetes. Ms. Conroy was severely demented, but she was not in a chronic vegetative

state, was not brain dead, was not comatose. Her medical conditions were not fatal, although one doctor thought that even with the feeding tube in place, she would probably die within one year. I decided that whether my doctors described me as terminal or not, vegetative or only with severe organic brain syndrome, I did not want to be kept alive artificially if I were in a medical state like Ms. Conroy's.

After reading these cases, I made a small chart. I listed the possibilities cited on the health treatment directive — "terminal condition"; "condition, disease, or injury without reasonable expectation that I will regain an acceptable quality of life"; and "substantial brain damage or brain disease which cannot be significantly reversed."

terminal	permanent unacceptable quality	vegetative; or substantial brain damage or disease
nonterminal	nonpermanent unacceptable quality	nonvegetative; nonsubstantial brain damage or disease

I tried to examine all possible combinations of these categories and concluded that if I am in a permanent, vegetative condition, whether terminal or non-terminal, I do not want to be kept alive by extraordinary medical means as I define them. If my condition is terminal as I define that word, then I do not want to be kept alive by extraordinary medical means as I define them. If my condition is permanent, and with severe brain damage or disease such that the quality of my life is unacceptable to me, whether vegetative or not, I do not want to be kept alive by extraordinary medical means as I define them.

Terminal for me is a short time to live, six months to one year. It is not an acceptable quality of life for me to be in a permanent vegetative state, in a permanently unconscious state in which purposeful interaction with the environment, awareness of pain or pleasure, and any cognitive ability are permanently absent, or in a state which, while not vegetative, is one of severe and permanent brain damage or disease.

Once I had answers to these questions, I turned to the Health Care Treatment Directive. Although I was able to decide without much hesitation that if I were terminal or permanently living in a quality of life unacceptable to me, then I wouldn't want surgery or CPR or antibiotics or dialysis or a respirator, I was less sure in deciding about artificial nutrition and hydration. Would it be painful? Drawn out?

So I went to the medical school library and read all the articles I could find about not having a feeding tube.² I concluded that, were I to be terminal or with no hope of regaining a quality of life acceptable to me, I did not want food or water through a feeding tube. I decided that a feeding tube prolongs the dying process, or prolongs a life of a quality unacceptable to me, and in doing so may cause more pain than I would have experienced without the tube. Some of the medical literature I read suggested that artificial nutrition and hydration interfere with the analgesics my body naturally would be producing in the process of shutting down. I do not know this positively, but I do know that I do not want artificial feeding and hydrating dragging out my dying or forcing me to live in a life of a quality unacceptable to me.

Although my route to filling out an advance directive form is not the route everyone need take, the process forced me to look at my life and values and determine what "Quality of Life" really meant to me. I was forced to let the thought of my own death become a little more real to me, and of course, I was forced to take charge of my end-of-life period now, in case I become incapacitated and unable to communicate these thoughts in the

future. I ended up feeling clearer, wiser, more self-determined, more responsible.

Endnotes

1. *Cruzan v. McCause*. 1988. 760 S.W. 2nd 408. Mo. banc. See also *Eicher v. Dillon*. 1091. 420 N.E. 2nd 64 N.Y.C.A. in which the Court said that an 83-year-old man who had previously orally indicated to his religious community that he did not want to be kept alive in the way Karen Ann Quinlan had been, and who now was himself permanently comatose, had expressed his wishes clearly enough such that the religious superior in the community could order the hospital to remove the respirator from him

2. These articles can be found in the reference list below.

References

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