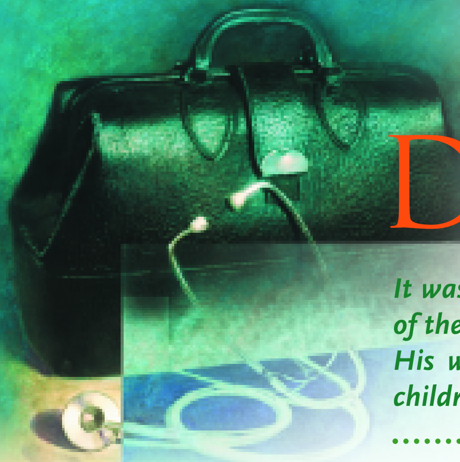


DOCTOR'S NOTES

It was another contentious situation. A family was disagreeing over the interpretation of the living will of a 85-year-old man who had a 10-year history of Alzheimer's disease. His wife wanted to discontinue care to respect her husband's wishes; however, his children had other plans.

Writing a living will: Is it still worthwhile?

By Dr. Michael Gordon

> "Opportunity may knock only once, but temptation leans on the doorbell."
> *Frank Noble*

The older man was now in a nursing home. He had a wife, who was his primary caregiver, and three children, two of whom lived in Toronto and one who was a physician living in Manitoba.

Years before, the patient had written a living will which stated that if he had a condition from which he would not recover he would not want to be kept alive by any "heroic" means and would like to "die in peace with dignity." So here he was, in such a state, which his wife believed was exactly what he had referred to in the document addressed to her. He was no longer able to eat without aspirating and had clearly refused a permanent feeding tube in his living will. It was evident to the wife that the end of his life was close. He had recently received treatment for an infection and was still receiving fluids subcutaneously.

The arguments begin

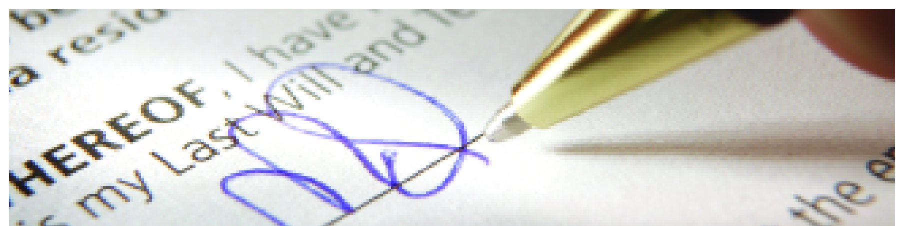
The wife's inclination was to discontinue the fluids and make him comfortable. The physician daughter, who arrived from Manitoba, disagreed vehemently. "How can you not give him fluids? It is cruel to let him die of thirst." The physician and nurses had explained that good mouth care would address issues of mouth dryness and discomfort, but the daughter would not hear of it. The wife wavered, not wanting to offend her daughter, who after all was a physician. One of the two siblings deferred to her as she always had throughout her life. The son, the youngest child, felt that fluids should be discontinued in respect to his father's expressed wishes. He strongly argued that his father's wishes as written in his living will must be adhered to with a goal of a death with "dignity and peace." Because of the family conflict, the ethics committee was invited to assist in resolving the situation.

How the issue was resolved is not what will be addressed in this article. It will be whether living wills are likely to help families when difficult end-of-life decisions have to be made.

Something is amiss

For many years, there was a strong movement supporting living wills. Many organizations, facilities and health care spokespeople promoted the living will as a useful method of assuring respect for the ethical principle of autonomy and the legal translation into consent to treatment. It was assumed that if people stated what they would want under a given set of circumstances, those making decisions on their behalf would know what to do, thereby eliminating decision-making uncertainty and family conflict. Health care professionals concurred with this belief and in essence supported the living will movement.

From this laudable concept, something serious has gone amiss. From various studies, there appears to be a profound reluctance by people to document their wishes for the future. And doctors are rarely involved in living will discussions. Also, legally the document is directed to the surrogate decision-maker, usually a family member, rather than health care providers who might be able to assist in interpreting the content.



During the famous Terri Schiavo case, many experts suggested that had she had a living will, all the challenges undertaken by her family, community, religious groups and governmental officials could have been avoided. After her case, there was a surge in requests for living wills from those organizations that provide living will "kits."

An unfulfilled promise

In the July 3, 2007, issue of the *Annals of Internal Medicine*, an article, written by Dr. Henry S. Perkins, appeared entitled "Controlling death: The false promise of advance directives" (i.e., living wills). His conclusion from 30 years' experience with living wills is that they have not fulfilled their initial promise, which was to remove the uncertainty from end-of-life decisions, avoid family conflicts and thus allow individuals to plan for their future.

Dr. Perkins postulates why living wills have not fulfilled their promise. The reasons include few people actually fill them out and physicians with whom patients and their families might wish to discuss the complex clinical events of end-of-life care are rarely meaningfully involved in such planning, and individuals often complete directives alone or with a family member and perhaps a lawyer, none of whom understands fully the clinical implications of a directive's wording. For example a crisis situation might result in the family requesting transfer to an emergency room when the person might indicate a preference by the person to die at home in "dignity and comfort."

Dr. Perkins also claims that the language used is often vague (e.g., "no heroics," "comfort care only," "dying with dignity"). Family members might interpret them differently as might various health care providers.

Preferences, wishes, values

I feel the uncertainty that often surrounds end-of-life care is best approached by open communication with those who will likely be involved in the final decision-making. Difficult though it may be, discussions should focus on preferences, wishes and values. Such knowledge and understanding can help guide loving family members to do the "right thing" even in complex, uncertain situations. Trying to capture it all in a written living will and then interpret it during an emotionally taxing situation is not likely to achieve a person's final wishes. ●

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