



A Living Will for Alzheimer's Disease

WRITTEN BY JAMES COMBS + PHOTO BY JAMES GIBSON

WHILE WORKING AS executive director of an Alzheimer's disease (AD) care facility, Henri Couture vividly remembers two women walking into his office with a special request. Their mother was in the seventh stage of AD, and the daughters did not want her life to be prolonged unnecessarily.

"They demanded that if she chose not to eat then we should not coerce her to eat," Henri said. "Their mom was a registered nurse for 35 years and knew about the various stages of this disease. She had verbally communicated to her daughters to allow her to die naturally and not intervene when she no longer had a good quality of life."

Having worked with AD victims for 25 years, Henri empathized with their situation. He had seen up close and personal the devastating effects the disease has in its latter stages. But their request presented him with a dilemma. At that time, no advanced medical directive existed for AD victims that would allow Henri to fulfill their wishes.

This frustrating situation weighed heavily on his mind. So he set out to become part of a much-needed solution. On Janu-

ary 9, Henri awoke at 3 a.m. and began writing a living will specifically for people afflicted with AD. Thoughts and ideas raced through his head, and within five hours he had written the main sections for *The Alzheimer's Disease Living Will*. In ensuing weeks he refined it after receiving suggestions from numerous doctors and attorneys.

The will was copyrighted in March.

EXISTING AFTER VIRTUAL DEATH

Henri's primary decision in writing the will was to address an important issue specific to all Alzheimer's victims—quality of life versus prolonging life. Throughout his career, he saw many spouses visit his health-care facility and cry at the sight of their loved one, often saying 'My husband/wife does not deserve to live like this.'

In the latter stages of the disease, many victims live for an extended period of time even when the potential for quality of life no longer exists. Common interventions such as dialysis, heart medication, nebulizers and diabetes treatment may unnecessarily prolong life.

"During all the years I've worked with Alzheimer's victims, I've seen

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people in the sixth or seventh stage who can no longer bathe, dress themselves or control bowel or bladder movements," Henri said. "They no longer recognize food as a basic necessity for life, which is something we learn as infants. So when you no longer recognize food and its use for everyday living you have degenerated to the point that you mechanically exist."

Thus, they are unable to make decisions. And without an advanced health care directive, victims' fate may be left in the hands of disagreeing family members or at the mercy of doctors who do everything necessary to prolong life—regardless of what the victim would want and whether the treatment adds quality of life.

"Medical professionals and long-term care providers automatically assume the responsibility of prolonging life. I'm not saying that's unethical because our medical system is based on prolonging life. But with an advanced directive you can communicate your health care preferences when you no longer have the capacity to make your own decisions. So it becomes a powerful communication tool."

A 'WILL' TO DIE PEACEFULLY

The will contains no language stating that a victim's life will automatically be shortened. However, it does address one's wishes concerning both medical treatments and non-medical interventions. Without an advanced directive, doctors and caregivers continually make decisions for the victims.

"As a society it's time we start accepting death," Henri said. "The bottom line is that Alzheimer's patients are not going to get better. They become incapacitated. Many of them fall and suffer head injuries and hip fractures. Violent behavior, inappropriate disrobing and significant incontinence issues are common. Seeing these behaviors is heart wrenching. You truly understand that there is no value in prolonging life."

John Feldman, an attorney with Cauthen and Feldman P.A. in Tavares, said that the living will addresses common concerns expressed by both victims and family members.

"Victims do not want intervention to extend their lives once they are in the latter stages of Alzheimer's disease. And family members fret over having to make both medical and non-medical decisions for loved ones and oftentimes second guess themselves. This living will helps alleviate apprehension for both parties. The best thing is that the wishes of the victim will be fulfilled. Out of the thousands of people I've represented over the years, very few told me they didn't want a living will. Most people do not wish to live life when they no longer experience any quality of life."

The Alzheimer's Disease Living Will can be an addendum to an existing living will, or it can stand on its own. A traditional Durable Power of Attorney and living will is still needed for instructions regarding property, bank accounts and other non-Alzheimer's disease healthcare decisions.

Henri welcomes the opportunity to speak to organizations, companies and other entities who would like to learn more about the Alzheimer's Disease Living Will. You can also visit his website at alzheimerslivingwill.com or email him at hcouture@comcast.net. ■

FREQUENTLY ASKED QUESTIONS

Q: Will this Alzheimer's Disease Living Will replace my existing will?

A: No. Either your standard living will or this Alzheimer's Disease Living Will should be considered to stand on its own merit. This Alzheimer's Disease Living Will can be an additional advance directive to complement your existing living will.

Q: I have already been diagnosed with Alzheimer's Disease. Can I still sign this document?

A: You may want to discuss this with your doctor or attorney. However, the fact that you have been diagnosed does not remove your competence. Legal decisions can be made in the early stages of this disease.

Q: Can I copy this document for my friends?

A: No. This document includes copyright material from American Psychiatric Publishing, Inc. and this Alzheimer's Disease Living Will is also a copyright document.

Q: What should I do with this Alzheimer's Disease Living Will after I have legally signed it?

A: Communicate. You should provide a copy to your primary care physician. Additionally, you should notify and provide a copy to any other person(s) that will be involved in your health care decisions.

Q: I don't have a standard living will. Should I get one?

A: Yes. This living will is specific to Alzheimer's Disease. It is strongly recommended that you have a standard living will relating to non-Alzheimer's end-of-life healthcare.

Source: alzheimerslivingwill.com