

Using Advance Medical Directives to Ensure Your End of Life Treatment Choices are Honored

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Judith Schwarz is a nationally and internationally known writer and speaker on advance directives and other end-of-life issues. These topics have not been previously addressed in the Torch, and we are fortunate to have such an experienced voice open the discussion.

I didn't know much about Waldenstrom's macroglobulinemia (WM) before reading the April 2017 issue of the *Torch* – despite having a dear friend who was diagnosed with WM more than 12 years ago. She doesn't speak much about her disease, and, until recently, I didn't know enough about it to ask questions. What we do talk about, however, are her end of life concerns, wishes, and values. We are old friends after all – plus, this is my field of expertise. I am the Clinical Director of a not-for-profit end of life advocacy and support organization. I spend my professional time talking to folks diagnosed with incurable and progressive or terminal illnesses and their families about their end of life concerns, fears, and values.

I would like to start this article about advance directives and planning for life's end by summarizing my “take away” from the wealth of information provided in the Spring *Torch* issue. All the articles in the *Torch* were exceptionally clear and informative and helped me to understand what WM is (Dr. Morie Gertz), how people live with it (Alice Riginos), and how people share and learn from each other in support groups and via the Internet (support group news from Belgium). From my perspective, in Dr. Gertz's article it was the age of onset (WM is typically diagnosed at 60 or 70), the long “survival path,” and the likelihood that those with WM will die of some other disease or cause that focused my attention and to which I will subsequently return. I also appreciated his succinct definition: he called it a rare form of malignant lymphoma that is currently incurable but very treatable.

What I was most struck by in Alice Riginos' description of her almost 14 year journey with this disease was her statement that she had lived a “normal” life that was periodically put on hold for a round of treatment. In her case she has had 5 such life-interrupting experiences. She added that, in each case, “we are impatient for treatment to be over and to return to our own daily rhythms of life.” She also added the cautionary note that “no promises can be made regarding the outcome of treatment.”

And finally, the report from the West Flanders region of Belgium which described

a symposium during the Spring of 2016 that was followed by a number of regional events around the country in the Fall. At the symposium, they addressed what was called a “challenging, yet rather obvious, topic: With the End of Life in Sight.” Apparently, even in Belgium where euthanasia is openly discussed and practiced, it was somewhat unusual for a group of people with WM to publicly discuss their wishes and concerns about the circumstances of dying. One thing most of the Belgian attendees agreed upon was their desire to die at home. Subsequent meetings addressed the benefits of palliative care and the importance of respect for the patient’s right to be self-determining.

We know that most Americans strongly agree with the desire to die at home, surrounded by familiar objects and loved ones. But what I also know is that realizing such a desire takes “advance” planning and discussions with family members, caregivers, and clinicians. Only about 30 % of adult Americans have completed some form of advance medical directive. That means that family members or other loved ones of the remaining 70% may be required to make very difficult treatment choices - often under the most emotionally difficult circumstances - in the waiting room outside a hospital Intensive Care Unit when doctors ask what they should do!

Returning to what I found particularly relevant about those living with WM, the following facts stand out: WM patients tend to be elderly when first diagnosed and often spend the next decade or two fighting the disease’s symptoms, which tend to ebb and wane for unknown reasons. And patients will likely die of some other disease or cause. If you spend much time and energy fighting against death by a known but wily disease, you may find it particularly difficult to consider death as anything but an enemy to be fought fiercely - forever. The problem with that approach is that death can become a taboo subject – maybe ‘bad karma’ to even mention such a topic – and certainly not anything one would want to plan for. At the risk of sounding banal, it must be noted that death is not optional for any of us, and some deaths are definitely worse than others.

What I propose to do next is provide a brief over-view of the various documents most often used to effectively plan for how one wishes to be treated when one is unable to participate in treatment decisions. I will then summarize some of the important life-prolonging interventions that folks living with an incurable and progressive disease ought to consider when completing an advance directive.

“Advance directive” is an umbrella term for the two kinds of documents frequently used to indicate your wishes about treatment when you cannot participate in health care discussions due to a temporary or permanent loss of decision-making

capacity. One is an *appointment* directive – called a durable power for health care (DPAHC) or a health care proxy, and the other is a *written* directive – commonly known as a living will. An appointment directive is the preferred form and will be discussed first. Each state passes health care legislation describing the advance directive “honored” in that state. The forms can be obtained online by going to the state’s department of health and seeking information about advance directive forms. Forms can also be obtained in physicians’ offices or in hospitals and community health clinics. Although most states now tend to honor each other’s documents, you ought to have a state-recognized document for each state in which you spend substantial time each year. It is also important to note that the instructions in an advance directive – written or appointment – become “operational” only after the person who completed the document loses decision-making capacity. Until that time, it is the patient who decides what will be done to himself or herself.

A DPAHC or health care proxy is the preferred document because the appointed person can interact with members of the health care team and share the patient’s long-held values and preferences re end of life conditions and treatments. However it must be said that this document is only as good as the discussion that has preceded the completion of the form. Your appointed agent must know what you fear and wish for – along with medical conditions that you would find intolerable. These can be difficult conversations to have – at least in the beginning – but having honest, complete (and regular) conversations about your wishes is a *gift* you give to your loved ones. Doing so will prevent the horrible situation where loved ones do not know what choice you would want when the physicians turn to them for guidance.

The role of the agent is to speak for the patient who is now silent. In other words, to bring her or his voice into the treatment discussion with clinicians and to choose as that person would if they could participate in the discussion. It can be hard to decide to stop a life-prolonging intervention – *even when* you know that the now-silent person would not want it continued. Yet it can be emotionally devastating to consider such a decision when you do not know what the incapacitated person would want. It can also be very difficult to make treatment decisions under conditions of clinical uncertainty. Physicians often are unable to be precise in either their prognostications or their predictions about whether a particular intervention will “succeed.” Often a good approach is to agree to a trial of treatment – say two weeks – and then have another meeting to determine whether the treatment worked or should be stopped. What most people fear is remaining unconscious, unresponsive, and attached to life-prolonging machinery indefinitely,

without hope of improvement or recovery. A trial of treatment, for example 2 weeks of aggressive pulmonary care, can be followed by a clinical assessment of the efficacy of such treatment and then an “informed” decision about whether or not to withdraw the ventilator.

When having a discussion with an agent about treatment values, you should also include your wishes about frequently used life-sustaining interventions such as feeding tubes, cardiac pace makers, and mechanical ventilation. Some people who feel strongly about not wanting their dying to be prolonged might also instruct their health care agent to withhold “simple” treatments like antibiotics or blood transfusions while requesting maximum pain relief even if doing so might secondarily hasten dying.

Living wills are documents completed by a person who stipulates in writing the end of life treatments they wish to receive or avoid under particular medical circumstances. One of the challenges of these documents is to include all interventions and conditions about which the person cares deeply. Plus, there are certain medical circumstances that must occur before such documents are honored; each state includes any pre-existing conditions in their health care legislation. Some of those circumstances include a diagnosis of terminal illness, or permanent unconsciousness.

All too often written directives become lost, or are misplaced in an emergency, or ignored by clinicians who find the directions clinically inappropriate for the circumstances or condition with which the patient presents in an emergency room. A completed living will may be better than nothing as a general indication of end of life values. It can also be the case that some individuals may have out-lived their family members and friends, or don't feel they have anyone they can ask or trust to be their health care agent. Yet, they are not the preferred mechanism for insuring that your treatment choices will be honored when capacity is lost.

Two final sorts of directives must be quickly mentioned. For hospitalized patients, a Do Not Resuscitate Order (DNR) is increasingly chosen by elderly people who want to avoid the trauma of attempts at cardio-pulmonary resuscitation along with intubation and mechanical ventilation in the event they stop breathing or have a cardiac arrhythmia. What we know is that such resuscitation attempts rarely are successful, particularly in frail, elderly people. By “successful” I mean that the person rarely attains their pre-arrest cognitive status and often is left with brain damage *and* broken ribs following the attempt.

Once the person leaves the hospital they must get their physician to write an “Out

of Hospital Do Not Resuscitate Order” as that is the only document that Emergency Medical Technicians (EMTs) recognize when called to a home by a 911 call. EMTs are otherwise required by law to attempt resuscitation, regardless of what the family may request to the contrary. This medical order should be taped on the outside of the refrigerator.

The second document that is being increasingly recommended for use by those who have become frail, elderly and ill and are getting “close” to death – two years or so as a physician guesstimate - is a Medical Orders for Life Sustaining Treatment (MOLST), sometimes called a POST (Physicians Orders for Life Sustaining Treatment). These documents combine all of the other advance instructions in a DPAHC, a living will, and an Out of hospital DNR, along with additional wishes to not be transported to the hospital and to request maximum pain relief. These patient wishes are then converted to a physician’s medical orders. Doing so increases the likelihood they will be honored by other physicians and clinicians. These medical orders are often printed on brightly colored paper so they are less likely to be misplaced.

Like all such important documents, patients at home are instructed to make many copies, give them to their health care agent, family members, and physicians, *and* tape the MOLST form to the outside of the refrigerator. That is where EMTs are trained to look for them.

In conclusion, I encourage all of you who have taken the time to read through to the end of this article to take the *next* step– take steps to begin the process of talking to your loved ones about your end of life choices, fears, goals, and concerns. Then document those wishes in your state’s recognized advance directive. These documents are not about giving up but affirmatively taking steps to be sure that your choices are the ones that will drive future decisions in the event that you cannot participate directly in treatment decisions. Your loved ones will be grateful that you cared so much for their feelings that you relieved them of the awful burden of not knowing what to do when treatment decisions must be made.