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UNADORNED: MY TESTAMENT

by Steven Miles, MD

Many of you in the Bioethics community know me as a physician-ethicist. Early in my career, in the 1980s, I was prominent in the ethics and practice of end-of-life care. I published extensively on that topic before moving on to other topics. As an internist and geriatrician, I had decades of experience in hospitals, clinics, nursing homes and hospices. As a physician who disproportionately worked with dying persons, I have a greater than normal skepticism of the utility of aggressive technology and heightened insights into the nature of institutionalized life.

At sixty-six years of age, I am not currently ill excepting for incrementally increasing mild chronic diseases—harbingers of the approaching cold front. This past year, I lost close friends and family. Some planned well, others not so well. It has been trying. My wife of thirty-four years and my children have asked about how to update advance directive in light of these difficult experiences with a medical system that still clumsily accommodates human mortality. One of my kids was surprised to learn that I had an advance directive and kept it in an unlocked fireproof, waterproof box in our home. We had talked about it several times before.

The experiences of the past year have made me realize the implications of the likelihood that I am in my last decade of being able to teach through written and spoken word. For me, this realization has made me more forthright, and less inclined to the dilly-dally polite talk of those who believe that they can (or will) speak frankly later.

Being in medical ethics and involved in the care of many dying persons, I have read a large number of advance directives. Most of them are bad. Some focus on treatments without discussing outcomes. Some focus on values without discussing treatments. Some offer a dismal set of scenarios so that people can check off little boxes as if servicing different kinds of airplanes. Most are interspersed with oases of three or four blank lines for the author to insert narratives. Ernest lawyers who know nothing of life or death or medical care counsel patients to fill them in. Doctors, like impatient waiters, solicit choices from a menu of “do-nots” so that they can type in orders. Nurses distribute and collect paperwork but may only describe the medical techniques stripped of the results or probabilities of restoring health. The process and the documents are by and large, sterile, superficial, and soulless. Dying, however, is none of these.

Anyway, with my family at my back, I decided to write another “Living Will.” No, not new-age euphemisms like Living Will, Five Wishes, Values History or LifeCare. Not anagrams: RC, POLST. Not the Medical

Directive. How dare ethicists charge a © ounce of flesh so that a person may buy a form to tell us how he or she would die?

Testament is a better term; it has gravitas. It evokes testifying with the solemnity of an oath rather than the weightlessness of preference. Testimony—the truth, the whole truth and nothing but the truth. Here is the draft. It is free.

My Testament

I have completed nearly three score and ten years and enjoyed health, family, career, travel and accomplishments. My wonderful profession gave me an extraordinary vantage point from which to view medical and long term care institutions for persons in the last decades of life. I believe that the health resources used on my behalf are most wisely used to alleviate pain and disability rather than employed to prolong my life.

There are many treatments that are commonly used on persons after sixty years of age that I do not want to receive. I make this directive to express my preferences and to relieve my family of the burden of reflecting on these complex decisions. Joline, my wife, is my health care agent for these decisions but this document is to guide her in exercising that power on my behalf. I do not wish to receive cardiopulmonary resuscitation, cardiac massage, countershock for ventricular fibrillation or agonal rhythms, pressors to raise my blood pressure or intracardiac injections of medications under any circumstances. I decline endotracheal intubation other than for elective medical procedures to which I have consented. In the event that an emergency medical provider inserts an endotracheal tube into me, I ask that it be removed within seventy-two hours. I entirely refuse enteral alimentation by nasogastric or percutaneous tubes or intravenous hyperalimentation. I refuse dialysis and bone marrow, kidney and liver transplants. With regard to other major interventions such as chemotherapy for cancer or surgery, I decline treatments of marginal utility: experience (not speculation) must have shown that an offered intervention has a high probability of resulting in at least three years of low disability life. I am entirely comfortable with early enrollment in hospice or palliative care programs as well as with palliative or terminal sedation.

I strongly prefer to live my remaining life at home but I realize that this may not be possible because of limited caregiving resources in my home or because of the need for those who love me to live their own lives in the event of my protracted disability. Should I require long-term care in an assisted living or skilled nursing facility, all of the preferences in the first paragraph apply. In addition under such circumstances, I do not want life-prolonging treatments such as antibiotics, antiarrhythmics, or laboratory tests for the purpose of guiding life-prolonging interventions. I consent to measures, such as vaccinations or serology testing, which are essential to protect the health of others that I come in contact within the

institution. I refuse all hospitalization except for the purpose of treating orthopedic emergencies, such as acute fractures or pain that cannot be managed in the institution.

Given that the principle of respect for my personal autonomy is robust enough to empower me to refuse various life-prolonging therapies, respect for my values rightfully extends to allowing me to insist that my preferences for living conditions also be honored. I want decent art rather than institutional décor on the walls. I want fresh flowers in my room. I want equipment to play talking books. My bed must be large enough to accommodate another person who wants to lay or cuddle with me. I do not want such encounters governed by medical orders, monitored according to nursing plans or channeled by pre-appointment to some special room for ‘conjugal visiting.’ Hope, spontaneity, and intimacy are the antidotes to being crushed by the loneliness created by professionally devised care plans. At my discretion, I want access to up to two servings of palatable wine or bourbon per day. I do not want medical orders that override my dietary preferences with regard to salt or the texture of my food. I want to be able to choose to own a dog and to pay for staffing and facilities to enable him/her to stay in my room. I have no illusion that accommodating these preferences will make institutional life delightful but I believe they will make it somewhat more human. As a *person* contemplating living in an institution, these preferences may have the added benefit of reminding the staff that I am not to be managed as simply a client, a case or a patient. I fear and reject any place that finds such human requests and needs to be bizarre or impossible.