

James L. Holly, M.D.

Seeking and Finding a “Good Death”

By James L. Holly, MD

Your Life Your Health

The Examiner

July 26, 2018

Ten years ago, in space of three weeks my wife and I have attended four funerals of relatives or friends. We realized at that time that we had arrived at that time in our lives where we would be attending more and more funerals. During that time, I also read a newspaper article about a friend who, as a prison chaplain, was responsible for walking 90 men to their execution. The article addressed a concept most often found among the American Indians, the idea of “finding a good death.” These experiences and others set me to thinking about a healthcare problem we often face but often try to ignore which is the fear of death.

Decisions about the care of loved ones are often made by a family on the premise that the “only good” in healthcare is to preserve physical existence for as long as is possible. In my life, I have experienced the death of a number of those whom I loved deeply. The most significant were my parents and grandparents. In each case, their health had deteriorated and they were experiencing irreversible chronic illnesses. A choice had to be made whether to preserve physical life with extraordinary means, or to help them find “a good death.”

As in all cases, the issue in these cases was, are we going to treat the one who is ill, or are we going to treat the family and/or friends? The decision to artificially support life in the face of terminal illness, or to perform extraordinary surgery or procedures on those who will not benefit is a function of treating the family and not treating the patient. In the case of my parents and grandparents, we made the decision, consistent with their desires, to make them comfortable, to love them and support them and to “let them go.” In each case, it was the right decision.

The article referenced above was about men, and women, who died without family, without friends and without anyone who cared for them. In the case of those who were executed, their graves are marked only with a wooden cross and their inmate number. If there could be a “bad death,” and there can be, this would be it. It is a great comfort to me to visit my parents’ and grandparents’ graves where I find their names, birth dates, dates of death, dates of marriage. The saddest way to die is alone, and the saddest way to be buried is anonymously in an unmarked grave which will never be visited.

The object of life, and even of healthcare, should not be the endless preservation of physical existence to any extreme, but it should be the living of a life which will make one's death significant, no matter how or when it comes. It is living a life of goodness, kindness, love and joy which will endear us to others and others to us. The foundation of a "good death" is a "good life." And, a good life is not marked by wealth, power or fame, or longevity, but by "making a difference in someone else's life." This phrase is commonly used in terms of religious activities, but I recently heard it in another context.

When visiting my School of Medicine, the Dean of Admissions listed the criteria used for selecting candidates for the freshman class. He noted that once it is established that a student can do the academic work, the admissions committee wants to know if the applicant "has made a difference in someone else's life." That is a provocative concept and it is novel in my experience as a qualification for admission to a professional school. The root of this standard is the belief that the "calling" to medicine is a calling to "making a difference in the lives of others," and the evidence of that calling is whether or not a person has participated in such an activity before seeking professional training. The logic is that the motivation to help others is not learned in professional school, it is only focused and directed there.

How does all of this help us in making end-of-life decisions for ourselves and for our loved ones? It helps because it lets us focus our attention on others and not ourselves. It allows us to know that our love for our father or our grandmother often requires us to "let them go," and to "let them go" without the trauma of ineffective, unnecessary and/or inappropriate tests, procedures, surgeries, treatments or other manipulations. It helps us know that death is not the ultimate enemy; anonymity, worthlessness, loneliness are the ultimate enemies. The good news in all of this is that while we cannot forever forestall death; we can forever eliminate anonymity, worthlessness and loneliness.

Medicalised, Professionalised, and Sanitised

Yet, that has not been the attitude of the past 50 years, and modern medicine may even have had the hubris to suggest implicitly, if not explicitly, that it could defeat death. If death is seen as a failure rather than as an important part of life, then individuals are diverted from preparing for death and medicine does not give the attention it should to helping people die a good death. Our society needs a new approach to death and that is not euthanasia or assisted suicide.

To bring death back to the center of life would not, of course, be new. Ivan Illich traced the history of death in his critique of modern medicine, *Limits to Medicine*. The dance of the dead painted on a cemetery wall in Paris in 1424 showed each character dancing with his or her own death throughout life. One of the first books published by William Caxton, England's first printer, was a manual of how to die. It remained a bestseller for two centuries. It was not until after the Reformation that European death became macabre, and Francis Bacon was the first to suggest that doctors might hold death at bay. Earlier Arab and Jewish doctors had thought it blasphemous for doctors to attempt to interfere with death. Most people today die in the hospital,

even though they say they would prefer to die at home, and a soulless death in intensive care is the most modern of deaths.

For the American Indian, a good death addressed the nobility and the bravery associated with that death. For me, a good death would be one surrounded by loved ones and friends, celebrating the life we have shared. In the Movie, *Exodus*, the Jewish leader David stands over the crude grave of his Arab friend, Taha, and says, he should have died “surrounded by his people and his sons...And death should have come to him...as an old friend...offering the gift of sleep.” The tragedy was not death, but untimely death which was intentionally caused by people filled with hatred.

The authors of the final report on *The Future of Health and Care of Older People* have identified 12 principles of a good death; they are:

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go and not to have life prolonged pointlessly.

Debate over whether people are dying badly or well obviously depends on a definition of a good death. It is clearly more than being free of pain, and three themes that emerged constantly in the debate of the age were control, autonomy, and independence. These are excellent principles and should surely be incorporated into the plans of individuals, professional codes, and the aims of institutions and whole health services.

The focus must not all be on the process of dying

Death should be brought more into life, and the report also recommends how this can be done. One suggestion is to introduce death education into schools. Another is to improve the quality and relevance of funerals. In Britain, the National Funerals College has introduced the *Dead Citizen's Charter*, and it criticizes many modern funerals for being “hypocritical, bureaucratic, dull, impersonal, and hurried.” A good funeral is a life enhancing experience, and I suggest that you think about yours now.

“Make way for others,” advises Montaigne, “as others did for you. Imagine how much more painful would be a life which lasts forever.” Mortality is one of the greatest of gifts we have;

that fact is often lost in the midst of an illness or a threat to our life. If this idea seems strange speak to someone who has outlived all of their family, friends and loved ones. They will tell you that the length of their life has ceased to be a blessing to them.

Dying is not the worst thing for you to do in this life. In fact, death can be a “healthy” capstone to your life. As you make health care decisions for yourself or for another, make them such that you will live well for as long as you live and when it is time “to go,” do so with dignity and grace, surrounded by something besides machines. And, if that is not possible, still celebrate life realizing that death is not a contradiction or a cancellation of life but an inevitable conclusion to life.