

means of death are administered by the doctor, it is less possible for the patient to change his mind at the last minute and stop the process; and physicians would experience an intolerable conflict in their professional mandate to promote health and healing if they were required to be agents of death.

I hope this list of possible interventions will help you discuss and decide how far the doctor should go in assisting the patient in dying. This is an ethical issue that physicians—and policy makers—wrestle with. In the absence of a clear, consensual answer, honest discussion is essential.

How do you decide what you want?

Lance writes.

Speaking as an ethicist, Bert has just given us a comprehensive framework for clarifying, documenting and protecting our wishes regarding end-of-life care. That guidance applies to medical care in general, but we will stay focused on end-of-life issues for the purposes of this book.

As a physician working with patients within the accepted ethical and legal guidelines of our society, I am glad that we have many safeguards built into our legal system that protect the rights of the individual. We pride ourselves on freedom of choice, and naturally we would each want understanding of our options before making a choice. In the medical system, as Bert mentioned, we call that *informed consent*. Informed consent implies that one understands what one is agreeing to and deciding upon. In the context of end-of-life care, some degree of awareness of the issues is implied when we fill out a living will or discuss what we would want. However, a full understanding of the range of possible medical interventions is difficult for the layperson to grasp, and generally takes doctors years to fully understand as well.

We must also acknowledge that some people will, understandably, want things that are simply impossible, or at least not based on a realistic

understanding. The extreme example is that a person may not ever want to die. In that case, one's wishes are currently not achievable. A slightly less extreme example is that a person may want to be kept alive on a ventilator indefinitely, regardless of the reason for being on it or their chance for ever living without artificial respiration. If that person made such a wish, it would normally be honored by their physician for some time. But eventually, if the case became so hopeless and prolonged that no physician would agree to continue treating the patient in that manner, there would be a conflict between what the patient wants and what the medical team can offer. Remember that although patients have certain rights, medical professionals do too. There are legal protections that prevent medical professionals from performing interventions that they feel are not in the patient's best interests.

So, we may say that many people are at risk of making advanced directives based on an incomplete understanding of the issues. Common sense, multiple studies and surveys, and professional experience indicate that most rational people will specifically want to avoid extremes of life support in the face of medical futility. However, there are shades of gray that require attention and awareness. As I approach this subject, I remain fully aware of the religious, political, emotional and social issues surrounding death in our society. I also affirm Bert's statement that I cannot and will not tell you the right decisions to make regarding your end-of-life plan. However, I will try to describe for you some of the facts and observations that I would impart to any patient seeking my professional advice. In order to do that, I will eventually make some conclusions and recommendations, which you are free to accept, to seek other opinions about or to simply disregard. The beauty here is that you are arming yourself to stand up for your rights and desires. I will ask of you one thing...if you find yourself reacting negatively to some things I recommend, ask yourself what you think my motivation is. Do you think I have some reason to lead you

to any conclusion other than hard-earned knowledge and experience? Would I have anything to gain by propagating one point of view over another? Even if you disagree with my words and advice, I maintain a gritty respect for your strength.

I will point out that many times, even after I give a patient or their surrogate a detailed, objective and comprehensive explanation of their options, I still get the following reply... “That’s all well and good , Doc, but what would YOU do if you were in my shoes? What would you do if this was your mother instead of mine?” That is a very honest and trusting response. What it means is that the person appreciates my attempts to inform them, but may be overwhelmed at so many choices. In that case they are saying, “I trust you to do your job”. I write the following with the understanding that some readers may want facts without opinion and others may want guidance along with information. In other words, I am trying to ensure that you do your end-of-life planning under the auspice of *informed consent*.

How do we die?

Let’s start with some basic science. You may initially want to run from this section. Please do not. Hang in there. You may learn some things that serve you well. In high school health class, you hopefully learned a few things about diet, exercise and lifestyle that gave you a better chance for living well. I doubt they covered the basics of the dying process which might serve you during a different phase of your life. I ask you to move through this awareness with me now.

All living things show a common trait that sets them apart from non-living things. We can call this trait the ability to defy *entropy*. Entropy is a word used in physics to describe the tendency for all systems to move from a state of order to disorder, from organization to chaos. You already know this on an intuitive level. A rock, once formed has only one direction to go...it will eventually crumble. A house does not