**Advance Directive Act of Texas Part IV:**
**Living with and Planning for Dying**
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Frequently, I have been asked to speak to Senior Citizens' groups. Typically, I begin with the statement, "I would like to say something positive, something encouraging, something hopeful: No matter how high your HDL; no matter how low your cholesterol; no matter how often you go to the doctor; no matter how many pills you take, you are all going to die." After the laughter dies down, I add, "When you start with the worst news, all of the rest can be good news."

There are many humorous ways in which we talk about the reality of death. With humor, we take the uncomfortable edge off our anxiety about our own mortality, but at some point, we must talk with those we love, and who are aging, about death, and ultimately we must talk about their death. For me, the comfort of faith is not a delusion with which we anesthetize ourselves against the pain and possible fear of dying. My faith, and hopefully your faith, allows us to live successfully and to die peacefully and hopefully.

Few things are more important to talk about than the issues surrounding dying. A will is not only a legal document whereby we distribute our tangible assets to those we love. A will, our will, which is the product of emotion, volition and cognition, is how we express what is important to us and it how we determine how important we are to others.

Talking about death is therapeutic. It relieves everyone from the pressure of wanting and needing to talk and not being able to. It allows everything to be said which should be said and helps everyone avoid those unresolvable, "I wish I had said….," regrets after the death of a person who was important to us.

**Healthcare Providers Need to Help Patients Prepare for Death**

Being willing to talk to patients and families about death is important for healthcare providers. The operative work here is "willing," as the healthcare provider should not and can not force anyone to talk about anything. He/she should provide the opportunity and express the willingness to address end-of-life issues with patients and/or with their families. It should be done in a non-confrontational but firm manner with the willingness to stop if the patient desires to deny the issue.

Twenty years ago, a young patient of mine was diagnosed with an incurable malignancy. The patient moved to the family's home in another state to prepare for death. Several months passed and the patient called me and said, "Can I come home to Beaumont? No one here will talk to me about what is happening to me." After the young person returned to Beaumont, through many hours of talking, praying and some crying, we lived through the dying. We could not change the course of the illness, but we could change the response to that illness. Perhaps the uniqueness of our being human is our ability to

communicate abstract feelings and ideas with a past, present and future context. The fact that we are going to die should not change our ability or willingness to communicate with one another.

We must all remember, also, that just because we die, and even just because we die suddenly, or unexpectedly, or even when we die when we don't want to die, it does not mean that someone is at fault for our death. When we are at peace with ourselves and with our own mortality, it is far less likely that we will feel the need to comfort ourselves over the death of a loved one by blaming someone else for their death. The Advanced Directive Act of Texas operates best in the midst of a dialogue among the family members who are together facing the potential death of someone about whom they care.

**Advanced Directives and Public Policy for Health Care Finance**

This year, Medicare will have to begin dipping into its trust fund to keep up with expenditures and will go broke by 2019 without changes in a program that is swelling because of rising health costs. On the other hand, this year, Social Security's finances showed little change, and its projected insolvency date remained 2042.

83% of people who die each year are eligible for Medicare At least 1/3 of all Medicare expenditures go for care of eventually fatal illnesses. 27-30% of total Medicare budget is spent in the last year of life. Costs per patient-year have increased from $3,488 per person-year (1976) to $13,316 per person-year (1988) in concert with increases in overall costs. Relative patterns and percentages of the total Medicare budget are unchanged over 12 years. Of the total amount spent in the last year of life, nearly 40% is spent in the last 30 days.

**Hospice Care: A Good Choice for Patients and Families**

Several studies suggest cost savings associated with the use of hospice care. In 1995, every dollar paid by Medicare for hospice patients saved the program $1.52 in Part A and Part B expenditures. Hospice is one of the most compassionate and excellent means of dealing with all of the issues surrounding death – anxiety, fear, often pain, and cost. Through Hospice care, with its emphasis on living well for as long as you live, while facing the reality and often the eminence of death, society can give the dignity to life which every person deserves, affirm the value of every life, each of which we hold dear and deal with the looming problems associated with both the longevity of patients and the ability to keep people alive longer without increasing the quality of their extended life.

**Dealing with Death**

As we prepare to conclude our discussion of Advanced Directives, we conclude with a discussion of why conflict develops around the death of patients in a clinical setting. Several years ago my wife called me about her elderly aunt who was in the hospital with pneumonia at an advanced age. She asked me what I thought. I told her, "Eighty-nine year olds often die." I cared deeply about this lady who was my friend as well, but I had

to face the reality as did my wife that body systems can only endure a certain amount of stress until a vital system fails and results in death. It is no one's fault and it is no one's wish, but it happens.

Last summer, my father was critically ill. I have been spoiled to have both of my parents alive and in good health as I enter the seventh decade of my own life. One of the characteristics of being spoiled is that while I am grateful for the gift of their longevity and good health, I am greedy to have more. As I sat beside my father's bed in what I thought would be his final illness and which thankfully was not, I realized that I could not blame anyone for his expected death. I could not even blame my father who had abused cigarettes all of his adult life. I could only be resolved to my father's mortality and the fact of having to live without him for the first time in my life.

**Resolving the Unresolved: Effectively Dealing with Guilt**

Most often, we look to blame someone else for the death of a loved one and particularly a loved one of advanced age, when there are unresolved issues in our relationship with that person. The guilt of imagined or real neglect often drives us to try and balance that guilt with blame. Unfortunately, it never works, for even if we successfully establish someone else's blame in some objective way, we are still left with our guilt. Guilt is only dealt with effectively through admission (some would call it confession) and asking for forgiveness (some would call it repentance). Guilt admitted and forgiven is eliminated as a negative life force. Guilt ignored or dealt with dysfunctionally only provides a life-time of pain.

Ignoring the issues of death facing a loved one with a terminal illness is often the means whereby we try to decrease our pain by transferring that pain to someone else, sometimes the dying loved one. If there is the possibility of recover and of a quality of life, every measure ought to be undertaken. If there is no possibility of recover, the comfort and dignity of our loved one should be our preeminent concern.

I adored my grandmother and cherish every memory of her. Yet, in her final illness, which was the result of incurable and terminal cancer, I wanted her comfortable while she died without inappropriate measures which while they may have added a few days to the length of her life, would actually have decreased her quality of her life. On the other hand, when my family was told that my grandfather was dying, from what I knew was a treatable condition from which he might recover, I demanded aggressive treatment. He recovered and lived five wonderful years. It takes a family devoid of unresolved issues and healthcare providers who can talk candidly with patients and their families about difficult issues to discern between the two and to make wise and compassionate decisions about end-of-life care.

In my second year of medical school, my wife's father fell ill. I went to my dean and told him that I needed to leave school and would probably be gone two weeks. We had just started a three-week, thirty-eight-hour-per-week hematology course. He told me that it would be improbable that I could pass the course if I left for two weeks.

As my wife and I drove home, I told her, “The reason that we are going at the risk of failing a course in medical school is not only because we love your father. It is also because this illness will result in his death, maybe not soon but eventually. And, when that time comes; when we shed our tears and you grieve the death of your beloved father, I want you to do it with the knowledge that we did everything and we risked everything for him.” Twelve years later, her father did die. We did shed tears but we had no guilt or regret, as we knew we had done everything we could. Oh, by the way, I passed the course.

As we make choices about living, often those choices are the way we successfully confront the reality of the death of those we cherish.

**Advanced Directive Discussions are Redemptive**

Talking about Advanced Directives and the desires of our loved ones provides an excellent venue for resolving all of the interpersonal issues which can arise even between people who love one another very much. It provides a place for saying, “I have always felt that I could have done better or been a better (child, spouse, friend, etc). I love you very much and I am sorry for not being everything that I could have been.”

Death is never easy when we lose someone we loved, cared for and even depended upon. It is much harder when we wish we had said many things which we never did. Take the time to tell those people whose death would cause you great pain how much you love them. Then, when you face their death, you do it with the peace that everything that needed to be said, everything that should have been said and everything that you wanted to say, was.

In preparing your own Advanced Directive, you will be motivated to provide an opportunity for all those who love you to do the same toward you, as you need to do toward others. In helping those you love to prepare their Advanced Directive, you can tell them of your love and affection. Few things will do as much for your life and for your health as how you deal with your own mortality and the mortality of those you care about.