
Estate Planning Insights

A Quarterly Publication of

Karen S. Gerstner & Associates, P.C.

Attorneys at Law

5615 Kirby Drive, Suite 306

Houston, Texas 77005-2448

(713) 520-5205

Vol. 12, No. 2

April 30, 2015

Being Mortal: Excerpts from the Book

Atul Gawande, Boston surgeon, staff writer for *The New Yorker*, and professor at Harvard Medical School and the Harvard School of Public Health, has written a thought-provoking book called, *Being Mortal*. The book includes stories of real patients near the end of their lives, including the author's own father and his wife's grandmother. Among the book's topics: the desire that older adults have to live independently versus the desire their family members have for them to be safe; the changes in medical care over the past 100 years and the effects of those changes on our lives today; and the tension between doing more for dying patients, medically, without any real hope of effecting a cure, versus being honest with dying patients so that they can live out their final days with dignity and spend meaningful end of life time with their loved ones. I learned quite a bit from reading *Being Mortal*, including, for example, the history and original purpose of assisted living; the difference between palliative care and hospice care; how people experience, rate and remember pain; the fact that most deaths occurred in the home as recently as 1945; and the fact that people aged 65 or older constituted less than 2 percent of the US population in 1790, while they constitute 14 percent today (and that number is growing). In the remainder of this newsletter, I am going to quote extensively from *Being Mortal*.

"Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers."

"Our reverence for independence takes no account of the reality of what happens in life: sooner or later, independence will become impossible. Serious illness or infirmity will strike. It is as inevitable as sunset. And then a new question arises: If independence is what we live for, what do we do when it can no longer be sustained?"

"Old age is not a diagnosis. There is always some final proximate cause that gets written down on the death certificate--respiratory failure, cardiac arrest. But in truth no single disease leads to the end; the culprit is just the accumulated crumbling of one's bodily systems while medicine carries out its maintenance measures and patch jobs."

"The progress of medicine and public health has been an incredible boon--people get to live longer, healthier, more productive lives than ever before. Yet traveling along these altered paths, we regard living in the downhill stretches with a kind of embarrassment. We need help, often for long periods of time, and regard that as a weakness rather than as the new normal and expected state of affairs."

As we age, all of our bodily systems decline. "... as the defects in a complex system increase, the time comes when just one more defect is enough to impair the whole, resulting in the condition known as frailty." People fall apart as they age. They wear out. "This is not, to say the least, an appealing prospect. People naturally prefer to avoid the subject of their decrepitude."

"...eventually the losses accumulate to the point where life's daily requirements become more than we can physically or mentally manage on our own. As fewer of us are struck dead out of the blue, most of us will spend significant periods of our lives too reduced and debilitated to live independently." "We do not like to think about this eventuality. As a result, most of us are unprepared for it."

When people are facing mortal circumstances, the question for the doctor and other health care providers is this: "When should we try to fix and when should we not?"

"In the United States, 25 percent of all Medicare spending is for the 5 percent of patients who are in their final year of life, and most of that money goes for care in their last couple of months that is of little apparent benefit."

The author was visiting a patient in ICU. He talked with the attending critical care doctor. She said, of the 10 patients in

her unit, only 2 were likely to leave for any length of time. "Almost all of these patients had known, for some time, that they had a terminal condition. Yet they--along with their families and doctors--were unprepared for the final stage."

"In 2008, the national Coping with Cancer project published a study showing that terminally ill cancer patients who were put on a mechanical ventilator, given electrical defibrillation or chest compressions, or admitted, near death, to intensive care had a substantially worse quality of life in their last week than those who received no such interventions. And, six months after their death, their care givers were three times as likely to suffer major depression. Spending one's final days in an ICU because of terminal illness is for most people a kind of failure. You lie attached to a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said good-bye or 'It's OK' or 'I'm sorry' or 'I love you.'"

"People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The question therefore is not how we can afford this system's expense. It is how we can build a health care system that will actually help people achieve what's most important to them at the end of their lives."

"These days, swift catastrophic illness is the exception. For most people, death comes only after long medical struggle with an ultimately unstoppable condition--advanced cancer, dementia, Parkinson's disease, progressive organ failure (most commonly, the heart, followed in frequency by lungs, kidneys, liver), or else just the accumulating debilities of very old age. In all such cases, death is certain, but the timing isn't. So everyone struggles with this uncertainty--with how, and when, to accept that the battle is lost. As for last words, they hardly seem to exist anymore. Technology can sustain our organs until we are well past the point of awareness and coherence. Besides, how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? Is someone with terminal cancer, dementia, or incurable heart failure dying, exactly?"

The author went on rounds with a hospice care nurse. He told her he was confused about what she was doing. A lot of it seemed to be about extending the patient's life. He asked her, "Wasn't the goal of hospice to let nature take its course?" 'That's not the goal,' [the hospice nurse] said. The difference between standard medical care and hospice is not the difference between treating and doing nothing, she explained. The difference was in the priorities. In ordinary medicine, the goal is to extend life. We'll sacrifice the quality of your existence now--by performing surgery, providing chemotherapy, putting you in intensive care--for the chance of gaining time later. Hospice deploys nurses, doctors, chaplains, and social workers to help people with a fatal illness have the fullest possible lives right now... In terminal illness that means focusing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as feasible, or getting out with family once in a while--not whether [the patient's] life would be longer or shorter. Nonetheless, when she [a particular patient the author was involved with] was transferred to hospice care, her doctors thought that she wouldn't live much longer than a few weeks. With the supportive hospice therapy she received, she had already lived for a year." Then the hospice nurse said, "Ninety-nine percent understand they're dying, but one hundred percent hope they're not."

Experienced doctors who are treating patients with terminal cancer ask themselves whether, *with* the treatment, they can get a pretty good additional year for the patient. Patients are thinking they will get 10-20 more years with the treatment.

"You'd think doctors would be well equipped to navigate the shoals here, but at least two things get in the way. First, our own views may be unrealistic. A study led by the sociologist Nicholas Christakis asked the doctors of almost five hundred terminally ill patients to estimate how long they thought their patients would survive and then followed the patients. Sixty-three percent of doctors overestimated their patients' survival time. Just 17 percent underestimated it. The average estimate was 530 percent too high.

"Second, we often avoid even voicing those sentiments. Studies find that although doctors usually tell patients when a cancer is not curable, most are reluctant to give a specific prognosis, even when pressed. More than 40 percent of oncologists admit to offering treatments that they believe are unlikely to work."

"This is a modern tragedy, replayed millions of times over. When there is no way of knowing exactly how long our skeins will run--and when we imagine ourselves to have much more time than we do--our every impulse is to fight, to die with chemo in our veins or a tube in our throats or fresh sutures in our flesh. The fact that we may be shortening or worsening the time we have left hardly seems to register. We imagine that we can wait until the doctors tell us that there is nothing more they can do. But rarely is there nothing more

that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of the tumor, put in a feeding tube if a person can't eat: there's always something. We want these choices. But that doesn't mean we are eager to make the choices ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do Something. Fix Something. Is there any way out of this?"

"There's a school of thought that says the problem is the absence of market forces. If terminal patients--rather than insurance companies or the government--had to pay the added costs for the treatment they chose instead of hospice, they would take the trade-offs into account more. Terminal cancer patients wouldn't pay \$80,000 for drugs, and end-stage heart failure patients wouldn't pay \$50,000 for defibrillators offering at best a few months extra survival. But this argument ignores an important factor: the people who opt for these treatments aren't thinking a few added months. They're thinking years."

"A landmark 2010 study from the Massachusetts General Hospital had even more startling findings. The researchers randomly assigned 151 patients with stage IV lung cancer . . . to one of two possible approaches to treatment. Half received usual oncology care. The other half received usual oncology care plus parallel visits with a palliative care specialist. These are specialists in preventing and relieving the suffering of patients, and to see one, no determination of whether they are dying or not is required. If a person has a serious, complex illness, palliative specialists are happy to help. The ones in the study discussed with the patients their goals and priorities for if and when their condition worsened. The result: those who saw a palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives--and *they lived 25 percent longer*. In other words, our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality."

"Patients entering hospice have had no less surprising results. Like many other people, I had believed that hospice care hastens death, because patients forego hospital treatments and are allowed high-dose narcotics to combat pain. But multiple studies find otherwise. In one, researchers followed 4,493 Medicare patients with either terminal cancer or end-stage congestive heart failure. For the patients with breast cancer, prostate cancer or colon cancer, the researchers found no difference in survival time between those who went into hospice and those who

didn't. And curiously, for some conditions, hospice care seemed to extend survival. Those with pancreatic cancer gained an average of three weeks, those with lung cancer gained six weeks, and those with congestive heart failure gained three months. The lesson seems almost Zen: you live longer only when you try to stop living longer."

A palliative care specialist had to deal with her own father's serious illness. She asked him, "... how much are you willing to go through to have a shot at being alive and what level of being alive is tolerable to you?" He said, if he is able to eat chocolate ice cream and watch a football game on TV, then he wants to stay alive. He said he is willing to endure a lot of pain and discomfort if he can do that. Shortly thereafter, her dad had surgery. Complications arose during surgery. The surgeons asked her what they should do--continue or stop? She asked them, if her father survived surgery, would he be able to eat chocolate ice cream and watch a football game on TV? They said "yes," so she consented to the continuation of the surgery. She advises all families to have that "breakpoint discussion"--when does the switch need to be made from fighting for more time to fighting for other things that people value--spending time with their family, getting out, traveling, eating chocolate ice cream?

"One of the beauties of the old [medical] system was that it made these decisions simple. You took the most aggressive treatment available. It wasn't a decision at all, really, but a default setting. This business of deliberating on your options--of figuring out your priorities and working with a doctor to match your treatment to them--was exhausting and complicated, particularly when you didn't have an expert ready to help you parse the unknowns and ambiguities. The pressure remains all in one direction, toward doing more, because the only mistake clinicians seem to fear is doing too little. Most have no appreciation that equally terrible mistakes are possible in the other direction--that doing too much could be no less devastating to a person's life."

"At least two kinds of courage are required in aging and sickness. The first is the courage to confront the reality of mortality--the courage to seek out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have many reasons to shrink from it. But even more daunting is the second kind of courage--the courage to act on the truth we find. The problem is that the wise course is so frequently unclear. For a long while, I thought that this was simply because of uncertainty. When it is hard to know what will happen, it is hard to know what to do. But the challenge, I've come to see, is more fundamental than that. One has to decide whether one's fears or one's hopes are what should matter most."

What sacrifice is one willing to endure now for the possibility of time later? And what about pain? Studies show that people experience and remember most the pain during the peak and at the very end. Do people really want

KAREN S. GERSTNER & ASSOCIATES, P. C.
A Professional Corporation
Attorneys at Law
5615 Kirby Drive, Suite 306
Houston, Texas 77005-2448

PRSR STD
U.S. POSTAGE
PAID
PERMIT NO. 600
HOUSTON, TX

Telephone: (713) 520-5205
Fax: (713) 520-5235

ADDRESS SERVICE REQUESTED



PRINTED ON RECYCLED PAPER

To download back issues and learn more about estate planning, visit our web site at www.gerstnerlaw.com

Karen S. Gerstner & Associates, P.C.

April 30, 2015

an end filled with pain? A person's life is like a story. The ending matters in a story.

"A few conclusions become clear when we understand this: that our [i.e., doctors'] most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."

"At root, the debate is about what mistakes we fear most--the mistake of prolonging suffering or the mistake of shortening valued life."

"We think our [i.e., the doctor's] job is to ensure health and survival. But it is really larger than that. It is to enable well-being. And well-being is about the reasons one wishes to live. Those reasons matter not just at the end of life, or when debility comes, but all along the way. Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"

Conclusion. Most of our clients have the standard medical-legal documents, i.e., Medical Powers of Attorney, HIPAA Authorizations and Directives to Physicians (also known as "Living Wills"). Some also have "Do Not Resuscitate" ("DNR") directives in place. However, legal documents only go so far. Not every situation can be covered, in advance, in a legal document. *Being Mortal* should be helpful in bringing some issues to the fore. Whether you read the book or not, we strongly encourage you to discuss "end of life issues" with your loved ones. This will require a great deal of honesty and courage, of course. However, such a discussion can help make *the end of your story on earth* what you want it to be.

Contact us:

If you have any questions about the material in this publication, or if we can be of assistance to you or someone you know regarding estate planning or probate matters, feel free to contact us by phone, fax or traditional mail at the address and phone number shown above. You can also reach us by email addressed to:

Karen S. Gerstner* karen@gerstnerlaw.com

Biljana Salamunovic biljana@gerstnerlaw.com
Laura Walbridge laura@gerstnerlaw.com
Nancy Baxley nancy@gerstnerlaw.com

* Board Certified, Estate Planning & Probate Law, Texas Board of Legal Specialization