THE END-OF-LIFE
(Two lectures – Oct 9 and 16, 2014)

Literally translated from the Greek, EUTHANASIA means a good death – what we all would want for ourselves or for our loved ones. Early usage implied a tranquil state of mind at death -- a passive process comparable to the current practice of palliative care. Since antiquity, philosophers and others have endlessly discussed how we die. All the famous Greek dramatists had their say -- with most of them rejecting active euthanasia as being against the will of the Gods. Some expressed the idea that all life is sacred, but Plato, for one, acknowledged that it was not reasonable to prolong the suffering of a man who was not useful to himself and to society. And there always have been some who’ve encouraged a more active form of euthanasia. To make the point, let me describe two fictional islands:

In his book Utopia, which appeared in 1516, Sir Thomas More told of a perfect society that existed on the island of Utopia which was located somewhere in the recently discovered New World. Here’s what he wrote about the end of life in this paradise,

*When people are permanent invalids, the nurses try to make them feel better by sitting and talking to them, and do all they can to relieve their symptoms. But if besides being incurable, the disease also causes constant excruciating pain, some priests and government officials visit the person concerned and say something like this: Let’s face it, you’ll never be able to live a normal life. You’re just a nuisance to other people and a burden to yourself. In fact, you’re really leading a sort of posthumous existence. So why go on feeding germs? Since your life’s a misery to you, why don’t you break out and escape to a better world?*
Or say the word and we’ll arrange for your release. It’s only common sense to cut your losses. It’s also an act of piety to take the advice of a priest because he speaks to God...If the patient finds these arguments convincing, he either starves himself to death or is given a soporific, and put painlessly out of his misery. But this is strictly voluntary, and if he prefers to stay alive, everyone will go on treating him as kindly as ever.

Not very much has changed in the last 500 years has it? Well now let’s fast forward roughly three centuries to 1880 when the Victorian novelist Anthony Trollope imagined an approach which didn’t require the patient’s willingness. In one of his last works, which was called The Fixed Period, Trollope described an island Republic called Britannula whose subjects had fled New Zealand some thirty years before events of the story and immediately had severed all relations with Great Britain. When they came to the island, all of the original settlers were relatively young and when they got around to establishing a legal system, they insisted upon compulsory limits of life in order to abolish what they called “the miseries and imbecility” of old age. And because they thought it would be too expensive to care for the nonproductive elderly, active euthanasia was seen as an obligatory act made for the sake of others. Of course Trollope was a satirist, but these sentiments were an ominous foretelling of actual events which occurred in Germany within a half century.

The novel was told in the first person by the dogmatic President of the Republic, appropriately named Mr. Neverbend -- and the time of action was projected ahead one hundred years to 1980. (George Orwell’s famous novel which anticipated the world of 1984 had projected ahead only 35 years.) With amazing prescience, Trollope foresaw that by 1980 people would be transported by wonderful steam tricycles, would converse over great
distances using wireless devices and would attend international cricket matches contested by teams of professional athletes.

After much debate, the leaders of Britannula agreed that upon reaching the age of 67 all citizens would be “deposited” in what was described as something like a college campus. They would spend six months of contemplation and dignified retirement there, but then “a euthanasia would be prepared for them and they would depart.” So Trollope’s title “the fixed period” referred to this time limit of 67 and a half years of life. After that the seniors were immersed in a warm bath, given morphine and their veins would be “opened.” This social legislation was intended to assure “a decent and comfortable departure” and it was justified not only because it would spare elders from “a useless and painful life” but also because it was good economics.

At first the law was enthusiastically supported by the still youthful citizens, but by the time the book’s narrative begins some thirty years after the law was enacted, some people were having misgivings. Then, just when the first unlucky old-timer was being led off to “college”, an English worship appeared in the harbor with a marvelous new technology – a 250 ton cannon. The leader, Mr. Neverbend, was taken prisoner, the island reverted to sensible English rule and the obnoxious law was rescinded. I can imagine Gilbert and Sullivan putting the whole story to music. Two years after his novel was published, Anthony Trollope died of a stroke at age 67 -- so he would have been approaching his own “fixed period” and heading off to college were he living on the island of Britannula instead of in Great Britain.

A few years later, in 1887, Charles Darwin wrote in his autobiography: “What a good thing if every scientific man would die at age sixty -- for afterward he would oppose all new things.” Apparently, Darwin was only
being ironic -- and, in that same spirit, some two decades later, the world’s most honored physician Sir William Osler made a speech for which he borrowed the title of Trollope’s novel *The Fixed Period*. His speech was delivered in 1905, just before Osler left Johns Hopkins for a teaching position at Oxford, and it caused an unexpected sensation. At the time Osler was 56 years old and what he had in mind was not a fixed period of *biologic* life but of *intellectual* life. Like Darwin before him, he doubted the creativity of men above 40 years of age. Osler viewed the period between ages 25 and 40 as what he called “the constructive period -- where as he said, there is always a balance in the mental bank and the credit is good.” Above age 60, men were intellectually useless and it would be of great benefit if they stopped WORK at this age and retired -- at a double allowance -- NOT killed but RETIRED. He added, “Whether Trollope’s suggestion of a college and chloroform should be carried out or not, I have become a little dubious as my own time is getting so short.” (Actually, Trollope had suggested using morphine, not chloroform.)

Osler’s disclaimer notwithstanding, yellow journalists seized upon his words and distorted them – so the next day’s headlines blared things like “Osler Recommends Chloroform at Sixty.” But the professor held his ground and said that he’d been misquoted and that he’d only been joking to make a point. A British writer suggested that “the Americans are somewhat deficient in a sense of humor when they themselves are directly concerned.” (No he didn’t work for Hearst – or for Murdoch.) Some people started speaking about “oslerizing” old timers and later Osler ruefully advised his students, “Boys, do not read Trollope. He is dangerous.” Incidentally, when William Osler died 14 years after his embarrassing *faux pas*, he was 70 years old.

In this month’s *Atlantic Monthly*, bioethicist Ezekiel Emanuel has an article titled, “Why I Hope to Die at 75.” He claims that when he gets to that age,
which will be in about 18 years, he’ll avoid active health care and just let nature take its course. He won’t kill himself and he’s firmly against euthanasia, but says that he won’t fight the inevitable either. Last week when Emanuel was interviewed on the PBS Newshour, he said that he wasn’t kidding – that by 75 we’d all seen and done enough and statistics show that by age 80 half of all people have functional disabilities. From then on it’s all down hill – loss of creativity, physical decline, dementia -- the whole catastrophe. (Don’t blame me – I’m just the messenger.) I suspect that Ezekiel Emanuel was just trying to be provocative and he has plenty of time to change his mind – like the people on the island of Britanula had. He can’t claim like William Osler that he was misquoted because he spelled it all out in the magazine and on television. In fact, Dr. Emanuel now is the same age that Osler was when he gave his famous speech. Naturally his arbitrary statement got a lot of attention – which, of course, was the idea. But it’s not easy to discount Ezekiel Emanuel as a nutcase. He’s a brilliant man, has had an extraordinary career and writes frequently in the Times and the New Yorker about various dilemmas facing both the medical profession and modern society.

We can argue about age limits of intellectual creativity and the quality of senior life, but during the early 20th century there was a serious debate which had its origins with what was called “Social Darwinism” – the question was what to do with the so-called “unfit”, society’s losers, those who were a drag on everyone else. The argument was posed in terms of the greater good of the public and, at the time, many intellectuals were attracted to the pseudoscience of eugenics – Teddy Roosevelt said “We have no business to permit the perpetuation of citizens of the wrong type.” What type was that? Margaret Sanger thought she knew: she believed that contraception, abortion and mandatory sterilization were good ways to lower the birth rate of such undesirables as “Hebrews, Catholics and Negroes.” You may be surprised to learn that, over time, more than 65,000
Americans were sterilized against their will. Of course, that immediately brings to mind the most egregious outcome of that mindset – Nazi abuses which during the 1930s quickly evolved from sterilization to “mercy killing” to the “Final Solution.”

But it wasn’t only Nazis who supported the idea of killing the dregs of society. Consider the French-born surgeon Alexis Carrel who in 1912 won the Nobel Prize in Medicine for his work suturing small blood vessels which opened the way for organ transplantation and modern surgery. For more than thirty years he was a respected scientist at the Rockefeller Institute in New York doing esoteric animal experiments in which he explored the biology of life. In fact, he claimed to have developed an immortal cell line from a chicken embryo’s heart and, with his friend Charles Lindbergh, invented a perfusion pump which enabled open heart surgery.

Alexis Carrel may have been a superb scientist, but he was a miserable human being -- arrogant, an outspoken elitist and a zealous eugenicist. Better breeding practices, like with racehorses or show dogs, wasn’t enough for him. Those who didn’t measure up to societal standards, the so-called “unfit,” needed to be eliminated and who were they? To be sure, the included hardened criminals but also those with mental illness, epilepsy and yes, once again, negroes and gypsies and Jews.

Carrel’s book *Man the Unknown* was an international best-seller in 1935 –it was published in fourteen languages and in this country was second in sales only to *Gone With The Wind*. Several million copies were sold and thousands of people flocked to the doctor’s frequent lectures. In his book Carrel said that society should be directed by what he called “a high council of experts…living in seclusion like monks…audacious men of science, unafraid of resorting to extreme, even ruthless measures.” He said
that what was needed was a bold ruling class – led by genetically superior people descended from heroic figures such as the Crusaders and Revolutionaries and great criminals and financial and industrial magnates - -- stouthearted men of courage. Some of Carrel’s words still give me a chill – listen to this: “Men are not created equal.” The unfit “should be humanely and economically disposed of in small euthanistic institutions supplied with the proper gasses [...]...Why preserve useless and harmful beings?” That was in 1935 – that same year Dr. Carrel’s face appeared on the cover of Time Magazine -- and the next year in the German edition of his book, he praised the German government for having taken “energetic measures against the propagation of the defective the mentally diseased and the criminal.” During the War he returned to his native France where he led an experimental hospital under the Vichy government and then, just after the war ended, while awaiting trial as a possible collaborator, he conveniently died of a heart attack. Of course, he’d protested his innocence and among his supporters was General Eisenhower.

Now let me give a more recent example of utilitarianism: in 1984 (just 30 years ago) Colorado’s Governor Richard Lamm made a speech and, unlike William Osler – or perhaps Ezekiel Emanuel -- he wasn’t kidding. By then, people were talking about having a so-called “RIGHT to die” (which we’ll discuss next week) but Governor Lamm explained that we have more than a right -- that “we all have a DUTY to die -- and get out of the way.” He didn’t explain the process of how that should happen, but to some people he seemed to be suggesting that timely death was a moral imperative -- and, predictably, his words provoked a firestorm of criticism. In fact Governor Lamm was referring to inappropriate use of life extending medical technology (which may be perfectly sensible) -- but many people perceived that he was encouraging voluntary euthanasia for the sake of the group’s interest – and feared that such reasoning might place us on a slippery slope.
Years later ex-Governor Lamm explained, “Public policy is a different world than the world of the bedside. Medical ethicists can educate and enlighten, but they cannot control public decision-making. They have important information but not the full facts. They are the trees but not the forest.”

So with that metaphor in mind, let’s drop back and begin again as if we are under the branches of a huge plane tree on the Greek Island of Cos. According to legend it was here that some 2,500 years ago Hippocrates taught medicine. Scholars still debate exactly who he was and what he said, but what’s come down to us as the Hippocratic Oath and the Hippocratic tradition formed the basis of the doctor-patient relationship almost to this day. Hippocrates taught that human health wasn’t dictated by the Gods but by events on earth and in his various writings he promoted the notion of doctors’ helping and not harming their patients -- that life should be preserved and death never hastened. The physician’s job was to consider every detail of his patient’s ailment and then act in his behalf. At the same time, he should be respectful of colleagues, his demeanor should be calm and serious, he should be honest and neat -- his fingernails clean and cut – decorum counted in those days.

It was the custom for members of the Hippocratic cult to publicly “profess” that they could be trusted to put their patient’s interest ahead of their own – and that’s the origin of the word “PROFESSIONalism” – publicly professing good intent. For centuries graduating medical students chanted the Hippocratic oath in unison -- and so did I in 1962 -- but I don’t recall that it made any impression on me or my fellow students – our minds were on other more mundane things. However, that’s the tradition I grew up with and its corollary was that patients always should obey doctor’s “ORDERS.” Most people seemed comfortable with the notion that doctor knows best – that medical knowledge was beyond the understanding of ordinary people,
and, after all, doctors could be trusted. Hippocrates may have said that doctors should be altruistic, but how to do it was contained in a usually overlooked phrase from the Oath: “I will do what *in my judgment* will benefit my patient” -- and it’s those three little words -- “in my judgment” -- that I’d like to consider now.

Just like a trustworthy father does for his helpless children, the physician’s job was to decide for them – and so the doctor-patient relationship was said to be “paternalistic.” When I began my practice in 1968, I proudly accepted that obligation, even relished the responsibility – and I rather liked the analogy to fatherhood since I soon had three children of my own. But as we’ll discuss next week, in recent years this notion of medical paternalism has taken on a pejorative meaning and, these days, sounds archaic and even inappropriate. A few months ago an internist in New York by the name of Barron Lerner published a book about his doctor father – whom I knew way back when. Because his father practiced in the old-fashioned paternalistic mode, I wrote a complimentary letter to his son and said that I agreed with his father’s approach. But this month when the NY Times and The New Yorker reviewed the book, there were many letters to the editor or messages appearing on the New Yorker’s blog site which indicated that many people objected – and they gave good reasons why.

In fact, the first book to bear the title *Medical Ethics* appeared in 1803. It was written by an English physician Thomas Percival and he went beyond Hippocrates to address the relationship of physicians not only to their patients but to society itself. As he saw it, by displaying what he called “urbanity and rectitude” the medical profession would earn public trust -- but concerning the dynamic between doctors and their patients, listen to what Percival said: “To a patient who makes inquiries which if faithfully answered might prove fatal to him, it would be a gross and unfeeling wrong
to reveal the truth.” In other words, don’t give bad news, don’t remove hope – and I’m sure that many of you feel the same way.

In 1847 Percival’s words resonated with more than two hundred American physicians when they gathered in New York to organize the AMA. At their first meeting the main agenda concerned fending off the financial threat of quacks and so-called “irregulars” – homeopaths, naturopaths and the like - but professional behavior also was on their minds and at their second meeting in Philadelphia the delegates passed a Code of Medical Ethics. The prime mover was a Jewish eye surgeon from Philadelphia by the name of Isaac Hays. He’s name virtually unknown today and its been suggested that he deliberately minimized his role because he was afraid that the Code wouldn’t be approved if a Jew was the visible author. So public credit was given to Thomas Percival -- and also to Benjamin Rush of Philadelphia. It’s interesting to examine some of the words of that first Code of Ethics. For example, it said that doctors should “unite tenderness with firmness, condescension (!) and authority” so as to inspire “gratitude, respect and confidence…The obedience of the patient to the prescription of his physician should be prompt and implicit. He should never permit his own crude opinions influence his attention to them.” It was presumed that a doctor’s orders were correct and final. How does that make you feel? Over the years the AMA’s Code of Ethics was revised piecemeal and currently there’s a major rewriting taking place – the first in 168 years. But that first version accurately reflected how physicians viewed patients’ ability to think for themselves – and patients seemed perfectly content to defer to the experts -- some still do but far fewer than before.

One of the delegates at those first AMA meetings was the proper Bostonian Oliver Wendell Holmes – the father of the Supreme Court chief justice of the same name. Many years later, speaking to the graduating class of Bellevue Hospital College, Dr. Holmes had this to say:
As far as possible, keep your doubts to yourself, and give the patient the benefit of your decision. Firmness, gentle firmness, is absolutely necessary. The community is very intelligent with respect to a great many subjects, but with regard to medicine it is hopelessly ignorant... You must take the community as it is and make the best of it... Your patient has no more right to all the truth you know than he has to all the medicine in your saddlebags... He should get only just so much as is good for him.

Dr. Holmes also was a poet – the author of Old Ironsides – and he always had a way with words: My favorite phrase, which I always try to sneak in, was “If all the medicines currently in use were thrown into the sea, no one would be worse off -- except for the fishes.” Supposedly, another time he said, “Give me opium, wine and milk and I will cure all diseases to which flesh is heir to.” Later he denied that he ever said that but it sounds just like him.

But let me drive the point home further by again quoting the esteemed William Osler who in 1889 had essentially the same message when he told his students that in medical matters the ordinary citizen has no sense – as he said, “Deal gently with this deliciously credulous old human nature with which we work and restrain your indignation.” Hippocrates would have been proud of Oliver Wendell Holmes and William Osler – and, as I’ve said, basically this is what I learned in medical school during the 1960s – in truth, we weren’t taught anything – its what I picked up from observing the behavior of my teachers and my peers.

I’d like to give two examples of what I mean – I might call this “Confessions of a Paternalist” – Mia culpa! I apologize if I talk too much about my own
experiences but I think they illustrate how these are not abstract or esoteric matters but are real world dilemmas.

Forty years ago, in about 1974, I had an elderly nursing home patient who had severe dementia and was virtually speechless. Everyone called him Clarence and he was the nurse’s pet. He was a handsome man and they liked to pat him on his shock of white hair as he sat by their station in his wheel chair -- no one seemed to care, or even notice, when periodically Clarence would suddenly erupt into curse words that would make a sailor blush – and at the top of his lungs -- then he’d smile and revert to his usual placid self. I knew nothing about Clarence’s past history and never met any family members, but one day I was in his room and noticed a book on his dresser that was opened to the frontispiece. It showed a photo of Clarence taken decades before and when I looked inside the book was about his distinguished career as the first president of the American Stock Exchange!

Among other things Clarence had a pacemaker and back then pacemakers had mercury batteries which needed to be changed about every two years. His battery time was about up and they would soon have to be replaced. What my partner and I didn’t know was that before Clarence was sent to our nursing home, he’d been a patient at New York Hospital and two years earlier when the batteries last needed to be changed, his family refused to give permission – they felt that the quality of his life was so reduced that it would be best to just let nature take its course. (Ezekiel Emanuel would have approved.) The hospital disagreed, went to court and got a surrogate appointed who approved of the battery change. And then he came to us. Not knowing any of this until years later, and not thinking to discuss this medical decision with his family – we independently came to the same conclusion as the family had in the past. So we let the pacemaker fail, and as it slowed down his own heart took over at a rate of about 30 per minute
– but to everyone’s surprise, nothing happened. He was so inactive that 30 beats was enough and he went on for a long time before dying from something else. Well we’d been paternalistic, had never agonized about our decision and thought that we’d done the right thing – and no one disagreed. There were other similar kinds of hard choices that we were accustomed to making – that’s what doctors did – that was our vocation, our responsibility. But there were some other kinds of decisions that we had to make for our patients that gave pause – that we hadn’t been taught about in medical school.

Pacemakers are fairly complicated machines but hollow feeding tubes aren’t. In those days feeding tubes were inserted through the nose, not directly into the stomach – and because they were uncomfortable, patients tried to pull them out so their hands often had to be tied down. To me that seemed barbaric – inhumane --and I began to wonder what we were actually accomplishing? There were no guidelines and we were left to our own instincts – in uncharted waters.

But this time I was uncomfortable so I decided to explore beyond the limited medical literature and do some ethical research – and I began by doing something very uncharacteristic for me – I decided to find out what my own Jewish tradition had to say. So I began to look through our synagogue’s library – there were no computers or Google yet – and I found that the first book about Jewish medical ethics had appeared only in 1959 – it was written by an English rabbi Immanuel Jakobovits but his book didn’t specifically address this specific subject of artificial feeding. So I wrote letters posing the question about feeding unwilling patients to various rabbis – and a few actually answered me. The outcome was that in 1980 I published an article called *No Heroics* which I believe was the first to ever address this issue from a Jewish perspective. So now, let’s pause for a few minutes to consider how Jewish bioethics compares with the secular
ethics which influences the kinds of court decisions which we’ll be discussing in depth next week.

The traditional Jewish approach can be reduced to one idea -- while standing (like Hillel would) on one foot. It’s that we don’t own our bodies – we don’t have title – we’re only tenants. It’s as if we rent our bodies from God and, therefore, are obliged to take good care of what doesn’t belong to us – a corollary is that we have to return it in good condition. And almost everything flows from this simple concept. For example, the Talmud teaches that Jews must live in places where there are doctors – and that they should follow their advice (paternalism again); and they also should pay the doctor’s fees – it’s all in there. The Jewish tradition is extremely pro-life – it teaches that every moment of life is of equal value -- quality of life is NOT a consideration; life itself trumps all else. Through the ages, when confronting difficult cases, rabbis have resorted to extrapolating from Talmudic parables to the present – which I personally, I find unsatisfactory. But one frequently cited story suggests that there may be some flexibility, after all, when it comes to the truly terminal patient.

In about 200 CE, Rabbi Judah – known as HaNasi – the Prince – was the leader of the Jewish community and the codifier of the Mishnah. The great rabbi was suffering as he lay dying and was surrounded by a group of rabbis praying for his delivery. Observing the scene was Judah HaNasi’s devoted hand-maiden – described in the Talmud as a wise old woman. All she wanted was for the Prince to be in peace – so she did something radical. She climbed up onto the roof of the house, seized a clay pot and threw it down to the stone courtyard below. It shattered and the loud noise shocked the praying rabbis – so for just a moment they stopped their incessant praying – and in that moment, Judah’s soul passed away. Over the centuries, in Talmudic commentaries, the handmaiden’s act was praised – she’d done the right thing albeit for the wrong reason. So there
was a quality of mercy even within traditional Jewish law – and there were other similar stories.

Well that was one way of stopping life-sustaining treatment -- in this case prayer was the equivalent of artificial technology -- but in the modern world, Jewish tradition sometimes can lead to strange choices. Many years ago I had a patient who was healthy and in her forties. But then she suffered a massive pulmonary embolism and was declared brain dead. While she still was hooked up to a respirator, I explained to her husband that he might consider organ donation so at least some good might come from this awful tragedy. They belonged to an orthodox synagogue whose rabbi didn’t recognize the concept of brain death. In olden days before there were EKS or EEGS, death was confirmed only by absence of a pulse or spontaneous breathing – there was no such thing as brain death. Well I didn’t want to get into a theological debate, so I left the option open but, after much agonizing, the husband decided to go against his rabbi’s advice and donated his wife’s organs. Many months later, he reported that he was comforted by the fact that afterwards he’d received a half dozen letters from grateful recipients.

Let me give another example of the sometimes convoluted thinking that arises when ancient rules are followed in modern settings. In cases when death seems imminent (goses) even the extreme orthodox agree that although it’s OK not to start life sustaining treatment, its never permissible to do anything active to stop it. Well in Israel in 2000, a commission was formed to draft a law concerning the rights of terminally ill patients. The group was headed by a respected pediatric neurologist Avraham Steinberg -- who also happened to be an orthodox rabbi. The commission’s members represented a variety of backgrounds and after two years of deliberation they came up with a compromise on this issue – it would be permissible to turn off a respirator for a dying patient, but not directly by human hands.
How? Well every machine would be equipped with a timer – like an oven timer – so when the timer ran down, the machine would shut off automatically. No active pulling of plugs or turning switches – so you see that there’s always a practical solution. This bizarre law actually passed the Knesset, I’ve been unable to learn how its being implemented. It seems to me that it’s comparable to a shabbas elevator or having a shabbas goy turn on the lights, but I won’t comment further – you can tell me what you think.

Enough of the Jewish perspective. Let me wrap up by returning to the secular world. In 1983 I read something which shook me to my paternalistic roots. I read in the newspaper about a Dr. Greco in Newark who, like me at the time, had many nursing home patients. He was being investigated by the state Board of Medical Examiners for his terrible behavior. What had he done? He’d actually permitted some of his terminally ill patients to die of pneumonia without sending them to the hospital. I reread the article – what was I missing? – wasn’t that exactly what I sometimes did? – and considered to be my finest acts as a doctor – doing the “right” thing, caring for the patient not just the disease, taking responsibility. Well Dr. Greco’s license was suspended – not by a court but by his own medical peers. I considered this judgment to be unfair and wondered how it would effect my own practice.

At about that same time I was starting my term as leader of New Jersey’s chapter of the American College of Physicians (the internist’s organization) and I decided to use that platform to get appointed to a newly forming state Bioethics Commission. So for several years I was involved in public policy discussions in New Jersey and I’ll discuss some of that next week. But let me close for now with one more look back – this time to 1906 and a new play written by George Bernard Shaw –called The Doctor’s Dilemma.
It told of a London doctor who’d devised a new treatment for TB, but supplies were limited and he was faced with the choice of giving the last dose either to a worthy but poor medical colleague or to a wealthy “no-goodnick” who had an attractive wife whom the doctor fancied. Like some of the current choices in West Africa, the play addressed the issue of who should receive scarce resources and it reflected Shaw’s cynicism about doctors who performed unnecessary but profitable procedures.

Apparently, this was based on his anger at a Harley Street throat surgeon who frequently removed uvulas – a useless operation which commanded exorbitant fees. In its published form the play was preceded by an 85 page preface (or rant) in which Shaw lambasted money-grubbing doctors. Of course he was an outspoken Socialist who advocated National Health Insurance forty years before it was implemented in England. Shaw said that doctors should be placed on fixed salaries so that they wouldn’t be corrupted by the profit motive. And, of course, many people are saying the same things today so some of the same doctors’ dilemmas remain with us -- the more things change, the more they are the same. These include a doctor’s conflicting responsibilities to the individual patient and to society in general – as well as to insurers and employers – and how to balance patient’s values against the medical and financial value of certain forms of treatment. Or why per capita health care expenditures in this country are two and a half times more than in any other developed nation, yet our outcomes are no better -- or worse? All modern medical dilemmas.
PART II.

Last week we discussed the forest and this week we’ll focus more on the trees. As I’ve told you, when I was in medical school between 1958 and 1962, not a word was ever spoken to us about “bioethics” – in fact that word hadn’t even been coined yet. But by the early 1970s things were changing rapidly. 1973 brought the Roe v. Wade decision which concerned abortion, but although the beginning of life remains a hot-button issue, it will effect no one in this room – but the end of life concerns all of us and I suspect we’ve all experienced difficult end-of-life scenarios for loved ones or friends. Even if not, eventually, we’ll all have to confront our own demise – unless we’re lucky and get killed in an accident. But with modern medicine most people don’t die suddenly and unexpectedly and, as we discussed last week, people live longer and, unfortunately, not necessarily all that well near the end. The question is what have you done to prepare for that time? Do you just ignore and hope for the best? Or do you move to Oregon…

Of course, once you get past the generalities, there aren’t any easy answers and every case differs, so today let’s talk a bit more about this difficult subject. Once again, I’ll frame my remarks within a historical context and illustrate with some of my own experiences. However, I’m especially interested in hearing your opinions so I plan to leave lots of time at the end for discussion.

Not only was 1973 the year of the Roe v. Wade decision, it marked the beginning of Senate Hearings chaired by Senator Edward Kennedy about the use of new medical technology – e.g. organ transplants and dialysis -- and one question concerned who should receive these costly treatments? And, increasingly, medical decision-making had to consider not just esoteric experiments, such as on human fetuses, but the kinds of choices
concerning things like pacemakers and feeding tubes which I discussed last week.

During the first quarter century after the end of WWII, many disturbing new challenges emerged. At the Nuremberg trials there were revelations of Nazi human experimentation, while in this country there were reports about unethical Tuskegee Syphilis Experiments on prisoners that were conducted for 40 years by our own government. You’ll recall that the 1960s was the time of the Thalidomide debacle (birth defects) and there were important Supreme Court decisions -- Griswold v. Connecticut (1965) and Roe v. Wade (1973) – which recognized an unwritten but implied zone of privacy within the Bill of Rights which affirmed that government should keep out of our bedrooms. Various well publicized scandals led to a loss of respect for most traditional authority figures – religious, political, educational leaders all were exposed as having human flaws – great surprise – and, yes, even doctors were fallible – traditionally the most respected profession, its members increasingly being sued for malpractice. The NIH and CDC had their problems, Big Pharma couldn’t be trusted and as for insurance companies – forget it. In bygone days physicians generally followed traditional religious guidelines but now this also was becoming increasingly problematic. Of course, many current dilemmas could not have been foreseen by the founders of the great religions and with all the new technology it was becoming difficult to distinguish between burdens and benefits of treatment.

And then in 1975 many of these issues seemed to crystalize when a 22 year old New Jersey girl by the name of Karen Ann Quinlan attended a party, drank a few gin and tonics and began to feel sick. Apparently she’d also taken some valium – how much and when was never determined – so friends took her home and put her to bed, and when they checked on her a short time later, they found that she wasn’t breathing -- 911 was called,
paramedics did CPR, she was intubated, taken to a local hospital and placed on a respirator.

After many months, when prayers for her recovery were unanswered, her parents asked the doctors to take her off the respirator. But although they may have been sympathetic, as they understood it, their job was to save lives, not end them – and, also, they worried about their legal risk. So Karen’s family appealed to the courts and her condition soon became an international cause celebre. Everyone knew her story. Karen was portrayed as a Sleeping Beauty” held captive by a machine. Her high school graduation picture appeared on the cover of news magazines all over the world and millions of people said, “I never want to be like Karen Quinlan.” New phrases became part of our vernacular: pull the plug, right to die, vegetative state – and people began to ask questions like whose life is it anyway? Or when is enough enough?

Just one hundred years ago, in 1914, New York State’s highest court Supreme Court (Benjamin Cardozzo) ruled that all adults have a right to decide what is done to their bodies and that before elective surgery could be performed there had to be informed patient consent. But in 1976 New Jersey’s Supreme Court ruled in Quinlan that patients could refuse unwanted medical treatment, even against doctor’s orders, and even at the risk of death. In effect, there were four legal outcomes of the Quinlan decision:

1. It extended a constitutional right of privacy from the bedroom to the hospital and because now it was permissible in some circumstances to refuse conventional medical treatment, this was the end of medical paternalism – the dynamic was reversed – now the patient had the last word. However, the Quinlan decision applied only to conditions just like
Karen’s—a newly described syndrome called PVS for “persistent vegetative state” which I’ll discuss again shortly.

2. Even if a patient has lost capacity to choose for him or herself, a surrogate can act for them in what’s legally called “substituted judgment.” If the patient hadn’t formally written a so-called Living Will” or designated a health care representative, then there was a legal hierarchy of first the spouse—then the family—then a friend. That’s why Terri Schiavo’s husband ultimately trumped her parents. But the surrogate’s decision should reflect the patient’s values rather than their own -- and, if they’re not known, then a calculus of life’s burdens v. benefits should be used.

3. A decision to either stop or not start life saving treatment for hospitalized patients like Karen should be reviewed by a multidiscipline Ethics Committee—not by a court because judges have no special expertise when it comes to ethical matters. The ethics committee’s role was to review the decision-making process and see that the patient’s interests were properly represented, but not to actually make the decision.

4. Doctors and others involved in decisions to terminate life support would be immune from prosecution so long as the process was followed in good faith and in the case of a vegetative patient like KAQ, experts deemed that there was no “reasonable likelihood of return to a cognitive state.”

What happened next? After the Court’s decision in 1976, Karen was weaned off the respirator, to everyone’s surprise, she didn’t die. In fact she lived for another nine years--off the respirator, but fed through a gastric tube. For their own reasons, her family chose not to contest that simple technology and when Karen died in 1985 at age 31, she weighed 65 pounds, half of her original body weight.
The Quinlan decision was a legal landmark which set the stage for dozens of cases to follow. In 1985, the next major court decision, which also occurred in New Jersey, conjured up a very different image – this time not of a Sleeping Beauty but an 84 year old nursing home patient by the name of Claire Conroy. She was not in PVS and not on a respirator, but she had advanced dementia and lay contracted in a fetal position, withered and wasted, occasionally moaning and fed through a tube surgically placed in her stomach. To many it seemed that such a life was worse than death, but others argued that feeding was basic care and to deprive anyone of fluid and nutrition would create more suffering -- equivalent to starving them to death or like a man lost in the desert. The rhetoric used by opponents in court implied neglect – they spoke of “cracked bleeding lips, sunken eyes and convulsions” – in fact, nothing like what happens in the real world. New Jersey’s Supreme Court wasn’t impressed with this argument and for the first time approved withdrawal of life support of treatments other than respirators. They considered tube feeding to be like any other form of medical treatment – nutrition no more basic than breathing – it was the context and not the content which mattered.

There was another wrinkle too. Because there’d recently been several well publicized Medicaid scandals in New Jersey, the state’s Supreme Court remarked that nursing home care in general was “troubled and troubling” -- so they added an additional level of review by a state ombudsman to certify that no abuse was involved. The Conroy decision in 1985 was followed by similar cases involving young women -- all in their twenties and in PVS -- Nancy Jobes (NJ 1987), Nancy Cruzan (Missouri 1990) and Terri Schiavo (Florida 2005). And despite publicity and furor, sound and fury, eventually each of these cases were decided by high courts in the same way – what was construed as the patient’s best interest prevailing-- although in the case of Terri Schiavo it took fifteen years before her feeding tube finally was removed. When discussing problem cases like these, its necessary to
be clear about what specific condition is involved because imprecise terminology adds to confusion. So let's review several terms:

1. Brain Death indicates that the “whole” brain isn’t working – not merely higher cortical function but the brain stem as well. In 1968 a committee at Harvard established diagnostic criteria which thirteen years later were endorsed by a President's Commission -- so there are specific tests that can be performed to establish the diagnosis. What drove this often acrimonious debate was that it facilitated using non-living organs for transplantation – the donors are legally dead even though the heart continues to beat – sometimes they’re called heart beating cadavers. Today in every state if your entire brain has been destroyed you’re legally dead – except in New York and New Jersey where the law recognizes religious exceptions for those who don’t accept the concept. (In effect, death is an option here.) Secular law is one thing, but what about religious law? Last week we discussed certain Jewish attitudes but other folks also have concerns.

You probably remember the recent case of Jahi McMath, a 13 year old in Oakland, CA who had a cardiac arrest during a tonsillectomy performed because of sleep-apnea and was declared brain dead. However, her family disagreed with the diagnosis and refused to have her respirator removed. They were Christians with firm religious beliefs, supported by their counselors, that as long as the heart is beating, that their daughter is alive. They brought in their own consultants who said that there was some brain activity but they didn’t follow standard protocols. The family got permission to move her to New Jersey where the brain death law is not absolute. So with funds provided by the Terri Schiavo Life & Hope Foundation, this past January she was moved to St. Peters Children's Hospital in New Brunswick still on a respirator. That was three months after the surgical mishap and all during this time her mother continued to play
music, braid her hair, polish her nails and claimed that she responded to them by moving and, as far as I know, still does – apparently she was eventually moved to a private home somewhere in New Jersey.

You may remember that at about the same time, there was the converse situation in Texas. Marlise Munoz, a pregnant woman with a viable fetus was legally brain dead but kept on a respirator for more than two months against her husband’s wishes because of a state law which says that life support can’t be removed from a pregnant woman until the fetus is viable and can be delivered. A Catholic theologian argued that life begins at conception so that removing the respirator would be criminally killing the fetus. But others said that the law only applied to living patients and not to someone who is already dead. No formal death certificate had been completed so, in effect, Mrs. Munoz was a living corpse. But after two months of public wrangling, a court finally ruled in the family’s favor and Mrs. Munoz was removed from the respirator. So you see that even death isn’t always final.

2. The condition known as Persistent Vegetative State (or PVS) – what KAQ, Nancy Cruzan and Terri Schiavo all had -- was first described in 1972 by a New York neurologist Fred Plum. The title of his paper in The Lancet was “A Syndrome In Search of a Name.” At times patients in PVS may appear to be awake, but they’re not aware; their eyes may be open and sometimes drift, simulating tracking, but although the eyes move they don’t see. There also may be certain reflex movements. Coma that lasts for more than a month is described as being “persistent” – after a year the nomenclature changes to “permanent vegetative state.” There are extremely rare cases of late awakenings which are widely reported and some of these patients had been misdiagnosed. In recent years functional MRIs sometimes have shown small islands of working cerebral cortex but their clinical significance is doubtful. Patients in PVS don’t meet neurologic criteria for
brain death because their brain stems still function but there’s no higher brain or cognitive function – or is there? It was reported that Ariel Sharon’s MRI scan sometimes would light up when family members spoke to him -- but if he actually understood them, perhaps he was trying to say please turn off the respirator.

I once reviewed the case of a man who’d been in PVS for 19 years after head trauma sustained in a motorcycle accident. His mother visited all day, every day and insisted that she could tell that he knew she was there. I interviewed all the nurses and therapists who cared for him and not one agreed with her -- nor did others in her family. But no one had the heart to dispute a mother’s love – of course, she wasn’t paying for his care and the hospital was being paid well for a head in a bed – whatever was going on inside. So were his doctors.

3. There’s a related condition called Minimally Conscious State – (it’s not the same as “minimum brain disorder” which applies to children with autism or certain related syndromes.) In fact, these patients do have some slight awareness, which may be intermittent and sometimes they make meaningful improvement, but the longer the condition lasts the poorer the prognosis. It’s unknown how many such cases there are and they may be part of a spectrum of coma syndromes.

4. Then there’s the so-called Locked-In Syndrome – an extremely rare condition when the patient IS fully wake but immobile – only able to communicate by blinking the eyes. Such a case was described several years ago in the movie “The Diving Bell and the Butterfly.” So there are gradations and distinctions that have to be kept in mind when we’re discussing this subject.
Now let’s consider the troublesome matter of what is called “Medical Futility” – its troublesome because what one person considers futile another disagrees with and says “keep trying – we’re praying for a miracle.” This returns us to the subject of “paternalism” which I discussed last week because usually it’s a doctor who determines whether a medical treatment is likely to work – or not work. Occasionally, a problem arises if a family disagrees that to start or continue aggressive treatment would only be prolonging the dying process. To one person a 20% chance of success is worth taking; someone else might say that even if the odds are 100 to 1 or even a remote possibility of success, to keep on trying, especially if it’s your loved one. And it’s particularly poignant if the patient is young – less so for someone who’s led a full life.

Such a case occurred in New Jersey in 2008 (Betancourt v. Trinitas) when a 78 year old man had a tumor removed from his chest, but in the recovery room lapsed into a coma – presumably due to lack of oxygen to the brain, anoxic encephalopathy. After a year in the ICU with everthing imaginable done but no improvement, the angry family wanted to keep treating. The man’s body was showing signs of decomposing and the hospital’s ethics committee felt that it was inhumane to continue, but he was kept in the ICU. And when his heart finally stopped and he died, the family sued the hospital and the doctors for writing a do not resuscitate order. In the end, the court deferred to the family. They said that this kind of decision really was not for judges to make (true) and since there was no societal consensus about what to do, it was a matter that needed legislation -- which, presumably, better reflects the community’s will. Needless to say, that legislation has never come – and except for a weak law in Texas, no state has tackled the futility issue.

As you know active euthanasia, (physician PERFORMED, not just prescribed) is legal in the Netherlands, Belgium and Luxembourg. There
hasn’t been any slippery-slope apparent yet although this year when Belgium amended their twelve year old active euthanasia law to include chronically ill children who seem to have uncontrollable suffering that has provoked considerable criticism.

25 years ago Jack Kevorkian was doing somewhat the same thing in his death van. “Dr. Death”, as he was called on the cover of Time Magazine, was part crusader, part show-man and usually had the patient trigger the “death machine” – an IV filled with drugs – 140 people died this way – none of whom were his patients. But in 1998 Kevorkian out-smarted himself. On a segment of 60 Minutes Dr. Death couldn’t resist doing it himself while on camera – so he personally administered the lethal brew to a patient – and later he paid the price. He was convicted of second degree murder and was imprisoned for eight years.

But at least Kevorkian brought the issue out of the closet and other more responsible doctors took up the cause of physician ASSISTED death. When the matter went to the USSCt in 1997 they ducked making a decision and ruled that each state should set its own policy – just like last week with gay marriage. So that’s exactly what’s happening now in six more states. In New Jersey a recent poll showed that 46% of people were in favor of physician assisted death, 38% against and 16% undecided. A bill passed the State Assembly earlier this year, but later was pulled from debate when groups with names such as “Not Dead Yet” objected. I've been against passing a doctor assisted death law in New Jersey -- because although I agree with it in principle, I don't believe that the general public is ready for such a nuanced subject and it's likely to open a counterproductive can of worms.

Despite my reservations, such a law is legal in five states. The movement began in Oregon in 1997 and after eight years other states began joining in
Washington, Montana, New Mexico, Vermont. After many years the experience in Oregon has been that even after a physician prescribed a lethal dose of some drug, terminally ill patients very rarely took them – but many of them expressed relief that, at least now they controlled their own fate. In 2003 of 30,000 people dying in Oregon, 1,800 received a prescription for lethal drugs but only 600 actually used them – that’s 1/3 with a Rx and 2% of all deaths.

Last month (9/17/14), after two years of study by a panel of experts, the Institute of Medicine issued a more than 500 page report titled “Dying in America.” No doubt some of you have heard about it. The report urged overhauling our health care system as it relates to the end-of-life and noted that there’s a disconnect between what most people would want for themselves or their loved ones and what they actually get. The default mode of the current system is geared towards doing more and more. Obviously, this is a major driver of health costs and whether or not its money well spent is problematic. Among other things, the panel suggested that the fee-for-service reimbursement structure should provide incentives for patients and doctors to talk about end-of-life options and should encourage low-tech approaches for comfort care and palliation rather than high cost technology and ICUs. Critics of the recent Institute of Medicine report’s emphasis on cost-savings said that it might create a not so subtle pressure for people to throw in the towel too soon in order to save money. Distasteful as it may be, we can’t just go on expecting that anything goes when it comes to us or our families and so long as someone else is paying.

A survey performed by the Pew Research Center last year found that only 37% of adults reported having thought much about their wishes regarding end-of-life care. Another 35% said they’d thought a little about it and 27% said that they’d never given it any thought. When asked more than 80% of people usually say that they wish to avoid hospitalizations and high
intensity care at the end of life but recent studies indicate that only
between 25 and 30% of people actually have completed advanced
directives.

Another study reported that more than 90% of people agreed that their end-
of-life preferences should be discussed with their doctors but less than
20% actually had. Most people still shun talking with others about death –
as if its too morbid or somehow might hasten the event. It’s not the kind of
subject that one talks with family about around the Thanksgiving dinner
table but some have suggested that it should be. But simply checking off
boxes and handing a document to an admissions clerk along with your
insurance card is a poor substitute for useful communication. And even
with properly completed forms there still may be disagreements between
family members or with doctors.

Last week the Times reviewed a new book by the Harvard surgeon Atul
Gawande (“Being Mortal: Medicine and What Matters at the End”) and the
previous week they printed a chapter from the book (“The Best Possible
Day,” Oct. 5) Dr. Gawande described how it took him many years of
practice until he learned what kinds of questions to ask a terminally ill
patient – things like: What are their goals if their condition worsens? What
are their fears? What trade offs are they willing to make? He described the
poignant case of a woman named Peg who was dying of leukemia who said
that she wanted just one more good day. Peg was Gawande’s young
daughter’s piano teacher. She had no children of her own and derived her
greatest pleasure from her students. What she wanted was one last chance
to teach and so it was arranged – she was discharged home, supervised by
hospice, and the students came and played for her in her living room. At
the end, Peg took each student aside and whispered something personal to
them. When she put her arm around Gawande’s daughter, she told her
“You’re special.” It was something she never wanted her students to
forget. Now that’s going out in style. This week the Times published several letters to the editor in response to Gawande’s oped article. One doctor wrote that concerning terminal illness we all should remember that there’s a difference between living longer and it only seeming to be longer because every day is marked by misery. Another writer encouraged more provision of palliative care, even when not specifically provided by hospice.

Surveys of what doctors want for themselves when they’re terminally ill find that most of them want to be at home and kept as comfortable as possible – they’re not interested in prolonging poor quality life at any cost. But that’s not what many doctors actually practice. Until very recently medical schools provided little or no training in palliative or hospice care – it took on the job training for providers like Dr. Gawande and me to learn how to ask the right questions. Thankfully, things are slowly changing. Last week I read an article about how Dartmouth Medical School has introduced a course which teaches the intangibles of doctoring to first year students – the so-called “art of medicine.” Another positive trend is the move toward a team approach to patient care – doctors don’t have to be soloists anymore – others may be better suited to counsel and support. When I said last week that I’d be uncomfortable practicing today, I was referring to the present system in which health care workers work – nurses having to spend more time record keeping than at the bedside; doctors glued to their computers – no time to make eye contact or hand-hold. These days there’s production line care, disincentives for young doctors in heavy debt to enter primary care positions, overspecialization. The current crop of doctors are no less compassionate than my generation, it’s just that the system doesn’t permit them to take the time to go beyond the immediate complaint, to listen to the patient’s fears and address their questions.
I suspect that most of you have advance directives -- and if not, why not? But even if you’ve gone on record about your wishes, you or your family may find that the system is stacked against you. Last week someone mentioned a recent article in the Times (9/26/14) which described the tragedy of one woman who although she tried to honor her 92 year old father’s request to die at home, found that he kept getting shuffled back and forth between hospitals and nursing homes, each of them extracting as much money as they could for unneeded or unwanted services. One expert said that “you can’t believe the forces that are arrayed against dying at home....The way the reimbursement system works, these decisions are not made on the basis of what individuals need but on what the institutions need.” Just this year my own family experienced a similar scenario and I suspect that some of yours have too – for, as you all know, these days it’s easier to get a $100,000 drug than a home health aid.

Whatever people may prefer, Medicare statistics from 2009 (the last year that data is available) indicates that 25% of people aged 65 or over died in acute hospitals – and a third of them were treated in the ICU during their last month of life. 28% of patients died in nursing homes and about 34% at home. 42% received some form of hospice or palliative care which was a small increase compared to a decade earlier. (JAMA 2/6/13) So although most people would prefer to die in their own beds, only about one third do.

Despite all this, there’s hope that things are starting to change. Perhaps by repetition and frequent discussion people will increasingly make sensible decisions that are cost-effective and in the future perhaps how hospitals, nursing homes and doctors are paid will better reflect what patients really need. Five years after Sarah Palin made her foolish “death panels” comment, the issue of paying doctors to talk to patients about their end-of-life preferences is making a comeback. Some private insurers have begun reimbursing doctors for advance care planning discussions – and one Blue
Cross-Blue Shield plan will pay doctors $150 for an hour of counseling. Financially incentivizing doctors to do what they should have been doing in the first place is fine, but it takes two to tango and patients should demand the opportunity to be register their wishes and not wait until it's too late.

The AMA has asked the Centers for Medicare and Medicaid which runs Medicare to change its rules and because Medicare covers some 50 million Americans, their cooperation will be crucial. Colorado and Oregon already cover end-of-life counseling for Medicaid patients and, although there are still opponents, there are ever more proponents – even including some Republicans.

The growth rate of medical spending has been slowing, but it’s projected to rise again and it’s unclear how Obamacare will change the trajectory? Although unnecessary tests and hospitalizations need to be reduced, this will be easier said than done. New York and New Jersey lead the nation in most days spent in hospital by terminally ill patients (NY 14.4, NJ 12.9, national average 9.8) and in most dollars spent on end-of-life care. The fee-for-service system to reimburse doctors is corrupting since it incentivizes everyone to do more -- call more consultants, order more tests and procedures. Physician payment will have to be modified in some way and there will need to be legitimate competition among hospitals and insurers; Big Pharma also needs to be reined in. But consumers also will have to play -- and probably pay -- a greater part. So if you say that you want everything to be done, better be careful what you wish for. That’s the time to have a serious discussion with a doctor who is prepared to listen and who is sensitive to social, psychological and religious matters -- in addition to being a competent clinician. Good luck in finding such an enlightened person!
More than a half century ago, in 1960, a conference was held at Dartmouth College called “Great Issues of Conscience in Modern Medicine.” In his opening remarks, the chairman René Dubos, a famous microbiologist at the Rockefeller Institute, addressed the subject of saving the lives of children with severe genetic defects and he predicted that this would be the most difficult problem of medical ethics in the coming decade. Here’s what he said:

*To what extent can we afford to prolong biological life in individuals who cannot derive either profit or pleasure from existence, and whose survival creates painful burdens for the community? This is not a decision for the physician whose duty is to save and prolong life. It will be up to the society to redefine these ethics…*

All these years later, René Dubos’s concern is more challenging than ever and not just for severely deformed infants. Last week I described how we’ve evolved away from traditional paternalism but now let’s consider what our society has accomplished in the ensuing time.