

THE LEGACY OF KAQ

On April 15, 1975 a 21 year old New Jersey woman attended a friend's birthday party and drank a few gin and tonics. She'd been taking an unknown amount of Valium and also she was on a crash diet. When she complained of feeling faint, friends took her home and put her to bed and when they checked on her a little later, she wasn't breathing. A rescue squad came quickly, attached her to a respirator - and the rest is history!

That young woman was Karen Ann Quinlan and before long her story was known throughout the world. Her high school graduation picture appeared on the cover of news magazines and new phrases relating to her case entered the vernacular: "pull the plug", "you're a vegetable," death with dignity, right to die. To some people Karen seemed like a pretty maiden held captive by a nasty machine. Every one could identify with her plight. Millions of people said, "I never want to be like Karen Quinlan." Probably some of you did too.

Why all the fuss? Because when it became clear that Karen wasn't waking up, her family asked for the respirator which was keeping her alive to be removed. But was she really alive? Biologically yes, but what kind of life was it? Barring a miracle recovery, was the quality of such an existence sufficient to warrant indefinite life in limbo waiting for a miracle to happen?

Neurologists diagnosed Karen as being in a recently described condition called a persistent vegetative state - or "PVS." Although her eyes were open they could not see. There were limited reflex movements but nothing purposeful. She didn't appear to be in pain and sometimes even seemed to be awake - but she was not aware. PVS is a form of coma in which higher brain function is lost but brain stem function continues. By definition, they are NOT "brain dead" - that would require absence of both cortical and brain stem function. Her brain stem worked fine.

At any given time there may be thousands of people in PVS - usually as a result of brain trauma, stroke or oxygen deprivation such as from drowning (some estimates go as high as 30,000.) Depending on the patient's age and the cause of the injury, some people recover after a few weeks or months while others can linger for years - the world record is more than 30 years. The longest of one of my patients was 19 years. He had been in a motor cycle accident and his mother sat beside his bed, all day every day, convinced that her son knew she was there. However, not a single doctor, nurse or caregiver could detect any sign of awareness or responsiveness on his part. Nevertheless, everyone respected a mother's determination to hold on while praying for a miracle to happen. And, of course, she wasn't paying the bills - an insurance company was.

Because there are several variants of coma (e.g. minimally conscious state, locked-in syndrome) it may be difficult to distinguish between them and in recent years supersensitive brain scans sometimes have shown small islands of partially functioning cerebral cortex in patients with PVS. Despite this, for the vast majority of prolonged comas, the prognosis is dismal. Occasionally one reads of a miraculous late recovery, but the longer that coma lasts, the less likely any possibility of meaningful improvement. And if PVS lasts for more than a year, the odds of recovery are thousands to one.

Although Karen Quinlan's doctors were sympathetic, they were afraid of being sued. As they understood it, to deliberately cause death, even by inaction, was against the law. Some doctors argued that their job was to save lives, not end them. So the Quinlan family went to court and on March 31 1976 (just 40 years and two days ago!), New Jersey's Supreme Court ruled that it would be permissible for her parents to have the life-sustaining machine removed so long as qualified doctors testified that there was no reasonable likelihood of her returning to a sapient (thinking) condition. In that case, death would not be considered to be a deliberate act of homicide, but allowing death to come naturally - and there would be no liability for anyone involved.

But when the respirator was removed after more than a year, to everyone's surprise Karen did not die but began to breathe on her own - and she lived on in

a nursing home for another nine years, fed through a tube and never waking up, until in 1985 at age 31, she died of pneumonia.

The Quinlan decision is often called a legal landmark. It was the first so-called “right-to-die” case and it established that an adult patient can refuse medical treatment even if by so doing death may result. Moreover, it ruled that others can exercise the patient’s known wishes or lacking that, act in their best interests. The Quinlan decision would be followed by many more judicial decisions which explored other circumstances when life-preserving treatment could be stopped - or not started. Some of the most problematic cases were when artificial tube feeding was involved because providing nutrition seemed to have symbolic meaning - not to feed suggested not caring, starving a person to death, causing suffering. In some cases the rhetoric got pretty gruesome. Nevertheless, most caregivers of such patients contend that during the final stages, these patients seem to be comfortable. Incidentally, regarding the matter of providing food and fluids, case law in New York State requires a higher standard of evidence than elsewhere (see *Mary O’Connor v. Westchester*, 1988.) So if you don’t want IVs and tubes at the end of life, you better specify it in writing.

Most people agree that a patient’s own choice about what should or should not be done to them should be honored. If they’ve never made their wishes known and no longer can choose for themselves, someone close to them can act in their best interest. The proxy, family or friend or court appointed guardian, should not decide what they would want for themselves but should ask what if, miraculously, the patient could momentarily awaken and speak - What would they want? I wonder how many people would choose many years of life in limbo with infinitesimal odds of returning to any semblance of normality. Would you?

Among the innovations to guide decision-making that emerged over the past four decades has been the introduction of living wills/advance directives. Another byproduct of the Quinlan decision was that in similar cases of patients in PVS, the decision making process must be supervised by a multi-disciplinary ethics committee. As it has evolved since, such a committee’s role is not to make the

final decision but to consult and confirm that everything has been done to respect the patient's own wish or, lacking knowledge of that, what would be in their best interest. Nevertheless, although in certain circumstances removing life-support might be legal, many people have asked, and continue to ask, whether it is "right" in a moral sense?

During the 1980s I began to wonder about how these legal and ethical matters effected my own practice? When I was elected governor of New Jersey's internal medicine organization (NJ-ACP), I was appointed to the state's bioethics commission which developed statutes concerning such issues as brain death and advance directives and for many years I served on hospital ethics committees which consulted in difficult cases. So I've been influenced by more than my own experiences as a practitioner. We could discuss the legacy of the Quinlan decision from several perspectives, but today I'd like to focus on three distinct areas:

1. The evolution throughout history of the doctor-patient relationship.
2. How individual choice sometimes conflicts with religious obligations.
3. Current options concerning end-of-life decision-making.

Let's begin by considering how medical decisions were made before the Quinlan decision of 40 years ago - not only in unusual cases, but also in mundane situations.

1. THE PATERNALISTIC TRADITION:

Everyone has heard of Hippocrates, the so-called Father of Medicine, who lived more than 2,000 years ago on the Greek island of Cos. And everyone knows of the oath that he supposedly wrote which, in effect, has served as the physician's moral compass. Although the Hippocratic Oath is often cited, few have read it - including most doctors; or at least not since they may have recited it in unison at medical school graduation.

In the Hippocratic Oath, the doctor publicly vows or professes (thus the word “professional”) to do what in his own judgement will benefit the patient. He pledges to do no harm - and specifically, will do nothing that might hasten death. The Oath says that patients should follow doctors “orders.” Indeed, the appropriate decision maker is the physician. It was believed that patients are not up to the task and should be treated like children by a benevolent father. The word used to describe that is “paternalism.” It’s based on the notion that doctor knows best and should be obeyed. Let me read what several famous doctors had to say about the doctor- patient relationship:

1803: Benjamin Rush in a speech to medical students in Philadelphia: “The sources of vexation to a physician arise from the ignorance of mankind of the nature of medicine....Yield to them {patients} in matters of little consequence, but maintain an inflexible authority over them in matters that are essential to life.”

1843: The AMA’S First Code of Ethics: Doctors should “unite tenderness with firmness and condescension with authority [so as to inspire the minds of their patients] with gratitude, respect and confidence. The obedience of the patient to the prescriptions of his physician should be prompt and implicit...He should never permit his [the patients] crude opinions...influence his (the doctors) attention to them.”

1868: Oliver Wendell Holmes, Sr: “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.”

1889: William Osler: “In matters medical the ordinary citizen of today has not one whit more sense than the old Romans, whom Lucian scourged for a credulity which made them fall easy victims to the quacks of the time...Deal gently then with this deliciously credulous old human nature in which we work, and restrain your indignation.” (Patients are a burden)

1914: U.S. Supreme Court (in *Schloendorff v. Society of New York Hospital*): “Every human being of adult years and sound mind has a right to determine what shall be done with his own body... a surgeon who performs an operation without his patient’s consent commits an assault for which he is liable in damages.” (Doctrine of informed consent)

1954: Dr. Francis Moore re kidney transplants: “Under no circumstances should the final decision be left in the hands of the patient; he has not the education, the background, the dispassionate view necessary to make the decision in his own self-interest.

However, since the Quinlan decision of forty years ago, the tradition of medical paternalism has taken a beating and these days the word often is used as a pejorative. The Quinlan decision changed doctor-patient dynamics and, as a result, the Age of Paternalism morphed into the Age of Autonomy. I’ll briefly mention five seminal court decisions that effected this evolution .

1976: KAREN QUINLAN: Based on a Constitutional Right to Privacy (recognized in *Griswold v. Connecticut* in 1965 and *Roe v. Wade* in 1973), patients (or their surrogates) have the right to refuse life-sustaining treatment even if such refusal might lead to death. Adult patients can balance their personal beliefs with conventional medical wisdom and if they fear losing the ability to express themselves, can leave advance directives about their wishes or have legitimate surrogates act in their behalf.

1985: CLAIRE CONROY: Another New Jersey Supreme Court decision involved a terminally ill minimally responsive 84 year old with no family or advance directive. It was the first case to address artificial feeding for life support. The court ruled that a feeding tube is morally neutral - what matters is not the tube per se but the context in which it is used. Just as with a respirator, it can be removed or not inserted in certain defined circumstances. But in the case of nursing home residents like her, a state ombudsman should review the process in order to rule out elder abuse.

1989: *LARGEY v. ROTHMAN*: New Jersey's Supreme Court overturned the traditional "professional standard" that a physician need disclose only what other physicians within the same medical community would reveal in similar circumstances. Instead, they adopted the so-called "prudent patient standard" which required physicians to tell whatever a "sensible" patient needs to know in order for THEM to make an informed decision.

1990: *NANCY CRUZAN*: Involved a 33 year old woman in PVS for eight years after a head injury sustained in an auto accident. Missouri law required "clear and convincing" evidence (usually a written advance directive) of a patient's wishes before life-support could be discontinued. This was the first and only time that the United States Supreme Court intervened in a right-to-die case. They ruled in favor of Missouri's right to have such a law and suggested that other states ("the laboratory of the states") should decide for themselves on such matters. Having "won" their legal battle before the USSCt, the state's district attorney (Ken Starr) decided that Nancy's verbal comment to a friend was sufficiently "clear and convincing" evidence of her wishes and permitted the tube to be removed - after ten years.

2004: *TERRI SCHIAVO*: A 33 year old woman in PVS for thirteen years whose parents wished to continue tube feeding despite her husband's insistence that's not what she would have wanted. They claimed that he only wanted to get her money. It took eighteen years for the the dispute to be resolved. There were fourteen court reviews over seven years and when the tube was removed, Governor Jeb Bush signed what was called "Terri's Law" which required that it be reinserted. President G.W. Bush also got involved but, In the end, Florida's Supreme Court ruled that the Terri's Law was unconstitutional that the president, and his brother the governor and the state legislature and Terri's parents had no right to override her husband's decision which seemed to best represent the patient's own preference.

So over the last four decades there's been legal recognition of a patient's right to decide for themselves and the dynamic changed from physician paternalism to patient autonomy - or at best, some degree of shared responsibility. But is that always good? Many doctors long for the good old days when decision-making was easier.

FUTILITY

Some people worry that the trend to autonomy has gone too far - that doctor's have lost all authority to do what they think is best. What happens if a doctor is convinced that its terribly bad judgement to start or continue to treat aggressively when nothing useful can be achieved - when treatment not only is terribly expensive but perhaps is wasteful of limited resources. That dilemma involves what's commonly referred to as "futile" care and what to do in that case continues to be problematic.

2008: Betancourt v. Trinitas Hospital was a rare instance where such a conflict about futility was argued in an appeals court in New Jersey. Ruben Betancourt was a 73 year old man who suffered brain damage during surgery for a malignant thymoma. For months he received dialysis in an ICU even though he was thought to be in PVS. Consultants and the hospital ethics committee believed that it was inhumane to prolong the process of dying - he was already developing necrotic pressure ulcers - and they wished to discontinue dialysis and write a DNR order - the time hospital costs were approaching \$2 million. But the patient's daughter wasn't ready to stop. She insisted that he was aware and wished to keep going. Also, at issue was a possible malpractice case since brain damage had occurred during surgery. A lower court ruled that she was an appropriate surrogate for her father and the case went to an appeals court. In the meantime, Mr. Betancourt died - still in the ICU and on dialysis - but the case continued because it might set a legal precedent for similar cases in the future. Well it didn't. The court waffled and said that because the patient had already died, the case was moot. Why argue about how to treat a dead man? They agreed that profound societal issues were involved, but that these should not be decided in courts but by legislatures which better reflect the voice of the people.

Needless to say, that hasn't happened. In fact, only one state has ever passed legislation regarding medical futility and that was Texas. A law was signed in 1999 by then governor George W. Bush that gave the last word to a hospital ethics committee which in unusual cases could override a patient or family's wishes. Apparently that authority has been used only a few dozen times in the ensuing nearly twenty years.

2. RELIGION:

Some people criticize this country's approach as being overly concerned with rights and insufficiently responsive to moral or religious issues. In other words, what's right might not always be correct. Karen Quinlan's family were devout Catholics and their choice was approved by their own priest, but the Catholic position on end-of-life care has been rather ambiguous. The Quinlan decision came just three years after Roe v. Wade so there was some symmetry between when life begins and when it ends. Just as with abortion decisions concerning the sanctity of life at its beginning, didn't the same principles apply at the very end of life? In an encyclical issued in 1957, Pope Pius XII distinguished between ordinary and extraordinary medical treatment so in a case like Karen's some Catholics argued whether the respirator was ordinary or extraordinary - again, what's ordinary in one circumstance might be considered extraordinary in another. The respirator itself is morally neutral. If context matters, so does intent. For example it is legally permissible to give a large dose of a narcotic in order to relieve pain even if an unintended consequence might be suppressed respiration and death. That's called the principle of "double effect." But who'd to say what the doctor really was thinking? How can we know whether covertly he or she wished to hurry things along?

JEHOVAH'S WITNESSES - Many years ago, I think during the 1970s, a challenging case played out at my hospital in NJ - Pascack Valley. A woman in her 20s who already had two young children had Cooley's Anemia, a hereditary condition for which there is no treatment other than blood transfusions. But she was a Jehovah's Witness and fundamental to her religion is that blood

transfusions can never be administered. Her hemoglobin had fallen to 2 which is incompatible with life, but she was being treated at Good Samaritan in Spring Valley where they insisted on transfusing her. Her husband arranged for her to be transferred to my hospital which has no religious affiliation. She was treated there by a well-respected hematologist who agreed to respect her choice which was endorsed both by her husband and her mother. When she died a front-page headline in the Bergen Record reported that her children were told "Momma's Gone to Heaven." But court decisions in Jehovah's Witness cases tend to be inconsistent - some courts will override a patient's autonomy if their avoidable death would adversely effect others - especially young children. In this instance since the husband and parents were able and willing to care for the kids, the woman's choice to enter heaven only with her own blood was honored.

JEWISH PERSPECTIVES:

What about Jewish perspectives? Everyone knows that there are wide divisions among Jews on religious and social issues and sometimes this effects medical matters. A recent Pew Research Center survey of more than 5,000 Israeli citizens found that of the 40% who identify as being secular, about 90% think that democratic principles should prevail over traditional religious law while about 90% of the roughly 20% who are orthodox or ultra-orthodox believe that religious law should predominate. The legal system reflects this division with both elements of orthodox interpretation of Jewish law - what's called halacha - as well as American-style law. Sometimes the hybrid creates conflict so lets consider some examples.

You might be surprised to know that attention to medical ethics from a Jewish religious perspective is fairly recent. The first modern text book on the subject was written only in 1959 - and in Ireland, no less - by then Chief Rabbi Immanuel Jakobovits. (He later went on to become the chief rabbi of England and was made a member of the House of Lords.) Before his book, any resolution of medical dilemmas could only be inferred by extrapolating from ancient Talmudic discussions.

Traditional Jewish religious thinking is extremely pro-life. Quality of life is not a concern - life itself is, regardless of its quality or how we feel as individuals may feel about it. When it comes to health, it is as if we are only tenants in our bodies and, as such, are obliged to take care of what we doesn't belong to us. God makes and God taketh away. Life itself is sacred and, with very rare exceptions, a Jew is obliged to doing everything possible to preserve life until death is imminent - that is when the so-called "goses" is in the process of dying; as it is written, when the "death rattle" can be heard. And, as we shall see, even then, nothing positive can be done to hasten the inevitable.

Naturally there are exceptions - rabbinic loopholes - and even among the orthodox who are explicitly guided by the Talmud. A well-known tale from about the year 200 CE, describes the death of the great leader Judah haNasi - known as Judah The Prince - who was the redactor of the Mishna. The old man lay dying of a natural cause and appeared to be in great pain. He was surrounded by many of his followers, all continuously praying that Rabbi Judah be allowed to live. Observing the scene was Rabbi Judah's loyal and long-time handmaiden who only wanted his suffering to stop. So what did she do? She climbed up onto the roof, saw a clay pot and hurled down into the stone courtyard. It made a loud noise and the praying rabbis were startled - and for just a moment or two, they stopped praying for life. And in that instant Rabbi Judah drew his last breath and passed away. A Talmudic example of stopping artificial life support - in this case, prayer.

Over the centuries, the story elicited much commentary, but the rabbinic consensus was that the handmaiden did the right thing. She had acted out of compassion - it seems that there is a place for quality of life after all - if only in extreme cases. In contemporary life, it remains for rabbis - not doctors or others - to decide when to apply that principle. I suspect that most of us would be very uncomfortable with that. Four years after the Quinlan decision, in 1980, Ruth Trebelsi was an 84 year old diabetic woman who lived in the northern Israeli city Tiberius. She had a gangrenous leg and doctors said that unless it was amputated she would surely die. Ruth was a feisty lady, fully alert and said that

she wasn't afraid of dying - but that when she arrived in heaven she wanted both legs to be intact. She and her family were religiously observant but no one could make her change her mind. Israel's chief Ashkenazic rabbi flew from Jerusalem to Tiberias in order to counsel her. He explained that as an orthodox Jew, it was her obligation to follow doctor's orders and God's command. Jewish law teaches that life has infinite value and should not be thrown away. You may not value your life but your family and your community, do. So Ruth Trebelsi gave in, the amputation was performed and she soon died of complications. And when she was buried along with her severed leg, she was praised for being a righteous woman - just like Judah HaNasi's handmaiden.

In 2005, twenty-five years after Ruth Trebelsi died, Israel's Knesset passed what was called "The Terminally Ill Patient Law." For five years a multi-disciplinary committee had discussed the tension between secular and religious law and tried to iron out compromises. There was token representation on the committee from minority groups, including a single conservative rabbi and even an Arab - there were no reform representatives. But most members were orthodox Jews including the chairman Dr. Avram Steinberg, chief of pediatrics at Share Zedek Hospital and an expert on Jewish bioethics. The "Steinberg Commission" - as it was called - and wanted to balance the sanctity of life with an individual's right to choose for him or her self and sometimes this created problems.

Israel's law is complex and little understood and, literally, an example of the Devil (!) being in the details. To my mind, the most bizarre recommendation concerns dying patients who are attached to respirators. Since God forbids doing anything active to hasten death, how can you pull the plug? In fact, if the plug get pulled out by accident, it need not be plugged back in, but deliberately pulling it is forbidden. But the Commission's big compromise was even more inventive. It said that for a terminally ill patient (<6 mos) you don't have to resume once a cycle of treatment is completed - and it's easy to understand not restarting chemotherapy. But based on this principle, the Steinberg Commission suggested using the equivalent of an oven timer attached to a respirator. When it runs down its not the doctor but the machine that's at fault - the timer runs down and the deed is done.

Or is it? After all, remember what happened to KAQ? She lived on for nine years. To me that's a too clever way of getting around religious law - its rather like using Shabbos elevators or letting a goy turn on the lights.

In 2014 a case was heard in a Tel Aviv court which involved a man with severe ALS. He was so incapacitated that for about seven years he could communicate only by blinking his eyes - and now feared he might be losing that ability. He wished to die with dignity but technically he wasn't "terminal" enough, because he might be kept going for more than the legal threshold of six months. Israel's attorney general reviewed the case and ruled in favor of the patient's request. This time the gimmick wouldn't use the equivalent of an oven timer but merely the ventilator's rate to much lower than normal. Presumably, death would come naturally, albeit at a slow and unpredictable pace and, at the same time, the man would be given "terminal sedation" to prevent suffering from asphyxia. Was this a case of euthanasia? mercy killing? doctor-assisted suicide? Naturally, there were objections and fears of starting down a slippery slope. I've been unable to find anything on-line about what happened next but I have the sense that once the court ruled, euthanasia, or whatever you call it, was accomplished.

But wait - the issue is further complicated because sometimes miracles do happen. Recently, Hadasah Hospital reported improvement in 90% of 29 patients with ALS using a technique in which stem cells from the patient's own bone marrow are reinfected into the spinal fluid and presumably become functioning neurons. So maybe praying for a miracle is the way to go after all.

3. END-OF-LIFE OPTIONS

You may recall Jack Kevorkian, the euthanasia activist who was nicknamed Dr. Death. In 1999 he was convicted of second degree murder and spent eight years in prison for euthanizing people in his death mobile. That same year, a landmark ruling by the USSCt (*Vacco v. Quill*) upheld a New York state law that bans deliberate euthanasia. The Court distinguished between letting die (passive euthanasia) by withdrawing or not starting treatment and active killing.

How do other countries handle these matters? Although euthanasia for terminally ill patients is prohibited here, it is legal in the Netherlands, Belgium, Switzerland, Columbia and since last year in Canada. In the past year both the Netherlands and Belgium have dropped the requirement of terminal illness - and some would say its a first step down a slippery slope.

Unlike those countries where physicians can actually administer a lethal dose, five states in this country now permit physicians to write a prescription for a lethal amount of a sedative (e.g. Seconal) which a terminally ill patient can self-administer when they judge the time to be right. What's now called "physician assisted death" has been legal in Oregon since 1987; in 2009 Montana, Washington and Vermont passed similar laws and last year so did California - so now one in six citizens lives in a state where physician aid in dying is an option. Thirty-eight states have statutory bans on the practice but several dozen states are currently considering similar permissive laws, including New Jersey where the legislature will debate the issue this year. Already, conservative elements are warning that replacing Justice Scalia with a liberal judge would guarantee that this will become the next Roe v. Wade debacle.

More than 50% of physicians approve of doctor assisted death in principle (the AMA doesn't), so do more than 70% of citizens polled and more than 80% of young people. Usually these laws require eligible adults to make two oral requests to a physician separated by a 15 day waiting period. In Oregon where the option has been available for nearly two decades, only about 1 in 6 terminally ill patients talk with their families about their wish to control the time of their death, 1 in 50 talks with their physicians about it and only 1 in 500 directly accesses the option. The usual reasons given by people who request lethal doses of sedatives are fear of losing autonomy (90%), less able to engage in enjoyable activities, loss of dignity or being a burden on others. All told, over the years, around 1,500 Oregonians received a lethal prescription and of them only about 2/3, actually took the pills and died as a result. Usually they are given 100 Seconal capsules which they have to empty and mix and usually within 5 minutes they are permanently asleep.

OTHER OPTIONS

In a sense the Quinlan case was inevitable. During the 1960s and 70s there were two parallel developments. As new medical technology became widely used - pacemakers, defibrillators, dialysis machines, modern respirators, organ transplants - there were new opportunities to extend life and a psychological imperative to use them. Medical machines could delay death but not prevent it altogether and increasingly, they create dilemmas about what kind of life was achieved by using them. People said, "I never want to be like KAQ." But both then and now, it was difficult to predict with any certainty who would achieve meaningful improvement and who would just linger for a long time. Many people began to ask when was enough? Are there no limits? In fact, during the past quarter century men are living about five years longer than before, women about 2.5 years longer so the current life expectancy for men is about 77 and for women 82. How much of this reflects more sophisticated technology or life style or environmental factors remains unclear.

While new life-prolonging medical treatments were proliferating, the trustworthiness of traditionally respected institutions and individuals were coming into question. The media reported various scandals - not only involving politicians but even educators and religious leaders. Nobody seemed to deserve unquestioned respect (Rodney Dangerfield) and that included doctors who usually ranked highest in public opinion polls of what profession is most trustworthy.

In 1973 in *Roe v. Wade* the U.S. Supreme Court ruled that a woman has a constitutionally protected right-of-privacy concerning abortion and, three years later, the Quinlan decision assured the same legal right to choose at the end of life. Just a few months after the Quinlan decision, California was the first state to enact a Natural Death Law which established the legality of so-called "Living Wills." In order to make sure that one's choice is clear and convincing, it is best to write it down. Within fifteen years, every state had similar laws concerning the preferred term Advance Directives. New York State recognizes two complementary documents - 1. a LW which indicates an individual's personal

wishes and 2. a Health Care Proxy which identifies who should act in a patient's behalf, even if their wishes in a specific situation are unknown.

A more recent development are POLST forms - which in New York are called MOLST forms. Unlike advance directives, these are legal doctor's orders, signed both by a terminally ill patient and their physician. They require thorough discussion regarding diagnosis, prognosis and treatment options and they are mobile - meaning they are applicable outside of hospitals, for example in nursing homes or even in the patient's own home. Mainly they involve DNR decisions, but they also can specify other things such as do not intubate or do not hospitalize. Some people post them on refrigerator doors. You can find the official New York State MOLST form on-line.

HOSPICE

In 1967 Cicely Saunders, a doctor and former nurse at St. Christopher's Hospital in London who specialized in treating terminally ill patients, established the first hospice which had emphasized pain and symptom relief and compassionate care. In this country, the first hospice opened in 1974 and the approach was approved as a reimbursable service by Medicare in 1982. By now nearly two million people have been treated in hospice programs. There continue to be issues concerning eligibility and also certain overlaps with palliative care, but I won't dwell on that. What I'd like to conclude with is what these days is called physician assisted death.

Death can be delayed but not avoided. Every year more than 2.6 million people die in this country - and although it's difficult to get reliable statistics, by far the commonest recorded cause of is heart disease which accounts for about 20% of deaths. Trailing far behind at about 10% is Alzheimer's Disease followed closely by lung cancer, COPD and strokes and everything else is down in about the 3% range.

The US leads the world in the use of expensive technology, especially use of ICUs but what are we getting from aggressive treatment and the associated high

cost? With whatever new thing that comes along, there is the impulse to use it, even if sometimes it may only prolong or create new suffering. We frequently hear macho metaphors of someone bravely fighting the battle or winning the war against death. But is that really what we want? Perhaps yes, but maybe not.

Many people worry more about the process of dying than of death itself. How we die matters, but at the end of life there are no clear right or wrong answers. Every case differs. Every person has a different point of view. Circumstances matter - e.g. age, condition, degree and kind of suffering, the impact on loved ones, religious values, cost, prognosis. Indeed, patients may change their minds. As more attention is being paid now to patient's wishes, it's true that some people want everything done regardless of the odds (after all most are not paying for it.) Various studies show that only about 1/3 of Americans have some form of advance directive and, of them, about 1/3 want to assure that everything WILL be done.

So think about it, talk about it, write your wishes down. If you don't have an advance directive or living will, why not do so? If you do have one, how long has it been since you last reviewed it and is it readily accessible for your proxy?