Not Compatible with Life

“Quality of life is the ability to give and receive love, nothing more, nothing less.”

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It was the most solemn day of the year when my father suffered the massive stroke from which he never woke. My brothers Harold, Eric, and Eric’s wife, Bonny, picked me up from the old air force base that is the now Austin airport, and brought me to the hospital where Poppy lay unconscious. There, he did not look any worse than he did two years earlier, when he was sedated and unconsciousness at a hospital in New Jersey, where I live, after suffering two heart attacks and a less severe stroke. This time he was not sedated. The doctors gave him no chance of a functional recovery.

Dr. Camp, my father’s neurologist, entered the room in the intensive care unit where my brothers and I stood by my father’s side. The cantor from Eric’s synagogue met him and Bonnie at the hospital to give his support. They joined us in the intensive care unit. It was the day after Rosh Hashanah. I offered him the customary wish for a good year that is said until Yom Kippur.

“Is he your rabbi?” the doctor asked Eric.
“No, I’m just a friend,” the cantor answered.

“My brother’s a rabbi,” Eric said, referring to me. “He just arrived from New Jersey.”

“So you don’t need a rabbi,” Dr. Camp said. That was pretty depressing to hear.

Dr. Camp was in his mid thirties, of short to medium height. He examined my father, showed us some x-rays and hurried the all into a conference room.

“Your father had the worst stroke that he could possibly have. Bilateral. He probably still has his cognitive faculties but won’t be able to move his body or head.”

“Will he be able to see?”

“He’ll probably have his vision and hearing.”

“How do you know that he can’t get better?” I asked.

“His condition is well documented. Often when patients suffer a basil artery infarct, they can’t wake up. The center for arousal is in the brain stem and that was severely damaged. After some time, other areas of the brain will take over to arouse him. I expect that when he wakes up, he’ll be in the so-called locked-in state, unable to interact with the world. He won’t be able to talk or write. The only way that he’ll be able to communicate is by blinking his eyes.”

How could he be so sure, was my immediate response. But I kept it to myself.

“Maybe when he wakes up he’ll be able to move a finger. After a few months, he’ll move an arm, then a leg. After a year, maybe he’ll have a reasonable recovery.”

“I’m not waiting a year,” Eric said.

“Ya’ll are going to have to decide what ya’ll want to do. Many patients don’t want to live like this,” Dr. Camp said.
“Is he feeling any pain?” I asked.

“No,” the doctor said. “Right now he’s sleeping. The electroencephalogram indicates a sleep mode. For all we know, he’s having vivid dreams.”

“So then what’s everyone’s rush? Let’s see what happens when he wakes up,” I said.

“That can be cruel,” Dr. Camp said. “If you wait until he wakes up, he’ll be aware of his state. It’s also harder on the family to make a decision once he’s conscious.”

“A decision for what? To pull the plug?” Now I was speaking my thoughts aloud.

“I’m not telling you what to do. My experience tells me that these are things that you have to consider.”

“I know that Daddy doesn’t want to live like this,” Eric said.

“How do you know?” Harold countered. “I think if he can communicate with the outside world, that’s enough for him to want to live.”

“Do you consider just moving a finger to communicate good enough?” I asked Harold.

“Yes.”

“I have a young stroke patient, a woman” the doctor said. “She was young at the time of her stroke, so her family decided to go for long term. After two years, she came to communicate by typing with her finger. She is now being treated for depression and cries a lot.”

Eric listened thoughtfully and then turned to Harold and I, to ask, “Is that what Daddy really wants?”
“Eric is right. It’s not his wishes,” I said quickly. I knew it. Poppy and I already discussed it. I was considering the reasons for the doctor’s point about the young woman patient. I could not see the correlation.

“That’s really the most important thing,” Dr. Camp said. “You have to go by what your father wants, not what you want.”

“But why does a person have that choice? I just don’t understand how a person has that choice.” Do we own our selves, as one owns an object? I went on thinking to myself, knowing passionately that I was inviting everyone into a discussion that might possible carry us into months and years ahead. I was firm in my understanding rushed on me like the tides on the shore near my Jersey home.

“What choice?”

“Not to live,” I said with matter-of-fact conviction.

“We have medical technology that can prolong a life,” Dr. Camp said, “but, sometimes people don’t want intervention if they know or sense they won’t have a quality of life.”

“Quality of life! This whole quality of life stuff is destroying our country!”

There was pause in the conversation. My wife and I went through this the previous year in New Jersey when doctors insisted that we pull the plug on our newborn. He had a severe chromosomal defect, and would assuredly have no quality of life. He was not compatible with life. In fairness to Dr. Camp, he at least allowed us to make the decision.

Dr. Camp assumed a more serious mien. He looked in some ways tentative, cautious.
“Sometimes we don’t want to let them go,” he said. “We can’t be selfish. We have to consider their feelings.”

“It’s got nothing to do with his feelings or mine,” I said. “It has to do with right and wrong.” Again the memories and arguments over my son Raphael flowed through me. They were stopped when Dr. Camp turned to a personal note.

“Let me tell you a personal story about my father,” he continued. “He had a weak heart. He was in and out of hospitals. Then finally he said he had enough. The day before he died, he told me not to resuscitate him no matter what happens to him. He had a heart attack. An ambulance came and I was confronted with a decision. Was I to do what I wanted or what he wanted? I told them not to resuscitate him. And he died.”

“You didn’t have to decide to take him off a respirator, which is a direct action,” I said. Prominent Jewish authorities classify withdrawal of patient from a ventilator as euthanasia, not an indirect omission of saving a life.

“That’s true, but it was still difficult,” Dr. Camp admitted.

“Why do they want to end their lives?” I asked. “Is it because of the pain?”

“We have pain killers now. We try to make patients as comfortable as possible.”

“So then why would someone want to die?”

“Maybe they don’t want to be a burden to their family,” Dr. Camp said.

“But isn’t it a mitzvoh to care for them?”

“Being a burden is a real consideration. Let me tell about a patient, a recent evacuee from New Orleans. He was already having some problems before the hurricane. When he came to Texas, I diagnosed him with amyotrophic lateral sclerosis.”

“Lou Gehrig’s disease?”
“Yes. He had only a few months. He didn’t want to burden his children, so he opted just to have pain management.”

“Was he going to die anyway or could he have lived like Steven Hawking?”

“He might have lived in a paralytic state,” the doctor said.

“Huh?” This conversation was not convincing me. Again I was brought to another place and time. Why do m conversations with doctors so often lack precision, especially when it comes to pulling the plug? Are they using emotional arguments to secure their point of view? Sure he had his experiences, and those of others in journals and papers, but there other precedents as well, others more encompassing.

“Besides the burden, why would someone not want to live?” I asked.

“Sometimes a person doesn’t have anything to live for,” Dr. Camp said.

We sat quietly in a conference room for some time when Bonnie, my sister-in-law, who up until this time had not responded or said a word. She looked at me strangely, as if I were a fanatic. She had enough of my continual questioning over pulling the plug.

“People don’t want to live like that,” she said to me bluntly. Then she addressed the group. “I want everyone to know, that if I ever become like that, do not keep me alive.”

No one responded. The room seemed to grow quieter.

“But still, you don’t know what his actual state will be when he wakes up,” I insisted, despite the silence.

“The best possible scenario is that he has his mental faculties but communicates only by blinking his eyes,” Dr. Camp said again. “That is what the medical records show in cases like this.”
I read through this, beyond the emotions. The doctor first said this was the expected scenario. What the doctor was really saying this was the best scenario.

“And with this understanding of recovery and the ability to communicate, people are ready to pull the plug and give up. Doesn’t this skew the statistics?” I asked.

“Not everyone wants to pull the plug,” Dr. Camp said. “I had an elderly woman patient who was dying, but she wanted to make it to her daughter’s wedding. She wanted to, but unfortunately, she didn’t make it.”

Whether one lives or does not live depends on an event or reason. Does life need a reason? People often say that it does.

“This is the most difficult decision that you’ll ever have to make,” the doctor said. “For some people it’s an easy decision.”

“Easy! How? To pull the plug?” I asked. “They’re deciding to end the life of a person and they don’t even struggle over the moral implications.”

“Maybe he’ll recover,” Harold said.

“No,” Eric said. “Harold, he has massive damage.”

“How do you know what he’d say now?” I asked. “We hear people say that they don’t want to live if they are in a vegetative condition, but they’re saying it when they’re healthy. Won’t they change their mind once they’re in that state?”

“We have to wait until he wakes up and lets us know what he wants,” Harold said.

“No. He doesn’t want to live like this,” Eric said.

“How do you know?” Harold asked.

“Eric’s right, he doesn’t want to live in such a state. I know it,” I said. “We went through it when Raphael was born.”
Beginnings

Chapter Two

As one enters High School, where I teach mathematics, one cannot help but
notice an outstanding showcase extolling character traits that, as educators, we wish to
impress upon the children entrusted to us. It is called “The Six Pillars of Character.”
Some of the virtues commended in the display are common to all great republics:
citizenship and respect for authority, fairness, honesty, loyalty, and the courage to do the
right thing. Most prominent here are human values, qualities that eluded the writers of
antiquity, yet are so fundamental to our nation and age. On the center poster, “Caring,” is
defined as “to be kind, to express gratitude, to forgive others, to help people in need, to
be compassionate, and to show that you care.” “Respect,” means, “to follow the Golden
Rule, to be tolerant of differences, and to be considerate of the feelings of others.”

Directly across the hall from the main entrance of the high school, is a tile mosaic
called, “A Wall of Prejudice, An Expression of Tolerance through Art.” Scores of hand
painted tiles individually replicate the anti-Semitic propaganda used by the Nazis in their

1 www.charactercounts.org
campaign against the ideals so manifestly praised by our school, and nation, while other tiles depict possible victim perspectives.

To the right of the Wall of Prejudice is the auditorium, and beyond that, is our program for the education of the severely handicapped. In that section of the high school building, one can witness the care of the cognitively challenged, the immobile and wheelchair bound, and those incapable of speech or motor coordination. To put it simply, one witnesses compassion.

Our federal law requires *inclusion*, the bringing of disabled students together with the general student population as much as possible, rather than their exclusion into separate institutions. All of the severely handicapped require a so-called “shadow,” an aid that follows and assists them with basic activities such as walking, eating, and simple tasks among which they are entitled to be taught. I often see even the most disabled moving about the regular student population during lunch periods, always animated by others, with their shadows following close behind.

I came to New Jersey in 1985 two years after graduating the University of Texas in Austin and deferring my acceptance to its notable school of law. I aspired becoming a lawyer and a public servant since the sixth grade and studied government as an undergraduate, full of ambition, with an intent to run for legislative office. I made the difficult decision to give up law school and the aspiration to become a statesman, and moved up north from our home in Houston, so that I could learn Torah, which I refer to as the Law, full-time in an advanced yeshiva.

I met my wife Rachel in December 1987, and we married the following March. She commuted to work in New York City as bookkeeper until 1997, while I learned. In
1994, I began teaching during the later afternoon hours when high school level yeshiva boys study math, science, history and English. I continued my Talmudic studies in the morning, early afternoon and night.

I became fully employed as a first year public school teacher in the local high school in 2003 teaching mathematics. I continued teaching history and science to yeshiva boys in the afternoon.

That year, my father had a heart attack, another heart attack after being released from the hospital, and then a small stroke while lying unconscious for six weeks in the hospital. That same year, we found out about Raphael.

One evening in February 2004, when I returned home from my afternoon teaching, Rachel brought me into our bedroom and shut the door so that our children could not hear her words. I forgot that Rachel, who was expecting our seventh child, was scheduled for a sonogram that afternoon, normally done during the fifth month of pregnancy.

“There’s something wrong with the baby.”

“What do you mean?”

“I don’t know, something about his brain. His stomach is sticking out, and his nose isn’t formed,” she said. “There’s just something wrong.”

“Is it Downs?” I did not want a retarded child. Let her miscarry, I thought.

“I don’t know,” she said. “No. It’s not that. He might not make it to the ninth month. They said he can’t live.”

Rachel was visibly upset. She sat staring at the wall with a blank look on her face. That expression was as powerful as her words.
“Tell me exactly what the doctor said. Did he give you a name for what it is? Did you write it down?”

“It’s something in how he’s formed. Something about his brain—encephalitis.”

“That’s sleeping sickness. Do you mean that he’s missing his brain like your friend’s baby?”

“No, no,” she said. “His brain’s not split in half.”

“Do you know if it is a boy or a girl?”

“I didn’t see.”

“Is he alive?”

“He was moving when we saw him”

“Maybe he won’t survive the nine months. You said it’s not Downs, right? Can we check it out to be sure?”

“I scheduled a higher level ultrasound. The doctor mentioned getting an amniocentesis.”

“So why don’t we? What’s the problem with that?”

“It might cause me to go into labor.”

“And that would just end this pregnancy. Your friend ended her pregnancy didn’t she? Didn’t she have an abortion?”

“That was different. The baby didn’t have a brain,” she said.

“But what happens if he’s born? What if he lives a little while? We’re not going to start doing all kinds of operations on him for no reason, are we?”

Rachel did not say anything. I went on to add, “Anyway, how do you know if they’re right?”
“They’re sending me to some high-risk group ultrasound in Jersey Shore, my favorite hospital,” Rachel said sarcastically. “First your father, now this.”

Rachel did not like this hospital. Poppy and I did not question the decision of the doctors to perform a short procedure and to immediately release him afterwards. Rachel felt that his condition needed more research and that he should not be released. Six hours later he had congestive heart failure.

“Maybe you should speak to someone,” Rachel continued, meaning that she wanted me to ask a rabbi what to do. Rachel is pious.

“Why should I speak to someone? So that he makes a decision for us? We’re the ones who must live with our decisions.”

“Someone else has experience dealing with people who unfortunately have these problems. You don’t know everything.”

“Can we develop our moral selves if we just follow what someone else says?” I asked. We have moral worth when we are believe in and are accountable for own actions.

“I don’t want to develop my moral self. I just want a healthy baby,” she said with a sad look on her face.

Rachel fell into depression. She did not speak with me over the next couple of months. We went for two more ultrasound examinations. The combination of fetal anomalies, indicated trisomy 13, or Patau’s syndrome. This is a condition that the experts described as fatal. If correct, every cell in the baby held an extra chromosome on the thirteenth pair, scrambling the genetic instructions.
Back at the high school, where I teach mathematics, I spoke to Caryn, a senior
teacher about twelve years older than me, who served as our department coordinator.
“The baby has holoprosencephaly. His brain doesn’t divide into two hemispheres. The
doctors told us that he might not make it to term.”

“I’m sorry,” she responded with deep sympathy. I often speak to Caryn about
professional and school matters and we have differed most of the time. She thinks highly
of my wife, just as I do, and understands her point of view. She is good to talk to.

“If my wife miscarries, it will be a quick end to her agony,” I said. “There’s no
joy in her pregnancy. She’s carrying a baby that’ll die in her. She feels as if she is
walking around with a dead baby in her.”

The joy of giving birth, new life and motherhood again was stolen away from my
wife. But it did not end at once, but became a slow ordeal of awaiting the emergence of a
something that cannot live. Was the harsh reality too cruel to discuss? What was my
colleague to respond? She nodded in sympathy.

“Even if he makes it to term, he can’t live long afterwards.”

“You know it’s a boy?” Caryn asked.

“No, we couldn’t see that. We saw that his brain doesn’t divide.”

“Will he have any cognition?”

“We don’t know,” I said. “He might have a certain chromosomal defect. They
also think he has a heart defect. What am I to do, surgery to fix his heart? How can you
justify putting a baby through that when he can’t live anyway?” I pointed toward our
office computer. “I looked up the government website, the National Institutes of Health’s
Medline. Ninety percent of these babies don’t make it to one year.”
It was as if I found a cruel comfort, even in the prospect of the baby dying after birth. I did not want a child with deformities. What if he lived many years, like a trisomy 21, Down’s child? The sooner this ended, the better. I did not share this thought with anyone.

After few weeks later, I visited a recently widowed and very learned rabbi with whom I spent many years learning the Law. The occasion was Purim, a celebration of Providence through an ironic chain of events. In an absurd oriental despotism, the subjugation of women was decreed. It sanctioned their iniquitous kidnapping and enslavement for life for indecencies and carnality. We were saved from destruction at the hands of anti-Semites by one of the tyrant’s female victims, who ended up ruling his petty kingdom.

“How could Abraham have been commanded to sacrifice Isaac?” I asked. The question bothered me for years. “If the Law is to be absolute truth and not arbitrary, how could Abraham be asked to murder the innocent?”

He told me of a story in the Talmud in which one rabbi slew another while drinking on Purim. He later resuscitated him from death. The next year, an invitation to feast with the same rabbi was declined.

“He didn’t want to risk his life again. But what was he to fear?” the widowed rabbi asked with a smile. I was not sure if he was serious.

“After he killed him, he brought him back to life,” he said.

“You mean to say that it’s just dying that’s so bad, but not death itself?”

“Isaac wanted nothing more, to be in a state that no one achieved, being with God.”
“I don’t know. There’s still the law that one cannot kill. It doesn’t matter if the result is some metaphysical good, even if the victim wants it.”

“Yes,” he nodded.

That was the first occasion that I spoke with him, since he sat shiva for his wife a few months earlier the same time my father was unconscious at Jersey Shore. I remember rows of Talmudic scholars sitting around him. He related that his wife died on the Sabbath. He asked her doctor, who was Jewish, not to break the Sabbath after she died. “Up until now, you had a mitzvah to save her life,” he said to the doctor. “Now she is gone, please wait until after the Sabbath for everything else.” I did not know his wife was not well and just found out about her death an hour before the funeral. I told him at the shiva that the funeral was surreal, as if it was not happening. “The world is only appearance; it’s not real,” he remarked to me. “Aren’t people real?” I asked myself, at the time mistaking this matter of religious profundity as epistemological idealism. He spoke at great length about medical care in general. He spoke with me about my father’s treatment. How can someone with such deep faith have so much knowledge in health care?

I did not want to speak to him about the baby, at least not on Purim. I came back the next week.

“My wife is expecting a baby with holoprosencephaly and maybe trisomy 13, which is about as bad as it can get,” I said.

He did not say anything. “We thought about doing an amniocentesis, but we’re not going to do an abortion anyway, so why risk it?”

He nodded.
“Even though my wife’s friend aborted an anencephalic baby, I don’t want to do that. But after he’s born, he might need heart surgery and I don’t know if I want to do that either. The doctors say he can’t live anyway.”

“Doctors don’t know everything.”

I nodded, though I dismissed the words of wisdom in my thoughts, this time as dogmatic faith. “What if he is born and does have so many anomalies? Many say that you don’t do anything, just offer comfort. His prognosis is very poor.”

After discussing some issues of the Law, he said to me, “You have to think about this logically. What are the reasons not to do anything?”

I hesitated. “First, maybe we’d be causing him pain. Two, it might be an unjustifiable allocation of resources. Three, what will it do to us?”

I was not looking for an easy answer. I had to work this through. He suggested calling a particular authority that often dealt with critical medical questions. Two weeks before the baby was born, Rachel also insisted that I call him.

He was difficult to contact, as he spent most of his time in the study hall a distance away from a telephone. After someone asked him to come to the phone, I immediately got to the point.

“Rabbi, usually trisomy babies have major heart defects. When he’s born, do we have to do anything to save him?” I asked.

“You do whatever is normal,” he told me.

“But it’s normal not to do anything. Our pediatrician told us that we only try to make them as comfortable as possible. Does that mean we shouldn’t be aggressive?”
“If you’re talking about surgeries, he might not survive an operation anyhow. You have to look at every situation. Call back when he is born.”
“I’m scared,” Rachel said to me in the birthing room in the third floor maternity ward at Jersey Shore University Medical Center. She was in her thirty-sixth week of pregnancy and experiencing pre-eclampsia.

Jersey Shore is a large facility with various specialties that serve our area of the State. It is not far from the shore off a state highway surrounded by three large parking lots. You have to pass a security guard and your identification bracelet to enter. In the afternoon, it is difficult to find parking, and late at night, the doors lock after the security booth closes. Then you have to wait for someone to exit and hold the door open so you can enter.

Dr. Fernandez, a high-risk obstetrician, gave Rachel an injection of Pertosin to induce early labor. She became his patient, not because of her dangerous condition, but months earlier when the baby was found to have multiple abnormalities.

“They’ll give you something to bring down your blood pressure,” I said, hardly reassuring her. “You’ll be okay.”
“My face, neck and legs are all swollen up. It’s not normal.”

My wife’s legs had been swollen for several weeks. The previous day, her doctor sent her straight to the hospital from his office after her monthly checkup visit. She considered canceling that appointment since she was already seen for pre-eclampsia in the emergency room three weeks earlier after relating her symptoms over the telephone to a nurse in the obstetrician’s office. At that previous time, I left the public school early to drive her, and remained with her for an hour-and-a-half, when an associate from the obstetrics group finally showed up and performed a precursory examination. He suggested waiting longer for some routine results, but I had to go teach in my afternoon yeshiva school, which cannot get substitutes. It cannot even get regular teachers for all subjects, certainly not teachers who went to college. Rachel remained alone in the hospital waiting room, without a car, until I picked her up several hours later.

“How can anyone think that my wife’s pre-eclampsia is not related to the baby?” I asked Dr. Fernandez. He said that my wife’s condition was not caused by the fetal abnormalities. “I’ve read the opposite.”

“Let’s just say that it was a difficult pregnancy,” Dr. Fernandez said.

I spent the night with Rachel in the birthing room. She continued to have high blood pressure. Her neck was in pain, her face was very swollen, and she did not sleep well.

The next morning the fetal monitor picked up an extremely low heartbeat showing that the baby was in distress. That was a dismal sign, since the majority of trisomy children are born with significant heart defects and the ultrasound specialists mentioned that they saw problems with the baby’s heart. They seemed to be correct.
My wife’s water broke and Dr. Fernandez arrived shortly afterward. Events began to move fast. He asked, “If the baby is in distress, do you want a caesarian?”

“No,” I answered without even looking at my wife.

“We’ll give you some oxygen, Rachel, to get the baby’s heart rate up,” Dr. Fernandez said as he put a mask on my wife.

A team of neonatologists came into the birthing room. That week, Dr. Bona, a serious blond-haired Polish woman of about forty, was the head of the neonatal intensive care unit or NICU for short. A resident, Dr. Thomas, a thirty-three year old woman from Brazil, accompanied her.

“I understand that you want to intubate the baby,” Dr. Bona said to us.

“If he can’t breathe on his own. We don’t even know for sure that he has trisomy. We want to give him a chance.” I had to give him a chance. It was a long shot. Maybe the doctors were wrong.

“I understand. We will respect your wishes,” Dr. Bona said to us.

Around 11:00, Rachel felt her first contraction. “It’s going to come out fast. I can feel it,” she shouted.

I ran to get Dr. Fernandez. Several nurses accompanied him. The neonatologists entered and stood in the back of the birthing room. It seemed that the room was full of doctors. At 11:10, Rachel said she needed to push.

“We don’t expect a lot out of this baby,” Dr. Fernandez told the nurses assisting him. The baby came out very quickly.

I heard a slight cry. The baby was handed over to the NICU team and laid on a table. The doctors put a mask over his face and began compressing his chest.
“Is the baby breathing?” I asked.

Dr. Thomas shook her head. The baby was blue. I began to panic. Rachel ordered me to sit down, to which I complied. I began to pray, but why? The baby won’t live. If he survived the initial hours, he won’t survive the initial days. He will always be dying. And even while alive, was he really alive? Not even a miracle would be my salvation; nonetheless, I expected him to live.

After three attempts, the doctors managed to get a breathing tube into the baby’s mouth. His color improved as the respirator gave him his first breath.

Dr. Thomas silently showed me a huge yellow hole on the back of the baby’s head, a sure mark of trisomy 13. She then showed me an extra finger on each hand. It was as if she was implying “give it up.” I saw the cavity where his nose should be. He had a cleft palate and lip.

“It’s a boy,” she said.

The baby was brought into NICU after he was intubated with the breathing tube and ventilator. When I arrived in NICU later that hour, I saw him being examined by Dr. Zales, a pediatric cardiologist. He was looking at the baby’s heart with a sonogram.

“His heart looks real good,” he said.

“Really?”

My research had paid off. I understood the encouraging news. The baby had serious brain defects yet the lack of a heart defect was all the information that I needed to have some hope. Up until he was born, I was determined only to put him on a respirator, but not to put him through heart surgery. Why do that to him? In a diabolic way, I was relying on that bad heart. It was a way out of the burden of caring for a special child. Yet
now I felt an unexpectedly profound sense of relief. Did I really not want the infant to survive as I had thought all along?

The literature that I reviewed indicated that the pregnancy was supposed to end before term. The statistics showed that trisomy babies who survived birth died soon afterwards. But all that information was based on non-intervention. It was not a question of how the medical profession interpreted the data, but how doctors were instrumental in making the data. What if one was to feed a trisomy baby? What if one gave the child a chance to breathe? What would the literature say then?

I wanted to tell Rachel the good news. On the other hand, what was so great about him having a good heart? His severe brain deformation was still his most serious defect. Why was I clinging onto this news as if it made all the difference? Before I left NICU, Dr. Bona told me that she would ask Dr. Turtel, the pediatric ophthalmologist, to look at the baby’s eyes.

By the time I returned to the maternity ward, Rachel was assigned a different room to stay for another two days. Dr. Petruka, a pediatric neurologist, who was an older, heavy-set woman, came in Rachel’s room to consult with us.

“You know the baby has no chance.” She was quick to dismiss any newfound hope.

“I’ve heard that before,” I said. “That’s nothing new.”

“I understand.”

“But his heart is good.” My optimism was not catching. “We still don’t know for sure if he has trisomy 13.”

“Either way, he has multiple anomalies,” she said. “I’ve ordered a CT scan.”
“Let’s see if anything different shows up.”

“Fair enough.”

After a short while, Dr. Pardone, a female ophthalmologist who worked with Dr. Turtel, come in the room to speak to us. “Normally, the eyes form out of the brain during gestation. In your son’s case, his eyes did not fully develop. The right eye is small and deformed without a discernable optic nerve. I don’t see any chance of vision in that eye.”

“So, the same problem with his brain will be with his eyes.”

“Yes.”

“What about his good eye, the left eye?”

“It is all cornea with no iris. There’s some optic nerve, but it’s unclear if it fully meets up with the eye. He might be able to see shadows through it.”

That evening I attended our high school graduation ceremony on the school’s football field. The audience cheered as one of our inclusion students, a young lady with trisomy 21, better known as Down’s syndrome, received her diploma. As I sat in the sweltering heat with other teachers, I kept sliding under my sleeve the hospital wristband that identified me as a parent of a newborn. I did not say anything to a fellow teacher sitting next to me with whom I was friendly. He must have thought that was strange, but I was too withdrawn and sad to care for explanations. As the teachers left the field at the end of the ceremony, I mentioned to some colleagues from the math department, who knew about the baby, that things did not look good. The results of the CT scan indicated that the prenatal sonograms were correct. The baby had almost no brain.
The next day, Dr. Bona escorted Rachel and me into the nursing room, a windowless cubicle that the neonatal staff used for conferences. Dr. Petruka, the neurologist, was waiting for us. She was going to tell us the details I had been trying to imagine throughout the night into the morning.

“The baby is not compatible with life,” Dr. Petruka said. She pointed to regions on the CT scan of his head. “You see that empty space in the middle of his brain. Ventricles. They are supposed to be small fissures. In this case, there are large cavities.”

“He’s missing most of his cerebrum.” How bleak, I thought. “Does that mean he will have no potential for awareness?”

“This baby will never have any cognition. He feels nothing.”

She is going to tell me to pull the plug, I thought. Up until then I had taken an ambivalent stand, a wait and see approach, not to do anything drastic. But is not pulling the plug something terribly drastic?
“Then if he feels nothing, we’re not causing harm by keeping him alive,” I said calmly. The question came to me: What compelling reason prevented us from giving him a chance? And how did she know that there is nobody in there? She said we are not causing pain. Did that not undermine her argument for pulling the plug? I did not believe her anyway.

More questions began rolling on me. My religion teaches that saving a life is the biggest mitzvah. Are there exceptions? Years of Talmudic study taught me to think through this matter logically. In retrospect, the answers came easier than expected.

“Some hold that pain is an acquired thing,” Dr. Bona added, agreeing with Dr. Petruka. “He may never have it.”

Are the doctors fools? They do not want to treat the baby, but they are claiming that he feels no pain. How are they going to be able to influence me now? Leave it to the neurologist. She knew what to tell me.

“If we leave him on the ventilator, he will become something grotesque. His head won’t grow while the rest of his body will. He will be some kind of monstrosity.”

I was a little taken back. I heard of brain-dead patients on life support, a kind of living death, a most unnatural preservation of life. Dr. Petruka said that our child will be a form of living dead, indeed, a monster. “But won’t his face grow?”

“Yes, it would.”

My questioning was irritating her, but she did not make sense. There was a need for clarity. He felt no pain but we should not let him live. His face will grow, but his head will not. Questions of life and death must be approached at the very least with the rigor of reason. Please give me non-contradictory answers! Yet, now I understood—it was
trisomy 13. You are not supposed to intervene because they cannot live. Oh, ye doctors of death, betrayers of reason, what happens if you try to help a trisomy baby live?

“There will be no development,” Dr. Petruka added.

“But his heart is good,” I said. “Most trisomy kids have a bad heart.”

“It’s not just trisomy 13. You need a brain to survive,” Dr. Petruka said. “We should take him off the ventilator and let nature take its course.”

So she said it. What right did she have to make that decision for me? Okay, let her have that opinion. “Why?”

“He will have no quality of life,” she said.

Understood. He will not play ball; he will not watch television. We do not even own a television. But he will not do anything that we normally associate with enjoying life. Really. Maybe he will be comforted.

“Isn’t some life better than no life? I asked

“He will have no cognition. He feels nothing.”

“How do you know? Can we do an EEG to see?”

“Look,” Dr. Petruka said, “As far as I am concerned, no more tests are needed.”

“Thank you, Dr. Petruka,” I said to her as I stood up. She got up and left the room.

I looked at Dr. Bona as she sympathetically said, “Think about what the baby would want if he were able to speak. What would he want you to do?”

“He wants to live, doesn’t he?”

I do not think she agreed.
Weeks later, I emailed Dr. Petruka’s quality of life comment to members of the trisomy email list, a support group of trisomy 13 and trisomy 18 parents. Karen, mother of Alex, a ten-year-old boy with trisomy 18, a similar defect, responded as follows: “The biggest mistake other people make is to compare the quality of life of our children to theirs and what they want out of life. If you do that, you’re right, our kids don’t have a quality of life. They will probably never drive a car, hold down a job, or even have children. People are confusing quality of life with expectations and if you take the expectations out of their views, then our kids have it all. They are happy, they enjoy their life, and enjoy it a lot more than most people. When it boils down to the nitty-gritty, they probably have a better quality of life than the rest of us. They enjoy what they are doing and they are happy. They don’t mourn for what they haven’t got, they rejoice in what they have, and what they have is what we all seek, being happy and comfortable in life with whom we are. Their dreams are different from ours; their expectations of life are different. That doesn’t make their quality of life better or worse, it just makes it different.”

Later I read the words of a woman, Penny, mother of eight year old Devon with trisomy 13, “quality of life is the ability to give love and receive love...nothing more...nothing less.”

It has been found that in postindustrial cultures, traditional authority and communal obligations have become less important than self-expression and
individualism. At the same time, the need for material security has been replaced by the concern over “quality of life.”

Our experience in the fight to save our baby is the manifestation of this larger transformation, one that has led to nothing less than the erosion of the American family.

We named the baby Raphael.

As I drove my wife home from the hospital I called our pediatrician for medical advice. He is a man of faith and I hoped that he would tell me what I wanted to hear, to go long term. Alas, he told me, “I would not put in a trach.” There was a limit to how far he thought we should go. I was alone without moral support.

Rachel was home recuperating. I took charge after Raphael was born and was with him on Friday morning when he was taken out of NICU for an omphalocele procedure. Among his many defects, he was born with part of his intestines sticking out of his abdomen. That was one of the anomalies that we saw on a prenatal ultrasound months earlier. Now a surgeon was going to repair that defect.

“You know he probably has trisomy 13,” I told to the anesthesiologist. “He sometimes desaturates because of apnea.”

“We’ll pay attention to his breathing. He’ll be all right.”

“So don’t be alarmed if the pulse oximeter temporarily drops,” I said. “That’s to be expected.”

A pulse oximeter is a device that indicates oxygen saturation in the blood. A lead coming off the pulse oximeter was wrapped around Raphael’s big toe, penetrating it with red light, to measure his blood oxygenation. We became familiar with the device months

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earlier when my father was in the same hospital. The pulse oximeter later became our most useful tool that warned us if Raphael was in trouble.

“What’s his oxygen set on?”

“One hundred percent,” the anesthesiologist said. “That’s normal for this kind of anesthesia. As soon as it wears off, we can lower the settings.”

“Give him a kiss,” Lynn, a NICU nurse told me. Lynn is a kind, older middle-aged woman, who was to become Raphael’s favorite.

I felt funny. I never gave him a kiss before and really did not feel a lot of affection. I kissed him quite awkwardly.

Lynn was one of Raphael’s biggest advocates. She did not excite herself over what the doctors were saying. As far as she was concerned, Raphael was going to go home. Lynn requested to be put in charge of Raphael every time she worked in PICU. She held him on a rocking chair and held him like one of her own.

After the surgery, Dr. Saad, the pediatric surgeon, appeared with a smile.

“How did it go?”

“Everything is perfect. It was one of the easiest omphaloceles I’ve done. Just a few stitches and that’s all.”

“Where is he?”

“He’s still in the recovery room. He’ll be brought back to NICU before you see him.”

Dr. Saad smiled and handed me his business card. “Come see us in three weeks if he is still alive.” Did he mean that he had a chance to be alive? Or on the contrary, was he affirming that had he no chance?
Back in NICU, before the baby returned, I spoke to Dr. Bona. “I’ve read on the Internet that there is some development in these kids.”

“You can’t trust what you read on-line,” a resident said, hearing my comment.

“Why is everyone opposed to me?” I cried out in desperation. Who asked him?

“We don’t want you to be misled,” Dr. Bona said. “We have a duty to let you know everything.”

“But I have done all kinds research in the hospital’s database. I read the same morbid literature the doctors read, the dry reports of infants dieing in NICU as nature took its institutional course.”

“Then you know the prognosis,” she said.

“Of course I know it. But I also read accounts of parents who didn’t allow the institutions to take their course. The parents argued with their doctors just as I am arguing with you. I’m even trying to contact families who have living trisomy children at home.”

“But it’s not just trisomy 13. It’s his brain. He has holoprosencephaly and lissencephaly,” she said.

“What’s lissencephaly?” How could it be worse than what I already knew?

“His brain is smooth. It has no gyri.” Her slight accent became more pronounced to me as I had difficulty comprehending. “I will print some literature for you to read.”

“And no children who made it home have the same problem?”

“They might not have as severe anomalies.”

“Do you know of any cases of surviving trisomy 13 children?”

“Dr. Graf told me about a twenty-one year old in a Puerto Rican institution. He just lies in a crib in a vegetative state.”
“Who is Dr. Graf?”

“He’s head of neonatology.”

Later that morning, Dr. Bona announced, “I’ve got good news for you. Dr. Rushika, the pediatric neurosurgeon agreed to fix the lesion in his head. Baby will have to transfer over to Robert Wood.” Dr. Rushika worked out of Robert Wood Johnson Hospital in New Brunswick, an affiliate of Jersey Shore where Raphael was born.

Somehow I was made to feel that the medical profession was doing me a favor.

“Can we come back here for the recovery?” I asked.

“Yes, of course. Dr. Rushika wants a copy of the CT scan before we transfer.”

I felt a sense of urgency. It was noontime on Friday and offices were soon to close. “I want this procedure to be done as soon as possible. He is liable of getting meningitis with that open lesion. Should I drive up to New Brunswick to drop off the images?”

“No, a neonatal team from Robert Wood is visiting today. They can bring them back there for us.”

I was happy that I wasn’t spending Friday afternoon on the road. New Brunswick was quite a distance and the Sabbath began at nightfall. I had to rush back to Jersey Shore before sunset, leaving me little time to prepare food, to see my family, and of course, to argue some more with the doctors.

“The whole situation might change once we receive the genetic report from Utah,” Dr. Bona said to me.

“What will change?”
“Once the trisomy is confirmed in the karyotypes, we might not be able to do anything else.”

“You can’t pull the plug without our consent, can you?” I asked her.

“No, but I was just speaking to Dr. Graf. He cautioned me that insurance might not cover once they know about the trisomy 13. We may not be able to do any more procedures here.”

“Are you sure? I have good insurance. Tell the insurance company that he has a good heart. They will certainly approve medical intervention.” If only they knew he had a chance, they would agree. However, I wondered if it was really the insurance company that wanted to terminate the baby?

“I’m just letting you know what Dr. Graf said. He’s the head of the hospital.” He was really only the head of neonatology.

I felt that we made a mistake to have the amnio fluid sent to the lab for screening after Raphael was born. No longer was my child simply an American with disabilities, but now he is a trisomy specimen. Even the government discriminates against trisomy 13 children, as the NIH web site recommends non-intervention. Our President's talk that medical decisions should be between doctor and patient implies that the insurance companies are evil. Mr. President, it’s not the insurance companies!

When I left the neonatal intensive care unit, I saw the team from Robert Wood Johnson in the corridor outside NICU. A man in a business suit was leading several people around, giving a tour. He quickly glanced at me without saying hello. He must have recognized who I was by my yarmulke, as he was probably told of the fanatical religious views of the trisomy baby’s parents. For the split second that I saw his eyes, I
realized that he was my coreligionist—yet those same eyes had such a different vision of how to treat my son.

My mother-in-law, who visited us in the hospital the previous day when Rachel was still admitted, called to urge me to again phone the same authority with whom I spoke two weeks before the baby was born. I did not have any doubt about the morality of intervening to save the baby, but she felt that it is an act of piety to call and to “ask a question.” I knew exactly what she meant. I went into the waiting room outside NICU to make the phone call. Once again I had to wait for him to be called out of the study hall.

“Hello Rabbi, you might remember me, with the trisomy baby.”

“Yes.”

“The doctors are putting intense pressure on us to pull the plug. I want to give this baby a chance to live.” I did not give him a chance to talk. Doubt began to break my self-assurance. “We need to do a plastic graft on his head. I want to put in a g-tube so he can eat. Maybe we are putting him through too much. Everyone’s against us. I’m not sure if he needs a trach. The doctors say that his brain doesn’t want him to breathe but I think it’s simply….”

“You are asking too many questions. Listen. It sounds like you are fighting for the baby. You should merit that he lives a long life. But you have to realize that you might reach a point where you might have to let him go.”

It is a blessing that Raphael should live a long life.
The Sabbath

Chapter Five

I called Rachel to tell her what the rabbi said. As I spoke to her, a blond-haired woman doctor in her mid thirties peeked into the waiting room where I was making the call. “Dr. Bona—oh, you look like Dr. Bona. I’m sorry,” I said to her. She was not Dr. Bona.

She did not say anything. When I reentered NICU she was standing next to Dr. Bona looking over some charts.

“I’m leaving now,” Dr. Bona said to me. “Dr. Rushika asked that we do an MRI. He wanted to see if the cutis aplasia on his scalp is draining before we transfer him to do the procedure.”

Dr. Bona motioned toward the new doctor. “This is Dr. Ross. She’s now in charge.”

“I understand that you want to take an aggressive approach,” Dr. Ross said to me.

“I wouldn’t call it aggressive. We’re not doing anything major.”
“You have him on a respirator. You want to put in a trach. Some would call that aggressive,” she said.

“We want to give him a chance,” I said to her. “I need to leave soon so I can make it back before sunset. I’ll be staying in the hospitality room for the Sabbath.”

“You might have to vacate the room if we need it,” Dr. Ross said to me.

“What? Once I stay for the Sabbath, I can’t leave. I can’t go home. I can’t even carry my belongings outside,” I said. “Besides, Reverend Cotton already said that I could stay there on the Sabbath.”

Reverend Cotton is the head of Pastoral Care at the hospital. He is tall middle-aged man with a full head of straight, neatly combed gray hair. We first met during the previous year when my father was in the intensive care unit, at which time he was very helpful in arranging Sabbath accommodations.

“Reverend Cotton is not the head of NICU,” she answered. “That room is reserved for mothers of children in NICU.”

For a moment, I actually believed that fathers were not allowed to stay.

“But my son is in NICU!” I protested after coming to my senses.

“There might be another patient that’s more urgent,” she said.

“And my baby isn’t entitled to a parent, at the very least, an advocate?” If not him, then whom?

“I’m sorry but if someone else needs the room you’ll have to leave.”

“You are forcing me to stay home until Saturday night. How am I to monitor what’s happening?”

“We can call,” she said.
“Haven’t you had Sabbath observers here? You know we can’t talk on the phone.” She knew good and well about the Sabbath, working in Jersey Shore.

I called Reverend Cotton.

“That room is yours,” he said to me. “I checked it out with hospital management. They can’t kick you out.”

I really did not want to stay in the hospital for the Sabbath but had to remain in contact with the doctors. I explained the predicament to the nurse attending Raphael.

“I don’t want to have to answer the phone every time it rings on the Sabbath. We get so many telemarketers.” I had not yet registered on the national no-call list.

“Do you have an answering machine?” The nurse asked. “We can call and speak into your answering machine.”

“Great idea. I could listen without picking up the receiver. Once the phone rings I’ll just stand over the machine. If a decision has to be made, say ‘pick up the phone.’ Otherwise, just let us know how he’s doing.”

“We’ve done that with other Sabbath observing parents. It’s no problem.”

Every patient needs an assertive advocate, and if it means talking on the telephone or traveling on the Sabbath, it is my opinion that those actions fall into the category of saving a life, which is not only permissible, but indeed an obligation. Lives cannot simply be entrusted to hospital staff.

I had to change my routine that Sabbath morning, not wanting to see any acquaintances. I went to the basement shul across the street from my house for services with the not so courteous intention to leave before the rabbi spoke. I stepped outside
before the speech, oblivious to everything around me, and reflected while sitting on a lawn chair. I had an excuse to be in my own world.

Over the last few years, I became somewhat reclusive, studious and contemplative, with no interest in small, parochial and uncultured talk. Long ago I extinguished my patience for the ubiquitous commercial media, finding too many mistakes on talk radio and irritated by the “in your face” promiscuity and hype presented in the news that makes the lowest common denominator into our greatest common factor. I disdain the practice of showing television programs and non-documentary Hollywood films in the classroom, implicitly sanctioning scenes that expose American children to values that parents and teachers ought not to approve. Needless to say, I hate commercials and the falsehoods and patronizing associated with advertising. I now only listen to the academics and dry reporting found in public broadcasting.

The phone rang after I returned home from shul. I ran to my answering machine and to my surprise, I heard Dr. Ross’s voice. “I can’t really talk since I don’t know if I have the right number, but there is no change.”

I was relieved. When I called back Saturday night, however, I found out that the Raphael started having seizures that afternoon, for which Phenobarbital and Dilantin were prescribed. We arrived at the hospital late Saturday night and noticed that his eyes were shut. They did not open again for another week.

His blood oxygenation sunk low in the afternoon, and so did our hopes that night. My wife and I watched the baby stretch out his arms and stiffen. I second-guessed the wisdom of prolonging his life. Perhaps it was time to take him off the breathing machine and let him go.
On Sunday morning, when I returned home from the hospital, my middle son said that he wanted to see the baby one last time before leaving to sleep-away camp in upstate New York. I told him that it was probably the last time he would see Raphael.

I tried to call the rabbinic authority again.

“Can we take the baby off the respirator?”

“If he’s ready to come off, but you can’t just take him off to kill him,” he said.

“We have to keep him on forever?” I asked.

“Why did you put him on to begin with?”

I paused. “I guess…do I have to answer that?”

“No,” he said. “If you take him off improperly, you have to put him back on.”

“Are we allowed to break the Sabbath on his behalf?”

“What’s the question? You are trying to save him aren’t you?”

The Talmud gives the case of the unviable infant, one that has no hope for survival. One is not allowed to break the Sabbath on his behalf. Did the rabbi know that I was asking if Raphael was considered the unviable infant?

I told Rachel what he said. “Why didn’t you call months ago to ask if we should get an amniocentesis?” She asked me.

“I didn’t have any question. I’m not interested in asking for the sake of asking.”

“A rabbi has experience with these things,” she said.

“Before he was born you wanted me to ask a question when there was nothing to ask. I called anyway because you were bothering me to call.”

“If you would’ve called about the amniocentesis we’d have confirmed the trisomy 13,” she said.
“I don’t remember you telling me to.”

“I did.”

“I spoke with someone. I mentioned that we weren’t going to do an amniocentesis.”

“But he doesn’t deal with these kinds of questions.”

“And let’s say we knew for sure that he had trisomy 13. Then what, call to ask if we should put him on a respirator? And if the rabbi said that once he goes on he can’t come off, then we don’t put him on because we can’t take him off?”

“But what are we putting him through? I just want to do what’s right,” Rachel sobbed.

“It would’ve been cowardly not to put him on a respirator fearing that we couldn’t take him off.”

“And now what do we do?”

“I don’t know.”

On Monday morning, July 1, I meet Dr. Ross in NICU.

“We really have to start making some decisions,” she said. “We can’t keep on giving him fluid intravenously. If we continue, he will need to begin feeding.”

“So why don’t we put in a g-tube?” A g-tube is a gastrointestinal feeding tube. It is used to feed formula directly to the stomach.

“We still have to decide where we’re going with his treatment,” she said. “You have three choices. We can extubate. We can put in a trach. We can leave him as he is.”
I was impressed that she gave me a choice. This was the first time that she consented to long term care.

“I guess once we’re putting in a gastrointestinal tube, shouldn’t we do a trach at the same time?” I asked.

“Remember, a trach is very difficult to care for. And you can’t bring him home on a respirator. I want an answer by Wednesday.”

“Can’t we put him into long-term care?”

“You can, but the local facility can’t take a child on a respirator. The one up north also probably won’t take a trisomy 13 child,” she said. “But is that what you want? What’s the morality of letting him rot in a home?”

When I returned home that morning, I suggested to Rachel that we had a duty to visit the long-term care facility. “We can’t deposit Raphael in some institution and go on with our lives. He’s not going through this alone, not without us. We have to suffer this through.”

One of our neighbors suggested that I call a rabbi who is a prominent medical ethicist associated with the Albert Einstein School of Medicine.

“The doctors insist that the baby can’t survive without the respirator and all our intervention,” I said to him over the telephone. “That’s not the issue to me. Logically, whatever is life is so, every moment. But, I don’t know if I am doing right by prolonging his suffering.”

“Don’t let anyone tell you that he feels pain. Is that what they told you?”

“No. In fact, the neurologist said he feels nothing. But I didn’t believe her.”

“There isn’t a shred of scientific evidence that they’re in pain,” the rabbi said.
“But everyone is saying he can’t live,” I responded.

“Of course if you leave a child with anencephaly in a corner of the nursery without feeding him, he will have a short life span. Any child, even a healthy one, will die without the care of adults.”

“Actually, he has holoprosencephaly and lissencephaly.”

“It’s the same thing,” the rabbi insisted. “Anencephaly is missing brain. What they are calling holoprosencephaly also means that he’s missing much of his brain.”

“But he’s only alive because of the respirator. Maybe he’s what the Talmud calls the unviable infant?”

“You know, I’ve reflected and researched that for thirteen years. It was a Jewish doctor working in a Catholic hospital who finally convinced me that today, there is no case of the unviable infant. There is no baby that’s impossible to survive.”

“I’m glad to hear that. That case troubled me for years.” The unviable infant does not exist. There is no infant that we give up on. This is what the other rabbi meant when he said, “You are trying to save him, aren’t you?”

The doctors differ. They would apply the law of the unviable infant and rule that we cannot break the Sabbath on behalf of Raphael because he is incompatible with life. However, it is a general principle of the Law that in matters of life, we rule leniently. The doctors lose.

“We are going to put in a gastrostomy tube on Friday,” I continued. “I think he also needs a trach.”

“It’s better if you do both at the same time. It’s not good to go under general anesthesia twice within a six month period.”
“But they already did an omphalocele last week,” I said. “It’s not been six months.”

“That’s not a reason to cancel surgery; it’s just better medically not to go under so often,” the rabbi said.

“The doctors are reluctant to put in the trach. I think he needs it but I’m not sure that the doctors are basing their opinion on medical prudence.”

“That’s completely discretionary. Your judgment can be as good as theirs in some things,” he said.

“But if he gets a trach, we might not be able to bring him home,” I said. “Maybe they’re reluctant because of that.”

“There are long-term care facilities that will take a child with a trach.”

“I know,” I said with a sigh.

There are no babies that cannot live. You have to save every child that is born. It seemed dogmatic, but was that not the logical conclusion of my argument? I was not ready to admit to a blanket position on saving all babies. Still, after all the intense emotional strain and opposition, I found solace in a outlook that supported that which we knew in our hearts. We had to save our child, Raphael.

I thought that Rachel should also speak with the rabbi. She was concerned about what the baby was feeling. She pitied him. I asked her to speak with him also about our responsibility to visit a long-term facility. That was one of our options.

“He’s not going to long-term care,” she said to me after concluding the phone call. “I don’t know why this was brought up. He’s coming home.”

“But shouldn’t we go there just in case?” I asked her. “What did he say?”
“He asked, what do you need to go for? To look at the paint?”
Rachel and I sat in the nursing room that afternoon waiting for Dr. Ross and two members of the hospital ethics committee, its chairman, Reverend Cotton, and Rabbi Karp. The meeting was arranged at the request of Dr. Ross.

“I’m not sure if we’re doing the right thing,” I said to Rachel. We were still alone. “Maybe I’m just scared to let him die.”

“You’re always against asking a rabbi what to do.” Rachel had the same expressionless look that she had for the last several months. “You think you know everything.”

I did not know everything. I am sure Rachel knew that I knew that.

“We know the parameters of how and what’s permissible and can do what’s right on our own. People don’t think for themselves,” I said. “That's why they do wrong.”

“We’re not talking about people who phrase retarded questions to do something wrong. If you ask correctly, you’ll get the right answer,” she said. “Some very honest people speak to a rabbi about every decision, even just to get everyday advice. You can’t appreciate the idea of asking a rabbi.”
My wife is right. If people do not ask for permission to do wrong, of course they will not do wrong. Still, how could questions of the conscious not be left to the conscious? We need to develop our own moral sensibilities.

“So then what’s the idea of a test?” I asked. “Is it to see whether you follow the dictates of others? If our actions are to be decided outside of ourselves, then how can we be held accountable for them?”

“I don’t want to be accountable. I don’t want to be tested.”

“I know.”

My wife is a caring, selfless person. My respect for her has only grown over the years. In ways, though, I have ruined her. I have prevented her from doing acts of kindness from time to time and that saddens her.

“Why must he go through this?” Rachel asked. “Why did he deserve to come into the world like this?”

“You assume that he was once something different, but from his beginning he was a child with trisomy 13.” I offered my version of the theodicy, a defense of God’s goodness and omnipotence in view of the existence of evil.

“Do we know that the soul pre-exists its conception so that we should anguish over its nature in this world, and ask why it didn’t come into the world as something else? Or was it simply nonexistent? We might want him to have been something else, but he would then not exist. That something else would not be he. Better for him to be than not to be.”

“You don’t believe in the next world?” Rachel asked me.

“I do,” I said. “But you asked about this world.”
The same argument can be made about the nature of evil in the world.

Shall we deduce, from God’s Being, perfection in all possible existence? If we envision a happy world, must there be no world unhappy? How presumptuous are we to demand that happy universe to be ours, for whom do we wish to cast into this less happy one? Yet, we would deduce that, in any possible world, there is hope and redemption, or a world to come.

I remembered the words of the rabbi. “The world is not real; it is only appearance.”

The world is only an instance of existence; it is an existence as such. As long as there is possibility in the multiverse of possibility, why should not our existence be an instance of that possibility? Imperfection is insufficient reason to conclude that such an instance should not be.

Rabbi Karp entered the nursing room. We first met him while Rachel was in the maternity ward. He told us then that he had a special needs child that lived for five years. When he sat down, I told him about the two different rabbinic approaches that I encountered.

“One rabbi makes the traditional distinction between putting someone on a respirator and taking him off. I spoke to another rabbi today who holds that you always have to intervene, even to put such an infant on a respirator from the beginning.”

“They don’t have any concept of what it is to ask a rabbi,” Rabbi Karp gently. Rabbi Karp meant that we, as Jews, appreciated the concept of asking a rabbi for guidance. There is nothing controversial in that, but it did not please me at the moment.
We heard a knock on the door. It was Reverend Cotton. I was happy that he came since he studied philosophy in college, although we never spoke at length.

“I’m a Kantian,” I said. “I mean, I’m a Jew, but Kant is my favorite philosopher.” I struggled through all three of Kant’s Critiques.

“And what would Kant say in this situation?”

“I think he would apply the categorical imperative of saving a life.” I was trying to approach everything from a rational point of view. “Some life is better than no life as long as there’s no pain. The trach and g-tube don’t cause pain. I don’t see the other side.”

Dr. Ross knocked and entered but there was no chair for her. Reverend Cotton gave her his chair, after which a nurse brought in another one for him.

“The baby’s been on a respirator for six days. He’s being fed intravenously. He needs to get his nutrition,” she said. “We can’t keep him like this for much longer.” Intravenous feeding cannot continue for an extended period of time. It was either time to let him go or put in a g-tube.

“Do we have to take him out of the hospital?” I figured that she was not going to give us the option of putting in a g-tube and try to evict us.

“The next step is surgery for a g-tube, possibly a tracheostomy. We have to make a decision. Have you spoken to your rabbi about taking him off the respirator?” She switched from life to death with ease.

“It seems that we did not necessarily have to put him on the respirator when he was born, but once he’s on it, we can’t take him off if it’ll immediately kill him.”
“If we took him off the vent he won’t immediately die,” she said. “He may even live for a few days or even months, but eventually his brain stem will start looking for a signal from his upper brain. But it will not get one. It will shut down his breathing.”

“Might that happen when he’s on the vent? If the vent is doing all of the breathing, not just assisting him, it may be permissible to take him off.”

“It will happen,” Dr. Ross said. “Why do you want to wait that long? Ultimately he’ll get an infection. That’s not a dignified way to go. Take him off and let him try to breathe on his own. Let him go with dignity,” she said.

It was not certain that he would die of infection but it was certain that he’d die if we took him off the machine. Should we take him off the machine to prevent an infection? Not a very Talmudic way to think! “Can’t we treat him with antibiotics? Should he die because we’re afraid of what might happen?”

“For all we know, he might breathe on his own when we take him off the respirator. The only way to know is by trying to take him off,” Dr. Ross said.

“Is that medically called for? I don’t want to take him off just because he has trisomy 13 and nobody wants to examine him. Can’t we have an ENT look at his breathing passage?”

“It’s normal to take someone off without knowing if he or she will breathe. We routinely take patients off and if they can’t breathe, we put them back on.”

“But Dr. Ross, you said that you might not be able to reintubate him. If we take him off, we might not be able to get him back on,” I said.

“Just because another doctor had a problem doesn’t mean that I can’t do it. I just can’t guarantee it.”
“I think that the same problem that made it hard to intubate him will make it hard for him to breathe. If it’s his brain that’s telling him not to breathe, I can accept that. But if he can’t breathe because his windpipe is constricted, why not give him a trach and give him a chance.”

“We can give him a chance and give him a trach. We can keep him here for months. I know that I can keep him alive. I have complete confidence in modern medicine. But eventually his brain will shut him down.”

“Can’t we wait until then?”

“No, that is unethical,” she insisted. “You have to have a goal. To keep him alive for the sake of keeping him alive is an abuse of medicine. People come to hospitals to recover. Recovery has to be the goal. There’s no recovery,” she said.

The room became quiet. No one spoke.

“What is life?” Dr. Ross began again. “Isn’t it interaction with others? He will never interact with people or with his environment.”

She asked a profound question. At the time, I did not know how to react, but is not interaction, “the ability to give love and receive love...nothing more...nothing less,” exactly what Penny wrote about quality of life?

“How can you be so sure that he’s not there, that he’s got no cognition?” I asked.

“What kind of outcome do you expect? He is blind. He has no upper brain. You must have some kind of goal in mind. A goal. What are you trying to accomplish?”

“I want to go day by day. Let’s do whatever medically needs to be done.”

“You still do not understand,” she said. “We can’t maintain him for the sake of maintaining him. There are other patients here. There must be an outcome.”
“I want to be able to bring him home.”

“Okay. We can work on getting him off the respirator so you can bring him home,” the doctor said.

Reverend Cotton spoke up, “So that’s what we’ll do, get him off the respirator so you can bring him home. That will be our goal.”

With that, we all agreed. The conference ended.

That evening, when I went home, the telephone rang, and as usual, I did not answer it. I heard the caller’s voice announce into our answer machine, “Hi. It’s Poppy. Give me a…” It was my father. I ran to pick up the receiver.

“I just got home,” I said as I walked onto the deck outside our kitchen.

“What did the doctor say?”

“I don’t know. The ophthalmologist said that his right eye is small and deformed. The left eye is all cornea, with no iris. She said that she saw that the optic nerve never developed and doesn’t meet his eye. She doesn’t know if he will ever see light. And the neurologist said that he has lissencephaly.”

“Oh no, what’s that?” Poppy’s voice began to moan.

“You already know that his brain does not divide into two hemispheres—that’s holoprosencephaly. Lissencephaly is when the brain is smooth. You know, how the brain is supposed to curl up on its surface with what they call gyri.”

I spoke to my father while sitting on a patio chair on our southern facing deck. The sun shines most intensely on the deck during the last hours of a summers day as its
rays skirt under the needles of the two majestically tall pine trees. The day was not hot and the warmth was pleasant.

“He has so many problems,” my father sobbed.

I leaned back in my chair taking in the heat. “But the cardiologist said his heart is good. He does have a chance doesn’t he?”

“He’s suffering so much. Can’t you just leave him be?”

“We’re not doing anything major. If his heart was bad, I don’t know if we’d put him through a complicated procedure.” I felt a pleasant breeze.

“You’re not going to start doing all kinds of surgeries on him now?”

“Just a g-tube on Friday. He doesn’t need anything else that’s major. I’m thankful we don’t have to make that kind of decision.” I really was not taking an aggressive approach. “Besides he might not survive such difficult surgery. It’s wrong to take from him the little time that he has otherwise.”

“But you’re putting in a g-tube on Friday?” Poppy asked.

“You had a g-tube. It’s nothing complicated. But he might need a trach.” For some reason, a tracheotomy on a trisomy baby is taboo. What if the child wanted to breathe? Did anyone consider that breathing problems might be anatomical, not mental?

“A trach? You’re going to put in a trach. You can’t put in a trach!”

I leaned forward in my chair. “Why, because then he’ll live? You had a trach too!”

“It’s not meant to be. Let him alone,” Poppy cried.

“You want me to pull the plug?”
“Don’t say ‘pull the plug.’ Don’t say it like that.” Poppy was especially sensitive ever since the stroke when he had the two heart attacks.

“But isn’t that what it is? If we do that, aren’t we killing him?”

“It’s not killing. Don’t say that! The baby has so many things wrong. He’s blind.”

A profound feeling of sadness hit me with the words, “He’s blind.” At once, my thoughts shifted from inquiring about his soul toward what his soul would be put through. I was so hard-pressed trying to conceive his humanity that I forgot to consider his humanity.

“Think about the kids. He’ll destroy your family.”

“But he is part of our family. He was born to us. Isn’t he our responsibility?”

“Don’t you realize what your life’s going to be like?”

Our lives were not going to be the same. We could not travel far from our house and would have to take care of Raphael constantly. However, it seemed to me that the scope and quantity of activities in which a person could participate did not give meaning to life.

“He dies because we don’t want to be bothered?” I asked. “Maybe he wants to live but needs to be given a chance. It’s not his fault how he was born.”

“What does Rachel say about this?”

“She doesn’t say anything. She doesn’t want to do what’s forbidden, and the rabbi said it’s forbidden to take him off the respirator if he’s initiating breathes on his own.”

“So why did you put him on it to begin with?”

“I don’t know. It seemed like the right thing. I guess we didn’t have to.” There was a moment of silence. “We are not doing anything extreme, just letting him breathe,
that’s all. But you can’t take someone off a respirator if you know it will kill—like your friend’s wife.” I mentioned a controversial point.

“That was different. Her kidneys and other organs failed.”

“But what about you? You had two heart attacks and a stroke. What if Dr. Weiss would have said that you wouldn’t wake up? Should we have listened to him? You’re my father, and he’s my son. I would have tried to save you just as I am trying to save him.”

“I don’t want to be kept alive like that. I know that’s not what the religion says, but that’s what I want.”

Is one who is not willing to withdraw treatment deemed as one who denies charity toward the sick?

“I’d never consent for them to pull the plug. I guess that’s why you gave your living will to my brother to make that decision. I hate that living will.”

Harold told us that he thought my father named him on one of his living wills because he saw how well he cared for his dog when the animal was sick.

“I spent almost every hour with you in the hospital. Rachel spent all her mornings there. I did it out of duty, to be there all the time, not to leave you alone.”

Logically, why did we do that? Why didn’t we go about our business when my father’s life was on balance? On the other hand, are we so profound as to share the pain of another without any appearance of suffering?

“I don’t want you to do that out of duty but out of love,” my father answered.

“But is not love none other than duty to a loved one?” I continued, “We are commanded to save a life and we make it a duty to stay on a twenty-four-seven hospital
vigil. Well, the commandment doesn’t just mean saving someone who can live a long life, but even saving some who only has short time.”

We never reached agreement on the issue.

When Rachel came home later that evening, her friend Michele came to visit. Michele recently gave birth to a handicapped child after losing another baby three weeks old.

“You never really know what the other is going through,” Rachel said. “Other people with similar experiences have recently spoken to me.”

“I don’t know why I had to go through all that,” Michele said. “After all the trouble I have getting pregnant because of my appendix that burst, then to lose a baby and now this.”

“Maybe the issues are related,” I said.

“That might be true with my little one. His legs did not fully develop because of my issues, but not the three-week old. His problems were totally unrelated,” she said.

Michele’s husband is an old yeshiva friend. We celebrated the birth of their son one Sabbath night several years ago. During the happy occasion, he told me that the child had heart problems. I did not know the severity of the problem and was shocked that the child did not make it.

“Everyone’s got to impose their values on you,” I said, changing the subject.

“Even my father thinks like the doctors.”
“My father wanted me to have an abortion when we found out that the baby wasn’t developing properly, and now he plays with him. I mentioned that to him. I said, ‘Dad, you wanted me to have an abortion and look now at how you appreciate him.’”

“It’s incomprehensible,” Rachel said. “It’s like when you look at children. What if their parents decided not to have them from the beginning? Who are we to decide these things?”

“But they did not yet exist. You see them now and ask that, but at the beginning there was no conception of them,” I tried to answer.

I felt sorry for Michele losing her baby after all she went through, but what of the child? The sorrow we express identifying with a mourner is not the same, or perhaps is rooted in, the profound incomprehension we conceive while pondering the individual who is gone.

“People used to call me up. One lady told me that I had no right to mourn the loss of my infant in light of the loss of the six million,” Michele said.

“She not only didn’t feel your pain, but she dismissed it. It’s as if you and the baby were not important,” I said. “Isn’t feeling the pain of another what distinguishes religion from philosophy.”

“He had to come into the world for some reason,” Michele said, begging a metaphysical explanation. “Everyone born has some mission in life and some thing that that he’s into this world for.” She did not sigh and I did not feel like nodding to the common dogma.

“Everyone has the same mission,” I said.
“What do you mean? We know that every soul needs to accomplish something. They talk about a soul having to come back to this world because of this or that sin in a previous life.”

My face contorted with disgust.

“Why do people believe in reincarnation? That’s like believing in astrology.”

“Science doesn’t know everything.”

“It knows enough to give me a satisfactory framework without having to resort to magic.”

“There are many early authorities that consider astrology as something true,” Michele said. Rachel was silent the whole time. She probably was not happy with my irreverence.

“That’s because in their worldview the constellations were real, on a two-dimensional sphere without any depth, and the stars went around the earth,” I continued. “Even then, many denied astrology for theological reasons. Why do you defend something so contemptible to monotheism when it has been completely rejected by science? The illusion is one of the sources of idolatry.”

“What if it’s real?”

“It’s against my religion,” I said.

“What about reincarnation?”

“It assumes that the innocent are sinners. It’s like saying they deserve their misery.”
“No,” Michele said. “My grandmother used to say, that all the bad in the world is like the back of a needlepoint. It looks like a mess, but when you turn it over there’s a wonderful picture on the other side.”

“I don’t think that the annihilation of a sentient being can be compared to a non-criminal act of ripping threads that have no individual worth other than their utility. It’s as if you make humans parts of a theoretic whole of whose existence we do not know. We only know of the individual,” I declared, denying the world any unity of existence as such that exists in the human individual.

“What are you saying?” Michele asked. “You, a rabbi, who has studied the Law! We are all connected.”

“We say it’s wrong to use a person as means for any end, but you expect that of God?” She nodded in agreement, but I was still looking for trouble. “There’s nothing more important than the individual!”

“How can you say there is nothing greater than the individual? You’re an Epicurian,” she said, calling me a heretic using a word that is much worse in meaning, but colloquially abused, as is the word “liberal” in contemporary politics, as if it’s un-American and irreligious to be a thinker, or one who puts process above results.

“We are connected. We’re all one nation,” she said.

I did not want to speak to her anymore. Name-calling is the end of rational discussion and I was insulted. Was it heresy to question transmigration and mysticism, doctrines that tend to glorify the creation rather than the Creator?

“Follow your logic. A person is in the world to accomplish some mission. A second person is in the world for another mission, maybe for the sake of the first. We
regress infinitely,” I said. “Unless we say that our moral worthiness, doing right for its own sake, not for any object, not even for happiness in this world or the next, is the final end of an individual. Doing Good is not for the arbitrary sake of this world. It is the end of any possible rational existence.”

After some later thought, I realized that we are all connected. If we abstract compassion towards our fellows from kindness and charity, which are duties of ethics, we find that the object of compassion is not happiness any more than the object of truth in the abstract is the welfare of society. Truth and compassion are good in their own right. We are worthy when we rejoice with, mourn with, pray for and give thanks for another. Our family, our tribe, our humanity make us worthy of love. We are worthy of the good with a good moral will, but we are worthy of compassion when we are in a caring community.

If someone were to wrong me, barring error, I comprehend that wrong and demand assent from all rational beings. Wrong is a logical concept, not a feeling like pleasure, subject to relation. Thus, my faculty of reason entitles me to human dignity, but what about Raphael?

He is my son. As such, he has my love. I can comprehend a wrong against him. He is also a member of the human family. Our institutions must also have that comprehension.

Compassion for a special child is not a mere analog like the prohibition of cruelty to animals (disregarding Bentham). Nor is it clear that we can rely upon the categorical imperative. One is worthy of love when one is a member of a family, community, state,
and humankind in general, all of which can be derivative of the love in the family.

Beyond the Realism of Aristotle, the compassion of parent and child is the ideal between individual persons, the love of the Thou, the analog to our relation with God. How did this insight of family get past Plato? Is it also getting past my fellow Americans, who have witnessed the attrition of the American family during the last century, from being very large to being very small, from being permanent to being temporary, and from having children to having a dog?

They are telling me that I was wrong to save the child. I was now firmer in my resolve.
“They’re talking about extubating to see what will happen,” I said to Raphael’s nurse late Monday night when I returned to the hospital. “I feel like I am caving in under pressure; even our pediatrician doesn’t recommend a trach.”

“Do you want to hold him?” she asked.

“I need to have exact information. Can I speak to Dr. Petruka? I read that there are three kinds of holoprosencephaly. Some of forms are not as bad as the others.”

“I can page her to call back,” the nurse said.

Dr. Petruka was the neurologist who wanted us to pull the plug. When she called, I asked her, what kind of holoprosencephaly he has?

“I don’t understand the question.”

“Is it alobar, semilobar or lobar holoprosencephaly?”

“What is all this leading to?”

“They all are different diagnoses with different prognoses. I want to know what he has.”
“It’s the worse one. His brain is just a bunch of fluid at the center that’s pushing against a mush of gray and white matter pressured against his cranium. There’s really no structure.”

“I see. Thank you.”

The description that the neurologist gave was dismal, but I remained resolute. The next morning, Tuesday, I arrived at NICU to tell Dr. Ross my decision a day early.

“I want to put in a tracheostomy.”

“Dr. Ross froze in her tracks. She gave me a stern look. “No, that’s not acceptable.”

“But you gave me three choices. Either we extubate, leave him on the ventilator, or put in a trach.”

“He’s got too many problems. Just look at the open lesion on the back of his head.” Dr. Ross did not really mean for us to actually look at the lesion, but just to see the rationale of her argument. “It’ll lead to meningitis.”

If I understood her correctly, I thought she was offering sound medical advice. Perhaps the tracheostomy should wait. Jersey Shore did not have a pediatric neurosurgeon to close the hole with a plastic graft, so the baby had to be transferred to another hospital for the more immediate procedure. Alas, I did not understand her correctly.

“Infection is an undignified end. Let him end with human dignity.”

“Why must he end? Put in a graft to prevent an infection, put in a trach so he can breathe, and put in a g-tube to so he can eat.” I thought none of these were major procedures. Why is a little life worse than no life?
“It’s not going to be done. I just spoke to Dr. Rushika, the surgeon. He won’t do it.”

“But I didn’t know that the graft was such a big procedure. I thought it’s not so bad.”

“What do you think?” She smirked slightly. “Do you think it feels good to have plastic surgically implanted on your head? Sorry, we can’t do it.”

“Dr. Petruka said he feels no pain.”

“I don’t think I agree with that opinion,” Dr. Ross said.

Dr. Ross was right; of course, he felt pain. Although I was not ready to give up, I wondered how far I was willing to push. What did I know about the surgery anyway? I needed to research and to think.

“But Dr. Rusheka told Dr. Bona that he will do it!”

“He changed his mind. Now that trisomy is confirmed, he will not put him through the procedure.”

“But we always knew it was trisomy 13. Why did he change his mind like that?”

“Now it’s been confirmed,” she said. “Look, you spoke to someone at Albert Einstein who thinks like you.” Now that got me worried. “Why don’t you transfer him there?”

“In New York? We live here. The baby was born here. How can we be thrown out? At least do the g-tube and trach here.”

“Maybe it’s better if you do everything somewhere else. Nobody here will do anything for him now that he has trisomy.”

“But Dr. Saad said that he’d put in a g-tube.”
“He won’t. He feels that it’s unnecessary to put him through it.”

“But the g-tube is a short five minute procedure. He needs to eat. It’s a minor procedure with minimal risk and discomfort—yet the benefit’s so great. Why’s everyone opposing me?”

“Excuse me,” Dr. Ross said as she walked out of the Neonatal Intensive Care Unit after a nurse called for her. I saw her talking on the telephone through the glass partition window that separates NICU and the reception area.

I was confused. I thought, “How could this be? Dr. Bona said that Dr. Graf advised her not to do any more procedures because they might not be covered once trisomy was confirmed. It’s the insurance company’s fault.”

Dr. Ross hung up and reentered the NICU. “I was just speaking to Dr. Rushika,” she said. She walked rather quickly towards Raphael. “I must’ve gotten the wrong message. He said he will do the graft after all, but first we must do an MRI to see if he needs to be drained.”

“Oh yea, Dr. Bona mentioned on Friday that he asked for an MRI. I forgot all about it.” I forgot to remind them to do the MRI.

“Let me check something.” She walked toward the baby and pulled off the hat that covered the gauze pad on his head to examine the lesion. I guess she finally decided to actually look at it.

“Just as I suspected, it’s cutis aplasia.” The baby was in NICU for eight days. Was this the first time that a doctor bothered to look at the baby’s wound?

“What’s that? What’s aplasia?”
“Oh, Dr. Rusheka asked me to check his scalp. He doesn’t need the graft. It’s healing by itself.”

What a runaround!

Later in the early afternoon, Reverend Cotton came up to NICU to see me.

“The Hospital Ethics Committee wants to weigh in on your case.”

I naively thought that maybe now I had a chance for some justice against the doctors for all they put us through. On the other hand, they called for the meeting.

“It’s better for all involved,” Reverend Cotton said.

“What do I say?”

“Explain what your faith means to you.”

“But my whole approach is rational, not just religious.”

“Your faith is important. Many Christians compartmentalize their faith, Sunday believers. Show them how much your beliefs influence all your activities. It will make a strong impression.”

“I guess,” I said. “I’ll start writing something now.”

“We’ll see you tomorrow morning. You’ll do fine.”

I immediately began scribbling as I sat on a rocking chair in the middle of NICU.

Rachel sat across the unit holding Raphael. I was not sure if I could win the Ethics Committee over with religious dogma, but Reverend Cotton had said something interesting. The key was what our religion meant to us.

On Wednesday, June 30, Rachel and I arrived at the hospital prepared for a summary trial. We encountered Mary Lou Kurowski, a Neonatal Social Worker, when
we entered NICU, and spoke with her briefly. Shortly thereafter, a pastoral assistant, whom I had seen at times with Reverend Cotton, came up to escort us downstairs to the hospital conference room where the Ethics Committee convened.

The pastoral assistant led us through the corridors of Jersey Shore University Medical Center. He told us that he was a medical student at Notre Dame.

“My father is a doctor and I’m studying to be the same.”

I thought that it was strange for a doctor, son of a doctor, to be on the pastoral staff of a hospital. “How did you end up here?”

“I signed up for a summer internship program. My school wants students to spend time experiencing what it’s like to be on the other side, the patient side. In the end, it’ll make us better doctors.”

“Notre Dame’s a private college—sectarian isn’t it?”

“Catholic,” he answered.

We arrived in an antechamber to the hospital conference room and waited only a very short time before Reverend Cotton, who chaired the committee, asked us to come in. The room was filled with several people seated around a large table and still others sitting off to the side. What immediately caught my eye was the sight of Dr. Graf standing up and excusing himself to leave. I was quite disappointed since I was looking forward to confronting him. I had never spoken to him, yet he had so much to say about our child.

He walked out of the room and Rachel and I were told where to sit. Reverend Cotton then asked the members of the committee to introduce themselves. I noticed Dr. Ross, who smiled, needing no introduction, and Mary Lou Kurowski, who just arrived.
Rabbi Karp was not there. I was asked to introduce myself and preceded to read a formal speech that I wrote.

“My name is Arthur Lang and I’m an adherent of the Jewish faith, a living tradition that has lasted over 3500 years. Questions of life and death are recorded in the Talmud, in responses to queries, and are still actively discussed. Whereas medical ethics is a relatively new field, I can cite rulings from 1800 years ago, 500 years ago and even last week. All these precedents are based on my religion. You might think it is some kind of fanatic ideal, a code that disregards morality, or the ethics of intolerance. Let me cite the following story to illustrate how my faith approaches life.

“This story took place last November. It involves a young Jewish man whose father suffered a heart attack and was transferred to the cardiac unit of a prestigious hospital. After the doctors originally thought the father required by-pass surgery, the young man and his father were relieved to learn that only a heart stent was required. The young man was surprised when his wife, who came from a very religious family, was not relieved. She wanted him to double check with the doctors, get a second opinion, and get the most information possible. The young man tried to calm her down. The stent was put in and the father was released. Six hours later, the father was on life-support after suffering a second, more massive heart attack.”

I was interrupted by a waiter from food services who barged into the room making a racket with a pile of hospital food trays. “Did anybody order—”?

“There’s an important meeting going on here now. Please excuse us,” Reverend Cotton said, asking him to leave.

“But there’s a luncheon that’s supposed to be here now,” the waiter insisted.
“Later,” Reverend Cotton said. “Please continue Mr. Lang.”

“The young man slept the next two nights in the ICU waiting room. He constantly asked the doctors questions, researched medical information, and prayed. He went home only for short periods and spent his Sabbaths in the hospital. His brothers, who were not very religious, came from out of state, but they did not sleep or stay in the hospital for extended periods.

“The young man met members of a very religious family whose father was also in the ICU after suffering a heart attack. The wife slept in the hospital every night and the children took turns spending time with her. The young man was happy that the wife knew the names of all the top doctors in New York and had phone numbers for all the organizations to get her in touch with the best medical care. The young man indeed consulted with whomever he could.

“The young man was intrigued. Although he was acting for his father’s sake, he wondered why his brothers did not sleep in the hospital. Why was he running around consulting with all the best doctors and taking the initiative? Wasn’t he the fanatic who only knew to pray? And the other family, they sat vigil, day after day, constantly on the phone with the greatest medical experts from all over the world, praying up a storm. Their devotion to their father encompassed the whole of their lives. The young man was bothered why his brother, the one who had the legal power to “pull the plug,” was rarely in the hospital, went out to eat, and ran about his normal business.

“The young man pondered the following contradiction: Who can have more faith in the God of Israel, that all is in His hands, than the Israelite himself? Yet, instead of non-intervention, the Hebrew is the biggest patient advocate that a doctor can meet.
During this time, the young man visited his rabbi who was mourning the loss of his wife. Sure enough, the rabbi talked about the different drugs that were coming out, the different doctors, and different hospitals. The young man then asked the older sage, ‘we have to get the best doctors, best hospital, yet we have faith that all is in the hands of God?’”

There were several knocks on the door. Some members of the ethics committee showed expressions of disgust over the interruptions. They seemed to be interested in my story, despite its proud religiosity.

“It’s no contradiction the rabbi explained. We have many mitzvahs or commandments. When we do a mitzvah, we do the best we can. We strive to make it nice and wholehearted. We hope to succeed, and with the help of heaven, perhaps we succeed. The greatest mitzvah is the saving of a life. Everything else is put on hold. We do not know if we will be successful but we pray and hope that we will. It’s ultimately not in our hands. Yet, we perform our duty because it’s the highest calling we have.

“This is my faith. It’s not fanaticism but the highest culture that I can imagine. We only give, perform our duty, do what is right, live according to principles. We cannot compartmentalize a mitzvah, performing it only when it is convenient. I cannot judge who is worthy of kindness, rationalize a wrong, or decide that a quality life is not worth living. All we know, that as long as there’s some life, whatever it is, we have a mitzvah to save it. There may be times when one does not try to prolong the dying process, and pain and suffering are considered, but we have our own tradition of how to evaluate these things. It is that same tradition that motivated the young man to do everything for his father that is now motivating him to do everything for his son. You see, the prestigious hospital was Jersey Shore University Medical Center and the young man was me.”
Members of the committee began to motion about in their chairs. They seemed to be moved. Reverend Cotton asked, “What is the criterion of life?”

“Traditionally, breathing, but even when there’s no breath, if there’s hope of recovery, then one puts a patient on a respirator. If recovery is unlikely, there’s a legal distinction between allowing someone to die and causing his death. If someone’s dying, you might not have to put him on a respirator. A five-hundred-year-old source rules that you can remove salts from the mouth of a patient, used as a stimulant that slows the dying process. You don’t need to prolong suffering. But once one is on a respirator, taking him off is considered causing him to die, not merely allowing.”

An ethics committee member who identified himself as a psychologist asked, “How do you resolve conflicts? What if a doctor feels that it’s a violation of the Hippocratic Oath, to do no harm, by putting in a g-tube, doing an omphalocele and putting in a trach? How do you reconcile your views with doctors who might differ from you?”

I thought that he was mistaken by mentioning the Hippocratic Oath. He seemed very sympathetic, but the Hippocratic Oath certainly favored our claim in saving a life, not terminating it. I answered, “We’re open to any idea, but really I have not yet heard a compelling reason for not treating our baby. I have no problem with people who disagree with my opinions. I feel that I’m being fair in my approach. I can discuss anything with anyone and listen to any rational argument. How can I not? I don’t know the absolute truth. Wasn’t that what the Founding Fathers held? None of us can be so absolutely sure of the truth to dictate to others. Well, besides our foreign policy—” I smiled.
Reverend Cotton chuckled at my last remark and asked, “Is there anything that you’d like to add, Mrs. Lang?”

“No, my husband said everything.”

“Thank you Mr. and Mrs. Lang,” Reverend Cotton said as he got up to escort us out.

“But maybe some people have questions?” I noticed that there were members of the committee that looked like they had questions. One even asked us to stay, but at the time, I thought that Reverend Cotton wanted to move on to the next case. I was disappointed. My speech was only supposed to be an introduction to a complete discussion over all aspects of the case.

The waiting room was packed with people. I figured that the Ethics Committee had a lot of business to cover that day.

We returned to NICU after the conference, but Raphael was not there. He was taken downstairs for an MRI. While we waited outside NICU for him to return, I met Dr. Ross in the hall.

“We never got a picture of his brain stem, the part of the brain that controls breathing. Will the MRI get a look at that?” I asked.

“It should. It’ll give us a better picture than the CT scan”

“Good. And what did you think about my speech?”

“Your story about your father was very moving.”

Moving, but not convincing, I thought.

“It’s true.”
I continued to talk about my family, my self, and my religion, even how many biblical commandments we have. “There are actually 613 commandments.”

“And I thought that there were only twelve commandments.”

As she said that, Reverend Cotton and the Notre Dame pastoral aid passed by us. Reverend Cotton smiled. Apparently he heard Dr. Ross’s “Twelve Commandments” comment. She should be involved in life ending decisions? I was too intensely focused to laugh.

The baby was later brought back into NICU. Shortly thereafter, Dr. Ross showed us his MRI. It was clear that much of the brain was missing in the middle. Whatever he had was certainly not being pressured against his skull, as even on the rim, his brain did not fill up the space along the circumference of his skull.

“Is his brain stem formed?” I asked.

“The radiologist will have to look closer. I don’t see anything,” she said. “But even though his brain stem causes him to breathe now, sooner or later, it’s going to expect messages from the upper brain and won’t receive them. The upper brain will interfere. Eventually he won’t want to breathe.”

“I still think his problems are anatomical. Look at how well he’s doing on the ventilator at the lowest setting. The breathing tube is giving him an opening and that’s all he needs,” I said. “Can we turn off the machine and see how well he breathes without taking the tube out?”

“Only for a short time. The tube is very narrow, so he needs pressure from the machine.”
When I returned to NICU, I asked the receptionist to call our local pediatrician and he called back.

“Why were you so against a trach?” I asked him.

“It’s very difficult to care for at home.” He now understood that we were determined to save the baby.

“Can’t we learn to care for it at home?”

“You can, but it’s easy for him to get infections.”

“He can just as easily get one in the hospital.”

“That’s true.”

“Is there any way of knowing if he’ll need the trach?”

“I recommend having an ENT look at his breathing passage.”

Reverend Cotton showed up in NICU as I was talking to the pediatrician, but he left before I was able to speak to him. I asked the receptionist to page him and he returned. He asked Rachel and me to sit down on some chairs in the hallway area with him to discuss our options.

“The ethics committee agreed with Dr. Graf that putting in a trach and a feeding tube is a violation of the Hippocratic Oath, to cause no harm.”

“What? To cause no harm?” I was astonished. “Why didn’t anyone mention this to me before? I thought Dr. Graf’s problem had something to do with insurance. Why didn’t he stay so I could answer him?”

“I didn’t want a shouting match between you and him. I initially requested that he leave before you arrive.”

“You had us leave too soon.”
“We were going overtime. There was supposed to be a medical conference in the room at the time of our meeting. The doctors were knocking on the door.”

“I don’t understand it. The Hippocratic Oath says not to cause abortions and they perform abortions.”

“Not all of them.”

“How’s it harmful to give food to a baby? Doesn’t it cause harm not to feed him? How’s it harmful to let him breathe?” I wanted an answer. I demanded an answer. If only I could confront Dr. Graf, I’d convince him for sure!

“And what makes them experts on morality?” I continued. “I’m the one who’s supposed to be the rabbi, yet I’m the only one talking science. All the doctors can do is to give me a moral lecture.”

“They’re looking at the whole picture, all that’s involved in taking care of the child,” Reverend Cotton said.

“Isn’t it we who must bear that burden?”

“People today don’t want to be bothered. They want to make sure you really are prepared.”

“And if we’re not prepared, he dies anyway doesn’t he?”

“Let me work out a compromise so you can take him home.”

“How can you? This ethics committee thing totally messed things up. Now that it’s made its ruling, no doctor in the hospital will help us.”

“The ethics committee didn’t rule against you. It just said that if no agreement is reached, the hospital staff is advised to try its best to assist you in finding another facility.”
“But how do I know if a trach is even medically indicated? We need an ENT to look at his throat and see if he has a clear breathing passage. Because of the ethics committee, no doctor will even examine him,” I said.

“Oh the contrary, we advised all staff to try to accommodate your wishes. We only said that no doctor should feel compelled to work against his conscience.”

“What if Dr. Graf tells Dr. Saad not to put in the trach if he needs it?”

“I don’t know if he’d do that,” Reverend Cotton said.

“I want to get the trach and the g-tube done before we move him,” I said. “I want to look into some of the more long-term facilities if necessary.”

“If he were my child, I’d want nothing else but to bring him home to a loving environment.”

He was right. *Inclusion!* With all my cold legality, I forgot about compassion. Was the baby to rot in an institution without any stimuli, without anyone holding him, without any love? Life is indeed interaction! On the other hand, how do I make the moral judgment to bring Raphael home, compromising his survival in violation of the moral law? But then, is one to follow the letter of the Law and so become despised? No, impossible, for such is not even the letter of the Law, but mere sloth and blind conformity, a sure lack of creativity and insight. We must be wholesome, a moral and lawful whole, without contradiction, for then surely we will be doing what is right in the eyes of the Creator, as our deeds would be right in the view of any rational judge.

“I guess you’re right, we’ll bring him home, but I’m not bringing him home to die. I want him to get everything he needs. There is no reason why we can’t give him proper care at home.”
“He’ll get better care at home. You and your wife will give him the love he needs to thrive.”

“Can you speak to Dr. Saad?”

“You’ll have to lay low and trust me. Give me twenty-four hours.”

“Why do you think that they’re fighting me so much?” I asked. “Is it because they feel that it’s not good for him to live?”

“Who was the first to decide who lives and who dies?” Reverend Cotton asked.

“I don’t know.”

“The Nazis. To me, it’s a slippery slope. Once you start saying that this one can’t live, you’ll say the same about another, and then another. Where do you end?”

“But let’s say they’re right, that it’s better that he doesn’t live. But to terminate a life is a bad action. Are we to do good by doing bad?”

“I guess they think that the ends justify the means. Hang in there.” With that, he got up and left.

I pride myself on my ability hear both sides of an issue, but somehow I was now at a loss. Was I being so dogmatic that I became close-minded, not to see the doctors’ point of view? Or was I simply swayed because Raphael was my own child? But, after all, is that not all that matters?
To Do No Harm.

Chapter Eight

“I just spoke to the radiologist,” Dr. Ross said to me in the hall outside of NICU later that day. It was unusual to see her outside of NICU, and even more unusual to speak to her there, but she seemed quite upbeat. “They sometimes can see things that other doctors don’t.”

“Was there a mistake?” My hopes were cautiously raised.

“His brain stem is fully formed.”

“Really?” I felt a boost, like when the cardiologist told me that the baby had a good heart. I needed something, something optimistic, to show that there was hope. “That means he’ll be able to breathe on his own.” At the very least, we will not be stuck with him on a machine.

“I hope so. But that doesn’t mean that down the road he isn’t going to stop breathing.” She was overall, pessimistic.

“At least we’ll get him off the respirator properly. Then it isn’t like we’re killing him by pulling the plug.” But was that what I really wanted, permission not to put him back on if he needed it?
“Then we can take him home,” I said. That was our goal.

“Home is the appropriate place,” she replied.

“If we have the proper equipment, we can monitor him and stimulate him if he forgets to breathe.” Home was indeed the appropriate place.

“You don’t understand. He might decide not to breathe at all anymore at some time after he is extubated.”

“Can’t we bring him back if he has trouble?”

“The goal is to take him home. He’s not coming back. You can’t just go on like this.”

“Why not? If he needed to come back, then we could take him home again after he got better. I don’t agree that he’s going to permanently stop breathing, needing the machine to always breathe for him,” I said. “Did you at least do that test that we discussed?”

“It was inconclusive.”

I spent the remainder of the day fretting over not hearing the doctors’ side of the life-argument. I was still dazed and confused at night when I approached NICU and yanked open the door. Parents were supposed to wait until a staff member pressed an electromagnetic release, but the tension in the door was rather weak compared with the tension in my body. I was not about to start negotiating with a door after spending the day talking to the wall.

By the time I scrubbed up and put a hospital gown over my clothing, my unannounced arrival was forgotten.
“Hi, Dad. Baby’s doing fine,” a young, caring nurse sitting behind the reception area said to me.

“How’s it a violation of the Hippocratic Oath to feed a baby?” I found no doctors to fight with so the receptionist had to make due. “If he doesn’t eat he can’t live. How is it causing harm to give him food? Dr. Petruka said we’re not causing pain. Whom am I harming by keeping him alive?”

“I’m sure everything will turn out okay.” She remained calm.

“This guy, Dr. Graff, told Dr. Bona last week not to do any procedures because of the insurance company. Then he took us to the Ethics Committee. All of a sudden, it’s a violation of the Hippocratic Oath to let our baby live. That’s the first time we heard that complaint. Why didn’t anyone tell us about it before? I spent the whole day trying to figure out what in the world it all means. We’re causing harm. Hmm. I can’t figure it out.”

“Doctors have their own ways of viewing things.” She said, not knowing what to say.

“And what about his ethics? I’ll take him to the Ethics Committee! He’s going around telling our doctors not to treat our baby. He’s not even our doctor. We never spoke to him. What does he have to do with us? Who is he?”

“Well, he’s the head of neonatology.”

“I know who he is. He could at least have the guts to confront us. How can he work behind our backs?” Again, she had no for answer me.

“Who’s our nurse tonight?”

“Judy. You can go on in.”
Judy, a middle-aged woman, was busy taking care of another infant when I walked into the NICU area. I stood over Raphael for a few minutes watching him and his monitor. Eventually Judy came over to us.

“Can I hold him?” I sat down in the chair next to his neonatal incubator.

“Sure.” Judy lifted up Raphael and put him in my lap.

“I really don’t understand what’s happening. I’m going haywire trying to figure this out. How are we violating the Hippocratic Oath to cause no harm? Are we causing pain?”

“He doesn’t seem to be in pain. I mean, he cries when he’s got a dirty diaper. But that’s normal. He might be uncomfortable when he has a seizure.”

“We’re getting that under control, aren’t we?” I asked her.

“Why don’t you just relax with him?” She smiled.

“They talk about the kind of life he’ll have. Isn’t there comfort in being held? Isn’t that better than nothing? Isn’t some life better than no life?” I really was hoping for an answer. I was sure that there was some way to contradict my logic but nobody attempted to point it out.

“As long as it’s not negative. Maybe that’s his life, to be held and comforted,” I said. “Why isn’t that worth preserving? If he lives only for a short time, isn’t a short time better than no time? Is Dr. Graf going to convince Dr. Saad not to put in a trach?”

I went on to answer my own question. “He won’t do that. It’s unethical. But we went through this before. We were told Dr. Rushika would fix his scalp. He will not fix it. Nobody even bothered to look at it. Now, how are we going to get the ENT to look at him and give us medical advice if he really needs a trach? What do we say to the ENT?
Do we just ask, ‘If this baby didn’t have trisomy, and his throat anatomy and cleft palate were his only problems, would you recommend extubating or putting in a trach?’”

“I think you shouldn’t talk about this so much. You’re holding the baby. He can feel the stress and it’s upsetting him.”

The next morning I returned to the hospital. I found Dr. Ross making a routine evaluation of each patient. Parents are not allowed in NICU during the morning or evening hour-long rounds in consideration of patient confidentiality. I however managed to sneak in for a quick request.

“Dr. Ross, real quickly,” I said. “Please order that ENT so we can see if he needs a trach.”

“Didn’t you hear? The Ethics Committee ruled against you. It’s unethical to put in a trach.”

“But, Dr. Saad said he’d put in a trach if the baby needs it.”

“It’s not going to happen.”

“What about the g-tube? Dr. Saad is planning to put in a g-tube.”

“He won’t do it. There is not a doctor in this hospital that’ll violate the Hippocratic Oath to do no harm.”

What hypocrites! They are explicitly violating it by giving advice to cause death.

“Do no harm?” I went on. “He needs to eat! Isn’t it harming him to starve him?”

“You have to leave now,” she sternly said. “We’re doing our rounds and you’re not allowed in here at this time.”

“I’ll talk to you latter,” I said, as I left in a huff.
I went downstairs to the first floor to find May Lou Kuralski in her office. She was assigned to our case.

“Look at what you’ve done,” I said. “Now no doctor in the hospital is going to treat our baby. Why did you have to interfere? Why didn’t you let me answer some questions during the ethics committee meeting?”

“There was a group that was trying to get in,” Mary Lou said. “We were kicked out.”

“I could’ve answered any question. Like, remember when that psychologist asked me about how I handled conflicting points of view. I thought the problem was the insurance or simply a conflict of opinions. Nobody ever mentioned to me anything about the Hippocratic oath binding doctors against treating my child.”

“I’m sorry,” Mary Lou said.

“Before the Ethics Committee meeting, at least Dr. Saad would have put in a g-tube. Look at the harm you caused!”

“It’s a really difficult situation. I feel for what you’re going through.”

I was just letting off some steam. I realized that she really had no influence over the doctors. Indeed, in our case, the findings of the committee amounted to nothing more than an excuse for the doctors, even though the members of the committee sympathized with us.

I went to the medical library, intending to email some of the trisomy parents on the support list, but somebody sent a message for me to return upstairs to NICU. When I returned up to NICU, Dr. Ross and Mary Lou asked me to meet with them in the nursing
room. The case manager probably arranged the conference and attended only because she knew that I was upset. She did not talk during the meeting.

“The trach is really not indicated,” Dr. Ross said.

“How can we know? Can’t we have an ENT look at his anatomy?” I asked.

“I spoke to an ENT. He said that the only way to know is by physically extubating.”

Why should I believe her? I thought.

“So that’s the procedure even for a normal baby, to extubate before looking at the throat?”

“Yes.”

“But what if he can’t breathe on his own?”

“Then we will reintubate him, but we’ll only do that once. Then you’ll have to look for another facility,” Dr. Ross said. “There are Catholic hospitals that take cases like yours. Why don’t you look into that?”

She’s kicking me out again, I thought. “If we get him off the vent and bring him home, we’ll need medical equipment and oxygen to revive him if he stops breathing.”

“He is going to stop breathing.”

“Then we’ll need a pulse oximeter to monitor him. We can’t constantly be looking at him. What if we take our eyes off him? We need some kind of alarm.”

“I don’t know if they’ll give you a pulse oximeter.” Dr. Ross said. “Some people from your community know how to get things from the government, even when there’s no medical necessity.”
What did she mean by “no medical necessity?” There was no necessity to keep Raphael alive? Also, I resented her “your community” comment, implying that my community had unfair political influence, or acted as a faction, the nemesis of a republic. On the contrary, the survival of a republic and its values is enhanced when its citizens have large intact families.

I am proud my community of families, where talking bad about another, *lashon hara*, is the most talked against bad. My community has a voluntary ambulance service, organizations that provide funds for nursing and relief, young people who visit the sick or stay with them in hospitals to relieve family members, networks connected to medical specialists, and even access to a database that couples genetic information for young men and women before courting for marriage. Much can be said about such a traditional community and its people who lead wholesome lives.

Much can be said about an insurance company that never denied us anything. Much can be said about a society and its provisions for the ill and indigent, a nation and its health care infrastructure, and a humanity that allows *inclusion* for those with special needs into our schools, into our homes, and into our lives.

I went down to the library after hearing Dr. Ross’s discouraging words to look at my email. While I sat in front of a computer screen, a female member of the pastoral staff stood next to my seat and said, “Everything’s in the hand of Heaven.”

She did not smile. She did not say anything else. She just stood there.

“But even logically, why shouldn’t we help the baby,” was my only response.
A simple nod from me would have been more appropriate. She was, after all, correct.

When I returned to NICU, to my surprise, Dr. Saad was examining the baby, while admiring his own work. That was not too much to my surprise.

“Look at how nicely that omphalocele’s stitched up.”

“What about the g-tube?”

“When we put it in, you want to begin with just a little bit of food. He never had anything in his stomach and needs to start stretching it just gradually,” the surgeon said.

“What about Dr. Ross? She said that you wouldn’t put in the g-tube.”

“I’m doing this because I’m a compassionate man. This child needs to eat. You can’t starve him.”

It is compassionate to save him? He said that he was treating our baby because he was a compassionate man, but Dr. Graf implied that it was compassionate to let the baby die. Are we to blame for making him an object of Dr. Saad’s compassion by keeping him alive? On the contrary, at what point in his life did he not require compassion?

Must society as a whole have compassion upon children born with such severe defects? Must public policy be formulated so that all those children are intubated and saved at any cost? I am American enough to know that I cannot impose my values upon other parents, although I feel for those orphans that have no one to fight for them. To ask whether Dr. Saad had compassion for the baby or he had compassion for my wife and me might really be irrelevant, for perhaps all compassion is only derivative of the compassion of a parent.
No matter how we decide as a nation to deal with trisomy babies, it will not arouse or suppress the compassion between parent and child. As long as that primary source of compassion exists, any law to undermine that compassion is cruel.

I have an emotional need to save my child but I only insisted on the assistance of others because I can make saving any life into a universal law. Indeed, my maxim can be called a categorical imperative. What could I say to Dr. Graf who feels that using medical arts “to cause harm” was a legitimate exception? Some philosophers say that there was no such thing as a categorical imperative, but only prescriptive moral judgments that apply in each type of situation or context.³ Thus in the particular circumstance of a child born with trisomy 13, one should not save him. He would require compliance in all similar cases.

Compassion can determine between two internally consistent conflicting sets of principles. Like the concept of good, compassion is not means to something else. It simply exists. It exists between man and man, parent and child, and between God and man. The compassion between parent and child correlates to the compassion between God and man. We pray that God has compassion for us as a parent has compassion for a child. This correlation is the source of the conception of the other man as the fellow man, someone worthy of compassion. Can anyone correctly think that his compassion is greater than the compassion of a parent for a child?

Rachel and I got to the hospital early on Friday, July 2. Dr. Saad scheduled the operating room for 12:30, but he said that we might be able to go in earlier.

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³ Hare, R.M. (1963). Freedom and reason, Oxford University Press
“This is the second time he’s going under general anesthesia in two weeks,” I said to the anesthesiologist.

“He’ll be okay. Often patients such as those with heart problems must go under several times in a short period,” he said.

“He’s not on the ventilator just because of the procedure. He’s never been off,” I said.

Rachel rolled her eyes and said, “He knows.” We thanked him and he went back into the operating area.

“I wonder where Saad’s ancestors come from,” I said to Rachel. “I bet he’s an Egyptian.”

“I don’t know. He once asked us about the circumcision and knows a lot of Jewish customs.”

“So what does that mean? He’s been living here his whole life; he doesn’t even have an accent.”

After Raphael was wheeled off, I stood in front of the entrance of a long corridor leading to several operating rooms. I saw surgeons and their assistants walking in and out of the operating rooms, covered with masks and gowns. I had a surreal feeling while I contemplated the gravity of the work that these people were doing.

The faithful profess that doctors are but instruments in God’s plan. Success is not in their hands. Medicine, like all the arts, requires creativity. How could that not be left to human freedom?

We invoke the distinction between prudence and morality. Prudence directs reason towards attaining an object. It can be described with underlying causes, including
the desire for an end, and the knowledge of and diligence in its attainment. We can imagine any temperament, need or emotion, more or less caused on a cellular, societal, or educational level. These are empirical and possible for study through the methods of the empiric sciences.

Such is not what we mean by freedom. The Law tells us that God hardened the heart of Pharaoh, meaning that He made him unnaturally apathetic towards his own safety and *imprudent* as a ruler of his own people. He was already *morally* evil. Morality has no object as its end. It is reason for its own sake, or goodness for its own sake. It can be described only with the terminology of freedom. Unlike prudence, which has an object as its end, either of this world or the next, morality cannot be said to be psychologically determined if it is to have worth. Freedom is simply the capacity to legislate or to comprehend legislation without any object as its goal other than law for its own sake. Thus, the reward of a *mitzvah* is the *mitzvah* itself.

Freedom, then, was not ordained so we may be tested by the rejection of given laws in order to enhance reward when we comply, for then our souls and their choices would be mere phenomena, delineated by the methodology of anthropology and psychology. While prudence is the use of maxims conditioned by the *accident* of inclination or desire, and is of this world, freedom legislates unconditional maxims out of its own *necessity*. Hence, *law is the essence of freedom*, not necessitated by the accident of *this world*. The Law preceded the creation of the world; it exists without the world. The realization of there being a clear distinction between prudence and morality is the greatest achievement of modern philosophy.
I objected when one of Rachel’s friends complained that physicians ethically opposed to treating Raphael were mere instruments. The implication, having no determination over the outcome of their actions, was that they had no right to determine their actions. Although I thought the doctors were wrong, and their object is not completely in their hands, a doctor certainly is not simply a cog in a machine, someone who does a job following the dictates of others, but a professional who must be a compassionate, ethical and thinking individual. Is it in the hands of heaven for someone to reflect upon the worth of a life?

The pagan image of the perfect servant, the perfect soldier, the perfect doctor, and the role that one is cast into, views the individual as a defective copy of an ideal. Freedom is nothing more than the use of reason to correct that defect by achieving knowledge of human perfection. There is no image. We have only our own selves to perfect.

Additionally, a professional in America is ethically accountable to patients and clients, students, peers, and society in general. Admiral Rickover made that point when he wrote, “Service ceases to be professional if it has in any way been dictated by the client or employer. The role of the professional man in society is to lend his special knowledge, his well-trained intellect, and his dispassionate habit of visualizing problems in terms of fundamental principles to whatever task is entrusted to him. Professional independence is not a special privilege, but rather an inner necessity for the true professional man, and a safeguard for his employers and the general public. Without it he
negates everything that makes him a professional person and becomes at best a routine technician or hired hand, at worst a hack.”

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After the surgery, Dr. Saad came into the waiting room to tell us that everything went well. “Did you expect anything less?”

“Boy,” I said. “You are confident.” From then on, I referred to him as the Magnificent.

“Well, you know,” he said. “Somebody must be calm. The parents are worried, but I know how these things go. It’s good to keep them optimistic.”

“I’m glad you did the surgery today instead of next week. I start teaching Summer School next Tuesday.”

“I have a sister who is a teacher. Three of us are doctors, three are professors, and one is a high school teacher.”

“Seven kids. That’s like our family,” I said.

He smiled. “Let me know if there are any problems.”

Before the surgery, I sent the following message onto the trisomy support group email list:
“Our baby was born last week with full trisomy 13. We are thankful that his heart is okay. He did not breathe when he was born and was put on a ventilator. Doctors wanted us to pull the plug but we refused. We had a lot of aggravation from them imposing their values upon us. He is breathing pretty good now and is on the lowest vent setting. My son has holoprosencephaly and lissencephaly, but apparently the brain stem and mid brain are formed. He is missing a large part of the upper brain. He has a cleft palate, so we are putting in a g-tube today for feeding, and hope to extubate him next week, God willing. Does anyone have any experience with a case like this?”

Jennifer, mom to four-year old Eleanor, of Boise, Idaho, wrote in response:

“Our daughter has trisomy 18, but she has a g tube and was on a ventilator for about 6 months (with a trach). She does fine on the g-tube, and breathes fine without a vent now. There are many on the lists that have gone through the same things you are going through, with the doctors' unwanted opinions and all. Just hang in there and love your little boy as much as you can! We will be praying for you!”

Teresa Cain, a recent trisomy 13 parent responded:

“Our baby girl was born on 6-10-04 with full trisomy 13. We experienced the same thing with the doctors, and we were heartbroken. They do not realize that it is the love of your life they are talking about. Tom and I knew a month in advance about Taylor's condition so we had time to educate and prepare ourselves. Some of these babies live longer than others. I will pray for your baby boy. Taylor had trouble breathing also and was on oxygen while she was in the hospital. She had a hole in her heart and her lungs were too small. I am glad your baby’s heart is fine. May God be with you and your family during this stressful and difficult time.”
And another parent responded:

“Hi Arthur, My name is Penny and I live with my husband Joe and our two boys Nicholas (13yrs) and Devon (9yrs) in Deland, Florida. Devon has full trisomy 13 with balanced translocation 5 and 13 and just June 15th celebrated his ninth birthday. Devon has no heart or brain anomalies...why? No one knows. Devon does have health and development issues, but I won't go into those at the moment until you're ready to hear some more...I know you're on information overload at the moment and everyone here knows how I can ramble on about our boys. I do, however, have a good friend, Suzanne, in Palm Coast, Florida, who had a beautiful little girl named Kaylee. Kaylee had holoprosencephaly, microcephaly, and she was missing her corpus callosum and hypothalamus. I believe she had a very severe cleft lip and palate. She was g-tube fed and had Nissan fundoplication (stomach wrap). Let me also say, she had the most biggest, beautiful and expressive brown doe eyes and longest eye lashes I've ever seen, and a smile that could outshine the sun! She passed away in January of 2000, at just over five years old. If you'd like, I can ask Suzanne if she'd mind if I gave out her email address and phone number. I'm so sorry you have to deal with doctors like that. Only you can make the decisions that need to be made for your son. What's his name, by the way? How much did he weigh...how long? Did he have lots of hair...what color? You know...all that stuff?

“It's true that the brain anomalies that your son has are not good...but it does not necessarily mean you have no quality time with your son...as I wrote about Kaylee...her family had five years with her that they wouldn't trade for anything and even though she could not sit or crawl or talk...she could express herself very well. I once heard that
quality of life is the ability to give love and receive love...nothing more...nothing less...I've always liked that and I believe it with all my heart.”

To answer some of Penny’s questions, I posted the following:

“My son Raphael was born at four and a half pounds in his thirty-fifth week. He has four brothers and two sisters. I do not know how the kids feel, but the older ones have come with us to the hospital. The doctors agreed to do the g-tube, and we did that. They are adamant against a trach, and it does not seem medically warranted. It was so hard just to get medical information out of them. In fact, I am very bothered by how they feel they can enforce their vague opinions without any specificity. I have my own religious beliefs (we are observant Jewish), but I cannot see how anyone is so arrogant as to say that my son's quality of life is not worthy of feeding or breathing. I know that is in the past now, but the experience bothers me.

“He seems to be doing fine, but we are nervous about extubating him on Tuesday. It seems the right thing to do medically. God willing, the doctors are looking to release him for care at home next week.”

Penny emailed back:

“What a big lovely family; you wouldn't be human if the attitudes you're getting didn't bother you.”

Loren of southeast Michigan, mother to Keren, who is twenty-one months, wrote:

“Thank you so much for sharing Raphael and your family with us. Our experience with our daughter, Keren (trisomy 18), has been very different from yours, but I'm sure you will find the wealth of information on this list a great help in dealing with doctors. I agree with you completely that it is so horrible the attitude some doctors take.
One wonders if they have forgotten what love is (I like Penny's comment on this: quality of life is love given and received). May your time with Raphael be a blessing! I know Keren has been that for us!”

Nanci, mother to Soleah, 10, with trisomy 18 wrote:

“I know this experience has been troubling. Having a child that doctors think is "incompatible with life" is a whole new world. At the beginning, I was very angry at the way I felt Soleah was treated, I was treated, etc. But over the years, I have come to learn that we are here to teach these medical professionals. They know nothing other than what they read and see--most of which is information dated from the 1960's in some cases. Many doctors never see a trisomy baby born, or certainly not alive. I have at least three conversations a week with a new parent--either newborn or newly diagnosed. These thoughts are global--just about everyone gets the same information. It is troubling and extremely sad to me because they give parents no hope. I just continue to pray and try to educate people, one at a time. I have both spoken and written to doctors and told them how I felt and suggested a better way to handle the situation the next time they faced it. God Bless you as you continue on in this journey.”

Another parent, Tina, wrote:

“Welcome Arthur and family. Medically, my son Logan doesn't have the issues with the brain that Raphael does. But the genetic doctor, whom I love, explained something very important about the brain to me when Logan was in trouble medically. He told me when he first started out in medicine he had a patient that “blew him away.” She was missing over half of her brain. But she had more of her facilities then most of the patients he treated. It all depends how the brain tissues connect and interact with each
other. Logan has more gray or white tissue in the brain then they would like to see. I don't remember which, if it was gray or white. Logan doesn't have the heart issues either.

“Logan was born three months premature, at a whole one pound, eleven ounces and thirteen inches long. He was on a vent for seven weeks. I heard all of the things that you have heard, and probably worse. I was told I was being selfish, cruel; I was causing Logan to suffer and torturing him. Logan is trisomy 13 mosaic. It was also explained to me that depending on where the cells in the body had the extra chromosome, mosaic could be worse then full trisomy 13.

“I fought tooth and nail and did not let them treat Logan as a comfort care case. It is by no means easy; I can say it is worth it. Logan is two and one half years old, twenty-four pounds, thirty-three inches long and is a piece of work. He keeps me on my toes.”

Jamie, father to Zion a three year old with trisomy 13 wrote:

“My son was born with full trisomy 13 and we received a similar welcome from the doctors when my son was in the hospital at birth. My son also had a bilateral cleft lip and palate, and it was quite severe. They told us not to feed him, and he would eventually just die. My son’s heart is good, but my son does not have the brain issues. My son has a trach because he had issues as a newborn, but it has been a wonderful thing. After it was placed, he no longer had spells of apnea. This may or may not be an option for you. I would talk to your doctor. Where do you live? What hospital is your child in? We are here if you need to talk.”

I wrote back:

“We live in New Jersey. Raphael is at Jersey Shore University Medical Center in Neptune. I did not mention that the ophthalmologist said that he probably will not see
functionally. One eye is small and the other apparently does not connect to its optic nerve. He seems to be doing well after the g-tube and the next hurdle is getting him off the ventilator. We are concerned since the medical team had trouble the first time they intubated him.”

Tina wrote back:

“Our kids should never have to do without, ever! Logan almost needed a trach but the second hospital we were in fixed his problems with the breathing. He was getting too much fluid, which caused him to aspirate on a regular basis. Once they balanced out the fluid he started actually growing and his lungs started to grow more tissue. Logan also has a g-tube.”
Poppy came to visit on Friday afternoon, July 2. He was sitting in the kitchen when I got home, waiting for me. We had asked him not to stay for the Sabbath, since we needed time alone, and also, quite selfishly, because he agreed with the doctors.

Like my father, my youngest brother, Eric, always did things for us. He just sent us his old laptop computer and an old desktop computer. That afternoon, however, I only wanted to talk about the baby and our decisions, and I already told Poppy not to get involved. He really had no choice but to talk about the computers.

“Did you set them up yet?” Poppy asked. He began talking about the desktop, explaining that it might not work, but I was not interested in mundane matters at that time. I told that to him, and he got upset and left the house. I called him on the telephone to apologize.

The Sabbath was uneventful. On Sunday, the Fourth of July, I visited the hospital in the morning and returned home, whereas Rachel did not there until 5:30 in the afternoon. I returned with the kids in the evening to visit the baby and to see the fireworks in one of the seaside towns near the hospital. Rachel stayed in the hospital with
our four-year-old daughter while the rest of us went about our patriotic duty. Someone permitted us sit on their front lawn to watch the fireworks.

The Fourth of July is a time to reflect on our nation and its communities. I live in a tightly knit religious community that some might characterize as having an outdated way of life, a kind of modern Puritanism. We do not have television or the Internet in our homes, so that our children should not be exposed to decadence, promiscuity and immodesty, and boys and girls go to separate religious schools. This costs each family from $20,000 to $40,000 per year, in addition to about $10,000 in property taxes. Since none of our children go to the public schools, the number of children receiving free education is so small compared to the population that the State forces us to finance public education almost completely locally, even though the median income is among the lowest in the State. The sovereign may not inhibit religion, but it sure can make it very expensive to practice.

We are a diverse community, both in opinions and in customs. We moral community, whose values are not much different than the virtues on which this great republic was founded. When the Congress of the Confederation in 1787 guaranteed equal statehood to its territories, creating the most democratic colonial policy ever, it declared, in Article Three of the Northwest Ordinance, “Religion, morality, and knowledge being necessary to good government and the happiness of mankind, schools shall forever be encouraged.”

Unlike the driving principle of honor in monarchy and of fear in tyranny, virtue, the driving principle of democracy, is sustained only through education. This country is what it is because it knows what it was. The teacher binds the nation to its past. A liberal
education in mathematics, science, history, and literature cultivates reason and knowledge, developing the ability to make practical choices and, most importantly, the moral sensibilities of the child. Ask me why I teach math and I answer, for the same reason why I teach history and government, to nurture the student into a thinking citizen with duty to nation and neighbors, and who seeks justice in the community. The school is a community.

*My fellow Americans, have you replaced your heterogeneous communities of families with homogeneous communities of interest?* Aside from the school, has the abortion community, right to life community, business community and other non-diverse factions, become the only remaining kind of community?

The country that Jefferson idealized and Tocqueville praised, even with its multitudes of associations, was a nation of federalism and families, and freedom, which is the acceptance of the laws that individuals legislate for themselves. Over the last century, artificial structural changes, creating a single hegemony, one rule for the whole country, have undermined those values far beyond the effects of urbanization and mobility. The judicial branch of government used substantive due process, not procedural, one hundred years ago to halt State social legislation such as minimum wages and maximum working hours. Since 1963, substantive due process was used to dictate the substance of State criminal codes, to curtail legislation over private morality, and to incorporate the limitations of the national government onto the people themselves in their States and communities. Many of the specific prohibitions in the Bill of Rights are not necessary for all government, but institutional rules for our *national government*. If the substance

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of the law must be subject to review, how arrogant to claim that liberty in the States, or in any republican form of government, cannot be served under other rules and procedures. But the Court does not end by imposing on the States the expressed prohibitions that the Constitution imposed on the federal government, but adds derivatives upon derivatives upon both community and government, ultimately to the strengthening of the later and to the annihilation of the former.

Ironically, substantive due process might be the most enduring legacy of the greatest advocate of States’ rights, John Calhoun, who imagined that the due process clause of the Fifth Amendment forbade Congress from restricting slavery in federal territories. His clever invention of substantive due process and its adoption by the Dred Scott Court allows men to enshrine their beliefs into the security of the Constitution beyond the reach of political discussion. In its original case, it contributed to turning our moderate election-oriented two-party system into a factional issue-oriented multi-party system, ending the possibility for all compromise short of a Constitutional amendment that would restore the regulatory power to Congress, effectively tearing apart a great nation.

The legislative branch has used its constitutional appropriations power to restrict the States and their subdivisions in determining their own affairs, and its legitimate interstate commerce power, as a national solution is demanded on almost every important issue. It has intruded into education, a power reserved to the States, and effectively replaced patriotism with global competition as the purpose of public schooling, holding teachers accountable for math, reading and science while ignoring American history and civics. The country as a whole is certainly not more divided now than in the past, just less
tolerant of diversity in practice. People in Texas always differed from people in New York, but those differences were reserved to the States, not fought out in Washington. Federalism and the family have weakened, is freedom next?

I blame many of our nation’s ills on the Supreme Court. It has confused what is thought the law ideally ought to say, which is an entirely political opinion, belonging to the non-legalistic branches of government, with that which the Constitution actually says. It is as if the people have acquiesced to accept the political views of nine.

“Constitutional” has come to mean “ought” or “right” to many Americans, who confuse that which they call constitutional with how they would vote at the polls. Constitutions do not gain their authority from abstract theory, Burke observed, but from actual historic achievement. Legal opinion into the intent of a clause of the Constitution or any statue, if doubtful, is not decided by the meaning of words, which can be as subjective as a political opinion, but requires examination of the historic circumstances or context surrounding enactment. There is a correct interpretation of the law.

The Fourteenth Amendment clearly meant impartiality and equality before the law, that a State cannot discriminatorily deprive life, liberty or property. But from 1895 to 1937 any regulation that did not fit into the Court’s old privacy philosophy of economics and from 1963 to the present, any law that did not fit into the Court’s new privacy philosophy of liberation was ruled unconstitutional. To those who advance the active participation of the Court in articulating goals of American society as a kind of national conscience, what is the difference between the Laissez Faire Court and the modern court? Has any justice, ever thought he was not upholding the American
democratic ideal?\textsuperscript{6} And is a tally of the laws of a majority of States sufficient to invalidate the law of the majority within one State, when reasonable people can disagree? It is irrelevant that times have changed, since in both eras, the Court is wrong. If the original meaning of a law is outdated, then ignore it, change it, or amend the Constitution! Do not destroy democracy and the political process by using history out of context to gain a result on a contemporary issue. Government of men concerns itself with the values of jurists, worrying whether justices are liberal or conservative, both of whom Holmes criticizes as setting “any limit but the sky.”\textsuperscript{7} By contrast, government of law limits itself to general constitutional principles that are blind to the result of any agenda.

It is irrational to counter that laws are made by men and judges are but men. The intellect has the capacity to turn away from its favored policy objective, even from its most cherished positions on issues, and to act for the sake of the law. It is the law that makes us as a nation; the law binds our generation with generations of the past. The nation is strong when it is true to its history, which is manifest in the rule of law, binding all people, past and present, into a nation. The people must follow the law; not the law should follow the people.

In his famous speech to the Young Men’s Lyceum of Springfield in 1838, A. Lincoln said, “Let the reverence of the laws be breathed by every American mother, to the lisping babe that prattles on her lap; let it be taught in schools, in seminaries, and in colleges; let it be written in Primers, spelling books, and in almanacs; let it be preached

\textsuperscript{6} ibid. pp.52-54

\textsuperscript{7} Baldwin v. Missouri. 281 U.S. 586 (1930)
from the pulpit, proclaimed in legislative halls, and enforced in halls of justice. And in short, let it become the political religion of the nation.⁸

Raphael seemed to be quite alert when we returned to the hospital on Independence Day night. Both of his eyes were open. The sedative effect of his anti-seizure drugs was wearing off and he did not have any seizures.

The next morning, Monday, July 5, was my last day before starting summer school. Rachel and I arrived at the hospital at 11:00.

“I want to extubate him tomorrow,” Dr. Ross said to us. “That’s the only way we’ll know if he’ll breathe.”

“But he just got the g-tube and he’s not used to eating. Maybe he’s using up too much energy on that,” I said.

“It’ll already be four days of feeding by tomorrow,” she said.

“I want be in the hospital when you do it and I begin teaching tomorrow.”

“We can wait until the afternoon.”

“But I don’t understand, Dr. Ross. If he couldn’t breathe when he was born, why should he be able to breathe now?” I asked.
“We have to move forward. You can’t bring him home on a respirator.”

We spoke with Lynn, Raphael’s nurse for that day. She was his nurse for most of his days in NICU.

“It’s my understanding that once he’s released, he will not be reintubated,” she said.

“Does that mean if we bring him back here with trouble breathing, they won’t admit him?” I asked.

“I don’t know. I think the goal is to get him home.”

“To die? Is that the plan?”

She shook her head. “No, it will be good for him to be at home.”

She was right. “Well, anyway, there are so many bugs that he can pick up in the hospital.”

“He needs a loving home. He will thrive at home.”

“I want to give him a chance. I think he wants to breathe, but he needs a trach to breathe through. I don’t want to take him off the respirator just so we can bring him home. Can’t we take him home with a trach once he’s off the respirator?”

“I don’t see why not.”

I continued my Internet searches for stories of trisomy children. I found the following letter posted by Barry and Deidri Alderson of Costa Mesa, California:

“Dear Josiah’s Doctors & Nurses, Just to remind you, through all the many patients you have, Josiah is a Trisomy 13 little boy born January 14, 1998. If you have not seen him recently, we’re sure you’ll enjoy his recent picture included. What a glorious time of year to be updating you on his progress. Though “specialists” and geneticists at
another hospital thought, "interrupting our pregnancy will be much better for our family," to the extreme that they refused to deliver him, abortion was never an option. This little child has been an incredible blessing to our entire family, and we believe he has touched some in the medical field also.

“Physically Josiah is diagnosed as a Trisomy 13 with holoprosencephaly and a Dandy-Walker cyst. His left eye has a coloboma and he is now fitted with (the cutest little) glasses. He has hearing aids, a ‘flattened’ windpipe, and one vocal cord is paralyzed. His cleft palate has not been repaired yet, but his lip has. A V.S.D. is in the past, and he has dextrocardia. He still uses a G-tube, and is just the stoutest little thing ever. Last, but not least, he has the cutest sixth toe on his left foot…

“Developmentally Josiah has proven previous doctors' predictions and even the CHOC Neonatology Team's belief of his disposition, to be wrong! To compare to what we were told, developmentally, Josiah is off the charts!! We are blessed to say, he has the most endearing personality! He sits on his own, crawls, is learning to pull himself up and is working with a walker. Now, how about that?! Starting January 16, 2001, he will be going to school. We are presently finding what school is best suited for him.

“Socially Josiah needs to be in the middle of everything. If his brother and sister move their play to another room, he will follow them. When the ‘bath-time’ song is sung, and ‘It's time to brush our teeth’ is called, he will come to the bathroom. Bath time is playtime and he loves to have his hair shampooed. He was brushing his own teeth for a while, but that has recently stopped. Maybe just proving to be a typical two-year old and showing his rebellious side. Kissing has become even more passionate and will embrace your neck while he kisses you. Even still, he prefers kissing women only (do you blame
My husband even once said, ‘It's a good thing you're my son, otherwise I'd be jealous.’ His distinguishable laughter fills the room. For those who don't know any better, they will turn and look, but once they see him bucking with a smile from ear to ear and his crescent moon eyes beaming, they smile at his frolicking.

“To any of you, that may come across a parent about to raise a Trisomy 13, let them; encourage them, give them hope and peace that they will be blessed with the endurance to handle such a special child, and could quite possibly be their ‘favorite’ for every reason. If any of you would like to do a study or have any questions to better yourself on this syndrome, please, please call us. We would love to show him off and update you on the possibilities of this syndrome, if only the child would be allowed to live, instead of being aborted. After all, it is a child not a choice.

“Thank you to all who have been there for our little guy and we will continue to update you at this special time of year. You have touched our lives in many ways. Each one of you, in your very own way, Thank you.”

Before I left the hospital, I called Mrs. Alderson.

“Does he have alobar holoprosencephaly?”

“I don’t know how to classify it, but Josiah’s holoprosencephaly is the one that’s not so severe,” she said.

“Can he see?”

“Yes, with glasses.”

“Can he walk?”
“He cruises. He walks around the room holding onto furniture. Our other kids love him; they always play together,” she said. “I don’t know if you’re a believer, but we’re real believers in the Lord. What’s your baby’s name?”

“Refoel.” I pronounced Raphael’s name in the Yiddish dialect of the original Hebrew. “We’re Jewish. Raphael is Hebrew for ‘God will heal.’ Josiah is also Hebrew; it’s Yoshiyahu, meaning, ‘God will save.’ Yoshiyahu was one of our righteous kings.”

I also read data on the SOFT website, the Support Organization for Trisomy, that surveyed how many trisomy 13 and trisomy 18 children had various procedures. None were on respirators and only few had tracheostomies. All the SOFT parents fought hard for the lives of their children, but why did so few of them have tracheostomies? With all their anatomical anomalies, how could so many be breathing without any aid? Was it possible that so many people just assumed that if a child could not breathe, that the child did not want to breathe and could not survive, the data representing just the outliers of all who were born?

Several days latter I spoke to the SOFT medical advisor, Dr. John Carey. He commented that my perception was correct.

“It does not seem to be common,” Dr. Carey said.

“The tracheostomy seems to be the Rubicon that nobody wants to cross. Once across, the side of termination if gone,” I said. “Is it because deep down inside, breathing is the threshold of life? If he can’t breathe on his own, then his life should not be preserved?”

“I don’t know. I never thought of it like that,” Dr Carey said.
Dr. Carey and Bonnie Baty, both in Utah, conducted the only research, of which I knew, on living trisomy children. Dr. Carey wrote a guidebook for pediatricians with growth charts, immunization schedules, and basic care, for both trisomy 13 children and trisomy 18 children. Bonnie Baty gathered information from scores of trisomy children, giving parents insight on what kind of development to expect. Their work differed from the usual trisomy literature that reported finding such as, “Baby X with such and such anomalies lived thirty-six hours.” Needless to say, Baby X was not given a breathing tube. Typically parents are told not expect their babies to live, so they do not live.

Although the hard data indicated that a tracheostomy was not often done, I had received many emails from parents on the trisomy list that told of living trisomy children with tracheostomies. When I got home from the hospital on Monday afternoon, I telephoned Barb, the president of SOFT, and expressed my confusion. She gave me the phone number for Anne in North Carolina, a registered nurse who was also the mother of a teenage daughter with trisomy 18. The young-lady has since passed away due respiratory failure after contracting a virus. North Carolina is one among several States that allow doctors to put on a DNR (die now request?) without consulting parents. The doctors that her parents were relying upon to save her life just let her die.⁹

“The doctors are insisting that eventually the baby will no longer want to breathe, but from what I read, it’s not some kind of condition that just kicks in,” I related to Anne.

“Every so often the kids have apnea.”

“Then it’s just intermittent. Will we be able to get a monitor at home to warn us if he stops breathing?”

“You have to be on the ball,” she said. “But an apnea monitor is okay to have at home. You also should get oxygen. He might need it at times.”

“Right now we’re trying to get him off the respirator but I really want to put in a trach.”

“A trach gives you more security. You can always pump in oxygen if he needs it,” she said.

“That makes sense—security. He doesn’t need to permanently stay on a respirator just because he has a trach. Why can’t he breathe through a trach just as one would normally breathe through a nose?”

“Well, it’s not exactly the same.”

I changed the subject to a familiar theme.

“The doctors pressured me to pull the plug when he was born. One even told me to imagine what the baby would want if he could talk. What does that mean? Are they thinking about that which the baby wants? Or perhaps that which they would want if they were the parents?”

“A lot of people just don’t want to be bothered,” she said.

“Who suffers more, the parents or the baby? They’re projecting their own emotions onto the baby.”

*How mature we humans are, to want to die?*

That night I held Raphael. He was cooing, or so I imagined. His eyes were open and he dropped his jaw as if to smile. He was moving around in his crib a lot and was very alert.
NICU was busy with a baby next to Raphael, who had to be transferred by helicopter to Children’s Hospital of Philadelphia. She had many doctors around her as they tried to keep her heart working, but no parents anywhere. Even when she left the hospital, I saw no parents.
Extubation
Chapter Twelve

After my first day of summer school on Tuesday, I made a long distance phone-call to an older man visiting Israel whose eleventh child had trisomy 18. The child had a small brain and no vision. His doctors were not able to lower the respirator or to extubate him, so the parents did not take him home. The child was put in a facility where he lived for four years, until he died. I hung up the telephone thankful for the hope that we might be able to bring Raphael home. Institutionalization seemed to be the extreme opposite of pulling the plug. It seemed that the Golden Mean was to bring him home, and we were thankful that we might have the opportunity for his inclusion into our family.

Rachel had been with the baby since the morning on my first day back at work. Once summer school started, she replaced me in caring for Raphael, far exceeding my knowledge and care of him. Typically, after getting the kids off to day camp, she went to the hospital around 10:00, arriving shortly after the doctors made their morning rounds and stayed well into the afternoon. I taught from 7:30 until 12:30 and did not arrive at the hospital until some time after that. One of us returned home for the rest of the afternoon,
while all parents had to be out around 6:00, the time that the nurses changed shifts. I returned at night for an hour or two before going back home.

I did not get to the hospital until later that afternoon on Tuesday, towards the end of Dr. Ross’s shift. Rachel told me that Dr. Ross was hesitant to extubate him because Raphael had an elevated temperature.

“Do you think you’ll try to extubate today?” I asked Dr. Ross.

“I’d rather wait till tomorrow morning.”

“But I have to teach. You know that I want to be around in case a decision has to be made.”

“I think it’ll be better in the morning when there are more doctors around in case we have to reintubate him.”

“You’re agreeing to reintubate if he can’t breathe on his own?”

“Yes, but if we reintubate, you’ll have transfer him to another hospital. He can’t stay here.”

“What happens if we take him home and he has trouble breathing? Will emergency room doctors will be able to get a tube into him?”

“It really isn’t that hard. They’re perfectly capable of reintubating him.”

“Then why can’t you try to extubate him now?”

“It’s better tomorrow, first thing in the morning. Then I’ll have the whole day on the floor to monitor him.”

“I don’t want you jumping to reintubate him too quickly. I don’t want to get thrown out of the hospital.” Doctors alone should never make the crucial decision to reintubate, when it is their patients that have to suffer the consequences of being evicted.
“Believe me; we won’t put him back on so quickly. He probably will still be off the machine by the time you come back tomorrow afternoon,” Dr. Ross said. “And then you’ll be able to bring him home.”

“Will we get all the equipment we need, like an apnea monitor?”

“The insurance won’t cover that and you don’t need it.” Up until then, she was making so much sense.

“What do you mean? What are we supposed to do, just stand over him twenty-four hours straight, watching to see if he stops breathing?”

“You’ll get oxygen tanks and maybe a pulse oximeter, but an apnea monitor will constantly go off with false alarms. You’ll need a prescription for it and I won’t give you one. It’s not called for.”

“Why, because nothing is called for in his case?” I was wrong. The pulse oximeter turned out to be our monitor of choice.

“The main thing you should be concentrating on is nursing.”

“The case manager is working on arranging the nursing,” I said.

“I already spoke to the case manager about the equipment. She said that your insurance company is going to deny everything. For sure, you won’t get an apnea monitor. Maybe you can get the pulse oximeter, but insurance companies are very difficult.”

I had good insurance. Why would they deny coverage? I asked to meet with our case manager and Mary Lou Kurowski. We met in the nursing room without Dr. Ross.
“Dr. Ross said that we wouldn’t be able to get an apnea monitor, maybe a pulse oximeter. How can I bring him home without proper equipment? Doesn’t it make sense for the insurance to want him home instead of in NICU?”

“Nobody said that you’d be denied anything. Insurance will give you whatever you need,” the case manager reassured me.

“But Dr. Ross said that you told her that the insurance company was going to drop us. They can’t do that, could they?”

“No. And you’ll get all the equipment you need. The only problem is nursing. Now if the baby had a trach, the case is considered custodial care and you’d qualify for more home nursing. Without a trach you probably will still get nursing, but there’s a nursing shortage out there and it’s difficult to find nurses.”

“Can you talk to Dr. Ross? There are other doctors that can give us a prescription for equipment if she doesn’t want to. She said that an emergency room couldn’t deny us medical service if we had to take the baby in. Is she right?”

“Yes. And let me make something clear. The insurance company cannot and will not drop you just because your baby has trisomy 13. It can’t refuse you emergency room coverage. You’ll get everything you need to help the baby. It’s just the nursing that we need to work on.”

The next day I called Dr. Ross at 10:00 from the high school.

“He’s got a temperature of 102,” she told me. “You know that his elevated temperature might be central, not from a bug.”

I ignored her diagnosis. I had little confidence in her. But she was right.

“Are you still going to extubate today?”
“I don’t see why his fever should slow us down,” she said. “I want to take some spinal fluid to see if he has meningitis.”

“Can’t a fever prevent his success at breathing? You’re only giving him one chance.”

“We can always try again if it doesn’t work this time.” I was surprised she said that he could stay for a second chance.

Rachel arrived at the hospital by 11:00 that morning when I called again.

“He was extubated. He’s doing okay,” she said. “He has an oxygen mask on his face.”

“Is that normal?”

“Yes.”

“Are they doing the spinal tap?”

“I don’t want them to. He doesn’t have meningitis. They’re just going to poke holes in him for no reason.” Rachel was becoming the primary caregiver and expert on Raphael. Over the next year, doctors sometimes would contradict her opinion for weeks, almost always in the end giving in to her initial advice.

After I finished my summer school day at 12:30 on Wednesday, I went straight to the hospital, arriving at 1:15. Raphael already had two episodes in which he had to be “bagged,” an artificial respiration that involved squeezing an Ambubag, a kind of balloon that manually pumped air over the mouth to inflate his lungs.

When I sat down to hold him, his oxygen saturation dipped way down. The nurse thought that the position in which I was holding him might be restricting his airway and I heard raspy noises. His eyes were open and his belly was jerking in and out, as he
breathed. However, I had already noticed the abdominal jerking while he was still on the ventilator.

Dr. Ross came over to our place in NICU and took the oxygen mask off Raphael’s face. He did fine and went to sleep. She told Rachel and me that she wanted to give him a blood transfusion and asked us to sign a consent form. She thought that Raphael was a little anemic, probably from all the blood taken for lab work, and that the transfusion will boost the capacity of his blood to hold oxygen.

I posted the following on the email list:

“Raphael came off the vent at 10:00 this morning. So far, he has had two episodes, but stabilized. He was on some oxygen and they just took it off. He is breathing rather hard, but the doctors say that it is not too bad. They are giving him some blood because he did show to be a little anemic. It is now 3:00 and his blood oxygen saturation is still about 100 percent. The doctors said if everything goes well, and we pray for that, they will let him go home next Wednesday.”

I decided to spend the night in the hospital since the baby was extubated. I arrived at 10:00 that night, just as his heart rate and blood saturation began to fall again.

“We might have to reintubate him,” Dr. Ahmed, the resident on duty that night, said to me.

“Please get me before you do so,” I requested. “I’ll be sleeping in the waiting room the whole night. Only do it as a last resort. He might be evicted if he fails.”

The waiting room had a couch, telephone and television set, and an entrance door that I shut. I stayed there to watch a PBS documentary about Robert Kennedy, for which I felt guilty, since I was not with Raphael. The program showed scenes of Martin Luther
King and his message of peace and compassion. I saw Kennedy breaking the news of King’s assassination to a crowd during a campaign speech, promising to carry on his work. A short time after that, Robert Kennedy was assassinated by Sirhan Sirhan.

A few months earlier, before we found out about Raphael, I had a related conversation with fellow teachers in the high school auditorium during a faculty meeting. I noticed a poster across from the Wall of Prejudice celebrating Elderige Cleaver, the Black Panther, during Black History month. Remembering Cleaver from the 1960’s, but forgetting his conviction, I later asked another mathematics teacher, Gary, sitting behind me, “Wasn’t he someone bad?”

“Elderige Cleaver was someone who fought for civil rights,” he answered.

“Then he was someone good.”

“He was tired of waiting for peaceable change like Martin Luther King,” Gary said. “He preached violence. Change was not happening fast enough.”

“Then he hurt people,” I said. “He wasn’t good after all.”

“He was a sexist so he wasn’t good anyway,” Gary said. His comment was strange.

The school librarian, sitting next to Gary, joined in the conversation. “What you might consider good, someone else might consider bad. One man’s terrorist is another man’s hero. My father fought in the Irgun for Israeli independence. To the British, he was a criminal.”

“We all aren’t proud of the Irgun,” I said. “And these things are not relative.”

“Didn’t the British think George Washington was a terrorist?” she asked.

“George Washington?”
“Yea, our Founding Fathers were wanted by the British,” Gary added.

“King George remarked that George Washington would be the greatest man of his time if he retires after serving two terms as President.” I was surprised how easy they made my argument. “That set precedent, as who would claim to be better than Washington?”

“Actually King George made the remark about Washington’s retirement after the Revolutionary War.”

“Edmund Burk, the famous Whig, called the American Revolution the American Conservation. The Patriots were fighting for principles long recognized under English law,” I said.

“Was that before or after Burke was paid off?” Gary is a former president of the Thomas Paine Society. Burke and Paine did not get along.

“There is a virtuous way to redress grievances. People can have different causes but we all ought to agree that the means of Washington were better than the means of Cleaver,” I said. “It’s like saying there is nothing wrong with what Yasser Arafat is doing.”

“To the Palestinians he’s a hero,” the daughter of Israel noted. “He has no other means of furthering his cause.”

“He’s got to give peace a chance,” I said. “The Middle East conflict is really a clash of two cultures, one that values life and the other that values martyrdom. I think that if the Palestinians followed King instead of Cleaver, they’d have their lives and their state. What is more salutary than civil disobedience in a democracy?”
“It’s not a clash to two different cultures. Both are based upon the same myth, both claiming to be descended from Abraham. You say Isaac was chosen and they say Ishmael was chosen.”

An answer to the question that had bothered me for some time dawned upon me.

“But who among us would think that he is better than Abraham? Yet Abraham was not allowed to make the greatest sacrifice. The command *not to sacrifice* Isaac forever purged fanaticism from our culture. Life became its quintessential value.”
I returned to NICU after the PBS documentary and held Raphael for a short time before retiring for the night. I slept until about 5:00 the next morning. When I reentered NICU, he was crying a lot and I sat down to hold him. I was able to hear his cries. He was on 100 percent oxygen using the mask, but his heart rate and oxygen saturation still dropped. The nurse paged Dr. Ahmed to come to NICU from the room in which he was sleeping. When he arrived, he stopped the g-tube feeding in case Raphael needed to be reintubated. He explained that the 100 percent measurement of oxygen going into his mask was a meaningless quantity since the mask did not fit his nose, which he lacked. He figured that he was getting thirty-five percent oxygen. The nurse commented that she thought he will need to be reintubated, but his numbers came back up.

Later, I wrote the following email to Bonnie Baty:

“Dear Dr. Baty, I do not know if you can help but I'll try. I will ask Dr. Carey when he calls. Raphael has been off the vent for about thirty hours now. He is laboring to breathe. We had a rough time around 5:30 this morning when his heart rate dropped and his saturation went down. He happened to be crying like a baby then. The doctor on call
considered reintubating him, but his blood showed good saturation. He has had several episodes similar to that. I have two questions as follows:

1. Raphael has the cleft palate. He cannot swallow and mucus builds up. Does this affect his breathing? How can we help that?

2. He is breathing with this jerky motion under his ribs. I think they called it “retractions.” It seems like he is struggling a bit, but his saturation is good. He breathed like that the last few days on the vent. What are we to make of that?

“The nurses are not sure if his problems breathing are part of the extubation process, if because he was somewhat premature, or if he actually will not be able to breathe properly because of his trisomy.”

Bonnie wrote back that she emailed my questions to Dr. Carey. Since my message went out to everyone on the list, Karen responded:

“Retractions are generally an indication of obstruction. When you next go in, have a look at the V-shaped notch at the top of the sternum. Is that being sucked in big-time with each breath? The breathing movement under the ribs sounds likes Cheyne-Stokes respirations, and that’s not good. If the problem is obstruction, and it sounds like it is to me, then it can be treated, and in my humble opinion, is worth treating. I am not a doctor but here goes for a crash course in apneas so that you can ask the intelligent questions of his doctors.

“There are essentially two types of apneas - central and obstructive. Central apneas are caused by the brain. They are the most difficult to treat, however they can be treated with drugs like caffeine and theophylline (Ventolin), and if need be, by Bi-PAP.
Basically, in a central apnea, the brain just stops telling the lungs to breathe. And they just stop breathing - there is no struggling for a breath they just stop. Central apneas are the most dangerous, but they are the type of apnea that our kids are most likely to grow out of - usually within three to twelve months.

“Obstructive apneas are different. In obstructive apneas there is some physical obstruction that makes it hard to breathe - that’s why breathing is labored. Their brain is working fine at trying to breathe but there is ‘something’ in the way that’s making it hard to get the air in. In our kids, that physical obstruction is usually anatomical, e.g. a cleft palate, low toned airways, tonsils, etc. That something can be any one of a dozen things or it can be a mixture. A cleft palate can definitely be a cause of obstruction. As can inflammation from being intubated.

“Obstructive apneas are still quite dangerous. They can lead to central apneas - their bodies get so tired from just breathing that their brains eventually say ‘enough’ and reset what it considers acceptable oxygen levels. Basically it’s too hard to get 100% saturations which, ‘I would like, so I will settle for 95%,’ and when that’s still too hard, it settles for 90%, and so on.

“Eventually they can suffocate themselves, that is, they are too tired and weak from all the work breathing that they don’t have the strength to breathe over the obstruction anymore. Obstructive apneas also burn up huge amounts of calories making them fail physically. Breathing takes priority. They also put a huge strain on the heart. Obstructive apneas are the ones most people understand as sleep apnea - in adults they snore. Same thing, it’s just happening in babies.

“That said, obstructive apneas are also the easiest to treat. And you have a
number of choices.

1. You can fix the obstruction - if it’s the cleft palate, then you repair it. If it’s being caused by tonsils etc., you take them out.

2. If repair or removal of the cause of the obstruction is not on the cards, then you can use a temporary device like C-PAP or Bi-PAP. A number of our kids use these to sleep. Basically it’s a vacuum cleaner in reverse. The child wears a mask or a nasal canula and that mask is connected to a machine. The machine pumps out room air (not oxygen, but the air can be sweetened with oxygen) at a high pressure (the actual pressure is determined very scientifically to be just enough to get past the obstruction) and into the baby’s airway.

“The difference between C-PAP and Bi-PAP, is that C-PAP uses one continuous pressure (the C). With Bi-Pap, there are two (hence the Bi), one pressure for breathing in and then a lower pressure for breathing out. Sort of like a ventilator but without the fancy stuff like tidal volumes etc.

“With Raphael having a cleft palate, you may have trouble using a mask or even a nasal canula. Also it appears that he is obstructing when he is awake (for most kids they breathe relatively okay when they are awake but not so when they are asleep). The PAPS are easier to handle via mask, if they are only used during sleep. In which case they can opt to place a tracheostomy - that’s a tube, which is inserted into the trachea and through which they breathe.

“This thought alarms a lot of people (me included when it was suggested that we may need to with Alex) but truly it’s not as bad as it may sound. If the primary obstruction is above the trach (e.g. the cleft palate) they won’t need anything else, just
the trach. If there is significant obstruction below the trach they may hook a bi-PAP up to the trach.

“The tracheostomy in this case is usually temporary. And as soon as Raphael is bigger and they can fix the obstruction they will remove it. If for some reason they can't remove the trach, he can still live a very long and happy life with it. There are a lot of kids out there with permanent trachs for a variety of reasons.

“The biggest risk in placing the trach is that the surgeon may accidentally injure the vocal cords when placing it. A trach of course immediately qualifies you for nursing care to help with Raphael when he comes home – don’t turn that down!!

“A number of our kids have had trachs, only one or two have stayed with them permanently. In each of those cases the problem and reason was secondary to additional complications, eg. lack of oxygen during surgery - NOT the trisomy.

“So what do you need to try and convince your doctors to do? You need to try and get them to get a pulmonologist, an Ear Nose and Throat specialist and a plastic surgeon in to see him and do a consultation. They should order a sleep study but may skip it as he is still in ICU and their monitoring equipment will give them almost as much information.

“When you talk to them just say that you understand that obstructive apneas are common in children with a trisomy (very true) and that you would like them to tell you what is causing the labored breathing. Then you ask them if they can circumvent the obstruction with C-PAP, surgery etc.

“If they refuse to get the consultation speedily then run, don't walk, to your hospital patient management person and also the hospitals ethicist. With Alex I fronted
up in the emergency room and REFUSED to leave until they got ‘the master’ breathing properly. I did make a fuss - I had to emotionally. I had just come back from the funeral of a friend’s son (he had Cerebral Palsy) and had died because they kept telling his ‘mum’ there was nothing they could do. After he died they admitted that there was a lot that they could have done - they just didn’t see the point in prolonging care for a winning smile.

“They gave me a hard time and told me I would wish we had never interfered. But nine years later ‘the master’ is still here. He rarely uses his Pap’s these days, they fixed most of the obstructions and he grew out of a lot of the others.”

Raphael was still breathing without the ventilator when I arrived at the hospital at 2:30, Thursday afternoon, July 8. Rachel was there. She was annoyed at Dr. Ross for being so negative. The doctor kept on saying that the feeding was not going through him and that he was spitting it back up. In our opinion, reflux was not the cause of his labored breathing.

Friday was to be Dr. Ross’s last day in NICU. Dr. Batista, who happened to be scheduled for a separate weekend shift, was to take over as head doctor for the next two weeks. He came in at 4:00 Thursday afternoon and took a serious look at the baby. I was impressed by his solemnity when he made his examination.

“Have there been any x-rays,” Dr. Batista asked, as he listened to his breathing.

“They brought the x-ray machine in here several times,” I said.

“I want to see if his lungs have been inflating since he was extubated. When was the last x-ray?”
“I don’t know.”

As it turned out, there were several x-rays on file. “I don’t see any problem with the x-rays,” he said. “It’s possible that his throat is swollen. After being on the vent for so long, the throat tends to swell up from the tubing. I’ll give him something that will relax the swelling.”


“Can you do some kind of test to determine it?”

“There is a test, but it involves sending a tube down into him,” she said. “I don’t think that his feeding should’ve been stopped last night. I restarted his feed this morning and I don’t think that it’s going through him.”

“Isn’t there some kind of medicine for reflux?”

“We started him on Zantac. But, I want to see what happens after a full day of feeding, if he has residuals. We’ll know around 10:00 tonight.”

“Dr. Batista thinks that he has swelling in his throat. That makes sense,” I said.

“I disagree with that,” Dr. Ross said. “I know this baby better than anyone. I’ve been treating him for two weeks.” I was glad that she showed some concern, but I just wanted to be finished with her.

I received an email from Suzanne in Florida:

“Hello Arthur! My name is Suzanne- I believe Penny may have told you about me, and our child, Kaylee. Kaylee was trisomy 13 mosaic with holoprosencephaly. She too had a bilateral cleft lip and palate and was therefore g-tube dependant. Although Kaylee was a very involved trisomy 13 (g-tube feedings and suctioning), she was a joy. I
know you and your wife must have a bazillion questions. I’m here to help you in any way. First let me tell you about our experience.

“Kaylee was born October 19, eight weeks premature. We had no idea that we were going to have a T13 child or that she would have a cleft lip and palate. So, when she arrived, it was definitely a shock! Still she was cute as a button- ten fingers and toes, head full of hair and beautiful brown eyes. It wasn’t until the chromosome test came back (two weeks later) that we found out she had T13 mosaic (mosaic just means that not all of her cells carry the extra chromosome). A MRI of the brain confirmed the brain anomaly. And of course we were given the devastating news that she would more than likely die within six months. We were then shuffled off to a hospital in Jacksonville, Florida, where she underwent surgery for a g-tube and then we were taught how to feed her. She came home just in time for Christmas. I won’t lie to you. The first year was [hard] for all of us. My husband and I had to take shifts caring for her (she got fed only two ounces every two hours round the clock). She had many visits to the doctor and hospital… Yeah I could say the first year was we adjusting to her, and her adjusting to life outside the womb. She was a pleasant baby, though. When she was six months old she had trouble keeping down her food and she started to loose weight. Although operations with T13’s are risky, we opted for an operation called the Nissan fundoplication, or wrapping of the stomach around the esophagus, so that she could not throw up (which if your child is getting the g-tube placed, I would strongly recommend having them do this procedure at the same time, it just saves another surgery down the road). From that point on, she started gaining weight and was a much happier baby. Just prior to her first birthday, Kaylee started having temperatures of 106 and 107! I would
rush her to the hospital and they would be amazed that she was still living with a temp that high. At any rate, she spent two months in the hospital in Orlando, Florida, just to determine that she was missing the hypothalamus, the part of the brain that regulates body temperature. So from that point on, she would about every three months or so have temperatures of “unknown origin” and be miserable for three days and then she would be fine. When she turned one, it was like someone switched a light switch. She was healthy and only went to see the pediatrician for routine visits. (I should mention that her first year of life, she would catch respiratory colds frequently and it seemed like I lived at the pediatricians door step. She had to go for weekly and, at one point daily, weigh-ins to make sure she was gaining weight). From age one and a half to five she was very healthy and lively. She could smile, coo and laugh. I guess you could say she was the equivalent of a six month old. During this time, we did have the plastic surgeon perform one surgery to connect her lip, in the hopes that she might try to speak or maybe eat by mouth. Unfortunately, neither of those occurred. She went to school under the ESE program when she was three. She really enjoyed school and being around other children. She was very aware of her surroundings. (I know this seems so odd to say that she went to school, but trust me these kids really progress with the interaction they receive, and their physical therapy, speech therapy and occupational therapy while at school.)

“Okay…. So I could go on and on about Kaylee. But I won’t. Please feel free to ask me anything. Believe me. It is beneficial to ask those who have already lived, ate and breathed in your situation. I know it all seems daunting now, and even outright depressing, but there are some pluses along the way. Please feel free to email me.”

Another email read:
“I live in Houston Texas; I have a seven-year-old trisomy 18 daughter, Morghan. She had open-heart surgery just before she was 2 months old. Our doctors are always willing to help families who are dealing with doctors such as yours. You are correct. It is not their decision, they are just the instruments. Faye Kaufman”

I wrote her back:

“Interesting Mrs. Kaufman. I am from Houston, and if you can refer me to doctors it may help. But, we are in New Jersey and we probably will not be going to Texas. It is interesting that you called the doctors “agents.” I hear that word used all the time by my friends.”

She wrote back:

“I will assume that Raphael has a heart condition, as many of our children do, and refer you first to our cardiologist and our heart surgeon. Neither our cardiologist nor surgeon considered Morghan’s genetic makeup reason to withhold surgery. Our list of other doctors is extensive and I would be happy to give you their names.

“If you do not get satisfaction from your doctors and would like to bring Raphael here, I am happy to help you arrange both appointments and make inquires for a place to stay. I gather you would need a Kosher home and that the local Ronald McDonald house may not be appropriate. Or possibly, since you are from here, you still have family. Sincerely, Faye J. Kaufman”

Another parent wrote, “Arthur, Keeping your new precious son in my thoughts and prayers! Michelle Wilson, mother to Faren (trisomy 18, three years-almost four!!)”

I wrote back to Suzanne:
“I am sorry that Kaylee is no longer with you. My baby has severe brain anomalies. The center of his brain seems to be one large ventricle. They say he has no gyri, which is lissencephaly, in addition to the holoprosencephaly. Were Kaylee's brain anomalies as severe? My son is also supposedly blind. He may not have a developed optic nerve and one eye is very deformed. My son seems to respond and even smile. The problem now is getting him off the respirator. He is at the lowest setting and seems ready to get off. I am just very nervous because the hospital keeps telling me that his brain will tell him to stop breathing. What does that mean? We want to go home with the apnea monitor and oxygen etc.”

She wrote back:

“From what I recall, the neurologist told us that Kaylee had the right side of the brain and the left side of the brain, but was missing the corpus callosum - which allows the right and left side to communicate, which is why she never opened her hands- she lacked that type of control/coordination. Kaylee was never on a ventilator and it wasn't until the end that she exhibited mild seizures. So, given the information that you have told me, I don't believe that Kaylee's brain anomaly was as severe as your child's. But don't give up hope. The one thing I do know is that their will to live is a lot stronger than what the medical community will give them credit for. The hospital and doctor has a duty to tell you the worst-case scenario. It is quite possible that the brain will not tell your son to breathe. However, it’s your choice as to whether they continue your son on the ventilator. Which as you know is not an easy decision to make. You haven’t told me how old your son is or more importantly, his name. Do you have any other children? How is your wife handling everything? Suzanne"
I found a site on the Internet set up by the Carter Center for Holoprosencephaly, in which parents posted stories about their children, many of whom also had trisomy 13. After copying the addresses, emails, or telephone numbers of the parents of children with the anomalies closest to Raphael’s, I wrote a letter to a couple in North Carolina about Raphael after reading a short story about their son with trisomy 13 and holoprosencephaly that they wrote a few years earlier.

The story went as follows:

“My husband and I went in for a routine ultrasound on May 21, 2001 to determine the sex. During the ultrasound the sonographer noticed something wrong with our baby's brain. On May 23, we were at UAB having a level-two ultrasound, with hopes and prayers that there had been a mistake. The doctor confirmed that our baby had semi or alobar holoprosencephaly. A word I never wanted to hear and had never heard before. He suspected a VSD and that a chromosomal defect was involved on 13 or 18. I was seventeen weeks pregnant at this time. We immediately did an amnio and left the hospital with broken hearts and dreams shot. The amnio came back the following week to confirm our baby had full trisomy 13 (an extra chromosome on the 13th pair). We met with a genetic counselor the following day to further understand our diagnosis. She explained that eighty percent diagnosed terminate. She explained that our situation was not hereditary (translocation can be). We explained that we had studied (through the Carter Center) information and knew this was a lethal diagnosis. We had already decided that we could not terminate. We were thankful that our children were not at an increased risk for this to happen. My husband has two children and we have a 2 1/2 year old together. Our life has changed and we are in a waiting period. We are taking one day at a time. I
have days that are incredibly sad, mad, scared, etc. My 2 1/2 year old is keeping me sane. I need him more than he needs me now. We have met with a neonatologist and at this time do not want any heroic actions taken if our baby makes it to term. I am having weekly sonograms to determine if our angel is still with us or not. We have named him Stephen Michael after the angel and my grandfather. Also our wonderful doctor is Michael. I have just read the book Empty Arms and Precious Lives, Painful Choices. These are fabulous helps. We have an outfit being sewn for our angel. We have visited the funeral home and are preparing the funeral arrangements. I get angry some days for I should be decorating a nursery not looking at coffins. I am trying to get peace. I am a Christian so I am looking for the good in this. I have seen this situation touch lives already (mine hugely).”

“Update 12/5/01. Stephen Michael was born on Sept 17, at thirty-four weeks gestation. He was full trisomy 13 and alobar holoprosencephaly confirmed by a CT scan. He was breathing in delivery, some on his own, but was ventilated to assist. He has trouble controlling his temperature, high liver enzyme levels, but no failure. He does have microcephaly, but no cleft lip. He does only have one nostril but it is not patent. He is on low ventilator settings. He has Phenobarbital for seizures, which are under control. He is tube fed. He is currently stable. He has brought much joy to our family and the lives of his caregivers and friends. We do not know how long we will have him. He opens his eyes and looks at us, he seems to hear, responds to touch and Mommy and Daddy. He cries when he is wet, needs to be suctioned or wants to be turned. It sounds like he does so little but incredible things to us. Our prayer remains that he will not suffer, and as of now, he does not. He is very alert at times and is comfortable and
peaceful (like an angel in waiting). We are prepared to let him go if suffering becomes any part of his life, but we want to give him any opportunity to succeed. We feel confident that his doctors and caregivers and our hearts will know when he no longer wants to live. He now does more that the CT scan can explain medically. We have incredible care and support for our baby and are very grateful to the doctors, nurses, and respiratory therapist of the NICU in Tuscaloosa Alabama where we live. There have been many miracles and blessings from this baby's life and we cherish every MOMENT with our beautiful son. I will update later but for now share a blessing in our experience:

“When Stephen Michael was born Frank entered our life. Frank is my 3-year-old son’s imaginary friend. Frank went everywhere with us. We had to make sure Frank was in the car, that we exchanged pleasantries with Frank. When I asked my son what Frank looked like he said he has black hair and pink eyes. Our relationship with Frank continued. One day in the NICU, my three year old, Will, said, ‘Mommy Frank is here.’ I said hello to him. He said Frank was looking at Stephen Michael. The nurse asked what Frank looked like. Will said again, “he has black hair and pink eyes.” The nurse asked what Frank was wearing. My three year old said, “Frank has wings and something over his head. Please pray for peace and comfort for our baby and God's peace for us. Thanks Renea.”

I received a message at home that Renea called after receiving my letter. “What ever happened to him?” I asked her when I called her back at night.

“He did not make it,” she said in a Southern accent. “But we did everything medically possible.”
“The doctors are trying to convince us to give up,” I said. “I spend more time fighting them than caring for the baby.”

“I know. We had the same problem. But I finally put that to an end.”

“How did you manage that?” I asked. “The NICU doctors can be so arrogant.”

“The doctor in charge, who was really giving us a hard time, had children of his own. I looked him in the eye and asked, ‘What would you do if your daughter was in a car accident and the doctors told you that she’s brain dead, but you held her hand and felt a squeeze?’ He was quiet afterwards.”

“Our son is on a respirator,” I said. “I don’t know if we’re doing right, but I want to put in a trach and the doctors are opposed to it. Now he has reflux. How much are we going to put him through?”

“Was he on a respirator?”

“Yes,” she answered. “And we were going to put in a trach, but he passed on.”

“How did he die if he was on a respirator?”

“He had heart troubles. We were going to do surgery to fix his heart, but it gave out.”

“How bad was his holoprosencephaly?”

“He almost had no brain, but he was there. I know it,” she said.

“How did you know?”

“It might sound strange, but a mother knows these things,” she said.

I did not say anything.

“But I do know it. We did a EEG.”

“They won’t do an EEG on our baby,” I said. “What did it show?”
“You won’t believe this. The neurologist showed me the first page of the results. The EEG was flat. The second page was flat—but then he said, ‘Look here.’ There was a spike on the third page. Right then I had walked in while he was doing the EEG. Stephen Michael knew it.”

“How?” I asked. “How can there be awareness if he had no brain.”

“It’s God,” she said.

“What do you mean?”

“It’s always God. His soul. He makes a child recognize his mother.”

Compare. Before the baby was born, she wrote, “We have met with a neonatologist and at this time do not want any heroic actions taken if our baby makes it to term.” After he was born, she said, “We did everything. If there was something else possible for us to have done, we would have done that.”

I spoke with Mrs. Hanson from our house and did not return to the hospital until very late that Thursday night. The nurse told me that Raphael’s vital signs fell very low earlier in the evening. I fell asleep while I held him in a chair next to his crib, so a nurse told me to go to bed. You are not allowed to sleep while holding a baby and parents are not permitted in NICU after 11:00, but that second rule was not strictly enforced. I slept in the waiting room on a couch until 3:30 when Dr. Sharon, a female resident, knocked on the door to tell me that the baby was having trouble.

“We have to intubate him,” she said. “He had three episodes.”

“When?”

“The first was at 7:00 and the other was just now.” That was only two times.
“You’ll have to stay outside while they do the procedure,” a nurse told me when I got to NICU. “You can go in now for a moment before they start.”

Several nurses and residents were around Raphael. One was holding a big hose over his mouth with a mist coming out of it. His blood saturation was in the sixties. I went into the reception area and watched as they put a curtain around his crib. After three attempts to get the breathing tube into his throat, finally they had him back on the respirator.

“What happened?” I asked Dr. Sharon.

“His heart rate fell to below sixty beats per minute and we had to do chest pumps. He stopped breathing completely.”

He seemed much better after being put back on the ventilator and his blood saturation went back up. His eyes were open and he even seemed to be happy. I held him until I went back to sleep at 4:30. I came back in at 5:30. He waved his hands and kicked his feet as I approached. I walked away and approached again and he turned toward me. He looked happy and alert. What difference oxygen can make! I quietly slipped away for the morning.

When I got home, I told Rachel that Raphael was reintubated. “I want them to figure out what happened.”

“Maybe he has a bug,” Rachel said.

“I don’t know. There’s something restricting his airway. I want them to look at all his x-rays from birth and compare them.”

“Dr. Ross is just going to say that it’s reflux,” she said.
“Today’s going to be our last day with her,” I said. “I don’t mind her making a diagnosis. I just don’t like talking to her about what to do about it.”

“It not that. It’s her negativity. She’s just so negative.”

“I hope Dr. Batista’s compassionate. He seems thoughtful. You need to be creative.”

When I arrived back at the hospital at 1:15, Friday afternoon, Raphael was alert and looked happy. Adhesive tape held the breathing tube and covered his face since he was born, giving him an almost faceless look. He cried like any other baby for the same reasons that any infant cries. If his diaper was dirty, he let us know. When he wanted to be held, he let us know.

Rachel told me that Dr. Ross said that Dr. Saad agreed to put in a trach. I wondered whether we should do a fundoplication at the same time.

“What’s involved in a stomach wrap?” I asked Dr. Ross.

“It’s a three hour procedure.”

“If Dr. Saad does the trach, shouldn’t he do the fundo at the same time?”

“He thinks it’s too dangerous for him.”

“Did he really think that?” I asked myself. But, even though I had been insisting on a trach for some time, the fundo was much more intrusive. I was reluctant to rush into it. “But you think he has reflux. How else can we treat it?”

“We are priming his stomach with medicine to help digestion. Tomorrow we’ll start him on a more basic formula, something easier to digest. He needs to be at thirty cc's per hour and he hasn’t even reached five. He needs to get more nutrition.”
“Is there a conclusive test to confirm reflux? What about going into him with a camera. A nurse mentioned something like a polysomnogram.”

“That’s done usually before discharge,” she said. “He’s had little residuals, but they’re not conclusive. You can’t pull back on a g-tube the way you can with a feeding tube. But he’s had several dirty diapers, so that’s a good sign.”

I went to the library to check my email.

“Hi Arthur, I am also from New Jersey and am going through a difficult time with the doctors treating my daughter. Maia is in St. Peter’s in New Brunswick. She was born on June 22nd. She is off the vent and on CPAP and started gavage feeding. She has an open PDA and a fairly large VSD. Everyone has been so wonderful in her care so far, but now we are up to the big stuff – heart surgery - and I feel the tide is changing. The docs are advising against surgery due her quality of life after surgery (or is it because they don’t want to use their resources on a trisomy 18 baby). This is the question I am trying to get answered. They were willing to do a surgery if she had an omphalocele two days after birth (thank God they were wrong and she didn't have one) and will do g-tube if she doesn’t eat, but heart surgery is a big maybe. We spoke with a cardio who was open to helping us but I am preparing myself in case they say no with second opinions. I am also realizing I am spending time arguing with cardiologists but once I get past them I have to deal with the surgeons! Jessica”

Gerri, mother of Leilani, a four-year old with full trisomy 18, wrote back to Jessica:

“It's a tough decision, but very feasible. Leilani had a large VSD, PDA and a double-outlet right ventricle. All three defects were repaired during one surgery when
she was two pounds fifteen ounces. I think Maia has already demonstrated her innate will to survive. Ask the docs for a bio-ethics committee meeting with the intent of exercising your right for intervention. The next step is finding a surgeon who has a ‘heart’ for our kids. Keep us posted.”

As it turned out, Maia did not make it.

I emailed the trisomy list:

“Raphael was reintubated last night. I feel that his breathing problem is not central but something restricting his airway. One doctor suspected reflux. The surgeon warned against jumping into the stomach wrap; it is a three-hour surgery. We got a new neonatologist and perhaps a fresh approach will help.”

One parent emailed back:

“Ruth was intubated for thirteen days. She pulled her tubes out several times. Her sats were usually in the eighties while she was in NICU. Her sats are better now. Ruth's breathing has always been labored. After she eats, she pants like a puppy. She has constant apnea spells that only last seconds...then she self-corrects. Her breathing is usually what they call ‘sub-sternal or subcostal.’ Occasionally her breathing is intracostal (you see her the muscles between her ribs sucking in.) When Ruth first came home we used the bulb syringe to suction her a lot. Eventually we realized that she could usually clear herself and that we were just irritating her mouth and throat. We took the syringe everywhere with us. Now it is collecting dust in the bottom of the diaper bag. It sounds like Raphael is working hard to be here on this earth with your family. Hang in there!”

Karen wrote:
“Hi Arthur, I am sorry that Raphael has had to be reintubated - I am sure though that it is temporary and you will soon get a handle on the problem. Reflux can definitely cause obstructive apneas - it’s usually intermittent though. Is he being fed orally? Could he be aspirating from the feeds? I realize that the stomach wrap (technical term is a fundoplication) sounds drastic but a lot of our kids, Alex included, have had it. Actually, even though Alex is now almost ten, I am considering getting an opinion on redoing his Nissen. The normal life of a Nissen is two months to four years - that we have had seven or eight years is pretty amazing.

“There are a couple of non surgical methods of assisting reflux: Positioning, raising the head of the bed (about brick height or higher) helps. Or you can actually sit them up, that sounds drastic, but truly they don’t seem to mind living life in a sitting position. Twenty plus years ago my daughter had severe reflux (no trisomy) and she spent the first nine months of her life never laying down, but sitting in what was called a Fraser chair. These days they just tend to use a baby car seat.

“There are two kinds of reflux medications - those that reduce the acid content. If Raphael is not in pain, that’s probably not what you need the most. The others speed up gastric motility (make the stomach empty faster so that there is nothing in there to reflux). The most common drug for that purpose is Reglan and also the antibiotic erythromycin. The latter may not be an option if Raphael has a heart problem. Erythromycin affects the heart and from memory, it helps close certain holes in the heart - but sometimes they actually want those holes to stay open.
“Stop feeding. Sounds drastic - you can do continuous tube feeds. This means that there is a minimal amount in the stomach to reflux at any one time. In really bad cases they can opt to go with intravenous nutrition.

“And of course surgery. Alex had his fundo done at fourteen months. Yes, it is a long surgery, but Alex breezed through. His problems in surgery have always been with the relative simple surgeries, not the big ones.”
A New Doctor

Chapter Fourteen

I came back Friday evening at 7:00 with my two youngest children. It was the first time they saw Raphael.

“You both have to put on these gowns and a mask,” I said to them as we washed our hands in the reception area.

“I don’t wanna,” my three year old said.

“But don’t you want to see the baby for the first time?”

“I want to see the baby, but I don’t want to put that on,” she said as she pointed to the mask.

“But you can’t go in unless you wear it.”

“Let’s just go in without her,” my seven year old said.

“You’re going to have to stay with her outside if she doesn’t come in,” I told him.

“Put it on!” He ordered her.

She just shrugged her shoulders.

“You can’t come in now,” the receptionist said as she walked toward us.
“Oh, I forgot, the nurses change shifts between 6:30 and eight.” I totally forgot that well-known fact. “We just drove here and it’s going to be the Sabbath soon. We won’t see him again until Saturday night. Can’t we just go in for two minutes?”

“I’m sorry. The nurses get upset if we let parents in.”

“The kids never saw their brother, can’t you just make an exception?”

“I’ll get your nurse and ask her.”

“Come on, put the mask on,” I said to my daughter as the receptionist went into NICU.

“You can come in just for two minutes but the kids have to wear a mask if they are old enough to go school,” our nurse said to us.

“She’s too young for school but I don’t want her going in without a mask. She’s going to have to stay out,” I said to the nurse. “Please stay with her,” I said to her brother.

“Okay.”

I gave the baby the traditional blessing of Aaron before the Sabbath. “May the Lord bless you and watch over you. May the Lord illuminate you with his face and you will have humanity. May the Lord raise His countenance toward you and give you peace.” May all view you with a face, as a father sees his child.

Dr. Batista called on the Sabbath. I ran to the machine to hear him say that Raphael had started feeding and that he will lower his rate of ventilation. Lynn, who by now was Raphael’s favorite nurse, also called. She mentioned that Raphael had two incidents in which his oxygen saturation dropped. At 6:40 that Saturday evening, he lost so much oxygen when his nurse suctioned him that he had to be bagged.
We visited him later that night after the Sabbath ended. He was stable. On Sunday morning, July 11, we did not arrive at the hospital until 11:00. Rachel held Raphael and I reviewed his medical charts. Dr. Ahmed, the resident on duty, noted that Raphael did not have any of his apneic episodes before the previous Sunday, the day that he began his feeding, indicating reflux. On the other hand, results of a blood culture taken on Friday began to grow a staff infection, which also might be the cause of his breathing problems.

“I don’t understand why they tried to extubate him on Wednesday if he had fever,” Lynn said.

“We don’t know that he’s got a bug. Dr. Ahmed mentioned that the staff might be some kind of contamination,” I said.

“But he had a temperature,” Lynn said. “Could be that an infection caused him to fail.”

“Maybe it’s a combination of feeding and an infection.”

“We can’t take spinal fluid because his platelets are low,” Lynn said.

“What does that mean?”

“Low platelets could mean he has an infection, but it’s probably because of all the blood we’ve been taking from him.” She looked at him. “You’ve been giving us too much blood.”

Raphael stared at us with his left eye wide open. His rarely opened his right eye more than half way. We had little hope for vision in that eye and I still was not convinced that he was able to see out of his left eye.

“He’s still premature,” Rachel said to us. “He would now only be in the ninth month.”
“If his apnea is central, he might grow out of it,” I said.

Lynn looked at me surprised. The doctors had been saying that the apnea would only grow worse with age. “After we extubate again, they can do a study to see if he has obstructions,” she said.

Dr. Ahmed came over to join in the discussion. “His apnea might be owing to his reflux. Why didn’t you do the fundo when you had the g-tube put in?”

“I have to speak to Dr. Saad. I’m told that he doesn’t want to do the fundo. I don’t know if it is true, or if true, if it’s for real medical reasons or because he has trisomy 13,” I said.

“He’s had no episodes on Friday,” Dr. Ahmed said. “I stopped his feed Thursday night and he had nothing in his stomach on Friday.”

“It’s one of the following or a combination,” I said. “It might be an obstruction, or it might be reflux, or it might be central, or it might be an infection.”

“He’s been on two antibiotics just in case he has a staff infection,” Dr. Ahmed said. “We cultured him again and we’re checking Friday’s culture to see if the antibiotics work.”

“He’s at the lowest vent setting now and his sats are around ninety-five percent, yet he still has episodes of desaturation,” I said. “That indicates that an obstruction is not the only problem. He has lots of mucus. I can hear it through the vent. The last episode and the one before were when he was being suctioned. What does all this mean?”

We had no answers. Later that day, after Rachel went home, Raphael had a long crying spell. I held him and gave him a large pacifier. He stopped crying and his sats
went down to seventy percent. He stopped breathing after calming himself down. Was he
crying the other two times before he was suctioned? A pattern was beginning to form.

The respiratory specialist did something on the ventilator and Raphael’s sats went
back up. As I held him, I noticed a jerky motion, like a spasm. The doctors recently
stopped giving him Dialantha for his seizures since it was only used temporarily to load
the Phenobarbital. I questioned the wisdom of taking him off the medicine, but the
doctors insisted that it was the right thing to do.

Monday, July 12, Dr. Batista was finally the doctor in charge of NICU.

“Dr. Zales, the cardiologist just looked at Raphael again. Let me see, I wrote all
this down,” I said as I looked into my journal. “His atrial septal defect is 4.8 millimeters,
but might close. His aorta is good, jugular shows no clots, and PDA is closed. What’s his
feeding rate?”

“He’s on four cc’s every hour. We want to get him to nineteen. I don’t want to
extubate until he’s been fed for nine days,” Dr. Batista said.

“Can you check his Phenobarbital level? He’s gained weight. He’s seizing an
awful amount since you took him off that other medicine.”

“He’s actually higher than the therapeutic level but his liver might not be
metabolizing the medicine,” Dr. Batista said. “The intravenous feeding harms liver
function, so we’re going to increase his g-tube feeding.”

“Did you get in contact with Dr. Saad?”

“Yes. He will do the tracheostomy if necessary, but does not want to do the
fundo,” Dr. Batista said. “Also, he has low platelets. I suspect that the PICC line may be
clotting, pulling away some. Or the bug that he has might be causing them fall. We
certainly don’t want the infection to cross the blood-brain barrier, so we’ll continue the antibiotics for fourteen to twenty-one days. We can also do a spinal tap.”

“A spinal tap is really being overcautious.”

“We’ll need to do one before we stop the antibiotics.”

“Did the culture show anything specific?” I asked.

“We identified the bacteria in the Petrie dish and changed antibiotics. His blood from the PICC line is negative. We’ll be doing a lot of blood work tomorrow.”

“Dr. Batista, please ask the ophthalmologist to look at his eyes again. I want to see if there’s a change.”

I was wrong about the spinal taps. Two years later Raphael got meningitis during one of the pseudomonas infections that would send him to the hospital. A radiologist found that certain veins in his scalp intertwined with veins in his brain making it easier for infections to pass through.

I sent out the following email:

“Raphael’s platelets are low. Is that common with T13? He has a bug that the peripherals showed as a staff infection. They are treating him for that and want to do a spinal tap to check if the bug passed the barrier, but will hold off until later, since the platelets are low. Now, the infection may itself be causing that, but I doubt it. He had a transfusion last week for that reason. Which brings me to another point. He had a fever of 102 F on the day they extubated him. The new doctor questioned the wisdom of that (not in so many words). The old doctor was our typical NICU doctor. Bad experience (I hope she isn't reading this)!
“Now the new doctor is taking his time. Isn’t that wonderful. He isn’t trying to evict us. I have confidence in him. He is increasing the feedings by two cc everyday. When he gets to nineteen cc’s and everything is well, THEN he will consider extubating. The only problem is that this doctor is only going to be in NICU for two weeks!

“Tomorrow they will check Raphael's level of Phenobarbital in the blood. He may have too much and that may be causing apnea. Even on the vent he seems to lose his sats, but I find that only when he is crying. Nevertheless, we have several possibilities of what caused him to have difficulty breathing when he was on his own. 1) reflux 2) infection 3) anatomy 4) central 5) Phenobarbital 6) mucus

“So when he is extubated again, I want a study of his breathing. Problem is, the pediatric surgeon refuses to do a fundo or even a bronchostomy study on him. He did agree to do a trach if needed. I cannot decide if he just does not care for a T13 baby or he is too arrogant to do a risky operation. I anyway would not want it if it were very risky. This doctor is so proud of his work, he brags about it! He is kind of funny in his arrogance. But if he needs a fundo, we have to transfer him out and then back again, unless we convince the doctor to do it. Anyway, maybe the ENT can do the bronch study.

“We had some good news. The cardiologist looked at his heart and it is good. There is a small PDA, 4.8 mm, but it may grow and close. He said that it is not a problem right now. Tomorrow we will get liver enzymes test to see if the intravenous feeding is a problem, since we are not up to full formula feeds yet. We are going to also check the Phenobarbital levels.
“So we seem to have a strategy, even though we are in NICU. That’s all we can do, try our best to do what is needed. We pray that our efforts will be fruitful.”

I received the following from Ohio:

“Arthur, you might find out if your hospital has an patient advocate or similar position. This person’s job is to help you get answers and procedures that you want for your child. I think all hospitals have an ethics board. The job of this board is to allow patient (or their family’s) to ask for procedures to be done when the attending doctor is not willing…Great news…Having a strategy is sooo comforting! We will be praying for you and little Raphael! Blessings, Chris mama to Mari full T18 (almost 3 yrs.)”

I responded:

“Chris, the ethics board might be an option, but we already were in front of one. A doctor Graff wanted us to pull the plug and he brought the case to the ethics board. They said that they could not make a doctor do something he perceived as a violation of the Hippocratic Oath. He considered a g-tube and trach to be causing harm. This guy was not even our doctor, but he was the director of neonatology. A violation of the H. Oath--where did that come from? I feel bad for our country.”

Another response:

“My GOD! I am so outraged for you! I feel this way because I know if they would have went to that length with Logan, they would have won. I am SO VERY sorry that you had to go through that. All I can say is, try to get transferred to a different hospital. I know it would be a hike and a half for you, but the hospital I deal with would do the g-tube and the trach if Raphael needs it. I am in Central Pennsylvania and Hershey Hospital is pretty good about listening to the parents’ wishes. Don't get me
wrong, I have hit heads with some of the doctors there, but as a whole I am very pleased. Write me off the board if you want more information. Tina”

Tina wrote again:

“I don't have any experience with that, but I think to some degree each one of our kids has different blends of issues even though there are many similar things. I just love the way they keep hitting ya with more good news. Even though you feel like you still need to hear it all but there are times when I felt like ENOUGH! I just want a day of no more bad news. Tina”

I responded:

“Tina, Hopefully that is in the past. The attendee over the next two weeks is wonderful. He is going slow and will not evict Raphael. He wants to wait until his feedings are up to 18.5 cc before trying to extubate, and that can take at least a week.”

I received:

“Arthur, Why is Raphael on the Phenobarbital? Several members of this list have had really bad experiences with Phenobarbital. Admittedly a few have also had good ones, but the bad far exceed the good...and some have been downright tragic. It turned my daughter into a zombie...totally wiped out her appetite...and gave her a pus filled rash all over her face, chest and back.

“You wrote, ‘the only problem is that this doctor is only going to be in NICU for two weeks!’ If the doctor's a good one, then that just might be long enough! When we finally found ours...he turned her around in the one week he was there. Best thing he did was just to listen to the answers to the questions he’d asked...so few actually do! His
parting gift was the order to wean her off the Phenobarbital, and that made all the
difference in the world!

“You wrote, ‘He did agree to do a trach if needed… Anyway, maybe the ENT can
do the bronch study.’ Perhaps, that’s who actually did ours in the hospital. Unfortunately
though, there really wasn’t any dialog going on between the ENT and the cardiologist,
and while one was breaking up cement consistency mucous plugs in her bronchia, the
other was still giving her Lasix…three failed extubations and she ended up with a trach.
Fortunately it was only temporary. But she still complains that it bothers her.

“You wrote, ‘we had some good news. The cardiologist looked at his heart and it
is good. There is a small PDA, 4.8 mm, but it may grow and close. He said that it is not a
problem right now.’ I hope he's right! They told me Philina's had closed when she was a
baby…but they were wrong. So even if they say it’s closed, keep an eye out for
symptoms of congestive heart failure…blue around the mouth was our first hint…then the
persistent vomiting, and then mysterious weight gain even though she’d thrown up for a
week. The good news is that even if it doesn’t close, a closed heart is fairly easy
repair these days. That can be done in the cath lab. Keep us posted…Fawna, mom to
Philina, 21yrs (PT6p & Moya Moya Syndrome)”

I responded: “Fawna, I got your comment about Phenobarbital. When Raphael
was about three days old, the seizures began. They began the Phenobarbital and Dilantin
and he was out for a week. However, the seizures stopped. When he was about ten days
old he opened his eyes again. He was awake and had very few or no seizures. Is there
something better than Phenobarbital for seizures that I should know about? Raphael has
severe holoprosencephaly and lissencephaly. Is there something different that I can do to help him?”

Fawna answered:

“I’m not a neurologist, or even a doctor...now that I’ve said that, I’ll add some other thoughts. Has he been seen by a neurologist? Preferably a ‘good’ pediatric one? There are numerous choices of drugs that can be prescribed for seizures. Phenobarbital is one of the older ones. But older does not necessarily equate to better. (Often just the opposite.) In that case, the downside is that it frequently causes lots and lots of really nasty side effects, even in people who don't have the added problems that these rare trisomy kids do. My daughter has never had seizures! Her Phenobarbital was a fluke that really never should have been ordered in the first place. But I have cared for children (handicapped daycare provider) and elderly patients (medication/treatment nurse) who had epilepsy. And there are numerous children on this list on assorted drugs for seizures. You’ll probably hear from some of them now too, that this is out there. I think my only other real seizure drug tip might be something I actually picked up second hand from the doctor of one of those kids I used to care for. He told Jake's mom not to buy the generic version of Tegretol, because it's not really identical, and he sure wouldn’t want his child taking it. I took her/his word for it...But Phenobarbital just always raises a red flag for me.”

Karen wrote:

“Unfortunately at Raphael’s age you would have a hard time convincing them to give him anything other than the two drugs he is on for seizures. There is a load of other
drugs out there, but their safety for infants has not been tested. Invariably for newborns doctors reach for the Phenobarbital and then the Dilantin.

“I missed Fawna's post on Phenobarbital but I know how she feels and I feel similarly. It’s not a drug that I would ever give to Alex again unless my back was totally against a wall. Not all of our kids have adverse reactions to it. However given that so many have such experience, it would be, in my opinion, a good idea to check on the side effects and just keep them in the back of your mind.

“I know you are well aware that having both holoprosencephaly and lissencephaly means that Raphael will most probably always have seizure issues and that they can be severe. The most important thing at this point would be to get them under control. If the Phenobarbital is working great – just watch for the side effects and jump if you see any of the nasty ones.”

I heard the click of Dr. Bona’s heels as she came into NICU with Dr. Lopez, one of the residents. They asked me to sit with them in the nursing room. I hated that room. That is where Dr. Bona brought us to confer with Dr. Petruka, the neurologist who insisted that we pull the plug. Dr. Bona was not now on NICU duty and I wondered what she wanted.

“Dr. Lopez wants to do a genetic report on trisomy. Do you want to help her?” Dr. Bona asked.

“What’s it for?”
“I’m submitting a paper on care of infants with defects. Can we take pictures?”

Dr. Lopez said.

“If it will help.” I wanted to change the attitudes of the profession. “Don’t use our names, just initials.”

What was I afraid of by hiding our names? Everyone and every thing needs to a return address. I have always abhorred the cowardly anonymous writer of letters and essays, who confident of his own pure intentions, insults by questioning the intelligence and fairness of his reader, by hiding his name from words that are often as irrational as his fear of disclosing his name.

“I need you to sign a consent form,” Dr. Lopez said.

“Wait. I have this.” I gave her the trisomy care-provider book from SOFT. “Here is an internet site set up by parents. Here’s another.” I gave her a list of sites.

“This is fine,” she said.

“Here is a study by Bonnie Baty who followed up trisomy kids as they grew. Here’s a copy of a newsletter for parents with trisomy children.” If she was going to write a report, she should know that these children could live. “Maybe you can speak to Anne, a nurse who has a trisomy 18 daughter.”

“I have enough. Thank you,” Dr. Lopez said with an awkward smile.

“Dr. Bona, are there other surgeons in the hospital besides Dr. Saad?”

“He’s the only pediatric surgeon in the two counties.”

“Unless he changes his mind, we’ll have to transfer him to another hospital for a fundo. Will they take him back here afterwards?”

“Of course.”
On Tuesday, an ophthalmologist examined him again. She was the same that saw him after birth. Again, she said that his right eye was small.

“The eye is microthrombi. It has a disorganized back with no normal structure. There’s no potential for vision.”

I was saddened, but I did not expect much from the right eye.

“The left eye,” she said as she looked into his eye. “The lens and optic nerve weren’t well formed and he has coloboma on the iris and optic nerve. It’s not as bad. It might have partial vision.”

“So he might see after all?”

“Yes. It doesn’t look as bad as the first time. The pupil fills up much of the iris, though. He might only see shadows. The optic nerve meets up with the eye, but has some dark areas.”

“Can he be fitted for glasses?”

“Yes.”

“How?”

“We can reflect light out of his eyes to indicate how to shape the corrective lenses.”

“Will he keep them on?”

“If he can see, he’ll keep them on. They’ll pull them off if they don’t help.”

I was gratified that he might see. However, we still had to get him out of NICU before we got him glasses.

I sent out the following email:
“Does anyone have experience with coloboma and trisomy 13. My son, Raphael has it. I will look it up. He has coloboma on the iris and optic nerve. The ophthalmologist said that he might be able to see shadows with his left eye. His right eye is not formed properly at all.”

I received from Karen:

“A coloboma is essentially a cleft of the eye (like a cleft palate, they are a cleft of the eye). It can affect any part of the eye, from the iris right through to the optic nerve.

“The effects of the coloboma depend on where they are located and just how large they are. With some people they can simply make the person light sensitive, in others they will lose part of their visual field, and in others they can be so situated to render the person legally blind (even though they can see).

“When Alex was born he was checked for colobomas a half a dozen times because his constellation of problems was indicative of him also having colobomas. Thankfully he doesn't.

“Colobomas are really quite common in T-13, a little less common in T-18 ,but they still occur in T-18 fairly frequently. Devon for example has colobomas that affect his lower field of vision. For the most part Devon copes with them just fine and has worked out his own way of seeing around them. Most people do.

“Fortunately colobomas are not life threatening, but they are something that nothing can be done for in the way of a cure.”

I also received from Penny:

“Hi Arthur. Devon has bilateral colobomas (colobomas in both eyes). They were described to me as a keyhole shaped cleft in the pupil. They can have no affect on vision
or they can cause total blindness or anything in between. Because of the placement of Devon’s (in the lower part of his iris...one measured 6mm at birth and the other 8 mm), he has no lower field of vision. It’s a moot point really in the right eye because he has retinal dysphagia (or incomplete retina) plus a flat mushroom shaped cyst on the optic nerve in that eye which mean his right eye is pretty much useless...although there's a slight possibility he may see shadows and light with his right eye peripherally...doubtful though because he has a cataract peripherally placed. His left eye has no lower field of vision either and a peripherally placed cataract....and until recently he was far sighted with astigmatism...but he quite surprisingly grew out of the farsightedness and the astigmatism. He also has nystagmus...but I really only notice his eyes kind of bouncing when he's really tired. He has micro cornea and micro ophthalmia as well...which means shallow orbits and small eyeballs (his right eye is smaller than the left) You'd think with all that that he wouldn't be able to see...but guess what? People are always shocked to hear he is visually impaired...what vision he has he uses very effectively! So, I guess what I'm telling you is, just wait and see. We were told the same thing.
“He pulled out his breathing tube earlier,” Dr. Jean-Louis, the resident on duty, said to me in her Haitian accent on Tuesday night. What she meant was that he knocked it out inadvertently. Raphael does not open his hands to grasp anything.

“Once it was out, we kept him off the ventilator. Around 9:55, his heart rate dropped and his sats went down to the forties. We tried to bag him and he did not come up as much as we wanted.”

“How was he doing before that?” I asked.

“I noticed that his chest was not expanding.”

“Was he difficult to intubate again with his abnormal anatomy?”

“I had to try two times.” She pulled the tube out of the garbage. It had about two inches on pinkish gunk in it.

“Maybe send some of this stuff into the lab for a culture,” I said.

“It’s too late, it’s already contaminated. We took a culture before he pulled it out.”
On Wednesday, I did not arrive in NICU until 3:30 in the afternoon. Rachel was in NICU since 9:30 in the morning and she held Raphael until she left. She held him the whole time whenever she was in the hospital. I only argued with the doctors when I was there. She was leaving when I met her in the hospital lobby.

“Dr. Saad said he’ll do the fundo,” she said.

“What made him change his mind?”

“Who said he changed his mind? Did he ever tell us that he wouldn’t do it?”

“I’m sure Dr. Batista didn’t make it up,” I said.

“He told me that if he can’t be extubated after getting up to 18.5 cc per hour of feeding, then he’ll put in the trach. Then he wants to wait a week before doing the fundo.”

“Why not do both together?”

“It’s too much all at once,” she said.

It was my turn to talk to the doctors. I met Dr. Batista when I got upstairs to NICU.

“I want to lower his Phenobarbital to twenty-three from forty-three. I think it might be contributing to his respiratory problems,” he said to me.

“But I noticed that he jerks a lot at night when he sleeps. He doesn’t open his eyes smoothly and he’s still seizing. I don’t think lowering Phenobarbital is good for him.” I said that despite what I read on the trisomy list.

I asked him about the fundoplication.

“Who told you that Dr. Saad wouldn’t do the fundo? Was it Dr. Saad? Or was it Dr. Ross?”
“Dr. Ross.” He smiled. “She just relayed what Dr. Saad said.”

“But you did not hear it from Dr. Saad?”

“No.”

“Oh, she just gets things confused,” I said.

On Thursday night, July 15, Raphael was very restless. He pulled out his breathing tube after I went home. Dr. Ahmed, on duty that night, let him try to breathe on his own. He gave him some oxygen, but since his heart rate was too low, he reintubated him.

On Friday, Raphael’s feed was up to thirteen cc’s per hour. He started his medicine for reflux. He seemed to be looking around and his oxygen saturation was good.

On Friday night, the Sabbath, we heard his nurse speak into our answering machine and say that everything was fine. On Saturday afternoon, she announced that he had only one incident of desaturation. We visited him Saturday night from 11:00 PM until 2:00 AM. His shaking was getting less, resolving itself into isolated incidents of outstretching his arms in front of him, almost like a yawn.

When I got to the hospital Sunday morning, Dr. Ross was about to make her rounds. She was back as the weekend doctor, but I did not speak to her at all the whole day. I noticed a white-clear liquid around the baby’s mouth. The nurse said that he had a wet burp a few moments earlier. Claudio, the breathing specialist, put a tissue box underneath Raphael’s mattress to incline it, helping his food stay down.

By Sunday night, he was up to fourteen cc’s. He was alert and looked at my twelve-year-old daughter that came with me to visit. She thought that he looked weak,
but I told her that is how he always looks. I realized that he just might not be strong enough to breathe on his own through his mouth.

On Monday, July 19 Raphael was extubated around noontime. An x-ray that morning showed that his lungs were hazy. Perhaps he had a clogged breathing tube and did not get enough oxygen? However, his breathing tube was clear. Perhaps a clog might have become dislodged from the tube upon extubation? Or perhaps he did not get enough oxygen while the tube was in him since it was so narrow and the ventilator settings were so low? Like almost everything else with this baby, it did not make sense.

If he had aspirated on his feed, then one lung would have taken in more liquid and looked hazier than the other, but both were equally hazy. If he had pneumonia, he would have had trouble breathing as soon as he was extubated, but he seemed to be fine, needing only his regular albuterol treatments. At least, now that his feeding finally reached the right level and was being digested, Dr. Batista was able to rule out reflux as a cause for breathing failure. For some reason though, he was not getting proper aeration.

That afternoon, Raphael vomited much of his feeding. At 4:45, his oxygen saturation dropped to the thirties. Lynn had just suctioned him at that time and told the nurse practitioner that his saturation levels were dropping too often. A nurse practitioner can prescribe medicine and other treatments just like a doctor. Since there was no doctor on duty that Sunday afternoon, Lynn asked the nurse practitioner to reintubate him, to which I consented.

The nurse practitioner had a hard time getting the breathing tube to fit into his trachea. The first time she tried, his heart rate and saturation level did not go back up.
There was too much liquid. They pulled out the tube and suctioned, to try again with a second tube. This time it went right in without much trouble.

I was concerned with his continuing apnea problem. He often stopped breathing, even while on the ventilator, only to resume after some stimulation. I did not think that he should have been extubated that morning since his lungs were so hazy. However, he was on the respirator with a new breathing tube. His lungs should begin to clear and we would then get some answers.

Rachel was in NICU late into the whole afternoon on Tuesday and had spoken to Dr. Batista.

“I asked Dr. Batista if he had any good news and he said that the ENT came in last night,” Rachel told me over the phone when I called from home.

“I was there until 6:30 yesterday afternoon. When did he come?” I asked.

“At 7:30, when you weren’t allowed to be there anyway. And he has no nose.”

“We know that. I wanted to know if he has sinuses or anything that can be reconstructed,” I said.

“He has no nasal cavity, whatever that means. I guess he just doesn’t have anything there.”

“Why can’t he breathe?”

“The ENT said that his vocal cords don’t move. But that’s not causing his problems. He said that if the vocal cords affected the breathing, he wouldn’t be able to breathe at all,” Rachel said.

“What does he think is his problem?”

“Who, the ENT or Dr. Batista?”
“Anyone. I don’t understand. You asked Dr. Batista if he had any good news and he told you nothing.”

“Well, at least we got the ENT to come.”

“I want him to ask Dr. Saad why he insists on doing the trach before the fundo. Maybe the reverse order makes more sense. His lungs are hazy and if he is aspirating, doesn’t it make more sense to fix the source of his breathing failure first?”

“Maybe with a trach, there won’t be any breathing failure. Why go through the fundo if you don’t know he needs it.” Rachel asked.

“Why go through the trach if you don’t know he needs it?”

“Isn’t the fundo more serious?” She asked.

“You’re right. He probably wants to do the simplest and least intrusive procedure first in case the other doesn’t have to be done.”

“They’re doing cultures on him because they’re suspecting pneumonia. He has a temperature of 99.2 and they’re giving him clindamycin as a precaution.”

On Wednesday July 21, I told a fellow math teacher about the baby in the high school parking lot after school.

“His lungs are hazy. He has temperature. We just can’t get him off the respirator,” I said. “We might need to do a trach. We might need to do a fundo.”

“It’s a shame that a little baby must go through all this.” She pitied him.

“Yea,” I said to her. I wanted to say, “What do you mean? Are you taking the side of Dr. Ross? Were we evil for trying to keep the baby alive?” But, she did not mean that. She just felt bad for the child. Then it hit me. Why do the fundo? It was quite an intrusive procedure, almost like the heart surgery that I wanted to avoid. I was too obsessed with
trying to figure out how to fix him to realize that maybe we could help him in another way. He was getting reflux medicine, we were inclining his crib mattress, and we tried to figure out the right amount of feed so that he should not throw up. We were not certain that he had reflux to begin with. He was not a machine that needed repair but a person.

When I finally got to the hospital at night, Dr. Batista was still there, even though attending doctors usually worked only the day shift.

“Rachel told me that his vocal cords don’t move.”

“They’re paralyzed,” Dr. Batista said.

“She said that the ENT said that it won’t affect his breathing. Why?”

“I don’t know.”

“It’s common for vocal cords to be swollen after being on the ventilator for so long,” Dr. Batista said. “His whole throat can be swollen.”

“What’s with the stuff that’s forming around his g-tube?”

“We’re putting something on for that. It’s a common fungus.”

“I figured out why Dr. Saad probably wants to do the trach before the fundo,” I said. “Doing the simpler operation first makes good medical prudence. And the nurse said that there’s a test to check on reflux but it is not done until discharge. That, by the way, does not make sense.”

“It can be done. You need an endoscopy, twenty-four hour ph study, and barium x-ray,” Dr. Batista said. “It’s possible that he has an esophageal sphincter. That means the valve isn’t staying closed. If that’s the problem the fundo will make things worse.”

“What do you think?”
“I have an idea,” Dr. Batista said. “We’ll give him some steroids to reduce the swelling in his throat. He’ll need about twenty-four hours. Around five o’clock in the morning we will stop his feeding. By 10:00 AM tomorrow morning, he shouldn’t have any food left in his stomach.”

“If he has reflux, he still might have food in his stomach.”

“We can check. We’ll send a tube down and see if anything is in there. Then, if his stomach is empty, we will extubate.”

“You know, Dr. Ross mentioned that he vomited the first time that he was extubated. If he does well, we’ll know that his problems are caused by reflux.”

“I still don’t think that reflux is the problem,” Dr. Batista said. “If he doesn’t do well, let’s put in the trach. A trach is reversible, and fundo is not. Once you tie the stomach, you can never eat normally.”

“Then the problem is an obstruction, possibly even the vocal cords.”

“Or anatomy.”

“Right.”

Dr. Batista increased the Raphael’s ventilator settings to inflate his lungs to aerate them. The x-ray came back looking good. He seemed to be ready for another try at breathing in the morning.

I went home and returned at night. His temperature shot up to 103 degrees.

“Maybe that’s why he keeps rolling his eyes,” I told the nurse.

“Could be,” she said. “I don’t think he’s ever been this high.”
“Could it be from the steroids? Do you have a drug book that lists side-effects?”

She showed me where the nursing staff keeps their medicine book. I looked up lecomethozone and it seemed pretty rough, not to be used routinely.

“That just means not to use it for long, thirty day periods. Twenty-four hours is not going to hurt him,” the nurse practitioner told me.

“I think the steroids are elevating his temperature.”

“I don’t know,” she said. “We’re doing a CBC to see if he has an infection.”

“What’s the problem of having a trach on a baby at home?” I asked her, changing the subject.

“You know that the g-tube is not sterile, but a trach has to remain clean. There is an increased risk of infection and pneumonia. Also, the canola can come out and you have to know how to put it back in.”

“What about partially open vocal cords. Can they contribute to his apnea?”

“It might be central. He’s missing nerve fibers.”

So on Thursday July 22, the next morning, Raphael was extubated again. His blood test did not indicate an infection, but his sodium level was high. The doctors gave him fluid through his PICC line to lower his sodium, in addition to the feeding that was just resumed. He was losing too much fluid; too much was passing through him. One of the residents, Dr. Birchwood, a woman from Africa who spoke with an accent, told me that the doctors were suspecting that he had diabetes insipidus, a failure of the body to maintain the right amount of chemicals in the blood.

“What do you mean? Why all of a sudden?” I asked her.

“His elevated sodium just showed up. His electrolytes are not right.”
“Can you give him a drug for that?”

“Yes, but he needs to be closely monitored. You need to take his electrolyte count every day. He can’t go home like this.”

“You mean we won’t be able to bring him home at all?”

“We don’t know. This can happen with brain anomalies. Either his brain is not supplying the hormone to his kidneys controlling his fluid level or the kidney is not reading the message.”

“How can we tell?”

“We can run tests.”

“Isn’t it more likely that his brain isn’t sending the right message?”

“Yes,” Dr. Birchwood replied. “If it is his brain, then we can do hormone therapy. But if it is his kidneys, we just have to keep giving him fluids.”

“Of course it’s his brain,” I said.

“It’s not so important now to figure out the cause as much as to give to him the fluid. We have to start another IV.”

“Can’t the fluid go through his g-tube?”

“No. The quantity of fluid is too great.”

“Is that also the cause of his high temperature this afternoon?”

“Possibly. But there could also be an infection. We might want to do a spinal tap to check for meningitis and to start antibiotics.”

The nurses began to weigh his diapers to determine the difference between the amount of fluid leaving his body and the amount going in to indicate how much he was retaining. I watched as the nurse practitioner used a calculator, and needless to say, I had
to explain that she made a mistake in arithmetic. By 4:00, that afternoon, the spinal tap came back negative and his sodium began to come down.
“Nobody names their baby before the circumcision,” Rachel said to me on Friday morning. It is customary to wait before naming a baby boy until his circumcision, which normally takes place on the eighth day. Understanding that Raphael would not have a circumcision for some time, we gave him his name and had it announced in the synagogue during the first reading of the Law on the Thursday after he was born.

“But he has to have a name,” I insisted. “What are we to call him, Baby Lang?”

“The hospital calls him that. Why couldn’t you ask a rabbi first?”

“The rabbi of the synagogue did not object. Many people do it. Anyway, I really don’t care what other people do. My child is not a thing, he’s a human being entitled to name just like anyone else,” I said.

“Conservative rabbi,” she called me. Observant Jews deride the Conservative movement for its lax adherence to the Law. “You’re making your own rules.”

I was insulted and did not telephone her the whole day. It was a Friday and she stayed in the hospital holding the baby. At 5:00 his vital signs began to fall while I was
still home preparing food and clothing to stay in the hospital for the Sabbath, that
evening. Raphael’s heart rate sank and his oxygen saturation went down. Judy, his nurse
on Friday, took him from Rachel and tried to suction him, to see if some phlegm was
blocking his breathing. It did not help. They then tried to bag him by manually pumping
oxygen into his mouth, but that did not help. They then started pumping his chest, but he
“coded,” meaning that his heart rate went down to forty beats per minute. He turned blue.
The nurses asked Rachel to step into the waiting area, as normal when a procedure must
be done, and Claudio, the pulmonary specialist, re-intubated him.

Rachel was extremely upset and began to cry.

“You wanted us to re-intubate him, didn’t you?” The nurse asked her. Rachel did
not say anything.

I was ready to leave the house with my hot plate, cooked food, and clothing when
Dr. Bona called. She was in NICU that evening and saw Rachel crying. She thought that
she should tell me what happened and how upset my wife was. I had not spoken to
Rachel since her remark that morning.

Later, we found out that the baby had an infection. The doctors already found
bacteria on his g-tube, and after taking a culture from his ET tube after he was intubated,
they found the infection there also. After two days, the pathologist identified the germ
and he was put on two different antibiotics to combat them.

Rachel was not the only person who often told me to speak to a rabbi. When I
expressed my doubts while explaining the choices involving the baby, often I heard the
same response, “Ask a rabbi.” Even the doctors told us to talk to our rabbi. On one
occasion, Rabbi H., the dean of my afternoon yeshiva, said to me, “Since there are
differences in opinion, you can do what you think is right. But it’s still good to ask so that you don’t feel guilty about your decision.”

One evening, I received a message that another rabbi that I respect, and with whom I was close in my younger years, Rabbi Mordecai, came from Jerusalem to collect money for his yeshiva in which I once studied the Law. He wanted to visit my home, as in past years, to enjoy thoughtful conversation, after which I made a donation. He called again when I was about to leave for the hospital to relieve Rachel and to stay there for the whole night.

“I was hoping to miss you,” I said. “Our baby has trisomy 13 and I was just going to the hospital.”

“I’m sorry to hear that. We can speak some other time.”

“I don’t have to leave this minute,” I said. “And I don’t know what to do. I didn’t want to answer the phone and go through the whole thing.”

“What’s there to go through? Go to the hospital. I’ll call you back when things are better.”

I was quite anxious. “I don’t know if he’s suffering. Maybe we’re wrong for keeping him alive. I need to have clarity.”

“Why don’t you just ask a rabbi?”

“There are differences of opinions.”

“Just find a rabbi whom you trust and stick with his opinion on all questions,”

“What? Are we robots? We need to think for ourselves.”

“I’m just saying that you’ll have peace of mind this way. You said you don’t know if you’re doing right.”
“But I need to be like that.”

Rabbi Mordecai did not call again for two years.

That Friday night was the first Sabbath that I spent in the hospital since Raphael was born. On Saturday morning, I spoke with Dr. Sharon who was the resident on duty. Dr. Bona was making rounds.

“I just don’t see the negative side. My wife was so upset yesterday seeing him turn blue. Maybe if I was there, I might have changed my thinking.”

“You were here Thursday night when we re-intubated him. He coded then also,” Dr. Sharon said.

“But I didn’t see him turn blue.”

“He did.”

“I didn’t see it,” I said. “What about this diabetes insipidus. I read that there is a certain drug that can treat it.”

“The vasopressin used to treat the condition has not been studied on infants.”

“But if we don’t get this diabetes insipidus under control, we won’t be able to bring him home.”

When Dr. Bona finished making her rounds, she asked me confer with her in the nursing room.

“Rachel is under a lot of stress. I saw it myself yesterday,” she said.

“I can’t speak for my wife. I don’t know what she’s thinking.”

“Why don’t you talk to her?”

“I do talk to her,” I said, even though I didn’t talk much yesterday. “I haven’t changed my mind.”
“Think about her.”

“How can you expect me to change my thinking for her sake if she’s never articulated anything to the contrary?”

“But I saw it in her yesterday. She was so upset.”

“What do you want me to do?”

“I want you, Rachel and me to decide tomorrow what to do.”

“We already decided.”

“We will end it tomorrow,” she said softly. “You will hold the baby, Rachel will hold him and we’ll take him off the respirator. He will go while in your or your wife’s arms. We’ll do it together.”

“No. I don’t consent to that.”

“You don’t have to feel that it is your decision, it’s all of us.”

“What do you mean? You can’t do it without us.”

“But you don’t have to feel that it’s your fault. It’s us-- the doctors, the nurses, and the whole medical profession. It’s not like you decided not to help the baby. It’s everyone with you.”

“You still can’t do it if I don’t agree.” I said. “This is old stuff that I heard before. And even if I change my mind, it won’t be until we put a trach into the baby. How will I ever know that he couldn’t have made it? I think his problem is that he doesn’t have a clear airway. It’s anatomical, not mental. I’m also concerned about the fundo. That’s a long procedure.”

“You said at the beginning that you won’t put in a trach, remember?”
“I did say that, but I was under a lot of pressure. Even my own pediatrician recommended not putting in a trach. But he said later that his opposition was only because a trach is difficult to care for at home. We can learn how to maintain it.”

After the Sabbath, Rachel told me that she did not change her mind.

Saturday afternoon, Dr. Sharon told me that someone did some research and found a drug that had been used on babies with diabetes insipitus. I held Raphael and took a little nap without the nurses noticing. If they saw me asleep while holding the baby, they would either wake me up or put him back in the crib.

On Sunday, the doctors began to give Raphael Diuril for his diabetes insipidus. It seemed strange, but Diuril is a diuretic that makes the kidney release more fluid. The plan was to stimulate the kidneys into releasing fluid and so that, paradoxically, the body compensates by retaining fluid.

Still, our hopes for bringing him hope began to fade, as the nurses began to constantly take blood to check his electrolytes, to weigh his diaper to see how much fluid he was retaining, and to improvise his fluid intake accordingly. I began researching blood analysis equipment, but nothing seemed to be available for home use. Were we to take his blood to the lab every day?

He had a seizure on Sunday night. Doctors gave him a bolus, or heavy dose, of Phenobarbital.

On Monday, all the babies from our NICU wing were moved into another wing of the hospital for routine cleaning and maintenance of the ward. Dr. Batista’s two-week shift expired and Raphael had a new place and new doctor, Dr. Ramos. I had trouble personally consulting with him and the endocrinologist, as they came in early every
morning to make rounds before Rachel arrived and while I was teaching in summer school. I left messages with the nurses to let Dr. Ramos know how much we wanted to bring him home.

Raphael was put on chlorathyside, a diuretic that sometime helps with diabetes insipidus in babies. We were told that it was unlikely that we can take him home because of the necessity to constantly monitor his fluids and electrolyte levels. But we did receive news that Dr. Saad would do a tracheostomy on Friday.

A nurse in NICU who was assigned to another baby, said to Rachel, “You know, it’s hard caring for this baby.” She only had Raphael once or twice.

“That’s funny,” Rachel thought. “This nurse never cared for the welfare of our baby before.” In fact, she was the same nurse who once made a negative remark about keeping Raphael alive.

“I would not want to care for him alone and have the responsibility,” the nurse said. “It’s hard to watch his suffering.” Rachel did not say anything.

Herein lays the distinction between pity and compassion. Pity is natural, chemical and empirical; it involves mirror neurons. Compassion is intelligible. The nurse had pity on our child, an aversion to suffering. Pity can apply to any living thing, including suffering animals, which are then terminated. Compassion, by contrast, can only apply to humanity. It is the profound incomprehension we ponder identifying with a person who is gone. Compassion is the substantiation of being, the recognition of personal existence as an end in itself. *Compassion is the affirmation of life.*

On Monday night, we were informed that Dr. Saad would do the tracheostomy the next day instead of Friday. He scheduled surgery at 12:30, but told us that we might get
into the operating room earlier. One week ago, we would have been thrilled with the news, but since we discovered the diabetes insipidus, many doctors were telling us that we could not bring him home. He needed to be confined to a hospital with a laboratory to obtain the results quickly.

I already notified the school back in June that I would not teach on Tuesday, the Ninth of Av, the day on the Hebrew calendar, when our holy Temple was destroyed. It is a sad day of fasting and remembrance of all those who had been murdered throughout Jewish history. There are those who say that the Jewish people should forgive. It is a foreign doctrine that allows sins against the individual to be forgiven by someone other than the victim. The assumption that grace can be attained for a wrong against a fellow without his forgiveness, that God will forgive sins against a man, or that the collective may forgive crimes against individuals, denies the affirmation of the existence of those individuals. We mention and remember the wicked when we forgive them. Whose name are we to affirm, that of the evildoer or that of the innocent?

Rachel and I arrived at the hospital at 9:30 that morning. Dr. Saad was not ready yet, but I had a chance to confer with all the doctors that I normally missed.

“Why can’t we give him the actual hormone that he’s not producing? You know it has to be his brain and not his kidneys,” I said to Dr. Birchwood.

“I agree that it's his brain.”

“You said that there’s a test to determine if he has Central Diabetes Insipidus. I even read about it. You can administer an amount as small as ten milligrams of vasopressin to an infant.”
“We can do the test, but you don’t want to prescribe vasopressin to treat CDI. You’ll end up giving him too much fluid.”

“Why? It’s done with older children with diabetes insipidus.”

“Older children know when they’re thirsty. If they have too much fluid, they won’t drink, but we’re feeding your baby through a g-tube. He has no choice in how much fluid goes in.”

“Now I get it. His electrolytes are messed up because he’s releasing all his fluids. If we give him the vasopressin that his brain isn’t producing, then he might hold back too much fluid. In his case, that can be dangerous because he has no way to show us whether he’s thirsty or not. There isn’t even a bottle for him to push away. But I don’t get why we’re giving diuretics, to release even more fluids?”

“The kidneys respond to the diuretics. Once we’ve established a proper dose, his release of fluids will be regulated.”

“You mean, we’ll be able to take him home?”

“I think so.”

“You know, it never made sense to me that we couldn’t take him home. I found nothing in the literature that indicated that a child had to be institutionalized because of diabetes insipidus. None of the articles noted great difficulty in treating this disorder. Certainly they all went home.”

“You have a lot of other things also going on.”

Raphael was still upstairs in NICU at 1:00, waiting to be called downstairs for surgery. I went down to the library and found a study on people with diabetes insipidus using a portable monitor at home. The doctors in NICU were not impressed. The monitor
was not being marketed and seemed a long shot. Even with the right equipment at home, the doctors were concerned that we would not be able to handle the elevated fluid rates.

Eventually, Raphael was brought down to the operating ward. Rachel and I spoke with Lynn, Raphael’s nurse, as we waited downstairs outside the operating room.

“Are you ready for the magnificent one?” I asked Raphael.

Lynn gave me a funny look.

“I didn’t mean the Magnificent One. I meant Saad. It didn’t come out right. You know, the magnificent doctor.”

Saad walked in smiling. “Did you sign the consent form?”

“They didn’t have it.”

He asked a nurse to find the form for us and we signed it. “You understand all that’s involved?”

We nodded.

“Good. It shouldn’t take more than one hour.”

When he finished surgery, he called us into the conference room.

“It went really good. You will need to keep a towel under his neck. He has a mask over the trach to give him oxygen until the anesthesia wears off. It is our hope that he’ll breathe on his own and you’ll take him home.”

“You really think so, Dr. Saad?”

“Yes. And I also took out the stitches from the g-tube. Start the feedings as soon as he wakes up. You should see an immediate improvement in his breathing. After about six months, maybe we’ll be able to remove it, but not before six months, even if he breathes on his own.”
“Where are you ancestors from?” I asked him quite bluntly.

“I’m from Haifa.”

“You’re a Palestinian?” I asked him. I was shocked. “I thought you were from Egypt.”

“Why’d you think that I’m from Egypt?”

“I don’t know. Your name is Saad A. Saad, kind of like Boutros Boutros Gali, the old UN Secretary General.”

“We came to America when I was very young. Take care.”

Raphael looked very pale when we saw him in NICU after surgery, so the doctor on call gave him a pint of blood. He explained that they have been taking a lot of blood for testing causing his count to go low.

I also spoke with Dr. Eapan, the endocrinologist, later in the afternoon.

“I really want to be aggressive with this diabetes insipidus,” I said. “We want to get him home.”

“We’ll try our best.”

“The alternative is not acceptable. We’re not going to institutionalize him. I’m willing to take reasonable risk with the vasopressin to get his fluids under control.”

“We might try them tomorrow,” he said.

“But they might make him retain too much fluid.”

“I know. Now, I will be going on vacation on Friday, but I’ll speak to my fellows and Dr. Ramos. We’ll confer on his treatment. We know you want to bring him home.”

“Can there be a problem if he is home?”

“If his I-V comes out, then he can dehydrate.”
“He has a g-tube. We can always rely on that,” I said.

“Well, that does help.”

Dr. Eapan spoke with Dr. Ramos on Wednesday. Raphael’s urine output dropped substantially indicating that the diuretics were successful in helping him retain fluids. The doctors decided to continue with the present treatment using Diuril.

Although diuretics normally cause the kidneys to release fluids, they also cause other fluid retaining hormones to be released. Such treatment was much safer than vasopressin, which tended to cause him to retain too much fluid.

Thursday was a bit of a setback. He lost more fluid than the day before. He also desaturated. The doctors temporarily discontinued the diuretics. On Friday, he was breathing much better. His feeds were back up to full, he was restarted on Diuril and began holding his fluids real well. Also, Claudio fashioned something to fit onto his trach collar to hold the oxygen mist onto his trach.

On Saturday night his temperature dropped to ninety-five degrees while we held him. It was odd for his temperature to drop so low. Usually when we held him, he was wrapped in hospital blankets and his temperature went way up. Also, the infant incubator was insulated, so he was not constantly exposed to room temperature. Apparently, without the blankets, the room temperature brought him down to the mid-nineties. The nurses put him under lights to warm up.

The next day, one of the doctors explained that Raphael did not have a hypothalamus to regulate his body temperature. Dr. Ross was right last month when she said that his temperature spikes might be central. The rises in temperature in the past did not always manifest a fever after all. His brain was simply not capable of keeping him at
ninety-eight degrees. Now, we simply unwrapped him if he got too hot, and wrapped him up if he got too cold. We soon found that his favorite temperature was between ninety-six and ninety-seven. If he got higher, he became cranky and cried. If lower, his heart rate would drop and he became sleepy.

On Monday, August 2, Raphael seemed to be breathing very well. His oxygen level was down to twenty-two percent, about the same as the atmosphere. We were not able to take him off oxygen entirely because the oxygen combined with a watery mist that was essential for patients with tracheostomies. The technicians figured out a way to keep his mist at a constant temperature to help maintain his internal temperature.

Dr. Ramos said that his fluids were good, but still not good enough for him to go home. Lynn taught Rachel how to suction the tracheostomy canula. Rachel gave him a sponge bath and I put lotion in his palms and between his fingers. His hands smelled bad since he did not open them. We had to keep them clean.

Raphael’s mouth stayed closed when he breathed through his tracheostomy. He always seemed to have secretions in it and in his windpipe. When he cried, you heard the gurgling sound of the liquid in his throat. Sometimes he gagged on the secretions, requiring suctioning.

On Tuesday, the nurses brought a crib into NICU for him. He was beginning to outgrow the infant incubator. He looked different in the crib, like a baby at home. He no longer had tape over his face to hold the ET tube and we saw all his features.

On Wednesday, he let out as much fluid as he was given, above his normal feeding, indicating that the diabetes insipidus was under control. The doctors then discontinued the intravenous supplement. On Thursday, Dr. Ramos said that any extra
fluids that he needed could go through the g-tube. We were getting closer and closer to bringing him home.
Moral Faith
Chapter Seventeen

I spent my first Sabbath in the hospital after Dr. Bona returned. I had placed my Sabbath morning food on a hotplate before sunset on Friday night so that I would have a warm meal on the Sabbath morning, an ancient tradition, and was set up for the next 25 hours, until nightfall on Saturday night. Nobody said anything about the possibility that my room might be needed for someone else.

On Friday night, I read a book, *When Bad Things Happen to Good People*, written by a Conservative rabbi who suffered a tragic loss. The author wrote about his belief that people are generally too concerned with God’s honor to honestly address the question of theodicy. Kushner’s solution was that God has no control over events in the world — No needle points, no transmigrations; only divine compassion. I felt sorry for what happened to the author’s son and for what happened to the author. That said, I cannot reference a reading of the Law or the prophets in support of his position.

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Philosophically, the “highest good” has been said to be that which is true, recognized, and accompanied by an appropriate emotion.\footnote{Moore, G. E. (1988) *Principia ethica* (Chapter VI. pp. 183-225). Amherst, NY: Prometheus Books.} What is the appropriate emotion accompanying recognition of good in the personal life? The Law commands thanksgiving. Indeed, compassion makes the other fellow significant in *my* eyes, but why deprive that fellow of worth in *his* own eyes, his own sense of Providence, and his own expression of *hakaros hatov*, the recognition of the good?

It is not a paradox that one with the strongest sense of Providence can be most compassionate. He views the shortcomings of his fellow man to have psychological root, whereas how can his own intelligible faults be from anything other than choice, indicative of a poor disposition? How can the believer be apathetic to a lesser lot of his fellow man, if the other is so innocent, while he, himself, is so undeserving?

The doctrine that God exists but has no control over the world is empirically untenable. Humans are not implanted in nature. Nature’s constants, laws and existences are not intrinsic to it. Spencer is wrong; the seeds of Shakespeare are not to be found the nebulae. The universe was not preprogrammed, neither was our world simply set into motion. There is no general principle that says man, a particular species, or even any life should exist. That which exists did not have to exist. There was no more necessary determination to nature as a whole, from the beginning, than there is a so-called fate to our individual lives. If destiny is manifest, then it is not general, but the destiny of *individuals* and individual happenings that are evident to have shaped natural and human history. There is no middle ground between direct individual Providence and random chance. Providence in the particular, is firmly established.
I also had a copy of a recent *Scientific American* with me on that first Sabbath. I had begun a subscription the previous year, after reading a copy that Gary brought to the mathematics office. After discussing an article, he once asked me, “How could a scientific man such as your self believe in all this religion? You see how the world is so ancient.”

“But, I'm a Jew. I can’t not believe in God and still be a Jew.”

Short of success, I must remain silent. To abandon my religion is an uncommon failure. Alternatively, I cannot believe in God and not keep the Law.

“My religious relatives are always telling me about their belief in creation, but that’s inconsistent with science,” Gary said.

“Are your relatives Jewish?”

“My grandmother was a Jewish woman who married an Italian. Some of my cousins are Jewish.”

“Was this grandmother your mother’s mother?” I asked.

“Yes. But my grandmother brought up her children as Catholics.”

On one occasion, in a throwback to the Kantian summon bonum (highest good), I asked Gary, “What connects the moral good with the objective good of happiness?”

“One can be moral without God,” he replied. I did not answer. Do I have an answer?

The categorical imperative disregards feeling and desire. It compels us to act on that rule which we willfully identify as the universal law for all rational beings. As final and inviolable, the *internal* law regards the humanity in others and in our selves as holy
because humanity is subject to it. Human beings are treated as ends, not as means to another end, because their ends are final.

The autonomous moral will wills the unconditioned internal law, not from feeling, which is pathological, but awes only after willing, which is moral. It wills to act on that esteemed feeling. The free will itself, however, is not completely undetermined; instead, it is an expression of its own continuity or disposition, which itself is determined by the free will.

It seems to me that those who seek the unconditioned, who seek rightness for no reason except that it is right, can be said to have moral faith, as that which is right is worthy of any pure will. Those who seek religious instruction can be said to have theoretical faith, because what is religious is an ideal object, worthy of a non-contradictory will. Those who cite authority without seeking resolution within their own will of theoretical contradictions can be said to have blind faith; their duty is not worthy of their own will, only conditional on attaining an object, approval or happiness in this world or the next.

All theoretical faith depends upon willing consistency of thought, which itself is moral duty. On the other hand, any particular theoretical faith is influenced by socialization and psychology, which is heteronomy and not freely willed. A person is not responsible for being born into a particular era or into a specific religion. Nor can a person be held accountable for being hard-headed or for having a skeptical inclination. Some people are more deferential to authority while others are more subjectively oriented. Nonetheless, all rational beings are capable of willing moral faith.
The *external other* is the moral being, not determined by the will, yet *worthy of willing*. Moral love, or compassion, makes possible the *fellow*, someone that *ought to be*, someone more than a particular instance of universal humanity, but a *thou*. This is the principle of moral relation, the foundation for moral community, the recognition of the fellow as one recognizes the self. Beyond innate sociality, the institutions of family and community are firmly established.

If one were physically informed of a momentary risk of conceiving a deformed child and nevertheless did so, his action might be called morally negligent. Yet, if that information was communicated in the form of a prophetic vision, if one could *see* a future moral being, then one would be praiseworthy in *willing* that *conceived* being. Without actual or potential being, there can be no external other, no recipient of moral love. Nevertheless, as compassion is esteemed, it is praiseworthy to will *some* moral being; hence, the sanctity of parenthood in general.

*Raphael is proof that love for the moral being takes precedent over moral law, for none ought to will such existence, yet all ought to will him.*

Even if the skeptic foiled proof of all moral law, the moral disposition nonetheless would inspire moral feeling of awe, because it conceives a principle of worth. So too, if no external moral being were capable of proof, the disposition nonetheless would inspire moral feelings of love and reject solipsism, for it wills the existence of others whom it recognizes as real. Reason cannot accept the possibility of the self as alone, even if created alone, or as ever alone, without completely annihilating that which it esteems.

The conception of God follows, to love Him and to trust in His compassion. Trust in His goodness, then, is not a hypothetical postulate of practical reason to connect moral
worthiness with happiness, nor is it proved by theoretical reason. Instead, it is but expression of the moral faith of the good disposition. Even if worthiness and happiness causally connected in this world attaining the summon bonum, even if we lived forever and did not fear our own demise, trust in God and in His love would still be an end in itself, for the disposition toward moral law and the love of moral being is the essence of the individual.

“When will my deeds be worthy like those of my fathers?” The faith of Abraham was not blind; he willed moral consistency from beginning to end. Nor was his theoretical faith; it was moral faith, worthy of the covenant and of bequeathing religious faith, which forever disposed his children to his purity of will. We postulated that affirmation of moral being takes primacy over the moral law. Abraham’s concrete vision of Eternal Being in his prophecy to sacrifice Isaac, his palpable recognition of Being, took precedent over eternal Law. However, whereas monotheism makes discovery of the Eternal Being, it opposes dissolution of human being to the higher being. The contradiction was unfathomable and incomprehensible. Without unambiguous revelation, possible only to the true prophet, and complete trust in Him for a moral solution, there will never be such a test again, for who can imagine justice in his own resolution?

“And all the nations of the world will be blessed by means of your descendents because you harkened to my voice.” Athens was enlightened by Jerusalem, as was all of civilization.

Love of moral being and moral law is the monumental discovery of monotheism. The covenant, sacrifices, prayer, worship, even the Promised Land and nationhood are all different manifestations of devotion to the Eternal Being, of whom nothing can be said,
except that His Law is moral and His relation with us correlates to compassion. The whole history of Israel is not development but epochal expression of the same love of God and affirmation of His Being.

The method of religion, however, is not characterized by deduction from moral faith but from legislation arising out of historic events, in particular, the covenant and the Exodus. Hence, the starting point is not the abstract moral law, but something as real as the Law.

Induction from the Law reveals the possibility of the individual through the longing for atonement and turning, during which one’s whole existence stands before the monotheistic God. Additionally, it is entirely foreign doctrine that the God of Israel should show favor in judgment simply because of religious faith without a resolution of the will for correct actions. Social justice is personified in the poor man, the widow, and the orphan, whom I call my righteous brethren. Through the prescription of holy matrimony, man and woman are sanctified and retain their moral dignity, not to be objects, but together a family, the cradle of human compassion, safeguarded by proscribed relations, together with the welfare of their children. On the holy Sabbath, we remember the Exodus and dissolve all relations of production, and with them, the basis of inequality. Out of the law of jubilee, we read the most salutary check on ancient tyranny, in which the citizen is never dispossessed of the land, the basis of aristocratic power, or perhaps of all power. There is procedural due process and majority rule under the law. From the prophets, we discover our individuality and existential selves; we are accountable only for our own sins, after which we long to return to His service. The prophets set our hearts toward future peace and a better world, not back to a mythical
Golden Age, longing for the Messiah to extend the virtue of moral community beyond the Jewish nation to all of humankind.

No image was seen at Sinai; the universe is not being. The aesthetic is not substance to become objectified into gods, nor is it form to be idolized into plastic. “I am and will be,” is the essence of monotheism. Is thy God nature or its spirit that ye seek what He is? “I am and will be,” the Eternal Thou will always be with thee, even while alone, “I am (the Name) your God.”

**Hear Oh Israel, the Lord our God, the Lord is the only One.** The great teaching of monotheism is that the only Being is God. This can be explained epistemologically. The concept of continuity gives rise to substance and law, both natural and moral. Unity, a regulatory faculty of reason toward simplicity, systemizes and advances scientific paradigms. Whereas the moral law tells us what continuously *ought to be* if freedom is real, and that following the law is what ought to be practically, substance is a category of the understanding of that which continuously *is*. Our intellect, being discursive, is only given objects of the senses; our knowledge is not intellectually intuited. Therefore, we can never have ontological knowledge of what *really is*. The only way for us to correlate to what *really is* is through what *really ought to be*, or through the law.

Substance and causation are categories of understanding that apply only to objects of space and time, which are the only forms for our understanding. Confusion over substance, which is limited to the objects of possible experience, gives rise to the idea that the natural order necessarily exists, having constituency of real being, or essence. God, then, is identified with the world in a kind of pantheism, often polytheism. Cult rites
are performed out of fear and or for the sake of pleasure or well-being. Humans are
dynamic wholes through which life energy flows.

The faculty of unity denies composition and identification of God with the
universe, yet if the categories of our understanding are still extended beyond space and
time, and substance is still thought of as metaphysical permanence, then God is identified
as the unifying principle. A hierarchy of Neoplatonic forms and intelligences mediate
between the One at the geometric center and the corporeal circumference, where a single
primeval soul is superficially partitioned into our many material bodies. Humans, then,
are parts of a whole, not distinct individuals. Ethics is either prudence or consensus, as
accidental as the caprice of nature or its unity. Losing one’s self or the attainment of
ecstatic bliss or eudemonism is the Good.

Monotheism dispels the notion that nature is real being. The world only exists;
God, in essence, is Being. All existence is equally founded upon nothing. We know His
Being only through attributes of action, which correlate to our own unconditional actions.
Ethics is thus elevated to necessity. The creed of the Israelite is not an ethereal fantasy
but a well-grounded nobility that the world now calls morality.

The words of Law teach us that the world is not an emanation. It was not created
out of God; instead, God created it out of nothing. It is not one because it is not God!
What greater meaning can individual days of creation have to us than the creation of
individuals? The world was not created on one day or with one word, teaching us the
fundamental worth and dignity of each. We are not parts. The person has individual
existence, as much an end as the whole world.
Compassion and morality transcend the state of nature. The six days of creation teaches us that nature is not necessary, but accidental. Nor is it determinative, but incidental to that which was created on each individual day. There is no vital force that spontaneously generates and unites all life. Species and the world are not one; neither are individuals and our specie. We have personal, singular significance. Our roles and places are not decisive, but our essence is as moral beings.

Hence, monotheism rejects the notion that the self is dissolved in a pantheism that joins him to a greater something, or the ubiquitous presumptive theology, so common to religion, that we are uncreated in some sense, that some part of us is identified with God. We are individuals who stand before the monotheistic God, forever distinct from us and from His creation. He requires us to be holy for its own sake, which is our own sake.

This great teaching dispels all forms of paganism by proclaiming that He, and only He, is Being. The world is only an instance of existence, but has no permanence of substance. There is no unity between God and the world, and no unity between the world and Being.\textsuperscript{12} The unity of the universe is not Being; it is non-existence. \textit{If you could find unity in the universe, you would find nothingness.}

Liberating compassion from the metaphysics of natural order, monotheism discovers humanity. The suffering of the other is not to be explained. How, then, is one to react, other than with love and with social justice? Has human history any more profound discovery?

Woe to the pagan! His transmigrated soul must atone for the errors of his clan and for sins in previous lives of which he has no memory. His sins are not always before his conscience because they are not his own doing. He cannot pray for a returning because

he is someone else or someone else is he. He has no identity. He is not an individual because he is dissolved into something else. He does not stand before his Creator.

Human beings are not essential to nature. Our species are as accidental to the universe as life itself. There is no order implanted into nature that says we must exist, our world must exist, that even the laws or constants of the universe must exist. If we are to have meaning, it will not be found metaphysically in the unity of nature or even in human perfection, but in self-perfection. Meaning is found in individual holiness.

Theologians have historically argued in favor of the scientific outlook. Magic and irrationality are grounded in the polytheistic or pantheistic belief in the substance of forces and life-energies as a kind of substratum to nature or as channel between the world and God. By contrast, scientific forces are capable of coherence because they are only incidental to or constituent of the existence of the universe, or to the commands of God. Although indecisive of whether the universe was created or actual substance in some kind of resonance, science agrees with monotheism; nature has no substratum and can have no sacred objects. The supernatural is sacred to the heathen because it is incoherent. Because of its incoherence, the supernatural is disclaimed by the theologian and dismissed by the scientist.

Although I appreciate what Einstein called his greatest blunder in his reluctance to abandon the eternal universe, the debate over Intelligent Design, despite its religious appeal, denigrates faith into mere utility. The human mind will always seek unity of principle, even in the most seemingly chaotic phenomenon. No paradigm will be final. Still, the insinuation is that religion would have no place if all can be naturally explained, as if we need it only to fill in the gaps. What is the difference to the object, the world,
between itself having being or God commanding it to be? The difference to ethics is *morality*; the difference to us is *life*.

It is said that the Books of Moses are the body of the Law, perhaps because they guard against extreme *perspectivism*, and the oral tradition is its soul. The autonomous person certainly wills rightness in itself, but he needs a legal structure to expound, which has practical and theoretical importance. Without reflection, there is no moral law; without learning, law cannot be cultivated. The soul is commanded by the Lawgiver, as monotheism conceives not of God within man so that man is God; nevertheless, the extent of heteronomy proper in the Oral Law arises out of the virtue of humility, respecting the expression of others, past and present, as a check on leniency, a fence for moral conduct, and a pillar of community. The Oral Law is internalized; it becomes part of the *individual*. It was with reluctance that written texts, bound to become venerated words, were introduced into this genuine commonwealth of ends.

As much as the Jew expounds, the ultimate test is acceptance in the study hall. Is the claim legal? Is it fair and just? Where is the proof in the Law?

Moral *judgment* is a faculty limited to the abstraction of personal benefit to universalize particular *situations*, and is ultimately consequential, whereas the moral *law* is the universal, *categorical* maxim. Both are necessary, but with only reverence for the law, one ought to consequentially improve the world. Compassion and zeal for the Law, doing God’s Will, recasts the parameters of the circumstance, transforming the prescriptions of simple, dispassionate moral judgment. There is no greater use of reason, no higher calling, and no deeper creativity.
Ancient Israel originally had no state to whither away. The polity was a community of scholars, possessed of order without a human sovereign and social harmony through ritual. A survey of the full range of Jewish literature from ancient to modern times reveals a continuous vein of deep thought and intellectualism. Israel originated in and has remained in the mainstream of civilization. Mr. Hume said about the Law, “the book was presented to us by a barbarous and ignorant people, written in an age when they were still more barbarous.”

What did he suppose we did, day and night, in the wilderness for 40 years? I would think we did, in that age, just as we do now: occupy ourselves with study and learning. Lest one think that our moral vigor was weak in the Europe of Hume, consider Mr. Justice Brandeis, who compared the spirit of justice and sense of ethics in Jewish immigrants present on both sides of a labor dispute to the Founding Fathers of America.

What struck me most was that each side had a great capacity for placing themselves in the other fellow’s shoes. There was the usual bitterness, but despite this, each side was willing to admit the reality of the other fellows’ predicament. They really understood each other and admitted the understanding. They argued but were willing to listen to argument. That set these people apart in my experience in labor disputes.

Others nations have risen and fallen, not without discovering community and morality, perhaps even compassion. Yet, as ideal and universal these values, their discovery alone cannot explain their continuous vitality in one nation and its own

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endurance. They are demands of the Law in which to inquire and reflect, a safeguard against any man or institution obtaining blind obedience. \(^{15}\)

Our attachment to belief is supported by many particular commandments, never meant for angels, for they are as peculiar as human nature and history. Few can persist outside of community, and none can withdraw and be *one with nature*, for then only with great difficulty would his food be kosher! Many have blindly criticized our strict adherence to the various commandments of the Law, while praising the originality of its teachings, but can the latter persist without the former? Such is the great riddle of Messianism.

\(^{15}\) Milgram, S. (1963). Behavioral study of obedience. *Journal of Abnormal and Social Psychology.* (67) 4. 371-378. “...obedience may be a deeply ingrained behavior tendency, indeed a prepotent impulse overriding training in ethics, sympathy, and moral conduct.”
It has been found that traditional authority and communal obligations have become less important in postindustrial culture than self-expression and individualism, and that the need for material security has been replaced by the concern over “quality of life.”  

I was on a moral mission the week before we found out about Raphael. I had been holding back my disgust since seeing the cover of an issue of Newsweek that blatantly sensationalized female infidelity. The next morning, I expressed my outrage in the presence of two female teachers, one of whom was also Jewish.

“It’s right there, in your face. Why do they push this trash on us?”

“I found the article interesting,” the Jewish teacher said. “Men have been doing it for years. Now the tables are turned.”

“It’s celebrating infidelity. Infidelity is like stealing. Why not celebrate stealing?”

“Why is it like stealing? Because everyone has to be monogamous? Abraham had two wives.”

“His wife consented and even requested that he take a second wife,” I said.

“Anyway, she couldn’t consent if it wasn’t at that time permissible for him to have two wives. It was never permissible for a woman to have two husbands.”

“Some cultures allow a woman to have two husbands.”

“Rarely, and only the most heathen,” I said.

“Modern society doesn’t differentiate between husband and wife.”

“True, and that’s the way it should be, but the depth of the sin is not the same. The Law forbids a man to remain with his wife if he knows that she had willingly been with someone else during their marriage.”

“The article is just saying that it’s no longer just a man’s prerogative to cheat. Now that women are in the workforce just like men, they have equal opportunity.”

“Are we proud to have equal opportunity to be immoral?” I asked. “Are you saying that because men have sinned, women should no longer be righteous? You know that we, as Jews, go through the mother. She is the nucleus of the family. She is the household.”

The second teacher, who was not Jewish, put her hands on her hips and smiled. “What’s the difference between a man and a woman?” She must have known that the Supreme Court opposed my nuclear position.17

“Husband and wife are like parent and child — a family. Each, both man and woman, have a responsibility to one another. Infidelity on either part is like a parent who abandons his or her child.”

“That’s different,” the second teacher said. “A parent had a choice in having a child.”

“And a couple made a choice to get married.”

“But one might have been misled.”

“Becoming a parent isn’t always planned.”

“Parent and child have a natural, innate relationship.”

“What about the person who becomes a parent by adopting a child?”

“Many people are in unhappy situations and need to find love,” the first teacher said.

“Then they should get divorced first.”

“There are children and other things to consider in a marriage. One can’t just get out so easily,” she said.

“I’m not advocating divorce, but you can’t have it both ways.”

“Why not?” She asked. “What if both agree? What if so-and-so (name of an actor) asked me to be intimate with him?”

“What about your husband?”

“My husband would say that I would be crazy to turn that down.”

The second woman laughed and nodded her head.

“Yeah, you’d have to be crazy to turn that down,” she said.

“I don’t believe you.”

“Why not?”

“You husband’s consent is meaningless. Your marriage isn’t a private contract between you and him; it’s a proscription upon all men in society. Short of divorce, your
husband doesn’t have whimsical authority over his fellow citizen to determine criminality at will. Can he lift the proscription from that actor so that he is permitted to have an affair with you with impunity, while enforcing it against another man that does not meet his approval? That’s the law of property, objects over which a master can allow or deny usage. Humans were born not to be chattel, even at their own disposal.”

Some time after that discussion, I asked one of the divorced teachers what she thought was the cause of a national increase in fighting between girls in school. “Was it because of the breakdown of the family?” Probably has something to do with wearing pants, I thought. It definitely has to do with lashon hara.

“You are not the norm!”

How could she know what I was thinking?

“What do you mean?” I asked confusedly.

“You know, a husband and wife with kids. Most families now are like mine, one parent.”

“I’m worried about the future of our country,” I said. “What’s it going to be like 50 years from now?”

What began as the diminution of family size in early industrial society was followed by attrition of family existence in late industrial society. The patterns of marriage and divorce, and even the number of nontraditional households have changed. Sociologists note an accompanying trend toward complete equality between men and women in the home and workplace. This is occurring in all post-industrial societies, but are the two necessarily connected? It was the pagan, whose god is nature, who based his ethics on the accident of what is deemed human perfection, who justified inequality

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18 Inglehart, R. & Norris, P. ibid.
between the genders and between master and slave. *Equality* is so extrinsic to the natural order that the pagan did not comprehend the term. He could not deduce the fundamental dignity of each individual, as our moral ends have no place in nature. Indeed, women should equal men in humanity, not in profanity, promiscuity, and brutality; of which in the want, men should equal women. The argument that justified equality itself cannot be the source of our decline.

Perhaps the degeneration of the family is the result of a desired rise in self-expression and individualism. But has not popular culture become more important than high culture? Millions for your vote, but not a penny for your thoughts! *Oh, you step-parents of consumers, have your traditions and obligations been trampled by the herd of homogeneity and massification?*

We find that the decline of faith in post-industrial societies is not just confined to the replacement of religious belief and authority with a more rational and secular orientation; instead, it is associated with a change in moral values as well. In the more developed nations and in post-modern philosophy, there is a greater acceptance of abortion, gays, prostitution, euthanasia, divorce, and suicide. Eudemonism, the ethics of happiness, and hedonism, the ethics of pleasure, have set desire as the motive to both virtue and vice, replacing the categorical imperative with the hypothetical imperative.

I reject the utilitarian ethic of the greatest happiness for the greatest number, despite its legitimate use as a check on draconian penalties and its success in the social sciences. Economic welfare requires consumption and self-interest in business; nevertheless, we still value abstinence and charity in the course of making a living.

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19 Inglehart, R. & Norris, P. ibid.
Many confuse legal tolerance with a false distinction between personal and public morality. The moral law is not imposed by society; it is commanded by conscience, to respect the dignity of the human person in ourselves as well as in others. Those who hold fast to duty for its own sake, in the private and public spheres of action, can be said to have a sort of faith, not wholly unrelated to religious faith, both being worthy of man. We called that faith “moral faith.”

A century and a half ago, American writers criticized the influence of industrialism for material things in life and big government’s glorification of power. They were feared to ignore and alienate the individual. Why do we now find that the historic constraints on industrialism and big government, traditional authority and communal obligations, are thought to be antithetical to self-expression and individualism? Are not the latter securer in the former? Have we have lost our revolutionary vigor, the republican virtue of duty, and the true meaning of freedom of expression, which is the expression of right and wrong and our sense of justice?

The erosion in the American family has one main source, the primacy given to quality of life. Quality of life breaks the bond of husband and wife who, together, form a kind of moral existence, a family, and breaks the bond between parent and child. Raphael is not for our happiness. Marriages are not solely for personal happiness. They are commands of the Law.

In fact, the decline of faith in late capitalistic societies is characterized by the replacement of religious belief and authority with an irrational orientation. The massive subjective turn of modern culture away from life as, life defined in terms of duties and

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roles, toward *subjective life*, life lived by reference to one’s own experience, has served to fuel the growth of *subjective life* spirituality and to undermine *life as religion*. The decline of religion based on transcendent authority is accompanied by a dramatic increase in holistic spirituality that cultivates the dynamic whole of mind, body and spirit, and the uniqueness of the individual as the sum of experiences, in the channeling of mystical forces and life energies. Although the majority of people in the post-industrial world still believe that “there’s something out there,” that something out there is the god of the pagan. It does not command your moral law.

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“A little more than a year passed since we brought Raphael home. During that year, he was circumcised when he was eight months old. A plastic surgeon connected his cleft lip, covering over his cleft palate, to separate his mouth from his nose giving him a face. A neurologist determined that he did not have seizures and that he never needed the anti-seizure medicines. His stiffening or outstretching happened less often, usually after a spell of crying, often followed by a short apnea.

Raphael was not left alone for more than a few minutes. Often he held his breathe as if he was trying to see how long he could get away with it since it happened only while he was awake. We patted him on the back or pinched his checks to remind him to breathe. Like the revolutionary twentieth century vacuum cleaner and washing machine,
the pulse oximeter became our twenty-first century devise of liberation. It enabled us to walk from one end of our house to the other, even to go upstairs, resting assured that if Raphael held his breath, he would call out to us with an alarm.

Raphael spat up his formula every so often, requiring a bath and fresh change of sheets in his crib. His automatic g-tube feeding was engaged for four hours followed by one hour of rest. Then the cycle began again. We gave him his most important medicines during the hour his stomach rested, when there was the least chance of reflux.

During his first year, Raphael breathed without support through his tracheotomy canula. He required extra oxygen only when ill. He became ill three times, requiring about one week of hospitalization each time. Every time he went in, his release was delayed. A change in his fluid intakes disturbed his electrolytes simply because the doctors did not listen to the advice of his mother. While at home, he had no problems with his diabetes insipidus; we took him to the lab for regular monitoring. Rachel remained the primary caregiver, coordinator, inventory manager, nurse in charge, and quasi-physician-in-charge. She always held Raphael while she watched him.

Our insurance company provided us with adequate nursing coverage, but the home-care agency did not always fill their slots. The same agency nurses came regularly. The same cannot be said about doctors in intensive care units. The home nursing help made it possible for my wife and me to sleep most nights. We were blessed with caring nurses, who also held him for the larger part of their shifts. Raphael cried for the same reasons for which any other baby cried, a dirty diaper, diaper rash, and of course, again, if he wanted to be held. He wanted to be held a lot.
My father visited us often, especially on the Sabbath, often becoming saddened when he saw Raphael. Typically, he was full of questions. “When is the nurse coming?” “Why is he crying?” “What’s that sound?” “What does that beep mean?” His questioning bothered Rachel. Was it because she felt it hypocritical for him to show concern after he did not want us to keep him alive? On the other hand, Rachel resents it when people are alarmed over the baby’s behavior or the sounds his equipment made. I never understood why she felt that way and she seldom explains herself about anything.

Rachel always says that I am not a people-person, I have no social skills, and that I am oblivious to the meaning of what people say. I say to her that she cannot be sure of underlying intent. She is too polite and sensitive to ask people why they said or asked something. She thinks it is better to keep your feelings to yourself.

Poppy never held Raphael when he came to our house. I do not remember seeing him hold any baby. When Rachel and I got married, I used to say that my father never held a baby, never pushed a carriage, and never changed a diaper. I did all those things, but in a fun way, denied doing them. I wanted to be like my father, but could not. He was likable person. My mother and her family adored him. Additionally, he was an executive officer at Shell Oil who supported his wife and his mother. I was a Yeshiva student who was in part supported by his wife and by his father.

I always saw my father as just and fair. When I fought with my brothers as a child, my mother sometimes reserved my consequence for when my father came home. This had an unintended effect on me. I figured my father would give me a chance to explain my side of the story. Now that I think back, my father more or less met out whatever my mother demanded.
The last time Poppy saw Raphael, or any of us, was at a wedding of one of my nieces on Rachel’s side. We arranged for my aunt to drive him to my afternoon school from which he and I would go straight to New York for the wedding. Poppy arrived before class dismissal. Students from other periods, characteristically not held down in their seats and in their classrooms, one by one met him in the hall. Each had a few words with him. The last time he met my students, they told him, “Rabbi Lang is the best teacher we ever had.” He answered back saying, “You must have had some pretty bad teachers!” This time he told my students to tell me that his old dog was better than mine. This contradicted what I had instructed them to tell him, “Your son’s old dog was better than yours.” We often joked around, especially about dogs. Our family always had one dog or another and my father and I had a light-hearted argument over which canine was the smartest.

The wedding was in Brooklyn, a place I never liked. At the wedding, as the newlywed couple was introduced, all stood up for the hasan and calah. The dancing around them was silly and entertaining, but that is part of their joy and celebration. I told my father that the honor of a hasan and a callah is like the honor of a learned elder or a king, for whom we have a mitzvah stand. I told my father that I also have a mitzvah to stand for him.

The next week was the beginning of the High Holidays. My father was staying at my brother’s in Austin. As I arrived home from services on Rosh Hashanah, my wife called me into the foyer to tell me that my father had a stroke. An ambulance rushed him to the hospital.
Shortly afterwards, Eric called. Sue, Raphael’s nurse, answered the phone. She relayed his messages to me. I dictated what she should say to my brother. I still regret not taking the phone myself.

“They did a CT scan and it shows a blockage in the brain stem. It’s in a bad place.”

“Is he awake?”

“No,” she said after asking Eric. “But, there is no bleeding. That’s a good sign.”

“Did they induce a coma?”

“He was incoherent before he got into the ambulance, where he lost consciousness.”

“Just like my mother after the car accident.” My mother and father were driving through Louisiana when a truck hit a torsion tube for drilling oil that fell off another truck and lost control, sending my parent’s car off a fifty-foot high railroad bridge. My father’s airbag knocked him unconscious while my mother, who did not have an airbag, fell unconscious after three hours. She succumbed to wounds induced by her seat belt.

Eric told Sue that he would soon call back. He had to speak to the neurologist.

Why did I not take the phone myself?

“Is it too late for the clot busters?”

“No, they are well within the time limit,” Sue said after relaying my question.

“They give you a choice between injecting CDA into the bloodstream or going directly into the clot.”

“What is the difference?”

She relayed the question to Eric.
“Injection directly into the clot will deliver the medicine to the spot where they it
is needed.”

“What’s the risk?”

“Oh,” Sue said, entering the conversation. “They can go in with a catheter and get
the whole clot. But they are liable to puncture the artery and cause hemorrhaging. Also,
they might not have time for that.”

“Why? It’s only been a couple of hours.”

“They need to assemble a team. The technicians have to be called at home.
Instead they can give the CDA without delay.”

“Is there a risk of heart problems or anything else?”

“There is a ninety percent success rate.”

“What of the other ten percent?”

I did not get a clear answer.

She interrupted our private exchange. “They said that there are no traces of
Coumadin in his blood,” Sue relayed to me. “So he’s a good candidate for CDA.”

“No Coumadin? Isn’t he on that to thin his blood to prevent a heart attack?” I was
confused since I was the one who took him to his cardiologist the previous month. “I just
can’t remember what his doctor said about the Coumadin.”

“The neurologist is on his way to the hospital. He wants them to give the CDA
before he gets there.”

“All right.”

“The doctors said that if successful, your father will be just as good he was at the
beginning of the day,” Sue said.
“When will they know?”

“Not for a few hours. Not until the morning.”

It seemed to me that something was lost in Sue’s relay. Was the alternative to the CDA an injection into his clot or some other kind of procedure? What was this catheter thing? Reviewing this now, I cannot help to think that if I had taken the phone, I would have clarified the alternatives and scrutinized the information presented. We might have pondered the effectiveness of a clot-buster for my father. He was a quick healer whenever cut, which makes me think that his blood tends to clot very well. His heart problems were also related to clots. I might have scrutinized this lame excuse of not having time to assemble a team to use the catheter.

Eric did not call back that night. I had every reason to think that my father was fine. And yet I did not even know if he was alive. I slept that night waiting for the phone to ring. It never rang. Was that a bad sign?

I left the house shortly after 5:00 AM the next morning for the early Rosh Hashana services in the Yeshiva. When I arrived home early in the afternoon, Jill, another nurse, told me that Eric called.

“It’s not good. He did not wake up. The clot did not clear.”

It was all over. I was determined to make up for my misdeed of not taking the phone. If only there was something left to be done I was prepared to make a medical decision. I asked Jill to check the caller ID and call Eric back at the hospital. I took the phone from her.

“There’s nothing they can do,” Eric said.

“Did they do an EEG?” I asked him.
“No.”

“Have them do an immediate EEG.”

There are those who say, “It was God’s Will, there is nothing that one could do otherwise.” That is beside the point. Yes, regret over something we did, or failed to, can never undo the past, but ethically, errors must be reflected upon. The duty of self-perfection demands introspection. Through it we determine whether or not we were adequately zealous in performing the mitzvah of saving a life. On the contrary, the great teaching of religion is compassion, the affirmation of the being of another, to will that the other, ought to be. And if the other ought to be, should not the other also actually be?
I flew to Texas the first day after Rosh Hashanah. This is a public fast day. Dr. Camp, the neurologist, introduced himself to me, Harold and Eric, Eric’s wife Bonnie, and the cantor from Eric’s synagogue and approached my father to examine him.

“Howdy partner!” the doctor said a loud voice. “Larry, can you hear me?” He took his hand. “Squeeze my hand if you can hear me.

My father had been in a deep sleep since his stroke. The ventilator tube in his mouth was the only external signs of distress or illness.

“I’m going to look into your eyes, partner,” he said, as he opened Poppy’s eyelids to check pupil dilation with a pocket flashlight. My father did not respond. The doctor lifted his arm and legs to check for response. He then stepped out of the room into the corridor and motioned for us to accompany him.

“I always assume that my patient can hear me,” he said to us. “Let’s talk out here. Your father has a basil artery infarct. He had a massive bilateral stroke that destroyed his pons and much of his brain stem.”
“He has an infarct or had an infarct?” I asked. I found it hard to believe that after all the time since the onset of the stroke, the blockage was not yet cleared. Did the clot-buster have no effect at all?

“Well, let’s look at the MRI.”

He brought us down the corridor to a three-window computer screen. It looked to be a smaller version of the three panel mirrors used in clothing stores. This display was an amazing example of technology: consecutive, still-picture radiology slides sequenced into a video-like image.

“Here’s the brain stem. Notice the surrounding tissue. It should be white. All of this gray indicates swelling.”

“Will it get better?” I asked. The images looked bleak.

“Probably not.”

“What causes the swelling?”

“Water accumulates when blood flow’s cut off,” the doctor explained. “There’s irreparable damage to his pons and parts of his medulla.”

He advanced the lateral slices upward, forming an animated picture. “Here’s his cerebrum. Look how little damage is here, except for his occipital lobe.” We saw only one tiny gray area surrounded by undamaged white tissue.

“Does that mean he’s blind?” Eric asked.

“No, but some of his peripheral vision in his right eye might be affected.”

“Will he be able to communicate by blinking his eyes at the least?”

“Yes.”
Dr. Camp showed us a scan of the arteries leading into the brain. “This is the basil artery. Notice how it just ends right here,” he said, pointing to the bottom of the brain. “It’s supposed to continue all the way up. That is where the clot is.”

The artery came to an abrupt end, going nowhere. How could the only channel to such a large area of the brain be completely cut off?

“But if he was given the clot-buster, maybe the artery is open by now?” I asked.

“How old is this MRI?”

“It was taken yesterday, several hours after the stroke. That was sufficient time for the clot to dissolve. As I was telling your brother, ten percent of the time, the drug doesn’t work. Your father, unfortunately, was in that ten percent.”

“I thought that the ten percent was a danger of side effects. I didn’t realize that it might not work at all.”

“No, it doesn’t always work.”

“How old is this MRI?”

“Can you go to the other image and back up?”

He showed me the image quickly and asked us to accompany him into the ICU conference room.

The conference room was bigger than the Jersey Shore nursing room, large enough for about ten people to sit. It had those institutional couches with a sandpaper-like weave fabric and vinyl coated chairs. Like the nursing room, there were no windows in the room, nothing to distract its captives.

“What was the other procedure that was originally brought up, some kind of injection into the clot?” I asked once we sat down.
“That was a possibility. A third option was going in with a catheter to remove the clot. That cleans it out completely, like a corkscrew. We didn’t think your father had time for that. There’s only a six hour window of opportunity.”

“But it wasn’t six hours yet when he arrived here.”

“It was at night. Radiologists are needed to monitor the movements of the device. By the time everyone would have been ready, it would be too late.”

I later read that this procedure can be effective up to twelve hours. In retrospect, the corkscrew was certainly appropriate. The team would have been there if I had been at the hospital, praying, urging and waiting. Never leave someone alone in the hospital.

“I spoke with your brother on the phone and had the emergency room administer the CDA before I arrived. I didn’t want to lose the window of opportunity to use it, which is even less than with the corkscrew.”

“Let’s not talk about ‘what if?’” Eric said to me.

“Can we all agree that if we do anything, we do it in a way that won’t be a direct and immediate cessation of life? We can’t just pull the plug. Whatever we do, shouldn’t be considered murdering according to halacha.”

“Jewish Law,” I clarified.

“Yea, we don’t have to do that,” Eric said. I felt some respite that we were not going fight over pulling the plug.

“But we have to abide by his wishes,” Eric said. Eric is like my father, very fair, a voice of reason. If someone asked him to do something, he would go out of his way to do it.
“Why?” I asked. “From where does someone get the choice to not live? I don’t understand such a concept. And what binds others to that choice?”

“What is this idea that a person can express his wishes?” I rolled my eyes up and swung my head back as I pondered the status of a living will in halacha.

“Is it a tzavah, a last will and testament? No, that only applies to those in control of moneys to be distributed. Is this the command of a sh’cheev m’rah, someone on a deathbed? No, that’s only binding if originally made testament while dying, immediately revoked upon recovery. And that also applies only to property. What is a living will? Does it having a lawful status? I can’t define it. Where does it fit into the halachic framework?”

It seemed to me that life and death ought not to be arbitrarily decided. It was inconceivable that the Law bound us to my father’s wishes in this case rather than to a general ruling. Are not all of us, including my father, bound to the Law?

Dr. Camp, my brothers, Bonnie, and the cantor remained silent as my memory poured over Talmudic sources. They sensed my struggle but I doubt they understood it. My emotional struggle was tied up in my legal struggle. Emotionally, I was numbed over the fact that my father was pretty much gone. Intellectually, I had to know what was right in the abstract. What ought my father wished? I must have been impious toward my father in my brother’s eyes, just as I surely am impious toward rabbinic authority in my wife’s eyes.

“You said that you can’t take someone off the respirator according to your religion,” Dr. Camp said. “I had a patient from Africa who had a rare virus, similar to E. bola, unheard of in America. He was brain dead, but his family said that clerics back
home told them that he can’t be taken him off the machine. I don’t think that they understood what a ventilator was. I got the family to allow me to take him off just to prove that he was no longer alive. I told them that if he gave the slightest gasp, I would immediately put him back on. He didn’t breathe and we kept him off.”

“My father isn’t brain dead. For all we know, he can breathe on his own,” I said.

“He made the living will.” Eric said.

“We have to read exactly what he wrote in that living will,” I said, even though I had seen it before. We all saw it.

“It just says that if he’s dying, and two doctors say that he has no chance for a recovery, his life should not be prolonged,” Harold said. Once authorized, doctors alone are empowered to make the decision to terminate a patient, even without the consent of family in the Great State of Texas.

Harold is the middle brother. He never married. He has an extraordinary sense of justice and hates criminals. We share that attribute. Just hearing about people who abuse power and extort others burns us up. Harold once drove a corrupt home-owners association president from office who was arbitrarily fining poor people in order to place liens on their property in order to gain possession of it. It helped that Harold’s lawyer’s father, who was a famous judge and buddy of President George H. W. Bush, showed up with his son when they went to court.

“Daddy’s not dying,” I said. “The living will does not apply.”

“We know that he doesn’t want to be a vegetable,” Eric said. “It does apply because it says he doesn’t want to be kept on life support.”

“But doesn’t a person have a moral obligation to live?” I asked.
“There was a conference of priests, pastors and a rabbi discussing end of life issues,” Dr. Camp said, trying to offer some insight.

Dr. Camp had good intentions, but with all due respects, I was not interested in his two cents. I already went through all this with Raphael. I was not in a humor to hear the doctor tell us the one about the rabbi, minister and priest. Still, I was somewhat relived to take a rest from my concentration and allow him to talk.

“There were several differences in opinion but they all agreed on one thing. If you took someone off the ventilator and God wanted him to live, then he would live.”

So I let him have his two cents. That was all it was worth, in my opinion. Did he think I was a moron? Is there no depth or respect for inquiry in dealing with the abstract? The popular conception of God is so superficial. He overlooks all private sins, overlooks people living in sin, since everyone is doing it, no wonder we are indecisive over what is possibly dying in sin. Go ahead, just do it! God will forgive you. We the People are the greatest authority and we the people are the blindest adherents. Many of the famous European thinkers who defied the will of their king were not so brave; at least they could find one or several princes or dukes to serve as patrons for their work. By contrast, what published thinker would be so self-righteous to question the will and authority of the People in America?

“That rabbi at the conference was not a real rabbi,” I said with indignity. It is common for Yeshiva rabbis to criticize Conservative and Reform rabbis for their abandonment of large areas of halacha.
Eric and Bonnie sighed in disgust. How quaint, or shall I say, how smug, had it been for me to speculate about what God commands. Now I crossed the line by attacking their rabbis.

“How can you say that he was not a real rabbi?” Bonnie said. She never liked me, probably because of a disagreement I had with my father over procedures at her wedding, without which, the whole ceremony was called into question. My father always believed that everyone should do whatever they wanted and I had no right to intrude. Come to think of it, he was very Utilitarian in that respect. After all, he was a big economist, somewhat of a Keynesian. I also liked Keynesian theory, but a little rusty lately. Yeshiva rabbis also advised me not to get involved in their wedding. They said that it was better that the marriage was not valid, so that if Eric and she should ever divorce, she would not have to worry about an invalid divorce, which is as bad as anything can get. Needless to say, I did not heed their advice, and needless to say, my father prevailed. I ended arguing with her rabbi who performed the ceremony, which was pretty stupid. Still, why could it not be done right?

“I mean that a Jew doesn’t think like that rabbi at the conference,” I explained to them.

“We have a covenant with God to keep His Law,” I said in the direction of Dr. Camp. “In the Torah, we strive to discover the truth and what’s right, and how to live our lives. There’s no such thing as throwing your hands up in the air without concern for what is lawful and non-contradictory in the hope that God will forgive our actions.”

In all fairness, Dr. Camp did not pressure us to pull the plug. Eric assured that to me the night before since the hospital was Catholic, it probably will not insist on
withdrawing treatment. Additionally, he was not playing me for a moron when he said, “If you took someone off the ventilator and God wanted him to live, then he would live.” It actually happened.

Parents of a fifteen-year old cystic fibrosis patient did not want to disqualify her for a lung transplant by putting her on a ventilator. When they were told that she could not breathe on her own without extra oxygen, they asked doctors to take off the oxygen mask she was using. She was prescribed morphine to ease her into death. To everyone’s surprise, she improved, breathed on her own without the mask and was transferred to a hospital in which Raphael was staying.²²

That story shows that Dr. Camp is right. If you take someone off the ventilator and God wants him to live, then he certainly will live. However, how will you explain your actions to God? How will you justify the morality of your actions? What will you say, not when the patient dies when you take him off, but when he lives?

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“How is it possible? May someone decide to end his life?” I asked myself as I paced back and forth alone near my father in the single bed ICU room. “No, it just can’t be. It can’t be.”

The sun shined bright through a large window that took up the entire wall opposite the room entrance. The room was not large, but big enough for a couple of cushiony chairs to fit on either side of the patient bed in the middle of the room. At night, I would shut the curtains, put the chairs together next to the window, and set up a little bed on which I could sleep. I shut the sliding glass doors leading to the noisy hospital corridor just enough for nurses and doctors to enter.

“What’s the logic of a living will? Is there a halachic precedent? A tzavah, a sh’cheev m’rah, all is only for property.”

“No, we’re not property!” I said to myself in a moment of apparent logical clarity. Just then, my brother walked in through the open entrance.
“I got it!” I said to Eric. “A living will can only work if you view your life as a kind of property that you own.”

“Keep your voice down,” Eric said. I was excited.

“Murderers are put to death in Texas. If someone snuck into this hospital and pulled the plug without our permission, he’d get the death penalty for murder, but not if we’d give him permission to pull the plug. How can capital punishment be arbitrarily dependent upon our will? Are we not then tyrants when we subject our fellow citizen to capital punishment for violation of our royal prerogative?”

“I’m leaving. You’re too loud.” People often tell me that I am too loud. My wife says it. My students say it. Even someone sitting next to me at a wedding with a deafening band said I was too loud.

“Sit down.” I tried to lower my voice, but why didn’t he care about what I was saying? There can be no precedent for the living will, certainly not euthanasia, because it is fundamentally contradictory. At least he was courteous and did not leave. It is a nice gesture when your younger brother still listens to you.

“It has nothing to do with us. Daddy made his will know,” Eric said.

“At what point in time is the killing of a patient not murder? Is it when a patient, if conscious, makes a decision to die? What if he decides to die, but has not yet informed the doctors? What if the patient is unconscious and a designated proxy instructs doctors over the telephone to give the patient another day because he wants to go out for dinner and can’t immediately come to the hospital to sign papers?”
“Be quiet. Daddy might hear us arguing,” Eric said. The doctor and Harold claimed that my father might hear us, but I doubted it. My father had no reaction to any stimulus. How could he hear or comprehend?

“How do you think he can hear?” I asked Eric.

“No”

“I don’t either.” I continued. “Take two cases of locked-in patients. One somehow communicates that he wants to live and the other communicates that he wants to die. The doctor kills both, perhaps to free the beds. The same act, with the same malice, but he is charged with murder for killing one and not for killing the other. Hence, we do not define the crime of murder as killing, but taking life *without permission.*”

“Lower your voice,” Eric said again.

“Why can’t you listen?” He was listening, just not hearing my side.

The entrance to the corridor outside my father’s room was wide open. It did not have rooms on the other side, but there was a nurses’ station and several computers and x-ray viewers where doctors, nurses and medical technicians worked and conferred. It was somewhat busy that Thursday afternoon.

“Is everyone okay?” A nurse came in to ask us.

“Yes,” Eric said.

“Yes. I guess I was too loud,” I admitted.

“Where the proprietary theory leads us?” I asked after she left. “Say a parent is on life-support and well within statutory guidelines, but otherwise wants to live—unless his child pulls the plug. The parent’s desire to live is explicitly stated, or perhaps assumed, to be conditional so that he is deemed to make a *conditional* legal will to die, or
perhaps to authorize one later with his last breathe, or when he gives up on convincing his child not to maliciously pull the plug, so that the child is ruled not guilty of murder. It’s like the parent who after unsuccessfully resisting his child from maliciously stealing his property conveys it as a gift to his child to prevent a felony. The State just made patricide, the most heinous of crimes, guiltless.”

“Only the doctor has the authority to pull the plug.”

Eric was listening to me and being very decent about hearing what many might interpret as close-mindedness. He was not interested in a philosophic debate but let me talk my reasoning through. To me, I was completely logical, even Talmudic. I was hungry from fasting but too intense to think about food.

“The State grants a man freedom to ask his personal doctor to take his life away. Anyone else, who takes it, even with his consent, commits murder. Let’s formulate a similar argument about marriage. Say a man grants his wife freedom to be intimate with his personal friend. Anyone else, who borrows her, even with her consent, commits adultery. That’s stupid and unjust. Adultery and murder, and incest, are nonconsensual crimes. The wrongs are unconditional; they do not require a claim.”

“A woman owns herself and a man owns himself.”

“It seems that the State owns the patient,” I was being facetious. “People are not property. The institution of marriage criminalizes adultery, and the sanctity of life criminalizes murder. If authority is granted to make exceptions, then there is no legal

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23 On the eve of the great Civil War, Andrew Johnson asked the Senate to consider the logic of recognizing the freedom to leave the Union. “If the doctrine of Secession is to be carried out upon the mere whim of a state… may not other states combine and eject a state from the Union?” Means, H. (2006). The avenger takes his place: Andrew Johnson and the 45 days that changed the nation. Orlando, Fl. Harcourt, Inc. 68
basis for marriage. If authority is granted to a limited class of patients to end their lives, then the whole category crossing the threshold, including those who want to live, is logically classified as legally disposable.”

I concluded. “We have three possible criteria in which killing ceases to be murder. 1) An arbitrary point in time is set when doctors are notified that a patient on life support wants to die. Before papers are signed, even if the patient watches someone pull the plug with approval, a killer is executed. 2) Murder is charged to anyone who is not a) the personal doctor, or b) authorized explicitly or by close relation, even if criterion one is met. 3) No one is ever executed for killing someone who needs life-support without chance of recovery, even if the victim wants to live and continue.”

“A person has a right to refuse treatment.”

“What about Raphael? Doctors categorically denied his right to life. And it happens all the time.”

“It doesn’t matter. This is what Daddy wants. I just want to carry out my father’s will,” Eric said. “Instead of figuring out why you can’t carry out his will, you should be trying to figure out how we may do it. He’s your father.”

“Yea, I guess your right.” I felt somewhat guilty and gave it some thought. “But no. There is no right to life, only a law for life. One can’t command another to break the law.”

“What about Abraham? God commanded Abraham to break the law.”

“He struggled with it. You asked a good question,” I said. “You know what I heard? Rabbi H., the rosh yeshiva of my afternoon school, said that Isaac complied only
because he knew about the miracles performed for his father, how he was saved when he was put into the furnace at Ur of the Chaldeans. He knew that he’d be saved also.”

“No,” Eric said emphatically. “He wanted to do God’s will. I want to do Daddy’s will.”

Eric left for a couple of hours and returned later to take me out to pick up something supper at the end of the fast at night. In my case, the fast lasted an extra hour because of my westward flight. We met a couple which just flew westward from England in the large Austin grocery store that housed the kosher delicatessen. They broke their fast for some reason even though it was not yet nightfall.

The feeling of summer in the Austin fall brought me pleasure. As we returned to Eric’s car in the parking lot, I took note of the height of sun, on it way down from its early October height, which is about ten degrees higher in Central Texas than in New Jersey. It was 5:30 in the afternoon and the temperature was about eighty. It was not humid, but just a clear blue sunny Austin day. That which they say about the Texas sky is so true.

Our family first toured Austin on a vacation to visit the State capital. I remember the governor holding the door for my mother as she left the capitol building, a structure very similar to the one in Washington. Growing up in Houston, I used to think that Austin was the best place to be, with the exception of when I lived there during college. It is nicer than Southern California, which is too much like Houston, with a heavy population and traffic, despite its Austin-like landscape and Mediterranean climate. My parents even bought property on Lake Travis long before I went to the University of Texas, but they never built on it. The lake was created by Mansfield Dam constructed on the Colorado
River by the Brown brothers, founders of Brown and Root (Halliburton), thanks to then Austin congressman Johnson. That first political contract led to the rise of two American giants, and unfortunately for Lyndon and our nation, connect with two giant tragedies.

We brought our food to Eric’s home, a large two story house, for a short visit. I still could not eat. Eric’s house did not have a basement since the Austin ground is limestone and cannot be excavated without expensive blasting. It had a bath and guest room downstairs in which my father usually stayed. I took a shower and submitted some work onto the internet until it was time to eat. I ate one or two sandwiches, said hello to my niece and nephew, looked at Eric’s power tools, I think, and went back to the hospital with him.

That was the only time I left the hospital grounds for more than a few minutes. From Thursday night until Monday afternoon, with the exception of the Sabbath, I stayed in my father’s room. On the Sabbath, I stayed in a guest house for family of patients on hospital grounds. I walked back and forth to my father’s room on the Sabbath, but did not want to sleep or spend extended periods of time in his room. Too many people who were not observant of the Sabbath were planning to visit and that bothered me.

It was still Thursday night and Eric was still with me and my father in the hospital room. Harold returned from somewhere. I never know where Harold goes. He came in the room and tuned into an important baseball game on television.

“The Yankees are losing,” Harold said loudly close to my father’s ears. Poppy was a big Yankee fan. He took my bothers and me to the original Yankee Stadium in the sixties and also took my children and me more recently. We were three generations of Yankee fans, but my brothers and I were also fans of the Houston Astros. We used to go
to the eight wonder of the world to see almost every Sunday home game. We saw the
Yankees play in the Astrodome only once when Poppy took us to an unusual three team
inter-league pre-season exhibition. Since childhood, we rooted for the Yankees to play
the Astros in the World Series and both were in the playoffs when my father was in the
hospital.

“He’s sleeping Harold.”

“How do you know? They say with locked-in syndrome; they can hear everything
but can’t respond.”

“We don’t know what he has. He hasn’t wakened yet.”

“Well it doesn’t hurt to act as if he hears us,” Harold said.

“And if he does hear us, then what do you think he is thinking? What do you think
a dying man’s thinking?” I was too dazed and philosophic to care about the game or
anything else.

“I don’t know,” Harold said.

“Don’t you think it’s cruel to put the TV speaker right next to him blaring in his
ear?”

“It doesn’t hurt to pass few hours. It’s just to pass the time.”

“Why would a dying man want to pass time?” I asked.

“He’s probably not thinking about that yet,” Eric said.

“Yea, he’s probably thinking why these dumbasses are keeping me alive!”

“Isn’t that thinking about his end?” I asked. “I don’t think he’s thinking at all. I
think he’s sleeping. But you think he’s awake. So according to you, why is it appropriate
to watch a ball game in his presence?”
Harold did not answer and looked up at the television. “There’s Cro-Magnon man.” Harold said, referring to an outfielder on the Red Sox who had a beard and long hair.

“I thought Cro-Magnon man was a homo sapien,” I said.

“Hey, you’re not supposed to believe in that!”

I brought back the debate over the right to die.

“It’s not our decision,” Eric said. Eric loves baseball but he was also not paying close attention to the game. In fact, Eric tries to visit as many major league ballparks as he can. We all love baseball and played it in our youth.

“But they’ll come to you,” I said to Eric, concerning the living will.

“It doesn’t matter what I say. It’s all on the paper,” Eric said.

“You have the paper.”

If it was wrong to follow the living will, was it right not to disclose it? On the other hand, if no one asks about it, was it right to disclose it?

“It’s a matter of public record,” Eric said.

“It’s in Harris County. Nobody’s going to look it up. They’ll be coming to you.”

“It’s his choice.”

“Just because someone has a right to make a choice doesn’t make it right. A person has an obligation to live.”

“Lower your voice,” Eric said.

I noticed a pattern. He became uncomfortable and said I was too loud whenever I discussed the religion.

“Do you believe in the Torah, Eric?”
“I don’t care. This is his wish. I’m leaving.”

“Sit down.” Again, it’s nice to know that he still listens to the oldest brother.

“We all want a lot of things. Rachel says she wants to go dancing in a nightclub but she can’t. We can’t just do what we want.”

“What’s wrong with dancing in a nightclub?” Harold asked.

“It’s immoral,” I said.

“Well, maybe with her husband,” Eric said.

“It’s just not a thing that one does if one lives his or her life according to certain principles.”

Jewish men and women do not dance together. Weddings have a partition separating the area where women dance from the area where men dance. Women always wear skirts to their knees and sleeves to their elbows, do not wear pants, and married women do not display their hair in public. But no burka for the Jewish woman! She makes the best of her modesty and dresses quite elegantly, and unlike the American woman of the nineteenth century that wore her hair up or covered, the Jewish woman today wears her long hair wig down and styled.

“Don’t be an—hole,” Harold said. People are meant to have fun in Harold’s opinion. Live and let live.

“You know Harold, that’s the third time you used profane language in front of a dying man.”

“Words don’t matter. They’re only words.”

“Should we also go around with no clothes?”

“What’s wrong with that?”
“That’s being like an animal, without intellect,” I said. “Also, children would not respect their parents.”

“You know the story of when Jacob was dying?” I asked. “He bowed toward the end of his bed when Joseph visited him. Rashi says that he was bowing at the Presence of God, which dwells at the end of the bed of a dying person. Simply, that means that the deathbed is a solemn place for reflection. It reminds us of our own end,” I said. “Why desecrate that mood?”

“I agree. We should not be joking around,” Eric said.

“Would you use profane language if you entered the Holy Temple in Jerusalem two thousand years ago?”

“I would if I hit my finger with a hammer,” Harold said. I have shamefully made that error in private and brought it up to my public school students to bestow upon them the shame of profanity. Profanity is so accepted and common that unless it is directed toward a teacher, it is not even considered a punishable offense.

“Why must we be discussing this here in front of him,” Eric asked.

“Where else? Have I been anywhere else?” That was smug of me to say.

“We can go into the lobby,” Eric said.

“Harold, all this TV stuff, magazines, it’s all emptiness. There’s so much more for the intellect to explore.”

“You mean religion. That’s the opposite of intelligence,” Harold said.

“Did you ever read the end of Newton’s *Principia*? Reading it shows that he was deeply religious. What about Kant?” I paused as he considered this and the gravity of witnessing the end of life. “What do you think the purpose of life is, Harold?”
“Pleasure,” Harold said, without hesitation.

“Did you ever read Plato?”

“I might have in school,” he said casually.

“Do you know who he is?” I hoped that he was familiar with the allegory of the cave. All philosophic discussion needs a framework based on common knowledge.

“He’s a guy who lived a long time ago.” His response indicated that there would be no discussion, perhaps just a lecture.

“I don’t think anyone advocates hedonism, the ethics of pleasure,” I said. “The two main schools build their ethics around either duty or happiness. It begins in antiquity with the Stoics and Epicureans and continues to modern times with deontology and Utilitarianism.”

“Why can’t there be a combination between the two?” Harold asked.

“You know Rabbi Salanter? He lived 150 years ago. He had a good combination. He said that another’s happiness is my duty.”

After they left, I called Rachel. I told her about our conversation.

“Why did you tell them that I wanted to go dancing?”

“That’s what you said when I said that my father wanted us to pull the plug.”

“I didn’t mean it. I used that as an example to show that we can’t just do what we want. I never wanted to go dancing.”

“Well that’s good because I’m a terrible dancer.”
“I know. You’re a neb.” A neb is a dork in Yiddish. This neb built his own house, works on his own car, and hires no illegal aliens, or anyone else to do his own work. But, I guess, it is all in the personality.

“Harold asked why duty and pleasure can’t be combined. I quoted from Rabbi Salanter.”

“Why didn’t you ask him what he thought about us?”

“What do you mean? That we’re fanatics?”

“You should have asked him if he thought we’re happy. Does he think that people who are religious are unhappy?”

“But we don’t do it for happiness.”

“What about the joy and beauty of the Sabbath and the mitzvahs?” She asked.

“Isn’t there happiness?”

“Yes.” I hesitated and then asked, “Are you happy?”

“I’m not talking about me.”

Rachel is loved by everyone in my family and her family, which cannot be said about me. She only wants to please. I am so unlike her. She says said that I am not sensitive to her feelings and to the feelings of others. Additionally, she considers me opinionated, mean and uncultured, while I consider her pious, kind and polite. I have asked her to study, take courses, or pursue her own interests, but she has no desire. She only wants to be the ideal wife and mother, cooking, cleaning, shopping, mothering, and pleasing. And she does all those things with virtue and excellence.

However, she is often in a bad mood, and I used to assume that I did something wrong to put her in that mood. Either I spoke my mind on some issue a few hours, days,
or weeks ago that embarrassed or angered her or I criticized something in private about our community or religiosity. Come to think, it is always something I said. I would ask her to tell me what was bothering her and she would say, “It’s just you being you.” However, the other day, after almost twenty years of marriage, I realized that she was angry about something that had nothing at all to do with me and that was a great relief.

“Americans are so dumb,” Harold said on Friday, reacting to something on television. He put the speaker next to Poppy’s ear. “People are not at all scientific.”

Dr. Deaton, the attendee, came in to speak to us while the baseball announcer was blaring out loud. “I fully anticipate that he’ll wake up,” he said. Dr. Deaton was a respectable, white-haired, Marcus Welby type.

“Will we be able to get him off the respirator?” I asked as I turned down the speaker.

“Yes, but we probably will need to leave the ET tube in. Swallowing is a rather complicated process. There are a lot of muscles involved and with the kind of damage he has, his secretions are liable to go down the wrong way.”

“Is there a concern with his diastolic blood pressure rate? It is thirty-five. That’s kind of low.”

“That’s to be expected after a stroke; also, he’s lying down. The main thing to look at is the middle number. It’s almost a mean between the diastolic and systolic.”

Harold turned up the television speaker.

“He wants to hear the game,” Harold said.

“He’s sleeping! You’re not being scientific,” I said.
“Doesn’t his EEG indicate that he is sleeping?” I asked the doctor.

“I’m not a neurologist. You can show me an EEG and it’s looks like just a bunch of squiggles to me.”

“He still doesn’t respond,” I said. “His pupils barely constrict when a flashlight is shined in them, he has no eye movement, and doesn’t blink. Have you seen this before?”

“It’s pretty bleak. Unfortunately, I’ve seen it before.”

“Check if he’s awake,” Harold said to me.

“I can’t,” I said. “I’m the rotten son who doesn’t want to follow his wishes.”

“When will you try to extubate?” I asked Dr. Deaton.

“I want to wait until there’s no swelling. If he gets too much carbon dioxide in his blood, it will increase the swelling.”

“Can’t you tell from the pulse oximeter if he’s not getting enough oxygen and infer the amount of carbon dioxide.”

“We can if there’s a large increase. But if he has a slight increase in carbon dioxide we won’t immediately know.”

Eric came in when Dr. Deaton was finishing his rounds on my father. For some reason, I reserved my moral arguments for Eric.

“Either it’s absolutely right to end a life or it’s not. If it’s up to the person, then morality is relative.”

“Maybe it depends on the situation. In his situation, he does not want to live.”

On Sunday morning, I spoke with the hospital’s pastor, Kevin, a thin middle-aged man. He often peeked into my father’s room, but never said anything me. Perhaps my
yarmulke intimidated him, but I noticed him talking to the doctors too much, and that concerned me.

“What’s your policy regarding those in a state like that of my father,” I asked him.

“When the doctors decide that they can’t do anything else here, they’ll send him out to a lower level care.”

“You mean to a hospice or something.”

“Yes.”

“We went through the same thing last year with our baby. The doctors pressured us to pull the plug. But this being a Catholic hospital, I don’t expect it here.”

“Yea, but there may be nothing left to be done.”

“All these people, with their shallow lives, with their TV, celebrities, and nonsense, they should decide who lives and who dies? All they care about is happiness. The religious have a calling to duty.”

“One can find happiness in religion,” he said.

I went through my argument against the right to die. “How can we execute someone for murdering an invalid, while at the same time allow doctors to pull the plug on him if he so desires?”

“Sometimes you can see it in a patient’s eyes,” he said. “They want you to let them go.”

How could I argue with a man who has seen such a pitiful sight?
Poppy was taken downstairs for another CT scan at 4:00 in the morning on Monday. A second EEG was taken at 10:00 AM. During the EEG, I called out-loud, “Daddy! Daddy!” It was a last chance.

The EEG technician shined a light in his eyes and raised his arm. There was no change in the EEG pattern at any time during the stimulation. It was certain that he was not in a locked-in state. He just was not there.

My prayer that morning was very intense. I did not tell anyone that I fasted during the daylight hours the previous day, Sunday, as private fasts are kept private. I was still pretty hungry on Monday when Eric brought a kosher lunch to the hospital for me. Bonnie came with him.

Dr. Camp came to the ICU to confer with us at 1:30.

“What did the EEG show?” I asked.

“He’s in a deep sleep, not awake,” he said. “And the CT scan looked worse than before. I don’t know if he’ll wake up at all.”

We were starting the think the same.

“There’s this trial in Minnesota using Viagra to regenerate brain cells,” Harold said. Harold spent the whole time researching experimental treatments on the Internet. “I spoke with the doctor there. He said my father’s a good candidate.”

“No,” Eric and I said together.

“Your father is not a good candidate for that kind of treatment, not with his heart problems,” Dr. Camp said. “Viagra lowers blood pressure by opening the arteries. He needs his pressure after his stroke.”
“You guys have to start making some decisions,” the Dr. Camp said. “He’ll need a trach next week.”

“Put in a trach,” I said adamantly.

“No,” Eric said. I saw Bonnie shaking her head.

“Can we bring him to New Jersey?”

“You can,” Dr. Camp said.

“No, you’re not bringing him to New Jersey,” Eric said.

“Well at least wait until he wakes up,” I said.

“We’re not going to wait years for him to wake up,” Eric said.

“Well what about months?” I asked.

“We’ll give him one more week,” Eric said. “He can go without a trach for another week.”

“Will you be around for another hour? I’m leaving in an hour,” I said to Dr. Camp.

“I really have to leave. I came just to speak to ya’ll.”

My brothers, Bonnie and I went into my father’s room.

“Eric, my son’s rebbe had a massive heart attack cutting off oxygen to his head. Some doctors said he was brain dead. The family, of course, wouldn’t pull the plug. He woke up and is now in a home. You see how smart the Torah is?”

“Stop shouting!”

“I’m not shouting!”

Bonnie walked out, probably angry, and Eric got up out of his chair after her.

“Harold, you’re not in a rush, are you?”
“What? To leave?”

“No. To let him die.”

“I think this Viagra thing would be good,” Harold said.

“I don’t know. Doesn’t it make the most sense to wait it out without any unproven experiments?”

“Every medicine is experimental at some time.”

“But this doesn’t make sense. It makes more sense to do nothing and wait. Daddy is sleeping, not in pain. Why cut off his feeding?”

Harold went out to find Eric. I decided to try to call the rabbi with whom I spoke when Raphael was first born. He was not in the study hall, so I asked if I could hold the line until he arrived. I waited almost a half hour.

“I don’t want to terminate my father’s treatment, but he signed a medical will that one of my brothers feels obligated to comply with. What is this medical will thing?”

“It’s what some people sign to determine whether to be treated,” he said.

“I mean, what is it? Are we obligated to follow it? Does it have legal force.”

“What’s the difference? Are your brothers going to listen to you?”

“No. But we all agreed that if we end treatment, it should be discontinued in a way that his death is not a direct act of our hands. My father is off the ventilator now and breathing on his own. However, he has an ET tube to prevent him from gagging. I assume that pulling it out is forbidden. What about withdrawing nutrition?”

“It’s not the same thing. The ET tube is already in him. Food is not something he already has.”

“You mean that it’s like a DNR?”
“Yes.”

“Well I don’t approve of this whole thing to begin with. He’s not dying,” I said.

“There’s no justification for ending his life.”

“Do you remember the baby I called you about sixteen months ago? He’s thriving.”

“Baruch Hashem,” the rabbi said.

“Have you heard about cases of people recovering from massive strokes?”

“You read about them, but they’re rare.”

Eric had returned and prodded me to hang up. We had to go.

I think the explanation is that removing a feeding tube takes away the availability of nutrition, requiring the patient to find another source of nourishment. Stealing food or the dentures of an invalid is not itself homicide. The crime needs a secondary action, the failure to feed or to assist. By contrast, removing the feeding tube stops a patient from breathing. It requires no secondary action. The failure to reintubate a patient improperly removed from a ventilator is like the failure to apply medical care after shooting someone, or after holding someone’s head under water. Strangulation requires no secondary action.

Eric drove my father’s car while I sat in the front seat and Harold sat in the back. The car stunk from dog. Harold had been driving the car over the last several weeks.

“You’ve got dog all over this car.”

“It’s from Shadow.” Shadow is Harold’s dog, our third Golden Retriever.

“Why is it all wet?”

“It’s from the rain,” Harold said. “I left the windows open.”
The radio played music, although not very loud. I turned it off. I was in a solemn mood. My father was not going to recover and my brothers were thinking about ending his life. Besides, mourners do not listen to music.

“What’s the matter with the seat belt?” Harold asked from the back seat, struggling with the seat belt. Eric and Harold discussed the seat belt for about a minute that seemed like five.

“Stop all the stupidity,” I said.

“The seat belt is important,” Harold said.

“So pull over so you can put it on.”

“That doctor in Michigan disagrees with Dr. Camp. He said Daddy is a good candidate for the Viagra trial.”

“The Viagra will kill him,” I said.

“But then it won’t be like we’re killing him since we are trying to cure him.”

“Harold, you have to approach everything with reason. You can’t just look for legal excuses,” I said. “And Eric, you’re so concerned with fulfilling his wishes. This Viagra thing goes against anything he’d want. He does not want to be a Guinea Pig for some experiment.”

“I agree. The Viagra isn’t for him,” Eric said.

“But it’s his only hope,” Harold said.

“He’ll wake up. Let him recuperate. You don’t even know what he’ll be like when he wakes up. Why do you want to destroy him in some risky procedure?”

“They wouldn’t be willing to take him if it was risky,” Harold said.
“Why not? Where else will they find someone with such extensive damage like Daddy? They’d love to give a shot at success in a case like his, despite the probability of failure.”

“I think the opposite,” Harold said. “Daddy might bring their statistics down if they didn’t think it’d work.”

“Well you guys want to terminate his treatment. I’m willing to consent to anything if it means that you’ll keep him alive. But, it’s still wrong.”

Why did I say that? I was not willing to consent to anything to keep him alive. The ends do not justify the means.

I went back to my teaching duties on Tuesday, missing only two days, since Monday was Columbus Day. I did not speak to Eric on Tuesday, not wanting to go through the whole debate all over again. I finally spoke to him Wednesday afternoon, a few hours before the start of Yom Kippur, the holiest day of the year.

“Eric, I know you can’t answer this, but what am I supposed to pray for. I prayed today without any thought. I just said the words.”

“I can’t answer that.”

“But don’t you see that it’s the human conflict that’s the problem. Before, I prayed for his recovery, but what am I supposed to pray for now?” I answered my own question. “Rachel said that I should pray for the wisdom to say and do the right things.”

“Artie, this is his will. You can’t blame me.”

“Rachel said the same thing. She said that it’s Daddy’s doing, not yours.”

“Eric, I don’t want to scare you, but there’s this legal concept of ein shlechos l’dvar aveira. That means that the deed of an agent who is appointed to do something,
owns that deed if it is a sin. If a party tells someone else to do something wrong, it is not considered the action of the first party, but the action of the agent who does it. This decision, if it is a sin, is your action.”

“But I don’t consider it wrong.”

“The rule is, ‘the word of the Master, and the word of the student, whom does one follow?’ That means that if the Law says something and someone commands you to do otherwise, the person who made the command can have no legal expectation for you to comply. If you do the deed, it is an act of your own volition, not a compliance with his.”

“Artie,” Eric sobbed. “It’s like we’re preventing him from going to heaven.”

I paused.

“Eric, we have to do what’s correct.”

“I issued a DNR order.”

“What does that mean, not to do CPR?”

“I guess.”

“Well you better find out,” I said. “You better make it clear what you expect. I hope it does not mean to withdraw his heart medication.”

“I think it’s just if he has a heart attack, not to resuscitate.”

Later I found out that a do not resuscitate order means much more than desisting from resuscitation. It is legal consent when die now is requested.

I did not call Eric again until Friday afternoon. I came up with a new argument every time I called, but it was always the same point.

“Are you going to hold this against us when it’s all over?” Eric asked.
“No. But I’ll argue my point until the end,” I said.

“I hope that he doesn’t wake up,” Eric said. “Why should he see what kind of state he is in?”

“The last minutes of one’s life can often be a valuable time for reflection.”

“They can also be full of bitterness,” Eric said.

“You mean he can get angry at us?”

“At everyone. At us, the doctors, the nurses—”

“And God? I still say that you shouldn’t hope that he doesn’t wake up. A man’s last minute of consciousness can give meaning for a whole lifetime.”

“I think he went through that in the ambulance,” Eric said.

“Well, I have to go. It is almost the Sabbath.”

I later asked Rachel if she thought that my father might become angry when he woke up. She said that Poppy was not like that. I agreed with her.

On the Sabbath I spoke to Jill about my father while she gave Raphael a bath.

“It might take up to six months for him to wake up,” she said.

“How do you know?”

“When I started working as a nurse, I had a patient who was thought to be brain dead. The doctor wanted to pull the plug on her but her parents said to give her more time. They pulled the plug after all, but she kept on breathing, like that famous case—”

“Karen Ann Quinlan?”

“Yes. One day, I was taking care of her and all of a sudden, she sat up. I had my back to her. I turned around and was speechless. I just pointed at her. I tried to call out but my voice did not come out.”
“Did she recover?”

“She walked out of the hospital six weeks later.”

“We’re not there yet, but this whole euthanasia thing is so contradictory.”

“It’s almost like that with the fetus. The law allows abortion up to twenty-four months. But soon a twenty-four month infant will be viable.”

“Under common law, the contradiction is avoided,” I explained. “Murder is defined as killing a human creature in being within the king’s peace, that is, one already born. The contradiction we face is that the mother has the right to abort or consent to an abortion and pay no penalty, while if someone else does the same act against her will, it’s not be just an assault on her person, but statutory *homicide* in some States.”

Sunday, I called Eric on his cell phone.

“Daddy’s in just a different state of being. He’s not dying.”

I heard sounds of cheering in the background.

“I’m at a baseball game.” I thought he was attending his son’s Little League game.

“What about Helen Keller? Would it be right for her to commit suicide? She couldn’t see or hear.”

“That’s her choice. I’ve got to go,” he said.

“Let’s extend the argument further. What if someone was physically healthy but undergoing emotional problems? What if the circumstances of his life made him not to want to live? Is that justified?”

“Yes.”
“Okay. Goodbye.”

There was nothing left to say.

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I’m All Alone

Chapter Twenty-two

I asked for another neurologist to give us a second opinion,” Eric told me on Monday.

“Was he old or young? I don’t trust young doctors.”

“He was young.”

“The young guys probably never saw anyone go for a long time in Daddy’s condition. Everyone always pulls the plug.”

“Well, another doctor, a sixty-five year old one, came in today and said that he’s seen this before. He said Daddy would never get better. I wasn’t too happy about that because we never asked his opinion.”

“Everyone has to rush for closure,” I commented.

“We’re not rushing.”
“We live in the Styrofoam generation, everything is disposable. Nothing is esteemed anymore,” I said, quoting Rabbi H. “Some of the nurses call Daddy by his first name. People call me up on the phone and call me by my first name. They don’t know me. For all they know, I might be an old man. I even might be a teacher.”

“I don’t like it either when kids call grown-ups by their first name.”

“Eric, you know, there are laws about Succos that you might not know about.”

Succos is a weeklong holiday in which we leave our houses to dwell in the succah, a temporary dwelling, beautifully decorated, to commemorate our dwelling in succos for forty years in the wilderness after we left Egypt.

“Yea, I have to ask you about that.”

“Well, I did not want to bring this up because I don’t want it to influence any decisions. But if he dies before Succos, the first day ends shiva, and the rest of the days are so formulated to multiply away most of the strict thirty-day mourning period after shiva. However, if he dies after Succos starts, not only must we mourn during Succos, albeit in private, but we must keep another seven days shiva after Succos and the whole thirty days.”

“Well we’re not going to do anything at least until Thursday when his sister comes to see him.”

“But I don’t even want the private days of shiva during Succos to influence your decision causing you to wait until after the holiday. It should not be in our hands to end his life at all, and certainly not for convenience.”

“It’s not in our hands. The doctor has his instructions.”

“But they asked us. They asked about a trach.”
“It’s the choice that Daddy has made.”

“Who are we to say that we don’t want to live in a certain state of being? It’s the same fallacy as that which people make when they ask about why there is evil in the world. They’re comparing our world with a better world. Because we prefer one state of existence, are we to say that the lesser state of existence should not be?”

I realized after some time that he got the second opinion because the living will required two doctors to say that recovery was futile for treatment to end.

I did not speak to Eric again for some time after the first two days of Succos, during the intermediary days in which we are permitted to do most work. We may not talk on the telephone on the first two days and on the eight and ninth days, those last two days considered a separate holiday. My initial thinking was that if Eric was going to do something drastic, I did not want to hear about it. I realized that I was being selfish, and during my fifth period supervision of students, I excused myself to call him. I reasoned that if I did not call, I would have regrets in the future.

“Eric, don’t tell me if anything should happen before the Sabbath or the last two days of the holiday, when we can’t travel and won’t be able to bury him anyway. You’ll have to use judgment. I wouldn’t be telling you this if this whole debate wasn’t going on.” If the time of death was going to be determined by choice, I did want to hear about it and begin mourning over the holiday, certainly not on Simchas Torah, the joyful last day.

“Okay,” Eric said. “And I think we saw him squint his eyes today, trying to communicate.”

“Yea, sure. How do you know?”
“He responded when we called him.”

“Is this any real change since I was there?”

“No.”

“I still think that he might recover.” I said.

“There is no possibility of recovery.”

“Why do you say that? Even Dr. Camp said he might wake up.”

“You didn’t see the second MRI.”

“Yes I did.”

“I mean the third one that the second doctor did. He said there’s no hope of recovery.”

“So now his living will is validated,” I said. “We can still wait.”

“What do you want to keep him alive for, as an ornament?”

“You need hard statistics, Eric. I want to see how many people recovered from this kind of stroke and the degree of their recovery.”

“He has no chance of recovery. What is he, a Christmas ornament?”

“Is that what you think is my purpose in all this?” I asked. “Why do you think you hear so many stories about religious people coming out of these things? Because they don’t pull the plug.”

“Here’s Edna, talk to her.” Eric put my father’s only sister, who was four years older than him, on the phone.

“Arthur, you’re dead wrong. I’ve seen this before. He can’t recover.”

“Why, because the doctor said so?” I asked.
“No because I saw the MRI. I saw the white areas and the gray areas. I know how to read them.”

“Why can’t we wait?” I asked.

“Your father is not an ornament. He’s a human being. He’s entitled to human dignity.”

I was warned that I had only one minute left on my calling card. “I can’t talk any longer. I’m getting cut off.”

Instead of going home to eat, as I normally did, I spent my whole lunch period doing research on the Internet in the mathematics office. I found some professional articles on stroke and emailed them to Eric. Afterwards, I spoke with two of my fellow math teachers.

“I don’t know how I can be my mother’s daughter,” Nancy said. “My mother agreed with my two sisters about everything. My sisters don’t care. I fought for my mother when she was dying. I can’t even let an animal go. I even got medicines for my dog when he was dying.”

“I put my dog to sleep when he was ill,” Cheryl said.

“How could you?” Nancy asked.

“He was in pain.”

“People are different. They’re not dogs,” I said. Cheryl nodded.

“You know, we’re teachers,” I said. “We can never say that a child is incapable of learning, yet doctors say that a man can’t recover. Even more, doctors can go beyond their professional boundaries and recommend pulling the plug. What is wrong with that
profession? We went through this same thing with the baby, doctors telling us that he’s 

*not compatible with life.*”

“I don’t think your father’s situation is the same thing as the baby’s,” Cheryl said.

“Maybe.” I said. “I regret even bringing up the baby.”

The rest of the day I was plagued with doubts. Could I be wrong about my father?

Was I wrong about Raphael?

“No it can’t be!” I said to Rachel that afternoon. “How can we be wrong and there still be a Law? Every case would be decided by the accident of the person’s own will.

What can be more arbitrary?”

“Why do you doubt yourself?”

“Because, I’m all alone.”

“You need to talk to someone.”

“I was talking to you.”

I went back to the high school to do more research. I found several studies, one that tracked the progress of 139 patients with locked-in syndrome, eighty-two of which also suffered infarction of the basis pontis.24 I emailed them to Eric and then called him from the math office.

“I read that book that Daddy’s nurse told us to read, *The Diving Bell and the Butterfly*25. The guy who wrote the book didn’t wake up until after sleeping for three weeks. He died after a year.”

“Daddy doesn’t want to live like him.”

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“Neither did he, but that’s what happened,” I said. “We don’t know how much movement he’ll have when he wakes up. I emailed you something that the doctors should be looking at, and what you should see. It’s actual data, not anecdotes.”

“I’ll look at it.”

“The study seems to be thorough. Most of the patients died within four months, but the ones that had some recovery, didn’t see any improvement until after months. I bet the doctors haven’t even seen it.”

“I’m sure they know about it.”

“I bet they don’t. How can they be telling us that he has no chance of recovery without pointing to statistics?”

“Because of the MRI,” Eric said. “It’s conclusive.”

“But how do they know it indicates no recovery at all without hard data? You’ve got to give it time.”

“The cases in your study probably didn’t show the same damage on an MRI.”

“It didn’t indicate any radiology. This study was as close as I could find that documented cases similar to his.”

“Here, Edna wants to talk.” Eric gave the phone to Aunt Edna.

“Hello, Arthur. Listen, your father’s a human being.”

“That’s why you can’t pull the plug,” I said. “You don’t just terminate a human being out of pity like a non-human.”

“It’s a pity how he’ll live,” she said. “I see these people all the time. They need nurses to wheel them around. They have to wear diapers. That’s no kind of life. We’ve had this discussion many times. Your father doesn’t want to live like that.”
“He doesn’t want you to keep him alive,” she continued. “What is he, a Christmas ornament? I can’t talk. You are causing me too much aggravation. Here’s your brother.”

Aunt Edna was always my match. She put on Harold.

“Harold, look at those studies that I emailed Eric.”

“Why didn’t you email me?”

“Maybe Eric can forward them. I don’t have your email address.”

When I got home, I told Rachel what Aunt Edna said.

“What did she go there for, to kill him?” Rachel asked.

“She wanted to see him before he dies.”

“Let me get on the phone with her. She had no right to say that to you. A Christmas ornament?”

“I’m proud of you,” I said to Rachel. “Speak your mind. But they’re going out to eat. They’re not going to be home.”

After she called Eric on his cell phone, she told me, “They’re already at the restaurant. I heard that stupid laughing in the background. I told them to ask Aunt Edna to call back when they get home.”

Aunt Edna called that evening while I was sitting in our Succah. Rachel explained to her the distress that I was under, standing alone, and then gave me the phone.

“Your father has the best doctors in Texas, but he didn’t use them. I don’t know why he kept using those same New Jersey cardiologists that almost killed him two years ago when he had a heart attack right after they released him from the hospital. He should have changed doctors right then and there.”
I was silent as she explained why she felt I was wrong over refusing to pull the plug on him.

“Listen to me, I’m older than you,” she said.

“I know that it’s not the law, but a sister is really closer by blood than a child.”

“Did the doctor tell you the story about his father?”

“Yes,” I finally said. “It didn’t impress me.”

“Listen. I didn’t mean that you’re doing this to keep your father as a Christmas ornament. It was something I said to my daughter. I meant an ornament. You know I’d never have a Christmas tree.”

I had a prepared statement for her. I planned to elevate my voice, word by word.

“All our religion, our laws, our philosophy our profundity—”

“Stop the bull-(expletive). Don’t use such big words.”

“Everything we believe in is just an ornament?”

“Arthur, do you love your father?”

“Yes.”

“Then why do you want to do this to him?”

“There are some things that we have no choice over.”

“You are giving me too much stress. My daughter wants me to hang up. It’s not good for my heart.”

“Then why did you pick up the phone this afternoon and get involved.”

“They gave me the phone.”

“I know that I don’t have the legal authority, but I won’t change my position,” I said. “I’m going to continue to argue my point.”
“Why did God make this happen? Your father was such a good man.”

“I never asked that question.”

“I don’t mean to question God. But I do with the Holocaust. My relatives were maybe more religious than you, but they were killed.”

“I’m religious to live a consistent life.”

“My daughter wants me to hang up. You’re causing me more stress than your father.”

I related to Rachel her question about why this happened to my father.

“Maybe it’s because he’s meant to go on to the next world,” Rachel said. “I hate myself for thinking these kind of things.”

“You hate yourself for thinking that he needs to die. It’s not your fault. All the time you hear things like that. The truth of the matter is, that we don’t need all that metaphysical speculation. Explanations may be true or false without making any difference whatsoever in the validity of our laws as the right ways of life. Metaphysics has no bearing on the rightness of actions and is ultimately meaningless.”

The next day, Rachel told me that Raphael’s nurse, Sue, agreed with us about Raphael, but not about my father. I heard that before. I had few allies in my opinion about my father.
There had to be other people that thought like me. During my lunch break on Friday, I did an Internet search on “Jewish living will.” One site said that life is infinite, not to be measured quantitatively. Therefore, even one minute of life cannot be said to have less value than many years of life. Another site quoted a story from the rabbi at Albert Einstein that I spoke with concerning Raphael when he was born. He wrote that he never understood the importance of the principle of prolonging life even for a short time, until one Friday afternoon when he visited an elderly woman whose son was fighting to keep her alive against the wishes of doctors. She said to the rabbi, “Good Sabbath.” It was that simple.

Water filled my eyes, not out of sadness, but the kind of tears that fill the eyes under intense emotion that accompanies something great and profound. All our good is objectified into the Sabbath. The Sabbath is the World to Come. We live for the Sabbath. That woman lived for her Sabbath.
That afternoon I visited my rabbi. I found in him in the almost empty study hall after most people went home in preparation for the Sabbath.

He posed the following scenario: “What if there was only one breathing machine and two people needed it, one like your father and another who was not as bad?”

“I don’t know.”

“It doesn’t seem that one has preference over the other.”

“Interesting.” We had no proof to the contrary.

I told him my definition of compassion. “Compassion is the affirmation of being. Pity is the sorrow one feels for the pain of a living thing.”

“Pity is feeling sorry for your self,” he said. “Compassion is feeling sorrow for the other.”

“But my father has said that he didn’t want to live under such circumstances. Everyone seems to agree that such a life isn’t good to maintain.”

“That’s because they’re looking at the activities of life, like skiing and traveling. They’re looking at the outcomes and what a person can accomplish. They’re not looking at life as something of value itself.”

I had to think it through. Is a life of twelve hours as worthy as another life with thirty years remaining? Sure twelve hours of reflection can be meaningful, but do we not expect one with only twelve hours to sacrifice them for another with thirty years, for an adult to sacrifice for a child, and not vice-versa? On the other hand, what if a solution to quantum-gravity or some other great service that enhanced, but did not necessarily lengthen human years, could be accomplished in those last twelve hours of life? Make an exception? If we are truly equal, one life cannot have legal preference over another, no
matter its social utility. One with lesser time may *forfeit* his life for the sake of another (perhaps the categorical imperative will not allow the opposite); but it is certain that we cannot forfeit our own lives when resources are available, for anything less than the sake of another life, certainly not for quality of life.

That Friday night, Raphael had to be taken to the hospital on the Sabbath. His nurse, Jill drove Rachel and Raphael. Rachel stayed with him until Sunday morning when we switched places. When I was driving to Jersey Shore Hospital on Sunday, I heard a commentary on MSNBC by Arthur Caplan, Ph.D. entitled, “Would you have allowed Bill Gates to be born? Advances in prenatal genetic testing pose tough questions.”

“Who needs Bill Gates? No, I don’t mean who needs a gazillionaire corporate titan, a man whose company, Microsoft, took in billions of dollars last year by controlling nearly all the software used to run nearly every computer on the planet.

No, I mean, literally, who needs him? If you could go back in time and stop the birth of the world’s most famous nerd, would you?

“You probably answered my question with a "no." Whatever Gates’ sins may be, he is the father of a computer revolution that has brought much good to many people throughout the world. Add to that achievement his current generous philanthropic activities supporting some very worthy causes, such as vaccine research and a center for autism research in Seattle, and the case for having Bill with us becomes pretty persuasive. (MSNBC is a Microsoft-NBC joint venture.)

“But what if I told you it’s possible that Gates has a medical condition that accounts, in part, for both his tremendous achievements and for his "nerdiness?"
Gates is widely reported to display many personality traits characteristic of a condition known as Asperger’s syndrome. Asperger’s is a mild version of autism, a more serious condition that renders many children unable to talk, be touched, communicate or socialize. While I certainly do not know if Gates has Asperger’s, his difficulties in social settings are nearly as legendary as his genius, so it's possible.

“That said, if you had been Gates' potential mom or dad 50 years ago, what would you have done if you knew about his abilities and flaws before he was born? Would you have wanted a child that would go on to do great things but would have a hyper-nerdy personality? What if the decision about whether to have a child like him also carried a risk that he might be born with far more serious disabilities? Would you have decided to carry the baby to term?

“The reason I ask these questions is that there is a good chance we will soon have a genetic test for detecting the risk of autism in an embryo or fetus. The development of such a screening tool raises the possibility that parents might one day have the option of preventing the birth of a child with even a mild case of the disorder.

“The thought is very upsetting to many in the autism community, including Apspies for Freedom, an advocacy group for people with Asperger's that is pushing to make June 18 "Autistic Pride Day." In their view, those with autism are no more suffering from a disease than are people who are short or have lighter or darker shades of skin. They want autism treated as merely a difference not a
disease. And they are aghast at the thought that anyone would abort a child because they might have any degree of autism.

“In the past decade, there has been an explosion in the number of U.S. children diagnosed with autism. Less well known is that there has been a parallel autism epidemic in other countries, such as Ireland and Britain. Whatever the reasons for the increase in the number of cases, it is highly likely that autism has a genetic component. Scientists and doctors have not yet nailed down what the genetic contribution to autism is, but the fact that males are far more likely to be affected than females and that autism appears in certain ethnic groups more than others are strong indicators.

“Like many genetic diseases, there is a broad range of severity associated with autism. And like some genetic diseases, such as sickle cell trait, there can be, in the right environment, an advantage to having a mild form.

“Asperger’s is the least disabling form of autism and research is beginning to show that it may also account for the presence of some special capabilities in areas like mathematics, computer science and engineering. But the same genes may also create a person who is socially awkward, easily distracted, very introspective and in many ways withdrawn and solitary.

“Gates was born on Oct. 28, 1955. When he arrived in the world the science of human genetics was truly in its infancy. Newborn babies were only tested for a few rare genetic conditions. Fifty years later, the field of human genetics is thriving. Tests have been established for detecting Tay-Sachs disease,
Huntington’s disease, some forms of breast cancer and Alzheimer’s disease, and hundreds of other fatal or disabling conditions.

“The drive for more genetic tests continues unabated. Undoubtedly the genes for autism and Asperger’s will soon be found. When they are, my question — would you have stopped Bill Gates from existing? — will take on a very real meaning.

“There are many in the autism and Asperger’s community, like the newly formed Auspies for Freedom, who worry that the minute a genetic test appears, it will spell the end for a lot of future geniuses, like Gates. Maybe there will be fewer Thomas Jeffersons or Lewis Carrolls — remarkable thinkers who also fit the profile for Asperger’s.

“As genetic testing moves into the world of mental health, we are going to face some very tough questions. Will medicine suggest that any and every variation from absolute normalcy is pathological? How can we draw lines between disabling diseases such as severe autism and more mild differences such as Asperger’s, which may give society some of its greatest achievers? Will parents have complete say over the kind of children they want to bear? And what sorts of messages will doctors and genetic counselors convey when talking about risks, probabilities and choices that involve not life and death but personality and sociability, genius and geekiness?

“All I can tell you is that neither medicine nor the general public are at all ready to deal with the emerging genetic knowledge about autism, Asperger’s or other aspects of mental health. But the future of our society may well hinge on how we answer these questions.”
“Society has no say in the matter,” I said to myself. “And what worth has the sum of all, if the worth of each to be measured by the utility to the whole?” Picking and choosing is only a concern in a society in which people have a limited number of children. The smaller family has weakened the family as an institution and our nation as a republic. It has diminished the virtue of self-renunciation and with it, the preference of public to private interest, which is necessary for love of country, the root principle of republican government.

Succos is rich in ritual. Besides eating and sleeping in the succah, on each day we would hold the biblical four species associated with the holiday, the lulav palm branch, the hadasim myrtle twigs, the aravos willow twigs, and the ethrog or citron fruit. At a point during the morning-prayer service, we walk around in a circle in harmony holding the four species. Year after year, when I taught my world history students about Confucius, I would point out the brotherhood felt on Succos as an illustration of social tranquility through ritual.

Raphael was released from the hospital on Monday, one of the intermediary days of Succos. We were so grateful that he came home, so that neither my wife nor I had to spend the two-day holiday at the end of Succos alone with him in the hospital, without any contact with the rest of the family. Simchas Torah is a most joyful festival for everyone and it would be unbearable for the family to be apart.

One of my friends in shul kept poking fun at the Astros during Simchas Torah celebrations, knowing that I was from Houston and they were losing three games to none in the World Series. Later in the day, we attended another synagogue, as the festivities of
each last well into the afternoon. As I left the second shul, I told one of my friends, Zalman, a very learned rabbi, a summary of what I thought about medical ethics.

“We’ve been reduced to the laws of property,” I pointed out.

“We’re property and property is human,” Rabbi Zalman said.

“What do you mean?”

“Animals are really property, right? But people claim that animals have rights.”

“The Torah also says that we can’t be cruel to animals,” I pointed out.

“But do they have rights?”

“I don’t think people really hold that animals have rights, although I’ve heard some people predict whether they’d pull the plug or not pull the plug on a human based on what they’ve done for their dog. There does seem to be confusion.”

This reminded me of an account of a famous demagogue, who nevertheless understood the patriotic duty of citizens in a republic to have many children, reacting to men cuddling pets as if they were their offspring. Plutarch relates that, “Caesar once, seeing some wealthy strangers at Rome, carrying up and down with them in their arms and bosoms puppy-dogs and monkeys, embracing and making much of them, took occasion not unnaturally to ask whether the women in their country were not used to bear children; by that prince-like reprimand gravely reflecting upon persons who spend and lavish upon brute beasts that affection and kindness which nature has implanted in us to bestowed upon those of our own kind.”
That year, I did not have to mourn on Simchas Torah after all, but not so in future years. Simchas Torah is now the Yar Zeit, or “time of year,” the day of remembrance for my father. When the holiday ended Wednesday night and we were able to talk on the telephone, my brother revealed to me that he moved my father the previous Sunday out of ICU and into a hospice. A nurse suctioned him every hour and when she came in at 3:00 AM on Wednesday, he was dead. I was told that he probably had a heart attack. The nurse said that he was fine the hour earlier, but it was impossible to know for certain since he did not have a heart monitor. I guess DNR really means to let them die.

I had just brought Poppy to his cardiologist, Dr. Adelstein, a week before his stroke. His group put in the heart stents after his heart attack two years earlier, and cared for him in Cardiac ICU after he suffered congestive heart failure the next day. Were they two heart attacks or one long one? Did the stents cause the second heart attack? Maybe it’s not wise to put in more stents now?

“Mr. Lang, the record indicates that we planned on putting in another stent two years ago. We never followed up on that.”

“Can I go to Texas for Rosh Hashanah and have it done when I return?” my father asked.

“Yes. There’s no rush. But we need to do it soon.”

“I won’t have a problem waiting two months?”

“No.” He was very blunt. “You can’t afford to have another heart attack. You won’t survive. This must be done.”

“What happened two years ago?” I asked.

“It seems that they should’ve kept you in the hospital longer.”
“How do you know it wasn’t the stent that caused his second heart attack?” I asked.

“It was not. Any other questions?”

“No.”

“You’ll be all right. I haven’t lost a patient on my watch.”

I am pretty sure he said something about the Coumadin, but I cannot remember what it was.

Eric told me that my father told the ambulance crew at his house in Austin, “I can’t have another heart attack. My doctor said I wouldn’t survive another heart attack.” They told Eric that it was not a heart attack. My father was unconscious shortly afterwards. Aunt Brenda, my mother’s sister, told me that when someone told Dr. Adelstein that my father died, he just looked at the ground and said, “I never lost a patient before.”

My wife made the arrangements for our flight to Houston for the funeral the next day, even though it was my responsibility as the bereaved.

“The funeral home said that we might have trouble with the grave-diggers under such short notice,” Eric told me.

“Isn’t it a Jewish cemetery? They know that the law is to bury right away. Tell them we are burying Daddy tomorrow.”

“Aunt Edna’s saying that she can’t get out so early in the morning.”

“I’ll go pick her up in New York. Or Rachel will go.”

“This is too much.” Rachel said to me. “Even this they must fit into their schedule.”
Rachel called a rabbi in Houston and asked him to call the funeral home. They realized our level of religious observance and agreed to have the burial the next day.

Hotel rooms in Houston just become vacant for Thursday since the Astros lost game four of the World Series on Wednesday night. My wife and I brought our three oldest children with us to Houston for the funeral. Poppy was buried the day after he passed away, Thursday, October 27.

While traveling back to New Jersey, I wore an overcoat to cover my ripped jacket and ripped shirt symbolic of bereavement. I usually wear leather shoes with wooden heels, but during shiva, I had to wear shoes made out of cloth. They had rubber soles with no heels.

“Should I put my coat onto the conveyer belt?” I asked the federal officer in charge of the scanner for carry-one baggage at the airport security check in Houston.

“Yes.” My ripped shirt and jacket was obvious but nobody seemed to notice.

“Please take off your shoes,” an expressionless, older, female officer requested to everyone in line.

“I have rubber soles,” I said to my wife. “You only have to take off dress shoes with wooden heels.”

“I don’t know,” Rachel said to me.

“You don’t have to take off tennis shoes.”

“Please take off your shoes,” the officer said again.

“These shoes have rubber soles.” I said to her. She did not object to my answer and I proceeded through the metal detector.

“Please step aside,” she said to me.
“Did it beep?” I asked her. “I’m a mourner. That’s why my clothing is ripped. Can I get my coat to cover myself?”

“Just stand right there,” she said to me. “I need a male officer,” she shouted to another guard.

“Why are you detaining me?”

“You did not take off your shoes.”

“Here, I’ll take them off now.”

“No, I need to test them for explosives.”

“But they have rubber soles!”

My wife, three children, and two aunts who traveled with us also did not notice. A male officer quickly came and rubbed some liquid on my shoes as if he was merely going through the motions. He did not seem concerned about finding anything on me.

“You can go,” he said. I think he felt foolish.

“Did he say you can go?” the female officer asked.

“Yes,” I said. “You know, you didn’t let me get my belongings. I’ve heard of people getting their wallets stolen during the security check.”

“You had your family with you to retrieve your belongings.”

Rachel was saying the morning prayers at the airport when Mary, Raphael’s night nurse, called us on our cellular phone. The police, emergency medical technicians, and our community’s voluntary ambulance service were all at our house in New Jersey.

“Are you sure he has to go to the hospital?” Rachel asked Sue, who just arrived for her shift. She was supposed to relieve Mary an hour earlier.

“The police aren’t letting me in,” Sue said. “I told them that I’m the nurse.”
“The EMT wants to talk to you.”

“He is in respiratory distress,” the ambulance man said.

“Let his nurse listen to him, she’ll recognize his breathes,” Rachel said.

“Why did they call an ambulance?” I asked Rachel after she hung up. “Are they just overreacting?”

“Like the other time a nurse panicked.”

“Well if Sue says he has to go, don’t you trust her?” I asked.

“She also panicked the time she had to bag him. She gave him CPR. Raphael just does those things.”

“But he’s been dry for a long time. He probably had a cold or something for a couple weeks now.”

“They just released him from the hospital and he had nothing in his blood.”

The airplane was packed. Although I sat next to my wife, my two aunts, my mother’s sister and father’s sister, and children did not sit together with us.

We called Sue again before the plane took off. She said that an ambulance was driving them to Jersey Shore Hospital. We were convinced that something was wrong.

“Your father’s stirring things up in heaven,” Rachel said to me.

“What do you mean?”

“You know he could never deal with Raphael,” she said. “He entered his room and cried when he visited.”

“Do you think he is dying?”

“Yes.”

“He will get over it.”
“What if they have to intubate him?”

“He has a trach. It’s not like they have to put in an ET tube. The ventilator just snaps onto the trach.”

“But what if he goes on the vent and can’t come off? What are you going to tell them?”

“I’ll tell them to put him on. He’ll come off.”

The plane flew along the Gulf Coast taking advantage of an unusually strong headwind, instead of flying more toward northeast, making excellent time. I never flew along that route. Looking out the window from my aisle seat, I saw what I recognized as Lake Ponchartrain, recalling driving over it more than once. I saw the Mississippi River. It was an amazing view, to see the Louisiana swampland and the Intracoastal Waterway from miles up in the air. If only I could get the kids to look. I could not see New Orleans, or at least any buildings. Rachel said that a woman was crying as we flew over the area.

I made an “Airphone” call to Sue, who was by then in the emergency room with Raphael.

“They’re going to release him,” Sue said.

“Tell her to make sure to do a complete blood count,” Rachel said to me. “I want to know if his white count went up.”

“Did they take blood?”

“No. They said they don’t need to.”

“I want a complete blood count. Don’t leave until they take his blood.”

“Okay.”
“That will tell us if his infection is spreading,” I said. “I can’t talk. This call is eight dollars for the first minute and four dollars every minute after that.”

Towards the end of the flight, I noticed the USA Today that the passenger seated in front of me was reading. It had an advertisement to subscribe to the newspaper, picturing a past issue that had two headlines in juxtaposition to each other. On the right side was an article entitled, “Justices to weigh assisted suicide,” as if the Supreme Court was to rule on that particular issue, and not on a general principle, such as federalism or interstate commerce, or the intent of Congress in passing legislation. In the center of the front page, taking up even more space, was a picture of a woman cuddling a dog under a large caption, “Trapped New Orleans pets still being rescued.”
I was disappointed with the scholarship shown by the dissent in Gonzales v Oregon. The majority was correct when it said, “Congress regulates medical practice insofar as it bars doctors from using their prescription-writing powers as a means to engage in illicit drug dealing and trafficking as conventionally understood. Beyond this, the [Controlled Substance] Act manifests no intent to regulate the practice of medicine generally, which is understandable given federalism’s structure and limitations. The CSA’s structure and operation presume and rely upon a functioning medical profession regulated under the States’ police powers.”

The opinion in this case is important because it demonstrates that the dissection of words should not be a substitute for the history behind those words. The personal opinions of the justices should have no influence over how the case is decided. The States have long regulated the prescription of pharmaceuticals. If and when Congress intends to limit the States from allowing the use of drugs for doctor assisted suicide, and to “regulate medical practice in the given scheme, it does so by explicit statutory language,”
in which case, we certainly will have a public debate, and a political decision of all
Americans, not just nine.

Doctor assisted suicide is a political issue that we cannot allow individuals on the
Court to decide for posterity by some subjective reading, such as “legitimate medical
use.” In the extreme case of word dissection, the Fifth Amendment protection against
being “deprived of life, liberty and property, without due process of the law,” was read by
the Court to destroy forty years of compromise that held this nation together by men such
as Clay and Webster. The Court held that Congress could not prohibit slavery in federal
territories, because it cannot deprive a person of the substantive use of his property. For
that matter, if not for the Thirteenth Amendment, the due process clause of the Fourteenth
Amendment, having almost the same wording as in the Fifth Amendment, could be
dissected outside of its historical context to impose slavery in the States, alike in north
and south! The Court could have easily done the opposite, and interpreted the word
liberty in the due process clause of the Fifth Amendment in favor of the substantive
liberty of the slave.

The truth is that the due process clause of the Fifth Amendment has nothing to do
with slavery. Just as the Third and Fourth amendments have nothing to do with
contraceptives and the Controlled Substance Act has nothing to do with euthanasia.
Laws usually do not need much interpretation. Their meanings are clear. The myth that
the Supreme Court must interpret the meaning of laws has made it acceptable for justices
to play with the language. It is not the place of the Court to decide the great issues of the
day, but for the messy, slow, uneven, institutional forces, and compromises and not so
perfect justice, that we call American democracy. If the people as a whole are determined
to resolve an issue, then let Congress use its interstate commerce power to do so. In the process, the arguments on all sides will be heard until the issue meets its natural conclusion in the national legislature, or remains where it was before, and most likely belongs, within the States to decide.

That is not to say that the Court may never decide a new issue. The institution of gender equality is an example of taking a historic achievement, equality before the law, and applying it to group that might not have been deemed worthy of its protection in the past. The extension of equality to women is not a new interpretation, but the same law consistently applied to another class. Is that not the role of judges? Are they not to appropriate the existing law logically to each of whom is governed, irrespective of the opinions of those who govern? By contrast, the judicial creation of a right for child labor and a right for abortion, is not the non-contradictory application of the same principle, or even its logical conclusion, such as Marshall derived for interstate commerce, corporations and federal sovereignty, but a whole new meaning to the law, the consequence of substituting the interpretation of words for history.
Rachel called Sue again at the hospital immediately after we arrived home. The doctors still did not do a blood test. Rachel pled with the nurses in the emergency room over the phone explaining that his blood count was already elevated when he left the hospital on Tuesday, and that a higher number is an indicator of an infection. Sue later told Rachel that when she came into the emergency room, the doctor said, “Oh, you’re with Mrs. Lang. She always likes to check into the hospital.”

Rachel was on her way to the emergency room to pick up Sue and Raphael when a nurse called the house.

“The doctor could not reach your wife on her cell phone. Would you like the doctor’s phone number so you can give it to your wife?”

“Let me talk to the doctor.”

“Mr. Lang, this is Dr. Goldstein. You remember me?”

“I think so. Why can’t you just take his blood?”

“It’s not necessary.”

“Why are you doing this to us?”
“We’re not doing anything to you. Taking blood is a procedure. It’s not medically called for.”

“But we need to know if his infection’s getting worse.”

“He’s fine. He’s already on an antibiotic. No matter what the results, there will be no change in his treatment.”

“Just do it. I’ll pay for it. It’s just a simple blood test.”

“It’s not so simple. Taking blood causes pain. There is no reason to subject him to pain if it doesn’t change his treatment.”

“What are you subjecting us to?” I shouted. “I’m sitting shiva. We just got back from my father’s funeral and our nurses freaked out by rushing him to the emergency room. Now you’re releasing him without doing anything? You’re just making us have to take him back to another emergency room when he gets home. I want you to do it!”

“I take full responsibility. I made a decision not to do it.”

“So, do it now!”

“Alright.”

When they came home, Rachel told me that the CBC showed 55,000, the highest he has ever had. The doctor gave her a prescription for a new antibiotic.

“He can’t stay home,” Rachel said.

“He’s got to be admitted,” Sue said.

“I’m not taking him back to Jersey Shore,” Rachel said. “We’ll go to Monmouth Medical Center.”

“Do you think they’ll put him on an IV?” I asked.

“With a white count like that, they have to put him on,” Sue said.
“Another Sabbath that you’ll have to spend in the hospital,” I said to Rachel.

“You won’t have time to make it there before it gets dark. Is there a rush now?”

“No, we can take him later,” Sue said.

It is hard when a family is separate for the Sabbath. Normally, the family gathers for three formal meals together. There are no telephones, no cars, no radio and no computers on the Sabbath, just family time together.

Raphael was admitted into the Pediatric Intensive Care Unit. I spoke to Rachel after the Sabbath.

“He’s swollen everywhere. They think it’s serious.”

“He’ll get better. Are they saying how long he’ll have to stay?”

“Why do you keep asking that? I’m sick of that question. They don’t know yet.”

“Are they like the NICU doctors?”

“It’s totally different than Jersey Shore. The doctor in PICU told me that there’s a special needs doctor that can take charge of all his care. He said that every time we come, he would just check us in. Do you know what that would be like, not to go through six hours in the emergency room before being admitted?”

“Yea.” The only time I brought Raphael to the hospital and sat in the emergency room was when Rachel was not home. I went with Sue. When Rachel found out, she said he did not have to go, and sure enough, he was released the next day.

“It’s important to have only one doctor in charge of everything. When you think about it, they were disgusting at the other hospital.”

“And we kept on using them.”

“Like your father and his cardiologists. Why didn’t we switch.”
“The hospital was so close. PICU was not as bad as NICU.”

“What about Dr. Thomas?”

“The one in NICU?” I asked.

“No, her husband in PICU.”

Raphael was admitted to PICU every time he went to the hospital. However, Dr. Thomas forced Raphael out of PICU into a regular pediatric ward the first time he got sick. Fortunately, Raphael was then assigned a day nurse with few patients. Still, one of us stayed with him almost all the time, especially during the night. There was not much that the nurse could do that we could not.

“Dr. Thomas was upstairs in PICU on Friday. He probably told Dr. Goldstein not to admit him,” Rachel said.

“You don’t know that. And Dr. Dodzie is in Jersey Shore.” Dr. Dodzie is a older, kind-hearted pulmonologist from Ghana who often is the PICU attendee.

“He’s out of the country right now.”

Rachel came home shortly after our conversation to visit the kids and to shower.

“Same thing with every new hospital,” she said to me in the foyer. “The doctor asked me if they should resuscitate him if he stops breathing.”

“I hope you said yes.”

“They said we might have to make decisions. He will never go to college. He will never drive.”

“We’ve heard that before.”

“But they’re not being nasty about it. They asked it in a nice way. I told them that we’re happy with the way he is when he’s well, and they stopped bothering me.”
“How long will he have to stay?”

She rolled her eyes. “The doctor said that his goal today was just to stabilize him.”

“Is the same doctor going to be there next week or we will have to start over with a new doctor?”

“He’ll be there just until tomorrow.”

“And as soon as the next doctor comes, he’ll say he can go home,” I said facetiously.

“You hit the nail on the head.”

Several people came to make a shiva-call after Rachel left that Saturday night and on Sunday. I sat on a low stool in the living room as a mourner sits. Many who visited had stories to tell about their own experiences with doctors.

“Doctors don’t aggressively treat a patient when they get a DNR order,” Rabbi Yaffe, the rabbi of the local hospital and the Old Shul said. “In New Jersey, the procedure for making decisions involves the doctors, the family and a clergy member. I once had about fifteen minutes between two meetings with families. As we were waiting in the hospital corridor, a neurologist told me that eight people would still be alive if not for him. He convinced reluctant families to pull the plug. They would’ve been vegetables, he said, but still alive.”

“They’re supposed to allow informed consent,” I said. “How can it be called consent if they pressure you?”

“Another time I was sitting with a man in a wheelchair next to his wife. The man shook my hand and squeezed tighter and tighter as his doctor told his wife to let him die.”
“I don’t know what is happening with that profession,” I said.

“One doctor I was surprised to see a doctor in shul on the Sabbath told me that he took no calls on the Sabbath. I asked him how he could abandon his patients. He told me that he ‘asked a question’ and a rabbi told him that it’s okay. It was the only way to do justice to his family and to have a normal Sabbath.”

“So he was wrong?”

“I told him that you made a decision to be a doctor. When he chose his profession, he accepted certain responsibilities. What if there’s an emergency. You can’t just say that you won’t help your patients at any time.”

“They don’t make doctors like they used to.” With that, he offered his condolences and left.

He was right. The pediatrician spoke on the phone on the Sabbath to direct medicines for Raphael. How could he not? Substitute doctors on call are not capable of making the same informed decisions.

The principal of the K-8 school that my boys attend told me about his father who had a hemorrhage stroke. “The neurologist said that he could recover.”

“So what happened?”

“He was a diabetic. The kidney doctor was reluctant to move forward. He kept on asking, ‘Are you sure you want to go through with this?’ In the end, his kidneys failed.”

“They’re too quick to pull the plug,” I said.

“I’m not so sure that you should always be so aggressive. My mother-in-law had bad blood circulation. The doctors said that she’d have better blood flow to her brain if you amputate her legs. My wife’s family wanted to do everything possible, even though
she had no chance of recovery. She lived only for a few more days after they cut off her legs.”

“Did you disagree with your in-laws?”

“I stayed out. They didn’t know it, but I spoke with someone.” He mentioned the name of an authority in whose school he once studied. “We felt that it was wrong in this case.”

“These things are very difficult.”

“The rabbi said that every case is different.”

“Generally, I think most authorities are more aggressive.”

“I know. The family also asked an authority who agreed with them. There are those with famous opinions one way or the other on the matter. People know who to go to.”

“I think that as individuals, we need to have clarity on this subject. Why should it be different than any other mitzvah that we learn about? It’s like a discourse in the Talmud. We don’t just close the book and ‘ask a question.’ We have to think through the problems, understand the different opinions, and try to see the truth as best as possible.”

“To me, it was a shame to do that to her. The family wanted to be able to say that they did all that was possible.”

“You can’t just do something not to feel guilty. You have to do what makes sense.”

“I stayed out.”

Sunday night, I spoke to the doctor taking care of Raphael at Monmouth hospital.
Before Rachel came home from Monmouth hospital Sunday night for a short break, I spoke with the PICU doctor. He actually encouraged us to use their hospital.

“Are you behind on his infection?”

“No. I think we have it under control. But I’m a little concerned about his urine output.”

“Maybe that’s because his fluids are messed up. Every time they start an IV, the amount of fluids change and his electrolytes get out of balance.”

He assured Rachel that Raphael was not in renal failure after she came home and called him, even though she spoke with him in person earlier. He called back fifteen minutes later to tell her that he was in renal failure. He suggested transferring Raphael to one of two hospitals that were capable of pediatric dialysis.

We went to the hospital together. I wore my ripped shirt and jacket as was customary for mourners sitting shiva.

Raphael was bloated. He was so puffed up that he looked like a balloon in a parade.

“Why do you think we should move him?” I asked the doctor.

“I think it’s better to have a machine ready in case he needs dialysis. We’re not capable of it here. I’m not saying that he’ll need it, but it’s better to have it ready.”

“If he needs it, will he always need it?” I could not imagine taking him for dialysis for the rest of his life.

“No. It’ll only be temporary. Just now we need to get some of the fluids out of him.”
“We want him to go to Children’s Hospital of Philadelphia.” CHOP was an easy choice. It was nationally recognized as a good hospital.

“Okay. I’ll call for transportation.”

I found a box to sit upon next to Raphael’s bed. I explained that I was sitting shiva. My appearance must have been unusual; usually one does not leave his or her house during shiva.

“We have to inform the police and fire department that a helicopter is coming,” the nurse said.

“Why are they sending a helicopter?” I was quite surprised because I thought he was being moved only as a precaution.

“I don’t know.”

“I wonder why they’re not taking him in an ambulance,” I said to Rachel. “I guess they had a helicopter available.”

The emergency crew from CHOP immediately took over care of Raphael after they arrived. I felt bad for the lone nurse caring for him, for she got the third degree from them. The professionalism or perhaps the arrogance of the CHOP team, was very pronounced and their questions were very blunt.

The flight nurse gave Raphael something to paralyze his breathing and immediately started pumping oxygen into him using the Ambubag. She bagged him for an hour before they left. The Monmouth nurse, who was very nice, answered their tough questions the whole time.

I told the flight crew that my wife and I would drive to the hospital and meet Raphael there.
When we arrived on the seventh floor PICU in Children’s’ Hospital of Philadelphia, we saw at least five people in Raphael’s room. They were still bagging him as flight crew bagged him during the whole flight.

“I’m Dr. Meany,” a serious looking young doctor said to us. “Your son’s very sick. He’s in septic shock.”

“What do you want us to do if—”

“I want you to do everything you can,” I said.

“I understand.”

The doctors kept putting dopamine into him to bring up his blood pressure. It reminded me of a rough Sabbath night two years earlier when my father was in the Cardiac Intensive Care Unit at Jersey Shore. I saw a lot of activity in my father’s room through a window where I was sleeping in the hospital, as I was not allowed to sleep in his room. A nurse came to awaken me and tell me that he was in trouble. They let me into the ICU where I watched his heart rate, which I knew was normally low, drop to an
extremely low rate. The doctors used dopamine in a heroic effort to bring it up. After they got his heart rate back up, he still needed a few more days to stabilize.

Raphael’s blood pressure was still going down. The dopamine was not working.

“The infection causes the blood vessels to swell and become leaky,” Dr. Meany said. “Since they are leaking, his pressure is dropping. He’s not getting adequate oxygen to his organs and that causes failure.”

“Will dialysis help?”

“Dialysis can get rid of some of the fluid but right now we need to raise his blood pressure to get his organs working to keep him alive.”

They kept on bagging, pumping breaths of oxygen into him, yet his blood saturation did not go up. The amounts of oxygen in his blood went lower and lower, and his blood pressure kept on dropping.

I asked a nurse to bring a box for me to sit on.

“He’s dying,” Rachel said to me.

“I know.”

“I can’t look.” She put her head down.

“You know he’s dying,” Dr. Meany said to me. “Would you like me to call a rabbi?”

“No. Just don’t give up.”

I asked a nurse to escort Rachel out of the room.

A cardiologist did a sonogram and found that his heart was surrounded with fluid.

“We have to try to drain some fluid out of his right lung to help him get oxygen. We can’t drain the fluid away from his heart.”
“Why isn’t the dopamine working?” I asked Dr. Meany.

“He’s anaerobic, like when you lift weights. Lactic acid is building up in his tissue since he is not getting blood flow. The medicines cannot work with the acid. We put sodium bicarbonate into his blood to help neutralize the acid.”

“You mean baking soda?”

“Yes.” It was not working.

I saw someone stick a needle into his side and pull out quite a bit of fluid. The doctor pumped furiously on the Ambubag.

“I want to try to get some of the carbon dioxide out of him.”

Raphael was not responding. I kept my eyes on the monitor. His blood saturation was in the low forties and his blood pressure was all but gone.

Then, all of a sudden, while looking at the monitor, I saw his blood pressure shoot up. His catheter filled with 90 cubic centimeters of urine. He made a bowel movement. His blood saturation went back up.

“What happened?”

“I don’t know,” Dr. Meany said. “Maybe it was a combination of draining his lungs, the dopamine, and the bagging.”

I went into the waiting room where Rachel was sitting and told her, “He came back.”

She just looked at me and said nothing. I went back out

A surgeon came into PICU and felt Raphael’s abdomen.

“Right now his intestines seem okay. They are hard, but that is to be expected during an infection. There’s no perforation and no need for surgery now.”
“His kidneys must be working if he urinated that much,” I said to Dr. Meany.

He agreed. Around 6:00 AM, I told Rachel that I had to leave. I had a duty to my father’s memory to lead prayers and to say the Kaddish. People were expected at the house at 8:00 Monday morning for me to lead the prayers, since one sitting shiva is not supposed to go out, even to go to synagogue. Rachel stayed at CHOP with Raphael.

“What if we had to do dialysis? Maybe it was the time that the rabbi told you that we might have to let him go,” she said when I called her later that morning.

“Maybe, but the dialysis would have been temporary.”

“And what if we have to shock him?”

“You should. Why are you asking?”

“They almost did the paddles last night.”

“When?”

“After you left.”

“Don’t make any decisions not to do something without calling me.”

Dr. Meany stayed with Raphael until 11:00 Monday morning even though he was supposed to end his shift five hours earlier at 6:00.

I spoke with the new doctor over the phone. “We put Raphael onto an oscillator. It’s a kind of ventilator that will help get the carbon dioxide out of him.”

“Last night was a miracle,” he said

“We weren’t even expecting a helicopter last night. Nobody had any idea of how sick he was,” I said. “How is he now?”

“It will take a slow steady effort. His intestines are little worse but his lungs are better. His blood pressure is good.”
“How’s my wife?”

“I’m keeping her informed, but she’s having a hard time.”

I finished sitting shiva Wednesday morning. I did not go to school on Wednesday, but went to Philadelphia to relieve my wife, bringing piles of quiz and test papers to grade. I was out for a long time between shiva and the four non-working days of the holiday. Anticipating my absence, I left a lot of work for the substitute. I returned to teaching on Thursday and came back to the hospital for the Sabbath and Sunday.

Raphael’s blood pressure again began to drop on Saturday night. This time the doctors seemed more relaxed in their efforts. They apparently did not think he was slipping. He had lost so much fluid into his tissue that they had to give him about 300 cubic centimeters of saline to bring his pressure up.

I noticed a red stiffness around his collarbone, the same discoloration that I noticed one month earlier at the onset of his sickness. When we first noticed the color, we though that possibly we pulled his arms out of joint by lifting him improperly. Then, his arms were limp for about a week. Eventually movement returned to his arms, but seeing the redness again concerned me.

The PICU doctor said he would keep an eye on it. I concluded that it probably was a bruise from the needle that drained the fluid from his lungs. Concerning the fluid behind his heart, the pulmonologist told me that we would have to wait for it to drain by itself. If it were to cause his heart to fail, then he would need surgery.
Rachel took over during the next week. For the next few weeks, she slept in the baby’s room in the hospital, coming home one night a week, while I relieved her for the weekends.

“My sister said that we’re wrong for spending so much time in the hospital,” Rachel said to me. “I don’t know if it’s right. What about our family?”

“There’s always one of us home,” I said. “We’re making him into a person with all the attention. He developed a personality because of all the interaction.”

“Still, maybe we should be home more often,” she said. “Tzivia’s niece volunteered to stay with him. There are also other girls that asked if they can stay with him for the night.”

It is customary that someone, either an immediate relative or someone else from our community, to continuously accompany a patient in the hospital. It is considered a big mitzvah.

The next weekend Rachel rebuked me for not following his blood count.

“What are you doing there if you’re not monitoring him? I could have had some of the girls stay with him.”

“I am watching him. I just forgot to ask.”

Dr. Huh, the attendee, came to examine Raphael. I called Rachel for her to speak with him. I did not want to forget to ask something.

“Oh, he was on Lasix?” I heard Dr. Huh ask her. We used Lasix on Raphael before he got sick to help keep his lungs clear and free from excess fluid. Even though we gave the doctors his medical charts and reviewed them with every new doctor, they did not follow his routine.
“But I don’t know if we can give Lasix while he is on the vasopressin. Do you want to speak to your husband?”

“Typical,” she said to me. “They just don’t listen.”

“Well why don’t they just give him the Diuril that he’s been on for the last sixteen months?”

“Why should they? What does his mother know?”

After I hung up, I saw the endocrinologist, a foreign-born young woman, standing by the door. Her team started Raphael on the vasopressin, the same drug that the endocrinologists in NICU insisted on avoiding. That kept Raphael from going home for so long when he was first born until the endocrinologists discovered that Diuril worked. Now, a year later, we were fighting in CHOP to take him off the vasopressin that CHOP put him on.

“The doctor said that giving him Lasix for his lungs might be a problem with the vasopressin.”

“We have no problem with Lasix,” she said.

I ran into the corridor to get Doctor Huh who was standing outside, two rooms away, making rounds on another patient.

“Doctor. The endocrinologist is here.”

“I’ll touch base with him after his rounds,” the endocrinologist said to me. Dr. Huh nodded in agreement.

“Are we going to be able to bring him home on the vasopressin?”

“Yes. We have him at a set level. You won’t have to keep on adjusting the dosage.”
“Why can’t you just give him Diuril as we did for the last sixteen months?”

“Diuril is not indicated for Central Diabetes Insipidus. It is for Neophrenic DI.”

“But it worked. How do you explain that?”

“Either he never had it or it just got worse because of the infection.”

“Right when he came into the hospital?” I asked. “He didn’t stop getting the Diuril until he came here and only now his sodium output went up.”

“It’s often that a child develops DI, or it get more difficult to manage, after a bad infection,” she said. “We want him to retain fluids. He is peeing too much and that’s elevating his sodium.”

“He always had DI. He didn’t go home from NICU for weeks because of it. I know that it’s counterintuitive, but I was told that other hormones compensate when you give diuretics. Isn’t there any logic to that?”

“I don’t know. The vasopressin help him retain fluids and that will lower his sodium level.”

“But we want to get rid of fluids,” I said. “I don’t want him to retain fluids. His lungs are hazy. His lungs always become hazy when he retains fluids.”

“The vasopressin holds fluids in the vascular system. The lungs are another issue. You can still give him the Lasix.”

“Look at his face. It’s all puffed up. His whole body has too much fluid, not just his lungs. I still say, what’s the sense of giving Lasix to expel fluid while giving vasopressin to retain them?”

“They work on different areas of the kidney. When someone has central DI, he leaves electrolytes in his blood while ridding a diluted fluid. The Lasix will help take out
the water with the sodium while the vasopressin will prevent excess free water from leaving.

“Okay, but why was NICU so against using vasopressin. I was fighting them for days to use it and they refused. I fought with them about many things, but this was a medical issue. They seemed adamant that you can’t use vasopressin on newborns because they don’t have a developed thirst mechanism.”

‘That’s correct. We also don’t like using them on neonates. We’d rather give them free water to regulate their electrolytes,” she said.

“He’s at no less risk than a newborn with the same thirst problem. You don’t know when he’s had enough fluid because he’s g-tube fed.”

“But we tried the free water and it didn’t help.”

“NICU also tried it. What changed? You didn’t try the Diuril.”

“I spoke with an older endocrinologist and he did mention that years ago, some treated central DI with diuretics.’

“Did you tell him about Raphael? Did you tell him that he was on them for so long? What would he say in his case?”

“He’s on his case and disagrees with using Diuril.”

“You know, this reminds me of a book I read about scientific paradigms.26 As long as meaningful work can be done, we might not conceive of things that do not fit in our experimental framework. But what if something makes sense under a different way of thinking?”

“Raphael doesn’t fit into any paradigm. He’s got his own rules.”

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26 Kuhn, T. The structure of scientific revolutions,
I attended synagogue services regularly in the Hillel Jewish Center at the University of Pennsylvania while Raphael was in CHOP, which was a short walk from the hospital. I was still well within the year of my father’s passing and had to say the Kaddish prayer in his honor. However, the college students at Penn went home for Thanksgiving and there were no other services within walking distance on the Sabbath. My problem was solved when I found another synagogue to drive to on Thursday, Friday and Sunday, and when we remembered that a young-lady from our community volunteered to stay with Raphael on the Sabbath. I was able to stay home with my family for the first time in five weeks.

About twenty minutes before the Sabbath started, Reemah, a doctor in PICU, called to tell us that she was beginning new antibiotics intravenously. I quickly concluded the phone call telling her to call and speak into the answering machine on the Sabbath. If there an important decision had to be made, she should ask us to pick up the phone. I was in such a hurry that I did not realize the significance of why she called. He needed a new
antibiotic. She was going to start new line instead of putting the medicine through his g-tube. It often took nurses several attempts to get a line into him.

When I returned home from services on Friday night, I heard my wife talking on the telephone behind a closed door. Reemah had called to tell us that she was putting Raphael back on the respirator. The whole day his blood saturation was poor and the attending doctor felt that he needed the extra support.

“She called before and I didn’t reach the phone on time,” Rachel said to me after she hung up. “I didn’t know what to do, but she called back. Did I do anything wrong?”

“Of course not.”

“But we should be there in the hospital.”

“We can’t have any time home together as a family?”

I enjoyed the Sabbath together with my family. After the Sabbath, I returned to the hospital Saturday night.

“So you’re going to stop the vasopressin,” I said to Dr. Huh Sunday morning. They finally realized that it did not work. Actually, the doctors stopped the vasopressin the previous day.

“It seems that his lungs are just staying wet, like when he first came in here,” he said. “His x-rays don’t seem to improve. When we began with the Lasix, he started breathing better, but he still has the fluid.”

“He’s been on Diuril his whole life and Lasix for most of it.”

“He is responding really good to the diuretics,” he said.

“So you’re going to start him on the Diuril?”

“Maybe tomorrow.”
“That’s exactly what Dr. Seefer realized sixteen months ago. He put him on the diuretic to keep the fluid out of his lungs,” Rachel told me over the phone. “They’re just not listening. He was doing fine last week. Then, when his sodium went up, they gave him the vasopressin. Then he started having the lung problems.”

“You mean that he does not need all those antibiotics?”

“Did any of his cultures come back positive?”

“I’ll check. Hold on.”

I was ashamed that I did not know the answer to her question. I went outside to ask his nurse. She had to check into the computer. All cultures were either negative or pending.

“Why does he have to be on all those antibiotics?” I asked the nurse.

“The doctors want him on them for forty-eight hours,” she said. “And his intravenous line stopped. I have to call the IV nurse to see why.”

“Why don’t you just stop the antibiotics instead of opening up a new line?”

“We have to see if there’s a kink.”

“So then you’re going to go into another vein,” I asked the nurse.

“No one wants to do that.”

An hour later, the endocrinologist came in.

“Are you going to tell me that I told you so,” she said with a smile.

“So you consent to the Diuril?”

“No. But I stopped the vasopressin.”

“He needs the Lasix for his lungs,” I insisted.

“I originally said that you can use the Lasix on top of the vasopressin,” she said.
“But if he did so well on all his medicines at home, why can’t we just give them?”

“That’s for the ICU doctors to decide. And if they think he needs the diuretics for his lungs, then they will prescribe them.”

I called Rachel back.

“His sodium is fine now, but if it goes up, the endocrinologist will start the vasopressin again. They’re still not listening,” I said. “But the attendee said he’ll start him on his regular medicines.”

“Make sure they get the right dosages. He’s gained weight since we set them. He got two doses of Lasix a day last time he was in the hospital. He was lowered to one when he came home.”

“Should I call the resident?”

“I’m sick of all the residents. You speak to the attendee and make sure that they put everything into his charts,” Rachel said. “Since the Lasix and Diuril made him lose fluid we gave him extra potassium and Polycitra-k. I don’t know if he’ll need the potassium, but he’ll need the Polycitra-k.”

I explained to the pulmonologists my suspicion that the vasopressin caused the beginning of his lung problems and that the diuretics alleviated them. We reviewed the daily lung x-rays and correlated them with the changes in his medications. We found that on November 20, his lungs looked best, yet we read that he began the vasopressin on the November 17. This indicated that the vasopressin did not necessarily cause the problem.

“They did not begin regular dosages of vasopressin until the twentieth,” Rachel said to me. “They only gave him one shot on the seventeenth. It is the vasopressin.”

“At least they agree that the Lasix is working.”
“Remember when he had pneumonia last year, they began giving him two doses each day.”

“They are afraid of drying him up now with too much Lasix and Diuril,” I said.

“They want to hold off on the Diuril until he’s ready to go home for long term care.”

“No, I want them to start it now. I want to see how his sodium does while on it. I don’t want to have to start figuring it out on the day we are ready to leave.”

“I’ll speak to Dr. Huh,” I said.

“I want a conference with all the doctors. They’re all in different books. I want to sit down with them all together.”

Later that Sunday, at 2:00, on the same floor in CHOP, there was a traditional celebration of inaugurating a new Torah scroll. A seventeen year old, who had been hospitalized for some time on the other side of PICU, requested that a Torah scroll be written for him. Rabbis from our New Jersey community and from Philadelphia, together with about fifty people, accompanied the Torah to the boy’s hospital room. Men danced under the canopy singing as the gravely ill young man was wheeled out.

Two weeks earlier, his mother said to me, “We are very lucky to have the Torah. Every question is in there. We just have to look inside. It’s the key to life.” It is true.

For a year, she did not leave her son’s side. Other family members took turns accompanying her with him. During the young man’s last week alive, he was in and out of a painful consciousness. Still, there was never a DNR and no withdrawal of treatment.

Raphael was moved out of PICU into a progressive care unit on Wednesday.
“Now his sodium is way up,” Rachel said when I called her from home. “They gave him the Diuril, but twice his normal dosage.”

“We are going in circles,” I said.

“I don’t know what I’m supposed to be doing. Should I always be here? They’re not listening to me anyway.”

“You’re doing the right thing. All the love is what makes him into something. The NICU doctors said he was just a nothing, but now he’s someone.”

“But, what about our family?”

“So then come home. Should I also stay home for the Sabbath?”

“Tzvia’s niece cannot stay with him for the Sabbath. Her friend asked if she could stay with him.”

We spent the Sabbath together again. When I returned to CHIP on Sunday, December 4, I spoke with Dr. Stanley from endocrinology.

“So you’re the older doctor?”

“Older?” He laughed.

“I mean most experienced. I think older doctors are better.”

“Who’s the baby’s doctor?” He asked.

“Mrs. Lang,” I said.

“Your wife’s a doctor?”

“No, but she knows more than any of the doctors. Our pediatrician is very good but he just says, ‘Mrs. Lang, what medicine should we give him?’”

“How does your wife know what medicine to give him if she is not a doctor?”
“She knows what works. This baby was on Diuril for sixteen months until he came here, without any problems. He came here and was taken off it. Low and behold, he needs vasopressin and fluids. Why can’t you guys just listen to her?”

“Years ago we used diuretics for Central DI. The idea has fallen out of favor. We usually try to control DI with fluid management if we can’t use the vasopressin. But we’ll put him back on his Diuril next week.”

“Thank you. And please—put him on his normal dose. You tried Diuril last week, but tripled his dose,” I said. “And we have a complaint. There are different doctors every day. Why can’t you just appoint one to be in charge and we’ll talk to him for his medicines?”

“We can do that.” It will never happen.

“Is it endocrinology that is holding us back from leaving?”

“No, the pulmonologists are not ready to let him go.”

“But they haven’t been in here since Wednesday,” I said.

“We want to do a study to make sure his thyroid is working properly,” he said.

On December 7, while Rachel was with Raphael in CHOP, and I was driving to a teachers’ professional development workshop, I heard the following commentary on National Public Radio by Ben Mattlin, a writer in Los Angeles:

“A few years ago a friend of mine died unexpectedly at thirty-nine. We both used motorized wheelchairs and needed assistance with tasks such as washing, dressing and eating, but his disability came from a motorcycle accident fourteen years earlier. Mine is from birth, the result of a congenital neuromuscular condition. So I’m used to being quadriplegic. He wasn't. He would sometimes ask,
with startling frankness, ‘How do you do it? How do you manage?’ I never knew how to answer.

“One morning my friend's attendant found him dead with a smile on his face, we’re told, at the packed memorial service. A young minister explained that he'd been, quote, ‘a free spirit, trapped in an unresponsive body. Now that spirit is truly free.’ We were told he'd gone to a place where he could walk again. His dad added, ‘Walk? He's probably playing basketball in the (indecent).’ The words stung. Mourners need to believe their loved one has gone to a better place. Yet what was the message here? Death sets you free and cures disability? Was he better off dead than disabled? I realize I'm biased. I have never ridden a motorcycle or done half the other physical things my friend used to love, but I do know one can live a pretty full life with a disability.

“Indeed, some people find life after disability more intense, more deeply appreciated than it was before. My lifelong experience, with disability, has made me a creative problem-solver, and, ironically, perhaps, a diehard optimist, if only because I've had to be. It's taught me a great deal about patience, tolerance and flexibility. My disability is part of who I am. Why couldn't my friend's family value the disabled man he'd become? How limited is this vision of life, and of the afterlife? Are there no wheelchairs in heaven? I'm not buying it. For me, if there is a heaven, it's not a place where I'll be able to walk. It's a place where it doesn't matter if you can't.”

Surgeons at CHOP replaced Raphael’s gastronesteostomy tube with a jejunal tube so that formula feeding went directly into the duodenum bypassing his stomach. The only
drawback was that another line came out of his stomach to drain his gastric juices, which he no longer needed, into a bag. We had to put the yellow fluid back into his J-tube intermittently, so as not to upset his electrolyte level. He no longer would have a problem with reflux and spitting up.

The endocrinologists finally relented and admitted that Rachel was right the whole time. They schedule Raphael to go home on Tuesday December 20 on a ventilator for c-pap. I had to be certified in use of the ventilator by the nurses as a caregiver. I put in eight hours of nursing him in the hospital and learned how to take apart the ventilator tubing and reassemble it. I also had to change his tracheotomy canula. The nurse did not appreciate my disagreeing with her on a particular detail and did not approve me, even though I did very well.

“This baby is coming home today,” my wife told the nurses on Tuesday.

“But your husband didn’t do well on the trach change.”

“I admit that he has not done that very often. Our old doctor only had us change the trach every two or three months. But this baby is coming home today!”

“You will have to sign a release.”

“Fine. But you have some nerve. These machines are beeping constantly and the nurses are sitting down the corridor with headphones listening to music and you can only say that you don’t like the way we care for the baby? You can all go home when you finish your shift, but this is our child, twenty-four hours day. We have to constantly care for him.”

“We’re sorry. We were only thinking about what was best for him.”
When he came home, Norah, the supervisor from the nursing agency, came to see him. She called after I came home from teaching.

“He looks so good. I’ve seen kids come home from the hospital looking pitiful. It’s only because we were with him the whole time.”

“He’s fighter.”

“Yes. He is.”
The students at the University of Pennsylvania allowed me to lead their prayer services while Raphael was in CHOP, even though there is no *public* canonical requirement for prayers to be led by a mourner. The recitation of *Kaddish* and, preferably, the leading of the entire prayer service, are *private* filial duties toward the memory of a parent during the year of mourning, most importantly during the first 30 days. As if by implicit agreement, my co-religionists everywhere entitled me and any guest with an obligation to fulfill their private obligation. There are rules such as giving preference in leading the prayers to a claimant within the first 30 days of mourning over another claimant with equal proprietary share but past the 30 days and with less obligation. All resident members of a synagogue have an equal claim to the property and privileges of that congregation, including the claim to lead the prayers; however, the intensity of personal duty creates a *right* that compels the cooperation of others.

We will argue that obligation creates rights.
Democracy is founded upon the fundamental worth of the individual. The nation is not an organic whole with each person restricted to a defined role. The group is not a single body that collective punishment of its members is justified by the crimes of its leaders. Nor are extra-legal punishments permitted, justifying the sacrifice of one to set an example for the good of the whole. The polity consists not of aristocracy and corporate entities, with exclusive privileges sanctioned by the state, nor of guilds and towns with the vested entitlement to protect members from outside competitors, but of individuals and commonwealth before the law, citizens with their own purposes in life. That is the meaning of the Pursuit of Happiness, not the paternalistic, collective or organic purpose, but to have one’s own purpose. In that sense, we are all equal.

The fundamental worth of the individual gives rise to the concept of the inalienable rights of life and liberty, claimable at any time regardless of any previous contract or hypothetical waiver to government. Simply understood, Hobbes is wrong; citizens do not give up their rights when they enter into the social contract. Historically, and hence constitutionally, no person can be denied life, liberty, or property without due process of the law. Theoretically, inalienable rights are those that are retained even when they are actually waived or contracted to others.

To use a statutory example, unwillingness to participate in health insurance does not relinquish the right to emergency room care. Certainly, financial imprudence itself does not imply renunciation of a right, but what if an uninsured were required by the State to offer community service in return for future lifesaving care? Would society then deny it to the individual who, under informed consent, opts out of the system? Can the uninsured or anyone else sign a contract to exempt hospitals and permanently lose the
ability to change his mind when medical care is needed? Certainly not! The right to life is inalienable because individuals have a duty to live, a duty that they cannot relinquish. Others have a duty to save them. This is a rebuttal against those who propose allowing lifesaving organ transplants only to those willing to have become donors.

The source of all inalienable rights, even the right to liberty, is not individual happiness per se, but the fundamental worth of the individual as a moral being. Not only can one not be divested of inalienable rights, but one is morally compelled to exercise them. Rights ought not to be viewed as privileges that are protected from community interference unless waived, but a compulsion against the State to facilitate the discharge of the moral law. The so-called substantive rights are such because they require others to affirm our being and all derivative dignities. The pursuit of happiness is a rejection of paternalism, not an endorsement of eudemonism. The right to liberty, properly understood, arises out of the individual requirement of autonomous consciousness, which cannot be forfeited. Even the right to privacy, arises not out of licentiousness, but from the worth of the individual to not debase his character with ridicule. On the contrary, the tendency to expose the privacy of contemporary and historic figures is manifestation of society’s fixation with deviance and licentiousness. Individuals can never be released from the responsibilities that accompany moral existence, from moral existence, or from their own existence.

In the context of the social contract, a person cannot be understood to have consented to a government that deprived individuals of those rights. A citizen who enters into a polity denying freedom of speech is still not absolved from the duty of speaking out against injustice. A civilization that regularly practices heathen sacrifice of anyone,
including its own members, is evil, even if all, including the victim, consent and waive the right to life. Rights are inalienable because they correlate to virtues that individuals cannot abandon. Our government cannot deprive a citizen of the right to own property, which is the capacity to acquire and hold property under the protection of law. Perhaps this too arises from obligations of family, sustenance, and procreation. The right to marry is also a so-called fundamental substantive right, as every man ought to marry a woman (apply the categorical imperative).

So understood, there cannot be a right to die. The argument in favor of the right to die is based on caprice, not moral duty. There is certainly no duty to die. Virtues, such as taking a principled stand, are not only measured quantitatively by the value of their consequences, the resulting good in each case, but by the categorical moral command that applies to all cases.

Contemporary ethics have been formulated so that there are few evils other than violations of personal rights. Barring harm to a third party, few admit approval of proscriptions on consenting adults. Murder is not the moral wrong of the destruction of life, but a violation of the right to a desired object, the right to life. If life is an object, why cannot one contract another to take his life? Even if the victim does not protest in the end, murder has been committed. If the destruction of human life is merely the violation of a right, there is little difficulty in the command for Abraham to sacrifice Isaac, for the object, the reward, was so great. Did not Isaac consent? Besides, can one be said to have a right against God?
Some argue that it is a mistake to conclude that the ethics of consent is *relative*, to imply moral relativism. They argue that morality is really *contextual* and, under certain circumstances, a person has a right to die.\(^{27}\) We argue that morality is *absolute*.

We defined compassion as the recognition that the other person exists and ought to exist. Compassion encompasses respect for the dignity of the other as an autonomous being, one with the capacity to determine ends, of which the moral law is the final end. The recognition of the individual as a being with ends, spiritual and material, immediate and final, mitigates the rigid imposition of moral judgment even when one voluntarily asks for advice. When people are free to internalize or to legislate the maxims that guide their actions, they utilize and express their faculty of freedom, which gives worth to those actions.

The moral law yields to compassion and favors the autonomy of the other as a *being with ends*. But how can an *end* be non-existence, that one ought *not* to exist, the antithesis of compassion? Indeed, to die is not an end but a cessation of ends.

The right to suicide is the focus of contention between those who adhere to absolute morality and those who consider right actions to be contextual. How can the absolutists account for lawful exceptions to the categorical imperative? For example, the validity of the universal proscription against lying has been questioned in the context of aiding a criminal intent on murder. Our solution follows the postulate that compassion is the affirmation of being, that human dignity is the recognition of the existence of the other. The categorical imperative defers toward compassion, in favor of *life*.

On the contrary, the regret and complaint against totalitarianism or a criminal for specifically *forcing one to lie* derives from the absolute nature of the categorical

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imperative, even though it is permissible in cases such as saving a life. If morality were merely contextual, then there is no logical moral violation because, under the circumstances of duress, there is no contextual proscription. Everyone in all such situations ought to lie. One who lied to save a life acted in a universally prescribed manner. In another case, suppose we all can agree on the inappropriateness of a personal question concerning a private matter that can cause great shame, in such a context that without contradiction it can be acknowledged as universally permissible to deny or at least refuse to answer, since the question itself has no legitimacy or consequences other than to shame the one being asked. In either case, the interrogator ought not to expect the truth, yet needs to ask for forgiveness for forcing the victim to lie and violate the truth. It is proved that telling the truth is an example of a categorical maxim regardless of context.

The categorical imperative never to commit suicide can be mitigated by compassion, such when a soldier sacrifices his own life to save others during war. The soldier would be giving a last measure of devotion, in recognition of the existence of his comrades and countrymen. However, compassion, the affirmation of existence of the other, cannot deny the existence of the other. Not only does the imperative against suicide remain categorical when ending one’s life does not save another, but we must instruct that it is wrong. Like all crimes, recognition of autonomy in this matter contradicts autonomy, for it misuses compassion in overriding the moral command against suicide by falsely using the principle of affirming existence to end existence. Euthanasia and its postulated right to suicide can only be founded on eudemonism, the ethics of happiness, not upon the ethics of morality.
Locke began his treatise on government in part as follows:

“But though this be a state of liberty, yet it is not a state of license; though man in that state have an uncontrollable liberty to dispose of his person or possessions, yet he has not liberty to destroy himself, or so much as any creature in his possession, but where some nobler use that its bare preservation call for it. The state of Nature has a law of Nature to govern it, which obliges every one, and reason, which is that law, teaches all mankind who will but consult it, that being all equal and independent, no one ought to harm another in his life, health, liberty or possessions; for men being all the workmanship of one omnipotent and wise Maker; all the servants of one sovereign Master, sent into the world by His order and about his business; they are all his property, whose workmanship they are made to last during His, not one another’s pleasure. And being furnished with like faculties, sharing all in one community of Nature, there cannot be supposed any such subordination among us that may authorize us to destroy one another, as if we were made for one another’s uses, as the inferior ranks of creatures are for ours. Every one as he is bound to preserve himself, and not to quit his station willfully, so by the like reason, when his own preservation comes not in competition, ought he as much as he can to preserve the rest of mankind, and not unless it be to do justice on an offender, take away or impair the life, or what tends to the preservation of the life, the liberty, health, limb, or goods of another.”

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28 Locke, J. (1952) Concerning the true original extent and end of civil government (Chapter II, Sect. 6). In Hutchins, R. M. (Ed.). Great books of the western world. Encyclopedia Britannica, Inc. 35.
311 – Not compatible with life