

INTRODUCTION

Why did I write this book?

I like to say I didn't want to, but that friends kept telling me I should. Well, that is true.

But, once I had decided to pursue a second and third transplant, maybe somewhere inside of me I wanted to write this book, not knowing what to expect as the outcome of my multiple surgeries, or what I could do to make this medical process worthwhile.

I decided that with this second transplant procedure, I should keep aware of what I experience, especially mentally and emotionally. Pain, drugs, encephalopathy, and immobility will not allow writing as an option, so I better really focus and remember when my faculties allow. I would be more conscious this second time of the mental and emotional struggles, where I failed, and most importantly how I coped... if I do.

Hopefully, I had learned something from my first journey through the transplant process that would serve me well in this second venture.

I had every reason to believe that this second surgery would be even more difficult. My body was ten years older, and weakened by the trauma of the first surgery.

And if I thought life was tough after the first transplant, to start from zero, rebuild my life, and find employment and financial stability at fifty-five, how easy would I find starting over at sixty-five?

I enter the hospital near death when I return for my second and third organ transplants. As I lay there awaiting hospital admission, I knew the issue in the surgeons' minds was not "Does he need a liver?" or "Can we get a liver?" but rather "Can this patient survive another grueling trauma of a liver and kidney transplant procedure?"

If I write, at least someone else could learn from all of this, conceivably find their road a little easier to navigate. If I survive, and could hold a pencil later, I could jot a few notes and give the paper to where my participation might do some good. Since I am faced with transplant again, I might as well make myself useful to the next person, even if my transplant proves a disaster for me. I certainly have nothing better to do at the moment.

The two transplant procedures ten years apart were totally different experiences in almost all areas: emotionally, mentally, spiritually, and physically— both pre-op and post-op. Financial devastation to my family remains the sole element common to both operations. The monetary havoc was not so much the direct medical costs, but the indirect costs and the total loss of income from me and my caregiver wife.

This book serves three purposes. First, a tribute to the magnificent staff at UCLA who

participate daily in the saving of human life by means unimaginable earlier in our lifetimes. The men and women in the Liver Transplant Department at UCLA are a super-select group. Their skills exceed all norms or they would not have been chosen for their roles. They demonstrate extraordinary dedication and strength, or they could not survive the everyday weight of serving each patient in a gruesome struggle at the outer edge of life, knowing some of their patients will not win this final game in life, and that each day may be their last.

Second, the book is an expression of my gratitude, and the gratitude of other transplant survivors, for our donors and their families whose love and generosity make a miracle of life possible; and for our caregivers, friends and supporters without whom we may not have survived, and would not have returned to a new normal life.

Donors and caregivers are the unsung heroes of every successful transplant procedure.

Finally, I want to pass the life lessons learned late in life and under the worst of circumstances, to anyone facing a life-changing crisis of any kind.

Which brings me to the frequently asked question: "Where did you get the title for the book?"

Five months after my last transplant, the Ronald Reagan Medical Center opened on the UCLA campus to replace the old hospital where I received treatment. The new facility offers only private rooms, which many observers laud.

Friendly conjecture arose whether private rooms or roommates were preferable. As I listened, I realized the future patients in the private rooms will all have roommates.

These roommates are four tigers we unknowingly bring with us to our hospital rooms. Spouses and caregivers have these same tigers waiting under their beds at home each night.

What I have dubbed 'tigers' are a part of our humanity and are constantly in our lives. The tiger names are Death, Control, Anger and Fear.

In a time of unparalleled crisis, alone in our rooms with these predators, they roar louder than ever. They will dominate our room and fill our thoughts if we allow them.

In a health crisis, we tame these man-eaters, or they may take our life before our illness does. If good fortune allows us to survive our crisis without controlling our tigers, they will follow us home and provoke chaos in our lives until we tame them.

This book will explore some of life's greatest challenges, and how we might cope with them, whether in life-and-death health crisis, a personal or business trauma, or in our daily living.

While I was writing the book, random chapters were critiqued by strangers for quality and editing purposes. Several readers commented to the effect, "It's surprising how many remarkable people are in your life."

I agree with them. My adaptations in crisis and my choices of the people close to me in life are the greatest determinants of my happiness. I offer they might want to read the entire book to better understand my luck.

I sincerely hope you will not wait fifty years, or until catastrophe strikes, to face and tame the tigers in your life.

CHAPTER 1: “Honey...”

“What is your name?”

More a demand than an inquiry, her tone commands the room to a standstill. She towers over me as I lay nearly flat on my back. With her head tilted slightly left to look directly in my eyes, her jawline casts both power and beauty, emphasized by an almost military-like white uniform. We engage center stage among motionless white pillars which fill the silent room around us. Whatever is happening, it must be important. I better get this answer right.

“Robert Scanlan.”

“Where are you, Mr. Scanlan?”

Without hesitation, “In the hospital,” I respond, proud of how I could match wits with her. I can even remember her name now. Sydney.

“More specific. What hospital?”

My mind goes blank! A touch of panic rises. What if I cannot answer? I calm and close my eyes. My eyeballs roll back to look into my skull to explore my brain. Only blackness appears; then small gold letters grow larger until they read ‘UCLA’.

“UCLA Hospital,” I say, hoping I have won this challenging and now too long quiz, but still not knowing my prize.

“Do you know why you are here, Mr. Scanlan?”

“To get a liver transplant.” I now have a hint of where this is heading.

“Do you know your options, Mr. Scanlan?”

Is this another trick question? Did I miss something the past two weeks that I should know about?

I pause long enough to scan my memory. Nothing there, so I proceed matter-of-factly with the obvious, “Yeah, I’ll die.”

“He’s Ready!” Sydney trumpets while throwing her head over her shoulder for all to hear. The alabaster pillars transform to white coats of the medical staff. The room bursts into a sudden flurry of motion. A low indiscernible hum of voices wafts through the room.

After her grueling interrogation, which probably lasted fewer than thirty seconds, I am exhausted and drift off. A few days ago I was managing millions of dollars in the stock market. I had an inkling life will be different when I regain consciousness.

How could I possibly land in this situation?

I would later come to my own rationalization. But for the moment it makes no sense. This experience is something you read about. It happens to an unknown someone else.

Just several days ago, I was embracing the American dream. I enjoyed good health, a loving

family, a beautiful home in Westlake Village, California, and a thriving investment management business. The business has grown so well, we are scheduled to move the operation to larger quarters that last weekend of March, 1998.

My wife Marie murmurs from our bed, "Honey..."

Like most married men hearing that syrupy attention-grabber, I cringe inside for what may follow.

"Better start exercising a little more. Your tummy's getting round."

This tease from my wife is no way to start an exciting week. My irritation escalates when the mirror says she is right.

How can a woman see twenty feet across a darkened room better than I can see myself standing in front of a bright mirror? Besides, how is this bulge possible when I exercise and jog a mile or two every day with our yellow lab Trader?

The next day the stomach grows rounder. On Wednesday I meet Dr. Larry Froch at UCLA. I have no medical history to tell him—nothing more serious than the common cold—never admitted to a hospital. I had presented the same dull information to the insurance company when I applied for, and received, a health insurance policy two months previous. Having good health and a need for cash to build a business, I had previously dropped health insurance coverage. When my son learned of this, he adamantly insisted I obtain coverage immediately. I am one of those lucky men who inherits intelligence from his child.

On Friday Dr. Froch phones with test results. "Your liver is in serious trouble. Report to UCLA Hospital Monday morning, 6 A.M. sharp. I'll be there for you."

Every word he says is true. My liver is in serious trouble. UCLA is the premier institute on the planet to seek liver treatment. When admitted to UCLA, I am no longer Dr. Froch's responsibility. He does not make decisions in my liver treatment, yet he is at my side every step of the way. Sixteen years later, he and I remain 'Larry' and 'Scan'.

This weekend, with skin in various shades of yellow and green, eyeballs brilliant orange, and a pot belly hanging over my drooped pants, I exhaust myself overseeing the office move. This weekend also marks my fifty-fifth birthday, an event totally ignored in the turbulence of the moment.

Reporting at six o'clock in the morning to UCLA is not a strange start time for my day. Strange is being told in the admissions process I weigh twenty-five pounds more than I did at the doctor's office a few days ago.

Hours later a hospital aide escorts me down the hallways toward my room. If I sported a longer hair style, a passer-by might think I am on my way to the maternity ward. Over my left forearm I carry a flimsy blue gown, the type that ties in the back and never quite adequately covers one's rear view. Unforeseeable to me, that gown and hundreds like it will fulfill the center-piece role of my wardrobe for longer than I could possibly imagine.

We approach my room and see activity inside. Something is amiss. The aide orders, "Wait right here," while he enters the room.

With the door left ajar, I can't help but hear bits of the conversation inside. The patient is dressed with his bag packed. He acknowledges his good health and his completed discharge papers. Yet he sits on the bed and refuses to leave.

Over the next few minutes, it becomes evident that the gentleman has nowhere to go, no one to go home to or to even offer him a ride home. The sense of irony overwhelms me. A man in good health clings to a hospital bed because he has nowhere to go and no one to go to; while ten feet away I feebly lean on a wall in a hospital hallway, a frail gown on my arm, with everything

in the world to live for. I desperately need that cot to either receive my cure or to create my deathbed. The first emotional wave of my personal tsunami has now struck.

An alternate room quickly becomes available, where I lay passively and semi-conscious for the next several hours while an endless parade of medical staff scurries in and out. By now, tubes and wires sprout from every part of my body.

In being admitted to a research hospital like UCLA, I do not lack bedside company. Singly, in pairs or in groups, a constant stream of veteran physicians, fellows, interns, nurses and others come to observe, question, poke, prod and whisper, often regrouping in the hall to comment more freely outside my earshot. Late that afternoon, I meet for the first time hepatologist Dr. Leonard Goldstein.

He greets with a flamboyant mustache reminiscent of a Nineteenth Century New York bartender, and a personal panache seldom dared in the hallowed hallways of a renowned medical institution. As often as not, he wears a blinding yellow, long-sleeved shirt, partnered with a neck tie which in kindness would bear the label: garish. He maintains shirt sleeves rolled to mid-forearm to reveal a collection of leather and woven wrist bands, stacked several inches up each arm. Pointed-toe, Western boots set off the look.

Dr. Goldstein explains that my liver is in total failure, and they don't know why. There is no cure, no way to fix it. My only hope for life is to receive a liver transplant.

The first step will be to get me on the waiting list so I would be eligible to receive a transplant if a liver could be found as a match to my body. In the meantime, Dr. Goldstein assures me that he and the UCLA staff will do everything possible to keep me alive day to day.

No assurance I would get a transplant. No assurance that I could even get on the wait list. No assurance that they could keep me alive day to day.

My first day draws into evening, and other curiosities begin to haunt me. *What is a liver? What does it do? Where is it?* My lack of basic knowledge is appalling.

The one thing clear to me is that this new best friend Dr. Goldstein is going to fight for me through this wait list process, though I'm not sure exactly what that involves. He bears unimaginably bad news, but he communicates with clarity, confidence and caring.

He delivers hope.

CHAPTER 2: Don't Pray He Gets Better

The next day—and the several days that follow—is a blur of tube insertions, tube removals, IV deliveries, tests and more tests, monitors, blood withdrawals, pills, nurses, and dozens of white-cloaked professionals from a myriad of medical specialties, all accentuated with physical pain, emotional hyper-stress, and delirium derived from internal toxins and administered drugs.

On the second evening, my brother-in-law Al comes to visit. As he leaves, he turns and says, “You’re in my prayers to get better, Bob.”

Marie leaps to her feet and practically shouts, “Don’t pray he gets better.” Al freezes with a mystified pall over his face. “Pray he gets a transplant!” she continues as she approaches her brother.

Forty-eight hours ago, Marie knew almost nothing about livers or transplants. With my life on the line, and the vision of her own future in jeopardy, she has gleaned every bit of information possible from anyone she could engage. Now she delivers a brief layman’s primer on organ transplant, which is mind-bending, counter-intuitive, and terrifying.

Marie tutors, “If he gets a little better, his fate doesn’t change. If they send him home, he would still be jaundiced, bloated, in pain, hallucinatory, with no control of bodily functions. He would sit at home miserable, hoping for a phone call that would tell us a liver became available before he died. Stranded at home with no way to provide the comforts of the hospital and the staff, he would suffer and I would be helpless.” Her picture would leave anyone overwhelmed by the magnitude and pervasiveness of the destruction we both face.

She then unravels for Al the mystery of the waiting list. The need for organs far exceeds the availability. Organ donation occurs only by the prior-expressed intention of a deceased patient, or by the compassionate choice of a deceased’s family.

Maintenance of a waiting-list at the state and national levels provides orderly access for all patients in need of a transplant. The patient at the top of the list receives the next matching organ. The way you move to the top is to become sicker—closer to death—than everyone else in your state.

Al listens intently, then shakes his head. “This is crazy. This makes no sense.”

From my bed I can see the wheels of his mind whirling to bring rationale or acceptability to what he hears.

The system defies the natural instinct of every living creature to live; of man’s mind to act rationally; of human compassion to relieve the suffering of others.

I observe and listen to this scene. I have not simply entered the hospital. I have entered a whole new world.

Late that night, while deep in some combination of sleep, encephalopathy, drug stupor, and exhaustion, I awaken to banshee-like crying. My first thought turns to the patient.

That patient must be in awful pain. Is that what’s in store for me tomorrow, or the next day?

As the static pitch continues uninterrupted, my interpretation shifts from the cry of pain to the wailing of loss.

Across my room, through a deep darkness barely relieved by a sliver of light from an unlatched hall door, an anonymous and sober voice dispassionately murmurs, "Someone died."

This is a tough neighborhood... a patient just passed away here, and that is just part of life on this hallway. I fall back to sleep.