

Cancer is a complex illness with biological, psychosocial, and spiritual facets. This book follows the odyssey of a physician who was diagnosed with a virulent blood cancer, multiple myeloma, and came to a new understanding of health and wellness as he underwent bone marrow transplant with massive chemotherapy, navigated the hazards of the health delivery system, learned to cope with the illness and then the treatment, and finally emerged into a whole new life with a new appreciation of the relationship of illness, health, trauma and resilience.



Allen R. Dyer, MD PhD

## One More Mountain to Climb

What My Illness Taught Me About Health



Allen R. Dyer, MD PhD

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 **LAMBERT**  
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**For Sue,**

**who, on our wedding day, promised  
“Whither Thou goest, I will go”  
never dreaming I would take her  
to Hell and back.**

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## **Introduction**

I feel I am fortunate to have gotten cancer. This is not to say that I would have chosen this path if the choice had been mine or that I would wish it on someone else. I have heard other cancer survivors say similar things. Cancer opens doors to a land beyond. Cancer teaches people things about themselves they might never have learned. They become aware of inner resources they didn't know they had. They meet challenges that make them stronger. They come closer to family and friends. They come closer to God. They appreciate life and learn something about how to live it.

As a physician, I was suddenly thrust into the world of patienthood and given the opportunity--at times terrifying--to learn what that was like. I was given the opportunity to test assumptions I had been teaching for over two decades, to test them in the laboratory of my own experience. As a psychiatrist and psychoanalyst, I was particularly interested about the interaction of mind and body, or mind-body and spirit. While I battled fears about my own mortality, I was also eager to get well. And I was curious about those factors that might enhance the likelihood that the technology would work. I read everything I could about the oncology of my illness, multiple myeloma. I must confess that oncology had not been a particular interest of mine in medical school. In that era--not so very long ago--oncologists gave toxic chemicals to people dying of cancer, making their final weeks even more miserable.

I have always been interested in the field once known as behavioral

medicine (now called mind-body or whole person medicine) and the studies of populations to determine who gets sick and who gets well. There are lessons from these studies that can be turned into practical approaches to living. There are decisions that must be made every day about hope and determination and support and response to adversity and to stress. These decisions affect what happens to us, even how those toxic chemicals work, how the mind (and spirit) affect how the body responds to chemotherapy, to surgery, to radiation. We even are beginning to understand scientifically how these psycho-spiritual attitudes affect the cells. But this is an area of medicine and healing that takes us into complexity and ambiguity.

Shortly after I was diagnosed, I had the following dream: I was talking to a group of people, my students, or perhaps my family. I said to them, “I want you to know I am not dying of cancer. I am living with cancer.”

Classical psychoanalytic dream theory would remind us that a dream is often a fulfillment of a wish. Even when bad or frightening things happen in dreams, we become aware of the possibility of unconscious wishes that we would otherwise have trouble acknowledging. Freud also talked about dreams “from above” in which the conscious thoughts of the day appear undisguised in dreams at night. I think of this dream as reflecting an almost conscious decision. I was (and am) a medical school professor. I wanted to do this cancer thing right. I wanted to learn and understand and teach. I hoped I could be a role model for others. I would have to act fast, however, because my adversary, the cancer, was acting fast. Fortunately I was not alone. And this has been one of the key lessons from cancer. *You are not alone*. Many people have dealt with cancer, and the number is increasing each year. Every year more and more people are surviving cancer. In the

last decade (even in recent months) stunning advances have been made in the war against one of the most catastrophic illnesses we face. As strange as this may sound, this is not a bad time to get cancer.

Next lesson: you can talk about what you are going through. In fact, I would say, *you MUST talk about what you are going through*. My first instinct was to crawl under a rock and hide from the reality that was facing me. I realized that this was impossible. The weight of secrecy and aloneness would crush me. By being open to others, I found that I gained support and encouragement I would never have imaged or hoped for.

The idea of writing a book about my experiences first came from my colleague and friend, Penny Smith, who was diagnosed with breast cancer four years earlier and was a pioneer in receiving a bone marrow (or stem cell) transplant, the treatment that was prescribed for me. Penny told me that a book was needed to help people know what to say to cancer patients. She said that many of her friends told her they just didn't know what to say. I thought of all the times that friends of mine received terrifying diagnoses or experienced devastating losses when I had felt at a loss to say the right thing. Having entered the Land Beyond myself, I realized a very simple truth: *it doesn't matter very much what you say. Anything is sufficient and welcome*. Even people who later said, "I meant to write, but didn't get around to it," or "I wanted to call but didn't know what to say"--even those comments are understandable and welcome.

So I quipped to Penny, shortly after my diagnosis, when I thought I knew what I was talking about, that such a book would be very short indeed: Just tell people that anything they say will be appreciated. A comment as simple as, "We've been thinking about you" could speak volumes.

As the months of treatment wore on, I came to realize how much I welcomed the calls, the cards, the visits and e-mails. Each day as I battled on, I looked forward to some surprise message. I looked for unexpected allies. I heard from people I hadn't heard from for decades. I heard from people in my hometown of Newport, Maine, from friends in Johnson City, Tennessee, and from old friends, who learned that I had returned to Duke, to *alma mater*, for treatment. I heard from people I had never met, friends of friends who were concerned about their friend's friend. Each day I focused on these contacts, these gifts. They were wonderful distractions from the pain and discomforts of cancer and cancer treatment. I came to realize more and more that these were key ingredients in the healing process. I was very grateful that friends and family rallied around me. The doctors, Physicians Associates (PA's), and nurses could focus on the technology, supportive—even inspirational, spiritual—in their own ways. I could focus on getting well. My wife Sue and I could focus on getting well.

Thus the idea of telling my story emerged. Perhaps a story of healing would be useful to someone else facing cancer, or another illness, or loss, or conflict. Perhaps it would be helpful in knowing how to respond to someone facing such crises. Perhaps the implications for health policy could become more vivid through a first-person narrative than they might be from my usual analytical academic writings that go into journals read primarily by specialists. In East Tennessee there is a viable tradition and revival of “storytelling”. Telling this story could be the opportunity offered by the crisis.

Among the storytellers I most admire are French film maker François Truffault and Japanese film maker Akira Kurosawa. In films like Truffault's

*Jules et Jim*, *Une Belle Femme Comme Moi* (Such a Gorgeous Kid) or Kurosawa's samurai epics or the stark Siberian *Dersu Usala* (The Hunter), for example, events unfold one after the other until the whole picture has emerged. How I would love to be able to tell my own story with such direct simplicity. But my experience lacked such direct simplicity. Each day I was tugged by memories of the past and anticipation of the future. It was the anticipation of the future that kept me going, things I yet wanted to do in life.

My story was less like a narrative film and more like a kaleidoscope, I realized. It was a series of shifting images, shards of conversation, memories, fantasies, and events. It is these shifting images, I realized, from which more or less stable insights emerged. I know now that in telling my story, there will emerge aspects which will resonate with the life experience of others, the developmental path that everyone must traverse, the issues of dependency, autonomy, control (over destiny or lack thereof), competition, intimacy. I also realize that everyone has traversed this developmental path in a unique way and some of what worked for me might not work for someone else. I realize that in many ways I have been lucky, not the random kind of luck you get from rolling the dice, but the kind of luck you get when the gods smile on you. I also realize that all my life I had been preparing myself to deal with adversity, and that cancer—as it turns out--was not an entirely negative experience. In balance cancer was a positive experience where friends and community gathered round.

So part of me now attempts to look at my experience as a scientist trying to determine what generalizations are possible. And part of me surrenders to what I have come to understand as the Zen spiritual aspects of

life, living with whatever harmony can be achieved in any situation, even chaos. I would fight the cancer in every way I could, but paradoxically I found that part of that fight meant submitting to the treatment and allowing those around me to join the battle.

For some time I had been working on an academic book on medical ethics and health policy. I had reached the point where I was making arrangements for a sabbatical to be able to devote full time working on the project. I never imagined I would encounter a life-threatening illness that would demand so much of me. This is not the sabbatical I had imagined taking. This is not the book I had imagined writing. But my own battle with cancer crystallized the issues in a way I might otherwise have missed.

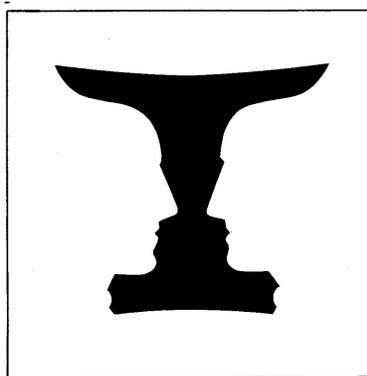
Cancer instructed me. It became my teacher. Many of its lessons were about life and living. Many of its lessons were about death and dying. These are lessons I came to realize were spiritual lessons. And spirituality in cancer, I came to appreciate, could be an important ingredient in healing, one that is even less well understood than the complex disease processes of the body. That is a lesson in itself. *Life is complex, and hence the healing process must be complex.*

### **The Cheshire Grin**

The sections of this book dealing with the cancer odyssey were written in the months following my treatment. As the years have gone by, I like Odysseus have tried to make my way back to Ithaca, to home, a life that was familiar and secure. Like Odysseus I have been changed by my experiences. This book, which was first written as an attempt to heal--to keep the wounds open long enough to realize what had happened to me—

then became an extended thank you note for those who had helped me along the journey. Ultimately it would be my hope that the lessons I have learned might be of use to someone else, so I have continued to work with it, to face the pain again, when it might be easier to forget, but also to savor the joys and the triumphs along the way.

A pivotal moment also occurred early in the treatment. I tried to make a ritual of meditation and relaxation. I sat in a reclining chair I had gotten to sleep in when-- because of the broken ribs-- I couldn't roll over in bed. I placed it beside our bed, looking out at the Blue Ridge Mountains along the North Carolina-Tennessee border. One could not hope for a more serene setting. Yet each time I looked at the mountains and tried to relax, I saw an ominous image. Right in front of the window, a limb from the black walnut tree, intersected with a limb from the red oak to form a grin very much like the Cheshire Cat, the one that Alice found so enigmatic in Wonderland. I would try to relax and the Cheshire Cat stared back at me as if to say, "Everything is not Okay. You have cancer. Deal with that."



Gradually I learned to ignore the Grin and look to the mountains beyond. It was like the figure-ground drawings of Gestalt psychology. View one drawing with the white parts as background and you see a goblet. Consider

the black part the background and you see two faces.

I realize now that this book also has two perspectives. It is the story of a patient viewing his illness and his treatment. It is also the story of a doctor coming to understand his “patienthood” and his profession. Figure-ground. From the regressions of my illness, I came in touch with the dependencies, the fears, and the uncertainties of childhood. This was not all bad. I also got in touch with the playfulness, the juvenile silliness, and the spontaneity of childhood. In keeping the inner child alive, I learned to keep myself alive. From the perspective of childhood, I learned a new view on adulthood. I became more accepting of myself and of others. I also became a better doctor, as I better understood what it was like to be a patient.

It may be helpful to the reader to understand this dual perspective. Figure-ground. Time in this narrative does not march forward, step after step. It was hard for me as a patient to stay focused in the present. I was always tugged by both memory and anticipation. The first part of this book is called *The Cancer Odyssey*, a journey through the illness and treatment, recalling the journey through life. It is interspersed with recollections as well as anticipations.

The second part of the book, *Lesson from Cancer*, is no less an adventure story. It is the application of the lessons learned from being a patient to new adventures that I have been so fortunate to experience. It is interspersed with reflections and with recollections. The adult looking back. The child looking forward.

The third part, *The Land Beyond*, is a collection of essays, various talks I was invited to give, which attempt to integrate the first person experiences with a broader understanding of health and global health. Back

on my feet in the 21<sup>st</sup> century, my career has taken an increasingly “global” turn. Through the auspices of a number of organizations, the WKKellogg Foundation, the Kellogg Fellows Leadership Alliance, People-to-People International, the International Medical Corps, the Willowcliff Foundation, and the US Department of State, I have been privileged and challenged to study and respond to a number of disasters, both natural and human made. After the “tsunami” of my own illness, I have learned from communities healing from the Indian Ocean tsunami, studied public health systems in Russia, China, Cuba, and elsewhere, and truth and reconciliation movements in Rwanda and South Africa, AIDS response in South Africa and Botswana, helped develop education programs after the Sichuan Earthquake and the Japan Triple Disaster, worked with health and mental health professionals in Iraq, which involved nine trips to that country during the war, studied post-traumatic stress responses and approaches to well-being in humanitarian workers, in Haiti, St. Lucia and various conflict zones. “Global” health, as I have come to understand it doesn’t just mean health around the globe, it means a *comprehensive* integration of biological, psycho-social and spiritual factors in individuals, families, and communities.

I would not presume that others would follow the same path. Everyone must find his or her own way. I have been encouraged to offer my story because there are times when it is not always certain which way to turn. At those times I would suggest there might be a way forward. Pause. Take a deep breath. Try to follow what has worked before and try to avoid that which has not. Try something new. Trust your instincts. Realize you are not alone. Look for companions and look for the guidance of others as you find your own unique solution and path.

Many books offer acknowledgment to those who have helped the author in some way. In my case, however, the “story” is about the very help that family and friends have offered to me; so in a sense the whole book is that acknowledgment. Many will make appearances in the pages that follow. I would also like to acknowledge those who do not make explicit appearances, but whose presence has nonetheless been felt and appreciated. To all my friends who have contributed so much to my health and well-being, I offer the following haiku:

### **MORNING DEW**

Morning dew on pine needles

Dissolved by noon sun

New friendship and love

Proceeds from this book will support the work of the Willowcliff Foundation. Willowcliff supports world citizenship and global stewardship. For more information: [www.willowcliff.org](http://www.willowcliff.org).

## **Prologue: A Helicopter Named Icarus**

I smiled to myself when I saw the name of our helicopter painted boldly on its underbelly as it descended toward us. *Icarus*. This is auspicious, I thought to myself, already feeling some trepidation about the heli-skiing adventure I had chosen for my son and me. I nudged Will in the ribs as the downdraft from its rotors engulfed us. He smiled, quick to appreciate the irony.

*Icarus* was a cute name for a helicopter. It seemed also a warning against too much hubris. In mythology, Icarus had a burning desire to fly, and constructed wings of feathers held together with paraffin wax. The wings worked! Icarus could fly, but he was ambitious. He was not content like the Wright Brothers (who perhaps remembered his folly) to fly just a few feet on his initial flight. Icarus was so exhilarated by his achievement that he flew straight into the sun, whose heat melted the paraffin, plunging him to his demise.

For me this little machine offered an incredible perspective, not only on the towering Alps of northern Italy, where Will and I encountered it, but also back in time to my ordeal with cancer and bone marrow transplant. The anticipation I felt about skiing off these towering alpine peaks was heightened by my memories of battling cancer. A year earlier I was much less certain that I would ever return to the mountain adventures which had so enriched my life over the years.

I am no stranger to high mountain peaks, but a ski vacation to the Courmayeur Mont Blanc region of Italy was particularly precious because

my twenty-four year old son, Will, was able to accompany me. Will was about to finish college and get married. So for this reason too, this was special father-and-son outing. Will speaks several European languages, the alpine languages in fact, French, German, and Italian. We chose Italy for this vacation because he was studying Italian at the time. We chose Courmayeur because of their helicopter ski outings this region offers. I had skied steep slopes, glaciers, deep powder, but never the spectacular runs that are accessible only by helicopter.

So Will and I engaged one of the famous Courmayeur guides, a gregarious young man named David (pronounced Da vide). His infectious enthusiasm and relaxed nature reinforced my confidence that we could tackle any challenge. He picked us up at our hotel and drove us to an Italian village with a French name, Bonne. Good. We were just a few miles from France. Bonne seemed auspicious. When the helicopter arrived and we noticed its name painted on its belly, we began to have second thoughts.

I was also exhilarated by my newly reclaimed health. I was ready to spread my wings, metaphorically speaking. As *Icarus* approached, we tucked our heads under our arms (like birds) to protect our eyes from the dust and debris stirred up by the turbulence. We strapped our skis to the underside of the helicopter and jumped into the cozy passenger compartment. As we rose above the village Bonne, we were met with a dazzling view of mountains on all sides. The pilot flew up a peaceful valley. My heart raced with excitement. I looked for the ski runs, which would soon greet us. The pilot rounded a corner, darted behind a ridge, and began to climb straight up a steep mountain face. I glanced at the altimeter. Up 1000 meters. 2000 meters. 3000 meters. The conversion was not complicated.

3000 meters is 9000 feet. What goes up must come down. I knew what was in store for us.

The helicopter landed on a little shoulder of the mountain, short of the summit. Of course it would be impossible to land on the pinnacle. We would have to climb to the top from this little shoulder, *klein sheidig, petite bisselle, spalla piccola*. The racing heart and labored breathing were not just from the excitement. These physiological signs told us how thin the air was at this altitude, and how hard we would have to work to get oxygen to our muscles.

The views were magnificent. The fact that we had to work for them made them all the more precious. In the distance, we could see the Matterhorn, Il Cervino it is called in Italy. Sue and I had climbed it on our honeymoon, 31 years earlier. It had lost none of its power to inspire.

The skiing was more challenging than I had expected. The descent was steep, and because it was a warm, spring day, the snow was heavy. When we finally reached Bonne, we had earned a hearty lunch of beetroots and pasta marinara, which we shared with some British sportscasters, who had also been skiing from the ambitious little helicopter.

That evening back in our hotel in Courmayeur, we shared our adventures of the day with our compatriots, most of whom went out to charter helicopters the next day. Our hotel was filled with *americanos*, mostly young professionals, younger than I, but older than Will. Will's Italian was pressed into service to assist with ordering meals, and he offered Italian pick-up lines when they were most needed.

The next day we were scheduled for a more relaxed outing: La Valle Blanche, a gentle, twenty kilometer glacier, flowing down the French side of

Mont Blanc into Chamonix. The Valle Blanche would be the gentler glacier I had imagined, but on this day, it would elude us. Perhaps this was our downfall. Perhaps we had exhibited too much pride in accepting the ascent in *Icarus*. The Valle Blanche was closed because it was snowing in France. There would be too much risk of losing skiers in crevasses. We couldn't have that. We were offered the Toula Glacier on the Italian side of Monte Bianco instead. It was suggested as a nice alternative. I should have known better.

We could see the steep Italian side of this highest Alp right from our hotel window. It rose straight up from the valley floor. More properly from a skier's point of view, it plunged straight down. There is no way this would be easy. It didn't occur to me not to accept the challenge. Three funiculars took us to the top of the part of Mont Blanc called Punta Heilbronner.

Before we could start skiing, it was necessary to rappel down a steep ice face on our skis. Rappelling was nothing new to Will and me. We were familiar with rope techniques and rappelling from earlier mountain adventures. Sue and I had attended a rope school in preparation for our Matterhorn ascent. Will, and his brother Cliff, and I had gone to the Philmont Boy Scout ranch in New Mexico. At Philmont Rock climbing had been part of the curriculum we had most enjoyed together. Rappelling on skis was an added twist.

But the rappelling was not the most difficult part of the descent. Once we got off the ice face, we were met with seven flights of fire-escape type open stairs, which carried us down to the glacier proper. These were even more intimidating. There was no turning back. Holding skis over one shoulder, we used the free hand to hold on to the railing as we clomped

down the icy stairs in heavy ski boots. I recalled a memory that I hadn't thought of in fifty years. I recalled the first fire drill in school when our class of five-year-olds had exit our second floor classroom by way of the outdoor fire escape. Confronting the open stairs provided occasion to reflect on fear. Fear is an emotion than galvanizes you to face challenges you can't avoid. I had chosen to come to Mont Blanc, and I was thrilled to be here. Mont Blanc was reminding me of the lessons the bone marrow transplant taught me. The bone marrow transplant was an adventure I hadn't chosen, but once set upon it, there was nothing to do but face what lay ahead.

Mont Blanc offered yet another challenge before we got to the glacier itself. Before we could start skiing, we had to traverse the lip of the glacial headwall. Without any hesitation, I assumed it would be my role to find the path across. I had brought Will here, and I owed him the benefit of my experience. It had always been my job to find the path. As a Registered Maine Guide in college and med school, as a Boy Scout leader, as a medical school administrator, that was my job: find the path.

Snow conditions were not ideal this day on Mont Blanc. They were what is technically known as "crud". Yesterday's tracks were frozen under this morning's powder. Our guide, Rudi, a more serious individual than David, made a motion with his arms to indicate where the track should be found. I glanced down the steep face of the headwall, took a deep breath, and pointed my skis in the direction the Rudi had indicated.

I think it would have been bad karma to anticipate a fall, but of course a fall would be a possibility. I don't remember catching a ski tip, but that must have been what happened. What I remember was suddenly glissading down the slope head over heels, not exactly a freefall, but close to it. I

remember looking up and seeing Will and our companions a long way up. I couldn't see down. I remember having a lot of time to think. First I thought I should try to self-arrest with my ski poles. That proved impossible. Then I calmly told myself I would not fall forever. Sooner or later I would come to a stop. It is the nature of glacial headwalls that they form a bowl for the ice. Eventually they level out. Finally, out of options, I contented myself to wait for that to happen. Eventually it did.

The kind of fall I took has a technical name. It is called a "yard sale." Everything you own is spread out on the side of the mountain: skis, poles, hat, camera, gloves. A yard sale is a skier's greatest embarrassment. I wondered what Will thought of his father at that moment. I decided it would be best not to ask him. Later his mother did. He said he was worried that he would be next. However, Will managed the traverse without any difficulty.

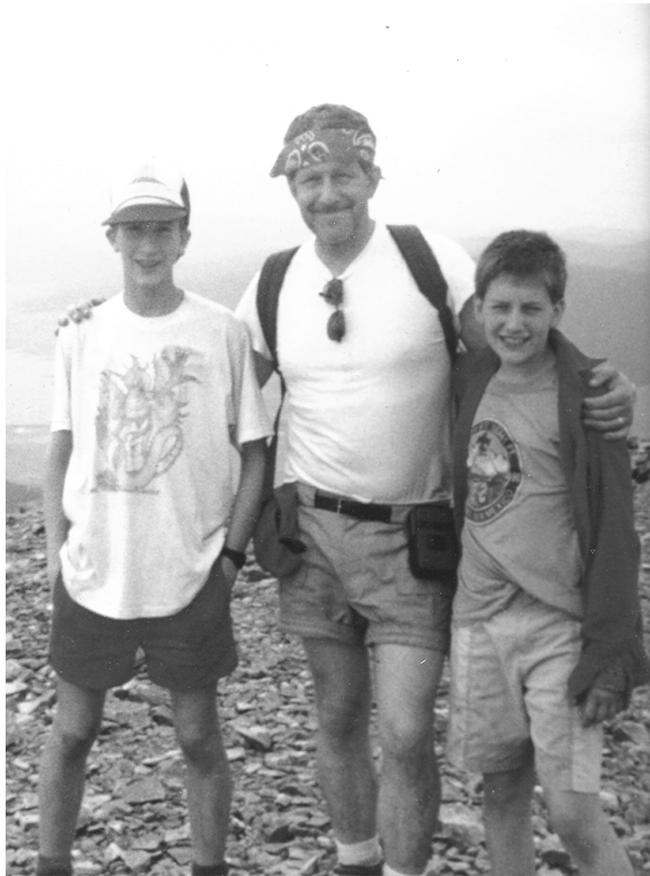
That night after dinner with our *amici americanos* and after the effects of the *vino rosa* wore off, I settled in for a contented, well-deserved, and hard-earned night's rest. I would sleep well. When I crawled into bed, I noticed I couldn't lie on my right side, my rib cage would not support my weight. I knew immediately that I had broken a rib. Another rib. It was a familiar occurrence to me. I had broken many ribs before my cancer, multiple myeloma, was diagnosed. At that time, broken ribs were so alien to my experience I couldn't comprehend what was happening to me. Now they were so familiar I know immediately what the sensation meant. For a few minutes, I wondered if this rib fracture were a telltale sign of a return of the cancer. No, I decided. I had a good enough explanation for this fracture. It was a souvenir of my most memorable fall on Mont Blanc. I had earned this one. Cancer was a thing of the past. There is life after cancer. Mountain

adventures would be as much a part of my future as they were of my history.

I rolled over onto my left side and drifted into a thoroughly contented sleep, dreaming of the sound of helicopters, putting anxieties to rest.

*“Life is a daring adventure,  
or nothing.”*

—Helen Kelle



**Will, Dad, Cliff on Mt. Baldy,  
Philmont Scout Ranch, New Mexico, 1990**

## **PART ONE - THE CANCER ODYSSEY**

### **1. The Drama of the Diagnosis**

One day you recognize a sensation as a symptom. It hits you. The subconscious becomes conscious. Something, which had previously been imperceptible, crosses the line and becomes perceptible as a warning: something is wrong. For me that sensation was chin numbness. At first it was a slight tingling. I said to myself, “This isn’t normal. This is a symptom of something, and I will have to figure out what it is.” I remember being aware of my symptom by November, 1997, because I had been invited to lecture in Berkeley at the Graduate Theological Union, and by then I was beginning to be worried, well, let’s just say, concerned.

When I arrived in San Francisco, I called my friends John and Lynne Simpson from the airport. They were soon to leave for Hawaii to see their son, J.D. Simpson, play basketball for our alma mater, Duke. We wouldn’t be able to get together on this trip so we visited a bit by phone. Lynne told me John had recently been diagnosed with multiple sclerosis. Almost too eagerly, I asked what his first symptoms were.

“Numbness,” she replied. Numbness. I was struck numb by her remark. Numbness was the symptom I had developed. Perhaps I had multiple sclerosis. For the next two hours as I went through baggage claim, car rental, and drove to the East Bay where I was staying, I tried to imagine what my life would be like with MS. I was scaring myself with my fantasies. MS runs in our family. I have watched several aunts and uncles

live with it. They have had good lives, but MS has been tough on them. I could live with MS. It wouldn't interfere too much with my life as a psychiatrist and as a teacher and a writer, but it would mean an end to my new career as a triathlete, which I enjoyed so much. One of my favorite activities has been my bicycle team, Team Psych, a group of medical students and faculty who ride each year in the MS 150 to raise money for multiple sclerosis. Ironic!

But of course it might not be MS. There are other things it could be, a brain tumor, for example. That would be worse, or would it? What a stupid question to ask. I wouldn't get to choose my illness. It had chosen me. It could be something minor, a neuropathy or neuritis, an inflamed nerve, a temporary viral illness. It could be nothing. It could be an hysterical conversion symptom, some repressed unconscious conflict. That would be the most likely possibility. Nah, I know myself too well. All those years in psychoanalysis.

In retrospect I realize the symptom had presented even earlier, perhaps August, in a not quite yet perceptible form. I thought I felt some pressure in my lower jaw. My dentist referred me to an orthodontist, who did a very thorough evaluation. Something was wrong, but it wasn't orthodontic, and at that point I didn't take it too seriously.

There was another symptom, which I did not recognize as such at the time: chest wall pain. This also began (or became perceptible) around the same time as the chin numbness though I did not associate the two until several months later. In medical school I was taught to try to explain as many symptoms as I could by one disease process, the law of parsimony. I teach my own students this, and I particularly emphasize the discipline of

differential diagnosis. Consider all possibilities before settling on your diagnosis. There is a medical saying: if you hear hoof beats outside, don't assume it is zebras. Consider common things first. But do consider zebras. My psychiatric colleagues sometimes tease me for teaching medical students to consider zebras. They say I do it was because I did a medical internship. Yes, that's the point. That's why psychiatrists are doctors. Sometimes unusual physical disorders cause psychiatric symptoms. The opposite is also true. Sometimes psychological conflicts manifest as physical symptoms.

I attributed the thoracic pain to pulled muscles from athletic activity. My exercise log shows that on October 28, I noted a pulled muscle on the right side during a massage therapy session. This pain, however, whatever it was, was beginning to affect my training. While it didn't affect my running, the twisting motions of swimming became difficult. I pressed on and continued training for the Memphis Marathon, which I ran on December 7. I remember that Thanksgiving weekend in California, playing tennis with the my hosts, the Post family, and noting some limitation of movement, but I was thinking strained muscle and forgetting possible zebras.

I have been playing tennis with Steve Post for years. Steve shared my sense of adventure, and over the years, we had shared some great adventures together. Once in Maine we decided to swim across Lake Messalonskee, about a mile across. No words were exchanged in making this plan. We looked at the far shore; then we looked at each other and dove in. Sue and Meg sat on iron chairs on the dock, watching our ladpoles, Will and Cliff and their ladpoles, Will and Tom and Patrick, frogging in and out of the water.

Another time when I was in San Francisco for a meeting, my Avis

rental car was struck by a speeding motorist on the San Rafael-Richmond Bay Bridge, bounced off the side of the bridge, and flipped onto its roof. I emerged shaken but unscathed except for a minor post-traumatic bridge phobia. Steve took me to Calistoga for a mud bath, wonderful therapy to soothe body, mind and spirit after such a jarring experience.

Our adventure on this occasion was a twelve-mile all-day walk across San Francisco. Breakfast was at the Presidio Golf Club. Then up and down over the hills of San Francisco, Russian Hill, Nob Hill, Telegraph Hill. Each meal was in a different neighborhood. Lunch was Asian fusion cuisine in North Beach, spicy Thai chicken and Asian pears. By mid-afternoon we were ready to refuel with a high calorie desert in the Embarcadero, chocolate ice cream brownies-- a “proper” training meal athletic endeavor. The nice part about marathon training is that you can eat anything with calories. Anything and often. Dinner was in Chinatown, Sichuan-style Alaskan crab legs. San Francisco is such a cosmopolitan city that really knows how to excite the senses. Sue and I were engaged in San Francisco, at Coit Tower. San Francisco always brings back the sweetness of early romance and young love.

This time a pall hung over Steve’s and my adventure. We did not know then that a cancer was lurking. The more immediate threat seemed to be managed care. Steve and I had wonderful medical educations. We had trained at the best programs and worked hard to be the best doctors we could be. Like so many physicians, we were finding that managed care impinged on the quality of care we had learned to deliver. Now we were being forced to compromise quality care for short-term corporate profits.

Throughout our long friendship, Steve Post and I have had a

numerous conversations about the practice of medicine. I admire the way Steve practices ophthalmology because he integrates the psycho-social care of his patients into his practice. He and his office staff in Alameda, speak four languages, Spanish, Vietnamese, and Korean, as well as English, but still he laments the limitations in serving people who do not speak one of those languages.

Shortly before my arrival, an article in one of the ophthalmology journals particularly annoyed Steve. It was called “The Ten Minute Cataract.” It implied that a well-organized practice should be able to do six cataracts an hour. The doctor wouldn’t even need to speak to the patients. She or he certainly wouldn’t need to spend time with the patients to understand their concerns, answer their questions, or give them reassurance.

By Christmas, my symptoms were worse. Chin numbness had occasionally become painful, and the chest wall pain had become more pronounced. It was time to start thinking about a work-up. I was still reluctant to think of the chest pain as anything other than an athletic injury. We went to Maine for Christmas, a modern version of over-the-river-and-through-the-woods and up the interstate to Grandmother’s house we go. En route, we stopped in Philadelphia to visit Matt and Janet Stern, friends from student days at Duke. Matt greeted us at the door of their new house and gave me a big, manly hug. I winced in pain. Something wasn’t right.

Matt is a neurology professor at Penn. Later that evening as Matt drove me to the airport to pick up our son Cliff, who was flying in from Reed College in Oregon, I asked Matt what sort of work-up he would consider for chin numbness. We were having this conversation as we drove past the boathouses on the Skukyll River. Outlined in white lights, they

suggested an air of festivity. Matt allowed that there were several horrible possibilities (brain tumor was understood, but not mentioned). But probably it was nothing. Wait a month and see if it got better. Temporize. Matt didn't want me to think about the worst, and he didn't need to remind me.

By early January (1998), numbness became real pain. Work was a distraction to the pain, which wasn't much of a problem during the day. By evening the pain was at times searing and demanded undivided attention. I went back to my dentist. He did a careful evaluation that included Panorex films and electrical conduction studies. He found nothing. He referred me to an oral surgeon. Nothing. Nothing was actually a nice, definitive answer. One of my colleagues was told he had an "allergy" to the mercury in his fillings and spend months having them drilled out while his cancer marched forward.

I wasn't particularly alarmed at this point. Perhaps I should have been. Perhaps this was the shadow side of athletic training, enduring pain stoically. No pain. No gain. I didn't really believe this, but I was acting as if I did.

One decision needed to be made sooner rather than later. I was taking a medication, Lamosil, one week out of each month for four months for a toe nail fungus. One of the possible side effects of Lamosil is peripheral neuropathy, so I inquired of my internist, Dr. Ken Olive, a colleague in the University Physicians Practice Group, whether I should continue to take it. He asked me to come into the office the following day and directly began a thorough work-up of a real symptom that led to the diagnosis of an illness, cancer, where early intervention is critical in prognosis. He ordered, in addition to the usual blood studies, an MRI (magnetic resonance imaging).

The MRI was normal, effectively ruling out the two diseases I worried about most, MS and brain tumor. Think zebras. But the sed rate, a non-specific indicator of disease, was elevated to 53 (normal is less than 20). Several things can cause it to be elevated, including the kind of inflammations that go along with infections. I had a winter virus at the time and didn't think too much about it. Dr. Olive asked me to get this repeated. Perhaps the chin pain was caused by a trigeminal neuralgia, a painful, but self-limiting condition.

Meanwhile, my chest wall pain had progressed. I was having to sleep in a reclining chair, because I couldn't roll over in bed. I was getting physical therapy for "pulled muscles," but found lying on the treatment tables painful. One of our medical students, Mary Beth Deering, who was a physical therapist prior to medical school, sat down with me and took a two-hour history. She went over every movement, every aspect of the symptoms. She went over my exercise log to develop a chronology. She compared function to the neuromuscular and skeletal anatomy, and concluded that I had a misalignment of one of the thoracic vertebrae, perhaps caused by massage therapy. She referred me to a physical therapist, who understood this kind of injury and who was big enough and strong enough to reduce the misalignment in someone my size (6', 1", 190 lbs).

He did the particular release maneuver, and instantly I felt better. With this problem solved, however, it soon became clear that there was another problem this one was obscuring. There was a zebra outside the door, pawing and snorting and demanding attention. I had spent several weeks now focusing on one aspect of a complex problem and ignoring the other. I had not related the thoracic pain and the chin pain as symptoms of

the same disease process-- was this denial? I knew it was a violation of the law of parsimony.

I had not yet mentioned the thoracic pain to Dr. Olive, thinking it would soon be resolved, but now it was taking center stage. I had learned to live with the chin pain, not really too bothersome and relieved (temporarily) by analgesics, acupuncture, and alcohol. The repeat sed rate came back at 107, alarmingly high. Dr. Olive called my office and told me he wanted to see me that afternoon. He wanted to go over me from head to toe. I am very grateful that he did not dismiss the symptoms and did not wait. He jumped on them like a duck on a June bug. He took the symptoms more seriously than I did. He later said, when my case was later presented at a medical school grand rounds, that such symptoms are most likely “functional” (psychogenic), he had known me for a long time, and I had never complained of anything before.

He did a complete physical exam, carefully palpating for swollen lymph nodes. There were none. He ordered a complete battery of tests including blood tests, chest, spine and rib X-rays, lyme disease titre (a real possibility for people who spend a lot of time outdoors in New England and could be exposed to deer ticks). He was working from a complex differential at this point, and he was considering zebras.

These studies revealed a number of abnormalities including elevated calcium and lowered hemoglobin (anemia), which promptly led to the specific diagnosis. I got the diagnosis on “Match Day,” March 18, the day the fourth-year medical students learn where they will match for their residencies. Their preferences are matched with the preferences of the training programs by a big computer. It is like a computerized dating

service. They get the results of their match in a sealed envelope. I too got my fate in a sealed envelope that day.

I stopped by the radiology department to get the results of my X-rays. I asked the receptionist for a printout of my report, which had been done the day before. She informed me politely but firmly that she could not give the report to the patient, even if the patient were a doctor. Johnson City Medical Center still subscribed to the paternalistic view that patients should be protected from information about their illnesses. I had spent enough time in hospitals to know what to do next. The next step was to wait politely and expectantly. If that didn't work, I could go beyond the receptionists. The supervisor, however, said they could print out reports and put them in envelopes for patients to take to their doctors. So I took my envelope, went out into the hall and read the following:

**The ribs reveal numerous punched out lytic lesions consistent with multiple myeloma or metastatic cancer. There is also evidence of recent fractures.**

I was overwhelmed. But strangely I was also relieved at the same time. Suddenly I was caught in a maelstrom of wild emotions. My mind struggled to hold on to a bit of rationality. I didn't have a brain tumor. It was a different kind of cancer. This explained the symptoms I was having. This explained the chest wall pain and the limitations on mobility. With a diagnosis I could get treatment. I was confident this could be treated. At least knowing what it was, I was confident I could deal with it.

In retrospect, I think I had known or at least suspected that it was cancer all along. I was in denial, as the literature says a patient will be at first. I wanted to pursue other possibilities, other explanations. Perhaps I

lost a bit of time, a few weeks, a month or so before I got the sed rate repeated, but here it was. During that period, I was thinking about cancer. Not me, the MRI had ruled out brain tumor, hadn't it? But I read Reynolds Price's book, *A Whole New Life*, about his ordeal with cancer (and his treatment at Duke). I remember as I read this thinking to myself. "Something is wrong, we have to figure out what it is." I also showed a group of medical students the film, *The Doctor*, at one of our Psychiatry Interest Group's "Movie Nites". It is a film about an oral surgeon who gets laryngeal cancer. He is a particularly arrogant physician, and as a patient, he encounters physicians much like himself. Consciously I wanted students to reflect on the pressures of their training and not let themselves fall into identifying with the hostile arrogance they will sometimes encounter in their training. Unconsciously, I was fixated on the story of a doctor with cancer.

I put the envelope with the diagnosis into my pocket, and returned to my office. I stared blankly at my computer screen in bewilderment as if it would offer some explanation. The default screen was a picture I downloaded of Mt. Rainier, which Sue and I were planning to climb later in the spring. Rainier, the computer, the walls of the office were all an indistinct blur. The phone rang. I raised the receiver from its cradle as I one does. It is the only way to stop the ringing. The receptionist announced Dr. Olive. He said he would call. His office was fifteen feet from mine on the floor below. He could have been across in another world.

"Ken," I said almost emphatically.

"Allen, I have the results of your studies and would like to go over them with you. Can you come down this afternoon?"

"Let's see. I have patients scheduled at two and three. Will four

o'clock work?"

"That will be fine."

"And, Ken, I have seen the X-ray report and know what we will be talking about."

"Would you like to bring Sue?" he asked.

"She is in Germany and won't be back until Saturday."

"Okay, four o'clock then."

I hung up the phone and began to cry. Somehow the knowledge that someone else knew of my misfortune confirmed the reality. It was now 11 o'clock. I had a patient scheduled who was already in the waiting room. Could I put aside my own feelings for an hour and do psychotherapy? I couldn't send him away; that would be too dramatic. Carry on. That's what you do in medicine. Put your own feelings aside and carry on. Fortunately in psychiatry you learn that you have to come back to your own feelings. You do have to deal with them somewhere. Unfortunately, many physicians do not get a chance to do this. Some training programs discourage residents from getting help. They focus on the technical aspects of medicine and ignore the person. At Duke, where I trained, psychotherapy was very much part of the training not only in psychiatry, but in medicine as well.

The next hour was the noon hour. It would be my third hour of living with the awareness that I had cancer. The novelty was excruciating. What was I supposed to do? How should I conduct myself? Noon was the hour on match day when the medical students would assemble to find out where they would be doing their residencies. Faculty would join them at Gatsby's Restaurant, where they would open their sealed envelopes and learn their fate just as I had opened my sealed envelope and learned my fate. Could I pass

up the opportunity to share in the emotions of this occasion? Could I bear to sit in my office and fight tears? I decided I would join them. After all I hadn't officially received the diagnosis yet. I had only inadvertently seen X-ray report. Carry on.

As I drove out of the parking lot of the University Physicians' office building, I saw Ken Olive crossing the street to the Medical Center. He would be reading my X-rays himself. Later I would also look at the films myself. Several ribs were broken like matchsticks with frayed ends floating loose in space. No wonder I couldn't roll over in bed. No wonder I couldn't lift weights.

As I drove down the State of Franklin Road, the lush Tennessee countryside might as well have been a sand desert. The green Appalachian Mountains that came right into the city could as well have been barren rock outcroppings for all I noticed. Although Gatsby's was familiar to me, as I had shared other match days with other classes, it felt uncomfortable. I felt so uncomfortable I might as well be entering the uncertainties of a cantina on some remote planet. Although none of these healthy physicians-to-be was smoking, the room was filled with a blue haze and it was hard to focus. All of the creatures looked familiar, but suddenly I was an alien. The image was a negative of the reality I had known. Black was white. Up was down. My previously ultra-healthy body was destroying itself from the inside. Monstrous invading cells were destroying my bones from the marrow where they lodged and were multiplying out of control. I knew instinctively that I had to be here surrounded by people, but I didn't know how I could communicate what I had just learned about myself.

The first person I saw was Keith Brown. Keith had ridden with my

bicycle team, Team Psych. He had recently taken up triathlon and challenged me at my own sport. Ordinarily triathlon is a solitary undertaking. You compete against yourself, your own best time at the distance. Or you compete against some stranger in your age group. Keith and one of his college buddies decided they would take me on. We had done triathlons in Tennessee, Alabama and Georgia. The Georgia meet was our championship. It was a logistical challenge worthy of a military operation. It was sandwiched between meetings I had in Washington and Nashville, airplane flights and road trips.

When I saw Keith at Gatsby's Restaurant, I began to relax. He knew instantly that something was wrong, Something was different. He already knew something was wrong. For weeks now, I had been unable to do our usual workouts. A few days earlier Keith had seen me in the lobby of the Clinical Education Building, backing through a door. He said, "You look awful." It was the kind of honesty you could count on from a true friend. I didn't know what to say at this point, so I said nothing.

I wandered through the room, greeting people as I passed. Steve Loyd was the president of his class. Mary Beth Deering was also a triathlete. She was the only person I knew beside myself who had actually done an Ironman, the grueling 2.4 mile swim, 112 mile bike, and 26.2 mile run. She commented on my size. She said that it was always a pleasure to draft behind me on the bike. I was used to having medical students draft behind me, following in my wake. Now I needed to enlist them as allies on this new journey on which I was about to embark. Join me please. The Millennium Falcon awaits outside. I'll take all the risk. Come along for the ride.

Next I ran into Glenn and Susan Douglas. Glenn would do internal medicine and Susan psychiatry. Glenn had ridden with Team Psych and had talked of running marathons. I said cryptically that I would be meeting with Dr. Olive that afternoon, but I wanted them to know right now that no matter what he told me, I had not run my last marathon. It was certainly a veiled disclosure, but at least I could bring myself to say something.

Glenn accurately perceived this as a somewhat ominous twist to marathon plans, and immediately called his father, the cardiology professor, our across-the-street neighbor, and asked him if he knew what was going on with Dr. Dyer. John Douglas called Ken Olive, who suggested he talk to me, which he did. I told him about the x-ray report, and he offered to be with me at 4 o'clock. I sensed when I met with Ken Olive that it was as hard for him to deliver this news than it was for me to receive it. That observation warrants reflection. In part I was in denial, not of the reality of the diagnosis, nor even of the emotional meaning. All that was clear. But I was holding my feelings in abeyance. University Physicians and Dr. Olive in particular make a point of teaching residents and medical students how to break bad news. Telling patients the truth about their diagnoses is still not entirely accepted, but is coming to be recognized as part of caring for a patient, emotionally as well as physically,

That evening John and Dorothy Douglas invited Susan and Glenn and me to a dinner gathering celebrating the match results and their March birthdays. It was a bizarre horoscope, four pisces and a cancer, my new and scary diagnosis. In spite of the cancer in our midst, it was a festive occasion, a celebration of friendship and of hopes for the future. It might otherwise have been the loneliest day of my life.

Sue, my wife of twenty-nine years, was in Germany on a business trip. Had we been able to choose, this is not the way it would have happened. We have been at each other's sides through good times and bad. But, these are not the kinds of choices we get to make. Through decades in academic medicine, it was usually I who did the traveling, but now the boys were grown; both were in college, Will at the University of Vermont and Cliff at Reed College. Sue had her own career, teaching English literature at East Tennessee State University, and doing technical writing for Siemens Energy and Automation. It was Siemens that sent her to Germany.

In fact diagnosis day was the day Sue and her colleagues were planning to go to the opera, *Madama Butterfly*, another birthday party. When she announced their plans, I said I would fly over for the night. Sue said she had told her friends I would make that remark. So although we were not physically together, we were united in the spirit of piscine celebration with mutual friends on both sides of a large ocean.

Sue and I had agreed that since she would only be gone a week and because of the time difference, we would not try to call back and forth, but use e-mail instead. Suddenly I realized I was at a disadvantage. I didn't want to leave this news on a stranger's e-mail, yet I didn't want to wait it until she got home. I tried to tell her what I could. I told her I was being "fleaed up," medical slang for doing a medical work up. The fleas are all over you. I told her there were some abnormalities showing up in the bones. I told her there would be more tests, and that I would share the results with her when she got back. I did not tell her that I had cancer.

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Date: March 19, 1998

Subject: Fleaing

Dear Allen,

I don't like the sound of all this fleaing. I hope everything is all right. Madam Butterfly was magnificent. We also went to dinner in Strasbourg. We'll be home soon.

I love you.

Sue

---

I told Sue the details of the workup and diagnosis when she got off the plane. Airports are often the site of separations and reunions, departures and arrivals, attachments and loss. The rides to and from airports become occasions for some of life's most important conversations. I tried to be matter-of-fact, but facts do not obscure feelings when cancer is being discussed. It was a very emotional ride home. Before we got to the only traffic light in this part of Tennessee, we were both in tears. I stumbled over the details of what I had been through. Sue was impatient. "Do you have cancer?" she demanded.

When I acknowledged that I did, she cried. When Sue cried, I cried.

A few hours later Sue returned to the airport to pick up Cliff returning home for his spring break. She shared the news with him. When he came through the door, he hugged me and seemed to be able to be more matter of fact than Sue and I had been.

"So, Dad, Mom tells me you have cancer." I was relieved that he knew. We were all learning how to deal with this unwelcome news and

unfamiliar reality. Cliff and I sat side-by-side in the kitchen talking over the details, facing an uncertain future. We were all trying to make things right in whatever way we could.

The next day we called Will in Vermont and told him the news. Though Will was far away physically, he remained close by phone and frequently expressed his concern. Often our calls had been to discuss what was going on in his life. Now the tables had turned. I took great comfort in the genuineness of his concern and in his maturity.

Dr. Olive's work-up proceeded directly to the diagnosis of multiple myeloma with John Douglas making sure there were no delays in scheduling. A bone scan performed was performed at the VA Medical Center because it could be scheduled there sooner. Even though I am not a veteran, I have a WOC (Without Compensation) appointment at the VA and donate time to their teaching programs. The bone scan revealed lesions throughout the spine and ribs more suggestive of multiple myeloma than a metastatic cancer, such as prostate or testicular cancer.

Ten rib biopsies were necessary to get enough bone marrow aspirate for a pathology slide. This was a dramatic time not only for me, but also for Dr. Don Donovan, whom John Douglas had selected to do the biopsy. He returned from vacation Monday morning to find a faculty member on his schedule. That faculty member was accompanied by a retinue of physicians. Cliff was there. Sue was there.

I allowed myself to be placed on the procedure table, stripped to the waist, and resolved to accept whatever was done to me without complaint. I wanted this done right. My life depended on it. A bright light was focused on my chest. It was the kind of light that might be focused on a criminal

suspect. I was under scrutiny. I let others do the focusing. I stopped focusing. I heard voices that sounded calm and reassuring as they talked over me. For some this seemed a routine procedure.

A rib biopsy is a fairly delicate operation. A trocar is inserted through the skin and into the rib. A trocar is a huge needle, not to be confused with the kind of needle used in sewing. The word “trocar” means “sword”. It requires enough pressure to get through the rib, but if too much pressure is applied, the trochar goes through the rib and punctures the lung, causing a pneumothorax (air in the lung), a serious complication.

Dr. Donovan was skilled at his craft, and I trusted him completely. He had to go into ten ribs in order to get enough tissue for a pathology slide. The pathologist examined each aspirate. “No, not enough,” she said over and over. Fortunately Dr. Donovan remained cool, and stuck another rib. Each aspirate was actually two sticks, a little needle to inject numbing medicine, then the trocar. After four aspirates, I learned that I could forego the numbing medicine and reduce the number of sticks.

Dr. Donovan finally came up with the needed cells. He produced a field of cancer cells, enough to confirm the diagnosis. Later the pathologist showed me the slide through a two-headed microscope. It did reveal a field of swollen balloon-shaped cells with huge blue nuclei, aesthetically beautiful, but menacing if you thought about how those blue cells were bullying aside the normal cells.

The next procedure was a very painful bone marrow biopsy and aspirate in the hip. No cancer cells were found at that location. Dr. Chad King had done hundreds of these procedures. He offered narcotic analgesics, but I didn't think they would be necessary. That was poor

judgment on my part, which I would later be able to reconsider when I realized that monitoring bone marrow biopsies was to become a regular feature of monitoring my cancer treatment. Bone is extremely sensitive to pain, covered with lots of nerve endings. I winced when the trocar was inserted. The pelvic bones are much stronger than the delicate ribs.

“Ugh, this is for Sue, I thought.”

Then an expletive from the usually mild-mannered Dr. King.

“Damn, I hate it when that happens!” The slice of tissue had broken and the needle had failed to aspirate any marrow. The procedure had to be repeated. It was no less painful the second time. I decided I would accept narcotics for subsequent bone marrow biopsies and aspirates. These were for science, for the research protocol.

The serum protein electrophoresis (SPEP) confirmed the diagnosis. It revealed the presence of a gamma protein spike characteristic of multiple myeloma. A Skeletal x-ray series revealed lytic lesions in the chest, spine, skull, humerus (arm), but none in weight-bearing bones. The beta-2 microglobulin was elevated but just barely, suggesting an intermediate prognosis: 60 months to live, 5 years, according to the textbook, which I and a lot of my colleagues were following closely.

It was understood that I would go to Duke for treatment. Sue and I had spent seventeen years of our lives there. Our children were born in Durham. I graduated from Duke medical school, did my internship and psychiatry residency and psychoanalytic training there. I also did a Ph.D. in medical ethics in the Department of Religion and remained on the faculty for many years. Sue did her Ph.D. in English and American literature there. John Douglas had also trained at Duke, and Ken Olive was a Duke graduate.

Duke was very much part of our lives and would soon become even more so. Sue spoke with old friends in Durham, who helped arrange a prompt referral. An appointment was set up with an oncologist specializing in myeloma, Dr. Joseph Moore, a former colleague of mine. A treatment plan was developed and treatment began without delay.

**Broken ribs.** In 1942, the year my parents married, two years before I was born, my father bought an Old Town Maine Guide canoe. It was (and remains to this day) a magnificent classic wooden boat, twenty feet long, lined with birch ribs, covered with canvas, painted dark green. We have cared for it well. It has lasted for decades. It is older than I am. It is Sue's favorite mode of transportation. We have generally used it on Lake Sebasticook, in my home town of Newport, Maine, on quiet days, when the lake is calm, but it has handled lake squalls when necessary, pounding through white caps.

This is the canoe traditionally used by Maine Guides on the rivers of Maine, where the going is a little rougher. White water rapids, full of rocks, challenge the guides and the canoe. The Old Town Canoe was built to take it, year after year. There is a particular romance surrounding the Allagash River, which has since become a national waterway. When I was in high school I became a Registered Maine Guide, which means I was licensed to take people into the woods for fishing, hunting, canoeing (and now sea kayaking has been added to the list). The pay wasn't great (about the same as working in the shoe factory, which I did one summer), but the work was a lot more interesting.

Usually I used aluminum canoes or fiberglass, but on occasion I

would take my father's Old Town Guide's canoe. Aluminum canoes dented, popped rivets, were always wet inside, and made tympanic noises when they bumped against rocks. No self-respecting Indian would ever have used such a vessel. We believe native Americans liked to go quietly through the woods. Fiberglass was an improvement, but I have seen a fiberglass canoe bent in half from the force of the water in a rapids. Built on the model of the birch-bark canoe, the Old Town wood-canvas design made for a surprisingly durable canoe. It could take a beating. Even if you broke a few ribs there were lots more. Even if you punctured the canvas, it could be patched. Even if you took on a little water, it settled between the ribs. And if you ran into a rock, as you inevitably would, the canoe would bounce off. If you tore the canvas, it could be patched.

Though I never would have thought of the analogy at the time, since I have given so much attention to ribs, it occurs to me that the human body is remarkably similar to a canoe. The rib cage is made from the most fragile and delicate bones, yet organized in a way to protect the most vital organs, the heart and the lungs, liver and spleen. Though ribs are easily broken, they are easily healed. Even if one or two or three are broken, there are others to maintain the structure of the thoracic space.

So far from my imagination were broken ribs that when it happened, I didn't recognize it. Call it denial; call it disbelief; it was quite a shock. And when the ribs became fragile, it didn't take much to break them: lifting a bookcase, rolling over in bed, shoveling snow, gardening, lifting weights, yoga, massage.

The night before treatment was to start, Sue and I went to a Chinese

restaurant and went to see the latest Jackie Chen movie (*Mr. Nice Guy*). I laughed so hard I broke another rib. It was painful, but bearable. The laughter had compensatory benefits, well worth the trade off.

Our fortune cookies that evening seemed particularly auspicious:

A faithful friend  
is a strong defense.

Everyone around you is rooting  
for you. Don't give up!

I had no idea what I had gotten us into or what was in store for us. But I did know that whatever happened we would not be alone.



**Team Psych, 1995**

## 2. Talking About Cancer

When I was in medical school in the late 60's and early 70's, we still heard debates about whether one should tell cancer patients their diagnosis. Those that argued that you should not tended to come from the old paternalistic school of medicine. They argued that to tell people a hopeless diagnosis deprived them of hope. Already patient autonomy was being recognized, and informed consent was very much part of the medical landscape, especially for research protocols. Cancer treatment was not always hopeless. Other voices argued that patients had a right to know what was going on; it was simply good medical care. Illnesses had psychological as well as physical dimensions.

One of the most forceful voices in favor of talking with patients was Dr. Elizabeth Kübler-Ross. Dr. Kübler-Ross was a psychiatrist who worked with cancer patients, particularly children with cancer. I attended one of her workshops. She was fiery, passionate, moving. She asked children to draw pictures and then talk about them. She showed slides of the pictures. Time after time she was able to demonstrate with pictures of tanks, bombs, and explosions, that children knew they had cancer or some destructive illness. And they wanted--indeed *needed*--to talk about it. Time after time, she demonstrated that it was the grown-ups, doctors as well as parents, that avoided talking about what was going on, perhaps out of their own fears or anxieties, insecurities about the illness, or even the fear that they would not be able to deal with their own feelings. Dr. Kübler-Ross's talks were a passionate and poignant indictment of her medical colleagues. Of course

all of us medical students promised ourselves we would never be as callous as the physicians Kübler-Ross described. Much of the time we lived up to our promises to ourselves, notwithstanding our own difficulties in facing up to the feelings we encounter in dealing with death, suffering, and illness--notwithstanding the feelings that being a doctor stirs up about facing one's own mortality.

Dr. Kübler-Ross offered a framework for discussing feelings. She suggested a developmental process that dying patients (and those facing loss) experience. She suggested stages that people progress through: denial, anger, bargaining, depression, acceptance. She suggested the need to recognize which stage a person is in and the importance of the physician in being with patients and helping them move through the stages to acceptance. Kübler-Ross's stages have become so much a part of our cultural heritage that you will hear patients, families, physicians, and counselors refer to "the stages." Recently I ate lunch with a ski patrol member whose father had undergone treatment for two cancers under Dr. Moore's care at Duke. He observed that his father and he went through the stages much more quickly the second time around.

Ever since my encounter with Kübler-Ross, I have been fascinated with this model, what it explained and what it didn't. When I developed cancer myself, I couldn't help becoming my own experiment in testing the observations I had been teaching. Would I go through these stages? Does depression inevitably accompany loss or is it a result of suppressing anger, turning it inward? Could depression be avoided, as I liked to suggest, by providing patients an opportunity to talk about their feelings, especially anger?

Talking about feelings is a difficult enterprise. The words we have for feelings are largely abstractions. We have few expressions that locate feelings as sensory experiences in the body. We might describe someone as a “pain in the neck,” which is more of a metaphor than a physical description of pain. We might say, “I feel despair.” In order for someone else to understand that feeling, they would have had to experience something similar and learn to identify it with the same vocabulary. To describe a wine as “fruity” means something to someone who understands that vocabulary. A certain connoisseurship is required. Eskimos have more words for snow than the English language has for feelings. So what’s a guy gonna do?

In the early weeks of living with the awareness that I had cancer, I felt miserable, but didn’t quite know how to communicate that misery. I had gotten beyond denial and was probably somewhere between Kübler-Ross anger and bargaining. A personified God would be useful at this point, someone to blame, someone with whom I could strike a bargain. But my theological views did not include a willful God or an entity that would sit down and negotiate every petty grievance. I did not think of God as a gray-bearded old man sitting on a cloud parceling out illness and misfortune. I tried to imagine a chic woman sitting behind a computer terminal with whom I could plead for a new program. This image was even less successful.

At every stage of my illness, there was someone to offer the gift I needed. When I was struggling for words to express my distress, our son Will wrote a paper for his German class that provided just those words. He wrote about a medieval German poem, “*Der Ackerman und der Tod*” (The Farmer and Death). In this poem Death visits an elderly farmer. Death has

come prematurely for the farmer's wife. At first the acre-man does not receive Death well; his wife was too young. But Death is patient, and counsels the farmer that everyone must die. Will characterized the stages the farmer goes through as

Unglaube (disbelief),

Zorn (anger),

Selbstmitleid (self-pity),

Traurigkeit (sadness),

Gott flehend (pleading with God), and

Anerkennung (acceptance, literally acknowledgment).

Perhaps Will was going through stages himself. He didn't say, and we didn't ask. Every time he called, he asked directly, "How is the treatment going, Dad? How are you doing?" He couldn't have been closer at those moments even though he was a thousand miles away in Vermont.

The words Will had chosen seemed much closer to my experience than did Kübler-Ross' stages. I would have to admit I had been in denial. I knew I might have cancer before I was diagnosed, and I was not surprised. But denial seems like a response to an accusation, a refusal to believe, a stubbornness, a stupidity. "Disbelief" exactly captured what I was feeling. *Unglaube*. Cancer? Me? How can that be?

I could recognize self-pity and sadness as something distinct from the listless lack of energy that is so characteristic of depression. *Selbstmitleid*. *Traurigkeit*. I often found myself driving along in my 7-year old Oldsmobile wondering why me? What did I do to deserve this? What's next? I was often overcome with waves of melancholy, I began to allow myself to use my little commutes to get in touch with my feelings of

sadness. One day when I was feeling my worst, I was invited to lunch with my faculty colleagues Brent and Carol Ann Coyle. Their five-year old daughter had drawn a get well card for me. It pictured a mermaid in a bikini under a vivid rainbow. It read: “Dr. Dyer. Live each day to the fullest.” I sensed that she really understood. I placed the card on our Chinese altar chest as a daily reminder of innocent wisdom.

My old Oldsmobile also became the location for getting in touch with another feeling, hope. Although many of its parts had become worn over the years, the sound system still worked just fine. As I drove around music became an important part of feeling and healing. I listened to an old Moody Blues CD, which wistfully captured the acceptance of things gone not quite the way one might have wished. Their tone of melancholy, moody blues, captured my moodiness. Cancer was a big disappointment, life taking a wrong turn.

One day all of that changed dramatically, however. The mail brought a package of mood elevating, spiritually uplifting music. Laurelyn Douglas, John and Dorothy’s daughter, sent a package of jazz CD’s by her fiancé, trumpeter Jon Faddis. They contained his famous *Legacies*, a tribute to the jazz greats, Louis Armstrong and Dizzy Gillespie, with whom he had played. It won a Grammy nomination later that year. My favorite was movie themes by Lalo Schfrin. Jon is known for purity of tone in the upper registers. And with that purity of tone goes a purity of spirit that is unmistakable. None of these was more inspiring to me and more uplifting than the lilting, driving, rhythmic intensity of the familiar theme from *Mission Impossible*. It became the perfect theme for my battle with cancer. Of course you will accept this assignment. It is time to look forward.

I would hope that physicians today are better prepared to talk with patients about their illnesses than were the physicians Kübler-Ross described. But physicians always face their own existential issues. It is always easier to focus on the technical aspects of care than it is to deal with the complex interactions of feelings and expectations. Increasingly, economic pressures are limiting the amount of time physicians get to spend with patients. One of our friends went to M.D. Anderson Cancer Center in Houston for treatment of breast cancer. She had chosen this hospital because so much important research had been done there. She reported that cancer was never discussed, only the treatment. Another friend who went to Will's Eye Hospital in Philadelphia for treatment of optic nerve cancer reported the same thing. Cancer was never discussed. Only the treatment. Her own psychologist offered to call the Will's psychologist to discuss her reactions to cancer. Will's no longer has a psychologist to talk with patients about their feelings and fears.

My own experience at Duke was much better in that regard. Dr. Moore was most willing to discuss cancer as well as cancer treatment. He was especially helpful to Sue and me in the early months of treatment in understanding what was going on and what to expect. Sue asked, for example, when my hair would fall out. Fourteen to eighteen days after chemotherapy began. When on the fourteenth day all my bushy hair came out in the shower in a Kafkaesque metamorphosis, covering my body and the shower stall, it was actually reassuring in some fundamental way to know that it was right on schedule.

Sue also asked what we needed to worry about. Dr. Moore replied, "Trucks." In his playful way, he was reassuring. "Cancer is probably not

what is going to kill your husband, Mrs. Dyer.”

One of Dr. Moore’s pearls of wisdom I will never forget: “Our days are numbered,” he said (whether we have cancer or not). “We just don’t know what the number is.” We don’t get to choose. We just accept what we get. And I wanted to do whatever I could to maximize that number.

Joe Moore and I had been colleagues on the Duke faculty. He, in fact, had written a paper with a neurologist friend of mine on mental nerve pain (chin pain) as a presenting feature of certain malignancies including multiple myeloma. One diagnosis was in fact explaining all the symptoms. Parsimony. Dr. Moore outlined a treatment program to include Bone Marrow Transplantation. He said it might be possible to “make the cancer go away. No guarantees.” He never used the word “cure”. I have never heard an oncologist use the word “cure”. Dr. Moore set up a lunch hour, work-in appointment the next day for me to meet the new director of the BMT program, Dr. Nelson Chao, whom Duke had just recruited from Stanford in a push to make the Duke program one of the premier programs in the country.

Bone Marrow Transplantation is an aggressive procedure. It involves several rounds of low-dose chemotherapy at monthly intervals, followed by several rounds of high-dose chemotherapy, killing not only cancer cells, but lots of good cells as well, i.e., anything that is growing: hair, skin, gut, enzymes that control protein synthesis and all body functions. After the high-dose chemo, stem cells (baby cells which later grow into red blood cells, white blood cells and platelets) are harvested. These stem cells from the bone marrow will be given back--the “rescue” after the final rounds of chemo. Bone Marrow Transplant (perhaps better called Stem Cell

Transplantation) has been described as the treatment from hell, a last-chance therapy for the desperate. It is designed to kill as much of the body as possible without killing the patient. Sometimes it is not successful in that it does not kill the cancer. Less often it is not successful in that complications of the treatment do kill the patient. But if you survive this, entire Bone Marrow Transplant does offer the hope of a complete cure, a complete remission.

Prognosis is much better now that the treatment is being more widely used, and it is more likely to be successful with early intervention in cases such as my own. When we first met Dr. Chao, it was in one of the small examining rooms in the old Bone Marrow Transplant clinic, a cramped building that was to be replaced by a modern, new facility by the time I would undergo treatment. Dr. Chao sat at the small desk while I sat on the examining table. Sue sat in the only other chair the room could accommodate. He told us that the success rate for complete remission was now 30%. I immediately “decided” (or determined or resolved) that I was going to be part of that 30%. Sue said playfully, “Why not? I was above average in everything else.” Sue was from Minnesota, not far from the mythic Lake Wobegone, where everyone is above average. One of the things Dr Chao asked about was my time at the Boston Marathon. At first I was surprised by the question. Was there a qualifying time for the Bone Marrow Transplant? Dr. Choa had run “Boston” when he was a student at Harvard. His time was 3:52, which coincidentally was my time as well. A bond. A kinship these two competitive physicians shared.

Dr. Chao indicated that the death rate for the treatment was 1-3%. This I knew was a dramatic drop from only a few years earlier when the

death rate was 10-15% or higher. I decided these odds were good enough for me.

I would receive my own stem cells in a procedure called “autologous transplantation,” thereby avoiding the risks and discomfort associated with allogenic, or donor transplantation. One of the major risks of allogenic transplantation is graft vs. host disease in which the new cells reject the recipient as foreign tissue. I would be spared that risk. When it was learned that I would receive a bone marrow transplant, several people including my sister Polly generously offered to be donors. The likelihood that any individual will be a genetic match is 1:24,000 (better for siblings), but of course one’s own cells are an exact match.

Technically, Bone Marrow Transplantation is experimental. Electing this procedure requires being part of a clinical investigation designed to evaluate the treatment with various diagnoses (myeloma, breast cancer, for example) and to compare variations of the treatment, one chemotherapeutic agent against another. This distinction is important because many insurance companies and managed care organizations had until quite recently refused to pay for treatments that are experimental, and some still do. Within the past few years, most states have passed laws requiring coverage of BMT, but the larger question of who has the responsibility for funding the research that will lead to innovative treatments remains. Insurance companies and managed care organizations argue that their first responsibility is to return a profit to their shareholders, not to the patients they are supposed to be serving.

In order to participate in the BMT for myeloma clinical trial, I was required to sign an “informed consent”. Informed consent is an area I have

studied extensively. I have written many articles and chapters about informed consent and given many talks on the subject. Informed consent is the communication between the scientist and experimental subject that gives the patient the right to choose what will be done to him or her. Some people have argued that there can be no such thing as a freely informed choice because anyone in need of treatment is really in no position to refuse. Informed consent should be the vehicle, which stimulates discussion about the treatment options. Informed consent is often reduced to the consent form.

When I was on the Duke faculty, I served on the IRB (Institutional Review Board), the committee charged with assuring that patients are given enough information in a manner they can understand in order to be able to make as free a choice as possible. We would routinely approve in a matter of minutes 60 cancer protocols in which patients would be asked to risk their lives, while a behavioral science protocol in which someone might experience some anxiety would bog the committee down in interminable discussion about risks and benefits. Duke still introduces about 60 new cancer protocols a month.

I was not surprised, therefore, to find my informed consent gruesomely explicit. “Informed Consent to Participate in a Research Study: High Dose Sequential Therapy and Autologous Stem Cell Rescue for Multiple Myeloma, the Myeloma Protocol.” After Dr. Chao left the little exam room, I sat down in his chair. I read the six pages stoically. I initialed each page at the bottom and signed my name at the end. I turned it over to Sue and watched her turn ashen-faced as she read what I had agreed to do.

“We hope to learn whether this treatment is curative in this disease in

which the average survival is about three years.” The consent form went on to outline the procedures and document the expected and possible complications of the various drugs and radiation. The list was extensive: nausea and vomiting, extremely sore mouth (which may require narcotic medications for pain relief) and diarrhea. It causes severe depression of blood counts with subsequent risk of bleeding and infection. “Permanent sterility is expected.” “Late complications include the development of cataracts which may require corrective surgery.” Decreased blood pressure. Dizziness. Allergic reactions. Decreased liver functions. Peripheral neuropathy. Confusion or headache. Skin rash. Hemorrhagic cystitis. Irreversible heart failure. Sterility (again). More diarrhea. Inflammation of the liver and blood clots in the liver (veno-occlusive disease), “which can prove fatal”. Bone pain. Fever.

“There is approximately a 1% risk of the blood stem cells failing to grow after reinfusion. This complication would be expected to cause death.”

I signed without hesitation, but I did not have a lot of questions at this time. It was all too clear. Death or the possibility of cure. It didn’t seem like a hard choice. Denial was over. Anger had yet to begin. There was nothing to bargain. Let the treatment begin. Bring it on.

Kübler-Ross’s scheme was based on the pioneering work of Eric Lindeman, who studied the survivors and relatives of those who perished in the Coconut Grove nightclub fire in Boston in 1943. Lindeman drew the important distinction between grief and depression, echoing Freud’s distinction between mourning and melancholia. Grief does not necessarily involve becoming clinically depressed, though for some it may.

A new diagnosis is a loss, a loss of one’s former self. Such losses

involve stress. Not only must one adjust to the illness, but one must adjust to the awareness that life is now different. Familiar routines no longer work. Life challenges must be solved anew. Illness can cause stress, but it is also known that stress can cause illness.

With this in mind, I reviewed the stresses in my life and the changes that an academic and administrative career have entailed. I have chosen to live life fully, adventurously. I have voluntarily taken on certain stresses, which for the most part I have managed well, even enjoyed. To equate stress with cancer is probably an exaggeration though stress may be a factor. To blame oneself for cancer is non-productive. Even in cases where the effects of smoking, alcohol or drugs are contributory, it is more important to assume responsibility for the future than to place blame for past mistakes. Nonetheless, I felt I should assess the stresses in my life and make whatever changes seemed appropriate. To that end I developed the following chronicle to serve as part of the medical history as well as to pose certain questions about my health and my cancer in order to make decisions about the future.

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## **Me and My Cancer**

(A Bio-Psycho-Social-Spiritual Approach)

Major Life Events/Changes/Stressors:

**1979 - 1987:** The Duke years - 17 years as med student, intern, resident, chief resident, grad student, assistant professor, assoc professor, psychoanalytic training.

**1987-1992** Albany Medical College:

Associate, then interim chair of psychiatry

Chief Medical Officer, Capital District Psychiatric Center

Psychiatrist-in-chief, Albany Medical Center Hospital

Professor of Health Policy and Management, SUNY Albany

**1992-1995** Chair of Psychiatry East Tennessee State University

**1993** First trip to Nepal

**1994** Cliff decides to leave home at 15 for Northfield Mount Hermon School in Massachusetts and starts school on 10<sup>th</sup> anniversary of my father's death

I take up Triathlon - "the spiritual quest of the warrior athlete"

**1994** –

June - complete first triathlon

July - first Olympic-distance triathlon

(1.5km swim, 40km bike, 10 km run)

Sept MS 150 - 150 mile, 2 day, bike tour, charity event for multiple sclerosis

October 8 - Half Ironman triathlon

(1.2 mile swim, 56 mile bike, 13.1 mile run)

October 23 - first Marathon: Marine Corps in Washington, DC

(26.2 miles)

**1995**

May - Toronto Marathon (Personal Record, 3:52)

Summer - 3 triathlons

August - resigned chair of psychiatry in a political shake-up

Sept - MS 150, Bike Ride Across Tennessee

Oct - **IRONMAN at 50!** (2.4-mile swim, 112-mile bike, 26.2-mile run)

## **1996**

April - Boston Marathon

Dr. Kenneth Cooper presents at sports medicine symposium:  
“Endurance athletes at greater risk of cancer and heart disease  
because of free radical production”

Begin taking antioxidants, the free radical scavengers.

## **1997**

August – 1<sup>st</sup> symptoms of cancer: feeling of pressure in lower  
jaw.

Summer: 3 triathlons, times dropping in all three events in each  
one

Lots of waterskiing, time on boat with friends

10 papers and chapters this year, good progress on new book

Work and play indistinguishable

Happiest, most contented, most exuberant period of life to date

Sue’s 50<sup>th</sup> birthday celebration. (? too much fun makes  
the gods jealous ? too many free radicals from too much  
exercise)

October - Decrease and stop swimming workouts  
because of “pulled muscles” in chest.

October 29 - zero balance massage results in torsion to T10  
vertebra

First awareness of numbness in chin

December 7 - Memphis Marathon (4:00)

## **1998**

Jan - MRI for chin numbness rules out demyelinating

disease (MS) or brain tumor

Elevated sed rate - 53 (normal = 0-20)

Chin numbness progress to bilateral searing pain.

March - physical therapy relieves vertebral misalignment and upper back pain

Sed rate increased to 107

New anemia: hemoglobin 14.8-->11.4

Mon, March 16 - Physical exam--> no localizing findings other than chest tenderness

Chest, spine, rib x-rays

Calcium 10.4 (normal = 2.2 - 2.6)

Creatinine 1.1 (normal < 1.5)

24 hr urine--> no protein in urine (good prognosis)

 -2 microglobulin 3.3 (stage I, intermediate prognosis)

Wed March 18 - Xrays read as multiple rib fracture and numerous bearing size lesions consistent with metastatic disease or multiple myeloma.

SPEP shows monoclonal protein spike, characteristic of myeloma

Fri March 19 - Bone scan --> 10+ hot lesions in ribs, clavicle, one in head, none in vertebrae

DREAM: I am with a group of people: students? Family?

I say: I want you to know I am not dying of cancer;

I am living with cancer.

Mon March 23 - Rib biopsy --> abnormal plasma cells

Wed March 25 - Bone marrow aspirate and bone biopsy  
find no cancer cells

Skeletal survey --> lytic lesions in right humerus, pelvis,  
head and ribs

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Had I brought about my own cancer? Had the stresses of a challenging administrative career or the physical challenges of my marathons and triathlons stressed my body beyond its ability to recover. The particular conversation I was interested in having with my physicians involved the hypothesis Cooper presented at the Boston Marathon about free radicals causing cell damage, cancer, and heart disease in endurance athletes. There were a number of celebrity examples: runners Jim Fixx and George Sheehan dying of heart attacks, Olympic cyclist Lance Armstrong developing prostate cancer. Had I brought about my own cancer by my athletic activities? (Psychologically this would be seen as the self-accusatory stage of a grief reaction). Putting aside the non-productive self-blame, should I return to such activities?

The Duke oncologists were unconvinced. Dr. Moore stated it most bluntly: "Exercise does not cause cancer." Dr. Chao, ever the scientist close to the data, felt that if a correlation existed, it would have been demonstrated by now. But perhaps there just weren't enough Ironmen to reach statistical significance? Dr. Jimmy Vredenberg, who could always be counted on for a trenchant observation: "There are certainly enough marathoners." And Dr. Clayton Smith, as astute at the "bedside" as he was in the lab: "There is always some unproven theory. Free radicals are the current vogue." Then he challenged me to do a triathlon with him next summer. Eager to put

cancer behind me, I accepted the challenge without hesitation. I could live without cancer. I couldn't live without challenges.

The causes of cancer are many and complex. It would be an exaggeration in most instances to suggest that some one thing caused a cancer. Cancer is a genetic disease but not necessarily a hereditary disease. It is a disease of gene dysregulation in that genes direct the replication of all cells. Although certain cancers have been found to have hereditary components, the expression of the genetics is complex, involving a cascade of events in cell replication. Most cells of the body turn over in time. Skin cells, for example, turn over about every seven years. We were told in grade school that we got a new skin every seven years. Cells are designed to die, a process called programmed cell death, or *apoptosis*. The genes on the chromosomes control both the death of the cells and the replication of new cells. Certain genes, called oncogenes, cause the uncontrolled growth of cancer cells, but there are also inhibitory tumor suppression genes, which prevent this from happening. Ordinarily this system of checks and balances keeps the mutations that may occur in the course of day to day living from running wild. But introduction of carcinogenic substances such as the tars in tobacco products may eventually overcome these inhibitory influences. If we live long enough we will all eventually get some kind of cancer or another. Stress (physical, emotional, spiritual) may accelerate that process. It may make it easier for one renegade cell to go on an unchecked rampage. One narcissistic cell unconcerned for the integrity of the organism or the needs of its fellow cells is all it takes to alter the balance of life from harmony to disarray. One selfish cell dividing and dividing, taking what it

needs and wants, becomes a traitor, predatorily destroying its host in the ultimate of ingratitude.

Talking about cancer meant talking about the feelings that cancer stirs up. Not long after our first visit to Duke, Sue and I met with Dr. Olive. We met in an examining room much like the one at Duke. Again as the patient, I sat on the examining table. Sue sat in the only chair. Dr. Olive sat on a rolling stool. I had a dozen questions to ask him about pills and procedures. He answered them very patiently, then said there were several questions he wanted to ask:

“How are you handling this emotionally?”

“How is this impacting you financially?”

“What are your spiritual resources?”

I was barely able to give perfunctory answers to these questions at the time. I recognized that these were the really important issues, more important than what laxative I was taking, but I needed to focus on details. Dr. Olive’s questions percolated into the soul. As I made adjustments to the many changes in my life, I could come back to these larger existential questions and deal with them later.

Another occasion to talk about feelings came shortly after the first trip to Duke. The medical students in our psychiatry interest group wanted me to talk about psychoanalytic training. Psychoanalytic training for me and many of my colleagues was an important opportunity in the Duke and Chapel Hill communities. Even at a time when there were important advances being made in biological psychiatry, having the opportunity to talk about feelings and past experiences in depth was an important part of

becoming a psychiatrist.

The value of psychoanalytic therapy was not just in having a comprehensive theory for explaining human behavior. Many of Freud's views had been challenged, reconsidered, and reformulated. The real advantage came in learning to deal with feelings, openly and honestly, to be able to discuss them, and to be able to tolerate them. Feelings of anxiety and depression are an inevitable part of human experience. The ability to go accept these feelings without having to work to defend against their unpleasantness is a relief that it is hard to appreciate. I have heard it described as seeing the world in color after assuming everything could only be black and white. Psychoanalysis can lift the weight of worry, which eats at the soul, much as cancer eats at the body. Both are threats to wholeness. Psychoanalysis has been particularly important for me in dealing with the challenges I have undertaken in life. This was especially the case when I developed cancer.

Even though I appreciate the value of talking about feelings, I was not ready to talk publicly so soon after receiving a diagnosis of cancer. I accepted the invitation to speak to the medical students more out of duty than desire. I recognized in myself something of the stigma that people with mental illness regularly face with when are blamed for their illnesses. I felt that I had done something to cause my illness. My body betrayed me at a time of my life when I was making health and fitness such a priority. I felt as if it were my fault, a personal shortcoming. I should have done something to prevent or avoid it. I realized in saying this out loud that it was an irrational belief. I did not need to blame myself.

The room was packed on a warm spring evening when everyone

might have enjoyed being out-of-doors. Students came up and hugged their professor. Guys too. One particularly astute student said she enjoyed hearing me express my own views rather than just facilitate them in exploring their ideas. Another (whom I often saw at the local running races) said it did not surprise her that I would treat cancer as a challenge to be mastered.

I discovered that by talking about my cancer--and letting others know what I was facing-- I opened myself to an outpouring of love and support I could neither have imagined nor wished for. Yet there it was. I would never have guessed how important such support would be in the battle that lay ahead.



**Tongue Mountain, Adirondacks, 1989**



### **3. The Early Rounds: Low-Dose Chemotherapy**

Bone Marrow Transplant could be likened to a boxing match. Round after round of chemotherapy. Combinations of punches. Hit you with this. Hit you with that. Deal with the expected. Deal with the unexpected. Sometimes you are on your feet. Sometimes you are on the ropes. If you get knocked down, get up and go back for more. Then they come at you again. And again. I was prepared to fight back. The more rounds I went through, the more I felt I knew what was coming and what it would take. I had fans in my corner. I had people rooting for me.

Low-dose chemotherapy is a misnomer. It involves massive doses of highly toxic chemicals. In my experience, it is worse than high-dose chemotherapy. Cancer chemotherapy was developed after World War II when it was discovered that biological weapons like mustard gas lowered blood cell counts. This side effect could be used therapeutically in cancers where cells were growing too rapidly. Over the years the treatments became more standardized, refined, and eventually, with new drugs to treat unwanted effects like nausea, cancer treatment became less uncomfortable.

Low-dose chemotherapy involves very powerful chemicals that radically alter the body's functioning. It involves drugs so toxic that they can't be put directly in peripheral veins, where they could cause destruction of the vein walls, but through central lines into the large vena cava just above the heart (or even into the heart directly). VAD was the drug combination prescribed for me. Vincristine, Adriamycin, and

Dexamethosone. Dexamethosone is a steroid, which was familiar to me because it was used in psychiatry as a diagnostic test for depression, the Dexamethasone Suppression Test (DST). In psychiatry we use a dose of 1 mg, large enough to alter the body's physiological balance. I was prescribed 40 mg a day, 4 days on, 4 days off, month after month after month. The largest tablet made is 4 mg, so I was to take 10 pills every morning. The local pharmacy called Duke when they got the first prescription. They thought there had been an error. They had never seen someone prescribed such large doses.

I came to have a very ambivalent relationship with these drugs, especially the steroids. They caused all kinds of complications, medical problems I had never imagined: blood clots, diabetes, pneumonia. But they made the cancer go away.

Being on steroids was a physical and emotional roller coaster. First I was up for four days. Full of energy. Full of ideas. Awake at night. Sexually aroused half the time. (More than enough, believe me.) Then I was thrown into lethargy. No energy. No enthusiasm. Then back again. Then tired when I was energetic. It is like being manic-depressive. Mood up. Mood down. Back again. Then both at once. Before long I learned to distrust my own feelings.

Steroid use is not uncommon among athletes, and the testosterone precursor androstendione received a lot of attention as the drug used by Chinese swimmers, East German gymnasts and more recently, baseball players. These anabolic steroids are popular because they build muscles tissue. Dexamethasone is a catabolic steroid. It has exactly the opposite effect. It breaks down muscle tissue. It causes a characteristic "Cushinoid"

appearance: truncal obesity, skinny extremities, “moon fascies” (rounded cheeks), fat pads on the shoulders, and bronzed or bluish skin.

But there were several surprises in store associated with the use of steroids. While I had accepted the idea of having cancer, I was not prepared to have blood clots, drug-induced diabetes, and pneumonia. I was reviewing most of what I learned in medical school, learning again the complex details of human physiology and pathology. But these complications were part of what I would have to deal with. They became my instructors. They helped me understand the health system and myself.

A blood clot in one of the deep veins (Deep Vein Thrombosis, DVT), especially of the lower extremities, is a serious, potentially life-threatening event. A blood clot can dislodge from the vein, travel through the heart and lodge in the lungs or the brain. This can be fatal. I knew this. But I didn't think it could happen to me. Denial all over again. When I developed some tenderness in the left calf, I was prepared to observe and see what happened. Dr. Olive was not so patient. He called me in immediately, ordered an ultrasound, and when it showed a DVT, he admitted me to the hospital.

Again, I have to be very grateful to Dr. Olive. At a time in history when economic forces discourage the use of hospitals, and educational philosophy driven by economics suggests that you can usually wait and see, Dr. Olive was prepared to jump on every symptom. This is my retrospective, rational conclusion. At the time I resisted being put in the hospital. I was wise enough to realize that I couldn't be my own physician, but I raised every argument I could think of. I insisted on a complete rationale for every decision. I made the routine “informed consent” of daily care a complex process, and once I was convinced, I did what I was told.

Pretty much. Unless I was told not to be active. I was incapable of that. Of course, that is what they tell you when you have a DVT.

Being a patient taught me a lot about being a teacher. It was fascinating to watch students I taught take care of me. It was fascinating to watch myself assume the sick role. We all behaved in ways that were characteristic of the people we were, and yet with each encounter, our experience became broader. We grew and changed. I couldn't resist teaching not only from the bedside, but from the bed. And my former students didn't hesitate to give me orders when necessary. I had six psychiatry patients of my own, right on the floor below. I could see them with my resident after the internists rounded on me. "No, there would be none of that!"

One of the things I had learned as a physician, reinforced as a teacher, and dramatically learned again as a patient is that medicine is complex. There are no successful routines because each patient is unique and each situation is unique. Seals can be trained to follow routines, but doctors have to be educated to assess the uniqueness of each situation. I have come to love the complexity of medicine, though at times in medical school I found it overwhelming. Medical school became fun when I realized that I wasn't the only one that found the complexity of medicine daunting. The task of the medical educator is to help students enjoy the complexity of medicine. The task of the medical school administrator is to make sure physicians acquire the skills they will need to take care of patients. One of the greatest challenges I faced in the years of my life that I devoted to medical school administration was to assure quality education when many felt it would be more economical to hire trained seals with one or two tricks. This tension

was for many years a major source of stress in my life.

The treatment for a DVT is anticoagulation. Anticoagulation is a complex procedure requiring close monitoring by blood studies. It requires walking a tightrope between the risk of further clots on the one hand and bleeds, bruising, hemorrhage, possibly stroke on the other. It means venipunctures at least daily, but I was coming to accept venipunctures as commonplace at this point. I was eventually to be stuck four or five hundred times. Eventually I lost count.

Aspirin is an anticoagulant, sometimes used daily in patients with heart disease for purpose of preventing clots in the heart. Intravenous Heparin is the quickest and surest anticoagulant and requires the close monitoring of a hospital, but once stable, the patient can be converted to Coumadin, rat poison. The original form came from clover and was discovered when cows were bleeding. Now there are low-molecular-weight forms of Heparin, which can be given by self-injection to patients who are not too squeamish to give themselves shots. I much preferred giving myself shots to being “detained” in the hospital.

Anticoagulation is pretty much a “routine” procedure for DVTs, but like anything else in medicine, complexities challenge the routines. The routine holds that after a first DVT, one should be anticoagulated for three months. After a second DVT, one should be anticoagulated forever. That is the routine. I faced a number of mitigating circumstances however. My DVT occurred while my veins were made brittle by the steroids. I was about to undergo chemotherapy, which would knock out platelets, the clotting factors in blood, and would require a surgical procedure for the placement of the central catheter.

I inquired of my resident physician, the one who wouldn't let me round on my own patients, how long I would need to be on Coumadin.

"Three months," he replied.

Did it matter that the DVT was probably caused by being on the steroids?

"It's three months," he said earnestly.

Did it matter that I was about to undergo more chemotherapy, where blood counts including platelets would be lowered?

"It's three months," he said sincerely.

Did it matter that I would be getting a Hickman catheter, which would be surgically placed, hence increasing the risk of bleeding?

"It has to be three months."

I knew this resident had gone through our medical school at a time when we were probably over-emphasizing board scores. I hoped he hadn't gotten the idea from this experience that there is one correct answer for every question.

I asked the same questions of Dr. Olive, who appreciated their complexity. He said he didn't know the answer and I should ask the doctors at Duke.

Back at Duke, the oncologists were less concerned about the risk of clots than they were about the risk of bleeds and took me off the Coumadin before the Hickman catheter was implanted. Another round of chemotherapy. Return to Tennessee. Another DVT. Two and a half months after the first. This one involved swelling of the right arm (while exercising on a treadmill) and a clot blocking the blood returning to the heart at the place under the clavicle where the Hickman catheter was implanted.

Primary care conventional wisdom would now hold that with a second DVT I would be on anticoagulants for the rest of my life. But the Duke doctors with all their sophistication and experience did not feel it was that simple a matter. And they did not presume to know the answers. They arranged for a consultation with a world authority on coagulation disorders, Dr. Tom Ortel, who explained that there were relative risk factors for coagulation, and cancer was one of them. Being on steroids was another. Having a Hickman catheter was a third. He would undertake to determine if there were any underlying abnormalities that would require on-going treatment. In all likelihood once the cancer was under control, we wouldn't have to worry about DVTs or venous thromboembolic disease. The work-up involved ten tubes of blood and studied the various factors in a cascade of clotting factors including such things as pit viper venom, a notorious anticoagulant. There were no additional factors to worry about. I was free of this concern.

The next surprise was glucocorticoid-induced hyperglycemia or steroid-induced diabetes. Again, symptoms become tip-offs of underlying pathology. Track it down. Figure out what is going on. I became so thirsty that my mouth felt like it was full of cotton. I started walking around with a cup of water in my hand. I asked the lab to draw electrolytes and blood sugar along with the bi-weekly blood counts. My blood sugar was elevated to 500 when normal is less than 120. When Dr. Olive saw the results, he quickly called me in for a shot of insulin, which quickly brought this back to normal, and a few days of oral anti-diabetic medication kept it normal.

By now the steroids had worked their magic as well as their mischief. The cancer had been brought under control. It would no longer be necessary

to take steroids. We could now move from “low-dose chemotherapy” to high-dose chemotherapy, the Bone Marrow Transplant proper.

But there would be one more steroid-induced surprise to deal with first: pneumonia.

I didn't feel particularly good when I went back to Duke to start the Bone Marrow Transplant. I was irritable and cranky. My body had been ravaged by the steroids. I already had two blood clots and a steroid-induced diabetes. I had been spiking fevers every night for an hour or so. When I returned to Duke I mentioned the fevers to Dr. Chao. He immediately ordered blood cultures and a \$2000 CT scan. The blood cultures turned up nothing. The CT scan turned up a pneumonia in the right lower lobe of the lung, behind the kidney. This was confirmed by X-ray and then by stethoscope.

It retrospect this sounds comical. Most people would diagnose pneumonia with a stethoscope, and then confirm it with an X-ray. No one expects to hear breath sounds behind the kidney, so not finding them would not arouse suspicions. It is an anatomical variation in a barrel-chested triathlete. Dr. Chao did exactly the right thing. You can't start a bone marrow transplant, which will knock the immune system to zero, in someone who has an infection.

I felt like I was being sent home like a naughty school child. Come back when you have done your homework. In this case the homework was ten days of IV antibiotics administered by a home health nurse, who came to the house every day to start an IV at the breakfast table. It was one more wearing inconvenience. It was one more delay. It would be that much longer before I could start the rounds of high-dose chemo and receive the

bone marrow transplant. It was a test of my patience at a time when I was growing impatient and irritable. But at least I didn't have to be hospitalized. I could enjoy the comforts of home while waiting for the chemicals to do their work.

#### 4. Obsessive Defenses

Psychological defense mechanisms are tricks the mind plays on itself to keep from being overwhelmed by feelings. Denial is a primitive way of dealing with feelings: This reality does not exist. I do not need to deal with the anger I would be feeling if I were feeling anything because there is nothing to make me angry or afraid. I do not need to be afraid because there is nothing to be afraid of. The news of cancer, like the loss of a loved one, is enough to send most people into denial, or disbelief, or *Unglaube*. It is enough to make most people try whistling in the dark.

Obsessive defenses are higher order defenses. They help provide a sense of order when things tend to chaos. They help organize one's life. Make a list. Check it twice. Obsessive behavior is often found in highly successful people, accountants, engineers, physicians. It is considered a desirable trait. It is sometimes said in a complimentary way of physicians, for example, that they behaved obsessive-compulsively. What is really appreciated is the thoroughness. Obsessive-compulsive behavior is tinged with neuroticism, which makes one behave in rigid, stereotyped ways. It can be a barrier to creativity and spontaneity. Cleaning a clean house, returning several times to check the locks, washing hands repeatedly. In its extreme forms obsessive-compulsiveness can be comical, as Jack Nicholson demonstrated in *As Good As It Gets*. But to someone suffering from obsessive-compulsive disorder, these repetitions are very painful. The conflicts they defend against, the disorder, the chaos, the anxiety, all are

very distressing.

Often obsessive defenses involve rituals. Double-checking to see that the stove is off and that the doors are locked and that you have your keys can prevent later embarrassment. Having to check repeatedly and never being sure may be incapacitating. Often obsessive defenses involve magical thinking and rituals.

Step on a crack.

Break your mother's back.

This childhood game can be an idle way to pass a few minutes and can bind ambivalence and hostility in an intimate relationship. However, if believed and repeated, it can become debilitating. Acknowledging that there is ambivalence in intimate relationships and that it is possible to hold onto irrational beliefs makes it possible to give up the symptom. It usually takes psychotherapy to come to acceptance and work through these conflicts.

Dealing with cancer and cancer treatment is a project. It requires numerous decisions. It requires you to organize your life. It requires you to move beyond denial quickly. And it requires you to deal with your feelings. There are things to be done. After the initial shock, the reality is all too readily apparent. Imagine a treatment that asks you to put your life on hold for a year. Imagine a treatment that might give you your life back after a year.

Probably the most difficult time for Sue and me in the whole treatment--psychologically at least—was the period between the low-dose and the high-dose chemotherapy. Reality had sunk in. I had cancer. I was getting a bone marrow transplant. The disease was awful. The treatment was worse. Here we stood on a little plateau. We had been through one

phase of treatment, which had proved uncomfortable and had unexpected complications. If high-dose therapy was that much worse, it would be unbearable. No, It would be barely bearable.

As difficult as dealing with cancer was for me and Sue, it was clearly even more difficult for our friends. We knew what we needed to do. We had goals. Our friends wanted to help, and they were enormously helpful, but they sometimes felt helpless. Probably no one felt more helpless than my mother. She wanted to help. She wanted to make things right, but she was a thousand miles away in Maine.

When I talked with Mother on the phone, we often talked about the weather. I used to think that talking about the weather was an evasion of talking about more important things. Over the years I have come to realize that weather is a metaphor for the most important things in life. People in Maine live close to the weather. It matters to their lives and livelihood. Mother was one of seven surviving children growing up on a dairy farm during the Depression. Their lives revolved around the weather. Grandmother Randall used to say that after the Fourth of July, it was time to start preparing for winter. Although we always laughed at this joke, we understood that it was always time to prepare for winter.

So when Mother announces the weather, she is expressing something about an important aspect of her life. I have learned to listen to the meaning in weather reports. It's raining, for example, means it's not snowing. It's snowing means there is nothing to worry about; they've experienced worse. It's ten-below means it's not twenty-below. Recently Allagash, Maine, a tiny village near the Canadian border, posted a record low temperature of sixty-five degrees below zero Fahrenheit. Mother said that was an

exaggeration; it was really only 52-below. You could get by in such temperatures as long as you wore a facemask. Newport was then only twenty below. She had put kerosene in the heating oil to keep it from freezing, plugged the holes in the chicken coop, and gotten the fuel line off the ground. She was prepared.

I remember twenty-below from my childhood. It was not an infrequent occurrence. Early winter mornings I would get up at five-thirty to deliver newspapers. Mother would already be up to fix hot oatmeal. She said it stuck to the ribs. The comment was understood not literally, and not figuratively, but as a definition of what oatmeal did. At twenty-below, everything was still and black. The air molecules barely moved. The river was frozen. Most people were asleep inside their houses. Trudging along, dry snow crunching under heavy boots, the only hint of motion was the smoke coming out of chimneys and the twinkling of the stars light years away. There was a sense of foreboding in those quiet early morning times, but I had the world to myself. There was little to fear because even scary things didn't go out when it was that cold.

In the environment in which I grew up, people were stoic about the weather. Mother is stoic about the weather. So when she started inquiring about the weather in Tennessee, I knew she was worried about what was going on down here. She was worried about me.

“I see from the Weather Channel, that the smoke from those forest fires in Mexico extends all the way to Tennessee.”

“Nothing to worry about, Ma. Just a little haze.”

“I heard there were tornados in Tennessee. Are you all right?”

“None anywhere near here. Tennessee is a big state. And I am doing

OK too.”

At that point I knew she would have to visit to see for herself. I sent her an airplane ticket. Soon I was returned to the refrigerator of my childhood, where nothing was ever thrown away, and a meal of leftovers could pass for a Thanksgiving feast. Mother wanted to treat me like I was a little boy, a position which was familiar and comfortable for her. She wanted to make everything right. I had struggled for my independence, and this position was familiar and uncomfortable for me. I had become accustomed to taking care of others, not being taken care of. I obliged her by acting like a petulant child. Mother, please, I’d rather do it myself.

Mother was most determined that I be well fed, and I was most determined not to overeat, especially when I was getting fat on steroids. I seemed to me that at fifty-three years of age I did not need to be told to eat. I confess sheepishly that I was overly sensitive on this point. Mother recalled that when she was growing up, she always felt hungry. I had the opposite experience. Her revelation startled me because The Randall Farm had always been prosperous even during the Depression when Mother and her siblings were growing up. This farm was known for always having fresh paint and wallpaper, a frequent necessity where there was always smoke from the wood fires used for both heating and cooking. But paint and paper required cash.

The Farm was a place where the work ethic was taken for granted. It was the survival ethic. And there were lots of hands to work the chores. But there were lots of animals and lots of chores. As Aunt Caroline recently observed, “In those days, a farmer’s crew was his family.”

Visiting The Farm as we often did during my childhood was like

visiting a museum of self-sufficiency. Built in 1804 with wood cleared from the first forty acres, it was a fourteen room colonial structure. Thomas Jefferson was then President and dispatched Lewis and Clark to explore the Louisiana Purchase. Maine was still part of Massachusetts and did not become a state until 1820.

Exploring The Farm was not just stepping back in time, it was an archeology of one's own family. Layers of experience and memory were to be pieced together from understanding the architecture and artifacts. My cousins and I learned how our parents had lived, which helped us understand why we were raised the way we were. No one except Uncle Coleman and Uncle Charlie remained in agriculture, but everyone carried the habits of hard work into their respective fields, science, engineering, education, nursing, and medicine.

Five sets of stairs linked the complex enterprise of this nineteenth and early twentieth century existence. The spiral front stairs were rarely used. My twenty-six Randall cousins and I used them in our explorations of the homestead. Entry to the house was through the woodshed into the kitchen. No one ever entered the house through the front door. In my lifetime, the winter storm door remained in place year round. Rarely did anyone ever enter the front parlor with its lace curtains. Shades were drawn to prevent their deterioration. The upright piano was out of tune. We could tell even when we played duets of chopsticks. The family Bible recorded important dates and genealogy, births, deaths, marriages. It reported honestly (we discovered) that our grandparents, Charles Randall and Mary Hannon, were married just two months before their first child was born.

The living room on the other side of the front hall was in constant use.

Originally it also served as the cooking room, an open hearth across the central wall had been bricked in with only a flu for the oil stove that provided heat in the winter. The stairs that went up and down from this room were in constant use. Up to the upstairs bedrooms, down to the basement, where rows of preserves were stored, where a large cistern collected water, which was pumped by hand to the kitchen above. Perhaps most remarkable was the foundation for this huge structure. It was granite, intended to last for centuries, and it did.

The fourth staircase ascended to the attic, full of trunks, cobwebs, and tools, which were no longer in use. The spinning wheel was retired to the attic when ready-made cloth became affordable and available. There was the dairy operation, the cream separator, the butter churn. In the sheds there were the rigs for the horses. Sleights. Wagons. The hayrack. By the time I was a child, haying was done with a tractor. Sometimes my cousins and I would help loading the heavy bails, which tired you but made you stronger, sharp straws scratching sweaty bodies. There was only a single hay crop a year in Maine, and it was precious. Getting it in before it rained was crucial.

There was a fifth stairway, actually outside the house proper that connected the loft above the woodshed to the main floor coming down just outside the kitchen door in an ell which was built on later. There was a secret door connecting the loft to the first upstairs bedroom. What this secret door was for was a source of wonderment that was never explained. Was it to sneak out in case of Indian attack, we wondered. Such a thing never occurred. Was it to escape military recruiters? Such a thing never occurred in this family. In 1863 Martin Hannan put his scythe on the branch of an oak tree at the end of a work day and that night enlisted in the 21<sup>st</sup>

Maine regiment, which fought at Gettysburg with the famous 20<sup>th</sup> Maine. The scythe was never recovered. The tree grew up around it. When Will and Cliff were little I took them there to see it. The rusty blade remained over a hundred years later. To get to that field you take the north road out of Liberty Village and turn left where the one- room schoolhouse used to be. The field and the tree are on the left. Those directions sounds like a bit of Maine humor, but it is no joke. Mother took me there once, and that is how we found it. Dead reckoning by the lay of the land. That is how a Maine Guide finds his way around in the Maine woods.

Many of Mother's stories of her childhood had to do with cold and warmth. Raising the baby sheep behind the wood stove in the kitchen. Slaughtering a pig at Thanksgiving and hanging the carcass in the back shed, where it would stay frozen until April. Recalling the time the Penobscot Bay froze so solid you could drive an automobile from Belfast to Isleboro. Skiing on barrel staves, really. Going to the one-room school by sled, the frost on the chain at the back of the sled that looked so inviting that she decided to lick it, only to get her tongue frozen on the iron links. I recall the old icebox, which was still in use even after the electric refrigerator arrived, and my astonishment the first time I saw a block of ice emerge from the sawdust in the icehouse in the heat of summer.

I think when Mother arrived in Tennessee, she was reassured to find that I was intact even if a bit battered by the steroids. I had lost my hair; I had gained some weight; my face had gotten "puffy". But the weather was not reassuring. While we were back at Duke for another round of chemotherapy, she was caught in our ridge-top home in a lightning storm. A bolt of lightning struck the telephone lines and knocked out the phones and

the computers. The important data was backed up, of course, one more example of obsessive behavior. But more seriously, Mother was cut off from the outside world. When the Douglasses discovered her the next day, she was trying to appear unfazed by the events. We had called John and Dorothy when we couldn't get through to my mother. They immediately stepped in to help for about the 700<sup>th</sup> time. Perhaps things were worse than any of us was willing to let on.

During this hiatus between the low-dose therapy and the high-dose therapy, there were a number of things that needed attention. One of them was the yard. It was a mess. Although our neighbors would have forgiven us, I felt it needed to be set right. I planted red and white impatiens everywhere. I planted geraniums around the mailbox. I divided the irises. I hauled in mulch. I broke another rib. I hired someone to do the heavy work. They didn't show up. I hired someone else. Ironically when I was training for my Ironman and my various marathons and triathlons, I could bicycle right by the weeds and never notice them. I certainly would have been fit enough then to do yard work. When I had cancer, I felt the yard at least must look right.

It was also time to rewrite the wills. When they were last written, the boys were children, and there was little money to worry about. Now they were adults, and we like so many people had benefited from the advances on Wall Street. Thinking seriously about what the boys might need and what we could do with our accumulations required some attention to detail. It provided a useful distraction from the worries about the impending high-dose rounds. It also provided a useful opportunity to discuss cancer, to discuss death, to discuss life. We held a family meeting at the food court in the

mall. It is a family tradition to eat out twice a week. Once is pizza night. And since the advent of food courts, the other night is often at the mall, where all of us can make our own choices. After talking to the lawyers, we gathered at the Food Court (a relatively quiet place on a Wednesday night in the summer) and had the kind of family discussion that rarely takes place. We talked about what we had written into the wills, what we value and how we value it, what role money plays in those values, especially education, travel, therapy, what could be done charitably with the money they might not need, what the doctors were saying about cancer, the unlikely event that cancer would kill their father (rather than a truck), the less likely event that something like a truck would kill both their parents, how proud we were of them and what they were doing with their lives, and how much we loved them.

This was also a good occasion to write living wills, advance directives, and durable powers of attorney for healthcare in both Tennessee and North Carolina. As a physician and medical ethicist, I had often discussed these matters with students, residents and colleagues. When North Carolina passed its natural death act in 1976, I had even written a paper (“Natural Death in Medical Practice”). These documents are not so complicated and bewildering as they might seem. They basically say that you recognize that when you are dead, you are dead. It’s OK to turn off the respirator should that be necessary. The purpose of such documents is to anticipate the complex way people die in a modern medical center and to provide some conversation in advance about how that death might happen. Such documents nudge a person in the direction of acceptance. They attempt to assure, or at least to start, the discussion so that all members of

the family are at the same stage. I signed the North Carolina document, but there was no discussion, so I never put it on the chart. Sue kept it in her pocketbook in case it should be needed, but nobody was thinking death at that point. Everyone was thinking cure.

My own patients needed attention at this point as well, and this was useful for my own sense of well-being. I am a physician. I take care of patients. My physicians will take care of me. If I focus on my patients' problems, I don't have to think so much about my own. I did some of the best psychotherapy during this period that I have done in some time. Patients needed to talk about the impending separation, and I needed to think about it. Specifically, since I would be closing my practice for six months and referring all my patients to residents or colleagues on the faculty, we had an opportunity to address separation issues and dependency issues in a way that seldom emerges with briefer therapies and less frequent visits. I had the opportunity to monitor and talk with my patients about their reaction to my illness and the impending separation. It was good for them, and it was good for me. One patient in particular who always amused me with his ability to state things clearly and colorfully, said it most bluntly, "When you have cancer, it occurs to you that you might die."

Not only did the patients require attention, so did the charts. Usually our charts are somewhat sterile documents, their content dictated by the crushing regulations governing documentation. Ordinarily charts merely document that a service took place. It is not customary to find in a modern chart very much about the uniqueness of any particular patient or the complexity of the thinking about the patient. They exist in case they might be audited at some time. This is one more example of how our non-system

of health care attempts to skew the values of excellent clinical care and reduces the physician-patient encounter into an economic transaction.

Now for once, my charts were to actually be used to communicate with other physicians. They would become opportunities not only for good patient care, but for teaching. I wanted to make sure that each chart reflected a detailed treatment plan and something of the complexity of what was going on in the treatment. Writing such charts gave me an opportunity not only to do what was right by my patients, but to focus on something other than myself and my own illness. It let me deal with my own feelings without being overwhelmed by them. It provided for a titration of affect, a balancing of thought, feeling, and action.

With great care, I attended to the charts and the papers on my desk, and when I left my office for the first of the high-dose rounds, every piece of paper on my desk had been attended to and you could see the beautiful wood of the furniture. I think this was the one day in my life that everything was attended to. If lightning, or a truck, had struck me there would be nothing left undone. That state lasted exactly one day. It lasted until the avalanch of the next day's mail.

These distractions proved useful, and people commented on how calm I was, how well I seemed to be taking things. I needed to be aware that inwardly things were not so calm. I was worried. My sister arrived from Georgia, bearing an account in the *Atlanta Constitution* of a woman, one of their reporters, who had just undergone a bone marrow transplant at Duke. It mentioned by name the doctors that were my doctors. She described their personalities and the things they said. She mentioned Nelson Chao, the director of the clinic, who is reported to have said, the BCNU (one of the

most toxic chemotherapeutic agents) came last because no one would come back for more if it came first. She described David Coniglio, who in fact had bought our house on Markham Ave when we left Duke, and Jimmy Vredenberg. She described a procedure that was horrific beyond belief. I was dismayed when I read her account. What had I gotten myself into?

One night in the midst of all this I had a dream. It was actually a nightmare.

I dreamed I heard a gunshot. I dreamed I was sleeping in my old bedroom in the house where I grew up, and where Mother still lives. The sound came from Center Street, the cross street a couple of houses from where we lived. The gunman was trying to get away and was just outside the window of my bedroom. I felt I needed to alert Sue, who was asleep beside me, so I nudged her and screamed.

In reality, I woke her up. My dream had become part of her dream. Once awake, it was reassuring to know that there was no gunman; it was “just a dream.” But in wakefulness, things didn’t seem to be so calm. Sue realized that downstairs my mother was awake. Apparently I had woken her too. Or a door slammed, which I dreamed was a gunshot. Sue went down to reassure her that everything was all right, at least immediately. Mother had also been waked up by a dream. She also dreamed someone was trying to break into her house in Newport. Clearly there was an intruder.

Awake, I began to mull over the events of the day and to associate to the dream. In psychoanalytic training, we learn that “the dream is the royal road to the unconscious,” in Freud’s classic words. We learn that in order to understand what a dream means to a particular person, you need to be aware

of not only the manifest content of the dream, but also the “day residue”. You also need to get the person’s associations to the dream, the thoughts that come to mind, uncensored.

Without any deliberate effort, I began to go over the events of the day. I had received a letter from a grade school chum, whom I had not seen in thirty years. His mother had given him my address, not knowing that I had cancer. I had been hearing from people in my hometown and all over, many cards, letters, calls, e-mails, from people I had not seen in years or heard from in decades. Each of these contacts and expressions of concern was a lift, a boost to my ego, a boost to my spirits, a boost to my sense of well-being, and probably a boost to my immune system. Steve’s letter was all of that. It was somewhat perplexing as well. Steve also had cancer and had just been through a bone marrow transplant in Boston. It begins

## OpporKnockity Tunes

Arlington, MA

June, 1998

Dear friends and colleagues,

As most of you know, my recovery from leukemia has been our family’s primary focus this year. My explorations of complementary approaches to healing have taken me down a number of paths. Not surprisingly, a most potent and personal medium has been sound. During that first month in the hospital, I spent much of the time trying to make sense of what had just happened to me. Through conversations and self-reflection, one thing became immediately clear: I was being forced medically and psychologically, to focus on myself and my needs in a way I

never had before. Although this went against the grain of my New England upbringing, I saw at practically every turn that I had no choice. As I worked on accepting this new perspective, I came to see that through the years, my fascination with theater and dance had led me to work for the most part collaboratively. However, in doing so, I had neglected to pursue admixtures of sound and music unique to me. Now the message was to use my relationship to sound for healing. As a psychic later put it: "You have developed your relationship to others; now your task is to develop your relationship to the universe." . . .

. . . Many thanks for all the ways you have chosen to join with us in this journey. Your cards, letters, calls, thoughts and prayers have helped immeasurably to illumine the process, and we have been encouraged and inspired by your loving attention. Please keep up the prayers. It buoys us immeasurably to know they are flowing in.

Peace,  
Steve

*Allen,*

*Pardon this way of letting you know, but at least you know. Thanks for your letter (my mother passed it on) and your Zen Christmas "speech". Catheter out on Tues. Spirits High.*

*Love,  
Steve*

My associations to the dream drifted back to Steve's letter and to our childhoods together. Carefree times, they were, or might seem in retrospect, though we had the task of growing up, not so easy as it might seem. We had the task of preparing for a future we could not anticipate. Who would ever imagine that either of us would ever get cancer? Who could believe that both of us would undergo a bone marrow transplant in the same year? Such technology was unimaginable when we were children.

One of my recollections took me back to Center Street. When we

were ten or so, a group of us used to hang out together. Russell, Charlie, Steve, and I, and sometimes Bobby Gray. That was his name, and he was always referred to as “Bobby Gray”. My son Will ran into him once while visiting his grandmother. Bobby Gray has been teaching junior high science for the past twenty-eight years. Russell went into his father’s refrigeration business. Charlie committed suicide. Carbon monoxide.

When we were kids in the process of growing up, we used to go to movies, Westerns where the good guys wore white hats and the bad guys wore black hats. You could tell their moral motives by their attire. We also went to the classic horror flicks, *Creature from the Black Lagoon*, *The Thing*, *Godzilla*, *King Kong*. We would walk home as far as we could together, up Center Street. Banded together we could defend against any Thing we might encounter in reality or in our imaginations better than we would be able to do on our own. Then at some point, about where the gun was shot in my dream, we would begin to peel off to our own homes, on our own, just as we would eventually take our own paths through life.

One of our favorite activities for a while was playing on the bales of shoddy, recycled cloth, in the warehouse of the woolen mill. It was great fun, jumping from bale to bale, huge bales larger than a full-size person. But it was also scary because we knew we weren’t supposed to be there. Periodically the watchman would make his rounds, and we would hide between or behind the bales. The fear and the excitement were palpable. I don’t know what we thought would happen to us if we were caught. Steve’s father owned the mill. I guess eventually we were found out because Steve explained that his father didn’t want us playing there any longer. He was afraid we might get hurt. No one thought of lawsuits in those days, though

no doubt King Cummings was aware of his liability if something were to happen. But what could happen? A bale tips over on boys not as invulnerable as they imagined themselves to be? Exposure to a carcinogen that forty years later would manifest as blood and bone marrow cancers?

Another of our gang-like activities was trying to knock out streetlights with snowballs. I don't think we did this often, once maybe. Streetlights in those days before mercury vapor lamps were essentially naked light bulbs suspended beneath a metal reflector, easy targets for a snowball, except that a snowball wouldn't do much to a light bulb, unless it had a rock in it. I remember that it was my snowball with my rock that finally knocked out the streetlight. Although it was a source of some recognition among my peers, I am not particularly proud of having done that. And the next day in school, the principal called our gang into his office for a stern talk. It was during my music lesson. I got neither the credit nor the blame for the snowball incident. We probably got into other mischief I don't recall or have managed to repress. I would say we were fortunate that the town was so small we didn't have to contend with a rival gang.

Russell, Ann, my sister Polly, and I all took piano lessons from a lovely woman who taught us to memorize progressively more difficult pieces. Like little prodigies, we could play a limited repertoire of Beethoven, Chopin, and Mozart. Steve took lessons from someone else who taught him chords. With chords he could improvise, he could create his own tunes. He could be Mozart. He could create OpporKnockity Tunes. By the time of the rock-in-snowball incident, I had switched to playing drums, something closer to my soul.

I was thrilled to hear from Steve again after all these years. I was

sorry to hear that he had cancer and had to undergo a bone marrow transplant. I was impressed that he had taken such a holistic and spiritual approach to his healing. As I look back on our childhood pranks, I realize that we chose to put ourselves into frightening situations in order to learn to deal with fear. We were trying to learn the difference between right and wrong for ourselves. And we were trying to master the kinds of situations we might get into later in life. We were little warriors. We might later go to battle on the playing fields, in the marketplace, or in the boardroom, but fortunately none of us had to go to war, except Charlie, who went to Vietnam.

## LETTER FROM AUNT MARY

April 21, 1998

Dear Allen,

Your mother came over last Tuesday, and we sat out on the sunny, warm sun porch and talked about many things, of course, as we have often done. She had told me about your sore ribs, and now, she told me of the diagnosis, at Duke!! Each of us wishes we could swap places with you for the weeks — or months — of the chemotherapy until they conquer the Demon. I attended the funeral, yesterday, of a 97 year old retired teacher who had taught for 51 years. At her funeral the minister said that she had told him that she had overheard a nurse say (thinking that the patient was unconscious) “She’ll never make it!” It made her so **mad** that she was determined to recover. She lived another 14 years because of her courage and determination.

Yesterday, as I watched the pictures of the Boston Marathon on Patriot’s Day, I thought of you and was reminded of what a full interesting life you’ve had up to now!!! You don’t have to be in the races to experience them; you have it locked in your memory. You have climbed mountains, biked and swum in Europe, hiked with the Boy Scouts in New Mexico and climbed the Tetons. I think of my Dad (your grandfather, Clifford Randall) at about the same age had never been outside of the State of Maine. He would have enjoyed the adventure, too, if he’d had the opportunity. I have said I never dreamed of climbing Mt. Katahdin, but I am thankful that I did climb it — 3 times! We also climbed Bigelow and Tumbledown (3 times) and others. These wonderful experiences are locked in my memory to be lived again and again. I would never have had the courage or imagination to do all the things you have participated in. Don’t think I haven’t worried that the next thing I’d hear would be that you were going to tackle Mt. Everest!!!! **PLEASE DON’T!!!!!!!!!!**

The lawns are getting green, spring flowers are blooming, the lilacs and crab tree buds are swelling and the yard is full of birdsongs.

I’ll be thinking of you and praying for your complete recovery.

Love to you, Sue, and the guys,  
Aunt Mary

## 5. High-Dose Chemotherapy: War Stories

From: "Stern, Matthew M.D."  
To: "Allen Dyer"  
Subject: hello  
Date: Fri, 19 Jun 1998 15:29:29 -0400

Allen,

Thanks so much for the beautiful photographs of Mt Washington. What a pleasant surprise. Fond memories for Janet and Jeffrey, nice to look at for the rest of us. I know that **Allen and Sue's Big Adventure** is about to begin. While I'm concerned, I just know that everything will be fine. It's your karma or something that simply exudes well-being and the conquest of any irritant. . . Deans, Chairmen, Administrators, roads, water and replicating cells. Our thoughts are with you. Be well, my friend.

Matt

Bone marrow transplant is a misnomer. What is usually called bone marrow transplant should more properly be called stem cell transfer. Stem cell transfer is not an organ transplantation like a heart transplant, where the old organ is thrown away and a new one implanted. That can be done with bone marrow, but in the modern bone marrow transplant, stem cells, or undifferentiated baby cells, the precursors of red blood cells, white blood cells and platelets, are "harvested" from the peripheral blood, stored in a freezer, then later used to "rescue" the patient from the certain death that would result from the massive doses of chemotherapy that kill all dividing cells: cancer cells, normal blood cells, hair cells, gut cells, skin cells, fingernails and toenails. Anything that moves, ZAP it! Because the little frosties are there waiting to do their bit for survival, much higher doses of chemotherapy can be used than a body could otherwise tolerate. The

immune system is completely destroyed, then reconstructed.

My transplant was to be an “autologous” transplant, meaning that the cells used would be my own. I was lucky in this regard (not the kind of luck you get from rolling the dice. . .) Donor transplants run enormous risks of complications. One of the most common is tissue rejection. The new cells are rejected by the body’s immune system as foreign material. One of the most dreaded complications is graft vs. host disease in which the foreign cells reject the host. I was lucky in that I got to use my own cells, a perfect immunological match.

When the full extent of my calamity became known, I began to think about what Job had gone through in the Bible. What became apparent was what Job’s friends went through. The bone marrow procedure I was having to undergo was psychologically more difficult on my friends that it was on me. I knew what I had to do. I was on a course. I had my marching orders. I was focused on survival. The professional staff, doctors, nurses, PAs, took care of my medical treatment. Sue was at my side constantly. My friends flooded me with the warmth of their affection, which made every day worth living, no matter how painful or uncomfortable. I felt inadequate in letting them know how much they meant to me.

I was lucky also in that the treatment I had consented to in April had been considerably improved by the time I actually started in July. A recent study from Stanford had found that patients who received total body irradiation did no better than patients that received a chemotherapeutic agent called BCNU by itself. I would receive BCNU but not the irradiation. This was fortunate because most of the risks of the procedure came from complications of the radiation.

The next innovation involved an improvement on one of the chemicals administered. A new agent, *Etopophos*, which was buffered by phosphorous, replaced *Etoposide*, which was buffered with ethylene glycol. Ethylene glycol, the main ingredient in anti-freeze, typically caused acidosis (lowering of the blood pH), which causes nausea and vomiting, and extreme discomfort. I imagined the effect of pumping the yellow-green liquid into my blood stream as if I were an automobile radiator, but fortunately I only had shaking chills, rigors, elevated temperature, and exhaustion. I was admitted to Duke hospital for just one day. The doctors felt the new drug wasn't much of an improvement over the old. I felt it could have been worse. I felt that perhaps I wouldn't overheat and could start on cold mornings.

Sue and I settled into enjoying the time together as we have enjoyed traveling together over the years. We enjoyed the fine restaurants that had sprung up in Durham in recent years, the cultural opportunities, the Durham Bulls baseball games, and visiting with old friends. We spent long days watching fluids flow in and out of my body through my new Hickman catheter, skillfully placed right into my heart by my old friend John Grant. The first catheter had been a bit of a problem. The radiologists had placed it. Somehow we expected that it would be a problem. A doctor so young he must have been a medical student did the informed consent in the hallway amidst boxes and hallway traffic. I didn't complain. When I joined the Duke faculty, I was so young I could have passed for a medical student. The radiologist who inserted the catheter introduced himself while I was lying on my back just before the anesthesia took effect. When I woke up I couldn't remember his name. The catheter never worked very well. Nurses struggled

to get it twisted just right in the vein so fluids would flow. The wound in the chest never healed and constantly oozed blood. Every morning the nurses carefully examined the wound and decided that another bandage change would be necessary. I tolerated this patiently. I did decide that if bandages would be ripped off every day, I could at least shave my chest. Shaving the body is something swimmers and triathletes do for speed, and bodybuilders do for vanity. I did it to minimize pain. Even hairless, the constant bandage changes left my skin red and raw.

As soon as we went home after the first round of high dose chemotherapy, the catheter clotted in the vein and had to be removed. I was on a treadmill at the time. Sue did complain. At least she politely noted that David Sabiston would never have tolerated such a lax operation. Sabiston was the famous head of surgery at Duke for three decades. A renowned surgeon placed the second catheter. It worked just fine.

Though parts of the treatment were painful and parts were uncomfortable, the biggest problem was boredom. As Sue noted, "No one ever died of boredom." It has been said that BMT is much like war, long periods of boredom, punctuated by brief moments of sheer terror. We watched war movies, rented videos, read more books than our busy schedules usually allowed. We knew that we were walking close to death, but there was nothing that would be done except face each situation as we encountered it and hope for the best.

The science of Bone Marrow Transplant is awesome. Textbooks still speak grimly about multiple myeloma, and my physician friends found it hard to shake their memories of what a dreaded disease this has been. Malignant myeloma it used to be called. A slight change in appellation

euphemistically adds a bit of hope or takes away at least some of the gloom: MM, Multiple Myeloma. But the management of the day-to-day care is truly an art. Cancer and cancer chemotherapy have three major symptoms: pain, nausea, and fatigue. They are all manageable. Pain can be managed by narcotics, which are administered liberally to cancer patients, in whom addiction is not a worry. There are new medicines that counter nausea before it gets out of control. Oncologists no longer wait for side effects to appear. They treat before side effects develop. Fatigue is usually caused by anemia, and blood transfusions are made available when needed.

I was lucky that I was able to tolerate the procedures more easily than some of my fellow patients. My physical conditioning helped enormously. I am of a fairly stoic disposition and became inured to the pain. Hundreds of needle sticks, blood draws, rib biopsies, repeated bone marrow aspirates (these were painful, I concede) became part of the routine. Though I was offered narcotics, I generally did not use them. The anti-emetics (anti-nausea medications) worked for me. Fatigue was my biggest problem, but I was transfused whenever my hematocrit dropped below 30 (42 is normal for men), and I was able to work out regularly, walk, lift weights, use cardio machines, throughout the treatment until the last round, the infamous BCNU, which just about flattened me. At this point my exercise consisted of getting out of bed, walking to the car, and walking across the street.

It may seem frivolous to think of cancer treatment as an adventure, but my friend Matt Stern knows me well. His e-mail of good wishes captured the spirit he had seen me use in tackling many challenges: academic, administrative, and athletic. My style of coping with adversity placed bone marrow transplant in the same part of my mind as other

adventures into the unknown. That would put it in its place. The unfamiliar and frightening would be dealt with as though it were familiar. It would be treated as an “inconvenience” as one of the cardiologists irreverently put it. I found myself dealing with this challenge as I had dealt with previous challenges, as an obstacle to be overcome. The physical aspects were being taken care of admirably by the doctors; the psychological defense mechanisms were in place, bolstered by my psychiatric and psychoanalytic training and by my own previous psychoanalysis and therapy. My friends and family provided a support system that one could hardly hope for, and yet there it was. Also there was a spiritual dimension, which in my mind was cast as an adventure, a journey, a battle. In my fantasies I was becoming like the children Kubler-Ross described, imagine tanks, battles, and explosions.

Aunt Mary knew me well enough to worry about my taking on Mt. Everest. Rationally, I can tell you I would never do it. I know better. But as Jon Krakauer observed in his famous account of the Everest disaster of 1996, “attempting to climb Everest is an intrinsically irrational act--a triumph of desire over sensibility.” Taking on an adventure involves knowing one’s limits, preparing to extend one’s skill in order to minimize the risk. Cancer is no different. Except that I didn’t get to choose the adventure.

Grimly aware of the risks I was facing, I thought of other adventures, particularly mountain adventures. The Everest Disaster of 1996 held a particular fascination for me. I read every account of it I could get my hands on. It would be melodramatic to suggest that my own experience in any way paralleled the climbing of Everest. Yet there was something about pitting

myself against an obstacle that I could not resist.

On May 10, 1996, several groups of climbers attempted the summit of Everest on the same day. Australian Rob Hall led one group. Scott Fisher from Seattle led another group called all too appropriately Mountain Madness. Both Hall and Fisher were highly respected mountain guides. A Taiwanese group also decided to attempt the summit on that day. There were delays in getting to the top. There was a bottle-neck getting through the fixed ropes at the Hilary Step. Firm turn-around times had not been established, but several of the climbers got to the top of the mountain late in the day. By the time they began their descent, a fierce storm had come up with hurricane-force winds and sub-zero temperatures. Several people were stranded on the mountain overnight. In all twelve people including, both Hall and Fisher, lost their lives. A Taiwanese climber lost his life when he left his tent to urinate. Failing to put on his boots and crampons, he slipped and fell to his death. One, an American physician, Dr. Beck Weathers, was left for dead, only to stagger into camp the next day. That would have been me. In my little drama, I was being cast as the determined physician who by sheer will power could overcome insurmountable odds. In addition to nine deaths on the Nepal side of Everest, three members of an Indian party climbing from Tibet lost their lives in the storm.

I have seen Everest—eyeball to eyeball—from 25,000 feet on a small Buddha Air twin-engine tourist flight. Its signature plume of spindrift ice crystals blows 30 miles to the east, a near constant reminder that this mountain stands six miles tall, high into the atmosphere, where the jet stream blows winds up to 100 miles an hour and higher. In Nepal Everest is called Sagamatha, the abode of the gods. In Tibet it is called Chomolungma,

the goddess mother of the earth. You had better behave yourself here and treat the mountain with the respect and reverence it deserves. In the half-century since Edmund Hillary and Tenzig Norgay first successfully climbed to the summit (and returned) in 1953, 640 others have made successful climbs. Nearly a quarter that number, 147, have lost their lives, horrible odds for a chosen adventure. Yet similar odds for the Bone Marrow Transplant seemed not so bad and would have to do for an unchosen adventure. In the face of such powerful majesty, there can be no question that one is in the presence of forces beyond oneself.

If one could somehow step out of the comfort of the pressurized cabin onto the wing of the airplane and step down on the summit of such a high mountain, he would die immediately. It takes the human body weeks to acclimate to the rarified atmosphere. The top section of the mountain is called the “Death Zone” and one cannot stay here long, even with supplemental oxygen. The thermometer plummets at night and often during the day to sub-zero temperatures. Fierce winds are common. Any exposed skin is soon frost bitten, and the body in its wisdom shuts down circulation to the extremities to protect the vital organs. Every breath is a labored effort. Dehydration can be lethal. So can pulmonary edema and cerebral edema can be lethal. Under such conditions judgment is impaired and every move can be risky. When one comes so close to death, life becomes more intense, and precious.

In 1993, I was invited to go to Nepal with a British Army expedition by friends Sam and Anne Cowan, whom Sue and I had met in 1983 while on sabbatical in Oxford. When we met Sam was a colonel, and I was an assistant professor. By the time of our trek in 1993 Sam had been promoted

several times to the rank of Major General. He was the very model of a modern major general, to quote the famous line from Gilbert and Sullivan's *Pirates of Penzance*. I say this with more reverence than irony because Sam of all the people I have ever met, has a keen appreciation of the role of the military in a democracy, the role of the officer in the military, and the global interrelationships that hold the world together. Over the years Sam and I have had many conversations about how to prepare military officers and physicians for their professions. Since our '93 trek, Sam has been promoted to Lieutenant ("Luftent") General, then to full General, and in 1995 was knighted for his contributions to the Realm. General Sir Sam Cowan, KCB, CBE.

When we went to Nepal, Sam was responsible for the Gurkha Welfare Scheme, so we were visiting the Gurung hill villages around Annapurna from which so many of the Gurkha soldiers are recruited, checking to see that soldiers' widows were getting the benefits to which they were entitled. We were also studying the Annapurna Conservation Area Project (ACAP), an organization designed to protect the Annapurna area as it is subjected to more and more tourism. One of the most serious problems faced by the region is deforestation. Wood is practically the only fuel available. When the wood is gone, the steep slopes are prone to serious erosion. So conservation becomes crucial to maintain a delicate ecological balance, and treks need to carry their own kerosene to use as fuel.

Our hosts at the British Embassy in Kathmandu before and after the trek were Colonel Mike Kefford and his wife Captain Carol Kefford. Mike and I became immediate fast friends, a friendship formed in part by a shared experience that few understand. We had both inherited problem units and

were administratively responsible for solving problems that had been neglected for too long.

Mike had just led the British Joint Services Expedition (Navy, Army, Air Force) to climb the West Ridge of Everest, an expedition that had been forced to turn back just before the top because of bad weather. Everyone made it back alive, but no one made it to the summit. So often the accounts of Himalayan expeditions, such as the 1978 American Women's Expedition to the Himalayas, which placed two women on the summit of Annapurna, tell of the great accomplishment of those who make it to the top, but also of the tragedy of two members of the party who were lost in a storm. Often the book about the expedition is dedicated to those who did not come back. Maurice Herzog's climb of Annapurna in 1950, the first time Annapurna or any mountain over 8,000 meters was climbed, was similar. Two members of the expedition made it to the top, but suffered such severe frostbite that all their fingers and toes had to be amputated along the trail by the expedition surgeon as they left the Himalayan region. Chris Bonington's 1970 conquest of Annapurna by the nearly vertical South Face was similar. Two members of the party achieved the summit. Bonington was eager to evacuate the mountain before the weather turned sour but was persuaded by two other members of the party to be allowed to make a summit attempt. One of them was killed in an avalanche.

This dilemma of how hard to push for success in reaching the top of a mountain was like a Zen koan for me, a paradox. What is the sound of one hand clapping? What is a successful expedition? Is it one in which the summit is attained, but at great cost, or one in which everyone returns safely? I would want to be with Mike Kefford. I understand all too well the

ambition to attain the summit, yet appreciate the need for caution. Mountaineering could be a metaphor for the administrative challenges I was facing at the time. It would be necessary to take my department to new heights in order to survive and be accredited. Yet it would be impossible to go too high, too fast without upsetting the established equilibrium, the *status quo*. Mountaineering adventures would become for me a metaphor for cancer survival as well. To the extent that will power and determination could make a difference, I was prepared to fight, but I had to recognize also that there were forces beyond my control that I would just have to accept.

The commercialization of Everest was a hot topic of conversation at the British Embassy in 1993. Already commercial guides were charging \$60,000 USD to put inexperienced climbers on the mountain. I think there was some lament that heretofore sacred Himalayan summits were being reduced to monetary exchange. The analogy to health care struck me inescapably. The sacred healing bond was becoming commodified, made into a commercial transaction. The time doctors get to spend with patients was being eroded by assembly line medicine.

It was predicated then that such commercialism was a recipe for disaster on Mt. Everest, and I think the same could be said for medicine. It would take a catastrophe to call attention to the situation, and even then market forces are hard to overcome and hard to regulate. When someone pays big bucks to climb Everest, they expect a summit experience, even if that means taking unnecessary and unwise risks. The May 10, 1996, disaster was not unexpected. But commercial mountaineering goes on, largely unregulated. As long as people are free to choose, they will choose to take risks. It is the nature of free markets to be risky. I read these accounts of

Everest even as the American stock market soared to unaccustomed heights--who is making these decisions?--who is taking these investments into thin air? I couldn't help but be fascinated by the men and women who were playing the odds in ways that perhaps prudence would suggest they ought not to do.

As I read these accounts, I thought of my own odds playing, the Bone Marrow Transplant, thirty percent chance of cure, 1-3% chance of death. Preparation, determination, luck (however you understood it), technology, all were to play a role in survival and in the excitement of the adventure.

Sue had written to Sam and Anne to tell them of my battle with cancer. It was at this point that they wrote back.

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From: General Sir Sam Cowan KCB CBE  
Headquarters Quartermaster General  
Andover, Hants

30 July 98

Dear Sue,

Many thanks for your letter giving us the bad news about the big struggle which Allen is now engaged in. I am writing immediately to tell you that you are both very much in our thoughts. I have never heard of multiple myeloma cancer before. It sounds nasty, to say the least, but it has sure chosen a tough character to battle against in Allen. What he has achieved in the last few years shows the tremendous strength and depth of his spirit and character and the way he has reacted to this terrible blow is just one more illustration of that.

Thank you for taking the trouble to explain everything to us in such detail. We are so grateful to you for taking us into your confidence because just hearing the stark news without some explanation of what it all involved

would have made it extremely difficult to handle the news. We now know the position exactly which means that we are able to empathize all the better with your struggle.

It would be fantastic if Allen could get to Nepal in November '99. I know his great friend Silajit would be thrilled to see him and would love to accompany him on another walk through the hills. It is an inspiring prospect, and even if events conspire against us, it is still worth aiming for. It is in the way of those who go on pilgrimages to the holy places along the Himalayan ridges that what counts is not arriving but the experience of the journey.

Thank you again for writing to us in such a personal and warm way. Our thoughts are really with both of you at such a testing time. Despite the terrible nature of the problem that confronts you, we know that your spirits are so strong and this inspires us to think that all in the end will be well whatever that end is. We often talk and think about you both and the really amusing times we have had together and, believe us, we will be doing a lot more of that over the next few months. Please so keep in touch.

Please give Allen my warmest regards--and all my news.

Love,  
Sam

---

Friday

*Dearest Sue,*

*Thank you so much for your letter, and we were so sad to hear of Allen's illness. I had been feeling that a blow was coming, but I did not know from which direction. Our thoughts are with you both, and Will and Cliff. I have a photograph of you all here beside me, and that will be an inspiration.*

*We move in three weeks— back to Oxford. We will keep in touch.*

*All love,  
Anne*

So it was decided: back to Nepal in '99. I would put this on my

determined reasons-to-live list (along with the Duke-Carolina game as a guest of player JD Simpson). This list was growing longer with each round of chemotherapy, and with each round I was increasingly confident of being well for these events. I could see the light at the end of the tunnel. I would start preparations immediately. Even in the midst of bone marrow transplant, I could undertake some physical training. I could also begin the spiritual discipline, the meditation, the imaging, the anticipation.

The mention of Silajit made me wistful. Silajit Gurung had recently been back to England for cancer treatment himself, and by all reports he was now doing well. Silajit had organized our '93 trek. Sam had known him for thirty years from the time when Sam was a lieutenant and Silajit was a 14-year-old boy-soldier. Silajit had risen to the rank of Gurkha Major, the highest rank in the Gurkha regiments. His most recent assignment had been to spend a year in the UK, accompanying The Queen on all her public appearances. I asked him what that was like. He replied with diplomacy and fealty, "It had been a very difficult year for Her Majesty with all the problems with the daughters-in-law."

That comment was so characteristic of his generosity of spirit. Silajit was a cheerful warrior. Each day I would awake to his greeting, "Tea, Sahib?" It was a fanciful reminder that I was waking to a world half a world away from anything familiar. Sahib, the way he said it made it sound like a Swedish car. "Himal view, Saab." There was a certain honor in being called "Sahib," General Sahib, Memsahib, American Doctor Sahib. As we entered each village long trumpets blared, and drums maintained the cadence. As we processed, we were draped with garlands of marigolds, and our faces painted red, white, and orange, according to ceremonial customs.

The appellation of “Sahib” is a vestige of colonialism, once accorded to the European masters by virtue of their position. It was now a chosen term of respect and even endearment. I suppose the closest American equivalent would be *kimo sabe*, friend.

This generosity was extended to me in a very special way one night in a village called Luwang. I was sick from eating a piece of fruit some women had given us on the trail. Silajit and Chandra waited outside my door all night in case I might need them. I was touched by their attentive concern. I wish I had known they were there and could have said, “I am all right, really.” My friends, here as well as in Nepal, would not accept my assurances easily. They knew I tended to minimize my difficulties. Through the cancer experience, they kept an uneasy vigil by phone, letters, cards, e-mail, and visits to the house. They worried about me. They worried about the cancer. They cared about me.

The following night I was again accorded generosity, which caused me to reflect. I was no longer sick, but still very tired from the lingering affects of the food poisoning and from a strenuous day of trekking. We reached the village of Landruck, one of the last villages before the Annapurna Base Camp in the Annapurna Sanctuary. A hotel keeper invited me to bunk in his establishment. Sam explained that this man was a Gurkha veteran, having served in the South Pacific during World War II. He was attached to a British unit trying to take one of the beaches, and they were experiencing extremely heavy casualties. They probably would have been decimated, but the US Air Force arrived to provide air cover and help them achieve their objective. He felt an enduring gratitude to the Americans and extended that gratitude to me. He was very proud to have recently hosted

President Reagan, whose helicopter had landed at the level spot outside the hotel where we made camp. I went to bed right after supper and slept a long and comfortable sleep with a roof over my head.

This appreciation of America's effort in World War II reminded me of another occasion with parallels to my own fight for life. It was another occasion in which the Dyer family was the beneficiary of a longstanding appreciation for U.S. military assistance. On the 45<sup>th</sup> anniversary of D-Day, we visited the Normandy beaches. When it was learned that we were going to France, my patients, colleagues and others recounted tales of their involvement. One of my patients had done underwater demolitions, blowing up pylons to make the beaches accessible to the amphibious landing craft. One of my mentors, Dr. Otto Guttentag, German by birth, American by choice when the choices in Germany were so constricted for someone with a Jewish grandparent, was part of the medical force that landed the second day. He was stationed at Saint Mère Église. We went to Saint Mère Église. My uncle Aubrey provided logistical support from England. He was under Eisenhower's command. Piecing these stories together one by one, it was hard to imagine the scope and complexity of the operation and what was at stake for Europe and for history. Seeing the cemeteries with rows and rows of graves, marked by crosses and stars, one gets some appreciation for the courage and sacrifice that were involved.

It was the largest invasion force ever assembled: 1200 fighting ships, 10,000 planes, 4,126 landing craft, 804 transport ships, hundreds of amphibious tanks, 156,000 troops, nearly half of them American. We read the histories, watched the movies, paced the battlefields. *The Longest Day*. *Victory at Sea*. *Saving Private Ryan* brought it all back. Wave after wave.

Life after life. Utah, Omaha, Gold, Juno, Sword, the Americans took the Western beaches, the British and Canadians took the Eastern beaches. It was like the forces the doctors threw against the cancer. Vincristine. Adriomycin. Dexamethasone. Cytosan. Etopophos. Casmustine. Melphalan. The Allied forces met the strongest resistance at Omaha, “bloody Omaha,” it was called.

One night we stayed in a hotel in Cherbourg. We were offered a separate room for Will and Cliff. At first I declined the offer, not wanting to assume the additional expense of a second room. But no, it was explained, we were Americans and the second room would be complimentary as was a bottle of the finest Moët et Chandon champagne. Will and Cliff were delighted to have their own room, where they could watch cartoons *en français* and order pizza from room service while their parents ate in the hotel dining room below. Sue and I enjoyed having our own room too. But the celebration was a solemn one.

Nepal is a very spiritual place. Spirituality is not confined to church buildings or monasteries. It is everywhere. When one goes to Nepal, one expects to see the Himalayas. They are, as would be expected, spectacular, towering, snow-capped mountains. But Nepal takes you by surprise because little in our experience prepares us for the harmony of the people with their environment. I am sorry to present this contrast to modern Western culture, where spirituality is so often rationalized, intellectualized, or ignored. In Nepal spirituality is not an idea, but a feeling, an experience, a familiar, everyday experience. Nepal is the third or fourth poorest nation on the planet in monetary terms. The main sources of income are tourism, foreign aid, the salaries paid to the Gurkha soldiers. Nepal only became a

democracy in 1991. On our trek we saw everywhere the signs of the two parties, sun for the communist party and tree for the congress party, which won the first ever election in the Kingdom of Nepal. But Nepal has riches incalculable if you count spiritual wealth.



**With Sam and Anne Cowan, Sikles, Nepal, November,1993**

Nepal was a turning point in my life in ways I couldn't completely articulate. Sam had alluded to this in a 1993 letter when he said, "One glimpse of these snowy peaks will change your life forever." I became a more spiritual person. That is to say I became more aware of being a

spiritual person. Though I was unreflective of it initially, it was becoming increasingly evident to me that spirituality was an important part of coping with cancer. I had grown up in a religious home, attended the Methodist church, and had been academically interested in religion and culture, ethics, medical ethics (the area of my Duke Ph.D.) But, of course, religion and spirituality are not the same thing. One would hope that religions would provide a spiritual experience, but the churches I had been associated with didn't always do this for me. Too often they became preoccupied with the mundane, the material, and the political.

Chandra had given me a special gift of spiritual understanding. He had recently been depressed and suffered some anxiety attacks while on jungle maneuvers in Brunei. He was diagnosed with panic disorder by an astute cardiologist whom he consulted because of an irregular heartbeat and was treated for three months with alprazolam, the most-studied drug for this condition. This trek was seen as a particular opportunity for him because he would get to spend time with an American psychiatrist. We talked about the fight-or-flight response of the autonomic nervous system, the fact that the symptoms are the worst part of the disorder, that as bad as it feels, it is unlikely to hurt you, and the role of relaxation and deep breathing in dealing with it.

Then he told me something very important in understanding what he was experiencing. His brother had recently died in a motorcycle crash. It was his closest brother. The *lama* had told him not to touch iron, but he was going home on his motorcycle to visit family. We talked about grief and ambivalence in close relationships. He told me he had talked with the *lama* about his brother's death. The *lama* told him his brother was holding on to

his soul and would not let go. After the trek the *lama* would go to the brother's grave at midnight with drums and supplicate the brother to let go of Chandra's soul. I couldn't think of a better way of explaining the problem.

In Nepal, a psychiatrist is an unusual phenomenon, and it is somewhat difficult to explain what a psychiatrist does. In several villages sick children were brought to me. I was a doctor. That was close enough. In one village, Sikles, I was actually presented with what we might understand as a psychiatric problem. A sixteen-year-old girl was having temper tantrums and throwing furniture around. I did not entirely comprehend what was going on. Levitation? Witchcraft? Anger too intense to be spoken? Abuse? The word was so overused in America that it could mean anything; explain anything. Sexual abuse. Physical abuse. Emotional abuse. Harsh words. Discipline.

While a fertility dance, much like synchronized swimming, was going on the village square, I was asked to see the sixteen-year old in a house lit by a single candle. I asked questions as I am inclined to do. Silajit acted as interpreter. The issues I raised were discussed by the father, by the extended family, by friends gathered around the candle. The girl did not speak. Finally an answer would be reported back to me. Usually after much discussion I was given a single word consensus. "Yes" or "no." I would try again and again until we had all reached a common understanding. Finally I was only able to suggest that both sides should compromise. The parents should stop striking her. She should stop throwing furniture. I hoped I might be able to say something wise and useful. I fear that my comments were mundane. Perhaps I could have invoked powers higher than

rationality. Perhaps I could have used the drums and chants in the background. Or perhaps that was part of what was happening. Perhaps the higher powers were working on me as the whole village slid into a trance-like state.

That night the spirits were active. They were summoned by the dance being performed in the village square. We were hosted in Sikles by the father of Dr. Chandra Gurung, who had developed the Annapurna Conservation Area Project (ACAP). Dr. Chandra Gurung is not to be confused with Sergeant Chandra Gurung. Dr. Chandra's father was known to us simply as Dr. Chandra's father. He had arranged for the fertility dance to be performed in our honor. Ordinarily a fertility dance would be performed in the spring. As two young girls danced in perfect synchrony, one of them went into a trance. Silajit explained that at this point the gods were entering her body. I tried to comprehend what I was being told. I had never heard of such a thing, yet it seemed so plausible. Of course that was what was happening.

That was the night the spirit of my father chose to visit. He returned in the form of a giant moth, which lit on the arm of Dr. Chandra's father, right beside me, and stayed for a very long time. I felt his presence as a warmth in the chill of the evening. My father died while I was in the mountains, ten years earlier, in the south of France. It should be no surprise that I would feel close to him in the mountains here. My father also loved the mountains. While I was growing up we had spent much time together in mountainous settings.

A Western explanation of this visit might be that I recalled my father's love, warmth and support that night in the village square at Sikles.

We might say that I felt my father's spirit in that setting. We might say that I remembered my father. In Nepal, the visit might be explained as *karma*, the belief that spirits take different forms in different incarnations, the belief that we all will occupy different forms in another life. I can think of no better way of explaining what happened that night in Sikles on the shoulder of the Annapurna Himal.

In Nepal it is the lama, the Buddhist priest, who fills many of the functions that might be filled by a Western psychiatrist. The *jhakri*, or shaman fills some of these functions. In one of the villages I was introduced to the *jhakri*. He proudly presented his drum, with which he drove away evil spirits. It was a symbol of his importance to the community. As a drummer myself, I appreciated that. It has been said dismissively of psychiatry by anti-psychiatry critics that psychiatry is little more than shamanism. This dismissal fails to appreciate, I believe, the power of the spirit and mind in shamanistic practices, and more directly the power of the spirit to heal. Psychiatry and western medicine would do well to be more attentive to the power of the spirit in healing practices.

The psychiatric interpretation that I offered that was probably most useful to Chandra concerned the two daughters he had when we visited his home in Pokhara at the end of the trek. They were animated, chatting, squabbling. He said they were usually better behaved. I explained to him that they had missed their father while he was away and were trying to make sure they got the attention they deserved. The concept of sibling rivalry became immediately evident. Chandra the father smiled and began to relax as he came to appreciate his own sibling rivalry with his lost brother.

## **6. Marathon**

Shortly after I returned from Nepal, our 15-year-old Cliff left home to attend the Northfield Mount Herman School in Massachusetts. It was a loss I was unprepared for. One day he approached me and said he wanted to go away to school. I had had the same conversation with my father when I was 15. I knew I couldn't say no, and I was thrilled that he wanted to take his education seriously. But I was not prepared for him to leave home so soon. In fact he left on the tenth anniversary of my father's death. The loss left a gap in my life. The time I had spent chauffeuring him to school and to wrestling practice, I would claim for myself. I organized a Master's swim team, I took up running, and I bought a bicycle. I was going to be a triathlete.

The training was delightful. Hard work, a little pain, were familiar companions. The congregation of athletes, the discipline (which comes from discipleship), the endorphin release, the focus on long-term goals, the sense of well-being, the opportunity to be out-of-doors, offered benefits I could scarcely have imagined. Running mile after mile, in harmony with the world, was a transcendent experience. I wouldn't necessarily have called this spiritual, but when applied, the term fit and made sense. I began to think of my life in different ways.

One of the things athletics taught me, and cancer reinforced the learning, was that spirituality takes many forms. In most of my experiences with religion, the exclusivity of claims has been stressed. This is The Way.

This is the only way. Traveling in Asia, thinking about Asian religion and spirituality helped me appreciate that there can be many paths to spirituality. There is a Zen saying that when the student is ready, the teacher will appear. That teacher for this part of life's journey was to be Dale Kirby. Dale sees athletic pursuit as a spiritual undertaking. He taught me to appreciate the Spiritual Quest of the Warrior Athlete. As an accomplished martial artist himself, U.S. National Karate and Weapons Champion in the 1980's, he teaches karate as a spiritual discipline, a way of life. Sue, Cliff and I were with him when he was inducted into the International Martial Arts Hall of Fame.

Dale's mother, Mama Doug everyone calls her, told me of her struggle with breast cancer, and of her belief in intercessory prayer. She told me that she and Granddaddy Kirby were praying for my recovery. When Dale was in Vietnam, they prayed that he would return alive, and he did.

Dale came home when his buddy, Russell Deitchler, was killed. Russell's parents requested that Dale accompany their son's body back to Montana. I visited the Vietnam Memorial in Washington and found Russell Deitchler's name on panel 51-E, line 45. I made a rubbing of it and gave it to Dale. I was on my way to Boston to join in the 100<sup>th</sup> running of the Boston Marathon. Matt Stern had invited me to give a talk in D.C. on the ethics of gene therapy in Parkinson's Disease, potentially another medical miracle, probably the first disease to be treatable with gene therapy. So I was in Washington en route to Boston. Dale was very much on my mind. Marathons had a military quality to them in my experience.

My first marathon had been the Marine Corps Marathon. It starts and finishes near the Iwo Jima Monument in Arlington National Cemetery.

Marines run the event, and Marines run in it. The Marines and I share a common birthday, November 10. They are much older, having been organized in 1775.

Marathons are not run casually. They require months of training, months of preparation. For everyone who attempts one, it means something special. Everyone has a story to tell. The day I ran in the Marine Corps Marathon, there were 16,000 runners. All them were facing their own challenges, inner battles symbolized by the external challenge of 26.2 miles. Oprah also ran it that day. She had she had publicized her struggles to accomplish a marathon. Her training schedule was news as I prepared for the event. Those who set out with her on that course shared her spirit of determination.

The route of the marathon passes all the major monuments, Vietnam, Washington, Jefferson, Lincoln, the White House, the Capitol, the Pentagon, Iwo Jima. It is hard to be there and not appreciate the complex history that makes it possible to be where you are. Like Oprah, I ran with my coach, Dan Finnegan, an ex-Navy underwater demolitions expert. Dan left one of his uniforms at the Vietnam Memorial. It is a custom for the Park Service to collect things left at the Memorial and distribute them to the needy. I left a jacket. Dan later traveled to Durham from Atlanta for a surprise visit to me during my cancer marathon. He again shared with me some of the spirited determination that he had offered in training for Marine Corps.

People have asked me what I think about when I run a marathon. It is a hard question to answer because I think of many things. Like many others, I do the math. This distance at this pace translates into this time. I think of the weather and how it impinges on my senses. I think of relationships. I

think of how I feel. I listen to my body, and unless it says “injury”, I go on. I often found myself reciting lyrics to the songs of the rock group Phish:

Put the gearshift in the high gear of your soul.

Run, run, run, run,

Run like an antelope out of control.

Your friends will find you in their worlds;

One by one, a string of pearls.

Laugh and laugh and fall apart.

My father would have loved Phish’s zany humor. He insisted that if there were any consistency in the English language “fish” would be spelled “ghoti”: *gh* as in *laugh*, *o* as in *women*, and *ti* as in *nation*. My sons loved Phish, and I certainly did. Will took me to a Phish concert in Charlotte for my 52<sup>nd</sup> birthday. It was a great Dad ‘n’ Lad outing. Sharing common interests had become a way of sharing in each other’s lives as the boys grew up and moved into their own lives. As a parent I take delight in seeing my children develop their own personalities and interests. I take delight in the enthusiasm they bring into our family when they give us a perspective on the world that we have not given them. It was while I was battling cancer that I noticed that my sons were no longer children. While I was distracted, they had become adults.

In frequent visits to Washington, I have come to appreciate that the Mall with its many monuments is a sacred place. As I ran the Marine Corps Marathon on this hallowed ground, I thought of history and all those who fought previous battles, real battles--military, political, artistic, social, and scientific battles. It felt a great privilege to be able to be there in such company.

I have discovered that marathons also have a mantra, a ritual phrase that is repeated until the words are forgotten and the meaning becomes part of your experience. Sometimes you choose the mantra; sometimes the mantra chooses you. When I did the Toronto Marathon with the Leukemia Society Team-in-Training, I chose the mantra “Strong, Free, and Happy” and shared it with my teammates. I ran the whole race with two of my teammates, and we chanted this phrase over and over. Strong. Free. Happy. Every now and then someone would say “strong”. It was a useful spiritual reminder to which the liturgical answer was “free” and then “happy”. Happy became a joke after about 30 kilometers (nineteen miles). “Strong and free and . . . still running”

When I went to Boston, I was wearing the dog tags of three of my uncles who had served in World War II: Uncle Aubrey, who had been in Europe on D-Day; Uncle Walter, ex-Navy, who had taught me to swim and taken me to my first Red Sox game at Fenway Park (where we saw Ted Williams hit a home run, forever etched in my memory), and Uncle Phil, who used to call me “Curly” because I had no hair when I was little. I, of course, had the last laugh on that one, and in later years started calling him Curly. Had he lived to see the effects of chemotherapy on my hairiness, I could have counted on a ribbing from him (if you will excuse the pun.)

Boston is run each year on Patriot’s Day in mid-April. I was dressed in red, white, and blue. This particular year, the 100<sup>th</sup>, many people were in costumes, representing countries around the globe. It was the Woodstock of running, proclaimed the greatest sporting event in American history. Ask anyone who was there, 40,000 runners, 2 million spectators over the 26.2 mile course.

I had not planned a mantra. There were many things on my mind at the time, and marathon preparation was only one of them. Washington. Parkinson's Disease. Cliff was also in Boston that weekend, and I went with him to a reception hosted by Reed College in one of the Beacon Hill mansions. I came to appreciate why he had chosen this academically challenging college. Cliff and I went to the State House to visit the statue of Mary Dyer, our immigrant ancestor, who was hanged on the Boston Common in 1660, "a martyr for religious freedom," the plaque says. She was a Quaker in Puritan Boston at a time before this land had learned to separate Church and State.

With all this going on, I did not have ambitious goals for the Boston Marathon: have fun, finish the second half faster than the first, run strong through the hills. "I am from Tennessee," I told myself. "I love the hills." When I got to Heartbreak Hill (mile 19), Japanese Warrior Drummers were there to beat out a cadence:

Pick up the pace.

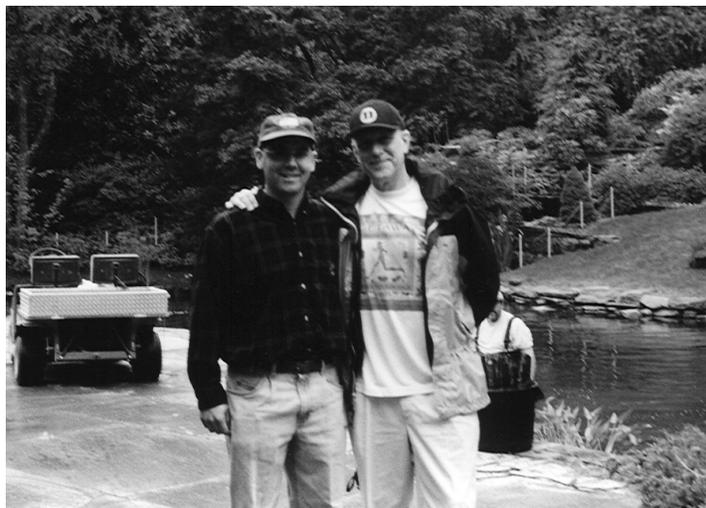
Pick up the pace.

I picked up the pace and began to think of Dale, Vietnam, World War II, and the dog tags of my uncles, lying against my sweaty chest. As I ran through the Newton Hills, a mantra emerged from my cadence: "Honoring the Warrior". I said it over and over again in my mind as I ran into Boston toward the Prudential Tower visible in the distance. Honoring the Warrior made this a particularly emotional run for me.

The myeloma marathon also had a mantra. It was given to me by Paige Kirby, Dale's daughter. Dale calls Paige the Beautiful Light Being because of her sunny disposition and spiritual radiance. Paige trained for

and ran the Memphis Marathon with me, the one I ran with broken ribs. When I was diagnosed with cancer, she asked Sue what she could do to help. If she had asked me, I would have been at a loss for words. I would have been unable to identify and articulate my needs. Sue said simply, “Stay close,” and she did.

Paige and brother Scott were concerned that I maintain a proper focus and guided my imagery during treatment. In a marathon, I tried to image success, not how bad I might feel, and cancer should be no different. Paige, of course, suggested an image of light, pink light, the energy of healing. The image was apt because the first rounds of chemo (VAD) were red in color, and appeared pink as they were pumped through transparent tubes into my veins. The mantra she suggested, “healthy, happy, whole” recalled the disciplined focus of the many miles we had run together along life’s path. I said it over and over, and often thought of it at times when I felt the worst. Some of my best times have been times when I felt the worst. Healthy, happy, whole.



**Marathon Treatment: A surprise visit from marathon coach Dan Finnegan, Duke Gardens, June, 1998**

## 7. The Rescue

Stem cell rescue is the scary part of Bone Marrow Transplant. It is where death is most likely to occur if the stem cells do not engraft. Prior to the advent of hematopoietic growth factors, which facilitate the growth of white blood cells, death rates of Bone Marrow transplant exceeded 15%. My colleague from residency and psychoanalytic training, Leslie Braasch, died of complications of a bone marrow transplant at this point in her treatment five years earlier. She was a pioneer. Refinements in technique since that era made things easier and safer for those of us undergoing the procedure now. Her husband Ernie, also a psychoanalytic colleague, was my main guide through the cancer experience. I stayed at his house in Durham. We cooked together, ate together, worked out together, and talked-talked about what I was going through and what my family was going through. He and Leslie and their children had been through it all. He knew the uncertainty, and he knew what could go wrong. Ernie has a way of being calm in the face of adversity. On one occasion when we were residents, Will cut his foot on a glass shard hidden in the sand at one of the North Carolina beaches, where several families had rented a large beach house. While others were near hysteria--a child is bleeding--Ernie quickly and calmly attended to the wound. His calmness calmed me.

The rescue occurs at the end of the last round of high-dose chemotherapy. The last round is the highest of the high doses, the most toxic, the most uncomfortable, and the most side effects. The big guns. It is calculated to kill the cancer and leave the patient alive. I was completely

deflated. Ordinarily the hot, humid, sticky Durham summers were a time of languishing. Add a bone marrow transplant, and subtract what little energy is left. I could barely stroll through the parking lot to the car.

As I read through the e-mails of this period, it is evident to me how many friends were on the journey with me. I recall from this period that about the only thing I was able to do was check my e-mail, glance at the newspaper, watch TV or video, sip some chicken soup. The days passed slowly.

From: Keith Brown

To: Allen R. Dyer

Subject: How are things going?

Date: Tuesday, September 22, 1998 4:11 PM

Hey Allen,

Just a friendly little note to say hi and let you know that I'm thanking about you. And so is everyone else that I talk to. They ask about you often. I would give you names, but it's everyone that I run into. Hope that you are doing well and that the cells are taking. I haven't heard from you in a while so I took the initiative.

Let me know how things are going and I hope to hear from you soon.

Tell Sue I said hello and that I'm thinking of her too.

Keith

By the end of each day, I was tired, but not sleepy. When morning came, it was an effort to get out of bed. The elevator carried me to the lobby of the hotel where I ate a bowl of Cheerios with skim milk and a mini-bun. I arrived the clinic late. All my fellow patients already had their daily blood work and were receiving whatever corrective chemicals were needed. No one complained about my tardiness. I took my place at the end of the line.

Each of the high-dose rounds involves a ritual of watching blood counts. Each day at the Adult Bone Marrow Transplant Clinic starts with blood counts and chemistries, drawn through the indwelling Hickman catheter conveniently placed through the wall of the chest. Blood out, chemicals in, or transfusions of whatever is out of balance on a particular day. The skilled Duke nurses run these decisions on protocol, checking with the doctors if there are any irregularities. Each day one of the doctors or the clinic PA (David Coniglio) visits and reviews the current status. These visits were occasions for medical-decision making, but they did so much to lift spirits that I would consider them spiritual visits.

Watching blood counts fall, then rise again, was a scary business. White blood cells drop to zero or near zero after each round of chemo. At this point there is no immune system for several days. Restaurants, malls, theaters are all off-limits during this period. The nurses described this as “house arrest.” Stay in the hotel. Do not go where crowds go. I took such delight in the company of my friends, almost creating a party atmosphere, that this part was particularly difficult for me. Germs, which I generally do not fear because of a strong immune system, suddenly became mortal enemies. And they are everywhere. You can’t be too careful. I was given prophylactic antibiotics, I was advised to use disinfectant spray, wash hands frequently, use fresh toothbrushes, lip balm, etc. It was another occasion where obsessive defenses became useful. Fortunately it was summer and not flu or cold season; people weren’t running around sneezing and coughing. It could have been worse.

Fortunately also David Coniglio was a baseball fan, and he gave us permission to go to some Durham Bulls games, as long as we sat away from

the crowds. He even wrote a special pass to park next to the stadium, which the Durham police honored. Baseball is a kind of excitement that does not require a lot of energy. Baseball is a sport designed for humid summer evenings, and the Durham Bulls do it as well as anyone. Their new stadium is a cross between big league polish and small town casual. The green grass is neatly manicured in a checkerboard pattern. The electronic scoreboard flashes fireworks against the emerging skyline of what is now becoming a real downtown.

Sue and I shared a bit of Durham history with David Coniglio. When we left Durham, the house we sold to him was considered for a set for the baseball movie Bull Durham, which was being made at that time. While we enjoyed baseball as a distraction from cancer, we recalled the images of Susan Sarandon waiting for Kevin Costner near the dugout, luring him to her house, it might have been our house, David's house, for a bit of mischief on the kitchen table.

At last the growth factor kicked in, and we waited for the white count to come back up. Bones ached and throbbed as the marrow began to crank out cells. This was one of the most painful aspects of the cancer treatment. It was a welcome pain because it signaled that the marrow was doing its expected job. Red cells and platelets were also killed by the chemotherapy, and transfusions were sometimes given if those counts fell too low. The fatigue that accompanied the chronic anemia was the side effect that most bothered me because this was what most limited my activity. Low platelets were an interesting complication. Because of the blood clots I had I was being anticoagulated, but the regimen was complicated by low platelet counts. Fortunately, Duke's coagulation disorders expert, Dr. Tom Ortel,

helped the oncologists manage the side effects of the side effects. This was one more example of the delicate balancing act that is bone marrow transplantation.

The blood cells are collected and separated by a big machine called a phoresis machine. It is basically a centrifuge, spinning the blood that comes out of one side of the Hickman catheter, separating the blood into its various components by weight, taking the white cells, to be frozen for future use, returning the plasma, red cells, and platelets back into your body on the other side of the Hickman, the “port” or door, as it is sometimes called.

Most of the Bone Marrow Transplant at Duke is an outpatient procedure. This is primarily for economic reasons. The hospital is there for emergencies, and we were instructed to report to the oncology floor if I developed a fever greater than 101.5°F. I appreciated the freedom, the mobility, and the flexibility. At some places, patients are hospitalized for months. In my case it was only a few days.

The last round of chemotherapy was so intense it was done in the hospital. It lasted five days. Sue was at the bedside throughout. Friends visited to the extent allowed and two of my own medical students, Eric Jelovsek and Mary Beth Deering, doing “audition” rotations for residencies at Duke, also visited. Eric was doing a rotation in GYN oncology. He reported that it was not nearly as depressing as he had imagined it would be. The patients were so optimistic about the treatment they were receiving. I understood that. I felt the same way.

The last round of chemotherapy consisted of two different chemotherapeutic agents in succession, BCNU, one of the most toxic, and melphalan, an old standard in the treatment of myeloma. The BCNU pretty

much flattened me, then the melphalan was administered a couple of days later. Melphalan has the liability of causing mouth sores, which are sometimes so painful as to require narcotics for pain relief. Sue was advised to feed me ice chips, which decreased the circulation in the mouth. This, it was thought, might reduce the mouth sores. Every twenty seconds for two and a half hours while the toxin ran into my body and I was semi-delirious, Sue put a spoonful of ice chips into my mouth. As soon as they melted she provided more. Fortunately (again good fortune) this technique worked and I was spared the dreaded mouth sores.

The greatest worry was that the stem cells would not engraft. That complication could be expected to cause death. The informed consent had made this very clear. I had agreed to accept this risk.

One day during this period, the e-mail took an unusually long time to download. I was getting a digital image. Would it be baby pictures from a medical student? A musical greeting card? When the picture emerged, there stood twenty-five of Sue's colleagues in front of the Siemens building. Sue had told them that I had produced 6 million white cells for the rescue. They were carrying a banner that read:

**ALLEN, YOU HAVE 6 MILLION CHANCES  
TO GET WELL. DON'T BLOW IT!**

There are a number of ways you can die of cancer or cancer treatment. When I was in medical school, I remember a lecture on GYN oncology turning into a horror show. Roy Parker, then Duke's chair of OB-GYN, recounted the ways a surgeon might encounter cancer. He focused largely on the solid tumors of the abdomen and the effect of their uncontrolled growth on the body. Such tumors could destroy the body by literally eating

away the internal organs. That is why they are called cancers, named for the crab, a scavenger, a bottom feeder. Such tumors could cause instant death when they wrapped around major blood vessels, ate through the walls and caused hemorrhage of blood into thoracic or abdominal cavities. Terminal events in such cases might be associated with coughing up blood (hemoptosis) or vomiting blood (hematemesis). Or the cancers could eat through the walls of the bowel, immediately evident to the surgeon by the foul smell that would be encountered on opening the abdominal cavity. Or they could metastasize from organ to organ, interfering with the function of first one and then another organ. Wherever there were nerves, they made themselves known by pain.

Blood tumors can also kill in a number of ways in their uncontrolled growth. Destruction of the white cells leaves the body unable to fight infections. Destruction of the red cells leaves the blood unable to carry oxygen; the person feels tired and is incapable of carrying out usual activities. Destruction of platelets leaves the blood unable to clot. In minor forms bruising may occur, but in more extreme forms, this can cause internal hemorrhage, bleeding into internal cavities, abdomen, lung, joints. Usually blood tumors are treated before they reach this stage. But breakdown of blood elements in organs like the liver or kidneys can cause failure of those organs by clogging the blood vessels that supply them. A common cause of death is multiple organ failure, hepato-renal syndrome, but especially kidney failure is not a bad way to go. When the kidney stops filtering toxins, they build up in the blood, and the person lapses into coma and dies. It is painless. The pores of the skin excrete some of the toxins, which have a characteristic ammonia smell, and white salts crystallize on the skin. It is

called “uremic death”.

Marrow tumors like myeloma cause destruction of bones. For me it was ribs. Mainly ribs. Sometimes it is the weight-bearing long bones of the legs or the vertebrae. Such complications would require orthopedic surgery, and one might spend weeks hanging out in an orthopedic ward.

I thought of all these things but I did not dwell on them. I focused on the good wishes of my friends. And I focused on getting better. It had been a long siege, but that is the nature of sieges. I had been backed up to the brink of a precipice, looked over the edge, and returned. The bone marrow transplant was successful. It had done its job. It had killed the cancer and left me alive.

We announced the good news by e-mail to our waiting friends:

From: Susan, Allen Dyer

To: Friends List

Subject: Shall We Dance?

Date: Sunday, September 27, 1998 9:24 PM

Cliff was 6 and Will was 8 the year we visited Japan on our 'round-the-world trip at the end of our Oxford sabbatical. That was also the year they started to study karate in Durham. Since then we can count on them to keep us up to date on Japanese culture, especially Japanese film. A recent lead, which we checked out on video a few days ago, was a new film called "Shall We Dance?" about a hard-working man who decides to add some passion to his life by taking ballroom dancing lessons. It reminded us of the classic Noh dramas, so much is conveyed by gestures, movements, particularly movements of the feet. Noh drama, Sue says, does not mean NO drama, it means SLOW drama. It also means dealing with feelings of shame, humiliation, embarrassment, restraint, which are almost unheard of in Western action dramas.

Such feelings seem to be almost totally missing in the American drama being played out in Washington,. Bill Clinton and Ken Starr locked in mortal combat, but I am not sure everyone else deserves to be dragged in, nor does it appear from the polls do most of the American people intend to be taken in,

Our international friends are astonished by the extent of the coverage and that we seem to be so confused about what to do and our inability to stay focused on important, urgent governmental issues. They seem to be astonished that a 25-year-old girl can bring our government to its knees, so to speak :-)

Now baseball--that is another story--, Mark McGwire and Sammy Sosa slugging it out.

My cells have engrafted at last and we are nearly through with this phase of the treatment. We are expecting to return to Tennessee on Wednesday, the last day of September as originally projected.

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From: John Douglas  
To: Allen and Susan Dyer  
Subject: "Early out" for good behavior.  
Date: Monday, September 21, 1998 1:10 PM

Dearest Allen and Sue,

It is exciting to anticipate seeing you in just a week; it is humbling to imagine what you have been enduring, and what still is to be endured during that week. Analogies with Greek mythologic characters are inevitable---Theseus, Hercules, Sysiphus, Ulysses.

Laurelyn joined Jon for his White House concert Friday night, and met V.Havel, Madeline Albright and other dignitaries. She said Hillary looked great, and Bill looked terrible. She also lamented that the concert, featured as promoting jazz for youth, was given to an audience devoid of youths.

We're both disheartened by the "stone casting" hypocrisy on Capital Hill, and I see so much of that is an eventual lose-lose strategy. Like "WAR GAMES"...the only way to win is not to play. This chapter in our political history will be excellent grist for an ethicist's mill, as well as for a comparative literary scholar's perspective. We look forward to your analyses.

Our loving thoughts to both of you during "house arrest." We are counting on "good behavior" by your stem cells winning you an early release.

As always.....John and Dottie

## **8. Recovery**

I found recovery the most difficult phase for me. I was done with the bone marrow transplant, and I was ready to return to normal. However, there was a period of cell repair: regrowing blood cells, hair cells, gut cells, skin, enzymes, a complete starting over. When cell counts returned to near normal, Sue and I were able to leave Duke and return home. I was ready to return to my normal life. It took a few months. Gradually I regained my strength. I extended my daily walks to a mile, then two miles. Dorothy Douglas accompanied me and kept me informed about Johnson City's Sister Cities exchange program with Rabinsk, Russia, which she organized. My own organizational abilities were shot. It was all I could do to sort out the medical bills and answer the essential mail. I was instructed to take two naps a day under the covers. The first one came before breakfast. Sue went off to work. I was left to look after the house and preside over the impeachment hearings on television. The afternoon nap prepared me to watch reruns of Baywatch, the high point of my days.

I was home about a week when I developed my first infection. It left me flatter than a pancake, the worst I felt through the whole experience, nearly lifeless. I had less energy than a wet dishrag. It was the only time I didn't mind being in the hospital. I didn't care where I was but the hospital seemed like a good place to get better. I now had 5200 white blood cells, which should have been enough to fight an infection, but each of them was a rookie; none of them knew what to do.

The second infection a few weeks later was a milestone. I had gone to

grand rounds to hear one of my colleagues present. A cold was going around. Everyone had it. I caught it. It was one of those absolutely miserable colds progressing over four or five days from sore throat to stuffed head to cough. I called the oncologists to see if I should take one of the high-powered and expensive antibiotics I had become so accustomed to. They said, sorry, I was just like anyone else at this point, just treat it symptomatically. I suffered gladly, thrilled that at last I had an immune system that could handle a simple cold.

During this period it struck me that recovery from cancer was much like recovery from an addiction; once you had it, you were always in recovery (or remission), never really cured. In the old medical model, if you thought of an illness as merely physiological, you would say you were cured when there were no longer any physiological changes in the body. With cancer you look for all the detectable signs, but you can never be sure there isn't some renegade cell somewhere ready to go on a rampage. None of us can be sure, of course.

With addiction as much as than anything else in medicine, the psycho-social and spiritual dimensions are an important part of the treatment. Even though we now know enough about addictions to realize that there is a physiological component (addiction propensity) and not just moral weakness, we think of the illness as a bio-psycho-social as well as spiritual disorder. Cancer is really no different.

I like the analogy for cancer. It is a real illness involving biological, with many dimensions. Biology alone does not explain the totality of the illness experience. As with addiction, spiritual aspects of healing are important, as is the technology. As with addiction, we need to understand

more about not only the biology of the illness, but how to integrate the various components that affect the balance of health and illness.

Alcoholism and other addictions are complex illnesses. They involve cravings which are mediated by neurotransmitters in the brain. Neurotransmitters are affected by the thoughts people have and the experiences that influence these thoughts, both in the present and remotely through memory. We have come to appreciate that addictions like other forms of mental (i.e. mind-body) illnesses, are “no fault” biological illnesses. It doesn’t help to blame the victim. At the same time, it does help to help people assume responsibility for their behavior and the consequences of their actions. We can say this about alcoholism and addictions.

We can also say this about cancers. Empirically, it has been demonstrated that people who attend support groups do better than those who do not. Such population studies do not say what will happen to any given individual but suggest factors that are worth considering. People who attend church do better. Why? Intercessory prayer has been demonstrated to improve success rates in cardiac surgery even if the people having the surgery do not know they are being prayed for. It is easier for me to understand this if the people know and respond to the good will of their friends. Penny Smith tells the story of the Monday she felt like she would live. For days she barely had enough energy to raise her eyelids. One Monday morning her husband, Stephen, asked her how she felt. She looked surprised and said she felt better. She felt like she was going to make it. Stephen smiled and told her that her church had an extended prayer meeting for her the night before.

As I was struggling with my recovery, Paige Kirby returned from a

trip to Maine. She and her friends had visited my mother who produced a Thanksgiving of leftovers. Knowing that they might visit, she had baked an apple pie, which awaited them on the sideboard. Paige and her friends climbed Mt. Washington in nearby New Hampshire. They raved about the experience.

Mount Washington is the mountain I climbed most in my youth, more even than Mount Katahdin. In recent years North Carolina's Grandfather Mountain has become a favorite. But again and again Washington was a worthy challenge. It is the highest mountain in New England and deserves respect. People have died of exposure even in the summer. It is the point of convergence of a number of weather systems, from Canada, from the Atlantic, from the South. Weather can change rapidly. The highest winds and coldest temperatures in North America have been recorded at the weather station atop the mountain. I climbed it from the East and West, North and South. Up the Lion's head, down the Amanoosic Ravine, across the whole Presidential Range from Mt. Madison or from Mt. Adams. There is a cog railroad with a steam engine, which has been in operation since the nineteenth century. There is even an auto road to the top. Once Russell, Charlie, Bobby Gray, and I hitched the travel trailer to my father's old jeep station wagon and camped at Dolly Copp in Pinkham Notch. We drove the jeep to the top of Mt. Washington. (Where was Steve? Probably away at prep school already. We were fifteen that summer. I would be the next to go off to school.) Legend has it that I skied Tuckerman's Ravine Headwall the day before Sue and I were married. That story is true. I did.

I know what my psychoanalytic colleagues would say about this. They would say it was counter-phobic behavior. They would not be entirely

wrong. I also know that behavioral geneticists would recognize such adventurousness as a correlate of what they call the novelty-seeking gene. My Aunt Mary alluded to this in noting a similarity between my adventurousness and the spirit of my Grandfather Randall. My Grandmother Dyer had the same gene. She loved to travel. Once she invited herself on a transcontinental automobile trip the day before departure when she found out that her sidekick was going. I could see adventurousness in myself not only with physical challenges, but also in taking on difficult administrative situations I could have avoided.

Paige and friends climbed down Tuckerman's Ravine Headwall with packs. They reported that it was nearly vertical. The most recent death on Mt. Washington occurred when a climber with a pack had bent over to pick up his sunglasses and fallen to his death. As the story of their Mt. Washington adventure was told, a bit of ancient history got thrown in. "Dr. Dyer skied this the day before his wedding, you know," Paige said at dinner one night.

Wait a minute. The legend was getting out of hand. I wanted to make sure my friends realized that the headwall, a glacial cirque or head of the glacier, was not so steep when the bowl was filled with snow. It was steep, and a fall to the boulders below could have meant death. But I determined that the prudent course was not wide traverses down the snow fan, where the turns would be taken above the boulders. Instead I felt that the safest course would be skiing straight down the fall line with quick checks to the snowy outrun. If there were a fall, which there wasn't, it would not be fatal. I was addicted to adventure, but not to danger.

For me the path to extreme skiing had been not one of reckless

abandon, but years of progressive challenges leading to mastery of the skills necessary. As a youngster skiing on Maine's big Sugarloaf, I recall the progression of trails, each bearing the name of some remnant of Maine's logging industry: Peavey, Cant Dog, Tote Road, Narrow Gauge, Upper Narrow Gauge, Sluice. A Peavey is a cant dog, named for the man who invented it. It was an important tool for lumberjacks on rivers such as the Androscoggin, Kennebec, Penobscot, and Allagash, the routes to the paper mills. A cant dog is a pole about eight feet long, with a sharp metal spike and a hook on the working end. It is designed to poke and/or roll the logs that are jammed to keep the logs moving downstream. I have never used one myself, but I have sometimes felt that as an administrator it was my job to break up logjams and to keep things moving. It is dangerous work, stressful work, but necessary work. It is also rewarding work.

For me the lure of the Maine outdoors was inculcated at early age. One might think that the way to survive a Maine winter would be to stay indoors as much as possible. In my experience, just the opposite was the case. I couldn't have been more than four or five when my father first took me into the North Woods to see the lumbering operations. I remember wading through the tracks he made in waist-deep snow (my waist) popping up and down like a playful puppy. The old jeep traversed the snowy track with ease in the valley between the piles of snow plowed beside the road, banked so high on both sides that you couldn't see over it. Uncle Aubrey, after his experiences with heavy equipment in World War II, established himself as a contractor. He had a road grader, a back hoe, and some dump trucks, which were also used as snow plows. My favorite was the one he always called "the Ten Wheelah." It was huge. This particular winter he had

a contract loading logs, trees actually, onto flatbeds. That was the operation my father and I went to inspect.

We went to a place called The Forks, where two branches of the upper Kennebec River came together. The way Maine people drop their *r*'s, it sounded like an animal. Sue was bewildered the first time she visited our home, and my mother asked her to put the fox on the table. "Why would she want me to do that?" thought Sue. But Sue is quick, and in a second realized that "silverware" was what was called for.

Not far from The Forks is a place called the Sluice, a steep bank, where logs are slid from the forest into the river. The ski trail at Sugarloaf called the Sluice, like its namesake, goes straight down the side of the mountain. Logging was a most impressive operation. I was impressed not only with the magnitude of the undertaking, but also with the logistics of a multi-national force (French-Canadian and Mainer) working together to get these trees onto flatbeds or into the river. Winter was prime logging time because the ground was frozen, and the heavy equipment wouldn't sink into the mud. Everything was magnified to the eyes of a small boy, but those really were big trucks, big logs, big men, and big tasks. My ambitions to attempt big things in the world were nurtured on outings like that into the Maine woods.

Most of the lessons of childhood were lessons of self-sufficiency, lessons of independence, lessons of how to get by in the world outside. The things my father and my uncles taught me were of this nature. How to pitch a baseball (or a snowball). How to swim. How to use a hammer. How to build a soap box derby racer and a kayak. How to make a fist. How to load hay bales. How to solve quadratic equations. Respect for respect women. It

is said that my grandfather Randall once horsewhipped a man. There is no doubt the man deserved it. It is less clear what he did. Perhaps he made a disparaging comment about a woman. Perhaps that woman was my grandmother, who carried eight pregnancies to term in thirteen years. Coleman, Mary, Nellie (who did not survive the first year), Audrey, Charles, Avis (my mother), Caroline, and Erma were all born between October, 1911, and March, 1924.

In comparison to my father and uncles, my mother, my grandmothers, and my aunts were solicitous. They were caring. They took care of me and us, my sister and cousins, everyone. Food. Attention. Concern. Worry. Scoldings. Advice. Whatever we needed. I never left Aunt Mary's driveway (often with a car full of friends to or from a ski trip) without her saying, "Drive carefully." Safe driving was always in focal awareness.

The lessons of the Maine woods, the rivers and lakes, The Farm, and growing up in a small town were all lessons about self-sufficiency. They were lessons about becoming independent and taking care of yourself. If you could take care of yourself, you could also take care of others. Dependency was a state you left behind. Certainly, you left it behind when you went off to college, maybe even earlier if you went away to high school. Choosing medicine as a profession meant taking care of others. To do it well required taking care of oneself also. Many doctors get themselves into emotional difficulty by ignoring their own needs while they take care of others. Cancer takes you back a step further. Not only must you take care of yourself. You must let others take care of you. You must regress.

The way we talk about dependency, it sounds like addiction, pathology. Like there is something wrong with dependency. Someone

might say they are dealing with their dependency in a twelve-step program. It would be less likely to hear someone say they were dealing with dependency issues in psychotherapy. In psychiatry we have a different take on dependency. Dependency is a feeling that needs to be recognized. The relationship between the feeling and the behaviors that stem from it need to be recognized and understood so that satisfying decisions about dependency can be made. Men in particular are likely to lack access to regression and consequently not get their dependency needs met. Men typically have difficulty even acknowledging and articulating their feelings and consequently have difficulty getting their emotional needs met. Men are likely to be *alexathymic*, without words for feelings. I was raised as a typical male. I have learned a great deal about myself from psychotherapy and psychoanalysis, and those lessons were important when confronted with a complex illness like cancer.

The Japanese do have a vocabulary for dealing with dependency. They have a concept, *amae*, which deals with the passive longings to be taken care of. In Japan *amae* is not shunned in adulthood, but is part of hospitality as well as familial interactions. Japanese psychiatrist Takeo Doi noticed the contrast in the way American culture and Japanese culture deal with dependency issues. He wrote about this in a book, *The Anatomy of Dependence*, which is taken as a key analysis of Japanese behavior. I find Doi's analysis informative not only of Japanese character, but offering a useful description for a phenomenon which has no real vocabulary in Western thought. The Japanese word *amae* describes the condition of passive love, for which European languages do not have an equivalent. *Amae* is the yearning to be taken care of. It is the experience of the infant at

the breast. It may also be the experience of the patient in time of illness or suffering.

During my first trip to Japan, I had an experience of *amae*, which I did not understand until sometime later. I met with Dr. Doi at the National Institute of Mental Health in Tokyo, which he founded and where he served as director. Later I was to give a lecture at one of the Tokyo universities. There was a conflict in scheduling which would have prevented me from accompanying Sue, Will and Cliff on a tour to Lake Hakone. No problem, it was explained. I could give the lecture in Tokyo then take the bullet train to catch up with my family at the first night's hotel.

After my lecture, I needed directions to get to Tokyo station. I knew that all trains led to Tokyo station, so if I could get to any train, I could find my way from there. A professor and a law student accompanied me on the bus to the train, got on the train with me, accompanied me all the way to Tokyo station, helped me buy my ticket, got me onto the train and did not take their leave until they had found a seat for me. What extraordinary courtesy to show a guest, I thought.

It was not until a couple of years later that I fully appreciated the cultural significance of this event. Back in Oxford, I was introduced to Dr. Junichi Suzuki, a psychiatrist and associate of Dr. Doi. After hearing about my experience, he asked simply, "Did you enjoy the regression?"

Nothing in my New England experience prepared me for this interpretation. Schooled as I was in Western notions of autonomy, independence, and Emersonian self-reliance, it never occurred to me to "enjoy the regression." I realized that I had missed an opportunity to *amaeru*, that is, to behave self-indulgently. I did recall a feeling of helpless

dependence on my translator that could best be described as *amae*, though at the time “gratitude” was as close as I could come to describing the feeling.

So now as a cancer patient, I again had an opportunity to *amaeru*. I can tell you survival depended on it. I can tell you that I enjoyed having the attention of family and friends. I can tell you that I realized that in order for the doctor to be a good patient, he would have to let go of being in charge, and do as he was told. I did that, and my doctors complimented me for not trying to do their job. I understood that. I wish I could tell you that I enjoyed the regression, but in fact, this was the part of the whole experience that was the most difficult for me.



**The Randall Farm, South Montville, Maine, about 1865**

## **Zen Thought**

The priest Tannen used to say in his daily talks that:

A monk cannot fulfill the Buddhist Way  
if he does not manifest compassion without  
and persistently store up courage within.

And if a warrior does not manifest courage on the outside  
and hold enough compassion within his heart to burst his chest,  
he cannot become a retainer.

Therefore, the monk pursues courage with the warrior as his model,  
and the warrior pursues the compassion of a the monk.

The Book of the Samurai Hagakure  
Tamamoto Tsunetomo  
Translated by William Scott Wilson  
Tokyo: Kodansha International, 1979

## **PART TWO – LESSONS FROM CANCER**

### **9. Managing Managed Care**

The decision to seek cancer treatment at Duke was an automatic one, given Sue's and my many ties with that institution and that community. It was not a reflected deliberation. When I was diagnosed with cancer, it was understood that I would return to alma mater. Sue and I had spent most of our adult lives at Duke. We still had family in Durham, and many, many friends there. It was the logical thing to do, not only for the technology, but for the support system. Also Duke was closer to Upper East Tennessee, where we live, than the major medical centers of Tennessee. However, Duke was not part of the Tennessee network, which my insurance company had set up. Therefore my benefit was to be reduced.

For all of the challenges involved in dealing with cancer and dealing with cancer treatment, nothing rivaled the challenges and frustrations in dealing with managed care. We got to experience first hand what everyone else is experiencing with managed care, and the experiences were not pleasant ones. I should qualify that observation only by noting with my fellow Kellogg Fellow, Letty Paez, that we are sophisticated professionals who know how the system is supposed to work, so in fact, we probably didn't have it as bad as most people do. Even so, it was bad enough to raise serious questions about the bizarre way our health care system has evolved and to question seriously whether our health care policies make sense for patients and for the country.

The network of Kellogg fellows was a group the W.K.Kellogg Foundation had assembled around the globe through sixteen years of Kellogg National Leadership Fellows and Kellogg International Fellows. We were planning a millennium conference to deal with issues of global policy, but I had to miss one of the planning meetings. Letty Paez, a true community leader in organizing healthcare services for the indigent in El Paso, sent the following e-mail:

Date: Thu, 27 Aug 1998 15:34:25 -0700

From: Letty Paez

To: "Susan, Allen Dyer"

CC: Forum executive committee list

Subject: Reminder: Forum '99 Executive Committee Conference Call...

Dear Allen,

I am so GLAD to hear that in spite of everything you are going through, things are generally going well for you. Your attitude and your spirits seem to be high which is more than half the battle!!!! I will continue to keep you in my thoughts and prayers and look forward to seeing you at our next Leadership Summit meeting. I would LOVE to hear your health care system stories. . . Can you imagine what the poor folks i.e. the ones I work with, go through !! If we, the sophisticated professionals with "adequate access" to health care have problems, can you just imagine what others go through? Lord help them. . . and us for that matter.

Hugs and smiles to you and yours,

Letty

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I responded to the members of the planning committee from the laptop computer we had taken to the hotel, our link to the outside world, with the following story and plea to make healthcare financing a priority for

the forum agenda:

Dear Letty and all,

My experience with physicians, nurses, PA's, phlebotomists (vampires: 400+ needle sticks so far) has been nothing short of wonderful (the needle sticks notwithstanding). My experience with managed care has been like everyone else's. It is a problem I have been studying for years, but now it is no longer an academic problem for us. Sue and I as a team have been able to force BC/BS of Tennessee to adhere to the contract that our university negotiated, but not without a struggle. I take the direct approach until I get so frustrated it is hopeless, when she takes over with her belief that rational patients--I really meant "patience"--will eventually bring a rational response.

When I was a college student reading Thomas Mann's "Death in Venice", I was stunned by a comment he made describing a gondolier who was trying to jack up the price. Said Mann's protagonist, "There was a standard response, which I made automatically: I won't pay you anything if you don't take me where I want to go." I marveled that anyone would have enough sophistication to know the automatic response. Perhaps that is what an education is for.

What I have learned as a physician dealing with managed care is that if you aren't happy with a decision, appeal it (and save your anger for later).

My first encounter with managed care came about a week after my first visit to Duke. It was a telephone message from my "bone marrow case manager" in Chattanooga informing me that she had some information about my bone marrow transplant.

"Oh boy" I thought. "I have an advocate in Chattanooga. "

Not so, the information was that since I had chosen a hospital out of network, my benefit would be reduced to 70%. On a \$150,000 procedure, this could be a pile of change. There was a standard response, which I made automatically: "I want to appeal that

decision." (I won't pretend I saved my anger for later. I was too stunned to be poised.) The appeal was successful. What I have learned as a patient is that EVERY request is initially denied, and if you have enough rational patience and a dedicated spouse and enough time, they will probably relent eventually.

The stories my mother tells about the little hospital in her town in rural Maine are very different. People are sent home too early, and they die. Period. End of story.

As Kellogg Fellows we can't let this be the end of the story. We have to work for a more sane health policy. I am sure the Millennium Summit can be a forum for that agenda.

Thanks to all of you for your good wishes. That is such an important ingredient in healing. That too must be part of the story and part of the agenda.

My best to all of you,  
Allen

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Appealing managed care decisions is a lesson physicians have learned from painful experience advocating for their patients. We have all had to deal with limitations placed on the care "allowed" and frustrating encounters with telephone reviewers, who tell us that their company is not going to pay for additional treatment. First encounters are typically with minimally educated people operating from protocols that specify criteria for denial. They really have little decision-making authority; they simply convey the denial. They talk to you like you are stupid for wanting to care for your patients and stupid to think that an insurance company would allow another X-ray or another day in the hospital. You waste your time talking to these people. You can appeal or you can request a physician-to-physician review. If you do this, you speak to someone with more education, but still someone working from a protocol, which specifies the criteria for denials.

Managed care views Bone Marrow Transplant as an interchangeable technology, a commodity, something you would pick up at the technology store, and they had already negotiated the cheapest price for their network providers. Their criteria for having someone in the network would not necessarily be the same as a patient's would be. For your own physician you might want the most competent person or program. Managed care might chose the most efficient or place a lower priority on quality or patient satisfaction. Time and again I have seen patients in my own specialty, psychiatry, who were diagnosed with bipolar disorder (manic depression) and placed on mood stabilizers and antidepressants. In listening carefully to their history, I often learn that the diagnosis was made say five years ago, the year their mother died. They were placed on medication in lieu of psychotherapy. They were never given the opportunity to talk about their grief and loss. The medications were renewed again and again at infrequent 15 minute med checks, and the real issues never dealt with. Often this history is elicited by medical students, the only ones who take the time to talk with the patients when the doctors on the panel are so overloaded that they just have time to write prescriptions. Doctors who schedule longer visits may be dropped from the panel and thus not available to patients who may want or need to talk about their problems.

We were lucky that our appeal for Bone Marrow Transplant at Duke was granted. I say "we" instead of "I" because at this point Sue was so much a part of these struggles. We were granted a "unique benefit" on the basis of a letter we wrote outlining the services available at Duke and our ties with that community. Duke has a reputation for excellent value for money in that the most advanced technologies are available at costs that are

about the same as other hospitals.

We were lucky also that Bone Marrow Transplant was even a consideration. It was still an experimental procedure. I was part of a clinical trial, a research protocol. Yet already BMT is pretty much standard treatment for certain conditions. Just a few years ago it was not available under many insurance plans, and patients had to litigate to get coverage. We were spared that complication and delay.

A recent John Grisham novel, *The Rainmaker*, had been made into a movie and video, which we watched in the hotel during one of the periods of my house arrest. In this story a young man dies because his insurance company repeatedly denies his mother's request for a life-saving treatment, a Bone Marrow Transplant. Grisham's young lawyer hero sues the insurance company on behalf of the young man's family. In gathering evidence he finds that it is the insurance company's policy to initially deny all claims. That is how they make their money. It is a grisly tale of greed, corruption, suffering, and right versus wrong. Even though Grisham tells the story with characteristic exaggeration, nothing in our own experience or that of our fellow patients in the Bone Marrow Transplant Clinic contradicts the premise of the story that insurance companies make their money by initially denying all claims. Yet that was also our experience, and we knew the automatic response to appeal all denials.

Nearly all the benefits that are provided by contract with my employer, the State of Tennessee, were initially denied, then granted on appeal. This included not only the bone marrow transplant itself, but each month's hospital bills, initially denied, then granted upon review. It included transportation to and from the hospital. It included certain

prescriptions. It included lodging in the hotel (\$60/night in lieu of staying in the hospital at \$900/night). This is a tremendous cost savings, but for someone such as myself who likes to be active, it is actually an improvement in quality of life during the treatment. Denied. Appealed. Eventually granted. Any number of times we heard fellow patients, exhausted by their treatment, comment that their insurance company refused to pay for some aspect of the care. They were overwhelmed by not only the treatment, but also the hassle of trying to keep track of the finances.

Another aspect of care that helped avoid expensive hospitals was home health care. Both in Durham and Johnson City, home health nurses could manage intravenous fluids, IV meds, and other treatments. The insurance company took a very negative view of home health care. Even though it was saving them a great deal of money, there were criteria for denying it. Basically it went something like this: if you weren't sick enough to be in the hospital, you didn't meet criteria for home health care. Home health was for people who should be in the hospital, but weren't critically ill enough to meet criteria for hospitalization.

I first needed home health to remove a PICC line. A PICC line is a Peripherally Inserted Central Catheter. It is a large IV (intravenous line). It pumps chemotherapeutic agents, which would be toxic to veins, directly into the superior vena cava, the great vein of the chest, where the chemicals quickly mix with blood. Once the PICC line is inserted in the hospital and its location confirmed by X-ray, the patient is free to roam about. A small battery-powered pump, worn in a fanny pack, pumps the chemicals into the veins. Once the chemicals were underway, we were allowed to go home, back to Tennessee. As we drove through the beautiful mountains of western

North Carolina, I called the home health agency from the car phone to notify them when it would need to be removed. The home health agency checked with the insurance company for pre-certification. Denied. The patient wasn't homebound and hence not eligible for home health care. I called the insurance company to argue the logic. I wasn't home bound because I had the pump without which I would be hospital bound. Sorry, they had their protocols. Could I speak to your supervisor? Automatic response. The supervisor said it didn't need to be pre-certified because it was an outpatient procedure. It couldn't be pre-certified anyway until Monday. It was the weekend. I could go to the emergency room. There were no nurses at the ER credentialed to remove a PICC line. It was the home health nurses that were trained to do that procedure. It could be done in a doctor's office, but doctors' offices were closed at 6PM on Saturday. It could be done at the walk-in clinic. They had a doctor on site, but they didn't have authorization for the billing codes to do it. I called the insurance company back, and told them that they could pay for an Emergency Room visit *and* a doctor visit to the ER or they could pay for a home health nurse. The home health nurse would cost less than half as much. They agreed to pay for the home health nurse. It took seven telephone calls. I logged them all and the names of the people to whom I spoke.

It was almost comical because at this point I had the energy to make seven telephone calls. It was also almost therapeutic because here was a tangible reason to be angry. At this point I felt angry and was glad to have a reason. I was also glad to have enough energy to use humor as a defense. I then had the presence of mind to say with more irony than anger at this point, "I am a cancer patient. I shouldn't have to hassle about details like

this.” Some of the home health care bills still remained in contention for months after the treatment was completed. More hassles. More telephone calls. More denials. More appeals.

Another of the tactics the insurance company use to save money is to send a letter after discharge saying that only a certain number of days of a hospital stay have been approved, say three days of a five-day stay. If more time is needed , more information will be required. These letters arrive several days after the information is required. If you have further questions, a number is provided. The person who handles these calls is not a happy camper. Anyone receiving a letter like this is not in a good frame of mind. I logged all these calls though the persons to whom I spoke were reluctant to give out their names. Usually they identified themselves by first name only.

Where did we go wrong? How did we come up with such a senseless non-system of health care delivery? The answers are certainly complex, but a few reflections are nonetheless in order. The cost of American medicine, the most sophisticated and most expensive in the world, has for several decades been a concern of politicians, health economists, employers, and the general public. Costs of health care rose faster than the national economy in general for many years, consuming an ever large slice of the economic pie. At the same time, increasing numbers of Americans were without insurance coverage and received only required Emergency Care if any at all. Insurance companies could make profits by denying care, or by shifting “risk” to other insurance companies. They did this by making insurance difficult to carry from one job to another, almost unobtainable if you were not working or not part of a young, healthy workforce, and by refusing to

cover “pre-existing conditions,” which in a time of chronic illnesses is just about everything except emergency care. Managed care has lowered the overall cost of healthcare by limiting services, but it has done nothing to improve access to care or improve (or maintain) quality of care.

All other developed countries in the world provide some kind of national health program, socialized medicine, a solution, which has been strenuously resisted in United States. Managed care was the market-driven solution that emerged as an alternative to socialized medicine. On the surface, the idea had some appeal. Decisions that doctors made on behalf of their patients would be reviewed to make sure unnecessary procedures were not done, or at least not paid for. If this is what had happened with development of managed care, no one would be complaining. But managed care organizations have effected major transformations in health care delivery. Doctors have been transformed into “providers”, and patients have been transformed into “consumers”. Healthcare is no longer a service, but now is a commodity, and in most instances it has become an “investment opportunity”. Increasing amounts of money are diverted from actual patient care to corporate shareholders and executive compensation. The “consumer” who makes the choices is no longer the patient, but the employer. Thus health care delivery focuses no longer on the individual and the individual’s needs, but on the balance of health of the population at risk. Medical decisions are often not made on scientific grounds but rather economic grounds. Medical decisions are often not made by doctors.

Much of the reduction of costs achieved by managed care has come by reducing mental health benefits. This targets a disenfranchised population, those with serious and persistent mental illnesses, who often

have difficulty advocating for their own needs. The erosion of mental health benefits erodes the quality of care for everyone by eroding a comprehensive approach that includes communication between the doctor and the patient, a bio-psycho-social understanding of illness. It also makes difficult recognition of the kinds of spiritual concerns that made such a difference to me in my cancer treatment, spiritual approaches that promote a general sense of health and well-being. Managed care in its current incarnation is almost dismissive of health and well-being. Economically it makes sense if you can accept a goal of shifting sick patients to other plans and ultimately back to the public sector Medicare and Medicaid programs.

Cardiovascular disease? Why is that our problem? Change the way you live. Depression? Get over it.

Problems with drugs or alcohol? Shame on you.

Hassles with managed care can actually undermine progress toward health. They often create unnecessary stressors. They can eat at the body and the immune system much in the insidious way a cancer does. At a time when one is emotionally most vulnerable, they can tilt the balance of health and wellness toward unwellness. They are discouraging. They are frightening. They are un-affirming.

The current revolution in health care financing is eroding many of the traditional assumptions of medical ethics, as well as assumptions about the doctor-patient relationship, the nature of health and even the role of persons in a society. Health care cannot be just about economic values; it must include human values. The most sobering change is the departure from a person-to-person doctor-patient relationship to assembly line panels of providers and networks of health care facilities. Yes, we need reasonable

cost controls but not at the expense of basic care.

In the economic model of marketplace transactions, much more is at stake than how the funding is managed. The metaphor of “healthcare as an industry” jeopardizes the healing process. Healthcare is reduced to physiological interventions that take place in a delimited period of time. Physicians become not merely providers but technicians, and patients become not merely consumers, but recipients of technology. Providers and consumers are likely to be strangers to one another. Medicine is transformed from a human service into a commodity. We all suffer.

In the interest of efficiency and reducing cost, these transformations might seem warranted, but the evolving practices we are currently witnessing must themselves be subjected to ethical and political scrutiny. Certainly much of what is going on is not ethically justifiable, nor does it serve the ends it was intended to serve. The value placed on autonomy, however, set the stage for a transformation in which consumers enjoy little choice about the healthcare they receive. The “market” solution has been a non-solution in that it has only succeeded in lowering costs without adequately addressing quality of service or the distribution and allocation of services. The resultant unregulated (or under-regulated) market resembles the lawlessness of the post-Civil War American frontier or early stages of industrialization, laissez-faire capitalism, the era of the “robber barons,” where efficiencies and wealth were achieved at the cost of environmental pollution and human suffering. In such markets the goal of business is to make profits for the owners or shareholders with no direct accountability for the services provided.

The cottage industry of personalized private practice medicine is

being replaced by assembly-line efficiency. This change is reminiscent of the way huge agri-businesses have replaced the family farm.

Whether managed care becomes an enduring aspect of the way health care is financed and delivered remains to be seen. As it is currently practiced, it is ethically problematic. The excess of free market solutions could be reined in by regulations delineating what services would be required. In other words the Managed Care Organizations could be held accountable. But when the incentives are tilted in the direction of denying needed care, the system remains worrisome.

My experiences with cancer have suggested to me that the problems with managed care are not just the difficulties with reimbursement that have been created, but also the emphasis on the physical aspects of care to the detriment of the psycho-social and spiritual aspects of care. It is such reflections on my own experiences as a patient first of all and as a physician trying to advocate for my patients' needs that have led me to consider the need for a new medical model. It is to those considerations that I devote myself in the next chapter.

## **10. The Need for a New Medical Model**

My experiences as a patient with cancer have helped me understand the complexity of illness in ways that as a physician, trying to be attentive to my own patients, I could not fully appreciate. My experiences with managed care helped me appreciate that our system of healthcare finance fundamentally misconstrues the nature of illness and what the healthcare system should be trying to accomplish. As a patient with cancer, I was thankful that there was such a sophisticated technology as Bone Marrow Transplant, but I now know first hand what a grim technology it is. Without the attentive care of the Duke physicians and nurses and the communities around me, I would have found it unbearable. I consider this the spiritual side of care, not necessarily in a supernatural sense, but certainly in a transcendent sense.

In calling for a “new medical model” I am suggesting a model than encompasses such spirituality, such transcendence. George Engel identified the need for “a new medical model” in 1977. The model he proposed was a bio-psycho-social model intended to expand the bio-reductionistic model then in force. The bio-reductionistic model held that everything you need to know about medicine could be explained by reducing illness to its biological components. That model was extremely successful up to a point. There had been many advances in biomedicine that supported the treat-the-body-as a machine approach. Even organs could be replaced intact like the worn out parts of an old automobile.

Now three decades after the publication of Engel’s article, we

appreciate that the biological model did not explain enough. We realize how mind (and stress) affect the body-machine and how so many of the illnesses people suffer stem from behavioral causes with physiological correlates. One could cite not only the somatoform disorders (formerly considered psychosomatic in the old dualistic mind-body dichotomy), pain syndromes, ulcers, asthma, but also sexually transmitted diseases, effects of smoking on the body/person and other addictions. A great deal of work has been done to understand the behavioral correlates of heart disease. We recognize, for example, that hard driving (hostile) type A personalities are more prone to coronary events like heart attacks. Chronic illnesses are complex problems demanding a comprehensive approach.

Jimmy Vredenberg, treating his psychiatrist patient (me) one day in the Duke Adult Bone Marrow Transplant Clinic, decided to get philosophical about the nature of medicine. He observed that psychiatry was half medicine, an assessment with which I agreed. He then went on to generously suggest that medicine was more than half psychiatry. I also agreed with him there. Estimates by primary care physicians of the amount of psychiatry or psychological problems presenting in their offices are much higher, 70-80 per cent. But this is still basically a dualistic view of medicine, physical on the one side and psychological on the other. I think it is time we consider not only integrating the bio-psycho-social approaches to health, but also integrating the spiritual component in a true bio-psycho-social-spiritual medical model.

In defense of Engel's originality and insight, I think it could be said that spirituality was implicit in his consideration of the psycho-social. But it must also be recognized that the discussion of spirituality in modern Western

thought is strained and uncomfortable. I think it could also be said that a failure to distinguish the spiritual from the religious has impeded a broader consideration of the spiritual. Each religion comes at spirituality in its own way, and those ways may conflict with someone else's approach to spirituality. So often those with fervently held beliefs are not open to consideration of other approaches to spirituality. Sometimes biomedicine becomes a fervently held belief, but increasingly alternative and complementary approaches to healing are being considered.

In opening up the possibility of a conversation about the role of spirituality in health care, I am aware that we would need to consider everything from organized religion to the most unique forms of New Age individualism. And that is precisely the point. Each patient, each person comes to medicine with his or her own unique experience and outlook and needs. And each person may find their a unique path to healing. The doctor and healthcare team do not need to share the same experience, but they need to understand the uniqueness of each person's psycho-social and spiritual needs.

Spiritual reflections were very much part of my experience of the Bone Marrow Transplant. Getting well was a consuming goal and the spirit of determination carried the day, day after day. This was one aspect of the treatment that I did not feel Duke handled particularly well. Duke University was founded with the motto *Eruditio et religio*, knowledge and religion. There are many people at Duke interested in religion and spirituality and their role in medicine. However any explicit discussion of spirituality was left to a wandering chaplain, whose role was ill-defined, and in my experience, intrusive. Every now and then he would stroll into the

clinic and make the rounds asking questions and trying to engage in conversation. It is possible that those conversations could have led to spiritual concerns, but they never seemed to. It was never clear to me if he was offering comfort, psychological counseling or looking for souls to save. It wasn't clear why he was there. Perhaps an introduction would have been helpful. A formal consultation. An option.

Our first encounters with this chaplain were in the old Bone Marrow Transplant Clinic, a small, cramped building where we were shoulder-to-shoulder with fellow patients like in old fashioned open wards. Here we made acquaintances easily. We made friends with other cancer patients, whose schedules might be different from ours and whose prognoses might be different. We made friends with people we weren't certain would be friends for long. Prognosis was never a topic of discussion, but some of these people were very sick. The chaplain's conversations in this setting were public, everyone overheard what everyone else said. We were understandably a bit guarded, more so with him than with each other.

My bone marrow transplant proper, the high dose rounds, started the day Duke opened its new Adult Bone Marrow Transplant Clinic. It was a spectacular architectural space. The treatment room had a curved wall of windows letting in lots of natural light. Materials were warm and colorful. There was lots of room to move around. There was so much space that at first we were well separated from each other and even isolated. As time went on we learned to use this space more humanly. One day Sue and I found our situation so preposterous we began to laugh. I couldn't say there was anything particularly funny, but nonetheless we began to laugh. Others joined in, not knowing why we were laughing. I don't think we knew why

we were laughing. Soon we began to pull our treatment chairs closer together so we could chat and keep each other company as we faced the ordeals of the treatment. It seemed easier to face things together rather than alone.

By comparison, I remember a visit from a chaplain in the Johnson City Medical Center, the local hospital where I went for the treatment of most of the cancer complications, of which I had my fair share. One day chaplain Calvin Ross came to my room and said simply, "I noticed your name on the list and came by to let you know the chaplain's staff were available to you if you wanted to us to be involved with you in any discussions of spiritual issues." He couldn't have been more clear about his reasons for coming or that I had the option of talking or not talking. At the time spiritual issues were not foremost on my mind, and that was certainly OK, but when I wanted to have those conversations, I turned to Calvin Ross and his colleague Carl Petering, with whom I had for several years been team teaching a medical ethics small group.

It was Carl Petering, who later offered a most trenchant comment about spirituality at a dinner party. A guest from Australia suggested that the great thing about religion was the music it inspired. As music lovers ourselves, Sue and I did not object to this view, but it did not sit well with Carl, who later in the evening suggested that the great thing about religion was that it offered us metaphors to deal with the uncertainties of life.

Robert Coles, the child psychiatrist who writes so much about the lives of children, tells the story about one time his mother was in the hospital, and a chaplain visited her. She became angry with him about something, and he reflected that she was in the anger stage. As I recall the

story this interpretation only made her angrier. She wanted someone to pray with her and to read the Bible verses she found so comforting. This would certainly be an appropriate role for a chaplain.

It strikes me as a little bit ironical that chaplains are often the ones that are called upon to do psychological counseling and that psychologists may be offering spiritual affirmations and guided imagery. But I take such confusion merely as an indication that the role of spirituality in medicine has not been well thought out.

Indeed in my experience the people I found most spiritual were the doctors and nurses though nothing they did might be identified in a formally religious sense. Their presence and their attentive concern again and again transcended the mundane concern of chemicals and lab values. This could be considered integration of the spiritual with the bio-psycho-social at its best. I would doubt that ultimately spiritual matters could be delegated to others any more than psycho-social matters can be split off, though busy physicians may enlist others to assist with such matters partly because time is so precious.

This leads to another perspective on the problems with managed care. In some ideal sense a responsible managed comprehensive approach to medical care could make sense. Prevention could mean a lot to the health of an individual and a population. Early intervention could prevent more complicated problems later on. However, managed care as it currently exists is not comprehensive and not integrated. Mental health services are “carved out”. “Carve out” is the economic term that is used to indicate that mental health services are not dealt with in the same way as other health services. In fact once carved out, they are often discarded or severely limited.

Engel's biopsychosocial model addressed these concerns by considering the place of psychiatry in medicine. Was psychiatry legitimately part of medicine because it dealt with illnesses in much the same manner as the rest of medicine or should it be split off (or to use the modern parlance, "carved out"?) I think it is reasonable to say that even now the issue has not been adequately settled. Engel's arguments for integration are convincing in terms of what a reasonable expectation of healthcare might be, but they do nothing to counter the take-dollars-out-of-healthcare-and-put-them-into-other-pockets approach that currently prevails. The current approach is completely materialistic with no room for the psycho-social and spiritual.

Engel contrasted diabetes and schizophrenia as examples of two illnesses, one from what traditionally might be understood as bio-medicine and the other psychiatry. In fact both require a biopsychosocial approach to adequately understand and treat them. In my reflections, I contrast cancer with addictions (dependencies) as perhaps even more extreme examples of the need for a comprehensive understanding of illness. Alcoholism and other dependencies are incomprehensible without an understanding of the role of spirituality, and so also, I would insist, is cancer.

Spirituality includes the recognition of something beyond the self, something transcendent, something more than just material. We recognized spirituality in medicine, for example, in the best treatment approaches to substance misuse, which affirm recognition of a "force greater than myself" not necessarily defined in any specific manner. Twelve step programs understand the force greater than myself as uniquely personal. We recognize something beyond self in friendships, families, fellowships, and

communities. Spirituality in health care is not only post-modern, it is also post-narcissistic.

My own reflections on spirituality while undergoing cancer treatment led me to recall my times in Nepal where spirituality seemed so natural and unstrained. I was also reminded of our own Native American spirituality, which shares with Nepali spirituality a central focus on harmony with the environment and finding spirit in the world around.

When I was in college I was privileged to have an opportunity to study weather symbolism of the Hopi and Navajo. I have already indicated that coming from Maine, weather was a central part of life. For the farmers of Maine as well as the seafarers, understanding weather, or Nature, was an important part of getting along in the world. I was invited to join a group at the Museum of Northern Arizona, most of whom were studying atmospheric physics. The program was established under a grant secured by Vincent Schaefer, who had serendipitously discovered cloud seeding. In the midst of summer, he was trying to get a deep freeze colder by putting dry ice into it. He noticed that the carbon dioxide crystals condensed the mist caused by his breath. Up he went in an airplane to demonstrate that carbon dioxide could also precipitate rain from a cloud.

I had previously spent a summer with Dr. Schaefer in Reno at the University of Nevada Desert Research Institute with a group of science students funded by the National Science Foundation. It was the post-Sputnik era. The Russians (Soviets actually but they were always called “Russians”) had put a rocket in space, and America was trying to catch up. One way of doing this was for the NSF to fund summer research institutes for science-oriented high school students. At the age of seventeen, I traveled

alone across the country to study atmospheric physics. Needless to say, my father's trenchant observations about the weather provided numerous hypotheses to test in this wonderful laboratory.

When I was invited back for a second experience at the Museum of Northern Arizona, it was the anthropology of the area that fascinated me more than the physics. So I took an old Land Rover belonging to the State University of New York and went out to the Hopi and Navajo reservations. I was introduced to people who were willing to share their understanding of their culture with an outsider, an eager, curious, sincere 19-year-old. In those days, anthropologists called such people "informants." The terms now sounds almost like a snitch, telling on their people, and even then there was some tension with anthropologists, who often had an agenda to "improve" the lives of Indians.

Now we would more respectfully identify such people as "story tellers" or "wisdom keepers". The two individuals who were most helpful to me were a man named Lomahaptewa and a woman named Elizabeth White. As might be inferred from their names, Lomahaptewa was completely immersed in his culture and saw things from a Hopi world-view. His descriptions were stark and direct like the world in which he lived. Elizabeth White, who was also Hopi, had more experiences with the outside world and understood better the world from which I came. In their own ways, each of them explained to me how a Hopi views the world<sup>1</sup>.

The Hopi world is a harsh world. While agriculture in Maine is

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<sup>1</sup> Years later I learned from Bill Timpson, one of my fellow Kellogg Fellows that Elizabeth White wrote an education classic *The Sun Girl. A True Story about Dawamana, the Little Hopi Indian Maid of Old Oraibi in Arizona, and of How She Learned to Dance the Butterfly Dance at Moencopi, as told by her lifelong friend Po-Lin-Gay-Si (Mrs. Elizabeth White).*

stalled half the year because of cold weather, there is no dearth of water. In Arizona the Hopi subsist on a corn diet, and they grow the corn in the most arid conditions imaginable. The Hopi reservation in northeast Arizona is situated atop three mesas, called First Mesa, Second Mesa, and Third Mesa. There are several pueblo villages atop each mesa. Lomahaptwea was from the Second Mesa Village of Shungopovi. Elizabeth White lived in a new house on First Mesa, near Old Oraibi. A peaceable people, the Hopi are surrounded by their traditional enemies, the Navajo, a more aggressive, nomadic people. The battles of old gave way to court battles and now the two are living in peaceful coexistence.

Hopi religion is focused on the weather. For the Navajo the focus is on health and healing rituals. Both their religions focus on “ultimate concerns” as theologian Paul Tillich suggested religions are likely to do. Each month each Hopi village has a ceremony which is basically a supplication to the Kachina gods for rain. In this era with many Hopi living and working off reservation, these ceremonies are also occasions to return home and reunite with family and clan. Particularly the Hemis or Home Dance in July is a time for Hopi to return to their village of origin.

Lomahaptewa invited me to attend the Hemis Dance in his village of Shungopovi. Outsiders were generally not welcome unless they were guests of a Hopi. Kachinas are three things, Lomahaptewa explained to me. They are the ancestral spirits that reside in the San Francisco peaks, near Flagstaff, about a hundred miles southwest of the mesas. They are the men dressed up to look like Kachinas, embodying the ancestral spirits, and they are the dolls, called “Kachinas” or “Kachina dolls”, carved from cottonwood and painted to look like the men dressed up to look like the gods. Hopi Kachina dolls

are highly collectable. Traditionally dolls are used to instruct children, boys and girls, about Hopi customs. Their instruction is not didactic like the instruction I was receiving, but a playful acting out of traditional ways.

Each month there is a unique costume, which is the same from village to village. The Hemis costume is adorned with clouds and weather symbols. Tall, stacked headdress represent the cumulus clouds which bring rain. These are painted with pictures of clouds with lightning and rain below them. Clouds are painted on the chests of the men taking part in the dance. Leather loin cloths are painted with corn stalks. They carry curved sticks like lightning. They dance to drums, the always important drums. The drums make a noise like thunder. They rub deer clavicles against notched sticks, which reverberate over hollow gourds. This also sounds like thunder. The men retreat to underground ceremonial rooms called “kivas” where they smoke pipes. I was not allowed to enter the kiva, the most sacred of places. The smoke from the kiva rises to the sky, where the kachinas in the San Francisco Peaks can see which village is making the supplication, and they send the clouds to that village. The clouds march across the desert like soldiers in formation. One after another, all in a row. Atmospheric physicists call these “cloud streets”. They dump their rain on the village which has asked for it, to help grow the corn.

My scientific colleagues at the museum pooh-poohed my accounts. They said atmospheric currents called the Bermuda current brought moisture from the Pacific Ocean, and these currents caused the cloud streets. They always occurred at that time of the year. What the Bermuda current was doing in the Pacific and in the American Southwest, I never got straight. I simply took an empirical approach. I pointed out to my friends that every

rain dance I attended was rained out, so draw your own conclusions.

For the Hopi there is the expectation that the ritual, repetitive actions will bring the rain on which they are so dependent. The ritual is constructed in such a way that everything that is done is done as a reminder of the purpose for which it is done, namely to get the attention of the Kachina gods. The Hopi believe that if everyone stays focused, the ritual will be successful, but if it fails, it is because someone allowed his mind to wander. Thus everything in the ritual is designed to serve as a reminder-- weather symbols, images of clouds, corn stalks, sounds like thunder. And the community must come together in a life of purity and wholeness or holiness. If someone is preoccupied with a marital infidelity, for example, then everyone must suffer. The community must work together to address the needs of all its members.

The Danish philosopher Soren Kierkegaard explained religious ritual in a similar fashion. He said "Purity of heart is to will one thing." Christian ritual is focused on the ultimate concern of salvation and eternal life. All of the symbols point to this focus, especially the cross on which Jesus was sacrificed. Purity of heart is to will one thing: Life triumphing over death.

My cancer ritual was like this. Each day we went through the ritual of blood counts and treatments. Nurses changed bandages, and doctors reviewed the progress. Each day the staff offered hope, and the community of friends gathered round to keep the focus on healing, wellness and recovery and return to their midst.

Navajo rituals also focus on health, the return to health from illness. Like the Hopi they live in a harsh arid environment and move in small groups with their sheep. Although a family may have a mud or perhaps log

or now even a cinder block hut called a hogan, they may still spend much of the year may in tents. Navajo crafts, pots, baskets, and blankets bear symbols from the environment shared with the Hopi, clouds, lightning, corn stalks, animals. One of the most striking of the Navajo crafts is the sand painting. Grains of colored sand are skillfully sifted through thumb and forefinger to create elaborate “paintings” of corn, people, animals, spirits, the four corners of the world, which predate and should not be confused with the Four Corners region where the Navajo Reservation is located at the intersection of Arizona, New Mexico, Colorado, and Utah. A Navajo sand painting takes days to create. Ultimately they may be four or five feet square. I was allowed to “paint” a feather on one. I was very proud of my contribution. I don’t think it had any ritual significance.

Typically a sand painting is used in a healing ritual. When someone is sick, the medicine man, at times with the help of male relatives, may construct an elaborate sand painting on which the sick person sits while the shaman dances around, drums playing of course, and sings a ritual chant. While the painting may take a long time to construct, its forms are precarious. A slight breeze, a slight motion of the hand will return the sand to a random mixture of grains. Like life itself, the painting is ephemeral. Chaos is the natural state of the universe. We may temporarily carve a little order, but the second law of thermodynamics always wins. Entropy in the universe always increases. Chaos and disorder reign.

Navajo healers now regularly coexist with Western healers. Nothing in the healing rituals precludes the use of antibiotics or other medications. Western medicine may be considered an alternative medicine or a complementary medicine in this setting.

I remember one Sunday morning on the Navajo reservation. I was invited to a church service in Chinle, Arizona near the beautiful Canyon de Chelly (pronounced Canyon d'Shay). It was a Presbyterian Church as I recall. Elegant Navajo men and women were dressed in colorful clothes and many wore silver and turquoise jewelry. The sermon was more like an anthropology lecture. The minister detailed the inferiority of “animism”, the belief that animals have spirits, a central tenet of the Navajo world-view. The Navajo present did not seem uncomfortable with his explications, but I was. He said nothing about his own faith, his own beliefs, or the power of his own spirit or spirituality. The discussion was entirely intellectual and critical. He seemed oblivious to the presence of a living spirit around him and intent on replacing a viable spirituality with a spiritless religion.

I would call this a negative spiritual moment. It was not just a-spiritual. It was dis-spiriting. By contrast, I would like to share a positive spiritual moment from my own treatment. The moment that impresses me most vividly occurred one morning in the Johnson City Medical Center. I had completed the low dose rounds of chemotherapy and was facing the full effect of the complications of the steroids. I had been hospitalized at what we call here, simply “the Medical Center” for a deep vein thrombosis. My own psychiatry resident and medical student were in the room with me, and we were discussing our psychiatry patients on the floor below, whom the resident and medical student would soon see although I would not be allowed to leave the bed. I was working as much as I could, but I had reached my limits. I would have to call in a colleague to cover for me.

At that point medicine rounds collided with psychiatry rounds. My own internist from the University Physicians Practice Group entered the

room with her residents and medical students and the oncology fellow. There were eleven physicians in the room, counting the student doctors, but not counting myself. They formed a circle around me, and as they (we) sorted out the medicines and the treatment plan, their good wishes for me were abundantly evident. Mary Beth Deering was on medicine at the time, and she was wearing her trademark ear-to-ear grin. Scott Guthrie, sat beside me on the bed and put his hand on mine. Scott was next up in the rotation. He would pick me up (in more ways than one). I would become his patient.

This was a positive spiritual moment. It was a moment that was uplifting and inspirational. Shortly after the official rounds, Steve Loyd, doing an accelerated residency (internship during the fourth year of medical school), circled back to my room. He told me his son Heath was praying for me every night. It was a powerful image, this articulate little four-year-old boy, wearing the flannel Superman pajamas I had seen him wear when I had been at their house, near the end of the day, down on his knees beside the bed, praying out loud for my health. Once when President Clinton was making a speech on television, Steve asked his son if he knew who that was? Heath said sincerely, "Is it Dr. Dyer?" My own prayers, when I prayed, were more likely to be silent meditations with the Great Spirit. Other friends, grown ups too, shared with me that they prayed for me out loud on their knees beside the bed at the end of the day. Purity of heart is to will one thing. I had to get better.

It was during this period that my blood counts returned to normal. The serum protein electrophoresis returned to normal. The beta-2-microglobulin returned to normal. The bone marrow aspirates returned to normal. All the markers of multiple myeloma returned to normal. For want

of any other way of describing it, I would have to say this was a miracle.

## **11. Affirmations**

The following presentation was made by Dr. Ron Franks,  
Dean of the James H. Quillen College of Medicine,  
at the Honors Convocation, May 1998:

The recipient of the 1997-98 Dean's Distinguished Teaching Award in the Clinical Sciences goes to an individual who has been an academician and clinician for 23 years. This individual earned an M.D. degree in 1972 and a Ph.D. degree in 1980 from Duke University. He came to the Quillen College of Medicine in 1992 as professor and chair of the Department of Psychiatry. As a scholar, he has published over 100 articles, written books, received 13 major grants and has been awarded seven fellowships. Of his effectiveness in instruction, his students have said: "He challenged us no matter what the situation, in the clinic, on a run, or on a bike ride. Any time was a good time to learn." Setting the standard for becoming a physician with intelligence, integrity, empathy, and pure zest for life is the gift this mentor and friend has given to us. This year's Distinguished Teaching Award in the Clinical Sciences goes to Dr. Allen Dyer.

Affirmation is the opposite of denial. Affirmations are statements of belief. Affirmations are becoming increasingly popular complements to medical therapy for cancer and other diseases. Along with guided imagery, relaxation training, and meditation, counselors and therapists are offering affirmations as adjuncts to healing. Audio and video tapes are available. With images and sounds of nature, water cascading down a stream, waves lapping on a beach, they promote relaxation and a positive outlook.

Affirmations are usually first person statements. As a psychiatrist and psychoanalyst who spends a lot of time teaching people to speak in the first

person and think of themselves as authoring their own lives, I especially appreciate the first-person statements.

I am discovering peace within myself.

I am comforted by nature's symphony.

I dedicate myself to recreating health.

I love and inspire those who are here for me.

I extend my vista beyond myself.

I welcome the healing journey ahead of me.

I seek to connect with my inner guide.

I know I am safe.

Other affirmations are in the form of imperatives, commands.

Awake to the dawn of a new beginning.

Feel the warmth of the healing Light within you.

Open your heart to universal love.

Express the creative energy within you.

Reflect on your infinite potential.

One affirmation, in particular, always released powerful emotions within me.

Your friends have surrounded you with love and warmth.

As I listened to these affirmations, they began to remind me of the Bible verses of my childhood.

I will lift up mine eyes unto the Hills from whence cometh my help.

Yea, though I walk through the valley of the shadow of death, I will fear no evil.

Make a joyful noise unto the Lord.

For God so loved the world . . .

When admitted to Duke Hospital for the first round of chemotherapy, I asked my doctors to consult psychologist Patrick Logue for some warm-fuzzy adjuncts to the treatment. Reynolds Price had reminded me of the excellent work my former colleague did with relaxation and biofeedback in his book, *A Whole New Life*. When I was on the Duke faculty, I often consulted Pat for help with my patients, particularly those with somataform disorders, those formerly known as psychosomatic. Pat came, and in his calm reassuring voice, hypnotized me (and Sue who was also in the room). At a time when I was high on steroids, I was taught to breathe deeply, relax my muscles, and focus my thoughts. Sue went to sleep. We discussed the images Pat had chosen, and I was invited to offer my own. I found water relaxing, and so images of water were introduced. The next day, Pat made a tape, which he left with me. The tape suggested that over time, other stimuli could be used to relax. Soon my reclining chair became that stimulus, and I would relax merely by sitting in it, looking out over the lake in the valley below and the mountains of Tennessee and North Carolina in the distance, breathing deeply and . . . relaxing.

Affirmations are like scientific statements in that they express something about the reality of the world. They are like religious statements in that they are validated by experience. They are like scientific statements in that once asserted they have the power to change the way we view the world. They are also like religious statements in that religious statements are often framed as affirmations of faith or belief. One might be tempted to say that scientific statements differ from these affirmations, perhaps because scientific statements deal with physical realities and affirmations are dealing with psychological or spiritual realities. I am not sure such distinctions are

really meaningful if science is broadly understood and spirituality is broadly understood. What we know is what we believe. Einstein, for example, took a very broad view of science and in proposing his theory of relativity forever altered the way we understand the physical world. Einstein understood the world in a very spiritual way, which enabled him to see beyond the constraints of the old mechanical view of the world. “God does not play dice with the universe.”

We know enough science at this point to believe that we understand how affirmations can improve health and well-being at a physical level. We understand how the signals sent from the higher centers of the brain affect the lower centers of the brain, and how the lower centers affect the whole body, mediated by hormones and neurotransmitters. A great deal of work has been done in cardiovascular disease to understand how stress affects the body and how it can be mediated. Positive, repetitive thoughts affect neurotransmitters such as serotonin, norepinephrine, and dopamine, which in turn affect the immune system. A slight alteration of focus, away from discomfort and toward healing, light, energy, love, or wellness alters the balance of the body’s chemistry in a way which over time impacts on physical health and well-being.

Here it is important not to be too concrete or to make generalizations too broad because each person is different; each person has come to illness by way of a unique history, and each person’s path to well-being (either physical cure or psychological acceptance) will be unique.

Much is made of miraculous cures. Books such as Bernie Segal’s *Love, Medicine, and Miracles* and Andrew Weil’s *Spontaneous Healing*, have deservedly received a great deal of attention. I must admit I have taken

great delight in stories of people who have recovered when they weren't expected to such as the woman who was told ten years ago that she had one year to live. But such expectations can be very misleading and even guilt inducing as well. People may feel that it is their own fault if they do not get better. They may feel that they should count on a cure. They may neglect the work necessary to recover and maintain good health, putting all their hope in miracles. Or they may feel that they are being punished if they get sick or don't get better. These rationalizations after the fact are not what I am talking about when I speak of affirmations.

The British philosopher of science, Michael Polanyi, made an interesting observation about knowledge. The things we know, he observed, have a from-to quality. They proceed from a proximal aspect (usually ourselves, our bodies, our sensory experience) to something more distal (away from ourselves). Usually we hold the distal in focal awareness, while the proximal is held in subsidiary awareness. In hammering a nail we focus on the nail going into the wood, while we are subsidiarily aware of holding the hammer in our hand. If we shift our focus to the muscles holding the hammer, we become awkward in the execution of our task, driving the nail. Affirmations are a way of keeping us focused. Affirmations are a way of keeping positive.

Polanyi also observed that all declarative statements are statements of belief. He suggested that in order to remind ourselves of this fact we begin each declarative sentence with the words, "I believe that . . ." Scientific assertions have this quality as well and in fact issue from the beliefs of the scientist and the scientific community. Science is a process of active knowing. Thus the change in my treatment protocol from one requiring total

body irradiation to one requiring only the BCNU was based on the scientific belief (affirmed in the recent Stanford study) that a patient would do just as well with the chemotherapy without the radiation. This was presented to me as much as a belief as a fact, and I did not believe I needed to review the Stanford study myself in order to accept its conclusions. I did review the French study that demonstrated Bone Marrow Transplant to be effective in treating multiple myeloma.

The belief in healing, expressed as affirmations, has both a physical and a spiritual basis. The difference lies in the specificity of the focus. Physically, changes can be affected in body chemistry and physiology by the administration of certain pharmacological agents. That is done with a focus on overall healing and well-being. The chemical changes are subsidiary. Similarly a change in attitude may affect changes in body chemistry and physiology mediated through nerve impulses, hormonal release and neurotransmitters.

I found that I always felt better when I heard from friends. Their inquires, calls, cards, e-mails, word of their prayers, prayer lists, flowers, food, hugs all made me feel better and kept the focus on the healing process. I had been looking for a word to describe the boost I got on these encounters. Penny Smith suggested “oomph,” but I wasn’t sure how to spell it. Another of our faculty colleagues who survived breast cancer suggested “lift.” She felt she always got a lift when she learned that people were praying for her. Fortunately there is a psychological term, which has a physiological correlate, “Uplift.” An uplift is something that goes right. It is the opposite of a hassle. A hassle is a micro-stressor. Hassles are the annoyances of day-to-day living when things go wrong. The physiological

correlate is the effect that stress has on wearing down the body. We may presume that uplifts have just the opposite effect, the effect of building the body up, the effect of healing.

**Example Items from the Hassles and Uplifts Scales**

<b>Hassles</b>	<b>Uplifts</b>
Misplacing or losing things	Getting enough sleep
Troublesome neighbors	The weather
The weather	On vacation
Concerns about owing money	Getting into good physical shape
Too many responsibilities	Quitting smoking
Planning meals	Sex
Having to wait	Spending time with family
Being lonely	Shopping
Too many things to do	Making a friend
Too many meetings	Looking forward to retirement
Gossip	Being complimented
Difficulties with friends	Going someplace that's different
Difficulties with getting pregnant	Giving love
Auto maintenance	Being "one" with the universe
Filling out forms	Flirting
Unchallenging work	Having good ideas at work
Problems with your lover	Socializing

**Kanner, Coyne, Schaefer, & Lazarus. Everyday Stressors Index (1981)**

As I scan these lists, I realize how fortunate I was that most of what was going on in my life was uplifting, cancer notwithstanding. I recall that

when my father and my uncle Maurice were near the ends of their lives, they planned trips that they would never be able to take. They were planning to take their travel equipment out west to the Canadian National Parks. They consulted maps and calculated driving times. Similarly, I focused on the things I would do when I finished the Bone Marrow Transplant. I made a list of things to look forward to.

I was fortunate to have work, patient care and teaching, which I felt to be worth doing, was exciting and was on the list of things I looked forward to getting back to. Also during this time, I received a number of tributes, which were real boosts, uplifting. In many ways these tributes were affirmations or validations of some of the choices I had made in life. The Dean's Distinguished Teaching Award, along with the residents' teaching award, the medical students' teaching award, and the Nancy Roetsky teaching award of the American Psychiatric Association—all in the same year--were precious because they affirmed for a sense of purpose and a determination to go on. In the academic world, faculty are evaluated on research, publications, and grants, things which can be counted and quantified. As important as teaching is, it is hard to evaluate. Teaching, like virtue, may be said to be its own reward.

Teaching--as I have come to understand it--involves not only teaching a subject, but also teaching students. Teaching involves demonstrating judgment and affirming students who in medicine must learn to make responsible choices. Teaching is not only an exploration of the subject, but also a coming of understanding of oneself in relation to the subject.

I often hear students repeating an affirmation, which I know is important to them. Stewart Smalley, a character on *Saturday Night Live*.

looks doubtfully into the mirror and repeats:

“I am good enough.

“I am smart enough, and Doggonit,

“People like me.”

Medicine is a profession filled with doubt. Can you ever be good enough, smart enough, or know enough? The drive for perfectionism humbles you with your own inadequacies.

To teach with humanity is to affirm the humanity of those you are teaching so they can affirm the humanity of those they care for. In order to test ideas critically, a teacher must create a safe environment where students learn the trust and confidence to express their most candid thoughts, feelings, and judgments. A teacher must create an environment where students do not fear intimidation or humiliation. Although there is a long tradition of teaching medicine by fear and intimidation, I find that most students are driven by a desire to be good doctors. They do not need to be brow beaten in order to learn.

I have been fortunate to have good teachers and mentors. Lessons I learned from my parents, lessons I learned in school, lessons I was learning from cancer were all part of my understanding of how to be a doctor. It was an occasion to reflect on the wonderful teachers I had who shared their enthusiasm for their subjects and also took an interest in the development of their students. Good teaching was mentoring. Good teaching was affirming.

At every turn there was a mentor who guided my path. In high school summer science camps, it was Dr. Vincent Schaefer, who discovered cloud seeding and fostered serendipitous curiosity. He found that carbon dioxide crystals precipitated moisture when putting dry ice in a deep freeze. In

college at Brown Fred Barnes and Milton Hamolsky were wonderful clinician-scientists who tempered incisive thinking with kindness. During a year I spent at the Pacific School of Religion, Charles McCoy and Dr. Otto Guttentag not only nurtured my academic interests in ethics but became friends for life. Dr. Guttentag always used to say, “You speak first, so you aren’t prejudiced by my views.” In medical school, it was Hans Lowenbach, psychiatrist extraordinaire, a disciplined observer of human behavior. Dr. Lowenbach taught common-sense psychiatry. He left Germany on a whaling boat and jumped ship in Baltimore, where he studied at Johns Hopkins. He died of cancer in 1985 and remained a teacher to the end, instructing others about what was going on and monitoring their feelings and his own. The last thing he said to me was, “Allen, ethics is going to be an increasingly important part of medicine.” In residency my own analyst, Dr. George Ham, taught me things about myself I wished I didn’t need to know. In graduate school, it was Bill Poteat, known simply as Poteat, who realized that even what was taken for granted in modern thought could be challenged. He taught that there was more to knowledge than the Cartesian dichotomy of mind and body is able to explain. And Ben Barker was the mentor of my Kellogg Fellowship. He taught me that leadership involves taking risks and having the courage to do what is right. That is what counts in the long run. These men march with me in memory and occasional reunions. They have become part of me, and I can always draw on their wisdom and insight.

My philosophy of education also evolved from my outdoor adventures. Classrooms were for indoor adventures. I sometimes said, not entirely in jest, that I learned as much about how to handle a busy

emergency room from running canoe trips on the Allagash as I did from anything I learned in medical school.

As I watched and interacted with the doctors at Duke, I recalled the excitement of being part of this stimulating learning environment, where science meant always questioning, and nothing was ever taken for granted. Recently I came across my admissions essay in a file in the basement. It recalled a teaching-learning experience, which was particularly formative and has stayed with me all these years. Sue and I had an important lesson about education affirmed when we climbed the Matterhorn on our honeymoon. I wrote about this in the essay. The skill of our guides in instilling confidence made indelible impression on us, which we have tried to incorporate in our own teaching.

Before going to the Matterhorn in Zermatt, Switzerland, Sue and I attended rock and ice climbing schools in Grindelwald. Prior preparation prevents poor performance. We learned to rappel, a rope maneuver in which you back down a cliff with a rope wrapped around your waist secured through metal loops called carabiners. You can stop quickly by increasing the friction in the carabiner. You are belayed by the guide above with another rope, wrapped around his waist and through his carabiner. He can put friction on his rope to stop you if necessary. It was all very exciting. However, after learning to repel, the guide proposed that we free repel down a rope dangling in space from an overhanging cliff. I decided this was a skill I did not need to know. When my turn came, I would decline. Better prudent than foolhardy. My new bride would appreciate this. She would want me around. But the guide had been observing his students, and he knew they had skills, abilities, and potential that they had yet to appreciate in

themselves.

It was the summer of 1969. One of the major news stories in Europe and around the world as well as in America was the Apollo mission to the moon. As we took a break, a French physician in our party pulled out a Japanese radio about the size of a pack of cigarettes and tuned in to a German news report. Periodically, we would get a direct link from the astronauts, our astronauts, en route from Earth to the Moon. They spoke in English of course. "It's quite a view up here." "Everything is A-OK."

The guide scanned the group and turned to me. "OK, Mister America, you first." Without a second thought, I roped myself in and disappeared backward over the cliff, just like I had seen done in the movies. It was one big step for mankind.

The Matterhorn is a steep, arduous, two-day climb. From a pyramidal base the mountain points straight up like an obelisk to a height of 14,688 feet (4478 meters). It is not a technically difficult climb as major mountains go. But it is a dangerous climb, and over the years, many lives have been lost on the Matterhorn. There is a cemetery in Zermatt with numerous graves marked, *Umgekommen auf dem Matterhorn*. "Killed on the Matterhorn". I meant to visit that cemetery but thirty-one years passed before I went there. As we climbed the top of the mountain was in focal awareness, but the cemetery remained in the background.

The first climb to the summit was by an Englishman, Edward Whymper, in 1865. We read his account. He was racing to the top up the North Face from Zermatt, which would be our route, while an Italian party was climbing from Italy to the south. Whymper's party was beset by tragedy, as is so often the case in mountaineering. His party of seven were

all roped together. After they had all reached the summit and started down, at a certain point near the top where the mountain is nearly vertical, someone fell. Our guides pointed out the spot. This one fall is a 4,000 vertical foot drop. The person that fell dragged three others with him. At this point the rope snapped, or was cut. There is some suspicion of foul play. Whymper and two others survived. Queen Victoria declared that mountain climbing was not a proper sport for Englishmen. It never occurred to her to even mention that women should not be doing it.

Sue and I presented ourselves to the Bergführerbüro (mountain-leader-office) and announced that we wished to climb the Matterhorn. It is not permitted to climb without a guide.

“Do you wish to climb today?” we were asked.

“No, tomorrow.” Because of weather, the mountain had not yet been climbed that year. “Wonderful, the weather is already better tomorrow.” This grammatical construction makes more sense in German than in English. So we were assigned guides, and climbed on Sue’s 22<sup>nd</sup> birthday. The guides spoke German better than English, though at that time their English was better than our German. Sue is now fluent in German, and I could take directions in German if I had to. At one point Sue’s guide, confusing right and left, told her to turn right, which would have meant a lethal step to the valley below, but Sue is quick and sorted this out without a misstep.

The first day, we climbed to the Matterhorn Hut, three-quarters of the way up the mountain. We slept until 2 AM, at which point we got up for an early assault. There are still a number of things that can go wrong, and it is important to have plenty of daylight on the other end of the day in case it is needed. The earlier the turn around time, the quicker you can get down in

case of inclement weather. We were roped to our guides who wore miner's lamps (head torches) on their foreheads. At 2 AM everything is still, quiet, and dark. When we climbed, the sky was full of stars; it would be a clear day. There was no moon, and the only way you could tell where the mountain was, was to note where the stars were not. The Matterhorn was a huge black hulk. The only hint of motion was the twinkling of the stars light years away and the twinkling of the village lights far below us. High on the mountain, the stars seemed closer.

When the sun came up, it illuminated first the top of the mountain, then the whole valley with an intense orange light. One of our climbing companions was Kathleen Kennedy, Bobby and Ethyl Kennedy's oldest daughter. Her father had been killed the year before. We took a picture of her at sunrise with this intense orange light illuminating her white sweater. Sunrise in Switzerland occurs when it is the middle of the night in Massachusetts. Just about the time I took the picture of Kathleen, her uncle Teddy Kennedy was plunging his Oldsmobile off the bridge at Chappaquiddick Island in his ill-fated accident. This was the other major news story of the summer of '69, according to friends who watched television.

The Matterhorn is certainly not a mountain you would want to undertake without guides. Shortly after daybreak, we donned our crampons and crossed the ice fields. Each of us was roped to our guide, who was secured to the ice wall. The guides cut steps into the ice. It seemed easier than we had any right to expect. Later in the summer the rock under this ice heated up, melting the ice closest to the mountain. The whole ice sheet let go and fell into the valley below, taking twenty people to their deaths.

*Umgekommen auf dem Matterhorn.*

Closer to the top we were able to use fixed ropes to pull ourselves up a nearly vertical rock face. My wedding ring, a shiny gold band for the first few weeks of our marriage, still decades later, bears the patina and scratches acquired on this section of the mountain. This was the section where four members of Whymper's party fell to their deaths. *Umgekommen auf dem Matterhorn.*

For years I have worried that Will and Cliff would announce one day that they were going to climb the Matterhorn. Or worse, perhaps, that they had already climbed the Matterhorn. When Sue and I climbed I had no idea how dangerous the mountain could be. I didn't know that an ice face could melt and fall from the mountain. I was confident in our abilities and in our guides. I thought that would be enough. The highest mountain Will and Cliff had climbed was 12,241 foot Mt. Baldy in the Philmont Boy Scout Ranch in New Mexico. We climbed it together when Cliff was twelve and Will was fourteen. I was delighted that we got to share this experience.

Baldy, however, is not the most difficult mountain we ever climbed. Katahdin is. Maine's biggest mountain, Katahdin is the northern terminus of the Appalachian Trail. It is the last five miles of the AT or the first five depending on which direction you go. We climbed up past the waterfalls, up past the moose (plural), up past the timberline where the trees diminish to little shrubs, then stop altogether, up over huge granite boulders left by ancient glaciers of the ice age, and still climbed higher into the sky.

The summit of the Matterhorn was something quite special, a small platform about the size of the head of a pin (room for about four angels). It was spectacular in the intense morning light. By now everything was white

with the Alps spread out all around us.

If climbing the Matterhorn was uplifting, coming down was a let-down. It was much more arduous and painful, using the muscles in reverse to break the fall of each step and protect the joints as much as possible. I remember feeling that I would give anything to be lifted off in a helicopter. Years later a friend of ours sent this postcard.

Belsize Park Gardens,  
London,

Dear Sue and Allen,

Ever since you climbed the Matterhorn, I have envied your experience and wanted to do the same. This summer I got my chance. After a very exciting climb to the top, we got snowed in at the Matterhorn Hut for three days without food. Finally we were rescued by helicopter. The first question they asked was how would we pay.

Fondly,  
Fred

Sue and I are still climbing mountains, and if cancer hadn't been this year's mountain, it would have been Rainier. We had been invited to join a group planning a climb on Rainier. We equipped ourselves with trekking poles and Gore-Tex parkas from L.L. Bean and began tackling the local mountains. Buffalo Mountain is right in Johnson City and has delightful trails and views. Grandfather in nearby North Carolina has been a favorite of ours for years. We once told Will and Cliff it was a billion years old. (It is 10 times the age of Everest, which is only 100 million years old.) The following year we came back from our sabbatical in Oxford, and Cliff asked if it were a billion and one now. I broke more ribs climbing Grandfather. It wasn't clear that I would be able to do Rainier.

Some friends of ours from Johnson City were also planning to climb

Rainier. They dedicated their climb to us. It was a tribute and an affirmation that we very much appreciated. Caroline Novak and her son John Thomas, along with Rachel Monderer, M.D., and Mary Williams, herself a cancer survivor, climbed in May. We heard news reports on CNN that an avalanche had endangered the lives of twelve climbers, some of whom were stranded in crevices, several of whom ultimately lost their lives. Quickly we checked the Internet against the maps and the itinerary they had given us to assure ourselves that they were all right. They had missed the avalanches by one day though they heard them crashing nearby the night they slept on the mountain. They had experienced adventure, excitement, and accomplishment. They had taken calculated risks, faced danger, and survived.



**Allen and Sue wedding on Mt Whittier, New Hampshire,  
honeymoon on Matterhorn, Zwitterland, summer1969**

## ODE

by Rick Fields

A little cell  
                  loses its way  
goes astray  
The gates of hell  
                          creak open  
stench of sulfurous decay  
A teenie tiny bit  
                          of living matter  
A cell  
Forgets to die  
                          takes upon itself  
to multiply  
Little cell  
                          where are you going?  
Please stop growing  
Like everything born  
                          both you and I  
have our time to die  
Don't be a thorn  
                          in the soul of my life  
don't be a knife  
in the heart  
                          of my life  
Go away you've had your fun  
I've got things to do  
                          places to see  
                          races to run

# Dyer Family Chronicle

Johnson City, TN 37615

December, 1998

Dear Friends,

In March of this year, as many of you know and many do not, Allen was diagnosed with multiple myeloma, a virulent kind of cancer that attacks the bone marrow. The story of our year has been an odyssey through high-tech medicine, low and high-dose chemotherapy that wiped out every dividing cell, and finally, in September, a bone marrow transplant to start him over. Allen's excellent physical conditioning helped him survive both the illness and the treatment. (He actually ran the Memphis Marathon last December with several broken ribs, which he thought were, strained muscles!) He also had wonderful, competent, caring doctors both here in Johnson City and at Duke, where we went for the main part of the treatment. But the thing that helped us the most was the love and support and creative kindness of friends and relatives who were there for us in big and little ways at every turn of the journey.

At Thanksgiving we returned to Durham, where the post-transplant assessment turned up no detectable sign of cancer. Allen will need to be checked at regular intervals, but we have definitely won the first round. He is regaining his strength and energy, working out with me at the gym, swimming and walking with friends. His hair has grown back enough so that he looks more like a Marine than a cancer patient. And he plans to be back at work full time in January.

Other news of the year: Allen won the Dean's Distinguished

Teaching award. He also won the residents' teaching award, the medical students' teaching award (and we forgot to mention in last year's letter, he received a teaching award from the American Psychiatric Association in San Diego). In March I went to Germany for a week on a Siemens project.

Cancer is not something that anyone would volunteer for, but it has brought us closer to each other and to our family and friends. It has given us a chance to rethink what matters and what doesn't, and to appreciate the little things that come with each day. Our friends have taught us a great deal about friendship, and we hope to be better friends ourselves because of it. It made us glad to be alive and plan to be doing it a lot longer.

So, after a long tough year, this is an especially merry Christmas for us. The boys, who have stayed close in person, by phone, and by e-mail through all of this, are coming home for a real visit. Cliff is at Reed College in Oregon, studying religion in school and Aikido, and he is working as a dorm dad. Will is studying math and computer science at the University of Vermont. He is a teaching assistant in the computer science course.

We wish all of you a joyous holiday season and a happy, healthy New Year.

Love,

Sue, Allen, Will, and Cliff

## 12. A Zen Christmas Message<sup>2</sup>

I appreciate the opportunity to say a few words at this holiday meeting. My title, "A Zen Christmas Message" might at first seem a bit paradoxical. "What does Zen Buddhism have to do with Christmas, a Christian holiday?" one might ask. It seems fitting, however, in view of the multi-cultural nature of our organization and our community, to think about our religious traditions in an ecumenical spirit.

I have been impressed in my three visits to Asia with the centrality of spirituality in Asian religion and daily life. Perhaps this should be no less so in the West. But in the era called "the Enlightenment" or the so-called "modern age", spirituality has been rationalized. We have a tendency to approach spirituality through our ideas rather than our experiences. Our specialty, psychiatry, exists at the intersection of thought and experience and may have something important to say about people's attempts to integrate their thoughts with their experiences. Our colleague George Engle has even coined a phrase, "the bio-psycho-social medical model," to try to capture the importance of integration of the patient's experience--not just in psychiatry but in all of medicine.

But even in the bio-psycho-social medical model, spirituality remains elusive. Perhaps as we approach the end of the twentieth century, new cultural models will emerge and with them a new medical model, a bio-

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<sup>2</sup> This chapter was originally presented as a talk to the Tennessee Psychiatric Association, Upper East Tennessee Chapter, December 5, 1995.

psycho-social-spiritual medical model. Some are suggesting that the modern age is over and that we are entering the post-modern age. It remains to be seen what that age will be like. But our experience of rapid change in medicine suggests that it could be change for the worse as easily as change for the better. We need to ask ourselves, "What aspects of medicine would we like to preserve and what would we like to improve?"

As psychiatrists we might take this opportunity to register objection to the "modern" view of the body-as-machine, a view which marginalizes mental life and emotional life. We might hope that the post-modern medical model will be a more integrated bio-psycho-social-spiritual model.

Let me reflect on the "Spirit of Christmas" as a way of trying to understand what that might mean. We all know that the spirit of Christmas has something to do with giving gifts. The central story is that of the birth of Jesus in a manger in Bethlehem under a star of unusual brilliance. This star led three men, who in retrospect are called "wise", to believe that they were being led to the promised Messiah. They brought gifts of gold, frankincense, and myrrh, hence the origin of Christmas presents. That is the origin of gift giving as part of the spirit of Christmas.

As modern psychiatrists we might reflect on the meaning of those original gifts. Gold we recognize even yet as something of value. What use did the baby Jesus have with frankincense and myrrh? And what is myrrh anyway? I looked it up. It is a gum resin used in perfume and incense. Perhaps we have in these original Christmas presents the beginnings of the idea that it is the thought that counts, not the gift. It is in the gift relationship--the relationship between the giver and the receiver--that we find the spirit of the gift.

So imagine the impact on young Jesus as he is told the story of his birth. His mother and her husband are traveling for the holidays. She is near term and shouldn't be traveling, but feels compelled to make this trip. Her husband professes not to be father of the child. There are some other confusing details about how the pregnancy occurred, which are barely comprehensible to a young mind. They pull off the road only to find that the ancient equivalents of the Motel 6, Super 8, Holiday Inn, etc. all have no vacancy. In an act of extraordinary generosity, one innkeeper offers bedding in the stable, where they will have the warmth of the animals to keep away the cold. The birth occurs there, and three wise men appear on camels bringing gold, frankincense, and myrrh. What impact would this story have on the mind of the developing child as he tried coping with life's tribulations?

The beauty of stories, of course, is that they admit to many interpretations. They evoke meaning based on the experiences of those hearing them. Jesus himself apparently recognized this when he spoke in parables. Did he have consciously defined educational objectives or did meaning evolve in the lives of those who were touched by his presence?

The tradition of gift-giving at Christmas builds on the tradition of giving gifts at the day of birth and establishes a relationship of complex emotions, including dependency and gratitude. In Western capitalist economies there is often a confusion or a tension between the material and the spiritual aspects of the gift. In the City of Joy, Calcutta's poorest slum, there is a saying that everything which is not given away is lost.

I will subsequently return to what I think might be the implications of gift-giving for medicine. But first I wish to make a few observations on

Christmas presents. Each year we see the stores displaying Christmas decorations earlier and earlier. Of course, they appear before Thanksgiving. We are not surprised or even offended to see Christmas displays before Halloween. This year I noted a number of people commenting in a nice quantitative way on the percentage of their Christmas shopping completed by such and such a time: 90% done by Thanksgiving. The modern wise man and woman have learned to pace the shopping so as not to be overwhelmed by the season.

I recall, as a small child in the Dyer household, a great deal of excitement and anticipation in the Christmas season. Stockings were hung by the furnace grate with care. There was no fireplace. It never occurred to the young minds of my sister and me to wonder how Santa would get through the furnace grate; such is the beauty of the magical thinking of childhood. The whole thing is almost too improbable to be believed--a fat man in a red suit descends a skinny chimney with a bag of toys. But children go on believing it generation after generation, just as my sister and I did, not wanting this wonderful belief to be challenged by mundane reality, as it eventually was by an older cousin, a more jaded, cynical, reality-oriented cousin.

The teachings of Zen--like the beliefs of children--often come in stories or riddles which confound the mind's attempts to understand the world around. "What is the sound of one hand clapping?" One I particularly like: "When you reach the top of the mountain, keep on climbing." Or one that Jack Kerouac mentions in *Dharma Bums*, which also appeals to my love of mountains: "Think of the mountain as a Buddha, all that patience, waiting all those years to bless all living things." These sayings are not irrational; I

would prefer to call them trans-rational. They make wonderful sense if you are prepared to believe. But they frustrate our obsessive attempts to understand our world in tightly ordered ways. Here I might equate obsessive with Western. The German philosopher Eugen Herrigel went to Japan to learn archery. He wrote about his experiences in a delightful book called *Zen in the Art of Archery*. He struggled hard to understand his master's attempts to get him to relax his mind, to focus on the totality of the experience of losing the arrow rather than analyzing its parts. At one point his frustration frustrates his master. He says, "You mean I am supposed to concentrate on not concentrating." The master replies "I do not know the proper answer to this question. No one has ever asked it before." Robert Pirsig made similar observations about the limitations of Western philosophy in *Zen and the Art of Motorcycle Maintenance*. The struggle to define quality will drive you mad.

The wisdom imparted in such lessons is like a gift. It may be a gift that the giver is not aware he is giving, a gift that is more spiritual than material. There is a Zen saying that when the student is ready to learn, the teacher will appear.

As an example, I think of the kinds of gifts athletes give each other, little lessons that help with the mind-body-spirit integration which athletic performance requires. I recall one day, one of my swim team buddies commenting as we were preparing for a swim meet: "The spiritual athlete transcends competition." I still ponder this remark. How does one compete and yet transcend competition?

A few months later I was in the final stages of preparing for my first marathon. I had followed the training schedules and done the physical

preparation; I had a mental plan about pacing, nutrition, and a hundred other things, but my excitement was overwhelming. At just this moment a friend sent me a book he had written on Satori, the Zen state of spiritual enlightenment, his attempt to bridge Eastern approaches to martial arts with Western life and Christianity. It could not have come at a more helpful moment for me to complete the spiritual preparation through meditation and imaging of the athletic event.

When the student is ready, the teacher will appear. I want to share one other example of a very important gift I received. Earlier this fall when I was preparing for my Ironman triathlon, I encountered a similar moment of doubt and anxiety. I dreamed one night that I was standing at the base of an enormous black mountain. I awoke cautiously and said to myself, "Dyer, you have been here before and always proceeded one step at a time." That day on attending rounds, one of our medical students shared with me his experiences as a runner and track coach. He discovered that as a runner it was possible to draw energy from the environment around, even the other runners. It was not a great secret of the universe, he said, but the advantage you had was that other people did not know this.

This immediately struck me as a useful spiritual metaphor, a supplement to all I knew biochemically about energy transfer, the role of ATP in the mitochondria, Coenzyme Q-10, lactate thresholds, heart-rate monitoring, glycogenolysis. It was something I could use on the course. I could draw energy from the water, the wind, the sun, the stars, my fellow competitors, my companions. In one frame of reference, a Western frame of reference, drawing energy from the environment makes no sense at all. But in a more holistic sense it was the perfect mantra, the perfect way to propel

oneself through the 2.4-mile swim, 112-mile bike and 26.2-mile run. Outer exhaustion was perfectly balanced by inner tranquility. What could have been one of the most miserable experiences of my life turned out to be one of the most joyous? I simply had to choose. In this instance it was more useful to believe in magical thinking--thoughts have power--than to interpret it rationally. I believe this is what my namesake, Wayne Dyer, means when he speaks of Real Magic.

I promised that I would return to the implications I see in this for medicine. In an ideal world, the doctor-patient relationship should be the prototype of the gift-relationship. The doctor gives to the patient something than can be got in no other way, not just technological knowledge, but also caring attention. The doctor-patient relationship is an important aspect of the healing process. Physicians, of course, come from a tradition of healers. Hippocrates, credited as being the father of scientific medicine, was also a religious figure. He and the other followers of the cult of Aesculapius were healers in the shamanistic sense. Their hospitals were essentially temples. The powers they had were naturalistic in the sense that they were primarily dietetic, but there was also magic in the belief that the contact with the physician would be healing.

In the modern age we don't much speak any more about magic in the powers of the physician. We may forget about the importance of our healing presence as a power in our patients' lives. Cervantes' errant knight, Don Quixote, the Man of La Mancha, has always struck me as something of a psychiatrist. He treats the whore, Dulcinea, like a lady, and she decides she likes the way she is treated and begins to think of herself differently. Similarly psychiatrists dignify the feelings of our patients, allowing them to

talk honestly about their impulses and longings. Our Chinese colleagues, sophisticated as they are in DSM-IV diagnoses and psychopharmacological interventions, find Western medicine incomplete. It is the yin without the yang. They find in our approaches no balance with the traditional way of life.

But in this holiday season, as we watch the Miracle on 34th Street for the 34th time, we are reminded of the innocence of childhood. We appreciate the beliefs of childhood and recall a time in our own lives when we found it easier to believe than doubt. We realize that the spirit of Christmas is found in the magic of Christmas.



**Allen and sister Polly, about 1950**

### 13. Rebirth

Even after I got better from my cancer and was pronounced in “complete remission” one year after the bone marrow transplant, Mama Doug and Granddaddy Kirby continued to send cards of good wishes. They never failed to buoy my spirits.

When Granddaddy was diagnosed with cancer, everyone including himself assumed he would “go first” as he put it. It therefore came as a shock to learn that Mama Doug had passed on. On one of the rare days that I got home for lunch, there were two messages on the answering machine, one from Dale and one from brother Jerry, telling me the sad news. I was instantly overcome with a familiar numbness I had learned to call “unbelief.” *Oh no, that can't be.* I caught my breath, choked back the tears, and returned both calls. I got more of the details: Mama Doug was at the church. She had two pies in her car to deliver to the nursing home where she did volunteer work. “Too busy to be depressed” read the last entry in her journal. She sat down behind the steering wheel and slumped over with a massive stroke. She never closed the door. She never regained consciousness. Both Jerry and Dale said she asked about me every time they saw her, and Granddaddy wanted to make sure I was notified. I said of course Sue and I would come to the funeral.

The funeral was a family reunion and community gathering in the little town of Westmoreland, Tennessee, much like the town of Newport, Maine, where I had grown up. Westmoreland is closer to Bowling Green, Kentucky, than it is to Nashville, but then Johnson City is closer to Windsor,

Ontario, than it is to Memphis. The land knows nothing of such boundaries. This is Tennessee. As we drove through the rolling hills on a sunny-cold autumn morning, green fields punctuated with red and yellow trees, Sue said, "Heaven couldn't be any prettier than this." The theological implications of that simple observation were too complex to grasp. What is next? Cancer taught us to cherish each day. Already the leaves were dropping from the trees, and soon the fields would turn brown. Then the cycle of life would begin again.

Sue and I were included as members of the family as we reunited with old friends we had met at other family gatherings over the years. Although Sue and I both came from close families, we did not have family close. Sue had lost both her parents. My father had died, and I never knew my grandfathers.

I agreed to say a few words at the funeral. I wanted to share something of the positive influence Mama Doug had been for me. The pain of her loss struck me most sharply when Sue and I were seated at Granddaddy's side waiting for the ceremony to begin. Sue pointed out how much it would mean to these people, who had been praying for me throughout my cancer treatment, to see that I was doing so well. Their prayers suddenly became very personal and very poignant. We had all just lost the woman whose kindness had touched so many of us and brought us together. I understood in a way that I never had before the power of a faith community. I knew then what I would need to say. The following is my best attempt at reconstructing those remarks:

October 23, 1999

I would like to share with you a lesson I learned from Mama Doug last year when I had cancer. It is a lesson about faith and hope and most importantly about love. I think it says a lot about the kind of person she was.

One day Mama Doug told me she believed in intercessory prayer. She said she and Granddaddy had prayed that Dale would return from Vietnam alive, and he did. She told me they were praying that I would get well from cancer, and I did.

Every few days there would be a card, or a call, and sometimes a visit. There were cards from Dale and Leslie and from Jerry and Linda. In Johnson City there were visits and shared meals with Paige and with Scott and Katie. These cards contained inspirational poems or sayings or prayers. There is one in particular I would like to share on this occasion.

### **The Warrior's prayer**

I asked God for strength that I might achieve  
I was made weak that I might learn humbly to obey  
I asked for health that I might do great things  
I was given infirmity that I might do even better things  
I asked for riches that I might be happy  
I was given poverty that I might be wise  
I asked for power that I might have the praise of men  
I was given weakness that I might feel the need of God  
I asked for all things that I might enjoy life  
I was given life that I might enjoy all things

I got nothing that I had asked for but everything I had hoped for  
Almost despite myself my unspoken prayers were answered  
And I am among all men most richly blessed.

I know Mama Doug involved many of you in this community in those prayers. I want you to know that your prayers worked, that I am well, and that Sue and I are deeply grateful.

I had heard the story of Mama Doug's prayers several times from her and from Dale. Each time it was told, more details were remembered. Dale recently told it again in this e-mail:

I do believe the prayer is what sustained me and protected me in Vietnam, as so many around me went down. At times, I was so scared that I just prayed over and over and over. I prayed to return and complete my planetary mission in this realm of existence. I promised to fulfill this mission, if I was given the gift to continue my life.

One time, near the end of my tour of duty, we were surrounded for days near the Aushaw Valley. We had run out of water and things looked pretty bleak. We would try to slip out of our perimeter and find water, but would get hit and retreat. We were in so close in contact, plus the mountain hills and terrain, that we could not call in air support or big guns. I remember calling out to GOD to help me and us through this experience, and then I called out to Mom in deep desperation. Before then, I never wrote to Mom what was really going on around me most of the time. Years later, she said that during that time, she was in the apartment in Jacksonville and heard me call out her name. She said it was so real and that I was in the back room. It freaked her out, as she knew that I was on the edge of death and no one had to tell her. She could also feel what

I was experiencing. She dropped to her knees and began to pray for her son's life. She would spend hours each day in prayer and go to her friend's house and they would go into the Light together with prayer.

She also did this each day and throughout each day for your healing. She took you into prayer in the church and in her prayer groups with her special request for You. She was a most unselfish spiritual being and spent much of her time helping others. She really loved you two and we talked of you every week when we'd sit and talk.

The stories that were told at Mama Doug's funeral were a celebration of the life she had led. For a few minutes longer, we all could continue to enjoy her presence. And she would return again and again. Her work was not done, and it was not ended with this chapter of her life. She would not see her great grandchildren, the one on the way and those not yet conceived. The cycle of life would go on. She would live on in memory and in spirit. I might even see her again in . . . Nepal. Who knows?

Sitting in that little Methodist church, united in the spirit of love, I understood in a way I never could before the strange mixture of sadness and joy that we call grief.

I could see in Mama Doug many of the qualities of my own mother, her generosity of spirit, her readiness to serve others. Even though my own struggles to achieve independence and self-reliance made it difficult for me to allow myself to continue to be in the role of being served, cancer had taught me that there is an appropriate place for that. It is not so bad to be cared for. Just as I admired Mama Doug for what she did for her community, her town, her circle of friends, I was also proud of my own mother. Diabetic crisis? Don't call 9-1-1. Call Avis. She would know what to do. Volunteers to read to school children. Of course she would be

there doing for others what her own children and grandchildren no longer needed. And of course she would remember the sick and visit when a visit might be most useful.

The ethic of service to others was something I had grown up with, inspired by both my mother and my father. It was part of the Hippocratic Oath, the service ideal of the medical profession. It was certainly part of the ethic of medical educators. A little known section of the Hippocratic Oath requires teachers to treat students as members of one's own family. I recall on our first trek in Nepal, General Sir Sam once speaking what is rarely spoken of the bond of love that develops between the officer and his soldiers. I could readily appreciate the parallel for a teacher and his or her students.

The Kellogg Fellowship extended the understanding of family and community to include an awareness of global interdependence. Brazil's economy is intertwined with the American economy. The problems of Southern Africa are our problems. Will and Cliff accompanied Sue and me on my lecture-study tours around Europe and across Asia by the time they were eight and six. Cliff once said, "Daddy, what are we going to do when the Kellogg Fellowship is over?" I explained that we would continue to be concerned with the peoples of the world and find a way to continue to travel.

The Kellogg Forum we had been planning through my bone marrow transplant was a call to rededication of the ideals of service. A meeting in Washington, "Leading Change in the New Millennium," brought together fellows from North America, South America, Southern Africa and Asia. It served as an important reminder of all we were working for in public service.

Cliff caught the Kellogg spirit as a small child. He was now studying world religions and accompanied me on the trip to Nepal. Glenn Douglas, ever eager like myself to understand health care in a broad social context, also went along. Glenn ran the Bermuda Marathon for the Leukemia Society's Team-in-Training, and--through the generosity of his friends and mine and our mutual colleagues on the East Tennessee faculty--he had raised money for the Leukemia Society. It seemed a curious irony that after running with Team-in-Training I would develop a form of leukemia, but three weeks after the Bermuda Marathon, Glenn, who had ridden with my bicycle team in the MS150, was diagnosed with optic neuritis, a form of optic nerve inflammation that sometimes progresses to multiple sclerosis. Glenn was left playing the medical probabilities as I had learned to do. Would he be able to run and hike and trek and climb mountains in the years to come? His residency-training director was sympathetic and said of course he could take time off to go to Nepal. Cliff's professors said the same thing.



**Silajit Gurung and Glenn Douglas, Cliff Dyer and  
Chandra Gurung, Kathmandu, 1999**

When we arrived in Kathmandu, Chandra met us at the airport, put white silk scarves around our necks, and took us to our hotel. Seated in the garden with a pot of tea, he introduced us to our Sherpa guide and presented the plan. After a reunion that evening with Silajit (now retired from the Gurkhas and working for an international manpower organization to find employment for ex-Gurkhas), we would trek for a week in the Langtang Valley north of Kathmandu near the Tibet border. We would leave at 0330 hours, the middle of the night, to get out of the Kathmandu Valley before a Communist demonstration made it impossible to leave. Nepal was now caught in the perilous transition from monarchy to democracy.

Then after our return to Kathmandu, we would take an airplane flight for some close up views of Mt. Everest (a real excursion to this fascinating peak, which I had climbed vicariously many times already). We would then fly to Pokhara for the 50<sup>th</sup> reunion of the Queen's Gurkha Signals regiment of which I was an honorary member. After our 1993 trek, Chandra gave me his regimental tie emblazoned with rows of regimental crests, The Crown over crossed *kukhari* knives, and Sam authorized me to wear it. I was official. The Gurkhas were honored that I had come so far for their reunion, and I was honored to be included in the festivities.

I saw this trek as a particular challenge one year after my Bone Marrow Transplant. Twelve months earlier I could barely walk a mile. Now I was determined to get face to face with the largest mountains in the world. I was ready.

As we trekked first through dense forests, then up, up, up through the gorge of the Langtang Khola and onto the glacial plane, everything which

had seemed so foreign on the earlier trek in '93 seemed familiar and natural. Most familiar were the lyrical Nepali sounds of Chandra's cheerful *basso*, offering words of encouragement to old women carrying heavy baskets of yak dung for the winter fires, instructing little children how to behave with foreign guests, inquiring of others on the trail where they had been and where they were going. Nearly every sentence was punctuated with a laugh. Those laughs had to be good for the immune system, his and mine. It also seemed familiar and natural in this setting to hear myself referred to as "Doctor Sahib". It seemed more of a nickname than a form of address.

We met a *lama* and a *jhakri*. The *lama* was a young man, twenty-one, Cliff's age, eager to share his knowledge, eager to show us his *gompa*, or temple. It was newly constructed of wood and stone with a metal roof. The statue of the Buddha inside was hundreds of years old, freshly repainted in bright colors. The lama quickly befriended Cliff. He wanted photographs made of them together. As I focused the camera, he straightened his collar and put his arm around Cliff.

We met a *jhakri* on the trail. One morning we were warming ourselves with lemon tea inside one of the teahouses that had sprung up to cater to trekkers. Chandra came bounding in and said, "We have a *jharkri* here!" I dashed out to find a ruggedly handsome, young Tibetan man wearing American-style combat fatigues and a Russian-style fur hat. He could have been a Marine. Or a Gurkha. He was good natured and outgoing and immediately inspired confidence. Like the *lama*, he was generous in sharing what he knew. Both the *lama* and the *jhakri* served to remind us that we were in a world where spirits were active and close at hand.

With Chandra acting as interpreter, they discussed how rituals, drums, prayers, and incantations could be used to set things right in the spirit world. Shamanism and Lamaism are a kind of ritual spiritual psychotherapy that is not limited to the consciousness of this lifetime. If something is causing distress (soul loss) that stems from unresolved issues with the spirits of deceased ancestors, it must be set right ritually. The *jhakri* cautiously showed us his tools: a drum, an antelope horn, a necklace made of snake vertebrae, carved figures to be driven into the ground to stake out the territory and protect him from any powerful evil spirits that might also be summoned. He showed us a white robe which he did not remove from its basket (presumably because of the power it held to induce a trance) and a white headdress with red, green, and yellow bands, which he did place on his head for effect. It was clear that grieving was hard work. The Nepalis made it a central part of their culture and gave it the attention it deserved.

Chandra told a story about grieving his brother's death. After thirteen days of mourning prayers, he looked in a pot at the rice dust covering the bottom for a sign that the spirits had been contacted. (I later learned that this ritual is called "rice divination".) He saw nothing. He was not happy, he told us, and ordered another day of prayers. This was a big effort for everyone. The next night he looked in the pot and saw a large print of a bird's foot. He said, "I was happy, and I cried, and everyone cried."

Contacting the spirit world involves danger and courage. The route to spiritual leadership, Chandra explained, involves putting oneself in a dangerous place where one might be attacked by ghosts or wild animals. Surviving this experience qualifies the survivor to help others. Our *jhakri* had been lost in the jungle when he was thirteen. He went crazy in the head

we were told. I understood that this kind of craziness was more like “excitement” than “psychosis.” Tourists went crazy over the mountain flight to Everest. We certainly did.

Finally the other *jhakris* found the lost thirteen-year-old. After they found him, they instructed him how to do *jhakri* things, how to contact the spirit world with drums and incantations, how to repeat the liturgical phrases and dance the liturgical steps that create the trances that let the spirits enter or fall into the body, how to make things right, how to protect oneself and others against powerful evil demons.

A trek such as this is not just an excursion from one place to another. Although there is an itinerary, the real destination is not a physical place, but that psycho-spiritual realm where generosity is met with gratitude. A trek is a spiritual quest. It requires cooperation and even interdependence. I carried with me the question that so many people who have trekked in Nepal have asked. What is it about Nepal that so changes people’s lives? I realized it was not just the scenery, not the spectacular mountains, but the people. I knew that no simple formulation could do justice to the depth of the experience. I sensed a harmony, tranquility and a serenity that seemed very special. Helping each other. Sharing. Caring. Our party (Cliff, Glenn, Chandra and I, Angelbu Sherpa, our guide, and Bim and Pala, our porters) was small compared to the ‘93 trek when we had a team of over a dozen porters carrying tents, food, cooking supplies, kerosene fuel, as well as our personal gear. The eagerness of everyone to be helpful, especially the porters carrying heavy loads, was humbling. Perhaps I could yet learn to enjoy the regressions. Perhaps I could accept being cared for. Perhaps this was the most important lesson I had learned from being a cancer patient.

*One of life's greatest blessings, the willingness of others to be helpful, was right at hand for anyone able to accept it.*

By the third day we had reached an altitude of 3049m (10,000 ft, up and down and up again from 1417m, 4650 ft). We were now positioned to climb a real mountain, not one of the high Himalayan peaks, but a mountain nonetheless. I had not realized that we would get to climb a mountain, and I was delighted. In Nepal the peak Angelbu chose for us did not actually have a name. It was merely identified on the map by its altitude, 5002m (16,407ft). The nearby mountains were called *ri*, Nepali for "hill". "5002" would have to do.

We climbed so easily to the first pinnacle we might have been levitated. From there we enjoyed spectacular views of the nearby Himalayas. That first pinnacle was 4773m (15,655 ft.) I made a mental note that this was higher than the Matterhorn (4478m, 14,688 ft.), the highest mountain I had ever climbed before. We did not experience the heavy steps, lighted-headedness or labored breathing we might expect at such altitudes. We had gotten here easily. It seemed more effort was in order. There was another peak beckoning beyond: 5002. I glanced up at it without speaking. Then I looked at Cliff.

He said, "Okay, Dad, Let's do it." On we went.

At each of the pinnacles there was a Buddhist *chorten*, a square monument with a conical top constructed as an act of devotion to commemorate the dead. Rows of red, green, blue, yellow and white prayer flags (representing earth, air, wind, fire and water), fluttered in the breeze, sending off mantras chosen by the *lamas*. They seemed particularly colorful against the pristine white wall of Langtang Lirung (7245m, 23,763ft). We

were surrounded by dazzling, towering, 7000 meter Himalayan peaks. They were so white in the intense sun that the sky appeared black. Gentle winds whistled about. The direct rays of the sun warmed our bodies in the chill of the morning. In the village below the brooks were still frozen solid. We were about a mile from Tibet. There could be no question we were in a sacred place.

When we reached the second pinnacle, Chandra assembled a *mani*, a stone pyramid, in remembrance of his brother. He, Angelbu, and Cliff helped me erect a similar monument for Mama Doug. Ritual Buddhist prayers were said.

OM MANI PADME HUM

OM MANI PADME HUM

OM MANI PADME HUM

It is a loving prayer of positive, glowing energy: May all be right with the universe.

The gentle smile of a single violet blossom high above the November snow fields assured me that we would not have to worry that Mama Doug's soul would find a happy resting place. I prayed instead that those of us left behind would find her generosity of spirit in our own lives. I also offered a prayer of Thanksgiving. A year earlier I had been flat on my back. Now with my born-again bone marrow and my renewed faith in the powers that make us whole, I was able to climb higher than I had ever been before. Here I was unexpectedly higher than Mt. Blanc, the highest point in Western Europe, higher than Mt. Rainier or Mt. Whitney, the highest point in the continental United States. Here I was cradled in a sacred space, held in the company of wonderful people sharing a very special moment. I could only

count myself as blessed. I was in no hurry to return to the world below. This was a time I would never forget. It would always be part of me.

I found in Nepal the words I had been looking for to explain what we were experiencing on our trek, the commitments of the Kellogg Fellowship, and what I had learned from cancer. They were in the form of a Nepali greeting, seen on one the teahouse lodges.

माया नमानु होला

(*maayaa namaarnu holaa*). Underneath was painted an English translation: “Please come back.” It is a familiar sentiment, which can rendered many ways, “Come again soon”, or in Southern US hospitality, “Y’all come back”. But the literal Nepali captures it best:

“Don’t let the love die.”



**Allen and Cliff, Langtang region, Nepal Himalaya, “5002”, 1999**

## 14. The Valley of Death

The phone rang once or twice, and a few seconds later Sue called down from her study,

“Allen, it’s Sam!”

Sam’s calls were always an occasion for excitement. New Year’s Eve to let us know that Europe had passed safely into the new millennium. Halftime of a Minnesota Vikings game being televised on the BBC, knowing that we would be watching Sue’s favorite team. This time Sam was calling to plan our next trip to Nepal. We had already decided our 2002 trek would be in the Solu Kumbu region because the bands of Maoist terrorists that were causing difficulties in some parts of Nepal could not operate in the high altitudes with such sparse agriculture. He assured us. British military intelligence. We recalled the stories he and Anne told about their last trek. The King of Nepal had offered a contingent of four Nepali soldiers with machine guns in their packs as a measure of added security for the famous general. They had in fact been stopped and questioned. The quick-thinking Nepali Sirdar said they were a trekking group out of Kathmandu. He made up a name on the spot. Himalayan Treks or some such thing. It sounded plausible; there were hundreds of trekking companies in Kathmandu. Apparently the four Nepali soldiers looked suspicious. But the packs were not searched, and the party was allowed to proceed along the trail. This time we would be proper tourists with a real trekking company: Summit Trek-Nepal, friends of friends. There would be no soldiers. No weapons. We would be innocent and safe.

Sam explained that we had three options and wanted my opinion. We could go to the Everest Base Camp, up the Gokyo Valley to Gokyo Ri, right beside Everest, or up past the village Thame to a new area near Tibet, which had just been opened to trekkers. Everything I had heard about Gokyo Ri was that it was one of the most spectacular spots on earth. At 18,000 feet it was a pretty significant little hill in its own right, but it sat right in the middle of four of the world's fourteen 8,000-meter peaks, Everest, Lhotse, Makalu, and Cho Oyo.

When I had cancer, Everest was a beacon to me. I read all the accounts all the accounts of the 1996 Everest disaster—who survived and who didn't. If people could risk death by climbing mountains, I could face the bone marrow transplant. Why Everest? Why Sagamatha, Abode of the Gods, as the Sherpas called it? Why Chomolungma, Earth Mother Goddess, as the Tibetans called her? I think Mallory got it all wrong when he said, "Because it is there." To climb Everest is to give thanks to the Gods. I had already learned that to spend time in the high Himalaya is to be in the presence of spirits.

Nepal beckoned with the familiarity of an old friend. This would be my third visit to this magnificent land, and Sue had arranged her teaching schedule so she could accompany me. "Whither thou goest, I will go," she had promised on our wedding day, thirty-three years earlier. Finally Memsahib would get to see Nepal and meet my Nepali friends. We set about our preparations with enthusiasm. We climbed the highest mountains in Tennessee, Virginia, and North Carolina. We made lists and ordered equipment from LL Bean.

I found myself more anxious about this climb than any of the previous treks. I found myself conscious of all the possible ways one might die in Nepal, and tried to calm my mind by proper preparation.

Terrorists loomed in consciousness, as is their strategy to do, in Nepali, at home, and in the airways. Each week more and more Nepalis were killed, but in fact no tourists had been harmed.

Germes were a more realistic concern. We got shots.

Altitude sickness. HAPE. High Altitude Pulmonary Edema. HACE. High Altitude Cerebral Edema. Fluid in the lungs, brain. These were common accompaniments to high altitude mountaineering. The Gokyo Valley was known as the Valley of Death because of the number of people that died there of altitude sickness. I reviewed pulmonary physiology. I read the latest textbooks. I did Internet searches. We would take acetazolamide, a drug that acidifies the blood to counter the effects of the thin air. We would take ginkgo biloba, which had been demonstrated to alleviate mountain sickness even though a recent study had showed no affect in forestalling the memory loss of Alzheimer's. And we would carry dexamethasone, my old nemesis, the steroid drug that brought the cancer under control, which is also the emergency treatment for HACE and HAPE. And we would acclimatize by ascending slowly from 8,000 feet to 18,000 with several days spent between 11,000 and 13, 000 feet in and around Namche Bazaar. But we would fly into Lukla, and that was danger itself.

Lukla is a small village with a landing strip carved in the side of a hill. Nothing is flat in the Himalaya, and certainly not the Lukla airstrip. The carcass of a previous wreck lies as a reminder to the pilots to get their bearings right. Sir Edmond Hilary, who with Sherpa Tensing Norgay, had

been the first to climb Everest forty-nine years earlier in 1953, built the Lukla air strip to ferry supplies for the schools and hospitals he built for the Sherpa people in the region. He later said he regretted building the airstrip because it made the Khumbu too accessible. He had another reason for regretting the airstrip. His wife and daughter were killed in a plane bringing them to join him and his son Peter in Lukla. We could only hope that the pilots knew their job.

Maps of the Gokyo Valley alluded to a number of possible dangers. At one spot an early November storm in 1995 caused a landslide crushing a lodge containing forty Japanese trekkers, killing all. Another spot, Machermo, was identified as the location where a Yeti killed three sheep and attacked a sherpa woman. All the guidebooks made reference to this event. No account of a Himalayan adventure would be complete without some reckoning of the Yeti, the abominable snowman. The existence of the Yeti is seriously doubted, but widely believed. Sherpas said matter of factly that at Machermo, you could hear the Yetis scream. Even Sir John Hunt's National Geographic Account of the 1953 British Expedition that put Edmond Hillary and Sherpa Tenzig Norgay on top of Everest felt the Yeti needed to be explained. Possibly it was some other animal, a large monkey, or a bear. Somehow the Yeti was not high on my list of worries. I hoped we would see one or at least hear one. Anne had seen a snow leopard in the remote Dolpo region of Nepal, the rare creature that had eluded Peter Mathieson in his famous book by that name, and Sam had caught a photograph of its tail, which he enlarged for tangible evidence.

Cancer was not high on my list of worries at this point. Other cancer

survivors I knew worried about their checkups. I assumed everything was OK until proven otherwise. I had my own patients to worry about, my students, the stock market, and world peace, which was becoming a growing perplexity. Although I lived with a constant awareness of cancer, it was a subsidiary awareness (as the philosopher Michael Polanyi would say) not a focal awareness.

“Alumni” of the Duke Bone Marrow Transplant Program are invited back each year to a reunion, a chance to reconnect with the staff that had meant so much to us, a chance to talk about the cancer experience and learn about the newest treatments, should we ever need them.

I went back to these reunions with mixed feelings. As the years past, cancer receded. I needed to be reminded that the situation had once been grave. It helped people starting their cancer odysseys and their cancer treatment odysseys to see that there could be survivors. By we had to realize that not everyone survived. The reunions were an occasion for seriousness and merriment. There was laughter and there were tears. Patients talked about what they had experienced. Families and caregivers talked about what they experienced. One year I was asked to talk about mountain climbing. The next year one of our favorite nurses was on the program. I assumed she would be talking about treatment, and was shocked to find that she was talking about her own experience with cancer. Why should I be surprised? She experienced the same sort of intensified mixed emotions we all experienced. Another man talked about participating in the Transplant Games. He was from Tennessee, and the Tennessee team had one some medals. That was inspiring.

Not everyone did so well. Most everyone was prematurely retired,

relapsed, or—it has to be said—dead. My childhood chum, Steve Cummings, succumbed to his cancer. “He left his body peacefully,” said the notice his wife sent out to his friends on the e-mail community he created.

At the Duke reunions we were divided into discussion groups by diagnosis. One year the myeloma group assembled in the corner of the lecture hall. The discussion turned to Oxycontin addiction. Everyone it seemed had become addicted to Oxycontin, the painkiller that was making international news. “Hillbilly heroin” *The Economist* called it, for its widespread use in Southern Appalachia. I saw Oxycontin addicts everyday in my psychiatry practice, people who had gotten addicted inadvertently and found the addiction was more of a problem than the pain that got them started. Cancer patients are given analgesics with few questions asked. In the days when cancer was usually fatal no one worried about the long-term consequences of addiction. Now cancer survivors faced problems with addictive narcotics.

We were all part of a research protocol. Sue kept asking my oncologist Dr. Gwynn Long, if the data had been analyzed, and after four years, we got the results. They were not good overall. Of 85 patients who had received bone marrow transplant for multiple myeloma, 40% were still living, and three were doing well. I was in a select group and could only consider myself fortunate, blessed.

We could say that we are in the realm of the inexplicable and the mysterious. But scientists and policy makers need to know if this is a recommended treatment and what factors need to be considered. BMT is a complex undertaking, a complex combination of drugs, treatment strategies, medical support, social support, spiritual support, community, friends,

family, and the all-important “caregiver,” the role Sue played for me. The data look better when long-term survival and survival free of disease-progression are the variables. But also credit intangible factors. Reduce stress. Indulge pleasures. Spend time with family and friends. Take time to relax, and enjoy what you enjoy most, or what you can in the midst of a complex and often uncomfortable treatment. These would be some of the important lessons to be learned from such an ordeal. Complain when it might make a difference, and learn to accept what you can’t change. One day at a time, of course, but imagine and plan for an exciting future.

Sue and I prepared for our Himalayan adventure, but little could have prepared us for the excitement we would soon face. Sam and Anne met us at the King Tribuvan airport in Kathmandu fresh from their trek to the remote Kingdoms of Mustang and Dolpo. A waiting Land Rover ferried us through the bustling streets of Kathmandu to the British Embassy, a garden oasis where we would freshen up, go over trek details, and catch up on old times.

I was eager to see my old Gurkha friends, Chandra and Silajit. Chandra had retired from the Gurkhas and was providing security for the “richest man in Asia” in Hong Kong. Silajit had had a relapse of his cancer. The tumor was pressing against his spinal cord causing a paralysis of his legs. He had been flown to a wonderful new Indian hospital in Pokhara for radiation treatment, but the needed equipment was not yet operational.

Although I would not get to see him, he phoned up the Embassy, so we could chat a bit by phone. Sam talked to him for a while then handed a portable phone to me, and I stepped out into the garden for a few quite

moments with my old friend. Silajit's voice was full of courage and good cheer as it always was. But it was also full of concern. I knew that this would be the last time I would talk with him, but I hoped it could be otherwise. He told me how much the '93 trek had meant to him as a Gurung to show us how his people lived in the hill villages. I reminded him how important his service to the Gurkhas had been and how much his friendship had meant to me, and we reminisced about the times we had spent together, on trek, in Kathmandu, the Queen's Gurkha Signals Reunion in Pokara, Cliff's visits to Nepal, his son's medical training, the exchange of cards and e-mails. I wanted to make the conversation last as long as I could, but at last it was time to say good by. I told him how disappointed Sue and I were not to be able to see him; but that we would remain together in spirit.

A few weeks later there was a characteristically cheerful New Year's greeting from Silajit and his family wishing us joy and prosperity. Then a few months later this e-mail from Sam:

Hi Allen

We got back on Thursday night. A great trip, but sad news. Our old friend Silajit died on Monday morning. He had been in intensive care for two days. Fortunately, I went to see him in hospital two weeks previously before going on trek. He had a private room in an excellent new hospital. I saw that there were 4 or 5 people in the room but the minute I reached the door he saw me. There was only one thing to do. I ignored everyone, went straight to him, leant over and hugged him. I could see that he had little movement but we had a great half hour talking of old times. His eyes were clear, his voice strong,

and his mind was as quick as ever. I promised to come and see him when I came back from trek. His reply was his last words to me. With a great smile he said, " I won't be here Sahib, I'll be at home"! I told him that I would see him there.

His funeral was yesterday at his old home in Bhairahwa and his Doctor son came home from China on Wednesday.

What a fine man he was. We shall miss him.

### Sam

There was much going on at the British Embassy, and our trek preparations were made against the backdrop of very real concerns about the Maoist insurgency, the impending *bundt*, or general strike, the change of government occasioned by the palace massacre the previous year, and the impending war in Iraq. Colonel Peter Sharland, the def and his savvy wife, Fiona, provided genial hospitality in this midst of these very pressing concerns.

In the wake of 9-11, terrorism was everyone's concern, but not everyone understood the problem the same way. "One man's terrorist is another man's freedom fighter." I was interested to get Sam's views on these situations as well as Peter's and those of Field Marshall Sir John Chapel, who has also a guest at the Embassy. I was particularly interested in the plight of the Iraqi Kurds as my university was working with a contingent of Kurdish medical leaders to help them develop a medical infrastructure in this sensitive area. These were the topics of conversation not only at the Embassy, but as we trekked from village to village.

It bears saying that these thoughtful military experts and statesmen

had long since left behind the old notions of “might makes right”. They were well aware of the limits of what could and could not be accomplished by military action, and were looking beyond to the practical challenges of making a government work for its people and the important interrelationships between the peoples of the world. These are concerns all nations face and share.

Terrorism in Nepal is a microcosm of the “war on terrorism” on a global front. Identifying and killing terrorists are not the same thing as addressing the root causes of terrorism. The setting of our conversations shifted from the comforts of the Embassy in Kathmandu to the more primitive conditions on the Himalayan slopes in the Khumbu. We chewed on big issues as we dined on Sherpa cuisine--dal bhat and rice, Spam and canned sardines, fresh potatoes and cauliflower-- in a dining tent that provided some protection against the cold nights at altitude.

The first thing I wanted to clarify was the role of the Chinese in this Maoist insurgency. Would Nepal become another Tibet? From an American vantage point, the equation was too simple: Maoist = communist = Chinese. But Sam insisted that this was not a revolution driven by ideology. These insurgents were driven by desperation. The economy of Nepal was an economy for the Kathmandu Valley. Foreign aid often went to governments rather than the people of a country. Nine years earlier when we visited the Gurung hill villages on the slopes of Annapurna, it was possible to eek out a living by hard work on the terraced fields. This worked for the people who remained there, but increasingly young people were going down to the cities, Kathmandu and Pokhara, in search of scarce jobs. Ironically people from the higher villages where agriculture was most

difficult, were finding it easier to prosper by going to India to trade for watches and transistor radios. The government was slow to recognize the needs of the people and not really responsive. People traveled from all over the world to trek in the Nepal high country, but trekkers were more likely to come from Tokyo or Dallas or Tel Aviv than Kathmandu.

Nepal is a country in the early stages of democracy, its first free elections only a decade earlier. In fact Nepal was still a monarchy, and its new king was trying to establish a working parliament able to address its mounting problems.

A year earlier, Nepal's King Birendra had been gunned down by the crown prince, Dipendra, in a palace massacre worthy of a Shakespearean tragedy, if there were some Fortinbras to tell the tale. Dipendra himself ended up dead, having shot himself or possibly having been shot by a palace guard. No one knows quite what happened or what to believe. But the Queen was involved; clearly disapproving of Dipendra's choice of mate, and the royal astrologers decreed that it would not be auspicious for the prince to marry before age 35. The Queen was also shot and killed by her son. Dipendra himself briefly became king in royal succession for a few hours in the hospital before the respirator was turned off, when his uncle Guyendra became king.

Sam, more officially General Sir Sam Cowan, would have an audience with the king after our trek. As we walked and talked, he rehearsed what he would need to say. It was clear that this would be an important meeting for both him and for Nepal. If Sam could capture the king's imagination and offer practical suggestions, there was a possibility of ending hostilities. The solution is not military. Nepalis must stop killing

Nepalis. The people must see that the government can work for them.

As we walked and talked, I was rehearsing for my own audience. I had been invited to give a keynote address for the Royal Australia New Zealand Congress of Psychiatry the following spring (actually autumn in the southern hemisphere). My topic was the knowledge of good and evil, a psychological and moral issue with clear political implications. With “evil” being used as justification for possible wars, it seemed urgent to try to focus some understanding on the meaning of good and evil. It had to mean more than “We are good; they are bad.” For evil to make any sense at all in a global context, it had to mean more than “that which is not in my interest”. The right and the good had to mean more than “I want”. Certainly if the United States as a single superpower, a hyperpower, were to have moral as well as military influence in the world, it had to demonstrate that it was capable of addressing the needs of others as well as self-interest. This was my theme. It was Biblical and it was immediate<sup>3</sup>.

To say that the trek was spectacular is to comment on the mind’s ability to compartmentalize. We have memories of the past and anticipations of the future, but we would be overwhelmed if we couldn’t live in the present. Nepal for all its problems grips one with immediacy. To tell you I am afraid of heights might lead you to question why I go back to Nepal again and again. The paragraphs ahead should answer that question.

A Zen master tells the story of a man who fell over a cliff. He grabbed hold of a vine and arrested his fall. He heard a gnawing sound, looked up, and saw a mouse eating through the vine. He heard a roar and

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<sup>3</sup> The lecture, slides, and bibliography are available at <http://faculty.etsu.edu/dyer>.

looked down to see the gaping maw of a hungry tiger below him. Next to him on the vine, he saw a grape. He ate it. It was delicious.

The traditional way to get to the Khumbu is to walk. Seven days up and down over the lush ridges serve as a physiological and cultural transition from the urban to the alpine. The body acclimatizes gradually to the altitude. The body produces more oxygen-carrying red blood cells as the mind adjusts to the rhythms of agricultural villages. But those villages were now supporting Maoists, men and boys with guns, whose acquaintance we would prefer not to make. So we would fly.

A perfectly rational calculation would lay odds with the Maoists. No tourist has ever been killed by a Maoist in Nepal. The same cannot be said of the pilots. We gambled on the pilot. We arrived early back at the Tribuvan airport and were ushered into the Gen Sir Sam Cowan waiting lounge. I took a photo of the general beside the photo of the general. We were served tea while we waited for the fog to clear. Our flight would be the first to leave the valley.

In thirty minutes we flew over what would take a week to walk. Steep ridges and deep gorges with snow white giants in the background. It was hard to imagine that there would be anyplace to set down a plane. Presently we saw the landing strip, not level as one might expect, but inclined up the side of a hill for quick stops and catapult takeoffs. The little plane slammed down and roared to a stop. I made a mental checkmark on my list of worries. One less worry: crashing at Lukla. We were here.

We met our team of Sherpa guides, cook staff, and porters at Lukla and started walking. Already the scenery was spectacular, lush green fields

and hills. Neat stone buildings with metal roofs, reflecting the relative prosperity. Schools and clinics built by Sir Edmund Hilliary. The route followed the banks of the Dudh Kosi, the milky river, named I later found out because of the pulverized stones called glacial flour kept the water a milky color, a gigantic milkshake fountain.

The trails were surprisingly busy considering the decline in tourism in Nepal. It was Tihar, the time of the Hindu festival when brothers travel to their sister's homes. Many trekkers were congregating in the Khumbu for the same reasons we were there. The Khumbu is a very cosmopolitan area with trekkers from Europe and North America, Australia, Israel, and very popular with the Japanese.

Namaste! Bonjour! Guttentag! G'day! Shalom!

We found we were also sharing the narrow trails with long caravans of yaks, who also of course made themselves at home on the suspension bridges as well. A new agreement with China had re-opened trade between Tibet and Nepal through the old Nangpa-la or high pass. Traditionally Nepalis carried barley and rice to Tibet in exchange for salt, a delicate balance of mutual necessity. Now anything a huge yak could carry was presented for trade: clothing, rugs, cooking utensils, trekking gear, lots of the famous North Face brand knockoffs, imitations designed to last a the duration of your trek before unraveling.

The first day was relatively easy, downhill (which meant there would be uphill to follow). The first night was one of relative comfort, a real hotel with real bunks, gardens of marigolds on the bank of Dudh Kosi. The next day would be all work, up 2500 feet to the famous village of Namche Bazaar.

Namche is famous as the starting point of all the Everest Expeditions from the Nepal side. It is a prosperous trading village of 600 or more houses, terraced up the slopes of a glacial cirque or headwall. Namche means dark; tall juniper forests, all of which have been cut down for building materials and for firewood, once shaded it. Reforestation efforts are now underway.

Namche was full of activity. The square was full of Yaks and Tibetan merchants. Every meter of ground was covered with their wares. Above the square terraces were covered with tent villages for the trekkers. The streets were full of people, going up and going down. We found the Everest Bakery and snacked on apple pie and cappuccino. I found an Internet café and sent a message off to Will and Cliff to let them know where we were (and that we were safe). Of course in this era people take laptops and satellite portable phones to the summit of Everest. I marvel that the huge jet airplane and the tiny microchip so easily transformed the world into a global village.

We had a shortwave radio, and each night Sam tuned in to BBC News and Nepal News. War drums were being sounded for Iraq and the Nepali Army was killing terrorists, a few each day. The Nepali Army maintained a formidable garrison just above our campsite. It was at the site of a very nice little Khumbu museum, which we visited. Nepalis were not allowed past the razor wire.

Having achieved this altitude (nearly 12,000 ft) we would spend several days acclimatizing, letting our bodies catch up with the altitude we had achieved. These would not be “rest” days in the sense of lying around. It would be more like a postman’s holiday, more walking. We could climb

up in the day and back down at night, up to the next village one day, down a side valley the next. We would savor the early morning and twilight alpenglow, when the white peaks turn pink or golden as light diffuses through the atmosphere, what atmosphere there is in such thin air. We would gaze up in awe at the Himalayan night sky, where the Milky Way was whiter than the Dudh Kosi, and where there were so many stars it was impossible to pick out constellations.

One morning after alpenglow, after the Khumbu museum guarded by sober Nepali soldiers, after breakfast back in our camp, and after a hike up another 1000 feet, we visited the renowned Everest View Hotel, built by Japanese with spectacular stone and glass architecture, views of Everest and the four hundred year old Tengboche Monastery, and oxygen in every room for the tourists helicoptered quickly to altitude. We had a second breakfast on the patio, the morning chill warmed by the direct rays of the sun, our spirits already elevated to the heights while our bodies caught up.

We met a couple of doctors from Philadelphia, East Coast, they reminded us. Their American provincialism was as evident as their uncertainty about their place in the world. I had a grandson in Philadelphia I bragged and produced a picture to prove it. They thought the Khumbu could be made more accessible, trains, cable cars; they were not enthusiastic about the idea of a pilgrimage, the reward going to those who make the effort. They were content with this view of Everest, really a peek at the peak, the summit pyramid over the top of the Lhotse-Nuptse ridge. The real reward, eyeball to eyeball with the unveiled naked Everest was still five days away. There were still obstacles to overcome, many obstacles. Oh for the comforts of Philadelphia, the sophistication. But how could we complain? We were

here by choice. And we would confront the obstacles and the dangers as they presented themselves.

Sharing the narrow trails with yaks proved to be difficult. It wasn't exactly running with the bulls, but yaks are massive beasts, a wrong move or poor choice of place to get out of the way could leave you crushed against a rock wall or bumped over a cliff. They weren't so much malicious creatures as indolent, resigned to their fate, very Himalayan in this regard. They knew their place. Just about anywhere they wanted to be.

When we descended back in to Namche, we were greeted with an uncommon commotion just above our camping terrace. A yak had fallen off one of the switchbacks in the trail and landed on a trekker below. The trekker was bloodied, hurt but not seriously. We recognized the man. He had inadvertently used our loo tent, our latrine, the night before, a forgivable offense, but bad karma.

Another night in Namche, then a walk up to the village of Thame, famous as the homes of many Sherpa climbers including Tensing Norgay, and a famous old monastery, sitting high on the cliffs above the village. Buddhist monks were treated with all the reverence they deserved; devoting many years, sometimes but not always a lifetime, to the preserving centuries old traditions. This was an avenue to education, writing, calculations, and the old texts. It was also a time for many lads to find direction in their lives. Our Sirdar had trained in the monastery and was a proper lama before becoming a trekking guide. He was still addressed as Lama, Lama Lakpa Sherpa.

Thame would again prosper as the trade route from Tibet reopened. It would likely never witness another flood it saw in 1980 when a huge earthen

dam washed out suddenly dumping millions of gallons of water into the Dudh Kosi, taking out bridges and villages and crops and villagers. Swiss engineers had replaced bridges with high steel cable suspension bridges. Foreign aid was now more likely to be directed to local projects, as the needs of countries' peoples became better understood. Micro-electric projects serving a single village were more likely now than huge dams and high-tension wires. Even so from these high bridges the awesome power of the rivers thundering down the valleys was not to be underestimated. There was an undercurrent of danger and the fragility of the moment even from the mastery of the high perch.

I recalled reading about a Brown University professor who took a group of geology students to Nepal. What an education that would be; what an opportunity to study the formation of the earth. As they trekked during the monsoon, they approached a bridge and scrambled to get across before the rising waters overtook them. The professor went last of course, and all of the students made it across just in time. The professor did not.

From Thame we went down the same valley we had ascending the day before, but instead of descending to Namche, we skirted it on the ridge and went up to Kumjung, an impressive little metropolis with a flat playing field outside the Hillary School. Houses nestled under the shoulder of the towering peaks above. There were a few fields where potatoes were grown. An impressive Gumpa for worship. And a branch of the Everest Bakery.

We stayed at the Gumpa View Hotel, which had two rooms with rickety decks overlooking the Gumpa, the village, the school, the playing fields, and the potato fields. It looked straight up at the towering white giants, who seemed quite content with the thin air. I found it hard to breath.

I was reminded of something I had seen on television about Everest climbers. To document the effects of altitude, they were asked to do simple calculations, their answers relayed by radio. As we sipped our afternoon tea, we calculated what we had spent on showers. It has a simple calculation: 4x100 rupees plus 3x150 rupees. I confidently announced that would be 950 rupees. It probably wasn't the dumbest thing I said on trek, but I decided to take an increased dose of Diamox. I began to breathe more easily and to think more clearly.

From Khumjung we would steadily be gaining altitude. I began to breathe more easily as the breathing became more difficult and as we passed the obstacles I had imagined. From Khumjung we climbed straight up a 1000-foot wall. It was technically speaking not a technical climb, and we were not roped. Long ago Nepali women had placed rocks securely at key places so there was always a place to step or someplace for a handhold. The views were breathtaking, as was the altitude.

This altitude gained, we descended a thousand feet before ascending another thousand feet. Conventional wisdom holds that if you have difficulty with symptoms of mountain sickness, particularly difficulty sleeping, you should descend. This little notch would make that impossible. To get down, it would be necessary to go up again. Fortunately I was beginning to acclimatize. We all were. In my mind I checked off the difficulties I had imagined. We passed the hamlet of Luze where the landslide in 1995 had killed 40 trekkers. Sam remembered that day. He was opening a welfare center in the East of Nepal. A freak storm in the Bay of Bengal suddenly roared in with crashing thunder and pelting rains. We were enjoying the expected clear days of late autumn, no rain and only occasional

snow at night, which made the rhododendron forests even more spectacular. It did not seem likely that we would encounter landslides or avalanches. But I recalled the one that Cliff narrowly missed on his trek to the Macchupachere and Annapurna base camps. He was trekking again with our friend Angelbu Sherpa. Two hours after they crossed a snowfield four trekkers they had just met were swept to their death. I was glad I heard about it after the fact, but the story was told over and over, by Cliff, then by Angelbu the next time we saw him in Japan on Mt. Fuji, then by Cliff again. Each time with more detail, and the details became easier to bear.

Machermo is a pleasant little high altitude village, seasonal, a few lodges for trekkers. They would close as soon as the winter snows arrived. The map—all the maps of the area—identified Yeti sightings at Machermo. As I have already indicated, I do not fear Yetis. I only include them in my list of potential worries for those so inclined. At Machermo, we stayed at a lodge run by the Snow Leopard's daughter. The Snow Leopard was a famous Sherpa climber who summated Everest 9 times. The daughter and her husband actually owned two houses; one was in Khumjung, where he stayed with their older son who attended the Hillary School while she ran the lodge, accompanied by their younger son, a mischievous lad of about three. Nepali children are indulged when young. Soon they must accept discipline and responsibility. We stayed at this lodge both on the way up and the way down.

Another day would bring us to Gokyo. It was not far, but involved more climbing. Again it was not technical climbing, but it was dangerous. Steep, precipitous, and dangerous. We were not roped, but that might have been a good idea. As we approached the lip of the plateau, a little rivulet from the

lowest of the series of Gokyo Lakes crossed our path. It froze as soon as the mountain above cast its shadow. The trail was now steep, precipitous, and icy. I took a deep breath, looked up and saw Sam flying backward over the cliff. As we reached the iced rivulet, the sherpa guide turned to see if we were alright. We stood up like reverse dominoes, and Sam lost his balance. I saw the look of horror on his face as he flew by just beyond my reach. I thought that there was no way this could end well. But miraculously he landed on a ledge about fifteen feet below, his fall cushioned by his backpack. I remembered the Zen Master's story. I heard the roar of the Dudh Kosi, hundreds of feet below. There was a gnawing excitement of what we were to find above. Suspended for the moment between a divide reward and an unbearable outcome, we savored the moment. I took a deep breath, a reassuring deep breath.

Gingerly we moved on, pulling ourselves over the lip, where we were met with first Gokyo Lake, a tranquil beauty that reminded us of the precariousness we had just passed, and rewarded us for our effort. Most but not all of our obstacles were behind us. Gokyo Ri was just a head of us. Massive Cho Oyo towered in the distance. Vegetation had been reduced to a few lichen. There were ducks on the lake, so there must have been a few bugs too. We found a stone hut where we could shelter ourselves from the cold, while the Sherpas prepared the evening meal and warmed themselves by the fire. Cho Oyo turned pink. Then disappeared into the blackness of the night.

The day of our ascent to Gokyo Ri was cold and cloudless. We were full of anticipation. Technically speaking, it was not a technical climb. Ropes and harnesses would not be needed. But Gokyo Ri is steep and big.

1500 feet vertical to go. Each of us was assigned a Sherpa to look after us. Sue's Sherpa, Talack, was the youngest, a handsome boy dressed in cross-stitched trousers he bought off the back of a yak. But he was not dressed warmly enough. Sue gave him her liner jacket. At each turn in the trail, he positioned himself directly below her. In case she should fall, he would be there to catch her.

It wasn't long before Everest revealed herself in all her majesty. From our vantage point, we could see all the ascent routes: the North Face in Tibet ; the famous southeast ridge from the Nepal side first climbed by Hillary and Norgay; and the west ridge conquered by Tom Heilburn and Willi Unsold, later the route of my friend Mike Kefford and the Combined British Forces expedition. Everest's signature plume of snow was blowing from the top as would be expected of a mountain that pierced the jetstream. We sheltered ourselves among the boulders to savor our privileged position. Luck and determination had given us a perspective on the world from our loft close to the heavens. We knew that all was not well below as people and nations struggled for momentary advantage. Yet for the moment we could sense a harmony in the universe, the perspective of geologic time, and of cosmic time.

Mountain climbers will tell you that going down is at least as hard as going up. I will not dispute that fact. But there is alpenglow, an internal satisfaction at having achieved a difficult goal. Prudence and vigilance must be maintained. But soaring with golden eagles or scrambling over rocks with mountain goats changes one's perspective on things. Ridge after ridge notched by the powerful river reminded us of where we had come from and

where we were going.

A trek of this sort warranted celebration. There was European beer, either flown in or carried on a yak's back. Our cook prepared a chocolate cake on which was a flag that said

HAPPY NICE TREK

GOKYO RI

2002

Sharing the common room in the Yeti Hotel were other trekkers from various continents. One group seemed to share our enthusiasm and weariness. We wondered if we could tell their nationality by their accents. Northern European. Swedish? No, Estonian it turned out. They had raised money for two years for an expedition to Laboche, a 20,000 ft peak near Everest and Gokyo. Some had made it to the summit. Some had not.

Sam knew something very important about Estonians--something very important to their experience and culture and ours. In the face of the Soviet oppression, Estonians had one weapon the Soviets could not overcome: their spirit. Estonians lifted their voices in song. They filled stadiums with choruses of thousands of voices, tens of thousands of voices. Sam commented on this and asked if they were singers. One of them had a guitar and all had songbooks. We were fêted with Estonian folksongs, high spirited, proud, and witty; our group offered Nepali songs and dance.

The party did not go late. By mid-evening an officious Nepali policeman complained that the noise might get out of hand. The ama ushered him out of her establishment, perhaps placating him with drink for himself. We were ready to drift into slumber.

We would need to get up early for our flight back to Kathmandu. If I

have said landing at Lukla was an adventure, I must tell you that little in aviation compares to taking off from Lukla. Plane schedules mean little in an area so dependent on weather. Often flights are backed up for days. Sometimes there are just a few hours when flying is possible between the morning fog in the Kathmandu Valley and the afternoon showers in the Solu-Khumbu. Then for several hours a gaggle of little planes dart back and forth getting in as many transports as possible.

Again we would be on the first flight out. We hurried through the baggage checks and security. Then waited. Presently the first plane dropped from the sky. Our bags were thrown in the back, and we scrambled for our seats. The pilot did not turn off the engine and barely slowed down, before pivoting at the end of the landing strip. He was already halfway down the runway before we could secure our seatbelts.

I was reminded of the unbelievable opening scene in the James Bond movie where the plane goes over the cliff and Bond skydives to catch it and pull it up just in time. Our pilot was airborne with at least ten feet to spare before the tarmac gave way to the next Himalayan valley. We cleared the first ridge by an equal margin.

“He’s trying to conserving petrol,” Sam wryly observed. I was prepared to believe anything.

Back in Kathmandu, there was a long list of things to do in a short period of time. Museums and hospitals to visit. Book shopping. Sue wanted a souvenir yak. I knew that there was one to be had at the Hotel Tibet. I had considered getting it for her the last time I was in Nepal. Cliff thought better of it: “Do you know what Mother would say if you brought

home a yak?” But now she had a special fondness for yaks; it seemed there should be one on our mantle.

Sam’s friend Col. Narayan Sing Pun visited at the Embassy. Narayan was Sandhust educated and ran a very successful helicopter company. His helicopters had ferried French film crews to the Dolpo to make the movie “Himilayan Caravan” known as “Himilaya” in America. Narayan told stories about Himalayan rescues, which confirmed some of my worst fears about altitude sickness. Once someone goes into pulmonary or cerebral edema, it is not always possible to get word out and a helicopter in before death occurs. But sometimes the helicopter is the difference between life and death.

Narayan was an energetic and determined man, urgently concerned about the insurgency and about the future of Nepal. He had formed his own political party and worked incessantly for the betterment of his people. He outlined a program of progress, which only made sense, if sense was to be listened to.

A few weeks later (April, 2003), we were to read on nepalnews.com that Narayan had in fact orchestrated a cease-fire between the Maoists and the government.

Narayan Singh Pun’s career, like the helicopters he pilots, was a vertical takeoff. In less than ten years he has gone from being an army pilot, to MP, to aviation tycoon, to minister, to forming his own political party, to being the only man King Gyanendra trusted to handle peace overtures with the Maoists.

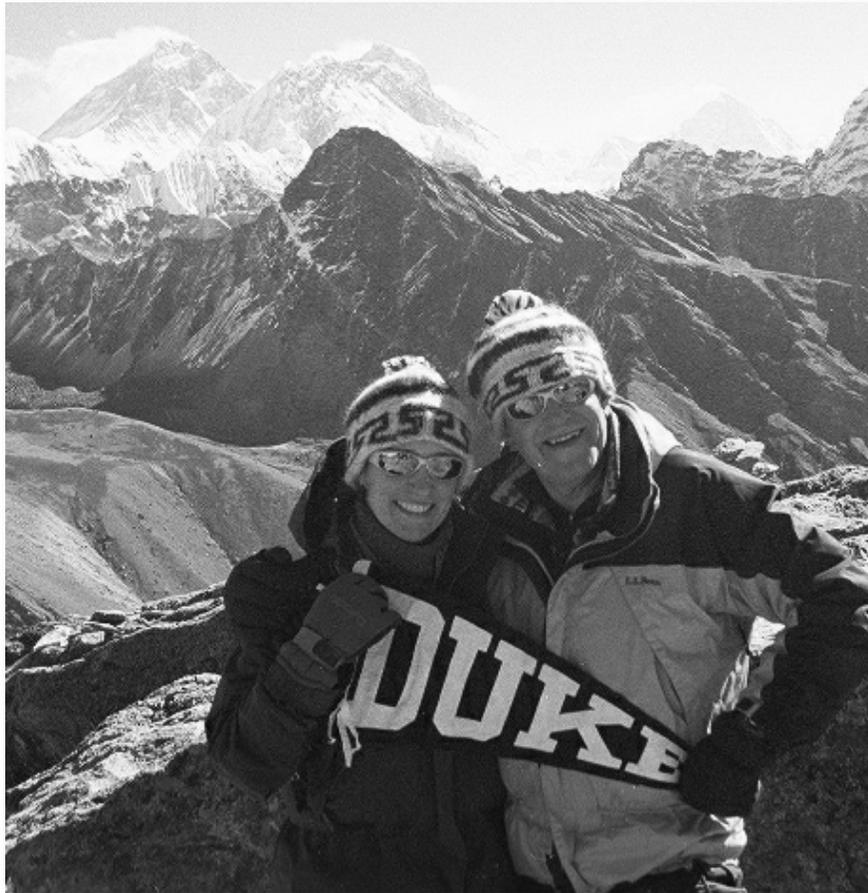
It might be added that he was the only person the Maoists trusted to negotiate with the king and that he had the initiative to bring them together.

It was to be a delicate truce. Maoists were not to be considered terrorists, and pressure would be on the government to show that it could make a difference. The gulf was enormous, the stakes high, and the terms fragile.

One could only hope that bit-by-bit, the future could be made better. Hope tempers reality. Principled and desperate insurgents on the one hand, an absolute monarch on the other. It would surely be a protracted conflict. Sometimes hope is the only thing that makes a difference. Sometimes there can be no difference without hope.

As time passed so did the prospects for peace, which were dealt a severe blow by the global war on terrorism. Bewilderment in face of a changing geopolitical climate led many to believe that the only way to deal with terrorists—or anyone so considered—was to kill them all “in the name of God.” Evil in the name of goodness. In this case, Nepalis killing Nepalis. Where would it end?

So terrorism could be seen as a malignancy to be eradicated. The analogy to cancer again became apparent. It was a two-way metaphor. Terror as cancer. Cancer as terror. Who judges good and evil? Who oppresses whom? Who stands for democracy in a monarchy? In a war? It would be nice to eliminate all cancers and all cancer cells. Such might happen in a utopian future. In the mean time it would be good to restore a truce between the good cells and the bad cells. It would be nice to achieve a balance in which the forces of good kept the forces of destruction in balance. Perhaps newer understandings of the relationship of biological and spiritual forces in the human body might one day be expanded to improvements in the health of the body politic.



**Sue and Allen carry the Duke banner to the top of Gokyo Ri, 2002.  
(Yes, that is Mt. Everest in the background!)  
Thank you, Duke Bone Marrow Transplant Team.**

The Duke banner is part of a Duke-Stanford rivalry. Back in the days when oncologists didn't have very encouraging data to report, Dr. Bloomer at Stanford reported that one of his patients climbed a 14,000 mountain after bone marrow transplant. At the next meeting Dr. Chou reported that one of his patients had climbed a 15,000 mountain, and so it went. I am personally very grateful to the Stanford team as well as the Duke team for research which made my treatment effective and less miserable than it might otherwise have been.

## **15. In the Wake of the Tsunami: What My Illness Taught Me About Health**

Cancer entered my life like a tsunami. It came from nowhere, completely unexpected, and in an instant sweep away everything familiar. Then it receded, leaving the ravages of destruction, much debris, and a new reality. Considering the massive devastation of the Indian Ocean tsunami of 26 December 2004, the private tsunamis of cancer intrusions are small by comparison. But the personal impact cannot be minimized. Years after my cancer treatment, I am ever mindful of my narrow brush with death, the perilous passage between the Scylla of the illness and the Charybdis of the treatment. I am a cancer survivor. I grieve the loss of many of my friends who did not survive.

Prior to the tsunami I had received an invitation to be a visiting professor at the National Institute of Mental Health and Neurosciences in Bangalore, India. I would be lecturing and consulting on medical ethics and bioethics. Increasingly I have become interested in questions of global health and particularly from my own experiences the role of mind-body connections in health. My visit was scheduled to coincide with the first anniversary of the tsunami. Studies of other disasters such as the 1943 Coconut Grove nightclub fire in Boston have taught us much about the role of time in healing. Grieving occurs in stages. The first year is difficult for survivors and families of victims. People experience a number of psychological and physical symptoms: sleeplessness, bad dreams, recurring memories, headaches, pain, and gastrointestinal upsets. After a number of

months, most but not all people begin to return to normal, accept their losses and move on to a new life. How would survivors of the Tsunami cope when whole families and communities were lost or injured?

Western Science is beginning to catch up with Eastern wisdom in the importance of mind-body connections and positive psychology in healing. Positive emotions can make a difference in the way a body responds to stress and trauma. But the balance between positive and negative emotions is a delicate one and both have a role. There is a big difference between an affirmation such as “Time heals all wounds,” which is a positive, but simply not true, and its counterpart, “All wounds take time to heal,” which is true but may be insufficient.

Eastern wisdom reminds us that “All life is suffering,” but that awareness does not require us to remain stuck in a position of victimization or masochistic enjoyment of that suffering. We start with awareness of our experience and look for paths that will lead us to a more comfortable and healthful position. It helps if we can share those paths with others. It helps to have guides and companions, communities. It helps not to be alone when facing such adversities.

Science has long understood the way a body responds to stress. The famous fight or flight response, a shot of adrenalin, increase in heart rate and respiratory rate, prepare one to encounter a saber tooth tiger on the path, either to attack or run away. Such responses are not so adaptive in the modern world where the stresses are not so much physical as emotional. Many people experience anxiety attacks even when there is no immediate danger. These attacks of panic are the same fight or flight response, and over time they make the body vulnerable to illness. The solution: learn to

counter panic with a relaxation response—sometimes easier said than done. Talk about specific worries with someone who will listen, identify the specific triggers to stress, recall and acknowledge unpleasant memories, go to the gym, take a run, climb a mountain, burn off “steam,” a nice 19<sup>th</sup> century metaphor for the body-as-machine.

Science is now beginning to look at the other side of the balance, the relaxation response. Take a deep breath. Be aware of sensations. Be aware of muscle tension. Be aware of conflict in one’s life. Be aware of feelings, both positive and negative. Deal with anger. Meditate. Find occasions to laugh. Be with other people. The effects are measurable. Blood pressure goes down. So does susceptibility to illness in ways that are demonstrable and are now beginning to be understood at a biochemical level through the immune system. A whole field of study called psychoneuroimmunology (PNI) has developed which studies these relationships.

A particularly interesting and important study by Robert Putnam is called *Bowling Alone: The Collapse and Revival of American Community*. Its provocative title comes from the fact that people are less likely in recent years to join bowling leagues that was the case in the 1950s and 1960s. Similar declines have occurred in church attendance, political participation, other civic organizations, voluntarism, and philanthropy. Extensive correlations show a relationship between these kinds of civic involvement, which Putnam calls “social capital,” and health outcomes, welfare of children, and success in education. One concrete example he gives is of a teenage bowling league team with a picture of the boys involved. Years later one of them needed a kidney transplant, and the donor came from one of the team members. Putnam’s study was particularly compelling for me

because of the communities that reconstituted around us at the time of my illness, friends in Johnson City, Tennessee, friends in Durham, NC, where we used to live and where we went for treatment, and friends from Newport, Maine, where I grew up.

For my sixtieth birthday, Sue gave me a spectacular party and a bicycle trip to Provence. Friends and family from far and near gathered at our house for a wonderful meal and an evening of bluegrass music. Such warmth and conviviality provide memories to be cherished. In her toast Sue reminded us that there were moments when we weren't sure there would be a sixtieth birthday. When I had cancer, we hoped for a future, but we never could have imagined the future we would have: productive and rewarding work, travel adventures around the globe, and especially the joys that grandchildren would bring to our lives. Their joy and spontaneity enhanced our own. Their enthusiasm for the music enhanced our own appreciation. Two-year-old Timothy twirled in the middle of the living room, lay on his back and kicked his feet, and went up to the bass fiddle and plucked on the strings to see what sounds he could make. Everyone was delighted. One of the presents I received was a book of aphorisms. The one that best fit the occasion: "Grandchildren are the compensation God gives us for growing old."

Although we didn't feel old, we could appreciate the grandchildren. Sue and I prepared carefully for our trip for months. We tend to take vacations with itineraries: Call 800-GO-ACTIVE. That's us. We dusted off the bikes and rode around the hills of East Tennessee. We went to the gym. We dusted off our French, listened to French tapes, and reviewed

grammar, even read books on French etiquette. And in preparation for a few days in the museums of Paris, we studied paintings of the Renaissance and the impressionists.

Bicycling in Provence couldn't be more idyllic. Ancient medieval and even Roman towns are perched high on hills surrounded by vineyards, olive and cherry groves, fields of poppies and lavender, picturesque farmhouses and wonderful inns. Then there was my little obsession with big mountains, notably Mont Ventoux, *Le Géant de Provence*, the famous *Haut Catagorie* mountain stage of the *Tour de France*, so steep it was beyond categorization. Like so many people, I had been inspired by Lance Armstrong's amazing *Tour de France* victories and by his amazing cancer recovery. As a cancer survivor myself and as a bicyclist and triathlete, I lived more than a few vicarious triumphs along with him. But his real inspiration for me was not just athletic, but the service he did for cancer awareness through the Livestrong Foundation. There were times I would just as soon forget I ever had cancer. Lance took the extra step for cancer survivors everywhere. After the tsunami recedes, life can go on.

The Lance Armstrong Foundation was an inspiration for a foundation I set up on the fifth anniversary of my Bone Marrow Transplant, Yom Kippur, 2003. It is called Willowcliff – The Dyer Family Foundation<sup>4</sup>, named for our children Will and Cliff who manage its assets, the honoraria and royalties I receive from my academic work. Its purpose is to promote global stewardship and world citizenship, which we feel are among the most urgent problems of our times. Three organizations in particular, the Kellogg Foundation, the Salzburg Seminar, and People to People International have

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<sup>4</sup> See Willowcliff.org

provided me with international communities and impressed on me the need to see the world's problems through other peoples' eyes. I should add especially that my ties with the Queen's Gurkha Signals regiment through the British Army have kept the big problems of little Nepal very much in my awareness, a painful awareness of the moral ambiguities of the "war on terror".

Mont Ventoux began to beckon to me as we made preparations for our trip. I realized that it would be there, and I would be there. "Prior Preparation" had been my motto in marathon and triathlon training, and I began to bicycle up some of the mountains I was so fortunate to live amongst, some of the same southern Appalachian mountains Lance and his friends used for training themselves.

For the first few days of our trip, the windy mountain loomed above us everywhere we went. Halfway through the trip we arrived at Crillon Le Brave, a charming village at the foot of Mont Ventoux, six kilometers from the official start of the Tour de France stage. I looked up at the mountain looming above our hotel room, lush forests at the lower levels, the upper third, a barren moonscape of limestone rocks, capped by a tall radio tower. I took a deep breath and committed myself.

The day of "The Ascention," as the French call it, offered perfect weather, not too hot, not too cool, not too windy, just perfect. The first third of the climb from the village of Bedoin is deceptively gradual. The toughest part is the middle third through a cool green forest, some compensation for the incline, which for about six kilometers averages between a 10 and 13 percent grade.

Cyclists sometimes sing to themselves to maintain their cadence. As

the incline steepened, I tried to push myself on:

**Row, Row, Row your boat**

Over and Over Again

**Merrily Merrily Merrily Merrily**

The irony was inescapable. I couldn't even pretend "merrily".

I tried the famous Provençal children's song:

**Sur le Pont D'Avignon**

L'on y dance

L'on y dance

Then I found myself humming the words to a song I had learned in French class years ago. I hadn't thought of it in at least forty years:

**Dominique - inique - inque.**

I remembered the mantras of my marathons. Sometimes you choose a mantra. Sometimes a mantra chooses you. How appropriate to be chosen by a Catholic mantra for the South of France. I remembered almost every word. Merci, Mme Forbes.

**Dominique, nique, nique**

**S'en allait tout simplement,**

**Routier, pauvre et chantant**

**En tous chemins, en tous lieux,**

**Il ne parle que du Bon Dieu,**

**Il ne parle que du Bon Dieu.**

Dominique went out simply,  
*Routier*, poor and singing.  
On all paths, in all places, wherever he went,  
He spoke only of the Good Lord.

“*Routier*” What did that mean? Everyone remembered the song and many sang verses I didn’t remember, but no one knew the exact translation here. A Canadian ski coach I met on an airplane suggested “roadman”. That made sense. A truck driver. I decided that “humble” was appropriate. The mountain was humbling. Dominique helped me grind out the kilometers.

At the shoulder of the Marathon Mountain, there is a restaurant, Chalet Renard, at the base of the ski station. About a kilometer before I reached the chalet, I paused to rest in the cool shade of a grove of Austrian Black Pine trees. A sign identified them as *Pin Noir d’Austerich*. I recalled the lesson a Zen mountain bike master had once taught me: try to get up the hill in as few heartbeats as possible. I understood that that started with awareness of the moment. Enjoy the journey and the destination will come soon enough. I took some relaxed breathes, oxygenated my muscles, applied *crème de soleil* and continued upward.

At the chalet, I caught up with my companion, who had a satellite phone. He beamed a message via Chicago to the base of the mountain. We had landed on the moon. Everything was AOK. Our spouses were reassured.

We decided that the presence of a restaurant meant we should eat. I had long ago learned from my Boy Scouts that “photo opportunity” was a

polite way of saying “rest stop”. Huge omelets provide fortification for the final assault. This was not a race. I marveled at those who raced up this incline. Lance had done it in 57 minutes. Our Backroads guide, Christopher Carey, had done it in 105 minutes. Anything under two hours was considered a good time. My triathlons had taught me the difference between getting a good time, and having a good time. Today we were having a good time.

The barren moonscape of Ventoux’s final six kilometers was familiar from the television coverage of *Le Tour*, which I confess I was addicted to. The names of the great riders were a litany of great moments and great dramas over the years, many of their names still painted on the roadway. Lance Armstrong. Greg LeMond. Eddy Merckx, Marco Pantani, Jan Ullrich. Tyler Hamilton. Tom Simpson, who actually died on the mountain in competition. A stone monument to him near the summit provided a resting place and a pause for reflection.

When I was diagnosed with cancer, I could hardly see around the next bend, and would never have imagined that there might be such adventures in store. Exhaustion was balanced by a glow of satisfaction and contentment.

Like the Tour de France riders, we did not have to descend the mountain after the ascension. We would be spared the risky and arduous descent. My companion beamed another message to the base of the mountain. Our generous Backroads guide, Chris Carey, retrieved us in a van, and his spouse and partner, Amy Kreischer, hosted a victory celebration worthy of television. Like professional riders we completed the day with a massage and a good meal. My *soigneur* was a true French *philosophe*: He suggested I leave my Cartesian mind behind--I hadn’t had a rational thought

since kilometer one--and suggested that by the end of the massage I would be just a breath--that's how it translated. At the end of the hour, I was so relaxed I was aware only of a gentle breeze rolling down the slopes of the Windy Giant and the singing of swallows outside our window.

Dominique would stay with me. I wanted to track down the music and scoured the bookstores and music shops in Paris. Yes, they knew it. There was a complication. Parisian friends told me this song has achieved a party status because of a sexual connotation for “nique nique” that has entered the language in recent years. Soeur Sourir would have been no more aware of this than I was. The early sixties were a time of innocence, if not naïveté. On the Windy Beast, I was all focus, if not innocence.

Dominique was made famous by a Belgian nun, whom the French call Soeur Sourir (the smiling sister), and whom Americans called “The Singing Nun”. She composed Dominique to raise money for a charity, to give away as a gift to contributors. It became a surprise international hit. She had to receive special permission to appear on the Ed Sullivan show. Apparently her Mother Superior felt her song was a bit familiar with the founder of their order.

Later my friend Matt Stern (who had irreverently but inspirationally described my cancer treatment as Allen and Sue's Great Adventure) asked why I found this music so uplifting. That was it. For me it was spirituality in a nutshell. I found mountain climbing uplifting not just in a literal sense, but also in a spiritual sense. But also spiritual in a literally uplifting sense. Mountains were heights that could be attained. Mountains and marathons—marathons of all sorts--offered transcendent experience without leaving *terra firma*.

There was one aspect of Souer Sourir's story that I found particularly poignant. One line of one of her songs of sweet innocence stayed with me, and I sang it over and over in my mind,

Je veux faire de ma vie  
quelque chose de bien.

I wish to make of my life something worthwhile. And she did, she used her talent to lift up the spirits of others, to amuse, to inspire. When her music was published, she gave all the proceeds to charity. Later the Belgian government made a claim for unpaid taxes, and she committed suicide.

As a psychiatrist I struggle to help people over difficult transitions. I have learned from my patients that often it isn't that life is no longer bearable—though I accept that there can be a rational suicide—but that today is not bearable. Patients say they just wanted relief. They took pills to ease the pain, just to sleep, just to get relief. A cloudy interval with no hope that tomorrow could be better, no thought of tomorrow. If only the humble nun had found a good psychiatrist. Or a good lawyer or accountant.

Visiting the charming village of Les-Baux de Provence, I came across an inscription, which might have helped Souer Sourir. It seemed to sum up my work as a physician as well as my life as a patient looking for hope. It was on the wall of a Roman library served as an invitation to the reason and wisdom that could come from learning:

POST TENEBRAS LVXIS

After the shadows, comes the light.

## **PART THREE – THE WORLD BEYOND**

### **16. Zen and the Art of Knowing - The Charles McCoy Lecture<sup>5</sup>**

I am pleased to be back at P.S.R. to deliver this Charles McCoy lecture. Glancing at the calendar reminds me that it was thirty-five years ago that Doug Adams and I first arrived at the Pacific School of Religion as newly minted college graduates, eager to study the mysteries of the theological world under Charles' wise tutelage. I remember being struck—as I am sure everyone is--by the stunning vistas of the Golden Gate at this campus on Scenic Avenue. I was certainly no less struck by the intellectual vitality of this community that had lured me away from my familiar East Coast Ivy League world. Nothing in my previous education had prepared me for what I was to encounter in my tutorial with Professor McCoy. Each week he made certain assignments, suggestions really, of things I might want to read to address questions I seemed to have posed—or questions he drew out of me. I set out to discern and articulate the importance of what H. Richard Niebuhr or George Herbert Meade had written. McCoy quizzed me intently, not on what they had to say—he had read them himself—but rather on what I was trying to say. It was my first important lesson in post-critical thinking, which subsequently led to reading Michael Polanyi and to subsequent work with William Poteat, my thesis advisor at Duke.

Today, I would like to start my reflections on Robert Pirsig and Michael Polanyi with a poem by Constantine Cavafy, written about a

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<sup>5</sup> Pacific School of Religion, Berkeley, California, March 11, 2002.

hundred years ago about a theme that goes back at least to Homer.

## ITHACA

When you start on your journey to Ithaca,  
Then pray that the road is long, full of adventure, full of knowledge.  
Do not fear the Lestrygonians and the Cyclopes and the angry  
Poseidon.

You will never meet such as these on your path,  
If your thoughts remain lofty, if a fine emotion touches your body and  
your spirit.

You will never meet the Lestrygonians, the Cyclopes and the fierce  
Poseidon,

If you do not carry them within your soul,  
If your soul does not raise them up before you.

Then pray that the road is long, that the summer mornings are many,  
That you will enter ports seen for the first time with such pleasure,  
with such joy!

Stop at Phoenician markets, and purchase fine merchandise, mother-  
of-pearl and corals, amber and ebony, and pleasurable perfumes of all  
kinds,

Buy as many pleasurable perfumes as you can;

Visit hosts of Egyptian cities, to learn and learn from those who have  
knowledge.

Always keep Ithaca fixed in your mind. To arrive there is your  
ultimate goal.

But do not hurry the voyage at all. It is better to let it last for long  
years;

And even to anchor at the isle when you are old,

Rich with all that you have gained on the way,

Not expecting that Ithaca will offer you riches.

Ithaca has given you the beautiful voyage.  
Without her you would never have taken the road.  
But she has nothing more to give you.

And if you find her poor, Ithaca has not defrauded you.  
With the great wisdom you have gained, with so much experience,  
You must surely have understood by then what Ithacas mean.

Cavafy makes the odyssey sound like fun. Do not fear the Lestrygonians and the Cyclopes and the angry Poseidon. Do not fear going off to war and risking your life for some abstract principle of national honor. Do not fear the sea journey. Do not fear sexual seduction or ruin upon the rocks or being swept into a vortex. Do not fear sickness. Do not fear impoverishment. Do not fear death.

Is he serious? Do not fear the Lestrygonians and the Cyclopes and the angry Poseidon. You will never meet such as these on your path, if your thoughts remain lofty, if a fine emotion touches your body and your spirit. You will never meet the Lestrygonians, the Cyclopes and the fierce Poseidon, if you do not carry them within your soul, if your soul does not raise them up before you. Does Cavafy expect us to believe that there are no such things as Lestrygonians, Cyclopes, and the fierce Poseidon except that we conjure them up before us? Well, literally, yes, these are mythic dangers, though of course, we may encounter very real dangers in our path.

Every story worth remembering and repeating carries a similar message. Go ahead, eat the forbidden fruit, wander in the desert, cross the waters, search for the promised land, live life affirmatively, maintain faith. Somehow as much as we suffer, some good may come of it.

Pray that the road is long and that summer mornings are many. Stop at Phoenician markets, and purchase fine merchandise, mother-of-pearl and corals, amber and ebony, and pleasurable perfumes of all kinds. And visit hosts of Egyptian cities and learn from those that have knowledge.

The stories, the odysseys, the journeys that we remember--and that are worth remembering--are those that bring us knowledge, those that help us learn how to live. Homer's *Odyssey* and Cavafy's *odyssey* are not just curious stories of a particular war and return home, they are everyone's story, and in a very real sense everyone's story, everyone's biography, everyone's history is similar in all the essential details. Every voyager, every crusader, every pilgrim, every drunk on the path to recovery, is living out a story that offers us a limited number of possibilities with an infinite number of variations. Birth, dependency, separation, trial and error, adversity, mastery of conflict, return to home and dependency, death. And . . . a few loose ends, unanswered questions, big questions.

The Swiss psychoanalyst, Carl Jung, identified a repertoire of archetypes, which Joseph Campbell suggested reoccur over and over in different guises in the myths and stories that are familiar. Everyman (and woman) is a hero; the hero has a thousand faces. Even the most mundane lives are epic in this mythic sense. And even if the classic myths remain remote from us, contemporary stories and movies retell the classic tales with endless variation. Chris Vogler, who has written a book, called *The Writer's Journey*, offers this mythic structure as a guide to writers. Hollywood studios often consult with Vogler, which prompted one popular magazine I found in the back of an airplane seat to suggest that all movies have essentially the same plot. This sounds heretical or at least iconoclastic given

all the reverence with which we ascribe to this story-telling medium, but if my insight is correct, all stories are alike or at least similar because they all deal in some way with the developmental trajectory each human must traverse.

What Vogler suggests and Campbell before him and Jung before him, what was really Freud's great insight, is that we all lead mythic lives or that the great myths such as the Oedipus story are universal across cultures because they frame something universal in human development or in human experience.

The Hero's Adventure (as described by Campbell and Vogler) involves certain steps:

- The Call to Adventure (Jonah called by God, the Nepali shaman called by dangerous experience, like being lost in the forest, encounters with ghosts; a medical diagnosis)
- Refusal of the Call (Jonah, Abraham)
- Encountering the Mentor or Supernatural Aid (almost all Biblical stories, the Fairy godmother for Cinderella, Yoda for Luke Skywalker)
- Crossing the Threshold, where the regions of the unknown (desert, forest, ocean, outer space) are free for the projection of unconscious fears and desires (the Sirens, The Cyclopes, and the angry Poseidon)
- The acquisition of allies and the confrontation of enemies (Luke and Obewan Kenobi (and R2D2 and C3PO) meet Han Solo and the Wookie in the desert cantina)
- Descent into the Underworld (Persephone, Innana)

- The Innermost Cave (Jonah in the Belly of the whale, Odysseus in the Cyclopes cave, Jesus in the Tomb). Life is lost to gain new life
- The Ordeal (war, bone marrow transplant)
- The Reward (riches or wisdom)
- The Road Back (most of Homer's Odyssey)
- Resurrection
- Return with the Elixir, the Master of Two Worlds: the everyday world, and the world of adventure, transcendence, adulthood. (Ithaca, The Gospels, the unconscious as recovered in psychoanalysis, the lost boy becomes Nepali *jhakri* or shaman after encountering spirits and ghosts in the deep forest, no longer afraid)

In my own experience I was surprised to find that when I attempted to write a chronological account of my cancer experience, it coincidentally followed this same outline:

- Prelude: A Helicopter Named Icarus
- The Drama of the Diagnosis
- Talking about Cancer
- The Early Rounds: Low-Dose Chemotherapy
- Obsessive Defenses
- High Dose War Stories
- The (stem-cell) Rescue
- The Need for a New Medical Model
- Managing Managed Care
- Recovery

- Affirmations
- Coda
- Rebirth

Can you think of any exceptions to this trajectory? Star Wars, Dune, Star Trek, Peter Pan, Pinocchio, Dumbo, Lord of the Rings, Harry Potter, Terminator, Romancing the Stone, Rob Roy, Pay Back, Pay It Forward, Othello (now with many popular retellings). Why do we read book after book? Why do we see new plays, films, and musical productions, endless variations on similar themes? Could it be that we are trying in some way to get it right? To make the best of the few choices that are available to us? Could it be that we are looking for ways to survive and prevail on our own personal odysseys, our little epic quests to confront conflict and come to some mastery of inner conflicts, struggles, or demons?

If I am right that we are all similarly situated in this larger quest, why are there such intense and fierce differences in how different people understand their position in these odysseys? Why are minor differences of opinion so intensely felt? Why are matters of little consequence so fiercely defended in say faculty meetings, committees, neighborhoods, in politics, religions, cultures, nations? Perhaps what seems a matter of small consequence at any particular moment in time is valued even overvalued, as a matter of great consequence among the bewildering options in this common human drama? Who knows? And how could one know?

One might say that the answers to such questions come to us fairly directly. They were given to Moses carved in stone. Jesus said so in the Sermon on the Mount. The answers to life's questions are contained in the text of the various religious traditions. Or they come to us hidden in the

fossil record or in our DNA. We could say we learn life's lessons, in families, in communities. I would not want to suggest that the answers to such questions are simple or that they are impossibly elusive. What I would suggest is that they require serious attention. And the meta-questions behind these questions, how we know what we know are worthy of consideration because they help us understand what we do believe: knowledge of the world, knowledge of God. Serious attention to the epistemological questions helps us understand ourselves and to recover ourselves in knowing.

I find Robert Pirsig as a useful counterpoint to Michael Polanyi. Where Polanyi uses philosophy, Pirsig uses narrative to raise epistemological questions. Both perceive a problem in modern, Western thought. They perceive a problem in how knowledge is valued and understood. They both recognize that like Odysseus we must live our lives, sensually, experientially, while at the same time viewing the larger perspective, looking at ourselves from outside ourselves, located in where we are without losing sight of where we are going. They both recognize that we can be misled by a science or a world-view that claims to be objective and claims too much for itself.

Pirsig tells his philosophical tale in two epic novels. His popular *Zen and the Art of Motorcycle Maintenance* tells the story of a journey from Minneapolis to San Francisco in which the hero has many hours to reflect on how his graduate studies in philosophy, reading the Great Books at the University of Chicago, drove him mad. Less well known, but even more insightful, his second novel *Lila* chronicles a voyage on a sailboat from the Great Lakes to New York City through the Empire State canals and down

the Hudson River with a descent into madness en route.

*Zen*, in its enduring popularity presents an interesting Zen paradox: how such an esoteric book can be so popular? Polanyi's *Personal Knowledge*, popular in certain circles, is strikingly esoteric. Pirsig and Polanyi both recognize that sanity and wisdom, successful living and knowing in the Modern Era, come from mastery of two worlds, the world of immediate sensory experience, and the world of detached abstraction on that experience. Their stories as such teach us important lessons about how to live. Polanyi teaches us about lessons that come from living the controversies of science with its false claims of "objectivity", while the quest of Pirsig's motorcycle mechanic shows us that even though we know what quality is, we can never precisely specify it. We know more than we can tell, Polanyi's mantra. We know more than we can tell, but we can tell nothing without relying on that which we know only tacitly.

These gurus both remind us that we cannot live successfully without mastering two worlds. Homer had a similar message. We leave the comforts of home to fight the battles of the world. We learn the survival skills of the warrior. Only by our wits and good fortune can we make our way back to the security of the world we once knew, only to find that that world no longer exists; that we have been transformed by our journey. Master of two worlds, with the knowledge gained from those that have knowledge, from visiting a host of Egyptian cities, prepared to take on the new challenges.

Do not fear the Lestrygonians. Or Captain Ahab. Or Cancer. Do not fear the Angry Poseidon. Or terrorists. Or politicians or Enron executives. Or rampaging plasma cells. Or runaway energy costs. Or a bear market.

Oh, for the securities of childhood, the comforts of home, Ithaca, the way things used to be or the way we might wish them to be. If only we could convince ourselves that things might be better, at another time or another place. Ithaca. The Garden of Eden. The Promised Land. Heaven. Then we could go on.

The modern world, in which we find ourselves, presents us with certain difficulties. Or perhaps I should say, the modern world with whose assumptions we grew up. Many would suggest that we have left the modern era and are now in some kind of after-modern, post-modernism, though there is certainly little consensus as to what that might be. Deconstructive post-modernists might suggest iconoclastically that there really is no certainty, the world is uniquely and individually constructed through acts of extraordinary deliberation. Religious traditionalists might suggest that received faith is to be vigorously adhered to though acts of similar extraordinary deliberation. Scientists and the scientifically faithful might look to all sorts of evidences for their certainties, but even these certainties are not without tension. We live with tensions we cannot completely reconcile.

Pirsig and Polanyi both offer ways beyond the received tensions. Pirsig's metaphysics of quality and Polanyi's post-critical philosophy both suggest that we apprehend the world at one level and try to make sense of it at another level of understanding. We rely on our own experience as a kind of common sense but we test that apprehension as reality in conversation with outside perception, our families, our cultures, the world of science, the world of religion. We could go mad as Pirsig's character Lila does, but even that madness is understandable as a culture of one, a world that she inhabits

uniquely but shares with no one else.

Lila had trouble trusting. In particular she had trouble trusting men, trusting that things might go right in the world, and trouble trusting her perceptions. Lila was mentally ill. She believed a doll she found in the river was a dead baby. No one else believed that, an observation that leads Pirsig to reflect on the nature of insanity and its accompanying delusions or beliefs.

The catch here, according to Pirsig, is the word, “delusion.” It is always the other person who’s “deluded.” Delusions can be held by whole groups of people, as long as we’re not part of that group. If we’re a member then the delusion becomes a “minority opinion.”

"An insane delusion can't be held by a group at all. A person isn't considered insane if there are a number of people who believe the same way. Insanity isn't supposed to be a communicable disease. If one other person starts to believe him, or maybe two or three, then it's a religion," according to Pirsig.

Pirsig realizes, of course, that “it sounds quite blasphemous to put religion and insanity on equal footing for comparison, but his point is not to undercut religion, only to illuminate insanity,” something he understands from his experiences at Chicago’s Great Books program. He thought that the intellectual separation of the topic of “sanity” from the topic of “religion” weakened our understanding of both.

Pirsig observes that religious mysticism and insanity are similar, but diverge as the mystic identifies his beliefs with a larger tradition, while the lunatic, remains isolated in an autistic world. When Socrates says in one of his dialogues, “our greatest blessings come to us by way of madness provided the madness is given us by divine gift,” the psychiatric profession

doesn't know what in the world he is talking about. Or when traces of this identification are found in the expression "touched in the head," meaning touched by God, the roots of this expression are ignored as ignorant and superstitious.

Nonetheless a post-modern psychiatrist informed the classical mythology Freud was so fond of, would probably be more appreciative of divine madness, than would say a modern Methodist (to illustrate from the tradition most familiar to me). Polanyi is suggesting something quite similar when he suggests that all declarative sentences should be preceded by the phrase "I believe that..." as a reminder that there is no objective reality outside of that which we choose to accredit. Such a reminder would be useful to the scientist who assumes that his or her beliefs are congruent with reality, but equally theists in the modern age are likely to couch their beliefs as statements of reality.

An evangelical Christian in the contemporary era would have learned the same lessons from elementary school grammar teachers, as did the future scientist. Write and speak in the third person, passive voice. Do not use first person pronouns except in colloquial speech. Thus someone overjoyed with the good news of the gospel would as likely as the scientist to forget the first person declaration, "I believe that..." Witnessing one's own faith often becomes an "in-your-face" exercise in criticizing someone else's reality. There is a big difference between saying "I believe Jesus died for my sins" and saying "You are damned if you do not accept Jesus." Both are statements of faith, but the former acknowledges the first person belief, while the second masquerades as a statement of objective reality.

An objectivist religion like an objectivist science leads to an

intolerable intolerance. It becomes a serious exercise in linguistics and epistemology and psychology to recover ourselves from this situation and to communicate with others about how we experience the world we live in.

Religion is problematic qua ecclesiastic authority, Descartes' difficulty, Galileo's difficulty. The problem of religion may be for the modern or post-modern individual a problem of language or semantics: what is meant and what is understood by the various claims of the texts and the faith community. What is meant by salvation, grace, sin, divine being, miracles, etc? What is understood by those terms? What occurs in prayer and how might it be effective?

There is much interest in medicine in the role of spirituality in healing. Many quantitative, empirical studies demonstrate better health outcomes from surgical and medical treatments, cardiac outcomes, for example, have been extensively studied. Cancer survivors do better if they attend support groups, churches, or other affiliated groups. It's a fact, an accreditable, measurable, fact. We believe it to be true. People who bowl in bowling leagues are less likely to become ill than people who bowl alone. How do we understand such studies? Some might say that these studies confirm the existence of God and divine intervention, confirm an image of God as a master puppeteer, pulling all the strings. Intercessory prayers call on the intervention of a person-like willful being. Others might understand these findings as a result of the modification of the immune system, the interactions of mind, brain, body, spirit at a cellular level in which neurotransmitters influence cytokines, which affect the body's ability to fight outside invaders like germs or cancer cells. It is interesting to me that one language carries so many levels of meaning. "Miracle" can mean

"extraordinary event" or it can imply "divine intervention." Of course the irony of seeking empirical confirmation for something which would be believed even without such confirmation is not lost. Negative results would not really challenge the beliefs that some might wish to hold anyway. Snake handlers in Appalachian religious services believe that God protects them from the venom should they be bitten, but should they die, which sometimes happens, God will save them. Hopi snake handlers have emetic herbs at hand. It pays to be practical.

However simplistic such traditional beliefs may seem, they are not uncontaminated by the felt need for objectification which is so characteristic of the modern era. So how could one get in touch with spirituality uncontaminated by Western modernism? Anthropologists offer us many examples of cultures that live closer to nature, cultures which may see spirits in animals or even inanimate objects. One can look to other traditions, Asian religions, for example. I have found Buddhist traditions in Nepal remarkably harmonious and inspiring. Pirsig finds possibilities closer to home in Native American or American Indian spirituality.

He tells an interesting story of walking one day with friends on the Northern Cheyenne reservation in Montana. A dog joined them and someone asked John Wooden Leg, the tribe's chief, what kind of dog it was. John replied, "That's a good dog." And it was a good answer to a question posed in an Aristotelian framework expecting some sort of categorization of species. One can get beyond the Greek western framework by observing the wisdom of cultures that don't try to delineate objects apart from our experience of them. It must have seemed a strange question to John Wooden Leg? Why would she ask? Not likely a dog that would bite you, a

good dog.

Pirsig observes that the American personality is mixture of European values and Indian values. The qualities Europeans associate with Americans, the plain spoken directness and lack of refinement are qualities of the Indians, whereas the qualities Indians see in white Americans, their elaborate talkativeness with many complex and undependable meanings are qualities Americans have learned in dealing with European cultures. It might be interesting to speculate whether the “forked tongue” Indians perceived in the white man might not always have been a deliberate attempt to prevaricate, but rather an accustomed familiarity with ambiguous and uncertain realities of those schooled in European philosophies.

Lest I have painted myself into a corner here, or spun off into a realm of abstraction, the relevance of which is not immediately clear, I would like to shift gears in my reflections. I would like to conclude by telling a story, which reveals some of my personal experiences in dealing with these issues. It is about my odyssey into the world of cancer and cancer treatment. Four years ago in 1998, I was diagnosed with multiple myeloma. The treatment I received was a bone marrow transplant, a grueling ordeal lasting the better part of the year. I would say that there is little in life-even my life as a physician-that prepared me for such a diagnosis. But I would also say that as much of a shock and surprise as the diagnosis was, it was even more surprising to recover, to return home and to return to my normal activities, to return to Ithaca.

As a physician-patient I became interested in the healing process, what I went through, what seemed to make a difference in positive and negative ways. As should be no surprise, I encountered much ambiguity in what to

believe, how to make sense of my experiences and how to tell what I learned.

It seemed at first almost an accident that my story unfolded as an adventure narrative, but in retrospect it could be no other way. Pirsig's *Zen and the Art of Motorcycle Maintenance* is an epic father-and-son journey across the United States and across the world of philosophy. Lila is a boat trip from the Great Lakes, the St. Lawrence Seaway and the Hudson River. Homer's epics are the story of every person, they are the developmental trajectory through life. Polanyi's great insight that all knowledge is personal is obvious once you catch on, yet freshly original.

Seen in the context of life's journeys, these epistemological questions--how can we know? --gain a certain immediacy. They are not abstractions for the philosopher or scientist or theologian, they become important for our day-to-day knowings and doings. How do we know the world around us? What would it mean to know God? How do we know ourselves? In a very real sense, these epistemological tensions are psychotherapeutic: How can we be comfortable with ourselves as we face the things we have to face in our journey through life? I think one would not need to be a psychiatrist to accept my conclusion that these are questions of therapeutics ultimately though a psychiatrist might be more accepting of the notion that one must look at and experience the things that one might rather prefer to forget. After all, it was not Freud who first said that the unexamined life is not worth living.



**Charles S. McCoy (1923 – 2002)**

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## 17. Fear of Feeling<sup>6</sup>

I am pleased to be with you on this occasion and honored to make some remarks. I would like to add my welcome to the new residents and express my congratulations to the graduates. I take great pleasure in watching your development and the competence and confidence you have attained over the past several years. You now have the credentials to match, which enable you to get a REAL JOB, but more importantly you have the education that will enable to you be professional leaders -- not just tradesmen.

I have chosen as the theme for my remarks, “Fear of Feeling”. In a very real sense, it would be nice if we could just medicate away symptoms and not have to deal with complex emotions and messy feelings. But it is also important to understand feelings, demonstrate to our patients that their feelings can be bourn, that they we can tolerate their feelings, and that they can learn to dear with them. It is said that Eskimos have 14 words for snow. The English language barely has that many words to convey the rich variety of emotional life. Indians have 22 words for love. We might pay attention to that. In an ideal world, children would learn the names of feelings when they learn the names of colors. They might start with a basic box of eight. If they are boys, that might be as far as they get.

Our focus on symptoms over feelings reminds me of the caution President Eisenhower offered about the military-industrial complex.

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<sup>6</sup> Graduation address, East Tennessee State University, Department of Psychiatry, June 25, 2006.

Psychiatry has developed a co-dependency with the drug industry, which might well be called a medical-industrial complex.

The close relationship of physician and pharmaceutical is of course not a new situation. Chaucer commented on it in his *Canterbury Tales*, written way back in the 1300's. The pilgrims traveling to Canterbury told stories to pass the time. Among them was a Doctor of Medicine:

“In all this world there was no one like him,  
to speak of medicine and surgery;  
He knew the cause of every malady.  
And all the apothecaries in a tribe  
gathered to make the remedies he prescribed.  
They had known each other for a goodly while  
and each profited from the other's guile.”

We marvel that Chaucer noticed these things so long ago. What is generally not known is that there were a number of psychiatry professors among Chaucer's pilgrims. First there was a Franklin.

“His beard was white as a daisy.  
And he well loved a bit of bread  
dipped in wine in the morning.”

Though our dean no longer has his white beard, we know that he maintains his sanguine disposition and his pleasure in epicurean delights.

Next there was a miller.

“The Miller was a stout fellow of 16 stone.  
He was strong of muscle and big of bone.”

“A Haberdasher, a Dyer, a Carpenter, and a Weaver  
were all there in the livery of one impressive guild-fraternity.

Each was wise and would have justified a plan  
to make each of them an older man.”

(Thus it says in the original or something like that.)

Chaucer’s tale did not include a Cancellaro, but mine does. I know you have been spending many months with Dr. C. learning neuroanatomy, and there is a question I would like to pose: Is it really necessary for the modern psychiatrist to know all those structures and pathways, OR -- is it sufficient to have forgotten them?

One part of the brain that is almost forgotten in modern psychiatry is the cerebral cortex, that part of the brain that deals with thinking, memory and association as opposed to the lower brain, especially the amygdala, the seat of the emotions. It is important that they be connected, and in many instances it is our job to make sure the connections are made.

A distinction from the old days of psychiatry that remains important is a distinction of cognitive styles, obsessive on the one hand and what we used to call “hysterical” on the other. Obsessiveness has become a disorder, and hysteria—such an unflattering term—is all but forgotten. But both are important defenses, defenses against feelings that might seem too uncomfortable to bear. The obsessive personality is a heady, cerebral, individual, given to thought, and distanced from feeling. The hysteric is just the opposite, prone to emotional volatility, overreaction, perhaps hurt feelings, and impulsive actions. In the old days, many situation comedies and much psychotherapy focused on this tension. The obsessive was attracted to the colorful passions of the hysteric, who in turn admired the logical order and stability of the obsessive. They drove each other mad. We might say they personify the tension between the cerebrum and the

amygdala;

Of course we hear these themes in our offices, in the stories that are told to us, but also they have been captured in the great stories of literature. One of the advantages of being married to an English professor is that these great characters come into our lives and become part of our conversations. On New Year's Day in Bangalore, Sue announced that her resolution for the New Year was to re-read Shakespeare, all thirty-eight plays. And of course I get to share in this theatrical feast, a bit of which I am going to share here this evening, a couple of scenes from Shakespeare, and a Shakespearian scene from real psychiatry.

Hamlet, for example, is an obsessional character, who cannot steel himself to the deeds he must do, namely avenge his father's murder. He is caught in a vicious Oedipal complex between his mother and his father, then step-father, and his adolescent love for Ophelia, whose father Polonius has told her to reject Hamlet. Sir Laurence Olivier interprets Hamlet so intelligently, cerebrally; Kenneth Branagh, so passionately, overwrought, hysterical. A very interesting and quite good production by Zepherelli, who also did an outstanding movie of *Romero and Juliet*, cast Mel Gibson as Hamlet, inspired by his role in *Lethal Weapon*, a crazy guy with little regard for his own fate.

I invite you to imagine how as a psychiatrist you would respond to Hamlet if he came into your office and presented his famous suicide soliloquy.

To be, or not to be: that is the question:  
Whether 'tis nobler in the mind to suffer  
The slings and arrows of outrageous fortune,  
Or to take arms against a sea of troubles,

And by opposing end them?

To die: to sleep;  
No more; and by a sleep to say we end  
The heart-ache and the thousand natural shocks  
That flesh is heir to, 'tis a consummation  
Devoutly to be wish'd.

To die, to sleep;  
To sleep: perchance to dream: ay, there's the rub;  
For in that sleep of death what dreams may come  
When we have shuffled off this mortal coil,  
Must give us pause: there's the respect  
That makes calamity of so long life;

For who would bear the whips and scorns of time,  
The oppressor's wrong, the proud man's insult,  
The pangs of despised love, the law's delay,  
The insolence of office and the spurns  
That patient merit of the unworthy takes,

Who would burdens bear,  
To grunt and sweat under a weary life,  
But that the dread of something after death,  
The undiscover'd country from whose bourn  
No traveller returns, puzzles the will  
And makes us rather bear those ills we have  
Than fly to others that we know not of?

Thus conscience does make cowards of us all;  
And thus the native hue of resolution  
Is sicklied o'er with the pale cast of thought,  
And enterprises of great pith and moment

With this regard their currents turn awry,  
And lose the name of action.

How would you deal with such a patient? How many times have you heard someone say they would kill themselves except that “the Almighty had set his cannon against self-slaughter”? Would you ask him if he could contract for safety? Place him on one-to-one with Rosencratz and Guildenstern? “Madness in great ones cannot unwatched go.”

Would you place him on an antidepressant medication? What would you make of his story of hearing his dead father speak to him from the ramparts? Auditory and visual hallucinations? Perhaps indication for an anti-psychotic medication? Or do you accredit the supernatural? Would you want to make these visions go away or try to understand their meaning? Would you approach this problem from above, at the level of the cortex, or below at the level of the amygdala?

Shakespeare, I think, is doing exactly what Freud taught us that we must do, keep in consciousness those things we would rather forget. He keeps alive those complex feelings and motives that compel us. He shows us that we have options and helps us imagine the consequences of our actions. He teaches us ethics by forcing us to look at ourselves. He, like Freud, teaches us how to look at ourselves.

Shakespeare, like Freud, understood that histories are developmental histories. He gives us evidence that we should always look for in understanding how our characters got to be the way they are.

Freud himself was interested in Shakespeare and most especially in the character of Richard III, the evil monarch who gave us such memorable lines as

“Off with his head”

or when his cruelty fails to achieve his aims,

“A horse, a horse, my kingdom for a horse.”

Freud felt that Richard III’s evil stemmed from a narcissistic injury, his deformities, hunched back and withered arm. Richard felt that he was cheated by fate and hence entitled to pursue his own ambitions.

One of his most fascinating historical characters is Henry V. Where Hamlet hesitates, Henry is decisive.

We meet Henry as young Prince Hal. As a young man Harry spends too much time in taverns, drinking and otherwise misbehaving, sometimes afoul of the law. His father understandably worries what will become of him.

At last his father dies; he grabs the crown and gets his own play. Henry V is in many ways a tale about growing up. Harry puts aside his old ways and his old friends and sets himself—rather ruthlessly-- on the task of administration. Henry V is often seen as a play about leadership. I think it is that and more. It is also a play about the politics of expediency.

Harry needs to establish himself and chooses the devise that is so often used to transition boys to men, a war. The play opens with his bishops reviewing some ancient claims against the French for lands he would like to control. The warrants for the claims don’t really matter; he has already decided that he wants a war. Does that sound familiar and timely?

The French ambassador arrives with a diplomatic solution and a gift, tennis balls. Harry understands the insult to his manhood. He lacks balls. At first he is enraged, amygdaloid. At first he has trouble finding his voice, not knowing what to say, but at last he threatens, “We will smash these balls across the courts of France.”

The key scenes in the play center around the battle of Agincourt, which ultimately the English win, even though they are seriously outnumbered. One day in a hundred year war. Olivier made a movie of this play near the end of World War II, which served as patriotic inspiration for the British. Kenneth Branagh -- an Ulsterman like Dr. Moore -- who has witnessed decades of insurgency in Northern Ireland, produced a spectacular movie version, which dwells more on the horrors of war.

Sue and I saw Branagh and Emma Thompson on the Royal Shakespeare stage in Stratford-on-Avon in 1984. The scene that most impressed us theatrically was the scene that occurs the night before the battle when Harry--disguised so his men won't recognize him--wanders through the camp taking the measure of his men. “A little bit of Harry in the night.”

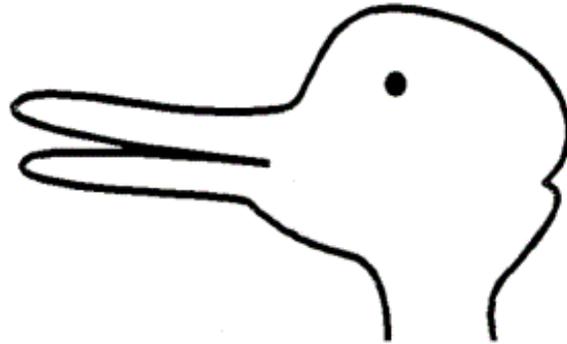
The Stratford production we saw employed spigots of real water, hundreds of gallons pouring down on the stage. It was very convincing and apparently historically accurate. The battlefield in 1415 was a muddy bog, favoring the English: when many of the French nobles in their heavy armor were knocked from their horses, they actually drowned in the mud.

Morning dawns, Harry dresses for battle; he has the pulse of his men; he knows their anxieties and their concerns. He climbs up on a wagon and delivers his famous inspirational speech:

This day is called the feast of Crispian:

He that outlives this day, and comes safe home,  
Will stand a tip-toe when this day is named,  
And rouse him at the name of Crispian.  
He that shall see this day and live old age,  
Will yearly on the vigil feast his neighbours,  
And say 'To-morrow is Saint Crispin's:'  
Then will he strip his sleeve and show his scars.  
And say 'These wounds I had on Crispin's day.'  
Old men forget: yet all shall be forgot,  
But he'll remember with advantages  
What feats he did that day.  
Then shall our names,  
Familiar in their mouths as household words,  
    Harry the king,  
Bedford and Exeter, Hamid and Goswami  
Warwick and Talbot, Simpson and Shah and Rosas  
Salisbury and Gloucester  
Be in their flowing cups freshly remember'd.  
This story shall the good man teach his son;  
And Crispin Crispian shall ne'er go by,  
From this day to the ending of the world,  
But we in it shall be remember'd;  
We few, we happy few, we band of brothers;  
For he to-day that sheds his blood with me  
Shall be my brother; be he ne'er so vile,  
This day shall gentle his condition:  
And gentlemen in England now a-bed  
Shall think themselves accursed they were not here,  
And hold their manhoods cheap whiles any speaks  
That fought with us upon Saint Crispin's day.

There is a scholarly paper called “Ducks, Rabbits, and Henry V”. It uses the famous figure-ground images of gestalt psychology, viewed one way it is a duck, the other a rabbit.



Henry V can be seen as a duck-rabbit depending on your perspective, pro-war, anti-war, Olivier interpretation, Brannagh interpretation, or psychiatric interpretation. Does Henry undergo an amazing transformation when he achieves manhood or is he still the charming rogue, now using power to serve his own purposes?

Shakespeare gives us a lot to consider. When Harry is wandering through the camp disguised, he encounters dissent, his own men questioning the justice of the war.

**KING HENRY V** (in disguise)

Methinks I could not die any where so  
contented as in the king's company; his cause being  
just and his quarrel honourable.

**WILLIAMS**

That's more than we know.

**BATES**

Ay, or more than we should seek after; for we know  
enough, if we know we are the kings subjects: if

his cause be wrong, our obedience to the king wipes  
the crime of it out of us.

**WILLIAMS**

But if the cause be not good,  
the king himself hath a heavy reckoning to make,  
when all those legs and arms and heads,  
chopped off in battle,  
shall join together at the latter day  
and cry all 'We died at such a place;  
some swearing, some crying for a surgeon,  
some upon their wives left poor behind them,  
some upon the debts they owe,  
some upon their children rawly left.

I am afraid there are few die well that die in a battle;  
for how can they charitably dispose of any thing,  
when blood is their argument?

Now, if these men do not die well,

It will be a black matter for the king that led them to it.

Duck? Rabbit?

Obsessive? Hysterical?

Cortex? Amygdala?

Conscious? Unconscious?

Remembered? Forgotten? Or repressed?

Those of us that are privileged to hear people's stories, their confessions as it were, and their worries, have responsibilities to help them understand their experience. We must demonstrate to them that we are not afraid of feelings and can witness their suffering. It is not enough just to medicate their symptoms.

I would like to bring this home by sharing one more scene, this from a recent student oral exam. It is not unlike the stories we hear every day. I think it is worthy of a Shakespearian source.

PATIENT: I got hurt a couple of times in explosions.  
Once I hit my head on the front of the Hummer and blacked out.  
Another time there was an explosion on the left.  
I was knocked to the right and the gunner fell on me.  
I broke a couple of discs. They say I'll have to have surgery.  
They give you some Valium and Percocet and send you out again.  
It was a good time, eating Valium and shooting the hoods off cars.  
Then I get crippling headaches.  
I can't go out and throw a ball with my sons.  
Then I got a negative drug screen. I don't know how it happened.  
You get 900 "Ataboys", and one "Oh Oh" and you're screwed.  
I considered killing myself with my 9mm, but that's no good.  
I've got my boys to think about.  
The smell of burning flesh stays in my mind. I saw an 11 y o girl  
with her back blown off. Her eyes and mouth were open, like  
"What happened?" There's no way to describe the feeling.  
MEDICAL STUDENT (noticing tearing): Can you say what you're  
feeling?  
PATIENT: I don't like to talk about it.  
MEDICAL STUDENT: (Pause) Can you say why it's hard to talk  
about it?  
PATIENT: I feel mad and sad at the same time.  
I seen three of my buddies blown to hell. (Excuse my language.)  
They scrape up the body parts and hand them to you in a plastic  
bag. What are you supposed to do with that?  
I blame the commanding officers. They think they know  
everything, and they don't listen. We should have never been out  
there doing missions without radio contact.  
I start crying and don't know why. I feel sorry for the kids.

You kick in the doors, and they're terrified. You have to do it. You never know who's going to pop at you next. They look at us like we're the most evil things on earth.

I credit the medical student with having the patience to listen to this story. It is human nature to disattend from intense feelings and keep such experiences at a distance. This is actually a hopeful story. An intelligent patient, who is aware of his feelings and able to articulate them. All the drugs he was given didn't dull his empathy. He cared about the children.

Story telling is an art, but equally important is story-listening. It is the art that we cultivate every day. It is the art that gives our patients the courage to feel-- and the courage to be.

## 18. DH Lawrence and the Metaphors of Illness<sup>7</sup>

DH Lawrence makes a remarkably bold assertion about illness: “One is ill because one doesn’t live properly.” (*Women in Love*) It is a comment Birkin makes with such casual indifference that one is tempted to dismiss it as utterly preposterous, yet it is made with such spontaneous confidence that it must be taken seriously. Is it credible? Does it capture something unique about Birkin’s experience of illness? Is it generalizable beyond his particular situation? Does the insight posited by Lawrence’s character transcend the understanding of early 20<sup>th</sup> century medical science? And finally, I would like to ask; can 21<sup>st</sup> century science illuminate this extraordinary claim?

Birkin makes his comment in reflecting on his own unspecified illness. Ursula comes upon him working on a boat. She notices that he looks ill: “He was very thin and hollow, with a ghastly look in his face.”

We are tempted to wonder at his illness. As a physician, I am tempted to try to match symptoms to diagnosis. Thin and hollow and a ghastly look suggest a chronic illness: it could be cancer, but probably a chronic infection. Knowing Lawrence’s preoccupation with tuberculosis, TB could be presented here as emblematic of malaise in general.

Ursula and Birkin’s conversation is telling, and Lawrence draws us into their world, their defiance of each other defying our attempts to maintain a stance of objective observation.

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<sup>7</sup> 11th International DH Lawrence Conference, Nottingham, England, August 18, 2007

“You’ve been ill, haven’t you?” she asked, rather *repulsed*.”  
[Emphasis added]

“Yes’, he replied *coldly*.”

Ursula inquires if the illness has made him frightened.

What of?” he asked. “Whether one is really afraid of death, or not, I have never decided. In one mood, not a bit, in another, very much.”

Ursula presses him, reflecting an attitude that was and is common, but usually unspoken:

“But doesn’t it make you feel ashamed? I think it makes one so ashamed, to be ill—illness is so terribly humiliating, don’t you think?”

“Maybe,” he said. “Though one knows all the time one’s life isn’t really right, at the source. That’s the humiliation. I don’t see that the illness counts so much, after that. One is ill because one doesn’t live properly—can’t. It’s the failure to live that makes one ill, and humiliates one.”

This is really quite a remarkable observation, remarkable in his perception of causality—one is ill *because*—and remarkable in his sense of the power of the individual, an almost grandiose egocentricity, relating his success or failure in life to the state of health. It is also a statement remarkable for its empiricism, a view of reality based on experience.

At one level, Birkin is simply explaining to Ursula, something that usually doesn’t enter conversation. Illness is humiliating, something too shameful to be spoken. Ursula has crossed a social boundary by speaking words and revealing her hidden feelings, disgust. Birkin does not deny this reality; he explains it.

So the Hamlet question in Lawrence, to be or not to be in face of TB, is here given an ontological context. One doesn’t get to choose one’s illness,

but must choose whether or not to talk about it. And if one is to talk about illness, with whom does one talk and how does one have that conversation? Shakespeare's character contemplates non-being in face of a life beyond his control. Lawrence's characters similarly struggle deliberately for self-determination when they are in fact repressed and socially constrained. One doesn't live properly *because* one can't. Freud, writing about the same time, said something similar. In one of his most important papers on psychoanalytic technique, "Remembering, Repeating and Working Thorough" (1915), Freud posited the repetition compulsion, the force that compels us to repeat what we don't remember: *can't remember*. Freud's answer was that we must remember and that we remember by talking about illness in a special kind of conversation, the kind of conversation created in psychoanalysis. In psychoanalysis one is supposed to be able to talk about things too shameful to be spoken in ordinary society, and thereby be liberated from the constraints to make better choices.

Susan Sontag opens her essay, *Illness as Metaphor*, with a fascinating metaphor. She says, "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place." (p.3)

She helpfully draws close to Lawrence by identifying two illnesses in particular as illnesses whose metaphors are particularly unhelpful, tuberculosis and cancer, the latter an illness with which she lived for thirty years before finally succumbing. Of cancer, Sontag says, "Twelve years ago,

when I became a cancer patient, what particularly enraged me—and distracted me from my own terror and despair at my doctors’ gloomy prognosis—was seeing how much the very reputation of this illness added to the suffering of those who have it.” (p 100).

When I became a cancer patient, I too reflected on my experience and my understanding of illness. Notably my first reaction on receiving the diagnosis was the desire to crawl under a rock. My body had betrayed me. I (like most patients) felt as though I had somehow caused my illness. Had I improperly dispensed of anger, as many theories would suggest? Had my mid-life marathoning demanded too much of my body? If given a choice of talking or not talking, my instinct at least initially was to hide and to withdraw from social discourse. Perhaps my salvation was that for a professor who has made his life talking about illness, there is no place to hide.

Sontag later writes about AIDS as another illness whose metaphors of causality draw us into the shame-blame-humiliation dynamics Lawrence called to our attention. Similarly neurosis (once called neurasthenia), the whole realm of psychosomatic medicine, headaches, back pain, alcoholism, even depression, Post-Traumatic Stress Disorder, accident proneness, and many others, all swirl in a vortex of metaphors and causality, which complicate Sontag’s claim that “Illness [physical illness] is not a metaphor, and that the most truthful way of regarding illness-and the healthiest way of being ill-is one most purified of, most resistant to, metaphoric thinking.”

Just last week one of my patients said something remarkably similar. In her free associations she observed, “I feel ashamed about being depressed. Being sick is our own fault. It’s even worse to talk about it. There’s

something taboo about talking—almost like you weren't supposed to get sick. It's not just mental illness, it's anything, and I don't understand where that idea comes from.”

Anthropologists have attempted binary distinctions between illness (what patients experience) and disease (patho-physiological abnormalities). But these distinctions don't hold up in face of the complex bio-psycho-social realities in which patients in families in communities experience their distress.

The question, which both scientist and artist tackle, is the extent to which the individual patient can be responsible for his or her own illness. It is a slightly different question than “Should be patient be blamed for his illness?” or even “Did the patient cause the illness?” or “Could the patient have avoided the illness by living better, more successfully?” Or does society cause the illness? Or does one just passively fall ill (or pregnant), like rain falls from the sky?

Obviously this a complex but important nest of questions, and a branch of science has evolved to deal with such complexities. It is called “complexity science”. It is a significant development because it challenges the oh-so-successful—but incomplete –science it replaces, namely the reductionistic science that believed that illness could be reduced to a single cause. Reductionistic science, the old biomedical model, doesn't explain such subtleties because it doesn't live successfully—can't. In its view, tuberculosis is caused by the tubercle bacillus, and AIDS is caused by the HIV virus. What more do we need to know?

Actually we need to know a great deal more. We need to know, for example, why not everyone who is exposed to infectious agents becomes

sick. We need to know why in a world full of carcinogens not everyone gets cancer. We need to know why some people respond to treatment and get better and some do not.

I will state my answers to these questions, and then suggest several lines of “evidence” that may support the hypotheses. I believe that in the early years of the twenty-first century we now are better able to understand the observations of early twentieth century writers like Lawrence and Freud.

My first conclusion is this: a modern understanding of the immune system helps us understand the balance of health and illness as an array of forces both internal and external to the organism, which in aggregate may tip the balance toward wellness or toward disease. The branch of complexity science that deals with these interrelationships of the mind, body, and external environment is descriptively named psycho-neuro-immunology (PNI). It may turn out not just to be a twig of the branch of medicine called complexity science, but one of the roots or even the trunk.

My second conclusion is perhaps more controversial. I believe that illnesses do not occur to individuals; they occur to communities. The success or failure of living that relates to illness is not the fault or credit of a particular individual, but of the communities that individual inhabits.

So far I have focused on the views of one author, Lawrence, in one book, *Women in Love*, in one conversation, in fact, one important word, “can’t”. The methodology that I think this leads us to might be called a narrative epistemology, the evidence coming from the story, from the context and from the relationships. So I will try to suggest some relationships that I hope will make this hypothesis (the social determinants of health hypothesis) compelling. I will do so by sketching several stories,

which taken together should make Lawrence's observation more plausible.

In the early days of the AIDS epidemic in the United States in the early 1980's three groups were most affected: male homosexuals, IV drug users, and hemophiliacs, who required frequent blood transfusions. This epidemiology inevitably invited its own metaphors, often blaming the victims for causing their own illnesses. But surely the hemophiliac children were innocent victims. One family had five sons, all with hemophilia, all of whom developed HIV/AIDS. The oldest son was speaking about his illness at his church and was asked, "Do you feel you are being tested?" The prejudice reflected in this question is an old one. People suffer because they deserve to. In the Biblical story of Job, Job's friends assume that he has done something bad for which he was being punished. Many people might be angered or embarrassed by such a pointed (and ignorant) question. This boy answered with a calm equanimity: "Perhaps the congregation is being tested."

All five of those boys subsequently died, as did most hemophiliacs of that generation. One who survived was a medical school classmate of mine, who recognized early on, what public health officials were slow to recognize, that there was something transmitted in the blood supply. He asked friends whom he trusted to donate blood that would be put aside for his transfusions. None of our local hospitals would cooperate with this scheme, so it was necessary to drive to a neighboring city every few weeks to donate blood.

These two stories taken together say something important about "community". The assumptions of the first community were prejudicial, a

pre-judgment of those with the illness. The second community was able to respond with more practical support. While the HIV/AIDS epidemic has been devastating on communities, communities have an important role to play in battling the disease and its multiple impacts.

In face of a humanitarian crisis, such as an epidemic, a natural disaster, or a man-made disaster, it is important to get the moral tone right. This is perhaps the most difficult level of complexity that confronts us. So it is not surprising that Sontag would turn to AIDS, an illness unprecedented in its textured metaphors: the new plague, a scourge. And in the case of the African epidemic, we add the metaphors of colonialism, primitivism, tribalism, and the Dark Continent. One is ill because one doesn't live well—can't. I was particularly interested last year to be invited to a conference in Johannesburg on the Role of Communities in HIV/AIDS, which specifically requested papers on PNI (Psycho-neuro-immunology). As I prepared my remarks I worried—and my medical students challenged me—that suggesting it might be important to attend to psycho-social concerns might undermine efforts to provide anti-retroviral therapies. But when I got to South Africa (and especially Botswana, which has the highest HIV incidence in the world, nearly 40%), it all made sense in an African context. It was not at all about biological fatalism or waiting for the West. It was about colonialism and tribalism and community. It was about taking care of oneself, nutrition, knowing one's HIV status and valuing it, empowerment of women, reproductive self-determination, AIDS orphans and how to care for them, coming together as communities and talking about what is going on, and planning for the future. It was more about hope than despair. We could say it was about creating new metaphors.

There are several lines of “evidence” I can only mention in passing.

Time does not permit elaborating the biochemistry of the immune system except to note it. I should also mention an important and compelling body of research, which does statistically analyze large populations, Robert Putnam’s *Bowling Alone* thesis, in which he analyzes something he calls “social capital,” the extent to which communities respond to the needs of their members. He compares all of the United States and subsequent research in industrialized nations, United Kingdom, Germany, Japan, and Australia, confirm his findings that none of us do as well as we used to, but individuals fare better in terms of health, education, life expectancy, and social well being in communities that organize to support individuals.

Social capital operates through psychological and biological processes to improve individuals’ lives.

People whose lives are rich in social capital cope better with traumas and fight illness more effectively.

Notable in my experience was the Indian response to the tsunami of Dec, 2004, in which government and NGO teams responded immediately (within 24 hours) to the needs of communities with not only physical relief but also psycho-social training programs. This contrasts starkly with Hurricane Katrina, which hit the US Gulf Coast the following year, for which there has yet to be an organized relief response!

Let me offer some historical and literary examples, which are equally compelling, perhaps more so because of the candor of their un-theoretical descriptions. Twenty-five hundred years ago, Thucydides observed that at the time of the Peloponnesian Wars, citizens of Athens were suddenly overcome by an outbreak of what he called and we would call, *The Plague*:

“As for what is called honour, no one showed himself willing to abide by its laws, so doubtful was it whether one would survive to enjoy the name for it . . . No fear of god or law of man had a restraining influence. As for the gods, it seemed not to matter whether one worshipped them or not, when one saw the good and the bad dying indiscriminately. As for offenses against human law, no one expected to live long enough to be brought to trial and punished.” (p 135) Our modern theories help us appreciate that war is a time of stress accompanied by immunological vulnerabilities, and we are now prepared to recognize Post-Traumatic Stress Disorders in veterans of these wars. Where Lawrence saw a malaise in the Great War, and Thucydides saw the coincidence (if not causality) of war, plague, and the breakdown of the social order with lawlessness, hedonism, and fatalism, we may attentive to similar comparisons in our current Not-So-Great War.

What impressed me most—medically and socially-- on a recent lecture trip to Iraq (Kurdistan) was the extent to which civilians (as well as the military) are suffering from PTSD or what I think would better be called OTSD (On-going Traumatic Stress Disorder). A famous Viennese psychiatrist (not Sigmund Freud) observed that everyone in Iraq is depressed. My observations were that nearly everyone was stressed with psychosomatic manifestations: headaches, gastrointestinal disturbances, dermatological conditions, heart symptoms, and premature cardiac death.

In many ways our current epidemics are much like the plague of the European Middle Ages. I am speaking metaphorically, of course, to be very mindful of how easily we slip into metaphor, using the symbol to stand for a reality which perhaps we would prefer not to look at too exactly: Old Plague as analogy of New Plague. The very magnitude of both plagues

initially overwhelmed creative and reasoned approaches to dealing with them and cast a shadows of fear and devastation. Boccaccio describes in his *Decameron* the situation when the plague hit Florence in the 1300s. People died in droves, and those who were well enough fled the city. The situation he describes for the sufferers was one of “lack of due attendance to the sick”. They were abandoned. No one attended to them. No one fed them or provided water. Most died in a matter of days, the natural course of dehydration and starvation even without infection. We could say that their community failed them; they lacked sufficient social capital, even that they lacked love. Fear overcame care.

By contrast Daniel DeFoe describes conditions of the Plague Year in London (1664-65). Still before the germ theory was well understood, doctors established a “plague house” where people were cared for humanely, with proper attention to their needs, adequate nutrition, and reasonable cleanliness. While tens of thousands died in London that year, no one died in the plague house.

We may pride ourselves that our current state of knowledge is so far advanced scientifically that we now have tools to battle our current plagues, but biological responses, the moral imperative of the international community, are by themselves not enough. The metaphors belie the reality. The social response in the twentieth century has been much like that in the thirteenth and seventeenth—denial and running away. And therein lies both the challenge—and the opportunity. Only by facing the truth unadorned by metaphor, can we make a different response.

## 19. Call Me Ishmael

I

Call me Ishmael.

You know my story.

I am the son of Abraham and his servant, Hagar.

I am the first-born son. But when late in life Abraham and Sarah had a son, Isaac, my mother and I were sent away.

You might think with your modern minds that I would be resentful. With your Freudian notions of the unconscious mind, you might think that I harbor jealousies that I am not aware of. But if you think that, you are forgetting that I too received the blessing of the Lord, and so did all my people.

It is said that history is not just a leap in time; it is a whole different world. I sometimes wonder if you in far off centuries can imagine the lives we led more than 4000 years ago, when gods spoke to us directly, and the one true god, Allah, spoke directly to my father, Ibrahim.

I know it has become fashionable to speak of Abraham as the father of three faiths. In your time when religion tends more to divide people than unite us, it is useful to remember that we have a common ancestry. Muslims, Jews and Christians have a common heritage, a common belief in the same god though called by different names. Jews and Christians claim decent from my half-brother, Isaac, and perhaps think themselves special because of his favored status, but I sometimes wonder if too much is made of the promise of land and being “a chosen people” rather than the

specialness of the relationship with God. Land, the mundane, the material. Has worldly preoccupation blinded future generations to what is truly precious, what is spiritual?

The Hebrew Bible, the Old Testament, tells of God's covenant with Abraham as a reward for Abraham's obedience. His faith was tested. In the account in Genesis (Chapter 22), God spoke Abraham's name and said to him, "Take your son, your only son Isaac, whom you love, and go to the land of Moriah, and offer him there as a burnt offering upon one of the mountains of which I shall tell you." And Abraham did as he was instructed, and when they came to the mountain, Isaac spoke to his father, and said, "Behold, the fire and the wood; but where is the lamb for a burnt offering?" (22:7) And Abraham said, "God will provide himself the lamb for a burnt offering, my son."

Abraham took, his son, Isaac, to the mountain, and he built the altar and laid out the wood, and he bound Isaac his son and laid him upon the altar, upon the wood, and took the knife to slay his son.

But just then the voices returned, an Angel of the Lord, "Abraham, Abraham." And he said, "Here am I." The angel said, "Do not lay your hand on the lad; for now I know that you fear God, seeing you have not withheld your son, your only son, from me."

Muslims tell this story slightly differently. The will of Allah is made known to Ibrahim in a series of dreams. Allah tells him to sacrifice that which is most precious to him. First he slaughters a lamb. The dream recurs. Then he slaughters a camel. The dream recurs. "Sacrifice that which is most precious to you." Then he realizes that Isaac is what is most precious to him.

So at this time of the year when Christians celebrate the birth of Jesus, Jews celebrate the defeat of the Macabees with Chanukah, Muslims celebrate Eid-al Adha, the festival of sacrifice in which is understood that animals may be sacrificed (not wantonly slaughtered) only if the name of Allah is spoken at the time of the sacrifice.

## II

Call me Ishmael.

This, one of the most famous lines in literature, opens Herman Melville's novel, *Moby Dick*. His story helps us understand our own:

Call me Ishmael. Some years ago - never mind how long precisely - having little or no money in my purse, and nothing particular to interest me on shore, I thought I would sail about a little and see the watery part of the world . . . . Whenever I find myself growing grim about the mouth; whenever it is a damp, drizzly November in my soul; whenever I find myself involuntarily pausing before coffin warehouses, and bringing up the rear of every funeral I meet; and especially whenever my hypos get such an upper hand of me, that it requires a strong moral principle to prevent me from deliberately stepping into the street, and methodically knocking people's hats off - then, I account it high time to get to sea as soon as I can. This is my substitute for pistol and ball. With a philosophical flourish Cato throws himself upon his sword; I quietly take to the ship.

Should you ever be athirst in the great American desert, try this experiment . . . Yes, as every one knows, meditation and water are wedded forever.

. . . When I go to sea, I go as a simple sailor, right before the mast,

True, they rather order me about some, and make me jump from spar to spar, like a grasshopper in a May meadow. And at first, this sort of thing is unpleasant enough. It touches one's sense of honor ...

And, doubtless, my going on this whaling voyage, formed part of the grand programme of Providence that was drawn up a long time ago. It came in as a sort of brief interlude and solo between more extensive performances. I take it that this part of the bill must have run something like this:

**Grand Contested Election for the Presidency of the United States**

**Whaling Voyage by one Ishmael**

**BLOODY BATTLE IN AFFGHANISTAN**

(Remember Moby Dick was published in 1851, not 2001.)

Though I cannot tell why it was exactly that those stage managers, the Fates, put me down for this shabby part of a whaling voyage, when others were set down for magnificent parts in high tragedies, and short and easy parts in genteel comedies, and jolly parts in farces.

Chief among these motives was the overwhelming idea of the great whale himself. Such a portentous and mysterious monster roused all my curiosity. Then the wild and distant seas where he rolled his island bulk; the undeliverable, nameless perils of the whale; these, with all the attending marvels of a thousand Patagonian sights and sounds, helped to sway me to my wish. With other men, perhaps, such things would not have been inducements; but as for me, I am tormented with an everlasting itch for things remote. I love to sail forbidden seas, and land on

barbarous coasts. Not ignoring what is good, I am quick to perceive a horror, and could still be social with it - would they let me - since it is but well to be on friendly terms with all the inmates of the place one lodges in.

By reason of these things, then, the whaling voyage was welcome; the great flood-gates of the wonder-world swung open, and in the wild conceits that swayed me to my purpose, two and two there floated into my inmost soul, endless processions of the whale, and, mid most of them all, one grand hooded phantom, like a snow hill in the air, the leviathan, the great white whale, Moby Dick.

The first chapter of Melville's book is called "Loomings". Looking back, it seems astonishingly prescient. Melville invites us to consider many metaphors: the journey in search of the soul, life as an odyssey, fatalism in face of forces we cannot control, the geographical cure for depression, the struggle between good and evil, the paradoxical contradictions of the Christian faith, the monomaniacal chief executive, commander-in-chief, pursuing his obsession without consideration of consequence, the Pequod as ship of state, the American ship of state, destroyed in the end by hubris, pride, narcissism, a watery grave in lieu of the thirsty and unfulfilling American desert, the flag being the last thing to sink.

**Grand Contested Election for the Presidency of the United States**  
**Whaling Voyage by one Ishmael**  
**BLOODY BATTLE IN AFGHANISTAN**

But I suspect Melville's purposes were not to predict the future, but to see

present conflicts as metaphor for larger human struggles, the great themes that we must work to understand and master.

### III

Call me Ishmael. As the name has come down to us, helped along by Melville's sea story, it has come to connote orphans, exiles, and social outcasts. It has come to be associated with wonderers who travel the globe to seek understanding. While Melville's Ishmael went to sea out of a feeling of alienation from human society, he also went *to see* in a visual and a metaphorical sense. He traveled to better understand. His salvation was his willingness to look at things others preferred not to see. He alone lived to tell the story. His lifeboat was a coffin. His obsession with death was ironically his salvation.

I have come to believe that the new millennium makes new demands for global understanding. I have come to believe that 180 nation-states pursuing their own interests like ships cast on the sea or islands onto themselves are obsolete. I believe we are called to be citizens of the world and stewards of the planet.

So when I received an e-mail last spring inviting me to go to Iraq to deliver a series of medical lectures, I hesitated about five minutes before deciding to accept the invitation. Several of us at ETSU had been working with Kurdish colleagues in northern Iraq to help develop a medical infrastructure. We have made many wonderful friends there, many of whom have visited us in Tennessee, and several of my colleagues had already traveled to northern Iraq, Iraqi Kurdistan. I was aware of the security issues

and concerned, of course, but also aware that security was very tight in Kurdistan. What was I going to say, “Sorry about your war; I’ll stay home?”

Iraq, what shall we call this place with its 1917 artificial boundaries, never really a state, a nation in any coherent sense? Northern Iraq, home of the Kurds, whom we know from the Bible as Meeds, the worlds largest nation without a state, Iraqi Kurdistan, a name that doesn’t satisfy everyone. Let’s call it Mesopotamia to locate the story I want to tell, that land between the Tigris and Euphrates rivers, cradle of the worlds oldest civilizations, its great religions.

Kurdistan is home to many Ishmaels. With its impressive security and its own regional government, Kurdistan has become a refuge to Iraqi Sunnis and Shi’ia, displaced Palestinians and Lebanese, Asian guest workers. It is where you will today find new skyscrapers, a Nas Daq [sic.] stock exchange, medical schools and universities. If you were a General Motors dealer from Singapore, as one man I met, Kurdistan is the likely the place in Iraq where you would find a ready market for Cadillacs.

In one sense the medical education program that I delivered with four Iraqi-British colleagues from the Royal College of Psychiatry (UK) was far from war. But in another sense it was not far from war. Everyone I met had been affected in some profound way by the ravages that have befallen that place.

One psychiatrist I met had lost her brother. He was murdered. No one knows by whom or why. Having professional skills, she was able to move her family to the north.

Another professional family, a professor and a dentist and their

children, had been forced to abandon the family's beautiful house in Baghdad upon threat of death. It was near a highway. They sometimes found body parts from the explosions. An arm in the garden; a spine on the roof. Their daughter had seen a schoolmate kidnapped. One night American soldiers shot off the locks and burst into the house. The children thought it was a dream, the soldiers faces horrifically painted with grease paint – like ghosts. When they realized it wasn't a dream, they were unable to sleep.

A Swedish couple, working for a Swiss NGO (Non-government organization), were kidnapped and held hostage. They lived for three days expecting to die before the community they were helping arranged for their release. They moved to the north, but life never returned to normal.

These people all suffered from PTSD, post-traumatic stress disorder, but it was an on-going stress, which inspires me to make up a new word for this phenomenon, OTSD, On-going Traumatic Stress Disorder, not just psychological symptoms, dreams, flashbacks, but psychophysiological correlates: high blood pressure, headaches, metabolic disturbances, skin rashes, and premature cardiac death, and greatly increased susceptibility to cancer.

The dominant image of my trip, which inspires these musings, occurred while visiting the Erbil citadel, also mentioned in the Bible. It is between 7000 and 8000 years old, according to the United Nations World Heritage website, continuously inhabited for over 7 millennia. It has seen a lot of history. The citadel, which covers about 20 acres, rises 30 meters, a hundred feet, above the Mesopotamian plane. Standing there with my Muslim colleagues, we realized that it had been there where we were

standing at the time of Moses and Abraham. Abraham may well have slept there. Alexander the Great defeated the Persian king Darius just outside its walls. Genghis Kahn did not succeed in conquering this Citadel, though he did capture Baghdad; it was one of twenty-one times Baghdad was invaded.

#### IV

Several years ago I became interested in what life might have been like 5000 years ago. History is not just a leap in time; it is a different world. My brother-in-law found a spear point on our family property in Maine, which archeologists estimated to be about 5000 years old. Several years before that a fish weir had been discovered in a stream that fed the lake. The wood of that fish-weir was carbon-dated at 5000 years old. One imagines that the spear point might have been used for spearing fish or perhaps for hunting game.

At a time when the pyramids were being built in Egypt and ziggurats in Mesopotamia, Native Americans were bundling in furs to keep warm through the long Nordic winters. Also social organization was changing from largely nomadic families and bands to organized tribes and villages. Hunter-gatherer societies were being replaced by agricultural and urban social organizations.

Also these more complex societies demanded new forms of religious organization. The gods rarely spoke directly to men. Religious life was organized around rituals, texts, and community life, supplanting the more individual relationships with the gods of the previous era.

Princeton psychologist Julian Jaynes sees the origin of individual consciousness (the awareness of self) in the breakdown of the bicameral

mind, the two part mind in which one part processed sensations from the environment, the other part processed the inner voices. We have come to see as either the voices of gods, angels, oracles, and demons on the one hand or possibly the raging of lunatics on the other. In our own time, people who have these hallucinatory experiences are marginalized as ill. In the time of Moses and Abraham and Hammurabi, such men were revered. The Trojan warriors Homer describes in the Iliad did not debate the merits of war, they were pushed around like pawns in a chess match by voices from above.

The other thing that happened about five thousand years ago was the beginning of constant warfare in every generation. Being in ancient Mesopotamia at a time of war in Iraq was for me a time of perplexity and wonderment. It makes me wonder if the new consciousness that Professor Jaynes speaks about is breaking down the way the way the bicameral mind once broke down. The old new consciousness I am thinking of is a consciousness of individualism and nationalism. It is an awareness of self that pursues self-interest and national interest. The awareness of the self and self-interest has served us well in many ways, but it also tends to divide us one from another and be too aware – too conscious -- of those who are different, the Others.

Perhaps the strife of our current situation will inspire a new New Consciousness in which we will come to appreciate our common threats, the vulnerability of the social order and the vulnerability of the environment. Perhaps the new New Consciousness will help us to get beyond self-awareness and national identities and to become more aware of humanity's common concerns and our common needs.

## 20. Let's Talk About the Elephant in the Sitting Room – The War in Iraq as a Mental Health Issue<sup>8</sup>

To set aside the sympathy we extend to others beset by war and murderous politics for a reflection on how our privileges are located on the same map as their suffering, and may—in ways we might prefer not to imagine—be linked to their suffering, as the wealth of some might imply the destitution of others, is a task for which the painful stirring images supply only an initial spark.

Susan Sontag, *Regarding the Pain of Others*

“In war, the first casualty is the truth”  
Aeschylus, 5<sup>th</sup> century BCE

War is often cast as a moral struggle, two opposing sides, Us versus Them, Good versus Evil. In the words of Carl von Clausewitz, the famous Prussian general and student of warfare --who gave us perhaps the most

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<sup>8</sup> This chapter brings together work with Iraqi physicians, mental health professionals, and Ministry of Health officials between 2001 and 2011, which included for me nine trips to Iraqi, Erbil, Baghdad, Basra, Sulymaniah, between 2007 and 2010 for Continuing Medical Education/Continuing Professional Development programs, as well as consultations with the Minister of Health and other MOH officials, and workshops on development of professional standards. The work was supported by the United States Department of State, the Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA) and the Iraq Ministry of Health, and the Royal College of Psychiatrists (UK). Curricula were developed by US, UK and Iraqi faculty to meet needs identified by Iraqi hosts. The section on “tolerance and reconciliation” was first presented at the SAMHSA Conference on Trauma and Behavioral Health Services: Lessons from the Iraq Experience” in Gaithersburg, MD, July 15, 2008 and subsequently at the Iraqi Mental Health Forum-UK Royal College of Psychiatrists, Leicester, England, November 15, 2008 and at the Iraq Cultural Center, Washington, DC, September 18, 2010. The sections on on-going trauma, stress and resilience have been presented at the XX World Congress of Social Psychiatry, Marrakech, Morocco, October 26, 2010 and at the World Psychiatric Association, Istanbul, Turkey, June 11, 2011 and published in the textbook chapter, “Global Disasters, War, Conflict, and Complex Emergencies” by Allen R. Dyer and Subhasis Bhadra in E. Sorel, ed., *21st Century Global Mental Health* (Jones and Barlett, 2012).

accepted definition of war as “the extension of policy by other means”-- “military action is never directed against material force alone: it is always aimed simultaneously at the moral forces which give it life, and the two cannot be separated.” (Clausewitz, 1984: p. 137) Whatever moral forces give rise to conflict, the effect is disastrous on ordinary people, soldier or civilian, caught in the crossfire.

My first trip to Iraq was the most memorable. What I remember about the first trip was the stunning contrasts and the urgency everyone was feeling in 2007 about how to turn the corner and bring a resolution to a country at war, which at that time felt very much like Humpty Dumpty. Over the ensuing years travelling to Iraq became more of a routine, giving medical lectures, setting up conferences, health planning, diplomacy through health and normalizing civic institutions, punctuated occasionally by security disruptions, random bombs, and the telltales signs of war, checkpoints, quiet meals with friends behind concrete blast walls, sleeping behind machine guns.

My first trip to Iraq was to Erbil, Kurdistan, one of the world’s ancient cities, its ancient Citadel continuously inhabited continuously for over 7000 years. It seemed far from war, far from the war raging in the south of Iraq, nestled at the foot of beautiful mountains. You could walk the streets of Erbil without a bodyguard, visit parks, shop the ancient souks. But war was every present, a daily feature of life in Iraq even in this relatively peaceful corner of the country. Many of the people I met had been displaced by the conflict, professionals, doctors, professors, teachers, families whose skills enabled them to find new jobs, and whose stories they were eager to entrust to the first American they met who had ventured to what was left of their

country.

“We are so glad you have come. Let us tell you what we have been through.”

“Let me tell you what it was like to be kidnapped and held hostage. We didn’t know if we would live. The villagers we had been working with saved us.”

“My brother was murdered. No one knows who did it or why.”

“We abandoned our beautiful house in Baghdad. They said we were cooperating with the Americans because we speak English.”

“One night the soldiers burst into the house. Their faces were painted. The children thought they were dreaming. What they realized it was real, after that they couldn’t sleep.”

All of the stories had an additional element, which interested me as a physician. Everyone had health problems, which they associated with chronic stress and uncertainty. People reported headaches, sleeplessness, eating difficulties, gastrointestinal problems, dermatologic rashes, sleeplessness, cardiac difficulties, heart attacks, and epidemiologically there were extraordinary numbers of premature cardiac deaths and vastly increased incidence of cancer.

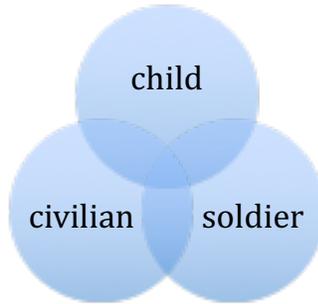
Yet another of the striking contrasts was how well people were doing nonetheless. How resilient in face of disaster. Strong family ties, strong religious faith, provided mitigating factors in face of adversity. Though many people were clearly experiencing PTSD, Post-traumatic Stress Disorder, characterized by recurrent intrusive memories, nightmares flashbacks, understood as the response to an overwhelming event, many

people did not. Some even joked that they became habituated to the violence. What I noticed was that people were suffering from a variety of health problems, which they recognized were related to the stress they were experiencing.

### **Iraq Population Profile**

- Extraordinary stress x 30 years
- Incredible resilience
- Decreased life expectancy
- Increased infant mortality
- Resurgence of tuberculosis
- Higher than expected incidence of cancer (7-8 times world rates)
- Higher incidence heart disease, diabetes, etc.
- High rates of depression, other psychiatric disorders, and substance use disorders

PTSD has been much studied in veterans of the Vietnam War, and its much better understood since its introduction into the diagnostic nomenclature in 1987. Once it was officially recognized as a diagnostic entity, similar symptoms were recognized in people who had suffered traumatic experiences (abuse) in childhood. Of course civilians in a war zone also experienced traumatic events, but the stories I was being told suggested that it was not so much isolated events that was traumatic, but the ongoing stress, which impacted the body, the whole person, with a variety of symptoms, evident as somatic symptoms, but clearly the effect of stress over time.



This suggested that perhaps the nomenclature was inadequate: For all that the “Post” in PTSD represented psychological symptoms after a traumatic event, what I was seeing were somatic symptoms as a result of on-going stress. Perhaps there was another disorder with an “O” for On-going Traumatic Stress:

<b>PTSD</b> <b>Post-traumatic Stress Disorder</b>	<b>OTSD</b> <b>Ongoing Traumatic Stress Disorder</b>	<b>Complex PTSD</b> <b>(after Judith Herman)</b>
A:Stressor (experienced or witnessed) Reaction of fear, helplessness or horror  B: Anxiety  C: Dissociation  D: Hyper-arousal  E: Nightmares  F: Flashbacks	Stress endures in time  Person experiences psychological symptoms plus  Physiological correlates  Changes in vital signs: temp, BP, heart rate, respiratory rate, pain  Endocrine/Metabolic changes  Difficulty maintaining internal milieu	<ul style="list-style-type: none"> <li>• Severe relationship impairments</li> <li>• Disturbances of mood regulation (e.g. outbursts of anger)</li> </ul>

Perhaps even “disorder” is a misnomer. Work with natural disasters has taught us that grief reactions and stress reactions are not pathological. They are *normal reactions to an abnormal situation*. The soldier coming home from war is not “disordered”; he or she might better be described as “injured”. The person who experienced traumatic abuse as a child is not “disordered”, better described as “injured”. Similarly individuals in conflict zones, who have suffered from displacement and disruption of support systems, are not so much in need to “treatment” as they are of restoration of normal conditions, the ability to live in security, in pursuit of livelihood, and family and community activities.

In 2007 there were fewer than 100 psychiatrists in Iraq for a country of 29 million people. Their efforts were largely focused on the seriously mentally ill in large hospitals. With growing recognition of the mental health needs of the broader population and increased attention to community service models such as integration of mental health into primary care, more medical students began to be attracted to psychiatry training, and psychiatrist began to develop community based care working in multi-disciplinary teams. The curricula that my colleagues and I developed were targeted to needs that our Iraqi hosts identified.

One program in particular focused mental health concerns in the context of broader socio-political events. I was asked to address the issue of “tolerance” from a mental health and ethical point of view. The challenge was clear: how can groups who once lived in harmony, then pitted against each other by forces beyond their control, learn to live side by side again? Alas the question was as old as time, but fortunately there were some models that were worthy of consideration: models of restorative justice that

attempted to get beyond justice as punishment and retribution. Also there were efforts at “truth and reconciliation”, processes in which communities came to acknowledge wrongdoing in very personal ways.

“Tolerance” is a very broad concept with psychological, biological, spiritual, social and political dimensions. Basically tolerance implies the ability to endure or put up with pain or hardship. More specifically tolerance implies the willingness to allow the existence of opinions or behavior that one does not necessarily agree with. Tolerance in this sense is related to justice, which is at once a political/legal concept and a moral concept. An individual person’s identity is linked to a sense of what is fair and right, concepts which are inculcated in development in a family in a community in a group. Justice is at once a guiding norm for individual behavior and a way of judging the fairness of civic institutions.

A number of notable historical examples of overcoming intolerance demonstrate the complexities of this process, acknowledge of truth and reconciliation of aggrieved parties.

First, the end of apartheid in South Africa. Apartheid was the official policy of the South African government from the time the Nationalist party gained control in 1948 until the agreement of Government of National Unity in 1993. In 1994, Nelson Mandela was elected president, and in 1995 a Truth and Reconciliation Commission was established to address the reparation of the victims of apartheid.

Second, the Rwandan genocide of 1994 in which over a million people were killed in 100 days. The number of perpetrators of violence, *génocidaires*, was beyond the capacity of the judicial system to handle and community based, *gacaca* “courts” (based on the ancient 100 people on a

lawn traditions) were established to deal with those who were willing to acknowledge their deeds and ask for clemency.

Beyond these dramatic national examples, some smaller examples suggest the dynamics of the process. The first application of truth and reconciliation models in the United States was the Greensboro Commission, which addressed the so-called “Greensboro Massacre” which occurred in North Carolina in 1979, which a demonstration against the Ku Klux Klan turned violent and several people were shot and injured or killed. The commission was designed to examine and learn from a divisive event in Greensboro’s past in order to build the foundation for a more racially unified future. It acknowledged that the rhetoric used by a group that called itself the Communist Workers Party was constitutionally protected speech, but that the CWP embraced inflammatory language and identified with violent symbols. “Death to the Klan” was an unfortunate slogan for the parade. Although most have expressed regret for this language, survivors have argued that such language was common at the time and was intended to threaten an institution and ideology, rather than individuals, but such nuance was likely lost on Klan members.

Canada has employed a process of restorative justice to acknowledge and make reparations to indigenous school children, who had been forced to relocate to isolated Arctic islands. Similarly restorative justice has been used in schools to deal with disciplinary problems, where punishment is often impersonal and ineffective. A community in Pennsylvania employed a process of restorative justice for a group of students who accidentally burned a historic wooden covered bridge during a graduation party. Judicial punishment was felt to be too harsh and impersonal when the real goal for

the community was to make sure the students understood why their behavior was so serious and what it meant to the community.

The process of reconciliation is in essence a community witnessing of the “story” of what happened. It involves separately the preparation of the victim or victims, a rehearsal of their story, the preparation of the offender or offenders, a rehearsal of the acknowledgment, and the “meeting” or “circle” or “conference” where they come together. At once this is a judicial process, a political process and a form of psychotherapy.

<b>Criminal justice</b>	<b>Restorative justice</b>
Crime is a violation of the law and the state	Crime is a violation of people and relationships
Violations create guilt	Violations create obligations
Justice requires the state to establish blame and impose punishment	Victims, offenders, and community work to put things right
Offenders get what they deserve	Focus on victim needs and offender responsibility

Beyond punishment, the deeper psychological questions of what to do about anger and what is the role of forgiveness need to be appreciated. Again, mundane examples inform the larger questions. A customer feels that an auto mechanic has overcharged him. His religious principles suggest that he should forgive the mechanic. Should the mechanic be forgiven? Should he be confronted? What should the customer do about his anger? In situations such as this, many people are tempted to overreact or to under react. Anger can be corrosive and damaging to the self. But without

confrontation there can be no acknowledgment and no resolution, certainly no reconciliation.

Forgiveness means to stop feeling angry or resentful for an offense. One cannot forget without remembering and acknowledging. Forgiveness involves a sense of felt unity with one who has hurt us. The Other needs to be recognized as a different person before there can be a health sense of unity. Forgiveness is often seen as an important part of healing, of therapy, but as the following case illustrates it cannot be a unilateral activity.

“John” reports he was molested while growing up by his paternal uncle. When he learns that another young man of his generation was molested by this uncle, he decides to talk to his parents about this. He hopes they will express regret over what he went through and that they will help limit this uncle’s access to other children. Instead, John’s parents encourage him to put the past behind him and forgive his uncle. They refuse to discuss the matter further and continue to invite the uncle to family functions. When John continues to try to talk about his uncle, his parents question why he is making so much trouble and suggest that if he were a good Christian, he would forgive his uncle.

John thinks a lot about forgiveness. Most of the time John does not want to forgive his uncle. He is angry and he is hurt. His uncles has not even admitted what he has done, let alone apologized. But sometimes he begins to doubt himself. At these times, John becomes even more despairing and suicidal.

“Must I forgive my brother’s murder?” I was asked. Does it matter if the murder doesn’t want to be forgiven? What sort of atonement might be possible? Are the interests of the state to not tolerate violence different from

victims and victims’ families? There are basically three questions that distinguish the approach of criminal justice from restorative justice.

Physicians have long recognized the close relationship between stress and illness (what we have come to call “physical” illness). Indeed ancient yogi masters appreciated the importance of inner harmony and balance in life in coping with adversity. In one of the earliest studies of the health and mental health impact of disaster, Lindemann studied the survivors and families of those who perished in the Coconut Grove nightclub fire in Boston in 1943. He found notably that people did better if they talked about their experiences, but most did not require long-term therapy. Significantly he found that many experienced somatic symptoms, headaches and gastrointestinal disturbances in particular. In the 1960s Holmes and Rahe developed a scale of life change events (positive as well as negative changes) and found that the more life change events, such as moving to a new city, getting a parking ticket, getting a promotion, or loss of a loved one), the more likely one was to acquire a physical illness.

One of the most compelling demonstrations of the impact of traumatic experiences – or adverse experiences—on health (outcomes) is the famous

<b>Criminal justice</b>	<b>Restorative justice</b>
What laws have been broken?	Who has been hurt?
Who did it?	What are their needs?
What do they deserve?	Whose obligations are these?

ACE (Adverse Childhood Experiences) study (Felitti, et al., 1998). Significant is the direct, rigorous, graded correlation of adverse childhood experiences (such as psychological, physical or sexual abuse, violence against mother, or living with household members who were alcohol and/or substance abusers, someone who is chronically depressed, mentally ill, institutionalized or suicidal, mentally ill or suicidal, or even imprisoned, having only one or no parents, and emotional or physical neglect) with (physical) symptoms and illnesses, leading causes of death including ischemic heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease. Perhaps even more important is the intermediate association with a number of maladaptive attempts to cope with the trauma including increased health risks for alcoholism, drug abuse, depression, and suicide attempts, 2-4 fold increase in smoking, poor self-rated health, sexual grazing (>50 sexual partners) and sexually transmitted disease, and increase in

Adverse Childhood Experience* Categories (Birth to 18)	Impact of Trauma and Health Risk Behaviors to Ease the Pain	Long-Term Consequences of Unaddressed Trauma (ACEs)
<p><b><i>Abuse of Child</i></b></p> <ul style="list-style-type: none"> <li>■ Emotional abuse</li> <li>■ Physical abuse</li> <li>■ Contact Sexual abuse</li> </ul> <p><b><i>Trauma in Child's Household Environment</i></b></p> <ul style="list-style-type: none"> <li>■ Alcohol and/or Drug User</li> <li>■ Chronically depressed, emotionally disturbed or suicidal</li> </ul>	<p><b><i>Neurobiologic Effects of Trauma</i></b></p> <ul style="list-style-type: none"> <li>■ Disrupted neuro-development</li> <li>■ Difficulty controlling anger-rage</li> <li>■ Hallucinations</li> <li>■ Depression - other MH Disorders</li> <li>■ Panic reactions</li> <li>■ Anxiety</li> <li>■ Multiple (6+) somatic problems</li> </ul>	<p><b><i>Disease and Disability</i></b></p> <ul style="list-style-type: none"> <li>■ Ischemic heart disease</li> <li>■ Cancer</li> <li>■ Chronic lung disease</li> <li>■ Chronic emphysema</li> <li>■ Asthma</li> <li>■ Liver disease</li> <li>■ Skeletal fractures</li> <li>■ Poor self rated health</li> <li>■ Sexually</li> </ul>

<p>household member</p> <ul style="list-style-type: none"> <li>■ Mother treated violently</li> <li>■ Imprisoned household member</li> <li>■ Not raised by both biological parents (Loss of parent – best by death unless suicide, - Worst by abandonment)</li> </ul> <p><b><i>Neglect of Child</i></b></p> <ul style="list-style-type: none"> <li>■ Physical neglect</li> <li>■ Emotional neglect</li> </ul> <p>* Above types of ACEs are the “heavy end” of abuse. *1 type = ACE score of 1</p>	<ul style="list-style-type: none"> <li>■ Sleep problems</li> <li>■ Impaired memory</li> <li>■ Flashbacks</li> <li>■ Dissociation</li> </ul> <p><b><i>Health Risk Behaviors</i></b></p> <ul style="list-style-type: none"> <li>■ Smoking</li> <li>■ Severe obesity</li> <li>■ Physical inactivity</li> <li>■ Suicide attempts</li> <li>■ Alcoholism</li> <li>■ Drug abuse</li> <li>■ 50+ sex partners</li> <li>■ Repetition of original trauma</li> <li>■ Self Injury</li> <li>■ Eating disorders</li> <li>■ Perpetrate interpersonal violence</li> </ul>	<p>transmitted disease</p> <ul style="list-style-type: none"> <li>■ HIV/AIDS</li> </ul> <p><b><i>Serious Social Problems</i></b></p> <ul style="list-style-type: none"> <li>■ Homelessness</li> <li>■ Prostitution</li> <li>■ Delinquency, violence, criminal</li> <li>■ Inability to sustain employment</li> <li>■ Re-victimization: rape, DV, bullying</li> <li>■ Compromised ability to parent</li> <li>■ Negative alterations in self perceptions and relationships with others</li> <li>■ Altered systems of meaning</li> <li>■ Intergenerational trauma</li> <li>■ Long-term use of multiple human service systems</li> </ul>
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**Table 4 Adverse Childhood Experiences (ACE)**

physical inactivity and severe obesity. These intermediate symptoms may be considered in isolation as problems in themselves, thus overlooking their multiple and antecedent causes and failing to respond appropriately and effectively to real need.

Briefly, the more types of adverse childhood experiences (Column 1), the greater the neurobiological impacts and health risk behaviors (Column 2), and the more serious the lifelong consequences to health and well-being (Column 3) (Feletti, 1998). Notable is the intermediate column of health risk behaviors—smoking, obesity (or eating disorders), alcohol or drug misuse, and other compulsive behaviors—which are often seen as problems

in themselves rather than being understood as unsuccessful attempts to ease the pain of dealing with the memories of adverse experiences. Furthermore a large array of chronic “medical” conditions may be understood biologically as entities unto themselves, when in fact they have complex psychosocial antecedents.

It is certainly an understatement to suggest that war is “traumatic”. The full implications, health implications, and mental health implications are appreciated not only at an individual level of death and injury, but also at a community level with the displacements, loss of social support and livelihood. It is an understatement to say that wars are incalculably costly, not only in financial terms, but also in the toll of human suffering.

Various approaches to “peace building” involve working directly with affected communities to help restore housing, security, and livelihoods. Peace-building activities recognize the multiple identities people may hold—ethnic, religious, nationalistic, and gender, which may be used to divide people—and work on a people-to-people basis to form shared community activities and educational, vocational, and recreational activities. Anthropologist Angeles Arrien has worked in numerous communities of traditional ethnic conflict, such as Northern Ireland and the Basque region of Spain, drawing on the cultural forms and rituals of numerous traditional cultures to demonstrate ways in which across cultures there is more that unites people than the tensions that divide them. Most notably, whatever one’s origins, beliefs, or legacies of injustice, everyone wants a secure and peaceful future for his or her children and grandchildren. Whatever the conflicts people may have experienced, they want a better future for their families. In the balance between trauma and resilience it is the hope for a

better future that everyone shares that may tip the balance toward resilience and coping.

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## 21. Healing a Community:

### The Hans Lowenbach Memorial Lecture<sup>9</sup>

It is a great honor to present this grand rounds lecture in memory of Hans Lowenbach, who was for me as he was for many people an important mentor, not only as a psychiatrist, but as a complete physician, a scientist attuned to the subtleties of human communication relevant to all aspects of being a physician and being human. I see there are several people in the audience including the dean<sup>10</sup> and the Gibbons Professor<sup>11</sup>, who will remember Hans, but for those of you who did not know him, it is worth recalling a few details of his remarkable life and career.

Dr. Lowenbach came to Duke in 1940 from the Phipps Clinic at Johns Hopkins University in Baltimore, where he studied “common sense psychiatry” with Adolph Meyer, whose name was synonymous with psychiatry here since our psychiatry ward was named “Meyer” in the Duke tradition of naming wards for the great Hopkins physicians who trained and inspired so many of Duke’s original faculty. Dr. Lowenbach left Germany in the 30’s as a ships surgeon and “jumped ship” in Baltimore to pursue training in psychiatry. He was already an accomplished physiologist and did

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<sup>9</sup> Department of Psychiatry, Duke University, April 9, 2009. Also presented the same day at the North Carolina Central Hospital, Butner, North Carolina. More information at Willowcliff.org.

<sup>10</sup> R. Sanders Williams, MD, Dean of the School of Medicine and Vice Chancellor for Academic Affairs, Duke University.

<sup>11</sup> *Dan German Blazer*, MD, PhD, J.P. Gibbons Professor of Psychiatry and Behavioral Sciences and Vice Chair for Education and Academic Affairs, *Duke* University Medical Center

important early research in the biological treatments in psychiatry, especially electroconvulsive therapy. But no less was he a dynamic psychiatrist, a humanist, drawing on the wisdom of literature, music, and the arts to understand and communicate with patients, his colleagues, and students.

Once when our boys were small, he said to me somewhat wistfully that perhaps one day my boys might study Westphalian dialects. In fact that did, or at least became enthusiastic students of German language and literature. I would like to use this connection as a point of departure for my remarks today on Healing a Community, the application of psychiatry and behavioral science to disaster affected communities, what we now call Mental Health and PsychoSocial response to disaster.

<b>E. Kübler -Ross</b>	<b>H. Lowenbach</b>	<b>W. Dyer</b>
Denial	Denial	<i>Unglaube</i> Disbelief
Anger	Anger	<i>Zorn</i> Anger
Bargaining	Accusatory	<i>Selbstmitleid</i> Self-pity
Depression	Self-accusatory	Traurigkeit Sadness
Acceptance	Acceptance	<i>Gott flehend</i> Pleading with God
		<i>Annerkennung</i> Acknowledgment

Before Kübler -Ross published her famous stages of grief in her book, “On Death and Dying”, it was recognized that there is a sequence of emotions that one is likely to go through in experience a loss, like loss of a loved one, loss of health, or even more mundane losses. The table contrasts the vocabulary we learned from Dr. Lowenbach with the similar nomenclature popularized by Dr. Kübler -Ross. The third column is words chosen by my son Will to describe the stages he recognized for a college paper he wrote on the German poem, *Der Ackermann und der Tod* (Death and the Farmer by Johannes von Saaz). The farmer goes through a number of stages when the grim reaper comes to claim the man’s wife, prematurely he feels.

The process of loss is something everyone experiences in one form or another. Although not everyone progresses through the stages at the same rate, it is useful to recognize that the experience someone has at one point in time may not be their experience over time. It is not true that “Time heals all wounds”, but all wounds require time to heal. Also not everyone would choose the same words to describe their feelings; it may be helpful when it is hard to find words to describe feelings to recognize that other people have similar experiences.

You will note that in all the lists, “anger” makes an appearance. This is a difficult emotion for most people. To whom is anger directed? When and how is it justified? When and how should it be expressed? Often it is the people closest who must absorb negative emotions. Often that is the physician’s role. Often anger takes a theological dimension. Blame God—or retaliate against the perpetrator. Sometimes often people are reluctant to express anger, or turn it inward, what Dr. Lowenbach called “self-

accusatory”

“Depression” makes the list in Dr. Kübler-Ross’ scheme, but it would be a mistake to conclude that depression is an invariant stage of the grieving process. It would be a mistake to conclude that all unhappiness or sadness is equivalent to depression. Freud in his classic paper on “Mourning and Melancholia” was careful to make this distinction as well as Burton before him in his *Anatomy of Melancholy*. Also we sometimes hear of “pathological grief”, grief which is prolonged and may involve clinical depression. The nomenclature is misleading here. Grief is not pathological. It is a normal reaction to an abnormal situation. This key understanding of grief has become an important cornerstone of disaster response. Normal reaction to an abnormal situation. Grief is an event of a community, not just an individual and the response is a community response. The rituals of remembrance and transition are ways various cultures have developed to help communities to come to “acceptance” or acknowledgement of the inevitable losses they experience.

Mass disasters, both natural and manmade (human-made)--such as tsunamis, earthquakes, hurricanes, typhoons, floods, fires, industrial mishaps, wars, conflicts, and complex emergencies--affect whole communities, even nations, some with even global impact. Clearly not all survivors need psychiatric attention, nor would such be possible. Psychiatric understanding of coping strategies for dealing with loss and grief inform community response to disasters.

Studies of two disasters in particular, the Coconut Grove nightclub fire in Boston in 1942 and the Bhopal chemical spill in India in 1967. In one

of the first systematic studies of the mental health impact of disaster, Erich Lindemann studied the survivors of the Coconut Grove fire and relatives of those who perished. In this tragedy, nearly five hundred people died after a fire broke out and the egress was impeded by emergency exits that had been chained to prevent people from entering without paying. Lindemann found that people did better if they talked about their experiences rather than trying to forget. He found that many people had somatic responses, particularly headaches and gastrointestinal disturbances, and often suffered from anxiety and depression; these symptoms generally subsided over a period of months. Intensive psychotherapy was generally not needed. He found that usually a series of counseling sessions, generally less than twelve in number, sufficed for most people, which was a surprisingly small number in the predominant treatment methods of the day.

Lindemann's work and much subsequent disaster work focus on the therapy of individuals. In much of the work conducted in India, however, the focus is on the community and the community response to the individual. While these differences may reflect differences in style and culture, they may be significant in terms of a larger understanding of health and mental health. Indeed, methods in India have proven to be so successful largely due to its emphasis on a communal and spiritual rebuilding.

On the night of December 2, 1986, forty tons of cyanate gas escaped from the Union Carbide chemical plant in Bhopal. The disaster, which caught India completely by surprise, left 2,000 dead and some 200,000 people suffering long-term consequences. At the time of the disaster, there were no psychiatrists in Bhopal, the mental health aspects of the disaster

were poorly understood, and, fearful of litigation and compensation, many administrators and health workers took complaints to be factitious. Teams of psychiatrists, psychologists, and psychiatric social workers were dispatched to Bhopal to treat survivors and to train general medical officers. They documented confusional states, reactive psychoses, anxiety/depression, and grief-reactions as immediate consequences. Long-term consequences included various disabilities, uncertainties about the future, broken social units, and problems related to rehabilitation.

A paradigm shift toward the community-based psychosocial support model happened after Orrisha Super-Cyclone in 1999, which left more than 10,000 people dead and a million people with broken homes and hearts. In this disaster, community level workers, middle-aged people from the community, were trained on basic psychosocial aspects and were supported by social workers. Medical professionals were trained on disaster mental health to provide support to those with higher mental health needs. Similar models were put in place after the Gujarat earthquake in 2001 and the Gujarat riots in 2002, the South Asia tsunami in 2004, and the Kashmir earthquake in 2005.

My own introduction to disaster mental health came in 2005, a year after the tsunami, which struck India on Boxing Day, December 26, 2004. I had been invited to give a series of lectures in Bangalore on medical ethics at the National Institute of Mental Health and NeuroSciences and the Karnataka Branch of the Indian Psychiatric Society and cancer survivorship at the Karunashraya Home for the Terminally Ill, Bangalore Hospice Trust, Indian Cancer Society. Perhaps it was my own experience with cancer, like a mini-tsunami that sweeps in unannounced and sweeps away everything

that is familiar, that focused my attention on the tsunami and disaster, but I was very interested to learn how people cope with disaster and how mental health professionals support those in disaster situations. My host in the NIMHANS psychiatry department, Dr. Srikala Bharath, arranged for me to meet the head of the psychiatric social work department, Dr. Sekar Kasi, who arranged for one of his graduate students, Subhasis Bharath, to take Sue and me on a weeklong field visit to the disaster affected villages of Tamilnadu. Here we got to see the training-of-trainers cascade, teachers teaching teachers teaching community level workers to understand the impacts of the disaster on individuals in families in communities and how to work together to rebuild communities to support families to support individuals, work which continued for months and years after the flood waters had receded.

At the time I was very grateful for these lessons in community-based applied mental health. I did not imagine that it would take my own career in new directions or that I would be called upon to help organize response to subsequent disasters, earthquakes, tsunamis, war, and to help define new understandings of global mental health.

The Great Sichuan Earthquake, which measured 8.0 on the Richter Scale occurred on May 12, 2008. It lasted 120 seconds and left over 69,000 people dead, more than 350,000 people injured and 5 million people homeless and displaced. The capital city of Sichuan, Chengdu, home of the famous panda preserve, is considered by many to be the most delightful part of China, warm hospitality and spicy food. I had previously lectured to the psychoanalytic group in Chengdu and subsequently been involved in providing internet Skype supervision through the China American

Psychoanalytic Association. I was asked to return to provide mental health training to help Chinese doctors respond to the disaster affected areas.

I was introduced to Dr. Jing Li at the Mental Health Center of the West China Hospital, Sichuan University in Chengdu, who identified the specific needs and coordinate the program. Specifically I was asked not to provide basic material, which would already be familiar to many of the trainees, but more advanced material.

I assembled a faculty of American, Indian, and Chinese experts, including my Bangalore colleagues, Srikala, Sekar, and Subhasis, and outlined a curriculum based on the NIMHANS model, a community-based train-the-trainers model focusing on the psycho-social rehabilitation of disasters victims.



**Drs. Wei Jiang, Rishi Mehta, Dyer, Sekar Kasi, Jing Li, Glen Xiong, Stephanie Hall**

One of the greatest challenges to such a program is having successful interpretation. Word-by-word translation does not convey what a skilled interpreter, who understands both the program and the cultural context in which it will be received. My trusted friend, Dr. Xishong “Charles” Li, whom I had met years earlier in Nanjing, had just become an American citizen and was unable to get a visa on his new American passport. By happy coincidence, a team from Duke University was in Sichuan at the same time and joined efforts with us in Chengdu. Dr. Wei Jiang, Dr. Glen L. Xiong and Mr. Yin Song generously provided translation, interpretation, and coordination of efforts.

The lectures were delivered at the West China Telemedicine Center. We were told that the lectures were broadcast to 15,000 participants at 150 remote sites. Before and after the Chengdu lectures, we split into teams to visit the disaster-affected villages. Dr. Sekar Kasi, who arrived early, went to the Deyang area and Shifang to assess the situation. After Chengdu, Dr. Srikala Bharath and Richi Mehta went to DuJiangyan, where they trained volunteers at the Communist Youth Program. This was fairly intensive training in a village severely affected by the earthquake with major destruction and loss of life. Drs. Stephanie Hall and Allen Dyer went to Schifang with a team of counselors working with volunteers. The first day there, we provided training to doctors and nurses at the Shifang 2<sup>nd</sup> People’s Hospital, damaged by the earthquake. Ceiling tiles had collapsed and wires were hanging down everywhere, but electrical mains worked, and so computers and PowerPoints were on. The next day we were taken to the

village of Luo Shui, which had been virtually destroyed by the earthquake. Huge factories were in shambles, their chimneys toppled, ductwork mangled. The Rocket Middle School was a pile of rubble. A hospital was destroyed, and care went on in temporary buildings that were erected in two weeks.

Perhaps more important than the academic content were these practical sessions, working with the counselors working with the disaster affected communities. Many were on the verge of burnout, some experienced vicarious trauma. Not only is training of trainers an important part of community training, but also the on-going supervision and providing counselors an opportunity to process their own feelings.

As difficult as natural disasters are, man-made disasters are even more so in that they involve an element of culpability and feelings of injustice often leading to actions of vengeance to settle the score. Wars, ethnic conflicts and complex emergencies are sometimes called “human-made,” but in truth they are usually man-made for reasons that may be innately sociobiological and require careful, concerted efforts to overcome.

I would like to comment on three such conflicts, the war in Iraq, the Rwandan genocide, and the Gujarat ethnic riots, in the context of my “healing a community” theme.

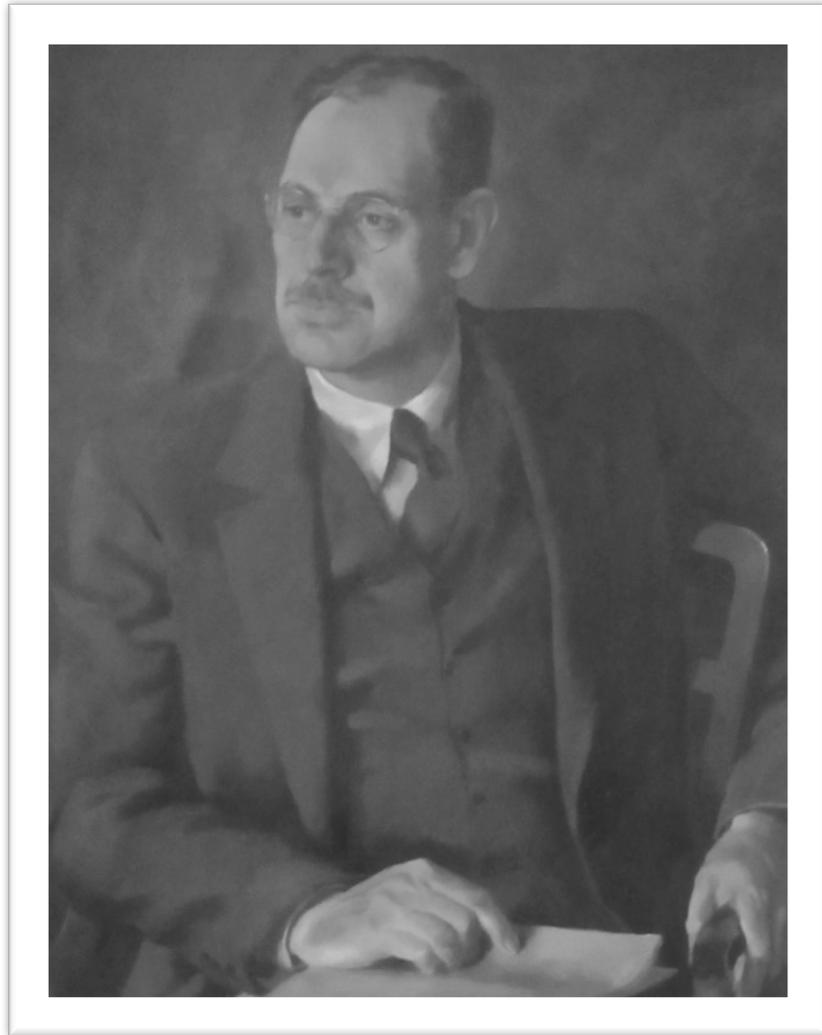
Iraq is a country of 29 million people with fewer than 100 psychiatrists. They have been impacted by not only the current war and the previous gulf war, but also the Iran-Iraq war, which took the lives of over a million young men, but also 30 years of economic embargo. The Iraqi people have demonstrated amazing resilience in the face of almost unimaginable adversity. The Iraqi people enjoy strong family and

community ties, and strong religious faith.

My own involvement with Iraq began in 2001, early 2001 before 9-11, when my East Tennessee State University received a grant from the US Department of State to “help the Kurds develop a medical infrastructure”. Initially teams of Kurdish physicians came to Tennessee to learn about our community-based health programs, then some of us started going to Kurdistan and ultimately Baghdad and Basra other parts of Iraq, when the security situation improved.

What I found in Iraq was that people were very eager to talk about what they had experienced, in many instances traumatic losses and horrific situations. Many experienced depression, anxiety, and some PTSD, but importantly there were many somatic manifestations of stress: headaches, gastrointestinal problems, diabetes, dermatologic conditions, increased incidence of cardiovascular disease and cancer. Notably these were not just observations of a physician, but associations they made with the stress and uncertainty that had become such a part of life in a war zone.

The programs my colleagues and I designed, always in response to needs our hosts defined, addressed many of these problems, along with policies of the Ministry of Health, for improved education and continuing medical education and research and integration of mental health and substance abuse into primary care. I think for me the greatest reward of this work was seeing the renewed interest in psychiatry and the increased numbers of board students (residents) choosing training in this specialty.



**Hans Lowenbach, MD (1905-1983)**

## **Epilogue - Drawn to Disaster:**

### **Global Health and Mental Health**

When I entered cancer treatment, it seemed like an epic battle, weeks and weeks of peril with no certain outcome, blindly following orders I barely understood. As toxic chemicals were pumped through portals lanced in my arms and chest, I tried to read passages from the Iliad, seeking some guidance from the the risks and rages the Trojan warriors had faced before me. And when the last battle had been fought, I was left, like Odysseus, trying to find my way back to the Ithica I remembered, only to find that Ithica was not as I had remembered it. Not only had Ithica changed, but I was changed by the experience. From the high ground of my memories, I could survey the debris. Somewhere between the metaphors of illness and the mysteries of life, I was left with the questions that tragedies leave everyone. Why me? How does one cope? What does it all mean? The scientist within me wanted understanding. I wanted generalizations. Had I learned anything from the experience? Would it be useful to anyone else?

I returned to my work as a physician, a psychiatrist, a teacher. I returned to triathlons a bit slower, but continued to swim, bike, run, trek in Nepal, climb mountains. Increasingly I was called to new challenges, and ultimately a new career in “global health”. Real tsunamis, earthquakes, even wars, conflicts, and complex humanitarian emergencies became objects of my concern. Like the thirteen-year old Nepali boy who became a *jhakri* after being lost in the woods, I learned to travel with two passports, the recovering patient, the wounded healer. I learned from others who had faced adversity as I tried to help those facing their own challenges.

In 2009, the Livestrong Foundation hosted a Global Cancer Summit in Dublin, Ireland. Lance Armstrong rode in the Tour of Ireland and keynoted the summit. Sue and I found vantage points along the course, particularly on the climbs, and watched Lance and the peloton ascend with amazing speed. Cancer activists from around the world gathered in Dublin to strategize the global fight against cancer. We had all learned that cancer was not hopeless. There were things that could be done, must be done, even in underresourced settings. I worked with Iraqi oncologists, health officials, and Jordanian royalty to improve cancer care in Iraq. We began conversations which extended to Baghdad, to Basra, to Amman, and to Washington that ranged from public awareness campaigns, smoking cessation programs, how many linear accelerators a country of twenty-nine million people needed, and how to prioritize who gets access to pediatric treatments. Doug Ulman, whose genius it was to organize the summit, looked me in the eye, and said, “Never forget that there are obligations that go with being a cancer survivor.” I understood this calling. I didn’t choose this path. It choose me.

By 2009 I was already deeply involved in the professional education, health and mental health programs in Iraq supported by the International Medical Corps. I was going back and forth to Iraq with some regularity, even as the war continued on and on. I loved the work, teaching physicians who were eager to learn. The invitation to come to Washington “to help us develop global health and mental health” was a challenge I felt I could not pass up. After nearly four decades in the academic world, I was ready to commit to the world of humanitarian disaster relief and medical diplomacy. It was an open-ended invitation with no particular definition. All my experiences as a doctor and as a patient had convinced me that health was as

much a community undertaking as the treatment of sick individuals. The “global” part of global health could best be appreciated as “comprehensive” as well as “international”. Disaster situations, like tsunamis, earthquakes, and especially wars, convinced me that physical health cannot really be separated from mental well-being. Health is a delicate balance between wellness and illness.

An invitation to give a keynote address at the Indian Disaster Management Congress as a guest of the Indian government was an opportunity to reconnect with Indian friends but also survey the world of disaster management. It was clear that the most important part of disaster response is disaster preparedness. Engineers in earthquake prone areas were trying to figure out which buildings could be reinforced and which would need to be demolished. Biologists were looking at the possibility of pandemic infections and how to control the spread of germs. My contribution focused on knitting together of communities in the mental health and psychosocial response to both human made and natural disasters.

Again in Indian I was very interested in the response to the Gujarat riots of 2002, where politicians had pitted Hindu and Muslim communities, who had traditionally lived side by side. Fueled by a train fire, which was later found to have been staged and not spontaneous, neighborhoods were burned, people killed, and whole communities displaced, living in fear. Again my dear friend Subhasis Bhadra, who had taught me so much about the community response to the tsunami in Tamilnadu, was on hand to show me the thoughtful and sustained commitment of some very decided people, whose organizations, with evocative names like “Gujarat Harmony Project”, worked to overcome fear and prejudice, re-establish community rituals,

acknowledgment of events and memorials, and provide jobs training and skills building for sustainable employment. Resentment need not last forever, and with careful effort generosity and forbearance can overcome fear and vengeance.

The Haiti Earthquake of January 12, 2010, was particularly devastating in terms of the number of people killed and injured, the concentration of the population in Port-au-Prince so close to the epicenter, and the lack of infrastructure on which to mount a response in such an impoverished country. My own involvement focused on the impact on the responders, and impressed on me the impact of vicarious, or empathic, trauma, both physical and mental. Perhaps it would be better to speak of mind-body connections or even “mindbody” integrations. With such overwhelming needs, many responders were working almost around the clock with diminishing effectiveness. Not only was the grief overwhelming but exhaustion took its toll, an important reminder that basic needs are basic: security, nutrition, sleep.

Japan’s tripple disaster, earthquake-tsunami-nuclear meltdown, started with a 9.0 earthquake on March 10, 2011, just off the coast of the beautiful city of Sendai. This one was closer to home for me, not geographically, but emotionally. My nephew, Eric DesMarais, had taught English in Sendai for several years, and in 2002 married Masayo Suzuki. Our family traveled to Japan for the wedding, and Masayo’s family hosted us to a magnificent feast in the seaside farmhouse where Masayo and her father before her had grown up. Masayo’s father gave me an antique iron teapot of the sort craftsmen of the area had been making for centuries. It became for our family a cherished heirloom as it had been for theirs. Our grandchildren loved to play with it.

“Tea” became a ritual social event, and when the grandchildren visited, Sue would make milk-tea or Kool-Aid tea in different colors of the children’s choosing. One morning morning Sue came down to the kitchen and found a note from our grandson Timmy that said, “BAKE THE COOKIES AND MAKE THE TEA PUPLE.”

By the time of Japan’s 2011 disaster, Eric and Masayo had moved to the United States, Eric had become a social worker and was now a doctoral student at the University of Denver, specializing in global mental health. He received an invitation from the prestigious Tohoku University in Sendai. “Help us know how to deal with the children.” A grant from a Jewish community group in Los Angeles enabled me to put together a program on the Mental Health and Psychosocial support for disaster, “Healing a Community,” and assemble a tri-national faculty Japanese, Indian and American. Eric and Masayo were part of the team<sup>12</sup>.

Japan and India of all the countries in the world are probably the best prepared to deal with disasters. The United States tends to be slow to prepare for likely disasters until they actually occur, as the 9-11 (the second and third attacks on the Twin Towers), and Hurricanes Katrina and Sandy sadly demonstrate. Japan and India have had their share of disasters. Japan sits on several fault lines and is no stranger to earthquakes, but nobody expected a magnitude 9.0. The skyscrapers we were in swayed to and from with the aftershocks, as they are designed to do. The Bangalore team were able to diplomatically present approaches that they had employed in dealing with their tsunami and earthquakes. Although it is often said that the

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<sup>12</sup> Course materials are available at <https://sites.google.com/site/imcsendai/> and field report at Willowcliff.org.

Japanese are not attuned to mental health needs, this has not been my experience. We found the psychologists and teachers attending the conference to be very aware of psychosocial issues and very receptive.

After the conference at Tohoku University, we visited Masayo's family. We had been concerned for their well-being. The first video clips of the tsunami shown over and over on television showed a house with a blue-tiled roof floating away. That was the Suzukis' next door neighbor, and for twenty-four hours Masayo was unsure if her family had survived. At last she got a message that everyone was okay, but the house was completely destroyed. Her father had gone back to get the dog and important papers and drove away with a wall of water visible in the rear view mirror.

We visited the village and saw that all that remained of the house was the granite foundation blocks and the tiles where the front door had been. These were the tiles where we had been welcomed the day before the wedding. We could recall where the table had been with dozens of carefully prepared dishes.

That night we shared another meal at a favorite restaurant. Masayo's mother was grateful that Masayo was there to help her arrange the furniture in their new house, which they would move into the next day. I returned the cherished iron teapot to Masayo's father. It would be the one thing from the old house that would be in the new house. Eric gave his father-in-law a fleace vest from LL Bean that his grandmother, my mother, had given him and which he had worn during the cold winters when he lived in Sendai. My gifts to our hosts and Tohoku University and to the faculty were enlargements of the famous cherry blossoms in my new home city of Washington, DC, which were originally a gift of the Japanese government to

the people of the United States.

*Ameru.* Dependency. Community. Support. Resilience.

By now the formula had become familiar. Once again, disaster responses reminded me of the lessons that had cancer had taught me. Complex illnesses and complex emergencies are complex. Health is really global in the sense of a comprehensive wholeness of mind, body, and spirit – bio-psychosocial and spiritual. Resilience is a community effort, and healing involves sustaining and rebuilding the ties that bind people together.