Inside Jacket if this book had one

IIf you aren't careful, you can become your illness, and your cancer can become your entire life, taking up every waking moment. Further, unless you correctly manage your friends and family to them, you can become just your illness.

You need to set boundaries, understand what your cancer is (and most importantly, is not), and learn strategies, techniques, and roadmaps to follow so you still have a meaningful existence. For example, three times in the author's life, the first 49 years ago, they told Ted to say goodbye to his wife because he probably wouldn't survive the night. Yet, he not only survived; he thrived. Ted says, "I wouldn't trade my life for anybody else's. I have a wife who loves me, a great son, a lovely daughter-in-law, and a granddaughter who is pure joy. Those are what give meaning."

Learn how to deal with your cancer, put it in perspective, and live positively. Your life is not over, and it can be wonderful.

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Chapter One

Life and Illness

A whole new life, not by choice,
As my old happy one slips by,
Perhaps never to reappear again,
I know not what I did to deserve this,
And now I must start again anew,
At a whole new normal, lesser life,
Wondering if my friends will still be,
And accept the new me.
Ted Gordon

You have to be careful, or your disease may define you. Your friends and family can fixate so exclusively on your condition that they worry about it and not you. "You don't look good, how do you feel today? Any pain? Where does it hurt?" If you hear these questions too frequently and allow your world to be all about your disease, you as a person can lose your identity to your sickness. This concept is discussed later in this chapter, but it can be a real concern for many patients experiencing their first encounter with cancer.

I know cancer centers that give out my book to its patients, having felt that the issues I discuss are those that are most beneficial and sadly not covered by many books on the subject. It is because I have a psychology minor, masters of business administration degree, and years of experience as an attorney that I can relate to the many areas of coverage needed by patients. Browse through the second half of the table of contents for the broad list of topics.

Just as in work, some people "live to work," spending most of their time at the office. Then they come home, do nothing at night, and go to bed so they can get up and go to work the next day. Such can be life for many individuals who are ill. Every waking moment is about their illness and the limitations of that sickness.

Yes, sickness requires considerable attention and adjustments, but it is not your whole life. Cancer is not who you are, what your future is, or how you should treat your family and friends. It is a priority that must be handled, but not at the expense of giving up your ability to live.

Issues Discussed

The first third of the book tells my story, what I learned, and how I dealt with my illness. Everyone deals differently with illness, but nothing beats listening to those that have blazed the trail and can tell you about the path, pitfalls, and expectations.

The remaining two-thirds of the book discussed information you will likely need to know. Illness does not happen in isolation but affects all aspects of life. Besides maintaining your balance in life, you have other immediate concerns. It is like a four-legged stool; each leg must be supported to keep the stool level (in equilibrium). Some of the many matters discussed in this book are the issues below.

1. **The Illness**. The first and most immediate reaction is to deal with the illness. How do you handle the first 48-hours after hearing of your diagnosis? You are adrift in a universe where the standard rules of life don't apply. If you don't have some guidelines, the unprecedented situation you face can throw you. It goes much easier if you have an idea of what you might encounter. Which treatments should you choose, and should you obtain a second opinion?

How soon must you decide on your treatment without a disadvantage to your health? How do you know you have an excellent doctor? Is your doctor following the correct protocol for your stage of cancer? These and many more questions need answers.

2. **Your Support System**. How do you set up a support system? If you have friends and family who want to help, how do you coordinate and decide what you need? How can they help without asking you each time? If you don't have access to such support, how do you get help and on-line or community-driven support systems? How do you let your family participate without smothering you and you overwhelming your supporters? Equally important, what is the procedure for them to let you know when you are unfair, over-burdening, and disrespectful. How do you tell your kids about your cancer?

3. **Survival in a Financial Environment**. If you have a job, what accommodations must your employer make? What rights are afforded you under the American's with Disability Laws? What about health insurance and other insurance? Can you run out and apply for life insurance, or is it too late? Can you continue driving? Can hotels, airports, and other enterprises discriminate against you? How do you obtain a disabled automobile license plate?

4. **Estate Planning Documents.** Should you execute a living will (durable power of attorney for health care), and if so, how do you fill it out? What does each paragraph mean, and how should you decide each of your choices? Should you do a will or update your trust? What about documents like the end of life

care and other legal documents about you`decisions? What is a POLST? How does it differ from a DNR, and do you need one? There are too many questions and issues, most very important, that need immediate attention, at a time when you are overwhelmed and in a different world, just trying to get by each day.

Overall Approach

I wish I knew back then what I know now! There are discoveries about living, dying, making friends, exploring love, and finding yourself, that all help open up whole new worlds. My life could have been so much easier, but life lessons sometimes come from difficult circumstances. Looking back, what I have learned about dealing with illness and how to live life is very different from the view I held when I was healthy.

Among the many lessons I had to learn was how to prevent my limitations from defining me? I had to discover how to make my family and friends realize that my life was more than just my illness. An illness shrinks your world, and if you are not careful, it can become your sole concern. Even if and when you can accept your illness, and place it in perspective as only a part of your life, you still have to educate those close to you that you are the same person – just sick – and that they should not change their view or feelings towards you. I discuss this at greater length in the book.

When my illness struck at age 26, like most young people, I had minimal experience with the idea of death. Intellectually I knew death is a part of life. However, I had lived too short to know what it would mean. I wasn't indestructible, though. As a young man, I remember taking many risks because I thought I was invincible. Too often, as a teenager, I had skied down mountains much too advanced for me, because I couldn't imagine hurting myself. Luckily, it was always, "the other guy," who broke his leg on the ski slopes—not me.

After my first open surgery, I had to admit that my life could end suddenly without warning. Then, when I kept on living, I had to accept that I needed to learn to live a new way. I had to adjust and find new meaning, capture the joy, and savor the beauty of life. Sometimes tragedy can be a mixed blessing—a rare chance to know yourself, a means to bring you closer to your spouse and those you love, and an opportunity to look at the world from a new perspective.

When I was in my early twenties and working as an attorney, I met a person who seemed to be an exceptionally well-informed criminologist. He was knowledgeable, articulate, and seemed to possess innate wisdom about the law. My acquaintance laughed when I asked him what law school he had attended. Sheepishly, the man replied that his education had come from years of being in and out of prison, and from learning to write his court appeals. I learned a good lesson.

Although the "school of hard knocks" can be a good teacher, the cost of tuition is very high and often very hard, and it is usually much faster and easier just to read about someone else's experiences. So, I have written this book with the hopes that my story might help enlighten others and perhaps make their life journey more manageable.

Research has shown that books like this one can provide such assistance. In one major study in England, people who survived a significant disease were asked if reading the stories of others with similar afflictions helped. *Over fifty percent of the respondents said such books provided a better understanding of their condition and offered useful solutions to everyday situations they faced* (Wachters-Kaufmann, 2000.) Think that concept needs repeating. We all need advice and help. Additionally, such books help family and friends understand the patient's disease and help strategize how best to help that patient.

My illness has forever changed my life outlook on life and helped me realize what is important in life. In spite of my hardships, I would not trade my life for that of anyone else. I have a wife, son, daughter-in-law, and granddaughter who love me dearly. We are a very close family. Regardless of the many burdens I've faced, I have a wonderful life! I once heard someone jokingly say that the "definition of life is that which gets in the way of your plans." This thought has indeed held true for me.

(It goes without saying); the detailed explanations in this book are based on all my personal beliefs and experiences. Nothing in the book should be deemed medical advice or considered as a substitute for professional medical advice. As much as I question doctors and even, on occasion, suggest possible treatments, I rarely go directly against the directions of my doctors. There is too much variation between individuals and diseases for anyone with a severe illness to self-treat because of something they read in a book.

Likewise, since I retired from the practice of law and allowed my license to go inactive, nothing in this book should be considered legal advice but only the opinions of a layperson. Any legal questions, or the use of any letter, information, or document in this book, should be thoroughly checked by your attorney since different situations require different strategies. All materials and notes in this book were written solely for my personal use, and they are not intended to be sample legal documents to address anyone's legal issues. For any questions, you should seek the advice of a practicing attorney.

Lessons Learned

Otto von Bismark, when Chancellor of Germany, had an excellent quote that I have always liked and found useful, "Any fool can learn from his own mistakes; a wise man learns from the mistakes of others."

Before the surgery, I found that adjusting to my new limitations, which varied day-by-day, was almost as tricky as trying to tell my weaknesses to others. After receiving numerous confused reactions to my explanations, I finally came up with an analogy which helps enormously to explain my situation.

Daily Limitation Fluctuate

Chemo and many cancer treatments leave you fatigued, and you need a good explanation to explain to your friends and family. I explain that my daily activity level is like having a glass of water. When you drink all the water, there is no more water. Should you drink all the water in the morning, then there is none left for the rest of the day.

In other words, I have only so much expendable energy in the day, and if I use too much vitality in the early part of the day, I have no more for later. Once the glass (my energy reservoir) is empty, I have no more physical and mental power for the rest of the day. Unlike healthy people whose energy glass seems to be continually refilling, mine has a daily limit with only a finite amount of energy.

To continue the analogy, on some days, I would wake up and find that the glass of energy for that day was only a small glass. It wasn't my normal-sized glass of energy, meaning that on those days, I didn't seem to have much energy.

The worst part of this was that I never knew the night before, what size glass I would have for the following day. Though on most days, my drink would be about the same size as the day before, on some days, without warning, I would wake up to find only a small-sized glass. This lack of motivation, power, and mental endurance necessitated the cancellation of any activities planned for that day. I called these days "throw-away days."

Accept Your New Normal

In my first full year as a practicing attorney, I experienced an incident that has to have been one of the most embarrassing moments of my life. I can't believe I'm talking about it now, except that it was so instructive for me that it is worth noting. When you first start practicing law, you know almost nothing about the real practice of law. In other words, you have intelligence, but not wisdom. (This is why I would never go to any legal or medical professional who hasn't had at least fifteen years of practical experience.)

On that particular day, my neighbor had come to see me about a legal case. I was trying to impress him, so instead of using my law office, I snuck into the senior attorney's large office and interviewed him there, as if it were my own large office. However, my neighbor also brought his dog with him. I don't remember the breed, but it was a large dog, bigger than a Labrador. The dog made so much noise barking while he was outside the office building that foolishly, I was persuaded to let the dog sit-in on the interview.

You can almost guess what happened next. Subsequently, the dog crapped on the carpet. This pile was not a small bowel movement but smelled like the huge mound befitting such a large animal. The client tried cleaning up the mess as best he could, but for the rest of the senior attorney's days in that office space, there was a large brown stain on the carpet.

I learned a lot of lessons that day, one of which is that you can't pretend to be something you're not. I was not a well-established attorney with a large office and years of experience. I was a new attorney just getting started, who had to admit who I was. In a similar vein, I couldn't pretend I didn't have an illness. Pretending it wasn't a limitation is the same as pretending I was a seasoned attorney. I was fooling nobody, especially not myself. The sooner I could accept who I was, the easier it was to acknowledge my limitations. I became comfortable with my persona and no longer had to hide that part of myself.

Redefine Your Self Image

My health problems began at the "old" age of 26, which required a significant adjustment in my self-identity. The difference between how a man and woman form their self-image is the type of material that author John Gray could have to put in his book *Men are from Mars, Woman from Venus.*

A boy's status among his peers is heavily influenced (if not determined) by his ability at sports, his strength, and his endurance. Boys often judge each other on how good they are athletically, especially in their younger years. These are also the years in which boys often form concepts of self-worth that carry over into manhood.

If you define who you are as a man by your athletic prowess and strength, it is easy to understand how a heart attack or cancer can put a heck of a dent in your self-image. There is a fear that you are a lesser man, no longer worthy of respect from yourself or your friends. Even though it's not true, this is a fear that confronts almost all young men with serious illnesses. If you don't understand your condition and its limitations , the blow to your self-concept can destroy much of your happiness.

I have talked to several women who have had mastectomies or other disfiguring surgeries, and it seems that for women, the effect on one's self-image is similar but for different reasons. According to these women, girls often obtain their status among other girls by their looks. This emphasis on how a young woman looks is especially dominant during middle school, high school, and college, and it can also carry over into later life. If her body defines a woman's self-concept, then a mastectomy can cause a heck of a dent in that woman's self-image.

I've been told these women often have a hard time (especially at first) believing that their husbands and boyfriends can love them just the same following loss of a breast or other disfigurement. They often view themselves as an unattractive one-breasted woman, and therefore, as a lesser woman. I think most men are just happy that the woman they love is alive and well, and love them just as much as before.

I found it essential for my wife, Sharon, to understand just how my self-image was affected by my illness. Over the years, as I learned more, I spelled out my initial troubles with my self-concept to Sharon, using the concept of a woman who had a mastectomy. I don't think most men can fully appreciate how devastating it is to a woman to lose a breast, because men don't define their self-concept by their body.

Similarly, I found that most women really couldn't appreciate just how devastating it is for a man to lose his ability to perform specific tasks and find himself limited in what he can do physically.

A friend of mine, Alfred, lost the total use of his right arm. He moaned, saw himself as useless, became embarrassed as he awkwardly ate with his left hand, refused to see many of his friends, and felt like less of a man. He defined himself by his illness and only saw himself through the lens of a one-armed man to be pitied. His wife finally cured that problem with the most ingenious technique. She asked if she could hold his lifeless right arm. When Alfred asked why, his wife replied that since he thought his right arm defined his life, she might as well not talk to his face—she would speak to his right arm! Alfred got the message that he was more than just his right arm and changed his outlook.

If you are struggling to accept your disease, you might like the movie about the dramatic story of Richard Turner. Although legally blind, he became a black belt in Karate. Turner wanted to take the same test as everyone else and refused to accept any accommodations. Incredibly, Turner earned his black belt, although he was severely (and in my opinion, unnecessarily) hurt during his ordeal by fighting ten fights against sighted opponents. Richard was also a master magician; sadly, Turner avoided telling people about his blindness. Turner worried that his disability was a defect that diminished who he was and how he saw himself.

When his son (who so often acted as his equivalent to a seeing-eye dog) went off to college, Mr. Turner found his restrictions so limited his ability to enjoy life. It was then that Turner began to use electronic aids and other devices. Richard's sister made an acute observation, that, "if you refuse to admit you have limitations, you cannot begin to conquer or adapt around them." (A search of the Internet for "Richard Turner," will bring up many clips on this amazing man.)

Neither athletic ability for a man nor beauty for a woman is who someone is. However, it takes considerable pain, self-inspection, and the necessity for many people to realize who they are inside their bodies. For me, all of these insights came years later. At age 26, I still had a long road to go before I could accept my condition and my limitations. I was also fearful that my family and friends would define me by my illness, and that my life would become centered on my shortcomings. As I mentioned, I hid the fact from my friends. (all of them), being too mentally fragile the let out this secret. Looking back it seems incredibly stupid, short-sides, and irresponsible.

Making Others Comfortable

As a result, you can't make others comfortable unless you are comfortable so you have come to terms with your disability or limitation. Telling others is a big step forward. How you tell them, varies from individual to individual. Looking back, I find the best approach is to explain to one close friend and see how that person reacts. I think you'll be surprised at how supportive that person is and how much support he or she can offer.

As you feel more comfortable, tell others your story. Each time, analyze what words you use in the telling, and note how you can modify your disclosure to be more positive. You want to make you and others more comfortable. Eventually, you will find that you don't mind talking about your limits to anyone, even though, statistically, there are always going to be a few jerks.

The trick is to think of your disability as a part of you, much as your skin color or sex, but not what defines you. Your disability or illness will only determine who you are if you let it. Be comfortable, and it will become a part of you, but not who you are.

Broader than Just Medical

Anyone who has been through illness will tell you that treating the medical problem is only a part of the recovery process. There are thousands of secondary issues that arise and need resolution.

There are so many things that you can only learn from experiences. For example, if possible, it is best to avoid being in a teaching hospital during July, because that is when each batch of new interns arrives, new to the medical profession and hospital procedures. Another example is removing the sticky residue from surgical bandages and adhesive tape. The trick here is to use nail polish remover as the acetate quickly removes the gummy areas left on your skin. For the easily removable adhesive tape often used today simple rubbing alcohol will remove the stickiness.

I discuss a range of personal issues such as: not blaming yourself for your illness; when to have sex; facing discrimination in the workplace, and the availability of disability insurance. I also cover other issues that have arisen in my life or those of my friends, such as: how to pick the best doctor; how to order in restaurants; what to bring to the hospital.

This book discusses how to keep track of medical bills, and even more importantly, how to appeal denied claims. It is one thing to know what to do, and something else to know how to accomplish that purpose. So, where appropriate, the book includes samples such as letters appealing an insurance claim, and a form letter to an employer requesting modification of one's job because of a disability under the Americans With Disabilities Act.

Chapter 28 is devoted to Advanced Health Care Directives (otherwise known as a Durable Power of Attorney for Health Care or as a Living Will). Too often, books tell you that such 'n' such a document is needed but don't explain what the instrument means. Then, upon arrival at the hospital, a legal-looking document with checkboxes and options is thrust into your hands, at which time it seems almost impossible to understand the material. Such vague discussions in books are what, in my M.B.A. program, we used to call "high relevance, low usability." You knew the paper was important, but you still didn't see the significance. I describe each paragraph of the Advanced Health Care Directive. I explain in simple language the purpose of each section, and why, where there are several available options, you might choose one paragraph over another similar clause.

My Illness

My problem is heart (three heart attacks, heat failure and finally a heart transplant) all brought on by heredity factors. In my opinion, recovery from heart disease and cancer are about the same. Sure, the treatments are different, and doctors will explain that at the cellular level, the illnesses have nothing in common. But they both affect humans; each can be life-threatening, each can require very uncomfortable recoveries, and all too often make your disease your life and redefine your existence.

Similarly, one's story of treatment for liquid cancers (like leukemia) might be significantly different from ex-perience with solid tumors (like carcinomas). Similarly, books by prostate cancer patients might be almost alien to biographies from glioblastoma (brain cancer). Yet, any stores from survivors can be relevant despite different treatments and histories.

The common thread is how you deal with your illness, adjust to your economic and family needs, and still manage to live your life. While my condition was heart-related, the issues I faced correlated to other illnesses, especially cancer, as it can take your life.

I still remember over 45 years ago what the doctor said, and those words are still as crystal clear as if they were spoken just yesterday. "What do you mean I've only got 18 months to live," I practically screamed at the doctor. "I'm only 28! This has to be a mistake." However, the doctor only looked at me sadly, shaking his head, and repeating his earlier statement: "Ted, your three heart attacks have severely damaged your heart." He continued, "With the state of medicine today, even the open heart surgery I just performed won't help you much, because your heart is in such bad shape." Limitations on life had little meaning for me until my first heart attack at age 26. I had to admit that my life could end suddenly without warning.

After the heart transplant in 2013 at age 67, I'm playing in a different "sandbox" now, with all new rules. As actor Christopher Reeve so sadly demonstrated, doctors cannot reconnect nerves.

When they replaced my heart and re-attached everything, they were naturally unable to reconnect the nerves. If you want to stand up from a chair and walk to the door, the brain sends a signal to your heart, telling it to beat a little faster, as you will need slightly more blood supply to stand and walk. My mind can't signal my heart so that I have learned, and am still learning, to get up slowly and meander carefully to the door until eventually, my heart realizes it is underpowered and needs to beat faster.

Probably the hardest adjustment for me since the transplant has been that I'm like the "bubble boy," with almost no immunity. This is a situation faced by many cancer patients after chemotherapy. To my body, my new transplanted heart is also an invader, so my immune system would try to kill it, the same as any foreign germ. To prevent that takes massive amounts of immunosuppressant medications, which shut down my immune system. I have almost no immunity against anything. The hardest part is that I can't shake hands with anybody or hug anyone, and for me, that is a difficult adjustment. Still, life is wonderful, and I have no complaints – just challenges.

Your illness doesn't define you, unless you let it!