A Survivor’s Story: We’re pleased to present Kevin’s story, part of which has already appeared in ThyCa’s Membership Messenger newsletter, in the Winter 2004 and Fall 2004 issues. Earlier, Kevin shared his experiences with his e-mail support group. As with all the survivor stories presented on our web site and at our events, this is a sharing of one person’s experience. It does not try to use medical terminology precisely and is not intended as medical advice. We thank Kevin for sharing his “Adventures in Thyroidland” with the visitors to ThyCa’s web site.

ADVENTURES IN THYROIDLAND

By Kevin Wychopen

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Part 1

Lumps

Lumps. Now there is an interesting word. It’s been around for a long time (since perhaps the 14th century) and I don’t think it has ever gotten really good press. Lumps are things to be avoided, whether in your gravy or in your body.

Some lumps are transitory. Like the ones you get as a kid when you jump from the log pile to the shed roof and you miss, sort of. Your shin hits the shed roof, you fling your body onto the roof, but you have a lump. Right there on your shin. It hurts. But, being a kid, you rub it a few times, and commence to figure out whether you can jump to the ground without breaking anything or attracting your mother’s attention.

Some lumps are permanent. The ones you have on your skull, for example. In fact, some people have dignified these lumps by calling them bumps and developing the science of phrenology, a method of investigating personality. According to the developers of this science (this is perhaps too generous a use of that title) one could tell, by studying the bumps, what kind of career a person would excel in, or what their personality was, or one could even embark on an effective self-improvement program—perhaps becoming a better piano player or learning to do better brain surgery. Of course, now that we think we know more about such things, I expect we don’t put much stock in assessing character by the lumpiness of someone’s head.
Some lumps are just annoying. I find lumps in my gravy, after I have stirred it and made every effort to make it creamy and smooth, to be aggravating. Lumps in my paint, cream of wheat, and all the other things I need and want to be smooth, can indeed be frustrating. It takes a lot of effort to remove these irksome insults to the order of my universe—I have to beat them with a whisk or paddle them into oblivion. Sometimes efforts to remove the lumpiness from life can have unfortunate consequences—as when I knock the paint can over in my efforts to remove the offending clumps or when gravy-smoothing efforts result in a stove that is bespeckled and besplattered.

Some lumps are just plain foreboding. When you find them on parts of your body that you know shouldn’t be lumpy, your stomach does a minor dip, your heart races a bit, and if you are cursed with a “worrying kinda mind,” you imagine that the end is near. Now a lump on your thigh or your arm might be dismissed as the leftover carnage from your last battle with a car door. A lump in your breast or testicle is not so easily dismissed—unless, of course, you are using these as battle weapons. I discovered my first foreboding lump right above my collarbone. But let me digress to my first encounter with this more ominous kind of lumpiness. It involves my mother’s own encounter with a lump.

**Mother’s Lump**

My mother, bless her heart, died in 1991 from throat cancer. She had conquered a serious case (is there really any other kind?) of lung cancer in 1985, and after extensive chemotherapy, which nearly killed her, she seemed to be doing well. Then, one day in 1990, she noticed a lump. A large lump. A lump that should not have been there. A lump that worried her. She didn’t want to give any contagious disease to her first grandchild (my daughter) who had just been born a few months earlier. So she went to the doctor.

My mother had a lot of interesting theories about why physical things happened. I think the one that she used the most was “Well, I left the window open last night. I think I might have caught a chill in...(at this point she would mention whatever was hurting or not working correctly).” She also blamed forgetting to take her vitamins as the cause of many of her afflictions. So I expect that she told the doctor that she had visited a friend with a cat and that maybe that’s why she had a lump in her throat. No matter the problem, she would have some explanation that satisfied her need for understanding why things weren’t the way she wanted them to be.

My problem is that for most of the aches and pains that afflict me, I, too, have an explanation, unfortunately not so benign as my mom’s: rampant tumors,
blood vessels about to explode, insidious neuromuscular diseases, or whatever
ailment I have recently read about that is sure to cause a quick and ugly or long and
lingering death. Never anything simple, like I slept in the wrong position last night.

Following the visit to the doctor, tests were run, and after some time she was
finally diagnosed with cancer of the throat. She then got to have some permanent
marks placed at strategic points on her head and neck so that she could sit under a
large radiation treatment device. The marks were to make certain that they put the
radiation into the correct place—if they didn’t, she might have developed green hair
or something. The idea, of course, was to kill all the cancer cells and thereby insure
that she could live to see her granddaughter graduate from high school.
Unfortunately, the radiation only succeeded in destroying her salivary glands and in
the end did not seem to help anything.

In 1991, my wife and I moved into her apartment, along with her one-year-old grandchild. We spent the last 6 weeks of her life taking care of her, with the help
of hospice, until she died in June.

My Lump

In 1991, I also developed a lump in my throat. In the same spot as my
mom’s. I knew this must be the beginning of the end. You see, I have one of those
“worrying kinda” minds—I have worried since I was a youth of seventeen that
every minor or major pain portended the end of my existence. This potential end of
existence is one of the features of the way the universe is set up that I am not fond
of. In fact, I find myself frequently highly irritated at this arrangement. I think death,
as the reward for all of our struggles, is not a satisfactory consolation prize. Of
course, an eternity of living, especially if you didn’t want to, would also be tiresome; however, I wouldn’t mind a chance to discover just how tiresome it might become.
Then, on the other hand, two thousand years of Bonanza reruns doesn’t appeal to
me. Perhaps it is best to let nature take its course.

When one finds lumps, one must do something. This time, I decided not to
ignore it—ignoring would be a good thing for me to do if I wasn’t consumed with
worry all the while I am ignoring whatever it is I don’t want to worry about.

So, with this lump, I went to my doctor and said, “I have a lump. Right here
in my throat.” I was relieved when he did not turn ashen white and say, “Well, I am
afraid you don’t have much time left.” Instead he said something like, “Well, let’s
take a look at this lump.” He did and said it was probably a swollen lymph node.
Now swollen lymph nodes can mean only one thing: rampant, uncontrolled cancer
of the lymph nodes. Why else would my lymph nodes get lumpy? Even though I
know they can get lumpy from doing their job of fighting infections, this knowledge often doesn’t help when I am in the middle of a doom and gloom moment.

**Needles and More Needles**

The next step in figuring this all out was going to be a fine needle biopsy (FNB). You can always tell something is going to be interesting when it has the word “needle” in it. At this point, I really wanted to know how much time I had left. My mental and emotional condition at this moment could be described as anxious, very anxious.

Speaking of anxiety, I think that when God, or whomever or whatever is in charge of such things, gave out the anxiety quotient, they gave me the large economy-size helping of this fear factor. I think I received enough anxiety for six or seven people. I sometimes wonder just who is in charge of quality control. I can tell that I received more than my fair share because I get anxious just looking up into the sky.

First, I realize that compared to the people on the other side of the earth, I am hanging upside down. I have enough trouble with body orientation as it is, so hanging upside down is not a good or desirable thing. In addition, I wonder why I don’t fall off into space, especially since I AM hanging upside down.

By the time I am through with this train of thought, I usually start feeling a little giddy or dizzy or disoriented or confused. Then I come up with the next level of explanation—I have a brain tumor that is pushing against some really important squishy brainy area, which is in turn making me feel unsteady. Once I have had this thought, I usually begin to feel really anxious and then I start breathing irregularly.

Now, breathing is supposed to be a normal, natural, easy sort of thing. I have managed to turn it into something akin to programming a VCR. As soon as I start thinking of breathing as something I need to “think” about, I am well on my way to panicking. After all, doesn’t it seem as though I am not getting the optimal amount of air? Therefore, I must breathe a littler deeper to make up for this lack. At this point, the part of the body that is in charge of breathing is beginning to think, “Just what is this guy up to?” A few more minutes into the process and it begins to think, “There is something seriously wrong with this guy.”

It all ends when I begin to feel as though I will never get enough air and that if things don’t change real soon, I shall pass out from oxygen starvation. This makes it pretty clear, I think, why I am of the opinion that God needs better quality control. The confusing aspect of this process is that I have NEVER passed out.
Don’t even know what it is like. Sometimes I believe that I am a few bricks short of a full load when it comes to learning from past experiences.

A fine needle biopsy is a fun affair, for those who have a truly warped sense of amusement. The physician takes a long thin needle and sticks it in your neck. Before he does this, however, he tells you all the thrilling and exciting things that might happen if things go amiss. The worst that I recall was the problem of the punctured artery. Or was it vein? The carotid artery or the jugular vein. You know, the one that Mack the Knife went after so effectively. If the person with the big needle doesn’t stick it in the right place—well, apparently this is less than good—a lot less. What makes it even more of an entertaining event is the fact that the good doctor is going to poke that needle in three, maybe four times, thus increasing his chances of hitting the wrong place.

Since medicine has become a big advocate of choice, I was given a choice of doing it with or without local anesthetic. I frankly didn’t view this as much of a choice. The problem is that they have to INJECT the anesthetic. I suppose the theory is that one painful puncture is better than three or four; however, I was not happy about the thought that soon my throat would be paralyzed and then I wouldn’t be able to swallow, and then the swallow mechanism would fail completely and I would choke to death on my own spit.

I decided to see how it would be without—less getting punctured that way. It was, surprisingly, not a big deal. The doctor asked me to hold still and then took what looked like a large syringe and put it into the area of interest. I must confess that holding still was NOT an issue. The vision of the doctor missing and poking my eye out because I was foolish enough to move, kept me rock solid. Then he pulled up on the plunger and ended up with some tissue from the nodule. He repeated the process three or four times and then it was all over. Nothing important was ruined as the cells that were needed were extracted.

At this point, my anxiety had risen to new heights and I asked the doctor to please look at my cells NOW. Not in a few minutes or hours but NOW. I would wait. No need to call me with results, as I would be right here—what could be easier? I think he could tell from the look on my face that he’d better check those newly acquired cells out now or he would be dealing with a quivering mass of pathetic humanity blubbering on the floor of his office. I think he decided that investing 10 minutes of his time now was a good thing to do. He fixed the slides, made them ready to put under the microscope, and took a look. Of course, he had me look, and if you have ever looked at cells under a microscope, you can really wonder what anyone could tell by viewing them. I personally think that what they teach in pathology school is how to most effectively terrorize the patient with horrible sounding words and phrases. They probably laugh a lot over the fact that
anyone could believe that anything could be figured out by looking at such a jumbled mess.

But the moment of truth finally arrived. Now I would find out what brand of doom I had and maybe even how long I had until check out time. Instead, I found out that we were looking at normal lymph tissue in a normal lymph node doing normal “lymphy” things.

Needless to say, dancing in the streets was called for. But since I am too inhibited to dance, let alone dance in streets, I settled for a huge smile, handshakes all around, and a brief skipping maneuver as I left the office.

**Showering In America**

This first experience with lumpiness did not really prepare me for my year 2000 lump issue. But before we get to this, I want to mention the issue of showering in America. We have turned showering into a medical sleuthing experience. We have little cards that show women how to do breast self-exams and men how to examine what we might call the “delicate danglers.” We are, of course, looking for lumps. In addition, we have to watch for moles that are misbehaving, as well as skin conditions that might foretell cancers of other sorts. So now, instead of being relaxing and refreshing experiences, showers can become harbingers of horror.

I found my lump while taking a bath. I noticed something near my collarbone that seemed lumpy. I didn’t think much about it, since I had grown less hypochondriacal in the last few years (ever since I actually managed to live until my 50th birthday). I figured it would go away. It didn’t. I kept thinking it was going away but thinking didn’t make it so. Then I noticed that it was getting bigger.

Now, as much as one might not like lumps, one likes even less lumps that are getting bigger. It was time to act. So I hid under my blankets and waited for things to get better. When that didn’t work, I went to see my doctor.

A word about doctors. Doctors impress me. A lot. Most general practitioners, as well as most specialists, deal with life and death issues on a daily basis. Each day they make decisions—whether to medicate or not, whether surgery is necessary, what does this symptom mean, what test is needed, and endless, important decisions—that substantially affect the lives of their patients. This seems like a really big responsibility to me. That’s why I want my doctor to be well paid and to be happy.

My doctor, who has been my physician for maybe 20 years, has always impressed me, mainly because he listens to me. He also seems to respect that I am
not stupid and that I can take an active role in my medical care. The following story is offered into evidence.

In the early 1980’s I began to suffer from anxiety or panic attacks on an ever-increasing basis (this would come as no surprise to anyone who knows me) and it was beginning to affect my ability to cope at work (as a teacher and counselor). More than once I had myself taken to the emergency room because I was certain I was dying. I began to read all the books I could on the subject of anxiety and panic. There have been lots written and after reading them I knew at least I wasn’t alone.

I read one book that seemed most closely to match my experiences, and decided to embark on a treatment plan outlined in one of the chapters. I went to my doctor and said, “This is what I want to do. Will you please prescribe this medication at this dose?” After a few questions and discussion, he said he would. It took about a year and a half, but at the end of that time, I weaned myself from the medication and now seldom experience full-blown, “take-me-to-the-hospital” panic attacks.

This is not to say that I don’t still have really dicey moments, make that hours, where I feel as though my body is not working right and my anxiety level just keeps moving on up until it reaches a fevered pitch. When this happens, I talk with my wife, who has grown quite used to the scenario. When these times come, she has the unenviable job of trying to convince me that I don’t need to run outside or to drive myself to the emergency room. When in the middle of a panic attack, it sometimes seems that medical help is essential or I will pass on, which makes it difficult to persuade me to stay put. Sometimes I will call a friend and discuss what is happening. Most of my close friends are used to this. As a last resort, I will take some medication that I keep handy—last resort because I really have always hated putting chemicals into my body or mind. This need for control, or at least the illusion of it, probably explains why I have never been drunk, smoked pot, or done any of the myriad other drug possibilities.

My gratitude and respect for doctors allows me to forgive them when they mess up. In my medical adventures I have experienced a number of medical errors, some that have affected me long term, others of only an inconvenient nature. My response, after my initial irritation, is to communicate what the problem is and then make suggestions for improving the situation. I don’t believe I would have it in my heart to sue my own personal doctor. Even if he made a horrible mistake. I hope I wouldn’t because I know he does his job with as much care and intelligence as he can.

When I visited my doctor (do you think “visit” is the right word?), he felt, he prodded, he looked, and then he said, “We need to find out what this is.” I had a
problematical protuberance.” It’s probably nothing, but we need to check it out.” Of course, I KNEW the end must be near and that soon he would be telling me to get my affairs in order (although there is not much chance of THAT happening because my affairs are extraordinarily out of order).

Most things do turn out to be nothing. Maybe up to 90% of visits to doctors are actually unnecessary—the problem would resolve itself with a little time. But then if you happen to be in that other 10%, it is important to do something. So it was time to start testing.

First we did an ultrasound to discover what kind of lump this was. What is interesting about ultrasounds is that there isn’t much that seems ultra about it and there seems to be even less sound. I also have a suggestion for people who like to invent stuff. Invent a gel for the technician to smear on you that feels warm and pleasant as opposed to cold and messy. Of course, nowadays with full disclosure thinking, they let you watch the ultrasound results on the pretty television screen. However, I think ultrasound people are probably trained just the same as pathologists—because, believe me, I sure can’t tell much about what is happening when I look at the ghostly flickering gray images on the monitor (color enhancements don’t help much, either). Nevertheless, they were going to answer the question, “Was it a cyst or something else on the thyroid?”

The test showed that it was not a cyst, which I thought was a little disappointing, since cysts are not the same as cancer. It was instead some sort of tumor or, as they like to say, nodule. Now I don’t like the word tumor or nodule for that matter. Tumor sounds sort of slimy and really lumpy and nodule sounds like a really tough bump that is growing where it shouldn’t be.

Once it was determined that it was a lump growing on my thyroid, it was time to decide whether this nodule was hot or cold. Now I thought it would be cool to have a “hot” nodule because that would mean it was less likely to be cancerous. And I didn’t like the idea of anything cold growing inside me—reminded me too much of being dead.

In order to figure out whether the nodule was hot, lukewarm, cool, or cold, it was necessary to ingest some radioactive iodine. So it was time to swallow two little pills and then have a scan, which would show how much iodine the nodule was soaking up. If it showed brightly on the scan, it was soaking up a lot and would be hot. If not much showed up it was cold. Mine was cold.

We knew it was a cold nodule, but that still didn’t tell us whether cancer had set up housekeeping or not. Time for another fine needle biopsy. Oh boy, more needles in the throat. I spoke to my general practitioner about which doctor I should see to have this procedure done. He suggested a local endocrinologist who was
experienced at poking stuff into lumpy thyroids. So, off I went to get more long sharp things thrust into my neck so that they could extract little bits of tissue from my nodule.

An FNB of a thyroid nodule is certainly not the most unpleasant thing one can have done, but it is definitely not the most pleasant either. I had to hold still and be calm while the doctor lunged at me with foot long spears designed to impale fish in tropical waters. Visions of a large needle entering my left eye helped me keep my head still (petrified would be more descriptive).

After four samples in various part of the nodule, we were done. I was glad we were done. I have decided that FNB is more fun when it is done on someone else. Since I had become more mature and sanguine about life, I was a lot less anxious to know the results. I was honing my denial skills, so I didn’t want to have anybody read the slides right away. I suggested that once he had the cells he should send them to a little pathology lab I had heard about—in Istanbul, Turkey.

Of course, as is so often the case, when the results came back two weeks later, they were inconclusive. I suppose inconclusive is better than, “Hey, this is a major, big-time life threatening cancer,” but then one must decide what to do to find out what is really going on. The “let’s wait and see” approach was becoming less and less an option, because if it was some sort of cancer, it would be best to find out now rather than waiting until it was, as they might say, too late. And with the lump gaining in size minute by minute (at least in my mind), I imagined that if we didn’t figure this out soon it would be a moot point—there would just be lump where my throat was, and this would effectively put me on a permanent diet.

At this point surgery became the next option. I don’t really enjoy having my body cut into. The whole idea of somebody knocking me out, taking sharp knife-like things and merrily cutting big holes in me is just not my idea of a good time. On the other hand, dying because I didn’t do something that needed doing was not an attractive option either. Life is a series of options, some more pleasant than others, so I needed to choose.

One of my positive characteristics is that I tend to be an active participant in my health care. In fact, I am a big pain in the derriere. I research everything I can about the problem, try a lot of different approaches, and then decide what I am going to do. I do recommend this approach to medicine as one way in which to feel less a victim and more of a person who is in control of their ship, or body in this case. Another approach is to totally trust that the doctors, technicians, and everyone else will get it all right and do the correct things and it will all work out. I am unable to do this, which probably explains why I have such issues around God and faith.
Alternatives to Surgery??

Before I played the surgery card, however, I decided to try a few alternative approaches. I didn’t pick up countless issues of Alternative Medicine for nothing.

Since hypnosis had worked to make my powerful fear of flying into a manageable problem, I thought it might not hurt to give that a try. Nodule reduction and disappearance through mind power. I liked that better than sharp knives. I tried a few sessions, but the nodule did not cooperate by going away. One of the perks of hypnosis was that it did give me a good excuse to sit quietly for a while and relax. I suppose I could have done more sessions, but the doctor who was doing it felt it was more prudent to get in there and find out what was really going on.

I also tried acupuncture. You know, the treatment where they poke a whole bunch of needles (there’s that lovely word again) into various special spots. I knew from a previous experience many years ago, that acupuncture could be painless or it could provide some moments of intense neurological excitation. The needles are very thin and I have never seen one go in—I always close my eyes around needles of any kind. I was willing to put up with the pain if the needling effort caused the growing mass to move away to more hospitable climes. It didn’t, but I did get to experience a few minutes of quiet as I lay upon the treatment table, and since I have never been talented at being still, this forced quiet was good practice. It is easy to be quiet and still when you have sharpened needles poking out from different body locations, especially when I never really knew exactly where they were.

Next came Chinese herbal medicine. That’s the one where you get to brew noxious-smelling and evil-looking potions and then, instead of rubbing them on the sore spot, you DRINK them. I think the theory here is that if you give the patient something so thoroughly unpleasant and distasteful, they will force themselves to get better so they don’t have to take it anymore. Unfortunately, it didn’t seem to have any effect on the thing growing in my neck, but I did learn to overcome my revulsion to horrible tasting concoctions.

I even got a treatment using a porcelain spoon and some mighty powerful scraping action done to my shoulders and back. I looked a bit like I had been in a losing battle with a wringer washer. It was never really clear to me how this would help, but you can see that I was devoted to avoiding surgery. These forays into alternative medicine did not make the nodule disappear, so it was now time to find the best surgeon on the west coast.

In my efforts to avoid a fate worse than death (is there really such a thing?) I traveled to the University of California San Francisco (UCSF) Medical School to have a consultation with the doctors in their thyroid clinic. You can tell if you have a popular disease by whether or not they have a clinic for it.
Surgery It Is

The doctors reviewed all of my tests and results and concluded that everything had been done well and that yes, it was time to slice away. I then asked the doctors one of my favorite medical questions: “If you were going to have someone cutting into your body, who would it be?” Word of mouth advertising is about the only way to choose a doctor to do something. Of course you could investigate insurance claims, malpractice suits, and other legal matters, but since just about every doctor has been sued, I am not sure that this information would be helpful—unless of course, the doctor had 250 malpractice suits in the last year. I tend to think that personal recommendations are probably the best way to find out which doctor does the best work.

Based on the input I received, I chose my surgeon. My wife and I then marched over to the sixth floor surgery practice to see when we might get an appointment. I could tell this surgeon was top notch when his office staff said, “The doctor has told us to fit people into his schedule if they have traveled a long way to come to the hospital,” so we were given an appointment a few hours later on the same day. When you have a lump that is enlarging by the minute, time always seems of the essence.

We met with the surgeon to discuss my many questions about the surgery. One of the reasons I became so fond of my surgeon was that he took a lot of time to answer each question completely. By the time we were done, I felt that if I was going to have someone cutting about in my throat, this was the man to do it. I had my first surgery on the day of my wedding anniversary. Now I ask you, can you think of a finer gift to give your wife than: “Hey, I think I’ll have some surgery on our wedding anniversary—doesn’t that sound like a fun time or what?” That was our 13th anniversary on the 23rd of July.

One of the joys of surgery is that one does not always remember much about it. I do remember that I was not looking forward to it. In fact, I kept trying to find others to go in my place—strangers, hospital workers, maintenance people or just innocent folks getting on the elevator—all were possible candidates. My efforts did not prove successful. NO ONE, I repeat NO ONE, wanted to volunteer to have their thyroid removed. So I was stuck with having to be present for my own surgery.

In that time before surgery, when I was “resting” on the gurney, waiting for the operating room to become free, I had a definite need for entertainment. Something to distract me from the events to soon transpire. I have always felt as though it gave me a small taste of what it must be like to be waiting to be executed. By that remark you can see how much of a worrier I am. I mean, almost no one dies on the operating table these days. But it made me nervous to think that soon a
friendly person dressed in lovely white clothes was going to come up to my bedside and say, “Here, we are going to give you a little of this in your I.V. It will help you relax.” What they didn’t tell me was that in a matter of seconds I would begin to feel my brains oozing away, the room beginning to slowly vanish and then... TA DA. I was struggling to wake up from the anesthesia three hours later. I do find it amazing that I could have a chemical injected into my pretty red bloodstream and then find myself in the recovery room. It might also be obvious that I did not participate in the festivities of the late 1960’s. My wife did manage to provide me with conversational distractions. In addition, she read to me from the well-wishes of my friends, who were gathered at the party described below.

I soon found myself being whisked along corridors to a strangely lit and colored room filled with odd odors and sounds. I know all of the following happened but only because I can still see the evidence of someone cutting about on my body. The anesthesiologist probably said something like, “Here, breathe in,” or, “Count backwards from 99,” or some other equally compelling command. Then he proceeded to take me to death’s door where I would spend the next few hours—completely oblivious to everything. It is a sobering thought to realize that for a time there, I was at the total and complete mercy of people who liked to play with knives and noxious chemicals. Of course, I must say that I am pleased not to have been present for the fun, because if I had been, I think there would have been a lot of screams echoing from that shiny tiled room. The surgeon then performed his rituals—cut, separate, look, tell a joke, and hopefully never say, “Oh Lord of Darkness, I give to you this sacrifice.” I imagine that there were a lot of other players in the drama of my thyroid surgery, but I did not have the pleasure of making most of their acquaintances.

Following the surgery, I suspect that I was wheeled quietly into the recovery room where I got to hang out with a lot of other nearly dead folks. My recovery was not uneventful. In fact, I found it so upsetting that they had to give me another dose of tranquilizer to calm me down. What happened was that when I attempted to wake up, I felt as though I could not breathe. I found this upsetting, I have always found it so, and I let them know about it—my exact words at the time were: “Help! I can’t breathe. Help! I can’t breathe” accompanied with the thoughts of “Where in the heck am I” and “I have no idea what is going on” followed by more “Help, I can’t breathe,” even though, in retrospect, I realize that it is difficult, if not impossible, to yell and not be breathing.

I did eventually apparently calm down (better living through chemistry triumphs again) and was able to act in a more dignified manner as I awaited my release from the recovery room. Fortunately, my wife was there to point out the foolish nature of many of my worries—it is nice to have someone who has a better grip on reality be in charge of things.
While I was “under the knife,” as they say, my wife had set up my shrine, which was created following my pre-surgery party that was held on the 21st of July. At this party, I invited about 20 people to come and give me moral support as I prepared for this life experience.

It was a great thing to do. I got to tell a lot of jokes (by this time you have figured out I am pretty self-centered and have a stand-up comedian buried somewhere inside who keeps trying to get out and say funny stuff) about surgery and life, and I made everyone take a quote (which I had put onto fancy paper—suitable for framing!) about friendship and read it. Quotes included: “Friends are as companions on a journey, who ought to aid each other to persevere on the road to a happier life” by Pythagoras, and “Keep a fair-sized cemetery in your backyard, in which to bury the faults of your friends” by Henry Ward Beecher, and “Good friends are good for your health” by Irwin Sarason, plus lots of others.

Then I asked everyone to write (on a small sheet of paper that would fit in with my protective amulet—which was blessed by His Holiness The Dalai Lama—I am spiritually eclectic) some good thought or encouraging message. We then made a game out of it by having people guess who wrote which one.

Okay, okay, I know this is getting to be a bit much, but I was scared and wanted all the support I could generate in the universe because I wanted to survive the experience. In any case, my wife read all of these messages to me before the surgery, and it was so helpful to feel connected to the positive thoughts of close friends.

This whole section is actually meant to be a suggestion as something really good to do for yourselves if you face more crisis times in the future.

Post Surgery—New Surgery

The results of the partial thyroidectomy were that the nodule was identified as follicular carcinoma. It’s odd how many different names we have for cancer—neoplasm, malignancy, tumor, etc.—I would have preferred an “ffc” (follicularly frolicking cells) diagnosis.

So my surgeon phoned me at home on the Friday following to give me this, may we call it UPSETTING news, and tell me that he had scheduled me for another surgery on the next Monday.
I said, “Hell no, I won’t go”—but I knew that was my thyroid, or what was left of it, talking, so I took control and said, “Sure, great excuse to see the fine views from UCSF medical center again (and it really does have some mighty fine views of the City). When I hung up the phone, I confess I used some very colorful language to describe my feelings about the news I had just heard.

When a doctor says that you have the big C, it can cause a shift in your view of life. First, I noticed that perhaps, contrary to thinking that had been going on for 40 or 50 years, I was not, after all, going to be immortal. As I mentioned before, I find this arrangement of the universe to be somewhat less than satisfactory. As Woody Allen is often quoted, “It’s not that I am afraid to die, I just don’t want to be there when it happens.” I would like to say it transformed me into a Mother Teresa type of guy, but it didn’t. On the other hand, it has made me more aware of how important it is to do the things I want to do—like write, talk with family and friends, and work on my spiritual life. As many cancer patients will tell you, it really does cause an improvement in certain aspects of our lives. I do imagine that most would rather not have it, although I have read of some who actually had such life-changing experiences that they wouldn’t trade the experience for anything.

Following the surgeon’s call, we again took the three and a half hour drive to San Francisco and the fine hospital views. When we arrived at UCSF medical center, we went into surgery check-in, which was always full of a variety of fascinating people. Family members hovered around the loved ones who were soon to disappear into the secret realms of the hospital. They nervously talked about who was going to feed the cat or when Uncle Bob would be coming to visit and who was going to stay with the patient and who would pick them up, or any of a thousand other little things that we all talk about. Others tried to immerse themselves in books or magazines in an effort to cope with the knowledge that illness had struck their family and soon they would be embarking into new territory. I usually chattered incessantly with my wife about whatever popped into my head (this was not always such a great idea).

Since one of the scheduled surgeries was completed really quickly (which I figured could either be a really good thing or a really bad thing) and another was canceled, I found myself being whisked through the system much more quickly than for the first surgery. In moments I was undressing for surgery before I was even officially admitted. I kind of hoped that maybe some high official might come up at the last moment and say, “Well, you just can’t do this, so you’ll just have to go home,” but instead I found myself lying upon my back trying to act cool and confident. But I mostly whined a lot and looked petrified.

I also had an extended and anxious conversation with the anesthesiologist about how I liked living and how much I liked her and couldn’t she see that and did she like me and what a rotten time I had had with coming out of the previous
anesthesia. The anesthesiologist (try typing that three or four times!) was very understanding, actually listened to my concerns, and assured me she would keep me alive. I was relieved to hear that. My surgeon told me that he had done many surgeries with this experienced anesthesiologist and had complete confidence in her. The “gas doctor” also told me she would use another formulation to make it easier on me. Apparently she did, and I had no trouble waking up from the surgery. I did not even have to use my sign that I had printed that shouted to me: “YOU CAN BREATHE.” It was obvious that I did not want to go through another “I can’t breathe” extravaganza.

The other thing I did for both surgeries was ask to speak to a Chaplain—because I like them to hold my hand in the recovery room—it makes me feel safer (Lordy, I am such a little kid sometimes). I suppose I had better address the issue of God and surgery. I think that whenever we feel threatened and perhaps out of control, we look to people or thoughts with more power than we feel we have. God is a perfect focus for these concerns. He/she/it is, at least according to most systems of thought, pretty darn powerful and can supposedly influence events here on our dustball. That’s why I call upon Chaplains. I hope they may have some influence with the big guy, and I know I need all the help I can get in order to survive the experience. I had intern Chaplains both times, and I always felt that I was doing them a service—providing them with the experience of dealing with a wreckage of nervousness and anxiety. They both did admirable jobs of helping me feel connected to the living. Of course, my wife managed to get into the recovery room both times (she can really let the hospital people know what they need to know and what they need to do—in ways that make it happen) and hold my hand, which was a big help.

One of the most helpful things that I did was discover a support group living in cyber space. I don’t know if they have green tentacles or gray skin, but I do know that their words of encouragement and their knowledge of thyroid issues was a tremendous help to me. I received large e-mail messages with advice about the low iodine diet and what to expect during treatments as well as lots of stories about successfully coping with thyroid cancer.

An online support group is a wonderful way to spare your family hours of incessant whining about how awful it is and how discouraging it all is. Using the wonders of technology, I can spill my inner most guts (metaphorically speaking) and know that the people who read it will understand and not get annoyed. Of course, all wives who have to care for their ill husbands need to be nominated for some form of sainthood. Even with all of my electronic moaning and groaning, I still managed to inflict a healthy helping of misery and complaining on my wife.

The surgeon reported that things went well (I think they always say that unless they accidentally remove the wrong organ or amputate things which were
meant to be left attached) and I eventually got a room (this due again to my wife’s persistence—because they said they did not have any beds and that I would be spending the night in the recovery room and she informed them that then she would be, too) on the 14th floor with a magnificent view of all of San Francisco and its myriad of “What power shortage?” lights.

I think a room with a view is a help in the medical healing process. It probably has to do with the fact that if we are looking at something more than the moaning curtain of the poor guy next door, we probably can think more uplifting thoughts. Thoughts such as “maybe I will survive this experience after all” or “I’ll be a better person if I make it through this.” No matter what, I really appreciated the fact that I had a panoramic view of the San Francisco skyline to take my worrying mind to better thoughts.

Probably the least pleasant experience while up there was the nurse who, not realizing she was dealing with an “ANXIETY PRONE HYPOCHONDRIACAL KINDA GUY,” said not to tilt my head or bend it or lean back or I would bleed. Now bleeding is something I don’t willingly do—period. I like every little red drop to stay right where it belongs. So I spent a lot of the night worrying about my head falling off and bleeding to death (this did not promote restful sleep). Since my head is a bit on the heavy side, not, I am sure, due to the size of my brain or the weight of my thinning hair, it tended to want to tilt this way and that. This was, I was certain, going to result in my untimely demise due to excessive bleeding. My 26 year-old stepson came up and held my hand for several hours, which was truly a very sweet thing. Human, loving contact when I am in a vulnerable position (which I mostly blame on the world-famous “gowns” they make you wear) really helps.

Well, I survived the night of worry (no blood except in my IV tube) and was able to greet the morning along with my wife (who always spends the night in my room—again this is such a support). I can’t say I felt rested, but gratitude was more powerful than weariness.

It was also time for the walk. You know, the one you have to take so you don’t die of blood clots or something. So I attempted to sit up. Of course being only hours from the surgery, I didn’t feel exactly steady. The hospital worries a great deal about being sued, so they make you sit up slowly and then wait. They don’t want you falling down and bumping your head, thus creating a lawsuit lump. Next you have to take a few steps and see how it goes. It is also necessary to make sure that you master the fine art of traveling while bringing along complicated medical equipment, namely the IV machine. The main thing is to not panic when it begins making ominous beeping noises. These beeping noises do not mean that it is going to explode or that it is going to start injecting deadly chemicals. Generally it
means that the machine is trying to let you know that it is there and that it is important and you should pay attention to it.

If you manage to roll the machine along without tipping it over or getting the many hoses, wires, and tubes caught on things, then you can begin the lovely, leisurely walk down the hospital corridors. Usually you will get the chance to see others ambulating hither and yon, all attempting to avoid blood clots that would bring their lives to an untimely end. I managed to make it to one end of the hallway where I then decided the best thing to do was to sit down. This was to avoid the problem of falling down and exposing my buns to the world because those hospital gowns never gracefully drape themselves over bodies lying on the floor. After a suitable rest period, I returned to my room and collapsed onto my bed.

That day I had a lengthy conversation with a pharmacist that I requested meet with me in my room. Our discussion centered around the question: “levothyroxine sodium—medication from Hades or Gift of the Gods.” He convinced me that levothyroxine sodium was not evil (since I had read some disturbing posts and articles about it), so I agreed to take it. I am already feeling quite attached to the little pill—in fact, having read so much about “Hypo Hell”, a place I do not wish to spend much vacation time visiting, I am trying to figure out how to make sure I always have a 6-month supply available. I am also trying to figure out if I’ve got what it takes to invade pig farms, steal the little porker’s thyroids, dice and mash them and make desiccated thyroid replacement—I know this is not a very generous attitude toward fellow creatures, but… The only other hurdle required at this time, was finding someone to say “Okay, let this man go.” Moses was not available. By one o’clock I was safely ensconced in a really nice apartment, provided by a long-time friend, about 11 blocks from the hospital.

The story now draws to a close. Following my first surgery, I took a couple of Tylenol doses, slept a lot for a couple of days, and began to feel my usual tired self. Following the second surgery, I took six or so Vicodine (I bet every person reading this knows what that is), some sleeping medication to aid sleep (it seemed to work well), and slept a great deal during the day.

Part 2

One of the downsides of not owning a thyroid any more was the fact that until the medication got adjusted, I couldn’t be sure of what my energy level was going to be. The best description was usually “tired.” In addition to feeling tired, it was often difficult to sleep. This paradoxical situation resulted in sleepless nights which then caused me to wonder if I was getting enough rest. Of course, with my mental bent I usually worried about what is going to happen if I never slept again. This could cause me to become slightly more unhinged than usual. Thus I did take
medications that induced sleep. I don’t really know how they did it—I imagine that the little molecules of sleep stuff ran up to my brain and then whispered into the cavern: “You are getting sleepy, very sleepy” and this resulted in my brain getting tired and falling asleep.

The scariest part was that several times during the day I would get a “sinking” feeling (reminds me of Victorian accounts of people having “spells”), which I addressed by crawling quickly under the covers and hiding. It was really strange—one moment I would be functioning fairly well, reading or watching television, when suddenly all the energy would depart in a matter of seconds. At that point I could think of only one remedy: go to bed NOW. Not two minutes from now, but now as in use whatever energy you have left and move rapidly into the bedroom before you pass out. I always made it, and then I would just huddle under the covers and wait to see if I was going to die or recover. Overall, I would rate this part of the experience a minus 5.

It was now two weeks past the first surgery and my energy level seemed close to normal, I had almost no pain in the surgery area, and this whole experience didn’t seem too awful (except when I thought: Arrgghh—I’ve got cancer, I’ve got to take medication the rest of my life, and I have treatments ahead that might be difficult—so I tried not to think much about that part).

The Week of the Scan

One of the aspects of my particular thyroid cancer that provides ongoing entertainment for me is the fact that for a number of years I will get to be scanned to see if there is any spread or, as they like to say in the trade, metastasis, of the cancer. The upside of scans is the opportunity to take time off work. The downside, for some people, is called “Hypo Hell.”

When the body doesn’t have a thyroid gland, there is actually nothing to produce thyroid hormone. This hormone is responsible for the body’s ability to produce energy from the food it takes in. No thyroid, no energy. No fun. Fortunately, in the late 1890’s, someone discovered that it was possible to use desiccated animal thyroid, which contained hormone to treat hypothyroidism. In the 1950’s, a synthetic hormone was made which made possible more availability of thyroid replacement treatment. Thus, there are now millions of people around the world who take a little pill once a day and keep on functioning.

In order to prepare for my scans, several things needed to happen. But there were a variety of viewpoints about each of these things. First, some of us need to go on the famous (at least in thyroid circles) LID. This stands for Lousy, Icky, Diet more commonly known as the Low Iodine Diet. Why low iodine? The theory is that
thyroid cells, even if they are cancerous, soak up iodine. So if you deprive them of the iodine they like, then when you offer them some they get really excited and take it all in. If you go on a low iodine diet for a couple of weeks before a scan, when it is time for the scan, which involves radioactive iodine, any cells in the body will take it up with gusto.

Let’s really look at this low iodine cuisine. One needs to avoid a number of things, most notably IODIZED SALT. Of course, EVERYTHING that is tasty, satisfying, filling and edible has iodized salt in it. So the diet I was given required that I never eat in any fast food restaurant, regular restaurant, or specialty restaurant. In addition I was told not to buy pre-made dinners, canned goods, or frozen dinners. So what is left to eat? This is America where we are not used to thinking about what we need to do to get food to eat. We just pay our money and eat. Okay, it’s not quite that bad, but it’s close. A positive aspect of this diet is that one is relegated to eating good healthy food. Fresh fruits and vegetables, homemade natural breads, and an absolute minimum of processed foods. So actually, the LID is a great diet. It just takes some getting used to.

In addition to the low iodine diet, some of us must venture into the territory fondly known by all who have been there as Hypo Hell. You are required to stop taking your medication in order to cause whatever thyroid tissue that is left in your body to want to absorb the radioactive iodine used in the scan.

Traversing Hypo Hell is a truly individual experience. During the two or three weeks that one is required to be without medication, a variety of responses can happen. Some people keep working until the day of their scan, while others find themselves so tired that they spend a lot of time just lying around.

I was somewhere in the middle. There were times where my energy sort of drifted away, floating into the sky, leaving me behind. When that happened, I would do the smartest thing I could, pretend it wasn’t happening. When that didn’t work, I would then fall back on that old favorite of going to bed.

Of course, as you have gathered from previous comments, going to bed does not mean going to sleep. I often didn’t feel like reading because while in the state of hyponess, I found that my mind was operating in some sort of state of mushiness which made reading a real challenge. Often I was forced to resort to that standby of many late night insomniacs, talk radio. Always something fascinating, whether out-of-body experiences, alien encounters, or time travelers. I’ve heard just about anything oddball or different on late night radio, so I don’t even feel that odd anymore.

Another aspect, for me, of being hypo, was the way in which my brain began to behave in new and different ways. There were times when my brain seemed to
slow down and sort of become foggy. There was one occasion at work where I was
given a piece of paper with information about an upcoming meeting. As I was
looking at it I was carrying on a conversation with a teacher and then wanted to tell
her something about the meeting. As I looked at the paper, I realized I couldn’t
figure out what it said. It gave me a bit of insight into what it must be like to have
learning disabilities. Of course, people who have these kinds of difficulties generally
live with them all of their lives—I hoped that this mind fogginess would dissipate
whenever things were back to normal.

Next follows a cautionary tale about preparing for scans.

My dear wife and I started out scan week on a stunning note—we spent 8
hours in her classroom getting ready for a substitute teacher for all of the week. The
stunning part was the fact that we didn't get on the Road to Tracy (Motel 6) until 1
a.m. This was well past my usual bedtime. Being at the end of my second week
without thyroid hormone, I was pretty useless as far as helping was concerned,
although I managed to trudge about a bit and deliver a few items. Mostly I made
vain attempts to sleep under a classroom table, which sort of blocked the bright
fluorescent light.

In any case, we left Copperopolis School at 1 a.m. under the clear dark
nights that very small hamlets away from any large town seem to have. This bright
clear night seemed to bode well for a quick trip to Tracy so that we could spend less
than $15 an hour for the privilege of a bed; however, this was not to be. We rounded
the last hill dipping into the valley when we noticed that mother nature and her
minions had created a little surprise for us—in this case rather dense fog (now we
weren't unaware that fog appears frequently in the valley, we were just unaware that
its blanketing curse would fall upon our little fellowship when we were so tired and
on such a noble quest). Carol didn't want me driving (nor did any other sane driver
on the road want a hypothyroid male who thought he was just fine, tooling about),
so she had to drive. Speed was not the operative word in this portion of the
adventure. We pulled into Tracy at 2:55 a.m. and were in bed by 3:10 a.m., with a
wake up call at 6:30. This did not result in a refreshing night's sleep for anyone.
Traveling to 10 a.m. appointments at University of California San Francisco
Medical Center or anywhere else in San Francisco is similar to getting ready to
make an international flight to Tahiti (which sounds like a better option
anyway)—you allow lots of time. Carol deftly drove her semi-conscious hubby
across the Bay Bridge, and we arrived at the parking garage with time to spare.

We next went to Nuclear Medicine (after a brief coffee stop for a caffeine
lift for my wife) and registered and I picked up my strip of stickers (see they even
give out stickers when you go to the doctor's—although I keep asking for Winnie-
the-Pooh, they just smile indulgently and hand me a rather boring set of names and
numbers and insurance information stickers) and then went off to get scanned.
At this point we paid a visit to a Fellow, in this case a pleasant woman, whose job was to ask me a lot of relevant questions about all my previous medical adventures. The purpose of this was to determine whether Nuclear Medicine was right for me. Unfortunately, she asked the right question at the right time, but the wrong time for me. She said, “Have you had any CAT scans in the recent past.” My answer was, “Yes, about a month ago.” At which point the entire nature of our conversation changed. She said, just a moment, and left. You know things are not going well when they leave mid-conversation.

She returned a few minutes later with news. Namely, she was uncertain whether I could have the scan, because the wonderful clear stuff that had been pumped (with some vigor, I might add) into my veins for the CAT scan could possibly mess up my current scan. This was not the kind of news people who had been planning for weeks to take a week off work wanted to hear. We had made numerous arrangements for lots of things, including preparing a week’s worth of lesson plans for my wife’s class, and arranging a place for our eleven-year-old daughter to stay, as well as transportation to school for her. We also had to stop the newspaper and mail and make sure that there was someone to take care of the cat, six chickens, and hamster.

Hope did momentarily rear its optimistic head after a conversation with one of the head doctors. He said that if we had a 24-hour urine test for the presence of iodine, and if it was low enough, I could go ahead. The part he didn’t know was that this test would not even be possible for me. First, I would need to collect the urine, not in itself too tough a job. Next I would need to take it to the lab and have it analyzed. Therein lay the problem. After much investigation by phone, including calling my own friendly local hospital lab, I discovered that short of owning my own private jet, the odds were zero that I could get this test done in a timely manner. The only place that performed this specific urinalysis was located in Minnesota. This is not particularly close to California. I found out, in addition, that they do this test only on Mondays, Wednesdays, and Fridays. Which meant that even if I collected all the required liquid on Tuesday, unless I could teleport the container by Wednesday, the earliest this test might have been done would have been Friday. At which point, we thought, “What’s the point?” So, taking my own medical future into my hands, we left. The lesson: I wish I’d known all the questions I needed to be asked so that they got asked at the right time—in my case at the pre-scan visit two weeks before.

So we had the task of redoing all the things we had done before; however, the good thing was that we were much more efficient at completing all the arrangements. We had the urine test done and the result was completely satisfactory and would allow me to have my scan. We rescheduled and embarked on the next chapter of our adventure.
Upon arriving at Nuclear Medicine (I think capitalized looks more impressive), we were ushered into the spacious conference room. A broom-like closet stuffed with linen, a radiation counting machine, a waste barrel, and a couple of stools. Someone was always saying, "Here, I'll go find another chair." Maybe most patients don't travel with an entourage—in my case, my wife.

The technician, who was from Belfast, Ireland, told us what would be happening; (believe me, on this visit, not much). I would take a pretty purple pill (PPP) and then come back on Tuesday to be scanned AND photographed. The thing about these PPPs is that they always come in lead cylinders that remind one of bowling balls in terms of weight. They really like to keep 'em safe. The technician then handed me gloves (I felt so Doctor-like), then opened the lid, picked it up and handed it to me saying, "Take this with some water and come back tomorrow." What I was getting was 3 milliCuries of radioactive Iodine. I took the PPP and then we left. Not the stuff drama is made of.

We then stopped by a church that we have driven by numerous times because Carol especially wanted to see the interior and it had always closed just before we got there—it is a sad state of affairs that Churches no longer remain open during much of the day. I went looking for a rest room (needing lots of rest in my "hypo" condition). The Church, St. Anne’s, was quite Churchlike and moderately magnificent. We then headed to some Chinese grocery stores to stock up on exotic low-iodine foods—but then what else is there to do when in some of the neighborhoods of San Francisco?

Having gotten our coconut milk, Halva, Dolmas, etc., we then headed to Pacifica and our complimentary stay (that's another whole story involving fire alarms, threatening phone calls, the Internet, and the police—just so you don't think we lead TOTALLY uneventful lives!) at the Big Chain motel with a fabulous view of the pounding seashore; well, actually, it was the ocean that was doing the pounding. We then spent a very pleasant afternoon and evening watching the surf and surfing the channels, which always brings home so clearly the concept of "A hundred channels but nothing to watch." We had a "brown bag buffet" in our room (where Carol discovered that the exotic pineapple salsa's main ingredient—it was deceptively colored—was cayenne pepper). We really enjoyed the quiet rest after our late night drive in the fog and early rising.

Tuesday morning we arrived at UCSF, parked in the garage and paid close attention to the location of the van. More than once we have misplaced our vehicle, which always causes a bit of a delay. We then went up to begin the day's festivities. The Belfastian technician sat me in the "conference" room on a stool and put the probe device up to my neck, and left it there to count the little radioactive particles that were leaping out of my thyroid area (did they know something I didn't). He left
it there for 6-8 minutes, came back, and then put it on my thigh to get a background level. Something I found out later was that it really only needed to be there for about 2 minutes—but the way I look at it, I got an extra 4 minutes of holding-still practice.

Then he escorted me into the "Room of Doom," or so it must look to little children and anxious adults. There is a huge machine with a narrow metal bed under an extra-extra-large pizza box sized square “thingy” that hovers over bodies that are prone upon the bed. This was to be the short 10-minute scan of my thyroid. But before they could do that, I had to be injected (what would a visit to any hospital be without at least 1 injection?) with the latest toxic brew, in this case Technisium 99 (sounds like a gasoline additive), which was going to help the machine see an outline of my body, otherwise any activity in the thyroid or elsewhere would just show up as bright star clusters floating in space and not, for example, tumor activity in the right femur. Helga, my injector told me that she hated people, especially anxious, wimpy men and that she was in a really bad mood because the whole place was full of idiots and she was into S & M especially the S part and….just kidding, but you can see what I think about whenever I come face to face with sharp pointy objects people want to stick in my body parts--in this case the back of my hand. I was then positioned on the cute little narrow bed with some fluffy pillows (well, not really fluffy—just serviceable) to support my knees and extend my neck in as uncomfortable position as could be managed.

Now comes the exciting part (there are, regrettably for the storyteller, very few exciting parts in this kind of an adventure). The great pizza box was maneuvered gently to within tongue-licking distance of my head, at which point I had to ask, just what stops this thing from squashing my head, which I am fond of, like a cigarette butt on a sidewalk? I was reassured that they were constructed in such a way that that couldn't happen (maybe lawyers do have a place in society!?). I was told to lie still (and I always do what I am told when the opposition has large, head-squashing equipment available), and the scan was completed in 10 minutes.

That was it, except to look at the pretty picture of my body and to be told that, “Yes, you don't have a thyroid, and yes, there is residual thyroid.” The thyroid tissue that had been tenacious enough to hang around after the surgery would have to be wiped out, killed, removed and made to disappear. Leftover thyroid after surgery is normal—if the surgeon tried to get it all, the odds are excellent that I would lose my voice permanently or have vital parts mangled, or any of a variety of things that are not desirable. All of this for the sake of being able to figure out if the thyroid tumor had spread anywhere else. That being done, we were off to Half Moon Bay to stay at a long-time friend of Carol's named Long-Time Friend (well, actually her name is Nancy)—me to rest under my heating blanket (being hypo means that I am not fond of temperatures below 95 degrees) and Carol to visit with her friend and do some reading.
Wednesday was a free day. Oh boy. The only problem was I was as energetic as a tired tomato worm, and so sightseeing was not in the cards. We did taxes instead—hoping to cause someone at the IRS to expire from shock because we were getting them in before October.

The next morning we left for UCSF Med Center and arrived promptly at 10. I went up to the third floor and my appointment while Carol went to park (hah, what silly people we hill folk are). The gargantuan, multi-story parking garage fills up at 9:59 (something only the locals know), and so Carol spent a frantic half-hour roaming the parking garage looking for a space. The search was fruitless, and she was forced to resort to the more treacherous waters outside the garage. Eventually, she located a spot some distance below the hospital, that would be good for two hours (which is about an hour less than what one always needs for appointments).

They then did another throat reading (“You are going to take a voyage soon with a tall dark stranger carrying your bags, which will be full of inherited money and your family will be moving to a new planet….“). It was now time for the Full Body Scan. During this time I was required to lie on that comfy little bed again, only this time for 45 minutes being perfectly still (they said I could breathe if I really needed to do so). Then this giant camera thingy (in case you didn’t know, that’s its technical name) moved slowly down my supine body, snapping happy little pictures as it made its merry journey. When it got to my feet, they decided that it needed to now go up my body, so it did. Being the somewhat prepared person I can be, I had brought my Discman with relaxing but alert music ready to play in order to pass the time (it did help).

After some sort of influential and hopefully very competent doctor looked at all of the lovely pictures that had been taken of my slightly radioactive body, it was now time to decide what to do next. The conclusion was that I needed to take another PPP. Only this time it was going to be a Particularly Big PPP full of 150 milliCuries of radioactive iodine. The purpose of this giant dose of radioactive iodine 131 is to ablate the leftover thyroid tissue. Ablate is a euphemism for annihilate or massacre or kill or bludgeon to death.

When all was done and decided, we were ushered into the “conference room” for a meeting with the Radiation Safety Officer. But we had to be moved to the photo room, because it seemed people were always needing to use the radiation-counter thingy.

The Radiation Safety Officer’s job is to make you realize that, after you take the next PPP, if you take a wrong step you could become a nuclear device suitable for small-time terrorists. In addition, he wants you to know that there is no such thing as radiation safety. The most exciting news (this is reaching) was that I was going to have really radioactive urine for the next few days, so there was lots of toilet
talk. I also received written instructions on what I was to do after I had become a radioactive monster—visions of the Attack of the 50-Foot Man came to mind. These instructions told me how far to stay away from people, where to sit in the car on the ride home, and what to do after answering nature’s call—flush twice. All of these admonitions were to stop me from contaminating my world and inducing radiation sickness in family and friends. Of course, I read one study that indicated that none of these precautions was even necessary. The world of medical information seems to be constantly changing and often full of contradicting studies, which, I must say, doesn’t really increase my faith in medicine a great deal. In fact, at times it is enough to make one just want to move to a tropical island and throw your fate into the hands of palm leaf shakers.

We then had a lunch break, which consisted mostly of trying to find the Big Red Van that we came in. Carol had misplaced it. If you have ever been to San Francisco, you know that it is famous for its steep streets. Gazing down one of these we thought we saw the red hood of the Big Red Van. So Carol sent me down the steep hill to look for it, but after an exhausting trek I discovered it was not even the right color red, let alone the missing van. Carol then came down the steep hill, while I went up the steep hill, to rest and, as someone famous once said, “The game is afoot.”

After about 15 minutes I began to worry that my wife had fallen into an earthquake crack, so I decided that it was time to move into action—hah, hah (hypo males/females may not be able to put much act into their action). I stood up, a feat in itself, and attempted to hail a cab. One came down the street and so I hailed it. I then said I was looking for a woman in a red sweater—I think he thought that was an interesting destination. I then explained the lost van and at that moment Carol appeared at the bottom of the street. I said to the cabbie, “There’s the woman in the red sweater,” and we were off. We picked Carol up and within a few moments were embarked, this time without the strain of walking up and down steep hills, on the continued search for the van.

Fortunately, in a matter of two or three minutes we were in sight of the van. Carol got out in order to embark on the next great search—finding a new parking space. The immensity of this task cannot be underestimated. The streets of San Francisco are littered with the bones of people who couldn’t find a parking space and made the mistake of leaving their cars for a few moments. Of course, the cars were immediately towed away to some clandestine garage somewhere, leaving their drivers to the hazards of the streets of San Francisco. We were thankful that we had not been ticketed or towed. I had the cab take me to the entrance of the hospital and I paid the fee for the nine-minute ride—came to about a dollar a minute.

I went to the cafeteria to get a bite to eat. The hospital cafeteria had a rather large selection of food items, none of which were labeled low iodine. Quite some
time later my ever-faithful, but very tired wife found me and accompanied me up to
the 3rd floor where the rest of the saga unfolds.

The final step in the process of preparing to be turned into a radioactive
menace was the signing of the consent forms. Before one can consent, one must be
“informed.” Therefore, the big Doctor took me to the broom closet area, and just as
we were warming up to have a really informative conversation, the technician came in
and said, “I need to use the pretty little throat-counting thingy machine,” so we
adjourned to another storage area. There the good doctor informed me about all the
unpleasant things that might happen after swallowing the PPP. Like my bladder
could get irritated, my saliva glands or tear ducts could go on strike, and I could end
up with a fun case of leukemia. However, most of these side effects are what they
like to call unlikely or even rare. Being the trusting soul I am, I signed.

Then it was time for the big event. The no-holds-barred, the no-turning-back
point. I was taken alone into the lead-lined special room with the noxious-fumes
hood and radioactive-materials signs everywhere and the constantly clicking Geiger
counter. There, inside the fume hood, was the big lead container with a PPP made
especially for me by gnomes living deep within caverns under the city. I was given a
very lovely set of latex gloves, which I immediately ripped while trying nonchalantly
to put them on.

The technician then took the PPP out of its leaden home and dropped it into
a paper cup and handed me the cup and a larger paper cup of water. Then, while they
both looked on in amazement, I threw it on the floor and ground it into a radioactive
cloud—wait, that must be someone else’s story! They looked on while I said,
“Well, here goes” and popped the PPP into my mouth, took a big swig of water,
and said adios to the rest of my thyroid. I must say I took a bit of pride in the fact
that I had just willingly swallowed radioactive waste from Chernobyl or somewhere,
all in the interest of staying alive another 30 years. They then took a Geiger counter
reading of me using a yardstick to measure the activity at 3 feet out. All of this was
to make sure I had really swallowed the thing. I guess some people do sleight-of-
hand tricks or maybe they just pretend to swallow, intending to spit out the PPP in
the first available planter. I guess I passed the three-foot test because they said I was
free to go.

It was now time to leave. So my wife who was now walking at the other end
of the hall (no, not really) led me in my semi-confused radioactive splendor to the
elevators. I kept expecting people to look at me, since I felt that I must at least be
glowing a little. I also wondered if I would set off any terrorist detection devices and
cause SWAT teams to appear out of the woodwork. Nothing unusual happened as
we wended our way back to the Big Red Van. We then headed back to Half Moon
Bay, bed, and the tale of the lemon wedge, onions, and a great deal of water.
Floods, Lemons Wedges and Onions

One of the unpleasant consequences of filling one’s body with radioactive sludge is that one risks permanently ruining one of life’s great pleasures. No, not that one. The one where you get to eat things. If one does not do the right things, one can end up with dying or dead salivary glands. The downside of this is that if you don’t have properly functioning glands, when you eat you feel as though you are chewing dry cardboard. The way recommended to me of avoiding this unhappy sequela (in works such as this there is an occasional need for just the right medical word) was to drink lots of water and to keep the saliva flowing. This was supposed to effectively “wash” out the nasty radioactive iodine particles which were hell-bent on snuffing out my delicate saliva-producing mechanisms. So I bought bottled water as well as all the sour candy in the hospital gift shop.

Unfortunately, the sour candy was more “sweet and sour” than sour, so I knew that I would have to bring in the cavalry. Lemon wedges it would have to be. Now just the thought of sucking on a lemon wedge is generally enough to get those ol’ glands to start pumping, but my glands had decided to go on strike to protest the assault on them. I didn’t think the radiation could kill them in a matter of hours, but it certainly seemed that something untoward was happening. Perhaps the glands were just feeling shy—in any case they were NOT producing much in the way of helpful fluids. Even when I sucked on the lemon, I only got a brief squirt, and then back to Sahara Mouth. But I persisted, and the first night I woke up every hour or so to take a drink of water and to tempt my glands with lots of raw lemon juice. The glands seem to be working well enough now, but at the time I was not convinced I would ever enjoy eating again.

Another set of glands that I felt were in danger was my lachrymal (tear producing) glands. Thus, the onions. I am lucky I am not blind. First, I just tried slicing them and putting my eyes in the general area. In the past, this had been more than enough to get the tears flowing. Next, I tried slicing and chopping and mincing whilst placing my eyes in close proximity to the action. It was truly disappointing when my eyes reacted as though they were watching a movie on the best ways to remove crab grass from a lawn. The next step was gingerly to put my finger in the juices on the cutting board and then smear a little under my eyes. By this time I was beginning to think that the rest of my life would involve hourly squirts of artificial tears into my eye sockets. I am lucky that this finally produced a little tear action, because I was getting ready to press freshly cut onions into my open eyes—in retrospect I think this would have been a BIG mistake.

Both saliva and tear glands are now performing at about 80% of capacity, which will allow me to eat and watch sad movies. Which now leads to the story of Life After Thyroid Theft Everyday, also known as LATTE.
Once my thyroid gland was completely removed and then attacked by radioactive iodine monsters, I was left with the task of getting on with life. I had first to try to find the right dose of synthetic thyroid hormone. This involves taking a tiny little pill that purports to be thyroid replacement hormone. How can you tell? It looks like a baby aspirin or a tiny mint or any of a dozen other things that one might stick in one’s mouth. I guess we just have to have faith in our pharmacists and drug companies. (All of you skeptics need to stop laughing). After taking the pill, one hopes to have more energy than before taking it. But it takes weeks to find out if the dose is the right amount.

During this time, one can feel somewhere between dead and near dead. My energy level varied between lethargy and lassitude or coma and slumber. It all depended on factors that were not really very clear. Sometimes I wish I were a little more like my mother, because she had an explanation for everything.

Besides an appalling lack of energy, I also suffered from a variety of aches and pains, over and above what my 54-year-old body normally experienced. One of the more annoying symptoms was the “Oh my, I have a major leg cramp coming on” feeling. This sensation would normally appear in my calf, usually the left one, but sometimes it also put in appearance in my upper thigh. These pre-cramp feelings almost never developed into a real cramp—it just felt like that at any moment my calf muscles would decide to tighten up into a Vulcan death grip. Suggestions when I consulted my on-line experts included taking calcium or magnesium supplements or amputation (you can see that all information found on the Internet is not equally useful or even believable).

Also there were just joint pains and muscle aches, which managed to nag and pester without turning into real “hand-me-the-morphine” type pains. I am certainly pleased that none of these things actually became full-blown pains, because life is tough enough as it is without having to deal with major torment.

The subject of pain has led me to consider the reasons why men are such wimps. We don’t seem to handle pain well—of course I am not referring to Navy SEALS or anything, just your garden-variety male. I have always subscribed to the theory that we are not trained to handle pain, except by the constant teasing of other males when we are young. Once we become married and we don’t have to prove how tough we are at every turn, we are then free to react to pain and discomfort as we wish, namely Ooowwwwwwccccchhhhh. Also, we must be wired differently than women, because we don’t have to give birth to anything except novel ideas or nations. Since we do not have to eject wriggling life forms through tiny orifices, we
are not prepared for pain. I am not sure there is much to be done about this, except for women to endure the whining and complaining of husbands, realizing that the men in their lives will probably never grow up. I hope they also recognize that men do contribute something to family life, so they probably should make an effort to keep them around.

Speaking of pain, I think I shall share just a little bit of private, personal history—the kind you only can read about after the author has died—but I am forging ahead whilst still alive. I had major stomach surgery about 6 years ago and I think a major mistake was made. Nothing like leaving in the scalpel or a bunch of sponges, more like forgetting to have my interior cleaned up, i.e., have my bowel system properly emptied. I was not going to be able to eat anything for 5 days after the surgery and my lower elimination system became, shall we say, inactive and rather dried out. This led to a difficult time when I finally was able to attempt to move things along. The problem was that the things I wanted to move along had long since dried out and were more interested in clogging that moving. The stress and strain required to get this material out of the system and into another system was great—so great that I was given an anal fissure.

Now that may sound benign, but it has added a new level of excitement to all future elimination procedures. This little tear in that most delicate portion of my lower region has caused considerable trouble. In fact, it has caused pain unequalled by any other, except perhaps my kidney stone. I have had women tell me that the pain created by this little fissure is greater than that experienced in childbirth. If this is true, I say no wonder women want drugs whilst giving birth. So the cautionary tale from this experience is to make sure, before major surgeries, to have a proper bowel cleansing so that things will move along in a fine and appropriate manner when it is time for such items to move along.

**Final Thoughts**

The things that have helped me include: a wonderfully supportive wife and children, a supportive and involved circle of friends, the e-mail messages from perfect strangers willing to take the time to share hope and help, and of course, a set of really fine medical folks. I have also used denial most effectively (I have yet to even look at the surgery—I just don’t like to think of it and so I mostly don’t) because I need a break from worry.

Also, researching everything, writing down all my questions, and having my wife accompany me to all appointments, since my brain becomes a quivering mass of gray ineffectiveness when I am face to face with the doctor. It is a real challenge to remember what the doctor might be saying.
He could be saying something like, “Now, for a few weeks you may have a little tenderness and sensations of tightness where the incision is, but this should lesson as time goes by.”

What I might be thinking, as he talks, could go along these lines: “My God, they have stolen my thyroid. Gone, it is gone forever and I can’t get it back. They just knocked me out and took it. Maybe it really wasn’t cancer and this whole thing was a big mistake. Tenderness, I’ll probably have nervous throat for the rest of my life. That’s an interesting poster on the wall and he certainly is not wearing a power tie and sensations of tightness—oh great, now I get to feel like someone is choking me all the time—boy, won’t that be a bucket o’ fun.” You can see why I find it a major challenge to remember anything that is said.

The final activity, which has really been a great help in this journey through Thyroidland, is laughing. I have worked in each and every situation to find something funny to notice or to comment upon. When facing life-threatening illness, I find it essential to find the humor, because if I can’t smile, I’ll probably just go crazy and be very depressed.

So there you have it. One man’s adventure into a newly found land, full of challenge and hope. Good luck to any of you who are embarking on a similar journey.

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