

# Letting Go of Mo

*an ordeal in pediatric brain tumor land*



*Don't it always seem to go, you don't know what you've got 'till its gone.*

--- Joni Mitchell, Big Yellow Taxi

For Anne, Becky, and of course, Maurice

# Preface

*When my mother read my writings from the ordeal, she called it a love story. I had never thought of it that way, but upon consideration, how could it not be?*

Here is a chronicle of our 19 month sojourn through the land of brain cancer treatment. It is told through website entries, correspondences, and journal writing, with a few other commentaries added as is befitting. It's not a secret how it ends - they were the last 569 days of Mo's life on earth. After he passed away, they became "the ordeal" (though most of the days did not seem that way when we lived through them). Most, if not all of them contained laughter. It is a tribute to a great little boy, and as painful as it is to accept, it was my privilege to be his father. He is greatly missed by many.

As I re-read the this chronicle, I am shocked at the difference between how I was feeling inside and how I presented our story to the public. If there is anything telling about how I was feeling throughout the ordeal, it was that whenever anyone asked me how I was doing, no matter how casually they asked the question, I would break down and start crying.

On Mo's website, I tried to present the ordeal as gently as possible, while my journal writing reflects how devastating and difficult it was to deal with Mo's cancer treatments and their side effects. I never felt great about glossing things over on the website, but we had a wide audience - many of whom were Mo's 4th and 5th grade classmates, and I didn't want to convey how painful the experience was. I hoped that the adults could read through the lines.

There are two things that I hope readers will take away from this book. First of course is what we lost in Mo, but I think that is impossible to convey. Most parents have very special relationships with their children, the depth and details of which are infinite. Maurice was a normal kid. Like all of us, he had his strengths and weaknesses. He was kind and gentle, a great conversationalist, well liked by adults. We received many compliments on his political knowledge, and other parents enjoyed his company so much they actually asked to borrow him. The universal lesson is to appreciate the good things in life and not take anything for granted - tragedies like this can happen to anyone - we were a completely 'normal' family before December 20, 2002. Second, I hope I can convey important lessons learned from dealing with the medical system. While I believe that most medical professionals have good intentions, it is clear that the system itself has become a disorganized complex medical bureaucracy. Many times people who observed the complexity of Mo's care asked what we would do if we didn't have a medical professional in the family (Anne is a family doc) - or what if we didn't speak English? The important take-home message here is that people must be their own best advocates if they want to receive the best medical treatments. I hate to say it, but, as with many things in life, once you are out of sight, you are out of mind. It feels like the world should stop for your tragedy, but it doesn't - everyone remains busy with their work and personal lives.

In this chronicle of you will not find much mention of the fact that we had to assist Mo every time he used the bathroom, and that there were many times when he did not make it there. I seldom mention that he never complained about throwing up (though we found it distressing every time it happened), and that I can only think of one time in which he couldn't hold it back until we had a bucket in place. Only a few times do I mention the extreme discomfort that Mo experience when trying to fall asleep (the "restlessness"). I did not mention these things because I didn't want the public to know how difficult Mo's life had become. These tasks were a part of what life demanded of all of us. I'd gladly resume them if I could trade them for a cure. In fact, I'd give anything to do so. I mention them here to add detail to the picture of life fighting cancer. It is an extreme, unpleasant life, and I mention it because, unlike so much of the literature focused on cancer, I don't believe in a cure. What we are fighting is an auto-immune illness caused by the toxification of our habitat. We are poisoning our family members and neighbors by spreading of billions of tons of chemicals throughout land, air and water as a result of our irresponsible production and consumption. This is proven by increasing rates of cancer, asthma, and learning disabilities (the fetal brain is very vulnerable to chemical attack). I mention it in the hope that each reader will realize that the people you know who are battling cancer

could be you, and if it does happen it's not about bravery and teeth gritting, it's about discomfort and sadness. I mention it in the hope that each reader will educate themselves on living an ecologically sound life which respects the sacred relationship between living beings and the Earth, which is not "the environment", but our life sustaining habitat. If we all work to minimize our environmental footprint, if we demand that production and consumption be sustainable, we will decrease the incidence of cancer and the many other very serious diseases caused by a self-poisoned habitat. I mention the degraded quality of life through which we held our heads high in the hope that each of us will pass this knowledge on.

Letting go of Mo is of course a process which won't end until Life lets go of me. Deep down there remains intense shock and pain that Mo developed (or was perhaps born with) brain cancer and left us - that the whole 19 month ordeal even happened. I can remember his laughter and his gentle, intelligent, bubbly character as though we were together yesterday. But a part of the process is burying that pain. I feel it as a thick mental scar that allows me to live a full life, which is of course, what he (and most of us) would want under the circumstances. He let go beautifully, which makes it all the harder. People have suggested that I might be thankful for the time I had with him, but thus far I have not been able to attain that state of mind.

# Day 1

Friday. 12/20/02

## **Journal Entry**

When he finally hugged his wife, it was a different kind of hug. They had been together for over 20 years, and most of the time physical contact was of a romantic nature. This was a different kind of comfort.

"Are you scared?"

Choked by tears, he could only shake his head. Finally, uttering no. He was very sad.

He walked the dog, not knowing how long it would be before they returned.

"I know they will have some, but maybe..."

He pulled a box of foam earplugs from his pocket. The MRI would be noisy.

"Oh, you already have some."

He opened the end of the box yet one more time to make sure they were in there.

So few things were available to confront the situation – a pocketful of handkerchiefs, a few of his son's favorite comic books, some favorite CD's - little comforts from home. Most things were shedding their meaning.

In the waiting room for the MRI, *The New Price Is Right* was blaring from the television – the ancient white-haired host and the pretty young women hawking material goods and money, the audience and contestants jumping up and down in a frenzy of materialism. An inner laugh at the irony. All of us caught up in ceaseless consumption of junk we don't need. Melting the North Pole, decimating the other species on the planet, our own, ourselves. Cancer rates are going up. But mostly it happens to other people. Who is the first to stop all the consumption? Where is the leader who can stand up to this and look it in the face, put the real issues front and center? On the contrary, our strategy is to take advantage of global warming - cruise ships and oil tankers sailing thru the North Pole.

"I will stay in here with him; you need to go talk to your wife."

The nurse sent him out to the hallway. His wife, who had accompanied the child during the MRI, had been called out a minute earlier. In a split second she countered the shaking of his head with a nod. Again, an embracement of sadness. Convulsions, rage, sadness. Reality cracked open like an abyss. This happened to other people. He had known several. He always imagined the private hell they must go through when dealing with a large personal crisis. Now he would find out. Shed your assumptions – he had learned that on Sept. 11. Or was that "shred" them? Back to reality. They will do some more MRI scans. They need to inject some dye. You must gather your strength and help your family. He can't see a broken down face when he looks for your support through the angled mirror from within the MRI.

Emotions deluged by waves of sadness and strength. Disbelief and denial and guilt. The constant wish to wake up from a nightmare. You would give anything for that.

Afterwards, in the waiting room, he had started to ask his son - "Do you know why we did this test?" He was breaking down. His wife, experienced in telling others this kind of news, shook her head: "Don't do it, you don't know how."

Deep inside he wanted to be the one to tell his son - he didn't want to wait for the doctor to tell him.

Grudgingly, I remained silent.

## Day 1 - Later

As we boarded the ferry to the land of children's brain cancer, everyone was friendly, most smiled - the staff in the pediatrician's reception room, the nurse who escorted us to an exam room. Didn't they understand that smiling wasn't true? But they see this every day, just like my wife did, which is why, earlier in the week, she had suspected a brain tumor. When Mo's pediatrician entered the room, I interrupted her pleasantries:

"We haven't told him what is happening."

She assessed the situation and sat down in front of Mo. I was extremely grateful I had waited to let her explain things. She knew how to say it.

"I don't want to die."

"You're not going to die, honey."

I wondered how she could be so sure; I desperately wanted to believe she could be sure.

There were tears and crying, fear of dying, assurances of life. A breakdown of three. Appropriate understanding on all levels. Reality: shredded.

Pick up daughter from school and go to the hospital to face it as a family. Doctors, pleasantries, more tests. More fears, more frustration, more helplessness, more tears. Look at frightening pictures of white spots on an image of his brain. A blur of oncologists and surgeon explaining things I can't comprehend. We need to act quickly. We can do brain surgery first thing in the morning to remove the tumor. To calm what must've been my shocked expression, the surgeon tells me this isn't a big deal, Mo will be back to playing football in a week.

We are given reassurances, which I know will be altered like political promises as the situation dictates. The hospital staff tries to be helpful.

"Is there anything I can get you?"

"Can you get me a guarantee?"

Cram 2 cots next to the hospital bed. Watch a movie. Call relatives. Even imagining a phone call triggers an emotional breakdown.

"Mom, are you sitting down? Maurice has a brain tumor."

"I will be there tomorrow."

People are coming to help, but we don't need help, this will be over in a few days - when a trip to the pharmacy goes back to picking up pain relief for temporary ailments. I am in denial, imagining an escape.

But the consent form said that our reality has been shredded. Walk down the hall and peer at the other personal tragedies. There are kids with no hair up here. A living hell for each family. What would it be like to be bombed in Iraq? To have your child dying and no medical care? To have your child terminally ill from depleted uranium, which we used in our last attack and no medical cure. It would be worse than this. We are so selfish and ruthless.

The pediatrician, whom we had left a reality ago, stops in with presents. She sits and talks politics with Mo. We rant and laugh. Like others, she marvels at the extent of his political knowledge and interest. For a moment I am transported off of this ferry - until a nurse comes in to draw blood. Reality hopping - back to tears. The nurse brings in junk food. I accompany the departing pediatrician as far as the pantry. I want to find something healthy. I dig through cereals, chips and crackers. I want to give him something healthy.

"What can I give him to eat from this?"

"Give him anything he wants." She replies.

Again, I am trying to fix things. I am grasping for something that will guarantee success. He eats a small handful of Doritos and is full.

I am desperate to bring comfort. To restore normalcy. I fetch half dozen videos from the collection on the children's floor. The video cabinet is outside the room full of children's activities. Again the bald. Those with short hair. Are we going to walk in those shoes? A new strategy for the future - be hopeful and try to dump any expectations. It wasn't like this yesterday, and certainly not a week ago. Carefully, I choose six favorite videos from the collection. I am trying to use the past to protect us from the present. I bring them back to the room. He chooses *The Princess Bride*. One of my favorites, also. We love the movies. They transport us out of our reality. Can *The Price is Right* do that for some people? Seems hard to believe.

A phone call from my sister. I am hardly able to talk. What does she think of me choking up like this? I don't want to make him more worried with my fears. We haven't used the C word yet. He talks to my sister. He is a trooper. A normal conversation in a normal tone of voice. He is doing better than I am. The least I can do is meet him there. His biggest fear is waking up during the surgery. He is reassured by everyone. Such is innocence - a narrow focus on the immediate.

I imagine the news spreading through the community. His friends at school and the parents who are our acquaintances. The universal thankfulness that they have been passed over this time. The thankfulness that I have felt so many times. The thankfulness that we are not Iraqis. The thankfulness that Hitler chose the Jews and not the Catholics next door. Such is the nature of life - survival before compassion.

Surprisingly, it only takes about a half-hour to cry myself to sleep. After choking back cries and convulsions my thoughts turn miraculously to computer animation (my profession) and I drift off. I am awakened 45 minutes later by a nurse who comes into the dark room to check vitals and add more equipment to his bedside arsenal. As sleep fades and duty calls it occurs to me that this is the first time I could've woken up and realized I had had a bad dream. Though I wish for the possibility, my reality is shredded and I must adjust to it. The trooper submits to the exam and dons the additional monitoring device, barely waking up.

I lie back down with a nasty migraine and after awhile I realize that ignoring it won't make it go away in this situation any better than in other situations. Reality has no justice. The nurse gives me some pain relievers and I sit down outside our room to write. It is mostly quiet, with noises that I imagine are routine for this part of the hospital. A little girl is watching TV a few rooms down the hall. I wonder why she is here. Several times I think I hear the voices of my wife and son, but all is quiet when I look in. Auditory hallucinations? I have had them in the past. A medical device beeps off a false alarm as the nurse warned me that it would. I open the door and look at it, of course not daring to touch any buttons on anything. I look for the button to call the nurse but the alarm stops before I find it.

At the hospital we ran into one of my wife's old medical school pals and one of the nurses on our floor was our nanny for a year when she was in nursing school. We hadn't seen either of them since the circumstances of life had brought us together in the past. I imagine they feel sorry for us the same way I would if the situation was reversed. But we're not one of those families who have childhood cancer from all the pollutions and poisons our society dumps into our habitat. But reality has been shredded and now we are.

## Day 2

Saturday. 12/21/02

### **Journal Entry**

Down to pre-op by 7:30, where a plethora of male nurses and a doctor or two told us more about the risks and procedures of the brain surgery. Once again, the trooper did better than I did, impressing his attendants with wit and wisdom, as they rolled him off to the operating room. Again, the blessing of not quite knowing the whole picture. What's going to happen when we tell him? I dread the thought of it.

Several phone calls from the operating room.

“Started at 9:00.”

“Going exceptionally well.”

“Finished removing the tumor and started closing.”

I know this could be a minor part of the battle, but I allow the good news to flood my consciousness with optimism. The time is passing much more quickly than expected. The surgeon shows up in our room. Like each person assigned to guide us in our battle, I want him to tell me we have totally destroyed the enemy. He tells us that the surgery went well and he is sure he has removed the entire tumor. He waited for the obvious question and offered his opinion that the tumor had been malignant. I have been waiting to explode, but I don't want to add my own pain to my wife's burden. Family arrives and I am able to unload some of this burden on my brother, who can absorb it and take it away.

Extreme anxiety must be subjugated to the appreciation of the first victory – especially in front of the trooper who looks much better than we had been prepared for. Through sleepy, squeaky statements he reveals that he is still in there and is in pain. I finally nap and wake up once again wishing that all this had been a nightmare. Who can remove this burden from my life? More hints are dropped that we will need chemo and/or radiation. The day wears away at my denial. Like an alcoholic, I must admit to myself that I have joined the ranks of the unfortunate. My brother-in-law tells me that there are only 2,000 cases like this per year in our country. I never play the lottery, but I have lost anyway. All day, I envision my counterpart – the father in Iraq. We will mortally wound his young son and he will have no medical care, no pain relievers, no bandages. He will know suffering – I will contribute to it. 36 hours ago I wasn't the father of a child with cancer. Now, I sit comfortably amidst the best care I the world. I am appreciative, but unhappy. I wish my counterpart would not have to suffer either.

As the day wears on, Mo starts to drink water and Gatorade. By 9 p.m., I can see that he is bored with being drugged. He is recovering rapidly, so I ask if he wants to watch a movie. I ask which of the other videos that I had brought last night he would like to watch. It is a test of his memory and he passes with flying colors. Outwardly, I am grateful as I run out of the ICU to fetch *Homeward Bound* from the children's section. Inwardly, I cannot let go of the fear of futility. I picture Wednesday and telling him about the cancer. I picture the chemo, the baldness, the home schooling, the pain, the vomiting, the never-ending possibility of recurrence. Our life has changed. I am out of denial. I don't want to be away from him. As always, I want to fix the situation - it seems so simple. Time is swallowing our lives. There are billions who are less fortunate. But then, there is his strength. He is recovering quickly. Perhaps, he will find the power to beat this. I must remain hopeful. But it is the solstice, the darkest day of the year.

## Day 3

Sunday. 12/22/02

### Journal Entry

I fall asleep. I wake up. The wish of reversing time is still faintly present in my consciousness. I hope it is morning. Is that daylight coming in around the shade? I risk a look. It is still dark. Over the years, I have developed the habit of getting by on 5-6 hours of sleep. Now, it seems like a cruel joke. I check the time - 6:45 - I have slept for 7 1/2 hours. But time doesn't exist for us, now. There is only the clock of recovery, so I must go to the recovery room to see what my wife and son are doing.

Along the way, like a hunter-gatherer, I wander between the various kitchens in the hospital, checking out what's available. Pretty much the same stuff everywhere. There is a hot water spigot and better juice in the children's section. I've heard that microwaving Styrofoam can release carcinogens into the water, so I'll walk over there to get water for tea.

Later in the day I am sitting in the hall writing. Nearby the nurses are chattering about their lives - stories of dating and cheating and travel. I imagine some of them hope they can hook up with some young intern. Nothing has changed for them. My sad face is a common sight. Managing personal tragedies is simply their job.

In the hospital, there is so much waste - plastic spoons, cups, and tons of plastic medical supplies. None of it recyclable or biodegradable, so it is all used once and then passed to future generations via the landfill. Some of it will add toxins to our habitat. The production and consumption of all this stuff creates a lot of pollution, which in turn toxifies our habitat, which increases the incidence of cancer and other diseases, and so we have come full circle. I can partially understand such waste in a hospital, where people are focused on their personal disasters and little else matters. What I find hopeless about our society is that we are so ignorant of the consequences of this irresponsible attitude toward consumption. We consume so much non-biodegradable and toxic material on a daily basis; we toxify our environment and warm the earth, and yet there is no leadership on educating the mass population of consequences of their behavior. In fact the producers, who have everything to gain from the status quo, spend billions to insure that this does not become the common understanding. What kind of person sells poisoned food?

Nursing only goes so far. Nurses check temperatures and blood pressure, administer medicines according to a doctor's orders. They will hold the bedpan and bathe patients, but nowhere near as well as you will. It can only be expected that there is a limit to their empathy. They will not be so gentle or thorough as you will with something like a bedpan, or scooting your child up in the bed. They don't have time to consider whether your family member might be drugged to boredom and might need something as simple as the TV to help pass the time. Nursing and being the parent of cancer are important skills in the new reality. It is a prison sentence for not having strong enough genes to resist our toxic society.

Post operative MRI. They told us about it, but there was too much else to worry about. New threats emerge like land mines in this reality. You can often see them coming, and they never kill, only maim, and you have to step on every one of them. The surgeon was sure he had removed the entire tumor, so I was certain this was a procedural necessity - obviously, we have to verify. A day and a half (plus a reality) after the first one, this MRI will take a half-hour. The nurse gets a kick out of the fact that I have brought my own foam earplugs:

"We could've given you new ones."

I want to tell her that these have special powers, because they came from our home, but she wouldn't understand that and I couldn't explain it. Besides, if our home had special powers, we wouldn't be here. During the scan I lose my confidence that this is only a procedural necessity. It could show things - and what if it does? The thought of returning to surgery is unbearable.

I peek into the control room and look at the MRI image on a computer screen. I see very bright areas on the scan. Didn't that indicate tumorous tissue on the original scan? I'm not a radiologist, so I can't let that bother me. The road is rough and rocky and we don't get to control the speed of our travels.

The MRI at the University Hospital is made by G.E. The MRI we used yesterday was made by Siemens. As we touch Mo's feet and listen to the loud frigid buzzing, beeping and clicking of the MRI, I consider G.E.'s role in the world. They manufacture a vast amount of material goods - from light bulbs, to weapons, to medical equipment. They own an entire television network so they can encourage war and rampant consumerism to bolster their profits. The rampant consumerism and weapons toxify the earth, which increases cancer. The weapons maim. And they have this magnificent device, which can detect that cancer and take pictures of war injuries. We use their products to harm ourselves and cure ourselves, our lives a conduit for their profits.

After the scan, I don't like the look on the face of the MRI technician. I think it was friendlier when we went in. Maybe I'm too sensitive.

Apparently the post operative MRI has gone as planned. In a little while we are cleared for takeoff – no more surgery so out of intensive care and back to the pediatric unit. Family arrives. A bit of pleasant conversation, in which Mo corrects us in his sleepy voice. A couple videos. More pain. Decisions about drugs. The oncologists return to tell us the pathology report will come back tomorrow. Like everyone, they are pleasant.

But today they are bearers of bad tidings. I follow them out of the room for a conversation the family shouldn't be privy to. I get more straight facts to develop a clearer picture of the future. We get no basic training; we have been dropped onto the battlefield unprepared. Look around and develop your skills. I am timid so I don't ask all my questions. The new skills grow like a cancer on the old personality. Use cancer to fight cancer. But it is not really cancer. It is inner strength, but how much do I need? Enough to tell him about the C word. If it weren't for that, brain surgery is a piece of cake. We had an excellent surgeon and excellent care. I need someone who can turn himself into a liquid, enter his body, and come out with the cancer. Like the nemesis in Terminator II. I wish I could do it myself. Sometime early next week, we will probably have to tell him. He will be completely frightened. What if he wants to give up? I will have to supply all the strength or completely shut down.

"Oh, and by the way, a neurosurgery resident will come by later with a report on the MRI." "But I thought it was clear; wasn't that the reason we left intensive care?"

"Well, it met neurosurgery's criteria to leave the ICU, but they will still come and talk to you about the results."

I find it hard to believe they haven't heard anything.

In the later afternoon a friend appears outside the door. The first one I have seen since the nightmare started 2 1/2 days ago. I give him a hug and completely break down. I unload my pain and my stories. He has three sons and I feel guilty for spreading this pain. We are in different realities now - I am no longer one of the thankful who have been passed over. But the new strength emerges, and I ask about his vacation plans and his new job. For a while, I speak in a normal tone of voice. He has listened and has tears in his eyes. He has taken some of my pain. I can now absorb a little from my wife. I can talk to my sister and another friend without breaking down. My little fish has been hooked, but I have more strength to hang onto him.

In child-sized veins, two IVs have gone bad and the morphine is wearing off. There has been some confusion in the protocol for administering painkillers. Despite everything, shots are still Mo's biggest fear. Two pediatric residents come to insert a new IV. They apply a numbing cream, which takes 45 minutes to work. They promise to return with a shot of morphine. The nurse had promised it a while ago. Mo's headache reaches a new level for the day. I go out to check on the nurse's order.

"It is still in the works with the pharmacy. But don't be afraid to ask."

Isn't that what I just did? I am angry and frustrated – my kid just had emergency brain surgery in what is supposed to be a world-class hospital; why is it taking so long to get him some painkillers? It arrives

soon after. The residents return with new IV equipment. They look for a good vein. There were none to begin with, and now the best ones have already failed. They find a suitable vein. But they are residents! They are working together and the way they are consulting each other about the procedure makes me nervous. Under the circumstances, they should have the judgment to know that this is not the patient to be practicing on. I want to ask what year they are and how many of these they have done, but I imagine what would happen if I raised a stink. We would suffer. The needle slides in perfectly. Do they know anything about the neurosurgery report on this morning's MRI? They will look into it.

Lots of soldiers report to you in this war, and so far I think they have all reported truthfully, that's why I know the battle has just started. However, in all the reports reside pieces of useful information, information you already know, and information which, while it may be interesting and designed to make you feel better, is useless in preparing for battle. You have to figure out what is useful and shuck the rest. If you miss something, nobody else may catch your error. After 9:00 p.m. the neurosurgery resident arrives. He is very bright. The important information in his report is that there is a little area on the periphery of the incision. It might be a few remnants of the tumor, or it could be tissue that was traumatized during the surgery. He says he doesn't have enough experience reading the scans to be sure which one it is. The neurologists should know...

When you are dropped onto this battlefield, you are the captain and it is your job to get the wounded in your squad off the field. One of the most difficult characteristics of this battlefield is that it is built on uncertainty. We get a lot of "shoulds" and "mights" and "chance". Like, "There is a chance of recovery." All of your soldiers' reports contain these uncertainties. They have been fighting on this battlefield for a long time, so they know its nature. Cancer reality: You meet helpful soldiers along the way, who use their special weapons and talents to help you fight a battle and when they can no longer help, they point you in a different direction, send you to someone else. They are experts, but none of them can offer proof that you will get off the field. We are like Alice or Dorothy, trying to find her way home. But that home is only a memory.

# Day 4

Monday. 12/23/02

## **Journal Entry**

We are still 3 sharing a hospital room. Sleep is easier to come by. I write until I fall asleep, then go to bed. Sleep is punctuated by visits from strangers who need to do their job helping out. Friendly shadows in the dark. Thankfully, I fall back asleep after each visit. I wake at six. Wishes for waking up from a nightmare bang on the door of my consciousness, I turn them away. Get up and face the day. Draw your sword.

"You live to provide comfort," I had told my friend on the previous day.

"Each comfort is a victory." I told a woman in the elevator who was bringing hot wax to comfort whomever she was visiting.

And each pain is a setback. The nurse comes in to draw blood - another needle stick. I crouch on the bed beside the trooper and lay my head gently on his bare chest and comfort him. The numbing cream has worked and he barely feels the procedure. Each comfort is a victory. He falls back asleep.

Out in the hallway, a small group of doctors-in-training/strangers/residents is stopping outside each room to discuss the details of the case. Words like "white count", "symptoms", and "IV" drift out of their conversation. The university hospital is a laboratory for researchers and a training ground for new soldiers in the disease industry. We are all lab rats.

It is so much easier and profitable to treat the ill than to clean things up for the living. It is morally hideous. But if there is one thing this vast, complex organism that is humanity lacks, it is morals. Justice and law are relative within each group. They are tools used by the powerful to advance their position, acquire new resources. Normally I gobble up the news to the point of depression. Now I am boycotting. I am in 'selfish mode' and I don't want to read or hear about the world's troubles. As I walk around the hospital I see the headlines in the newspaper boxes and I have enough knowledge in reserve to discern the picture. Our regime is putting 50,000 troops on standby to go to invade Iraq and take control of their oil – the regime itself will profit handsomely from the war and its spoils. They are arresting middle easterners in this country. What would I do if this new Hitler targeted the Jews? What would happen if I had to throw my son over my shoulder and head for the border? The entourage of residents visit all the other rooms on this floor. I wonder if a father sitting outside the room will prevent them from coming down here to discuss our case. They don't come, but a team of neurosurgery residents shows up to conduct a quick exam. They ask Mo to perform some exercises. All go well, but when asked to simply move his right hand quickly between his nose and the resident's hand, he misses his nose several times.

There had been some indication of this "deficit" yesterday, but I chalked it up to the IV being on his arm. This time it is unmistakable, though he is still under the influence of a lot of medication. I imagine the cancer laughing at me - it has scored a major wound. As the residents disappear, the hall becomes quiet. The rooms around us are unoccupied. The echoes of the nurses' chatter about their Christmas plans bounce and fade down the hall.

# Day 5

Tuesday, 12/24/02

## **Journal Entry**

I wake up at 4 a.m. There is an IV alarm going off in the room across the hall. It has been beeping for the last half-hour. 4 1/2 hours of sleep is plenty. I can hear the chatter from the nurse's station - can't they hear the alarm? A bit angry, I walk down there and let them know. The noise from the refrigerators in the kitchen drowns out the beeping before I get there.

Yesterday was good and bad. Friends visited in the afternoon. We are starting to spread the shock and pain into our circle of friends. Score another big one for the cancer, but remember we are doing it to ourselves. It is a byproduct of our way of life.

More visits from doctors. Rehab, psychology, neurosurgery, oncology. All are encouraging. Some have nothing to say, they are just playing their part in the bureaucracy that is modern hospital care. We had hoped to be up and out of bed, but there was too much pain in his head. We get different opinions about how much progress he should have made. I realize I am basing my expectation on their predictions, but he just had a walnut scooped out of his brain two days ago. I can't believe a few days of bed rest can hurt. The surgeon stops in to tell us that the pathology needs further staining, and with Christmas on Wednesday, we won't get the report back until Thursday or Friday.

"You are both staying here?" He chuckles at the 2 cots crammed beside Mo's bed.

Neither of us has slept at home since Friday morning.

We get conflicting reports about when we will meet with the pediatric brain tumor specialist. Most likely, she will tell us about the chemotherapy. She is the next soldier. She will be back from vacation on Friday, but if we are home, we might have to wait until Monday to meet with her. Frustrated, we decide we need to get the bad news consolidated. Have the tumor specialist give us the report about the cancer and the treatment at one time and on Friday please. There are too many people on the case; they are not corroborating their reports. Like all the intelligence agencies before Sept. 11, one hand does not know what the other is doing. You are the general, time to coordinate the troops.

Chatter about calling in sick to get out of working before Christmas echoes from the nursing station down the hall.

The radiation oncologist stops in to introduce himself. We had been told he would stop in for a routine visit. He introduces himself to Maurice. Asks a few questions, performs the same tests of his ability to use his arms and legs that all the other doctors perform. As he talks to Mo, he drops a bombshell: He will be seeing Maurice frequently over the next few months. This does not please Mo, because he doesn't understand it. My wife and I connect in a devastated look. The cancer is laughing. I have been painting my picture of the future, one stroke at a time. The painting is a mess. The strokes overlap and cancel each other out. I want it to be finished. But then I don't. I have a vague idea of the difference between chemotherapy and radiation. If I think about them, I can figure out that they are very different, but who thinks about these things? I had been expecting to find out more about this on Friday, but one of the troops has snuck through the lines with an early report. Fortuitously, a friend showed up a few minutes earlier. She stays with Mo while we follow the radiation doc and his assistant out of the room for a debriefing. Between the room and the lounge twenty feet away, you adjust your demeanor. You have been waiting for this all along.

The radiation specialist is incredibly patient. Out of respect for my physician/wife, we get a very thorough description of the battlefield as seen through his eyes. He is an Indian man with warm eyes and a gentle demeanor. I am crying, shaking my head, changing my body position on the couch next to my wife. I am agitated, not hysterical. My sorrow doesn't break the cadence of his speech. His eyes indicate that he understands, perhaps he has had this conversation hundreds of times. He acknowledges that we are still waiting for the results of the pathology and then shares his encyclopedic knowledge of

the treatment of pediatric brain cancer. He is dispensing with formality. For an hour he describes the evolution of brain tumor treatment since the 1940's. The introduction of radiation in the sixties or so. The milestones and setbacks over the last 40 years. The long list of side effects - short term, long term, and permanent. The odds of recovery, the studies, survival statistics, the attempts to reduce the side effects of treatment. Everything is based on studies and clinical trials. Are we not lab rats?

We will have five weeks of radiation, followed by chemotherapy. Our lives will be turned upside down. His prognosis for "cure" is good, based on Mo's age, the fact that the tumor was completely removed, and the type of tumor it probably is. We will meet again to go over all of this and select a treatment procedure. This General is reporting from the front line where our best researchers are developing chemical weapons to kill the enemy. This is the nature of this war: When they drop you on the battlefield, you become part of the experiment. There are no magical pills or potions. The enemy is deft. You get access to the best research available when you arrive. You will be monitored and you will contribute to the knowledge base. The alternative is recurrence in two years. Could we risk not taking this guy at his word? We are on the bleeding edge of modern medicine and we are bleeding.

Later we are visited by a psychologist. He leads us off to a different room to tell us about psychological services available to Mo. There are many, even special schools. I continue to assess the situation. I try to transform his words and his experience into something I can paint on the canvas. How this will fit into the future? I am focused on my own pain. I know how I feel. I am sorting it out and grudgingly rebuilding my personality to deal with this. I have been wondering all along what Mo is thinking under all that physical pain. More than anything, the thing I am least looking forward to is the discussion of the C word. I can't imagine how he will deal with it. I am somewhat fanatic about environmental issues. I have taught him about the dangers of cancer because of the chemical saturation of our society. We dump them on our lawns, we spray them in our houses to clean things or make the air smell what we have been sold as "pleasant". Chemicals are available to make so many things in our lives "convenient" or easy to do. We use them in packaging and in toys. Even the psychologist and the hospital Santa gave him toys that are made of chemicals, which will be used once and then dumped in the landfill - degassing petrochemicals all the while. Cancer is increasing dramatically, and these chemicals are a major cause. My fear, vigilance and ranting have planted a healthy fear of cancer in Mo. Recently he accompanied me to a public hearing on the use of pesticides in city parks where I publicly expressed my concerns about recklessly exposing the public to toxic chemicals. Who would've believed that cancer had already exacerbated its revenge? It was there in my son's chair.

"Just wait." it was laughing...

The radiation oncologist suggested that Mo's cancer may have been present at birth, but we will never know. When Mo was born we lived near a major freeway in LA. We bought a new car which had that "new car smell", which is produced by an artificial chemical, for several years.

The only certainty is that we have been very unlucky. This is why we are on the battlefield. You play the hand you are dealt, step up to the plate.

At the end of the meeting, he gives us his card. We can call him anytime. I am uncertain as to when that will be necessary, but I assume I will recognize the moment. My wife, intimately familiar with the inner workings of the medical system, asks if his services are covered by insurance. Some of them are, and some are not. I have been wondering how much all of this will cost. The last few days must've cost \$50 - \$100,000. I assume it is all covered by our insurance. In my usual assessment of the possibilities, I imagine the insurance company trying to wriggle out of the responsibility to pay for it, to devise some technicality to absolve themselves, but I realize that, of all the things that are going wrong, that is unlikely to happen. I assume the radiation, chemo, MRIs, and the rest will be covered also... but not necessarily the psychological services. They will pay the vast amount of money for you to participate in the experiment, but if you can't handle the stress, you're on your own.

# Day 6

Wednesday. 12/25/02

## **Journal Entry**

Most of us love a hot shower. It is an immersion in comfort, a chance to wash off the grunginess of the past. It is a place for privacy. On the day of the first MRI I learned that using our hands to hide the grief on our face does not require the presence of someone to hide it from. In subsequent days each shower would be accompanied by the wish that I could cleanse my life of this nightmare. Someone has poisoned my drink, please let me sweat it out and watch it flow down off my body and into the drain.

I have always wanted time to stop when I am enjoying it. It doesn't have to be at an elaborate event, it could be as simple as enjoying a game with friends and family. If one could stop time during a happy moment, they would never have to face an unhappy moment. Now every comfortable situation offers sanctuary. If time would stop while we are sitting around his hospital bed with friends and family, we wouldn't have to face rehabilitating him after this major surgery, only to grab him and plunge into the acidic land of radiation and chemotherapy, hoping against hope for minimal side effects and dreading re-occurrence forever.

My brother-in-law calls. Like everyone, he is shocked and sympathetic. He recognizes that this is a war and we have to do whatever is necessary to ensure victory. He generously offers to help pay for any type of treatment anywhere in the world. It opens up the possibilities, but I realize he does not understand the nature of the war. I would welcome any help in the war room, so I want to give him my report after four days on the frontline, but the room is full of visitors and he doesn't have time anyway.

Cancer reality: Despite my most basic instinct to want to control the situation, there is little I can do to influence the final outcome – no matter the cost. We have a rare condition that even the world's greatest surgeon can't correct. Our enemy is a primitive auto-immune disorder. Our weapons are toxic chemicals, toxic radiation, and a complex matrix of statistics and probability. Developing a treatment is more like investment counseling than military strategy. Our weapons are developed by teams of researchers who develop complex, toxic models for poisoning the body enough to eliminate the cancer, but spare the life, with no guarantee whatsoever of success. At this point, if any of them guaranteed success, I wouldn't even consider their services. This is the battlefield that I would like to debrief my brother-in-law about. Perhaps I would be remiss not to shop around for treatments. On the other hand, how could I be convinced that a different facility would do a better job than the physicians here? I am good at math, but I have no foundation from which to assess the situation. I wouldn't even consider something new and unproven over something that has a proven track record, no matter how bad the success rate. Failure would carry too much guilt. Even if the tumor is mostly benign, how could I face the remorse if they recommended treatment and I refused it? We are too weak or too strong not to follow their recommendations. Maybe if the first treatment fails we will try something less tested. I am a deer on the tracks, blinded by the headlight of a locomotive.

It is 7:30 a.m. The neurosurgery resident wakes us from a restful night. We discuss the previous day's progress. Based on our initial conversation with the surgeon, we thought Mo would've been walking two days ago, and home yesterday. With the idea of a quick recovery planted in my head, I think we are close, perhaps by tomorrow. I am counting the number of healing days we will have before we have to tell him about the C word, dreading the future after that day.

It turns out that pediatric rehabilitation should've been called in, but they have been on Christmas vacation. Yet another soldier to prep us for battle. We may be moved to a separate section of the hospital just for rehab. Another hill emerges in the landscape directly in front of us. I hear the echoing laughter of cancer from an undeterminable direction. The hill is steep at the bottom so I can't see very far up to assess the terrain and height. Still operating on the notion of kids bouncing back quickly, I imagine the hill isn't very high. You'd think I would know better, but it's the only way I can prepare myself for the first step.

# Day 7

Thursday, 12/26/02

## **Journal Entry**

I awaken after four hours. I actually slept through one of his scheduled medications. I consider this a good sign. This is our sixth night and we decide that it is time for one of us to go home at night - things are piling up. For me, another illusion is dissolving - we can protect ourselves from the future by spending all of our waking and sleeping moments with him.

I have taken the first shift in the hospital. The time between waking and sleeping is more fragile now. There are demons that jolt you back toward wakefulness. In the early morning hours, the nurse comes in to administer medications. Another comes and draws blood. Friendly shadows that keep the machine humming. I drift fitfully back to sleep between the visits. A knock on the door and a team for five or six doctors and residents pile into the room. I recognize a couple of the faces, but the names and specialties are a blur. I give them a full report of yesterday's progress and ask about rehab. I am frustrated because nobody has helped me paint a clear picture of recovery. For better or worse, I want to be able to visualize the next few days. Their comments are guarded. They tell me that the pediatric rehab staff is unavailable during the holidays. I try not to hold it against them - I don't expect them to make their plans around the possibility of my family popping in with a rare brain tumor. I am frustrated and hope that I don't appear ungrateful. Pediatric rehab should be back today and will definitely be consulted. The residents have a busy schedule and quickly and pile out of the room leaving us to ponder all this chaos.

The early morning light begins pouring in under the shade. It is doubtful, but perhaps I can get a bit more sleep- avoid the day for a little while longer. I am drifting off in the cot next to his bed when I have a dream of a child with very short hair. I recognize that the child is my son. I get out of bed.

Yesterday he ate a good breakfast, serving himself cereal with milk with a spoon. There were few, if any headaches, with most of the pain coming from the incision. He sat in a wheelchair for a good part of the day. He talked on the phone and watched movies. Today should be better.

# Day 8

Friday, 12/27/02

## **Journal Entry**

The train is coming. I finally know its schedule. I have been telling myself and everyone else that I am prepared for it, perhaps this is true, but I am dreading it. I am standing on the tracks and I am going to let it run me over. I have a clean handkerchief in one pocket. I have gone to the bathroom to empty my body - the only preparations I can think of. The next general, a very important person, stopped by earlier. She is not what my imagination has been conjuring all week. With her Italian name, I was expecting an Italian accent. The surgeon is from Iran, the radiation oncologist from India, and the anesthesiologist from somewhere else in the Middle East or Mediterranean. But she is an American, a small woman with bright lipstick. She is assimilating our case. Finding things to talk about to meet Maurice, to assess his soul so she can comfort it, be a guide, or so I hope. Into each of these peoples' hands you are placing your son's life and your future happiness. You hope that each is an angel, but really they are just workers here on Earth doing their jobs. Take this poison away from me I want to tell her. Please take this poison out of my life. I had imagined all along that if it came to this, I would vomit, but now I don't think that will happen. She will return to our room within the hour to discuss the pathology results. My mother will keep Mo company. Apprehension, fear, and sadness are squeezing my soul. I can feel it throughout my body.

"How long have the signs been there?" is a recurrent theme. Mo had some nausea, I think it was November. Several people have brought up the subject, including his pediatrician. It may explain why he needed therapy for audio processing issues before kindergarten. Why he showed no preference for handedness. Each time it comes up I steer clear of an in-depth discussion. Time does not exist; it is merely an artificial device for measuring the moment. Therefore, we cannot go back into it. "What ifs" are a foolish pursuit which amplify the current pain. Last week he had flu-like symptoms, and by the second day my wife suspected a brain tumor. A fool of a husband, I thought she was way over-concerned. Before the surgery, the surgeon told us that these kids often come in with swollen brains or in a coma. I am the most negative and skeptical person I know. The curse of perfectionism flows through my veins. In this, the detection of the illness, we have been lucky. The present holds two simple tasks, one easy, one difficult. The easy one is to support Maurice to the best of my ability; at least I hope it will be easy. The second is to remain hopeful. As I have unloaded this burden on family and friends, I have realized that I am unable to manage that. I will have to ask the general about it. A half-hour remains. Before getting the next glimpse of the future, I go take one more look at my son playing Monopoly with my mother.

# Day 9

Saturday. 12/28/02

## Journal Entry

Yesterday the Cancer Train finally arrived and ran us over. It really does not hurt physically. A cowcatcher pushes you under the train and you lie tense under the deafening, rhythmical clatter of the cars. Then, you get up and look for the next danger. I am getting used to this landscape. Our lives had been focused on that moment for a week, but the doctor was on call, so she had limited time to talk to us. However she clarified the picture: Medulloblastoma, a malignant brain tumor. To ensure that the frying pan is red hot, a new threat materialized: They will do a spinal tap 7 - 10 days after surgery to look for cancer cells in the cerebral fluid. If they did it now, they would definitely be present as a result of the surgery. However, if cancer cells are still present after 7 -10 days, the severity of the treatment goes up and the chances of survival go down.

Treatment won't start for a week or so. I again express my desire not to tell Mo for a few days. I truly believe he will recover from the surgery better without the stress of obsessing about cancer. My wife and the other doctors veto the idea. They have their reasons, and the experience. I have no ground from which to argue. The doctor leaves to answer the pager messages she has accumulated during the visit. She will stop in later to see how we are doing. Nonverbally, these two have conspired to tell him soon.

For the first time in the ordeal, the day's activities have left the dog unwalked. People have offered to help, but we have covered it. It is a reason to leave the hospital and get some fresh air, to go home and adjust. As I prepare to leave, my wife decides she wants to tell him now. I ask her to wait until the doctor comes back - surely with her experience she will make important contributions to the task. I wonder if my wife feels the way I did after the first MRI - that she doesn't want an outsider breaking the news. I am trying to hang onto the pre-cancerous Mo, perhaps my last vestige of denial. She agrees.

At home, I call a neighbor to accompany me while walking the dog. He is one of the most intelligent people I know and a straight shooter. After I break down and pull myself back together, we talk about brain anatomy and the resilience of children and the nervous system. There might be 500 cases of this type of tumor in the U.S. each year, the probability of us getting one is next to impossible, and yet we have taken a square hit. The odds of this happening are killing me and I want him to tell me why they shouldn't. He reminds me that as Jews we are the chosen and pulls some other ideas from Karate, which Mo loves to do. He uses the "f" word on statistics and probability. As I've struggled with the question of hope it has occurred to me that it could be the result of having purged religion and all other "isms" from my life. But what am I supposed to do? Fake my belief in something? Adopt a superstition? He is doing his best to reduce my stress and tells me that I need to have complete faith in my son and myself. Children are incredibly resilient.

After feeding the dog, I call another close friend to give him a progress report. We discuss many things. I rant a bit and cry. I am spreading out the pain; I begin to feel better. We discuss the country's move toward fascism. All of this personal tragedy doesn't affect that at all. I wonder if the greedy, power hungry men who have taken over our Country will steal the funds for our medical treatments in order to support their imperialism.

Back in the hospital, the doctor returns to our room after rounding on other patients. We turn off the video. The time has come and there is nothing I can do to stop it. My wife starts out gently. The C-word floats between mother and child. He is frightened and crying. I realize a delay would have only been a delay, now we have more time to prepare. He has more time to rebuild his soul, as we have been doing all week, and we are there to help him. First we must tell him that he is not going to die. The tumor has been completely removed. It was cancer and we just found out today. He will have to have treatments to ensure that the tumor will not come back. He will still be able to become President and study politics. I rest my head on his body. I paint the picture, as I have been able to discern it. We are in this together. We will not leave his side. The doctor mentions patients she has had who have had

this same tumor and treatment. How old they were when they started the treatment, how old they are now. If the spinal tap comes back clean, there is 80-90% chance of cure. I wonder what her total success rate is. I don't think I will ask. We are one of one. I am surprised by what I am able to contribute. The strength is there, and so, mostly, are the words. We acknowledge fear, sadness, difficulty, and love. The burden passes and the conversation turns to other topics. I feel lighter. Now we are all in the landscape together, each with our own skills and our own part to play. He is tired. We all are. It is my wife's turn to go home, but she decides to stay the night.

I have had dizzy spells every night for several months. Last Spring I discovered that brewed decaf coffee or tea gives me headaches if I drink them every day. I have had headaches since I was a kid. Intermittent dizziness showed up when I was twenty. I have never been much of one for seeing doctors, not out of fear, but there are always other things to do and I hate focusing on myself. This has kindled a new fear - now I know what is possible. I imagine my son and myself, bald, going through chemo together. I can't imagine burdening my family if I were to have a tumor and I can't imagine burdening them if I didn't take a look. Of course, now, I am hearing all kinds of stories. Some of the tumors are slow growing. If that's what I have a few more months won't make a difference.

Today we are going home. Earlier in the week, while returning a call from concerned friends, I mentioned that Mo was in a wheelchair. He had just gotten out of bed for the first time, so it was an achievement, the first step toward walking. The conversation had been brief, and I realized that I might have left them with the impression that he was wheelchair-bound after the brain surgery. They were going out of town for the rest of the week, so I called back to dispel erroneous impression I may have given of his condition. I, after all, was of the impression that he would turn around one day soon and be mostly back to normal. But today we are going home in a wheelchair. The road back to walking is more of a narrow trail over difficult terrain than a paved highway.

The rehabilitation department is still on vacation, so the hospital, with its generals, soldiers and attendants, has little more to offer us before the spinal tap. We will pack up our PT and OT paraphernalia, our medicines, our will and our love and we will go set up a command and recovery center in the comfort of our home. We will read their literature, we will develop a strategy, and we will adjust. Because we have no other choices.

**Commentary:**

With hindsight I can look back on my naiveté and offer additional insight. As it turned out there was another widely accepted treatment option available at St. Jude. Had we discovered the Pediatric Brain Tumor Listserv at this time, other parents roaming Children's Brain Tumor Land would've recommended that we contact St. Jude immediately for a second opinion. Further we would learn that there is a consortium of less than a dozen medical institutions that specialize in pediatric brain tumors, and our hospital is not among them. Some parents feel all pediatric brain tumors should be funneled to one of these institutions, as expertise is built by experience, and our hospital only sees a few pediatric brain tumors each year, it is hard to argue against this. In any case, we did not make the connection with other PBT families at this point, and none of our doctors recommended contacting St. Jude. Place the blame where you will, this was definitely a mistake.