

~ Chapter 4: The Valley of the Shadow of Death ~

“He delivers the afflicted by their affliction and opens their ear by adversity.”

Job 36:15

Tragedy ~ Torment ~ Triumph

Is it competence or incompetence? PotÃto – potato? TomÃto – tomato?

Information is powerful. We live in an age that's ushered in some of the most incredible technological explosions. The products of electrical, mechanical and software engineering have afforded us with devices of such convenience, entertainment and especially great comfort. I think anyone who's had the pleasure to sit in a massage chair would agree. I'm learning that power, if not wielded wisely, can be terribly dangerous. I think Albert Einstein would agree.

There's a sun rising on my horizon – a ray of hope. My mother is an ardent reader. While I spend my days in an opiate induced stupor she's searching out ways to bring an end to my days of misery. She subscribed to New Mobility, a publication specializing in enlightening disabled and wheelchair bound people with the latest and greatest resources and solutions to life's difficulties.

The ray of hope has taken the form of a shiny titanium cylindrical disk similar to a hockey puck. This titanium puck, known as an Intrathecal Injection Pump or more commonly called a Pain Pump, has a much more noble cause than being unwittingly bashed around on a cold sheet of ice. It's a godsend and blessed with the ability to deliver small amounts of morphine directly into the spinal fluid bathing the brain in a soothing bubble bath of powerful pain relief. Its capabilities sound too good to be true.

Nothing is simple with spinal cord injury. I learn that acquiring a pain pump is a courting process. I feel like an exotic bird in the farthest recesses of the Amazon jungle puffing my decrepit chest, bobbing my head, hopping and flapping my feeble wings in a hopeful dance to entice this magical beauty into becoming my betrothed – my beloved. I'm thinking of Genesis 2:18 when God said "It is not good that man should be alone" if He was

Tragedy ~ Torment ~ Triumph

referring to the pain pump and myself but in fact He was speaking of man's lost state of loneliness had He not created woman. I'm in a lost state.

First dates are when we bring our "A" game. I was checked into Concord, Massachusetts' Emerson Hospital's Outpatient Department bright and early. My "A" game consisted of an undefinable burning coupled with all of the horrendous opiate addiction withdrawal symptoms of extreme anxiety, agitation, every muscle crawling out of my skin and I'm especially emotional as if I'm having a nervous breakdown. It's the spring of '94 and I've been indulging in Demerol shots for about two years. The neurosurgeon wants me clean of Demerol for a few days as a controlled way to test the efficacy of the pump. I find it unbelievable that letting uncontrolled pain run wild is his idea of a controlled test.

"Rob, we're going to give you an epidural to simulate what the pain pump does." I'm positioned into a fetal position and the irony strikes me. I'm curled on my side and all I want to do is suck my thumb and drift off to a sleep that I don't wake from. I don't feel the puncture of the IV popping into my spinal cord. I'm rolled onto my back and a fentanyl pump is started. Within seconds I was hit by a powerful tidal wave of euphoria. It's a state of unmistakable bliss and I feel as though I'm soaring with angels.

"Rob, are you feeling the fentanyl?" He doesn't see this aura of tranquility radiating from me? I can't hide my desire to propose to this man who in just the shortest of instants not only brought an end the searing agony but released me into an unimaginable angelic and godly realm.

"So it's working Rob?" "Absolutely! I don't feel any burning whatsoever! I didn't think this was possible" "Ok Rob, I will order a pump and we'll schedule a day to implant it."

Tragedy ~ Torment ~ Triumph

A few weeks later I'm nervous knowing that the surgery is extensive and I have to undergo anesthesia again. I fear waking on a vent, unable to breathe on my own and suffer the never-ending battle to be extubated from another ventilator. Given the chance to spend my days flying with angels I welcome the possibility of that fight.

As extensive as it may have been the surgery was instantaneous. As soon as they were telling me I was going to get sleepy I woke to a loud "Rob? Rob, we're done. The pump is in and it all went well." I spent a few hours in recovery and was transferred to a room on the floor.

The next day I woke to the sound of a breakfast tray being placed on my bedside table. The attendant took off the cover exposing scrambled eggs, butter oozing into all the crevices, bubbling greasy sizzling sausages and him saying my nurse will be right in before he abruptly left my room. I spend the next hour smelling the deliciousness and watching it cool into a yellow heap surrounded by a gelatinous gray of sausage sludge as I wait for my nurse.

The nurse came in with my morning medications and asked if I'd like to eat. "Would you like me to heat this for you?" I'm guessing it was a rhetorical question. As I'm eating I asked her when are they going to start the pump. "Oh, they started it as soon as they put it in." I looked at her in disbelief. "Are you sure?" "Yes! Why? Don't you feel pain relief?" "No, not at all. Everything is burning. They must not have started it." The nurse said the doctors will be making their rounds soon and I'll be able to discuss it with them.

When the doctors came I was upset and told them of my excruciating pain. This hockey puck device was surgically implanted in my abdomen just to the right of my bellybutton. It's under my skin but because I'm quite thin it protrudes from my stomach. There is a thin plastic tube that runs from

Tragedy ~ Torment ~ Triumph

the pump and through my body where it enters my spinal column halfway up my back.

The doctors open a suitcase containing a marvel of technology designed to interrogate and program the pump. The suitcase is equipped with a round wand that hovers over the protruding hockey puck. The doctors are able to communicate with the pump through a telemetry between the wand and the pump. They tell me that it is full of medication and pumping correctly. "Rob, you should be feeling some pain relief." I tell them I'm not. I reminded them of the incredible reaction to the epidural and that there is absolutely no relief now. I'm in intense pain. They suggested that I give it time and they'd be back tomorrow.

Tomorrow is today and the inquisition is the same. "I'm REALLY burning!!!" "Ok Rob, let's increase the pump rate." "Great but in the meantime can you give me something for this burning? Please?" "Yes Rob, we'll give you some Demerol but you should feel a lot more relief with the rate increase."

The days of inquisitions and troubleshooting turn into weeks. The days of burning turn into weeks of battling for pain relief and begging for Demerol injections because the relentless searing is dogging me again. The nursing staff is getting irritated and becoming cold and abrasive. The doctors are no longer interrogating the pump for reasons as to why my pain is there nor can they program any more increases. They've exhausted all options. Their interrogations are now savagely directed at me accusing me of being nothing more than an addict.

It all culminates in an explosion of fury when my mother came to visit me and found my room door closed, TV off and my water bottle straw bent out of my reach as punishment for yelling out for pain medication. Through the closed door I can hear my mother, irate and in a tirade telling

Tragedy ~ Torment ~ Triumph

the entire nursing station the biggest fear a quadriplegic faces is abandonment and they closed my door shutting me out?

I can't escape that lightning bolt. It has turned into a tempest. The burning is now a constant state of electrocution.

I'm surrounded by a team of doctors, a select group of nurses, my psychiatrist from New England Rehab Hospital, my childhood priest, my sister Ellen from the Cape and my parents. They've decided as a last resort it is time for an intervention to convince me that I have an addiction problem. In my frustration I scream out through tears and crying "No! No! No! I HAVE A PAIN PROBLEM!!!!!!"

Lying on my bed unable to move encircled by a pack of vicious wolves. I don't know where it came from but in a moment of clarity I blared out the most basic of questions. A question that should have been posed five weeks ago. In a past life I was an electrical engineer and knew how to troubleshoot the inexplicable. "CAN'T YOU TEST THE PUMP ASIDE FROM ASKING IT?" Stop interrogating it. Stop interrogating me!

The doctors conferred and said they could do a dye study where they fill the pump with a radioactive dye and watch it pump under a type of x-ray that would dynamically show the flow.

The next day I was in a dark room equipped with a large table, a track system enabling a special x-ray machine to move where needed and a large screen hanging from the ceiling. I watched as the needle went through my stomach and into the rubbery access port in the pump. In went the radioactive fluid which filled the pump cavity. The doctors programmed the pump and we all watched as the purple fluid exited the hockey puck. Out it went in a snail's pace traversing its way through the plastic tube en route to my spinal cord and brain.

Tragedy ~ Torment ~ Triumph

The purple radioactive fluid got midway toward my spinal cord then began to diffuse throughout my abdomen. We all watched it transition from a discernible purple to an opaque mist then to nothing. It did not continue to my spinal cord. It went to no place of value.

The doctors scheduled surgery and it was then that the renowned neurosurgeon, while implanting his first intrathecal pain pump, discovered he'd broken the plastic tubing midway to my spinal cord and didn't realize it.

I say tomato and I say potato. The word is incompetence.

I am vindicated! Five weeks after the initial surgery they discovered their woeful error and corrected it. When I woke I was finally experiencing pain relief. Because they couldn't use fentanyl long term the pain relief was not as effectual as the epidural trial but I was feeling significantly less burning than in my prior two years. And because the morphine was contained within my spinal fluid I did not experience the systemic effects – no more opiate stupor. I regained my appetite not to mention a mental awakening. I can't help but wonder if that renown neurosurgeon's middle name is Debacle.

The volume of morphine in the pump lasts one month. Each month is the same. As it nears empty I hear the faintest of beeping from my stomach. The pump, with its beeping, is letting me know it has but a few days of morphine left before it runs dry ending my existence in a fantastic mushroom cloud. I've grown accustomed to the routine. I hear the beeping and call my primary care physician who schedules an appointment usually the next day for a refill.

Tragedy ~ Torment ~ Triumph

I own a big Ford van that's been modified with a lowered floor and a hydraulically lifted platform that lowers out of the sliding side door. I have to back onto the platform and once on, a 6 inch plate flips up protecting me from rolling off the end of the lift until I'm up and I can back safely into the van. It's treacherous and shaky 3 foot lift till I'm level with the van floor. There's a lock-down device on the floor that secures my chair in the front passenger side preventing me from flying through the windshield should the unthinkable happen.

It's the next day and I'm at my doctor's office a few towns away from Burlington. I've been seeing him for just a handful of months; just a handful of refills. I'm his first and only patient with a pain pump but he is eager to break into the field and welcomes the opportunity to add this specialty to his practice.

Practice. In my opinion doctors should be well past the practicing phase when they begin seeing patients. They should be using phrases such as "this is where I accomplish medicine." But alas, it is a practice and I'm left to say "have at it!"

I'm in an exam room availing myself to my doctor that he might fill my pump. The procedure is the same. I tilt back in my power chair to an astronaut position. Once again, God has me on my back and I'm looking up. My doctor pulls up my shirt and the pump is unmistakable. It protrudes from my stomach in the way hard apples in a pie stick out when raw dough is placed over the top of the pie before it goes into the oven.

My doctor begins by placing the suitcases round wand over the pump to interrogate it and see how much morphine is left. It's nearly empty. The first thing he wants to do is remove the remaining morphine in order to start with an empty pump. He doesn't want to put a month's supply of morphine into a nonempty pump and risk damage.

Tragedy ~ Torment ~ Triumph

In the middle of the pump's flat cylindrical surface there's a smaller round indentation that he feels for. It is the rubber portal, the access point where a syringe needle penetrates to remove or inject morphine; or radioactive dye in dire situations. He uses a long curved syringe that goes into the pump cavity. His fingers are like sonar feeling for the ping when the needle hits the bottom. Ping! He's hit bottom and draws out the remaining small amount of morphine.

Time to fill it. I've seen this before. From my vantage point I see him with a mask and wearing protective glasses. There's bright surgical light shining off of his glasses and in the reflection I see my stomach brown with disinfecting betadine. He is holding a large syringe filled with a month's supply of morphine. At the end of the syringe there's a thin, thin flexible tube leading to the curved needle. I can't help but think about the thin tube that had broken during the surgical implanting and puck bashing.

Ping! "Ok Rob, we're in." He pushes the fluid in at a pace that would make a tortoise pant. He's done and the room smells of the alcohol his nurse uses to clean the betadine from my stomach.

I sit up and by the time I wheel to his waiting room I'm dizzy and disoriented. Mary held the door open. I'm able to negotiate my way to the parking lot and my van. It's a beautiful warm fall day filled with bright reds and yellows and the unmistakable smell of fallen leaves. I'm lost in the beautiful sound as they're blown around by a gentle breeze. Mary opened the door, lowered the lift to the pavement but I'm unable to back onto the lift. I stare up at the sky while she takes control of the joystick and backs me onto the lift.

The drive home is a blur. I have an ad in the local paper because I'm in need of an aide. She is scheduled to come at 5pm. Mary invites her in but

Tragedy ~ Torment ~ Triumph

I am unable to speak. I don't know what's happening. All I know is she is brunette and keeps looking at me with concern as Mary describes my routine. I'm in and out unable to keep my eyes open. I ask Mary how the interview went as I'm getting transferred to bed.

The night is endless. I'm gasping my way through the valley of the shadow of death. We are in bed and Mary has one eye on the TV and one eye on me. I try to focus on the TV but my eyes keep rolling uncontrollably. I can hear the TV and I'm thinking just concentrate. Stay focused. Breathe. What is going on? I don't understand it. I fade in and out. I wake gasping for air. There's no burning. I'm lying in bed paralyzed unable to use my body and now I'm losing control of my mind. Why is this happening? What changed? What changed?

The lights are out. The TV is off. I'm losing my fight. I'm too tired to struggle. I'm too tired to continue to breathe. Mary keeps shaking me awake. "What? What?" "Rob, you stopped breathing." I can see her face as my eyelids fall closed again. Another shake and another "What? What?"

Night leads to morning. I'm a little more alert and a little more aware of my surroundings when my morning aide arrives. As he dresses me and gets me up in my chair I feel burning coming on. Will this dog ever die? The longer I'm up the worse the pain gets. It's late morning. I'm shaky, sad and emotional – really emotional. The pain is searing and now I'm crying. I'm not the type to cry but I can't control it. I call my doctor and explain to his receptionist of my prior afternoon and night. I describe my emotional state and the level of pain. She relayed the message and came back saying he'd like me to come in so he can check the pump.

I'm weepy, burning and have no interest in watching the reflection in his glasses. Out comes the suitcase. He waves his magic wand and interrogates the pump. He didn't say anything. Now I'm curious so I do glance up when

Tragedy ~ Torment ~ Triumph

the ping happens. His complexion goes shades whiter. Physically he doesn't look John the mousy maze runner but I've seen this shade of white before. As he draws the plunger of the large syringe back there's no morphine returning through the needle and thin plastic tube. He stepped to the side and said something to his nurse who left the room and returned with a new morphine kit.

At the time I'm too emotional and too lost in pain to deduce anything. With the new kit he carefully filled the pump and programmed it for normal rate and operation. It wasn't long before I started to feel pain relief.

I spent the next week lost in a state of depression I've never had before. Admittedly I have some degree of depression. I was doing the job most electrical engineers would give anything to do. I was newly married and just starting to enjoy the payoff of busting my butt those endless years in school. It's all been stripped away. Yeah, I've had depression but this depression is different. I have always felt, even during the first years of my injury, that happiness is a choice. If you make up your mind and decide to be happy, going as far as audibly saying "I'm going to be happy!" you will be. Not anymore. I have no choice in this. This emotion and depression is unbearable.

A week later I learned my primary care physician in filling my pain pump missed the pump. In one moment on that beautiful fall day my doctor injected an entire month's worth of morphine into my abdominal cavity. In learning that I had an extraordinary sense of optimism. It was a strange sense of relief that I wasn't without explanation or control losing my mind. There was a cause and the effect was that I felt less vulnerable, less unstable. I felt a sense of safe knowing, or at least feeling, the probability of

Tragedy ~ Torment ~ Triumph

that happening again was relatively quite low. It also became crystal clear why doctors call what they do a practice.

Through this adversity I began to see God in all things and watching over me.

“Yea, though I walk through the valley of the shadow of death,
I will fear no evil;
For You are with me;
Your rod and Your staff, they comfort me.”
Psalm 23:4