IT'S NOT MY TURN TO DIE

An autobiography by James Kish

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Foreword

Fortunately or maybe unfortunately, few people are offered the opportunity to feel the hot breath of death at their neck and live to tell about it. I was lucky enough to live through this possibility of dying and it changed my way of thinking and living drastically. Although the waiting nearly took my mind it also provided me with new values and a special secret. It is the secret to total happiness and satisfaction. It is expensive. It costs you everything. You must forgo paying for your house, you must drive less than new or beautiful cars and settle for less steak and more potatoes than you probably do now. There will be money arguments along the way but they will pass. Some of these changes are hard to make at first but after a while you become accustomed to them and they seem trivial when compared to the pay back. There is a point at which you reach this secret, it is not always apparent. You have to watch for it but when you have reached it you will find that you are living more happily on less income, spending more time with your family and you feel... yes, actually feel happy or sad to the point of tears over things you once didn't even notice. The biggest change though, is when you realize and find yourself thinking "God, ain't life grand. Isn't the world a beautiful place to be?"
I can't come right out and explain exactly what the secret is. It is far too complicated or maybe too simple to put into words but you'll know when you have and realize that it is what God wants us all to strive for.
I dedicate this book to Sarah, my first born, Andrew, my only son, Kaitlin, my last baby and Ann Marie, my confidante, my saviour and wife. Also to Drs. Bill Wall, Cameron Ghent, and Susan Munro for I owe them my life... twice. Finally to the fellowship doctors, organ coordinators, nurses in the MOTU ward and all of the other very professional people at London's University Hospital, which I think is the best transplant facility in the world.
Finally to the seventeen year old boy and the seventy-two year man from Western Canada who made the ultimate sacrifice at their deaths. They gave their organs so others like me could live. They died true heroes. I stand in their shadow, humbled by their compassion and generosity. There can be no more sacred gift to give than the gift of yourself, your organs or body after death. Surely there is a special place in heaven for those that give the final gift of life in the face of their own death.
GOD WATCH OVER THEM ALL FOR EACH IS SPECIAL AND I THANK THEM.

Chapter One: Whence Came the Disease

The first catheter came out glistening a brilliant red. About one eighth inch in diameter sheathed in a now blood soaked white nylon jacket. It was bent at crazy angle and although it entered straight and sharp it now resembled a crochet hook. The surgeon perspired and muttered soft curses, the muscle tissue in the center of the back on the right side is usually soft and easy to penetrate. Mine was as tough as rawhide and I was in, what the medical profession calls, "considerable discomfort."
"Considerable Discomfort", this is a medical term that means white pain, just short of passing out pain, excruciating pain, or otherwise any pain you could imagine in your worst nightmare.
The initial pain was the novocaine sting like that of a hornet that simply burns on the surface, like laying a burning cigarette on your back. This causes you to wince and concentrate on that pain alone. Then as the needle penetrates deeper the pains change to sharp shooting pains deep within the abdomen and upper groin. This is followed by a full feeling in your stomach and a positive feeling that you are going to throw up as never before. Then the needle is withdrawn and the pain leaves with it. After that all was supposed to be painless. The surgeon made a small incision half way up the right side of my back and I didn't even feel it. Next a three or four inch needle (they call it a catheter) was inserted into the incision and then into the cavity of the chest that contains the lungs. However, the muscle tissue at the point of entry is extraordinarily tough and the surgeon is actually forcing me ahead in the chair as he pushes in the

catheter. This definitely causes "considerable discomfort." A member of the staff left for another biopsy kit with more catheters. I sit in the chair and wait, hoping that the freezing will hold till the procedure is finished.
Finally, the new kit arrives and the new catheter is in place and a cloudy pink fluid runs through a tube connected to the catheter and into a plastic container. A sample of this fluid is rushed to the pathology lab. The doctors suspect that it is infected.
Paul, the out patient nurse, is asking if I'm alright for the millionth time and I responded by asking if I can relax or expect some more pain. That, I think, is the toughest part of any of these procedures. Not the pain itself but the anticipation of it. You don't want it to take you by surprise. By being ready for it you can put on a better front. Maybe even a better front than is necessary.
"The drain is in place and there will be no more pain for a while. "Paul says.
Very slowly, cautiously, so I don't move anything, I allow... even force my shoulder muscles down. They ache from being tensed up for so long. My head is throbbing. Beads of perspiration trickle down my face and I'm suddenly very tired. I'm physically and mentally drained, but most of all relieved that the bad part was over. In about thirty minutes I'd be on my way home.
The purpose of this minor surgical procedure is to drain off fluid that has collected around the right
lung and was impairing my ability to breathe properly. The fluid has collected there due to damage done to my diaphragm during my second liver transplant. The surgeon was a "fellow" or qualified surgeon working on a fellowship program, under a master surgeon. While I waited for the fluid to drain off, my mind wandered to an earlier time, 1982 and the events leading up to a trip to a similar room in a different hospital that set this whirlwind of events into motion.

1982
I was working in the garage at the Canadian Fram Automotive Research Facility, in 1982 when I started to have some minor chest pains. I've had these all my life and just learned to live with them. However, when they progressed down my left arm I decided to get them checked out at the emergency unit of Chathams', Public General Hospital. Once again turned out to be muscle spasms.
Leftover pain from open heart surgery I had in 1960. As I said I've had them before, ever since I was five. But, like a blind or deaf child who has never seen nor heard, I was the same. I didn't know what it was like to run a mile or be without chest pains for months on end.
I was born with congenital heart disease. My pulmonary heart valve was not properly formed at birth and allowed blood to leak back into the heart even when it the valve was fully closed. My parents were
informed at my birth that I would not probably live to the age of three and that technology was not advanced far enough to make my condition operable. I surprised them all and lived to the ripe old age of five. By this time my heart murmur had become quite pronounced and the doctors were concerned that I would not live much longer. A procedure utilizing the newly developed heart lung machine had made my condition operable. Very dangerous and with a high mortality rate but still operable. The doctors gave me a fifty per cent chance of living.
I know the feeling of what it is like to make a choice concerning major surgery. There is no decision. None what so ever. It's undergo the surgery or die. No decision. I'm sure it is a different feeling when you are making the decision for your child. Will the decision kill your baby? Maybe your child will not stand the rigours of surgery anyway. Maybe it is God's will for your child to be called "home" early.
My parents did of course decide to allow the surgery and the doctors termed it a complete success. Later when I was in elementary school it was found that the valve had been over repaired and this caused the occasional chest pain and shortness of breath. It was not life threatening but more a condition that I'd have to learn to live with. So I did. I still played hockey, football and lifted weights but not as well or as long as the other boys in high school. The chest pains seemed to come and go. There never seemed to be a reason like being over tired or over stressed, they just came and then left usually as quickly as they appeared.
The pains that I was suffering that day in the garage appeared to be no different except that they lasted longer than usual and scared me into the hospital. The doctor who saw me, admitted me for
couple of days to run some tests. Everything except a couple of blood tests came back normal. The doctor asked me if he could do a liver biopsy since the blood levels showed some liver function irregularities. I'm not a hospital person. I never was and never will be. I felt fine after the two day rest and the doctor was not my family doctor. I decided this problem could wait till my family doctor could check it out the next time I went to see her. Besides a liver biopsy didn't sound like much fun especially considering that it was more exploratory than anything else.

In my work I tested various components for cars, from cooling fans to air filtering systems to the switch that detonates the air bags in the newer cars. I was twenty-eight years old. Married with one child and a newly purchased home. I worked heavy hours in an attempt to afford all those things newly weds need in new homes. I wanted to work hard and long while I was young so I could ease off once things started to get paid for. In the research world there is usually lots of overtime and I worked more than my fair share of it. My family and myself lived a financially unrestricted life and so for me to be ill was just not financially feasible.

When the time came to buy our first home I had to pass a physical examination to life insure the mortgage. During this physical once again the doctor flagged the same irregularities in the blood tests as had been found earlier. My family doctor, Susan Munro, was concerned about liver function enzymes that were abnormally high and the possibility of me having hepatitis. She recommended that I see a liver specialist in London, Ontario. This time I had no excuse avoid further investigation. Dr. Munro was my doctor and I trusted her blindly. If she wanted to know more then I felt obligated to do as she asked.

His name was Dr. M Belshiem. The "M" was no doubt for Mohamad. I didn't particularly like East Indian doctors, a trait that I have since lost and I am glad of it. The East Indians are not only thorough but sincere and straight to the point. This man turned out be not a "Mohammad" but a "Martin". In his thirties (too young to be a good doctor?), white and Canadian.

He asked about a million questions about my previous lifestyle and health. Had I ever used intravenous drugs? Had I ever been or was I currently a homosexual? Had I ever had a tattoo? Had I ever left a wound unattended to the point of lock jaw? There is something you should know about me. I'm a country boy, pure and simple so when it comes to any of the above atrocities or "sins against the body" well we country boys just don't abide them. So it was a safe bet that I answered NO and fairly indignantly too.

Dr. Belshiem ran more blood tests and then asked for consent to do a liver biopsy. I signed.

A liver biopsy is most commonly done by inserting a biopsy need through the rib cage into the liver where it retrieves a piece of liver tissue. This sample is analyzed for various diseases. The more common ones are hepatitis and cancer. Hepatitis is divided into various sub groups. Acute, chronic, Type A, Type B, Type C, Non A, Non B, Non A Non B, Non A B or C and so on.

Each has its own set of characteristics, prognosis and causes. The biopsy is done in much the same manner as in draining fluid off a lung only the surgeon uses biopsy syringe instead of a catheter. Entrance is made between the ninth and tenth rib on the right side of the chest. The freezing as always is the worst part. In performing the actual biopsy the surgeon asks you to take a deep breath in and hold it. This causes minimal movement of the organs in your abdomen. If the liver is pierced while it is moving there is a chance of tearing a hole in the liver and bleeding to death. The surgeon wants the hole in the liver to be as small and non traumatic as possible. Medical statistics show
that one person in one thousand patients randomly bleeds. There is no determining factor to pick out the bleeders so the same precautions must be taken with everyone. The actual moment of the biopsy is much like a punch in the ribs. It's quite a surprise but you are not in any great pain for long. The body's reaction following the invasion of this needle is much like if you had been stabbed with a long thin knife. Blood pressure, pulse and respiration may trampoline. You break out in a cold sweat and feel just generally lousy for a couple of hours. You have lots of time to recover because the next part of the procedure involves lying completely flat on your right side with your arm extended over your head and pressure on the wound. Then you get to lie flat on your back for another four hours just to ensure that you are not bleeding internally. A nurse takes your vital signs every fifteen minutes for the first hour, then every half hour there after. This works out to be just often enough to prevent you from falling asleep… Bring a good book!

About one week later Dr. Belshiem informed me that pathology had established that I had Chronic Active Non A Non B viral hepatitis. The virus was probably contracted through a contaminated blood transfusion when I underwent open heart surgery in the sixties. Technology just couldn't screen blood as well then. Apparently someone with hepatitis had donated and it didn't get stopped in the screening. Hepatitis is highly contagious through any type of transfusion. Dr. Belshiem informed me that although the disease was deadly, that at its current rate I would be a very old man when it killed me if indeed something else like old age didn't get me first.

"I am going to put you on a steroid drug called prednisone just to see if we can arrest this thing once and for all." He said.

I went on high doses of prednisone for about nine months. This drug is not a nice one to be on. Some of the side effects include moon facedness, weak limbs, weight gain, fluid retention, depressed immunities, and sometimes vertigo. I got the latter. My first attack happened while shingling a roof. Vertigo is a disease that fighter pilots ore often stricken with. It

effects the balance center of the ear somehow and creates random bouts of dizziness. Not often, but completely without warning. As I said I was on a roof when mine hit the first time. Once I had hit the ground and regained my wind I wished someone had caught it on video tape. It must have looked comical as hell to see a full grown man go from a crouch on a roof to the standing position and then topple off like a drunken idiot.
Dr. Belshiem ran blood tests all along the nine months that I was on prednisone and decided that the drug was not helping substantially enough to bother continuing its use in light of the vertigo. He ordered me off the drug. Prednisone occurs in the blood stream naturally, thus the body must be weaned on and off the drug or the body may quit producing its own. This took a couple of weeks of which I could not be at work for my own safety. Prednisone is an anti inflammatory drug. It reduces inflammation throughout the body, the liver included. This reduction of inflammation does not cure the liver but allows the liver time to regenerate new liver cells. A trait that only it and the brain are capable of. The rest of the body is also affected in that you don't bruise or feel strained muscles from over exertion. This was great during hockey season and I didn't have a chest pain for the whole nine months.
So it was that Dr. Belshsiem released me from his care and sent home with no drugs.
"Don't donate blood, have your blood tested yearly just as a precaution and don't give this a second thought otherwise. Many people live with minor blood abnormalities all of their lives." He said.
And so I did... for two more babies and one new house or chronologically speaking six years.
The liver is one of the most marvellous and yet most unsung organs in the human body. Some of its functions are the production of bile to break down our food into energy the body can use, controlling how much water how bodies retain, and filtering out deadly toxins in the bloodstream, like alcohol and nicotine. It appears that the liver may be the home of our immune system although this is not known for sure. The immune system is the army of disease fighting cells that our body produces and modifies as we grow. It has also been found that much of the liver can be destroyed and the remainder of it can be on its way to destruction and yet the remaining portion of functioning liver can still keep the average person relatively healthy. One or more of these characteristics was probably the reason that for the next six years I remained feeling good and looking healthy.
Hepatitis is an odd disease in the way it works. Sometimes fast and other times slow, sometimes very fast for a while and then falls into complete dormancy. How ever it occurred is not important, but it was found that in six years better than ninety per cent of my liver had been destroyed. Had any other organ in the body been damaged to that extent I'm sure I'd have been a very sick man.
That's how it started. Now thirteen months and two transplants later here I am sitting with a tube coming out of my back. The freezing is starting to let go and I find I'm praying "God don't let this happen again "

Chapter Two: In The Beginning

In the spring of 1987, my youngest daughter, Kaitlin was born and this event finally squeezed our family to the point were our three bedroom bungalow just didn't hold our family any longer. As we looked for a new home we found ourselves caught in the age old dilemma of price and size. Our available money just didn't seem to buy enough rooms. We listed our home with a Realtor at a price that would allow us to make a small profit but it was definitely a buyer's market so we didn't plan on making a fortune on our first home. We began the search for a new residence on a slightly pessimistic note.
On the west side of town there was a house that Ann and I had always wanted to own. It was currently for sale because of the current owners were divorcing. It seemed to take forever before we decided to go through the home and see what it was like. This was just to satisfy our curiosity and take a look mind you. We didn't think we could ever afford it. But then it happened. Our Realtor came to us with a buyer. Not an offer, a buyer. We had no choice in weather or not to accept. The buyer had accepted all terms.
We went to look at the house of our dreams. We had our Realtor take us through the home. She recommended that we offer about twenty thousand less than the asking price.
"Hey kids, these people want out of this house. It is the only thing in the world that is keeping them from divorcing. If they sell it they can go their separate ways and that's just what they want." She advised.
We couldn't believe it when the owners accepted our offer of more than twelve thousand less than they were asking. We set a closing date and in September of that year moved into our fifteen year old split level on a two hundred by one hundred and sixty foot lot. It had an in-ground pool, a car port, lots of room and was in pretty good condition. It would

take every penny of my pay cheque to cover our expenses. We would have to live on a budget, but we could live there and that was what we wanted.
Over the next two years we finished the pool deck and change room. We also refurbished the living room. Family get togethers were almost always at our house since it was the largest and we loved to entertain. We also had parties. Lots and lots of parties. The kids were growing happy and healthy and Ann and I were as happy as we had ever been. We opened the pool in 1989 looking forward to another summer of pool parties and fun with family and friends.
It was late July as I lounged out on the deck near the pool in a hot afternoon sun. I glanced down at my bare legs and noticed that they seemed fat or puffy. I have always had muscular legs and I am short and stocky so it was not something that alarmed me at first. I began to notice that when I removed my socks at the end of the day, they left large dents in my skin where the elastic tightened around my legs. This didn't bother me either but I did notice it getting progressively worse. My younger sister Jodi joked about my legs when she first noticed them and said I looked like Popeye the Sailor Man. Then came the itch. My legs would itch. Not bad at first but eventually I would scratch until they bled. I noticed that tiny water blisters had formed. So tiny that one hardly noticed them until they got scratched and broke open leaving scars.
In my job, I often stand over a microscope for hours on end and so when my legs started to get worse I found that by the end of an eight hour day my feet were killing me. I made an appointment with my doctor.
Dr. Munro immediately suspected a liver problem and ordered more blood tests and set up another appointment with Dr. Belshiem in London. She (Dr. Munro) was about to go on holidays and referred me to her partner Dr. Pearce. Glen Pearce is a wonderful soft spoken man who interpreted the blood results and ordered me off work as of August tenth, 1989. I had worked nearly thirteen years with my only time off being for the prednisone withdrawal six years ago so I guess I didn't probably adapt well to being home in bed as Dr. Pearce had instructed. He also put me on two drugs. The first was Questran (cholestyramine). This is a yummy yellow powder that one mixes with water and forces down. It is flavored lemon but when mixed it resembles coarse chalk dust in water. It was probably the hardest drug I've ever had to ingest and often had to try two or three times before successfully keeping it down. This drug bonds with the bile salts in the blood and simply exits the body via stools with them. It is one of the few drugs that simulates one of the livers' functions. The other drug was a diuretic. It simply removed excess water from the body and would hopefully reduce the swelling in my legs. It also however makes you pee many times in a day and night. This marked the start of a zillion nights of interrupted sleep. All my life I have been a sound sleeper but since the start of the diuretics till even now I am up at least once a night.
At first being off work was novel, like an extended vacation. I didn't feel sick and often felt well enough to take my son Andrew fishing or to my Dad's Auto Body Shop to put in time helping or getting parts or whatever. Andrew who was four then called these "men things ". I often heard, "Hey Daddy, are we going to do men things today?"
Another man that became special to me was Reed Menzies. He was a seventy year old ex town clerk and the man who introduced me to two institutions that I have become a firm believer in. They are the Masonic Lodge and Dale Carnegie Courses. I met Reed while doing a term of municipal politics several years earlier. He became my mentor. A man who was as rough as hewn timber on the outside and a compassionate as any person I've ever met at heart. A man who knew what living life was about and wanted to share it with me.
Andrew and I spent many afternoons with Reed, fishing on his boat, or taking drives in the fall or talking about anything and everything. I discovered that time spent with other men be it sons, fathers or friends is more than just a way to put in time, it is therapy. Therapy that most men need and few rarely get. Time to express views on life, love, politics, morals, and religion seems something that Socrates or Plato had time for, but now I see that all men need this time. It allows one to come to terms with himself and his conscience. I spent the months of September, October and November with Ann, Reed, Dad and my children. This is time I shall always remember and was one benefit of being ill.
The primary and most noticeable symptom of liver disease is extreme fatigue. It was not too bad at first but by October I was almost always tired. I slept at least twelve hours each night and napped during the day. On the Thursday prior to Labour Day weekend I went to St. Josephs Hospital in London for a liver biopsy. This experience was for lack of a better word "unique". The surgeon was a young oriental doctor who didn't show a great deal of self-confidence. This small amount of self-confidence was shattered when, after fighting his way in past my leather tough skin, he couldn't seem to find my liver.
First he tried between the ninth and tenth rib were it was supposed to be and then over the tenth and again under the ninth. Still no liver! Doctors are not accustomed to making mistakes. Especially second or third mistakes and this young intern apologized profusely. He called Dr. Belshiem for help. Dr. Belshiem seemed mildly distressed as he entered the

room and carried that look that said "If you want something done right...". He apologized also and said he only take a few more minutes and he'd be done. He injected more anaesthetic. Those minutes passed and he attempted a biopsy and also failed. The doctors then conversed quietly between themselves for a moment and came back to tell me that they would like to keep me for the night and try an ultrasonically guided biopsy in the morning. During this type of biopsy the doctors can actually see the liver via an ultra sound picture.

I was left alone to recuperate for a few hours and arrangements were made for an ultra sound later that day, just to locate the liver. As for the recuperation, now that wasn't pleasant at all. My body had just been attacked four times by four inches of biopsy needles and so it reacted in much the same way

as would a multiple stabbing. I fell into shock, my blood pressure soared, my body temperature soared and I felt bad enough that death seemed a reasonable alternative. Ann, her sister Eleanor and a close friend Lisa were with me for the afternoon and that made matters worse. When I am sick I want just to be alone or alone with Ann. No sympathy, no talking just let me be miserable alone. However their intentions were good so I tolerated them.

It was decided to do the ultra sound just a few hours after the biopsy instead of waiting till the next day. Within about two hours I felt human again and went for the ultra sound later the same day. About an hour after the ultra sound Dr. Belshiem entered the room looking distraught and alarmed. The women had all left for coffee. He sat on the edge of my bed and put his hand on my shoulder.

"I'm so sorry." He said. "The ultra sound shows that over ninety per cent of your liver is gone. It has shrivelled up and died. There is almost nothing left. The only hope you have of living is a transplant. The problem is that it appears that things are happening rather rapidly and I think you may need one very soon. I'm so sorry. If we just kept a better watch over it maybe we could have caught it sooner".

Then he was silent. Everything was silent, no sounds except one. Only the sound of a omni-present wind in my mind. A lonely whine that seemed to penetrate my whole being. My mind filled with thoughts.

Death stands alone. Nothing in the world compares to comprehending ones own demise. The brain overloads with emotions. Why me? When? Will it hurt? Who'd take care of my family? Is there a heaven? Death must be faced alone. No matter how close anyone is to you, it is you alone who must deal with it. Perhaps it is the fact that no-one knows what happens after death. There is no documented proof of what happens after death. No one has been there and returned with a shirt that says "My dad died and went to Hell and all he brought me was this crummy T-shirt". I've yet to see a thimble or a tea spoon collection with Heaven or Purgatory engraved on it. So that is what makes death unique, the fact that it happens to us all and we know nothing about it. Forever man has feared and avoided death.

My first question and I guess the big question is "How long do I have?"

"A month perhaps but more likely three months definitely less than six months." He said.

Ann returned from a coffee break and I told her. She too was quiet.

"Dr. Belshiem said I could go home for the weekend. "I said. "But they want me back in Tuesday at University Hospital for a Trans-jugular biopsy."

She smiled and went to pack my things.

Dr. Belshiem had also explained that although I seemed to be an ideal recipient for a transplant there would be many tests and other hurdles to overcome before I would be put on the waiting list. He also said that even if I made the list that transplants were a highly technical operation and the most difficult of all transplants to perform. The recovery road was difficult and not always successful. There was always rejection to deal with and if you reject totally you must start all over again on the waiting list.

"Be prepared for a couple of years of real testing times." He said. And just before he left he warned me "Your disease is definitely terminal, if left unattended it will most assuredly take your life. That will happen fairly soon although medical science can't accurately predict when. Be optimistic about the transplant, that is an important factor for success but also take this thing seriously or it will kill you. Jim, you'll never know how badly I feel about this. Take care and good luck." He shook my hand and left quietly.

Ann and I went home for the long weekend and fell in love all over again. Suddenly we appreciated each other. A clock had been set and we became aware that we could be cheated out of growing old together. She could be left alone on earth to bring up three children by herself and I, well who knows were I'd be. We held hands in the day and slept with our arms around each other. We were like newlyweds. We talked. We discussed our will, my death, our finances and insurance policies. Not all pleasant topics but it was essential that Ann and the kids were looked after if I should die. We looked into and updated all of the aforementioned within two weeks.

Monday I returned to London, to University Hospital for the Trans-jugular biopsy. Monday of course was wasted on blood tests, x-rays, ultrasounds and a host of other tests. Every intern, doctor or nurse that saw me wanted a complete medical history on me. Finally, Tuesday a nurse came in about ten o-clock and gave me a tiny yellow pill and said they would be in to take me to radiology soon. The yellow pill was Valium. At about ten thirty I went via stretcher to a room much like an x-ray theatre. Valuim is a wonderful drug in that it allows a patient to be fairly much aware of what is going on yet not really care about the pain. You still feel the pain but you develop an attitude that you just don't care that it hurts like hell.

The surgeon, Dr. Rankin, froze a portion of skin about four inches below my ear on the left side of my neck. He made a small incision there and cut into the jugular vein. Into this hole he inserted a catheter which he then fed down my neck and into my abdomen. He does this with the guidance of an over head monitor that allows you to watch the catheter travelling inside your body. When the liver is reached a small mechanism on the end of the catheter cuts a sample of liver tissue from the inside of the liver. The catheter is removed and the tiny wound in the neck receives a bandage. There is no post operative wait since any bleeding that occurs, happens inside the blood system. I went home the same day.

About a week later I met Dr. Cameron Ghent, Team Leader of the Liver Transplant Team at University Hospital. He was a slightly greying man in his fifties. I suspect of English origin. Dry humour, straight to the point, an exacting man whom I imagine is a stickler for details. Maybe not the man I'd want to work for, but definitely a man I'd trust my life with. I found out later that his bark is much worse than his bite and I must admit that I enjoy his company now. I remember during the preliminary screenings how he drilled the interns and medical clerks on the symptoms of my disease. He scared the hell out of them the same way he scared the hell out me the first time I met him. He was not the type of man to raise false hopes. He informed me that so far I had met the criteria for a recipient and that my name would be put on the waiting list immediately. I was to return later to the hospital to meet the rest of the team and finalize the preoperative tests and interviews. He then sent me home with a pager to begin the wait.

Chapter Three: The Transplant Team

The transplant team is much larger than what one might assume at the start of this shemozzle. I have broken them down into three categories. The preoperative team, the surgical team and the postoperative team. The cost of a transplant is not easily arrived at. The surgical cost alone is over one hundred thousand dollars. There is also however the cost of preoperative tests and appointments and postoperative tests, which continue for at least one year. Add in the drug and diet training, physiotherapy, and extra hospitalizations and drugs to combat rejection of which roughly fifty per cent of the patients suffer from, at some time or another. I don't think that a quarter of a million dollars would be too far off the mark for total costs. A major portion of these monies are wages for this small army of specialized people we call the transplant team.

The Preoperative Team: This I suppose, includes the family general practitioners, who flagged the internist original problem with the liver, the internist who performed the initial tests and diagnosed the specific liver disease, the liver specialist that decides weather the disease is treatable and how to treat it. Also the blood technicians, medical clerks in their third year of medical school, they document medical history. This too includes the fourth year medical students serving their internship as practising doctors under the supervision of specialists. There is also the out patient clinic staff who keep the current medical records straight. Their names are Karen and Paul and they are two of my favourite people. Karen is a doll and Paul is OK as men go although my wife thinks he is very handsome also. The fellowship doctors are also part of the surgical team. They are involved in all phases of the transplant. They are studying via medical fellowships under the master surgeons in hopes of someday becoming masters themselves. These "fellows" as they are called do most of the doctoring that the masters just don't have time to do. They change every year in July. It becomes very hard to see them leave after building a relationship of trust and understanding with them. There is also a social worker who is an emotional catch-all. He takes care of everything from financial headaches, and heartaches of broken marriages (which are quite common), to telling the kids that Dad is real sick and might die, to helping the patient or patient's wife deal with death, drugs, diet, and any other thing that might upset the patient or his family mentally.

Finally there is the Recipient

Coordinator. This was a young lady in my case. She is the keeper of the almighty list. The list that says who is where and how many are ahead or behind you. She is also keeper of the pagers. She is the one that activates your pager

when your time is near. She also keeps a constant watch over your current medical state and revises the lists with the doctors as medical conditions change. Her name was Debra Sieb.
The Surgical Team: This team is much larger than most people think. On TV we see five or six people in an operating room when in real life, in the transplant business there may be more like twenty at any given time. There is of course the head surgeon who performs the actual transplant or changing of the organ and hooking up of the various blood vessels. But he does not usually open or close the abdominal cavity. That is usually done by a fellowship doctor. The Team Leader is a member of all three teams but may or may not be in the operating room. There is the anaesthetist who is a specialist doctor and is there from start to end and is in contact with virtually everyone in the room keeping tabs on just how deep your sleep gets. A respiratory technologist who constantly monitors
breathing and the machinery that provides oxygen to the patient. The small army of highly specialized surgical nurses who service every need in the room. Often there are a few, top of the class, interns serving their internship. The fellowship doctors who may open or close the abdominal cavity (or both) and are also often in charge of the air lifting and retrieval of the donor organ. Blood gas specialists, vital signs specialists, kidney specialists and I'm sure I've forgotten someone.
This assembly of professionals is so massive that it is hard to believe that each one knows what the other one is doing much less function as one large well oiled machine. They pull off these performances on a daily basis with such an air of ease it makes you wonder if they are not functioning on another frequency altogether.
The Post Operative Team: The surgical team is kept on standby for a short period after the patient is removed to the recovery room as a precaution should something go wrong bad enough that they should have to go back in. So I suppose they are part of the postoperative team as well. One of the fellowship doctors remains on call for the rest of the day also. The Intensive Care Unit is where post operative care really starts. This consists of one to one nursing care twenty four hours a day. This is supplemented by other members who's tasks are more specialized. The respiratory technologists, intravenous blood technicians, blood gas technicians, and portable x-ray technicians all work closely with the Intensive Care Unit staff. When you have progressed well enough to leave the IC unit you go to the MOTU multi organ transplant unit staff. This is where the remainder of recuperation will occur. There is one nurse for every two patients. There is also a physiotherapist to assist in physical rehabilitation. There is also a post operative dietitian, and teaching team.
Thus probably well over fifty people directly involved and over one hundred indirectly involved in every single transplant. Thank God for Canada's social assistance and world class health programs. This generally costs the patient nothing! Not one dime!

Chapter Four: Eligibility & Meeting Transplant Criteria

At first it seemed that every intern, nurse and doctor that I encountered while at the various hospitals I was sent to wanted first to do a detailed medical case history, blood tests, urine tests, stool samples and then insert their finger up my rectum. At times I wondered just how they planned on inserting this new liver I was to get! They listened to my heart and did cardiovascular dopplar studies to determine weather I could physically stand major surgery. They did a thousand x-rays, it's a wonder that I don't glow in the dark. Ultra sound scans of my abdomen to the point where I think I could have done them myself just from watching. The x-rays and ultra sounds I think were monitoring just how quickly the liver was degenerating. Blood samples, just in quick rough figures, I think that in the last eighteen months I have given over one thousand vials of blood. In rough volume I have let about twenty quarts or two and a half times the volume normally in the body at one time. I have also received around seven hundred needles and over fifteen hundred finger pricks. I have also undergone several electrocardiograms and echo-grams to again be sure of the heart's strength. I have undergone respiratory testing to ensure that my lungs were strong and not diseased and several more liver biopsies to study the progress of the disease. An HIV virus test was done to ensure that I did not have the aids virus. The HIV virus test is done prior to all surgical procedures at University Hospital. Although the test itself is only a blood sample, the interview prior to the blood sample involves a doctor explaining the ramifications should you test positive. The Board of Health must be notified and surgery may be cancelled. After this a doctor explains exactly the same thing to you and you are required to sign a consent form.
The physical criteria is fairly simple. Livers are matched by blood type and size. You can't put a five pound liver in a four pound hole and you can't put an A positive liver into a Type B recipient. Women and children need smaller livers

because they generally have a smaller abdominal cavity. The liver must be completely intact when it is transplanted and it cannot be trimmed to fit. There is however experimentation with a process where by a portion of a mothers liver can be severed to transplant into an offspring with some success but this is still very experimental. It will be years, if ever such a procedure becomes common.

Each time I went in for a battery of tests I met more members of the transplant team. We became friends and got to know each other almost intimately. As I progressed through the meeting of the criteria I also came to know Dr. Ghent, the team leader and finally the head surgeon, Dr. Wall. They were fantastic men. Both calm and gentle and unusually quiet. Both had a good sense of humour and both were pure science and logic minded. They appeared to be very capable of reading people. They were not proud but really quite humble and seemed to consider their jobs just a necessary part of science. I came to admire them and found myself wondering just what made them tick. It was their job not to let personal feelings get in the way of who was where on the list. After the transplant I found that a special feeling. A feeling that can not be explained and a feeling that one has only after he owes his life to another person. You can never show enough gratitude.

The third Thursday of each month is evaluation day. Mine finally came. This is when the list is revised and new names are added. Ann and I met with Dr. Ghent and Dr. Wall in a small room in the out patient clinic office. Dr. Wall said that statistically speaking the mortality rate was about fifteen percent. With my previous heart surgery that might make me closer to twenty percent. He asked how I felt about having part of another person's body in mine. Was I scared or doubtful about the operation and finally did I want to think this thing over before signing up to the program? I had decided a long time ago that I would just do it. I put my trust in this vast medical team and decided to let them do what they do best. When one considered the alternative, I really didn't have a choice. It was clear that I needed a transplant and not to have it done, as soon as possible, was just dumb.

There are overall considerations also. Such as current physical condition, because people in poor health don't tolerate major surgery well. Is the patient the type of person who will conform well to the strict regime of drugs and diet the must be followed for the rest of his life? Is the patient currently or has he ever been a substance abuser? Is he prone to alcohol abuse? Does he have a criminal past? Does he have the available family support, the positive frame of mind and physical age to tolerate major surgery? All of these questions are part of what determines who gets a liver and who may die waiting. This is truly playing God and I'm sure the doctors have spent many sleepless nights over whether or not the right person was chosen. It is a decision that most people wouldn't want to make but considering the cost of the operation and the availability of donor organs the medical team must get the best value for its money and organ as possible. The process is fair and based on empirical scientific data as far as possible. The social worker plays an important role in this process also. After several sessions he decides the mental state of the patient. A transplant is like a mental rebirth. The enormity of the process is awesome. One has a hard time comprehending what has happened to him. You feel physically changed. Your religious beliefs are usually strengthened. You are so incredibly thankful for another chance at life. It seems that you find yourself thanking God for everything from the taste of food to the antics of your children. Everything in life takes on a new meaning. The social worker has seen this so often that he gets to know what type of personality handles it well and what type ends up worse off than if he were allowed to die.

Some people are truly better off dying. Some just can't handle the post operative pain, the long road back to good health and living a new life of drug schedules and doctors appointments or even the ever constant threat of transplant organ rejection.

I lucked out and was considered an ideal candidate, capable of handling it in virtually all aspects they thought. Now all I had to do was wait for the call and then prove that the transplant team in all their knowledge was right.

Chapter Five: The Waiting Season (Fall 1989)

I often wondered how I would react to being told that I had a terminal disease. I think this thought has crossed most peoples' minds at some time in life. How well could you cope? Would you be brave or collapse? Would you be strong for the kids? Would you feel it to be more noble not to tell anyone?

There is a realization time period. A time were most people get used to the idea of dying. A time when you realize you were always dying. It’s just that now you have a better idea of when it will happen and are aware of the fact that it will happen sooner than you had expected. I suppose that knowing when is the real clincher. Mythology tells that of all the

secrets that escaped Pandora's Box, the only one that did not escape was the knowledge of when death would occur for it was said that no man could live with that knowledge.
I awoke in the middle of the night about two weeks after I had received a prognosis. I went to the bathroom. I sat down on the floor in my underwear and cried. I cried like I had never before. I mourned my own passing. I cried tears of rage at being robbed of a life with my wife and children. I cried tears of sorrow at having to leave them behind to fend for themselves. I cried tears of fear, fear of death and fear of pain of the surgery I was about to go through. And I finally cried tears of self pity, that enraged me for the last thing I needed was to become self centred and sorry for myself. I cried only one other time before the surgery and that is a later tale. I went back to bed and slept well.
I have lived a good life. I don't steal (sample) grapes at the super market. I don't cheat on my income tax, I never teased the school flea bag and never intentionally hurt anyone in the world. So, why me? Why don't I get to watch my kids grow up? Why can't I grow old with my wife? I want to meet my grandchildren. I don't want fame nor wealth, just the chance to grow old with my family. I love them more than life and thought of leaving them behind was more than I could bear to think about.
Something happened that night in the bathroom. Something else that I didn't realize until months later. I had dealt with dying! I had analyzed it, processed it, accepted its' reality and mostly I had accepted the fact that there was absolutely nothing I could do about it and therefore let's get on with life
and do it with gusto. I had found a unique area of my brain. It is a space that is reserved for special moments. Mostly bad ones. All the times that you were laughed at as a child. The dates that were turned down or stood up. All of lifes' most embarrassing moments are in this place. You rarely use this space and definitely don't like to revisit there. You feel panicky and unstable when you visit that portion of your memory. You know the place. We all know it. Some much better than others but we have all been there and we hate it. That is where death is stored for most of us. We rarely think about or even like to think how we will die. This is the natural place to store the concept of a premature death. Once it is there it will leave you alone to carry on living.
I was now at liberty to fall in love with living life to it's fullest. I would learn to praise each day for something good. I would revel in my children's joys and live and love to the fullest extent. If these days were to be my last they would be the grandest days of my life.
Oh yes, the other cry! Ann and I have a one in a billion marriage. We know that ours is good and special. We are in many ways direct opposites but I love her sense of humour and her little quirks and odd ways of saying things. We are capable of spending unlimited amounts of time together without wearing each other thin or irritable. In our dating days we went fishing together and spent hours talking about our views on various facets of life. We spent a great deal of time laughing. Those days seemed far away and precious. Everything we did was done together. Our trip to Florida, our wedding day and even painting our pickup truck. Now it seemed there was a possibility of those memories becoming the start of a sad story.
One day about a month after I had been diagnosed, we were in the kitchen in the middle of the afternoon. Sarah and Andrew were at school and Katie was down for her nap. We were just done the dishes and finishing the counter tops and table when we bumped into each other.
"Hey watch where you're going, you bonehead." I said.
"You watch were I'm going bonehead." She replied.
We body checked each other playfully and then our eyes met... We fell into each others' arms weeping remorsefully. Our tears fell on each other and we wept for two or three minutes without saying a word.
"I love you, my sweet. I'll never leave you." I promised.
"I'll love you forever." She said. Perhaps we were mourning the potential death of our marriage. Maybe saying that we were sorry that our relationship had to end prematurely. Maybe it was both, combined with pent up stress and pressure to be strong. But whatever the reason it was necessary that we cry together that one time. We needed to re-enforce the fact that neither one of us could make it through this alone. That neither one of us wanted out. More importantly that we would face it together and fully intended on winning. It was an emotionally cleansing cry and one that we both needed although maybe neither of us will really ever know all of the reasons why.
In meeting people who were terminally ill I have found that the ones that fare the poorest are those that let their death become the centre of their existence. I don't think that this is a good time to make any long term career moves or plans to change your life but I have found that this was an excellent time to plan a career change after the transplant. I decided to change jobs and start a new life with my new liver. It was something I came to look forward to, a post operative plan of my life.

Eventually I found that my transplant marked the birth of a new life style that I would anticipate and enjoy more that I ever could have imagined.

Chapter Six: The Wait Continues

It was late September when I was officially put on the list. At that point my symptoms were still not bad enough to give me any kind of priority on the list. I continued to work with Dad and spend time with Reed and Andrew. There were many days when I felt so incredibly healthy that I wondered how I could be terminally ill.
Reed became my confidante. I told him things that I could never tell anyone. He was a religious man and we talked often about religion. I had never planned on a funeral and had always signed my donor consent card but Reed said that the funeral was more for those left behind and I should ask Ann how she felt. Fortunately she did not want a funeral either. Reed was a natural born politician so we talked politics too. He is the best listener in the world and I came to depend on him to unload on. Ann also became Reed's friend and she confided in him also. He never told me specifically what they talked about, he steered me in the direction that would best aid Ann's needs. Sometimes I think without me knowing what he was up to. That is Reed's forte.
My Dad and I became like a real father and son. He never really had much time left for us kids when where growing up. He worked long hard hours all of his life. There was still time for the odd camp out or fishing expedition but not a lot of time to just sit and talk or watch the world go by. This we did now. I took him fishing for the first time with a rod and reel. As kids we fished the Thames River with a dip net. A net is much more productive that a rod and reel. One day I went out on a fishing expedition with Andrew, Reed, Pete Newby (a close personal friend) and Dad. We never caught a thing. Dad said that was why he had never fished with a rod and reel before. No one on the trip could believe that a fifty-five year old man had never fished with a rod and reel before! I'm glad I showed him that, he does it all the time with Reed now.
I carried a pager, or beeper, on my side all the time so the hospital could reach me twenty - four hours a day. I lost this thing on a regular basis and it often ended up under the seats of cars, under the couch cushions and came close to getting washed several times. It also caused great alarm when it when off during supper a couple of times. Apparently the micro wave oven was capable of setting it off. The first time the pager sounded everyone at the table froze and turned white while I got up and called the hospital. The hospital assured me that they had not called and that it was probably just the microwave. There was a whole round of relieving sighs. I'm sure it looked comical as hell.
Ann's birthday is in November and I wanted to shop for it and Christmas well in advance just in case I got called. All three kids and I went into London one day and shopped the whole day away. We all had the time of our lives. We drew names among the kids and then went birthday shopping for Ann and next Christmas shopping for Ann and then each other. We were all exhausted when we got home but it was the most fun I can remember having in a long long time. We stayed up late the next night wrapping the gifts. Each of my children came to my room alone and we wrapped their presents and made secrets. Then finally all of them came into wrap Mom's presents. This time was precious to me. It was just me and my kids. Keeping secrets and sharing the gift of giving, each one assured that their present was the one Mom would like best. I prayed to God for more time with them.
In early November I spent two or three days decorating the house with the kids. We put up outdoor lights, flood lights, a Santa Claus and an outdoor tree. We even put up the indoor Christmas tree early which was something Ann abhorred. She thought the indoor tree should go up about a week before Christmas but I'm too much of a kid for that.
There, I was all done. The shopping finished, the house decorated and Ann's Birthday shopping completed. This was something that I had to deal with mentally. For all outward appearances it looked as if I was preparing to die. But I wasn't. I just wanted the kids to be ready for Christmas and Mom's birthday. If I hadn't done it myself it may not have gotten done or at least not the way I would have wanted it done.
The pool had been closed, the yard work cleaned up. Now that all my chores were completed I noticed that "the wait" had begun. If I didn't go in November I was hoping to wait till the new year. I love Christmas and really didn't want to miss it.
I have operated a small computer programming business for four or five years and my programmer Mike Ross, and myself, had written some custom software packages. One such package was for a hospital or foundation. This program kept track of people who made donations to the hospital. It kept a running total of their donations and issued annual receipts for income tax purposes. It also rated donors as Bronze, Silver, or Gold Leaf status which was displayed on a

tree in the hospital lobby and generated a variety of reports. This program was fairly complex and often showed bugs in its early stages. It was December first when the foundation office called me to see if I could stop by on the weekend and look at a couple of bugs.
I stopped in Saturday morning and sat down to the computer and after about an hour I found that I had to take care of some major problems. I was very much in doubt of the integrity of the computer's hard memory and felt that I should contact the dealer to have it replaced. The last thing I wanted to happen was for the hospital to lose any data at this point. I went home at noon Saturday and called Mike. I told him about the problem and he agreed that it was faulty hardware. We decided that
Monday we would replace the hard memory.
I never got to make that service call. Monday morning, December the fourth, at one thirty a. m. the phone rang. They had a donor!!

Chapter Seven: Surgery

Ann's heart was pounding as she lifted the receiver. Somehow she had made it to the phone ahead of me. I don't recall that ever happening before. She was never one to interrupt anything just to answer the phone. I came down just seconds behind her. She had just hung up. She said that it was the hospital and that they would call back to authenticate themselves in about three minutes.
Again the phone rang. "Hello. "I said.
"Yes Mr. Kish, this is Dr. Abhujoudi, I am a fellowship doctor from University Hospital in London and I am calling to inform you that we have a liver for you." Said a voice in broken English. He was obviously East Indian and very hard to understand. "I will call you back in about five minutes to authenticate this call." He said and we hung up.

I was surprisingly awake and calm. The wait was finally over and in twenty-four hours I'd know if I was to be given another chance at life. It seemed that an incredible weight had been removed from me. I was upset that I might be in the hospital for Christmas but that was detail. Ann and the kids would understand.
When the phone finally rang for the third time I answered and the hospital informed that I should pack my things and head immediately for the hospital. It was snowing and there was about four inches
accumulation. They said that there was no hurry to get there. The donor organ has not yet been removed but get ready and drive as quickly and safely as possible to the hospital.
I called my Mom since we had a preoperative plan for both night and day. I told her the hospital had just called and she said she would come right in. Mom arrived in about ten minutes. She suddenly looked tired to me. How hard had my life been on her? Being a parent now I realized that it must have been a tremendous load to bear for her with me sick as a child and now as an adult. It is not natural for a son or daughter to die before their parents. I felt sorry for the heartaches I had made for her life and I hugged her and asked God to forgive me for all the times I had been insensitive.
In the wait for Mom, Ann and I had grabbed our bags and loaded them into the car so that we were ready to go when she got there.
I had promised my eldest daughter Sarah that I would wake her if I got the call in the night. Andrew and Kaitlin were too young to understand what was going on so I let them sleep. When it came right down to it I realized that I couldn't wake Sarah. She might worry the night away and so I was surprised when I went into her room and found her sitting up in bed.
"You're going now aren't you?" She asked.
"Yes, my love, I'll see you in a couple of days." I replied.
"Good luck Daddy, I love you." She said and we held each other tight.
"I love you my Sweet, please be good for Mommy." I said and left the room before I started to cry.
Andrew and Sarah and I had discussed my operation. I had told them that I was going into the hospital some day soon and that I was going to have a very dangerous operation. I told them that I might die in that operation and asked them what they thought that meant. Sarah knew! Death was forever and she asked if I was scared. To Andrew death was less serious. More like the Roadrunner and Coyote or cartoons. It didn't appear to bother any of them to the point were they were sleepless or suffered nightmares about it.

I went into Andrew's room and kissed him softly and sat for a moment watching my only son sleep peacefully. I thought a thousand thoughts and tried hard to remember what they looked like now. I prayed that if I died I could watch them from above. I said a silent prayer for my children. My heart ached that my children would not probably remember me if I died. I kissed Kaitlin, my last baby, still so tiny and helpless. I have never done anything so hard in my life.
Ann was still giving Mom a million last minute instructions. It appeared that she was saying "I don't want to do this yet, let's just talk for a minute more." I finally dragged her to the car and we started out. It was still snowing and about three o-clock by the time we were on the road. It was a lovely slow soft snow, big flakes that hypnotized you if you looked too long at them. In about an hour and a half we were in the parking lot at the hospital. It was incredibly cold and I can still feel that cold as we walked first to the front door of the hospital. I don't know if we were shaking from the cold or fear or anticipation but for now I'll call it cold. Every time I enter the hospital my mind travels back to that cold night and the feelings that went with it. The front doors were locked we went around to the side emergency doors and allowed in. The magic phrase seemed to be "I am here for a transplant today". This phrase made people scamper. There was no admitting, no waiting, and people were courteous and efficient. All other jobs appeared to take second priority to me. I was soon in the MOTU (multi organ transplant unit.)
This unit has twelve rooms that form a semi circle around a glassed in nurses station. It looks rather like something you'd see on a space ship. Each room has its' own oxygen, suction, heart monitor, toilet and sink and twenty inch overhead colour TV. The beds are adjustable six ways with the push of a button. The room is glassed in completely with a sliding door and made private with the use of mini blinds. This may be were University Hospital gets it's nickname "The University Hilton." The rooms are very private with separate heating controls for each room, carpet and just plain overall comfort throughout.
"Mr. Kish, please shower now, use this soap and scrub everything till it hurts." A nurse said with a smile.
An orderly brought Ann a fold up cot and she laid down and read while I showered.
When I returned wearing a surgical gown, Ann smiled and sat up. A dozen nurses and technicians were waiting to do preoperative blood tests, blood gases, urinalysis and vital signs. They too were quick and efficient and soon the room was empty again.
It was about six a.m. and I laid down on my bed and looked at Ann. She moved to my side and laid her hand on my face. We said nothing. We just sat and looked at each other. We made small talk I guess but I think most of all we just sat and contemplated our love and what was about to occur. I felt as if I knew everything about her and yet I wanted more time to know her even more intimately. Our time together had been far too short. I'm not sure I knew what true love was until that day when I sat with my wife for what could be the last time before I went to challenge death. I fell asleep on and off. So did Ann.
About nine a.m. Dr. Ghent came in the room. I awoke. He smiled and said "Are you all ready?"
"As ready as I'll ever be." I answered.
"Are you scared?" He asked.
I thought about this question and answered truthfully "No, should I be?"
His face showed a quizzical look and he said "I'm not sure if you know what you're getting into if your not scared."
"You said that you are the best and I trusted in that, so don't shatter my dreams of you now." I said.
"Good luck, James." He said with a smile and he left the room. But I'm sure he was still somewhat puzzled.
Soon it was noon and the team was ready for me. A porter came to my room with a stretcher and I was loaded on and taken to the second floor where the operating theatres are located. We stopped just short of a large pair of sliding doors and the porter said that Ann couldn't come any further.
There were tears in her eyes. She was so beautiful. She was so scared and alone and brave and frail and I hated myself. I had no right to do this to her. How could I put her through this? How selfish and thoughtless I had been. I had been so tied up with my death, my liver, my disease that I had never had the time to ask how she felt. She had to be as scared as I was. If I died, she was going to be left alone in this world with three children to raise and no husband to help. I cursed the Gods for my lack of insight and promised to make amends after this surgery. That was what I considered to be my only big error. I had felt so sorry for me that I had forgotten that Ann would have to carry on after I was gone. What I had done was unforgivable. Ann of course never gave it another thought. She is the most wonderful person in the world. I decided that all I could do was try to be deserving of her when this was over.

I don't remember much after that. I entered a kind of a staging area full of pre-op patients. I wasn't in there long. Maybe five minutes, tops. I remember the lady doctor who administered the anaesthetic. She had a wide pretty smile and a lovely personality. She froze the inside of my left wrist with a series of small needles. Only the first one hurt. Then she warned me that this next needle was for all the bad things in life I had done. It was about the diameter of the lead in a pencil and about two inches or maybe three long. When she pushed it in I just about flew off the table.
"There there, Love it's in and all over now. I'll finish with it later. Start counting now backwards from one hundred." She said.
My voice shook. "Ninety-nine, ninety-eight, ninety-sev.."

Chapter Eight: Ann's Story

I left Jim at the sliding doors to the operating theatres and went to the bathroom. I hadn't dare before in case they took him while I was gone. Then I acquainted myself with the hospital volunteers. They were there to keep on top of things and promised to let me know the minute they knew of anybody asking for me for anything.
I figured I'd better go have a smoke. It was something to do and I needed some time to collect my thoughts. There were other people in the nine by eight windowless smoking room but visiting was discouraged in favour of finishing your smoke and getting the hell out for air.
I called my sister, Eleanor, to let her know this was it and to tell her to get in touch of our friend, Eileen, that she worked with who, I knew, would come at a moments notice and stay with me. I really don't mind being alone but Eileen is excellent company even if you don't want company. Anyway, my sister said that Eileen was on afternoons so I figured she wasn't even at work yet. I called at the beginning of the next shift for Eileen and was told she was on days. Now what? I knew if I called her at home she would think nothing of the hour drive back into the city but I didn't want to do that to her because who knew when we would get out of there. I decided that it was probably better alone anyway, I would be less apt to break down or blubber or some other fool thing.
I tried to read. I love to read and was in the middle of an exceptional book but I found myself simply turning pages and not actually retaining a thing. A gentleman across from me in the waiting room asked what I was reading so I held the book up for him to see the cover, he said, "No, *what* are you reading?" I think he knew I wasn't really with it.
I wore a path from the smoking to waiting room. I didn't want to leave for the cafeteria in case the Dr.s came out with some information.
I noticed a weary looking woman sort of making the same trips as me, back and forth aimlessly, she cried now and again and had the same vague expression I must be wearing. Once when we were alone in the smoking room I asked her what she was in for. I found out that her husband was having a heart transplant from the same donor as Jim. We became friends through that common bond and talked of our husbands illness', job problems, travel inconveniences (they were from Sault St. Marie) and of course of THE WAIT and how it affected our families.
I was quite disheartened when after only four hours the Drs. came and told her they were done, I was happy for her and we hugged and cried but it seemed my wait would never end. I knew the operation was to last eight or so hours but time was quite irrelevant at this point and I wanted things over.
I met a few other people in the waiting room. One young lady named Brandon from the United States. Her husband was a surgeon and had come to Canada for a heart operation. We discussed the differences in hospitals and procedures and the list of items her "Yankee" friends had asked her to bring back. I found it all very intriguing that there are actually people in this world that can't get Laura Secord chocolate, back bacon or good cheese. She was around that day and I saw her again while we were visiting intensive care but it seems when she left I was really alone.
The waiting room tale cannot be told without mentioning the obviously well off people from Tennessee who set up their offices in the waiting room. They had a sister who needed brain surgery and it was to be in London or Switzerland so fate (and logistics) directed them to us. We talked with the familiarity of partners in stress and I really enjoyed watching them commandeer the phones and even when a pay phone would ring, which it did several times a day, they would hop up knowing it was for them. They were really kind and amusing and it was nice to have people you "knew" to distract you from the reason for being there in the first place.
About 9:15 that night Dr. Wall came out. He looked totally exhausted and the wall supported him while he told me all was well. He reported that the left side of Jim's liver was virtually gone and they had to reconstruct his bile duct with a piece of intestine and I could go see him in twenty minutes. I called home and reported that all was well and I would get

to see him soon. The twenty minutes turned into sixty but at 10:30 I saw Jim looking quite peaceful despite all the gross tubing. Jim's Mom and Dad asked Reed if he would mind driving them up to see Jim. Of course Reed didn't mind. He is so kind and knows how important the little things in life can be. It was late and foggy but he understood that was their baby in that hospital and it was necessary to see for themselves that he was indeed okay.

After we had all peeked at Jim, Glenda and John went home and I camped out in the waiting room. Trish and Lynn, my Tennessee cohorts, knew where the supplies were kept and snatched me a pillow & blanket, dimmed the lights and even made a big production of trying to find out how on Earth to turn off the music. They made me a chair bed and wished me good night before they left for the comfort of their hotel room. About three a.m. someone approached me and said that they had been in the hospitality suite but they had no use of it anymore since their mother had died. It was sad to get such comfort from someone else's pain but I hit the couch and zonked out until eight the next morning.

I realize all of this is quite off the subject of Jim but it is important to me for others to know how strangers can bond in similar situations and you are only alone if you want to be, in anything you do. Plus it does the soul good to see how the "other half" lives and that no matter how unique you think your situation is, someone before you has gone through it. There are always those that are worse off than you. And people from all walks of life can find themselves in the same situations.

After I got up and washed, changed and put on some makeup I wanted to go see Jim. Visiting hours in ICU begin at noon and it was only nine but I told the nurses that I hadn't seen him yet so they allowed me in. Jim was awake and looking around and looked glad to see me but wasted no time indicating he wanted a clipboard and pen. He wrote, Hi, I feel great, where did you sleep and thanks. Dr. Wall came in and Jim shook his hand and gave him the okay sign with his fingers. The rest of the day was much the same. I left and had a huge breakfast, made some phone calls and went back in at regular visiting hours. discussion was limited, Jim seemed fine, comfortable and weary so I left for home around three. I have never been comfortable leaving my kids for any length of time no matter how competent the care that I have left them in. I just missed them and needed them so I was glad Jim was fine and I was relieved to be going home.

My sister was there helping out and it was great to really relax. Until I remembered it was Tuesday. During THE WAIT I had given all the kids instructions about what to do if, and one of Sarah's instructions was, if it was a Tuesday don't forget your piano lesson. She did. I'm sure to her the bonus of all of this mess was that it did happen on a Tuesday. She knew if she stayed quiet no one would remember and I was so muddled it took me a good hour after getting home to remember too. How could such a together organized person neglect to do something I'd been doing every Tuesday for three years? That's when I began to think maybe this thing was bothering me a bit.

I am a very firm believer in fate, "que sera, sera", and all that, consequently I don't worry a whole lot or get too bent out of shape over a lot of things. I was confident things would go well and I never really thought Jim could die. Looking back I wonder if it was my fatalist attitude or my habit of sticking my head in the sand that really kept me from breaking down.

Wednesday Glenda and I went to visit. Jim no longer wanted to write but would nod or shake his head no to our questions. We visited a while with him, went to the smoking tomb and checked in with my cohorts in the ICU waiting room. Then after seeing Jim again we left for home glad the worst was over.

Thursday I went back and expected Jim would be out of ICU but he wasn't. Even more discouraging, he was no longer responding to my questions. If I said a name he would open his eyes and he would look at me but through me at the same time. He was also very restless, he kept kicking and batting his hands around until finally they restrained his hands so he wouldn't yank out his tubes. Each time I went to see him that day he seemed further away from me but I could see him fighting to get through.

Jim's Mom and Aunt Linda came up expecting the best and were very disheartened to find what I had, that Jim just wasn't there!

We wondered back to the waiting room wondering what was going on and looking for some answers. The fellowship doctor on his case reminded us too much of John Boy Walton and though we laughed a lot about this we really needed someone to make us feel more confident. Doing something I really disapprove of when I see others do it, but not caring a whit, I spied Dr. Wall getting on to the elevator so I ran and grabbed his arm. I asked if he knew what was going on with Jim. He assured me he would look into it and would be back momentarily. He was kind enough to sit down in a private spot with us and assure us Jim would be alright in a matter of time. I put all my trust in that man and I think that trust calmed me considerably. Glenda wasn't as sure. She has been through so much illness with her family that she finds it very difficult to accept a positive prognosis when things look so grim. The ride home was spent with us consoling each other and much mimicking of what Dr. Wall had said.

Friday Jim's sister came up with me. By this time Jim had developed a shrug like a nervous twitch and he wasn't opening his eyes or squeezing our hand or anything. I really did start to worry when a neurologist looked us up and questioned Jodi and I about Jim's mental capabilities. Jodi has the same weird sense of humour that I do and even though we were worried sick we found it really amusing that mental state was being questioned. (The neurologist didn't) Finally they did a cat scan and a spinal tap looking for a problem but found none.
Saturday Jim looked like the folks you see on tv in a coma. This is not my life. Things like this don't happen to me. I am “tres ordinaire” and my life was taking on a nightmarish quality. I was functioning mechanically, Glenda said it's the brain's way of keeping you sane, to do a partial shut down. I was tired and, yes I will admit to it, worried.
On Friday night our friend Mike came over to see how things were. It was all I could do not to collapse into his arms and bawl for an hour or so. Maybe I should have, I would have felt that much better. Reed was around a lot too. The moments I was home he always checked in with me wanting to help, I should have used his shoulder too but something in me insisted I be brave. To cry out of sheer terror would admit the possibility of Jim's dying and I wasn't about to do that.
At the hospital Saturday it got to the point where I didn't even want to see Jim. What I don't know can't hurt me. That afternoon our dear friend Brian came in (yes we really do have that many dear and wonderful friends) and I waited for him outside the ICU room. When he came out he looked at me in a way that suggested "Holy shit, now what" and I hugged him and cried and said I was scared and he said he knew and I cried some more. It felt good and helped to relieve some pressure to admit to someone else my fears.
About three that afternoon one of the chaplains from the hospitality service came and asked if I was Mrs. Kish, I said yeah, not thinking what one would expect me to be thinking when a priest came for me. (We are not even catholic and that would have been too movie-esque). He informed me I was wanted in ICU. I ran down and some doctor, I don't remember who, asked me to see if I could get a response from him. I went in and the doctor told me to tell him to move his tongue. He wouldn't for me but the doctor's more authoritative tone got him to do it. On a whim I said "Smile Jim", and he did! I was so pleased to see this strained grimace. It was the best smile I've ever gotten. From then on it was a constant stream of stimulation. Me, Glenda, John, Aunt Linda, Brian, John JR., Reed, Eileen everyone we knew went in to get him going and by Sunday we had our Jim back. I don't know where he was and neither does he. I think the first few days he was running on adrenaline and when that wore off he simply had to sleep off the anaesthetics.
There was so much more that happened. Dozens of phone calls, letters, cards, gifts of money and fruit baskets, people truly concerned and caring. I spent the first week crying in gratitude and then going over it all again with Jim the next week and crying together again over the kindness of it all. We both had our faith in human kind restored and we just realized how terribly much people need each other and how important and wonderful each individual really is. Yes, out of all bad comes some good. Even so I was glad it was all over…

Chapter Nine: I Don’t Recall Much

Everything is hazy. My brain felt thick and heavy. My eyes opened. I felt no pain. I do remember feeling fat. Someone handed me an aluminum clip board with a white writing surface and a pencil. Ann was there. I remember writing "Hi.", but as I wrote I couldn't move my arm along the page. I simply wrote an "H "and then an "i" right over top of the "H". I couldn't talk and didn't know why.
From then on it was only bits and pieces. Like photographs with no chronological order. Ann's hair falling over my face or her perfume. My Mom and Aunt Linda, not their faces just their presence. No doctors or nurses. I remember it seemed to be taking a long time. I remember the voices of Brian Chambers, a life long friend, Reed and my Dad. One of those three, I'm not sure which one said "I couldn't wish this on my worst enemy." But I couldn't see them, I just heard them and recognized the voices. It's funny how I remember these things, yet not what they said or when and how long they were there.
There were many very sick people were I was. Many open wounds. A kid younger than I but not much smiled at me from across the room and gave the thumbs up sign. I smiled back and returned it. He did it again when they wheeled him out later as if to say "I made it pal, so will you." I never saw him again and wish I could have.
Nursing care is one on one in this ward. I remember only one nurse. Jill Smith, who sang Christmas carols to me at night. She drank diet coke constantly and I worried about her diet habits.

I had constant fluid collecting on my lungs and I can remember that when the fluid became too great, I would start to cough. That hurt my abdomen like crazy so I would make some kind of sign to indicate that I needed suction. This procedure is usually done by two nurses but can be done alone. I have since then done it all by myself. There is a line with a hard clear plastic tube attached to it. The tube is simply inserted down the throat and the gag reflex does the rest. The tube has a constant suction on it and it more or less vacuums up the excess fluid that is vomited up. This procedure is not a pleasant one but breathing becomes so much easier afterwards that it got so I would ask for it to be done.
I opened my eyes again. And again my brain was thick and heavy. There was a large clock in front of me with the big hand at the five and the short hand between the twelve and one. I couldn't for the life of me figure out what time it was. My arms wouldn't move. I wiggled a finger toward the clock. Jill was there in a flash.
"Well, Good Morning my love, you've over slept." She said "Oh, it's twelve thirty at night." She finished as she saw my wagging finger. "If I untie your hands do you promise not to squirm? You came mighty close to pulling some of these lines out and we can't do that just yet." She said.
I shook my head a wee bit up and down. She untied my hands and as I performed some awfully feeble attempts at sign language she filled me in on what had happened in the last few days.
"It's Sunday morning, Jim, you've slept a whole week. Ann was terribly worried. She'll call in the morning and I'll tell her you are back with us now. You still need a lot of sleep, Jim, so why don't you
close your eyes again and I'll get you up in the morning." She promised.
"Sleep! God no! Not sleep! Please lady I've been in a coma for a week and the last thing I'm going to do is shut my eyes for a period longer than a blink." I thought. I was terrified for my life and it must have shown on my face.
"Listen, Jim, you close your eyes and I'll wake you every fifteen minutes just so you don't fall into too deep a sleep. I'll do that all night if you want." She said. This girl had a sixth sense, it was almost
scary.
I was still tired and so I shook my head and closed my eyes. She held true to her promise but we later settled on thirty minutes and finally one hour. This fear of falling comatose again followed me for a good week after I was out of the intensive care unit. I can still remember waking up in a cold sweat, hyper-ventilating like a mad man because I thought I had slept too long again.
Sunday morning, December tenth, I awoke to find a respiratory technologist at my side. She was pretty and told me that if my lungs were up to it she would remove the ventilator. The doctors don't like leaving these things down you throat for long periods of time since they do great damage to the vocal cords. The technologist explained that the ventilator forced oxygen into your lungs and it is expelled naturally as the diaphragm muscle relaxes. She said that she could vary both the amount of oxygen in volume and concentration. I was on seventy per cent oxygen. She began to cut the volume back and then the oxygen. I noticed immediately when she did this. It's rather like having a two hundred pound person sit on your chest. You fight for every breathe. I was afraid that this is what breathing would be like from now on. I feared that I would suffocate. But she did not increase the pump. Soon I could breath again.
Ann had called and was coming in early in order to make it home in time for the kids Sunday School
Christmas Concert. I simply had to have the respirator tube out. I had to talk to her. They removed the
respirator tube that morning.
The pretty tech looked at me and said "There, I'll bet that feels a lot better, eh, Jim?"
I shook my head and answered "yes." My God! Never had a single syllable word been uttered in such pain. My throat was on fire and someone had just tried to douse it with rubbing alcohol! No more talking. I would never speak again that's all. There would be no pain if I didn't talk so I'd just have to quit. A small price to pay to evade the agony of my throat.
It had been a week since I'd had solid food so I was fed clear liquids to start off with. This included apple juice, water, broth and jello. Food had never tasted so good. Lime jello had a special taste that I shall always remember. Perhaps my sense of taste had become more acute since I had not smoked for the past week either. I was never a heavy smoker so it was no big task to quit and I never missed cigarettes and never smoked until about a year and a half later when I started to seriously write this book.
Another source of discomfort was the lines. Even after the respirator was removed I had to have an oxygen line to my nose. The nourishment tube was left in my nose until Sunday it caused a good deal of discomfort. I had two IV lines in one arm and another large IV line in my jugular vein. There was a sub-hepatic drain line coming from my abdomen and a biliary tree line used to

perform a test called a cholangiogram, to check for biliary tree blockage, also from my abdomen. I also had a catheter to relieve my bladder and was wired into a heart monitor at both ankles and my chest.
After all the anticipation of Ann's Sunday visit I can barely remember it. We cried the second we saw each other. I don't recall being happier than that day with her however I was somewhat of a suck when she went to leave. She had to go early for the kids and promised to be in the next day and bring them with her.
Pain was starting to set in now. I can't say it felt good but I was pleased that this is more of what I had expected. Not an unbearable pain, only enough that one couldn't be without drugs for very long.
The second conscious night in the ICU was a fitful one.
I was still afraid to fall asleep and for some reason worried about Jill, the nurse, and her Diet Coke habit. She drank it constantly. I'm sure all of the nurses thought I was quite silly. The nurses sang Christmas carols on the night shift and I could have listened forever.
The next morning, a pretty girl came in with the portable x-ray machine and although it took a few minutes I finally recognized her from my teenage years as Connie Johnston, she was still very pretty and she stopped for a few minutes to talk even though she was very busy. Another girl from my high school years who worked at the hospital came up also, Carol Simpson. She too stayed awhile and talked. It was very comforting to know that in this old world of fast cars, fast food and high technology that some of my oldest friends still stopped in. Maybe our values haven't changed as much as I'd thought.
I was supposed to be moved up to the fourth floor MOTU (multi organ transplant unit) Monday morning but there was some kind of delay and it didn't happen until about three that afternoon. The trip was exhausting. It was a two floor move on a stretcher.
Ann and the kids came up that afternoon. It had been a week since my kids had seen me and that had never happened before. I couldn't help but cry although I tried as hard as I could not to. They didn't understand why Daddy was crying. Andrew had drawn a picture of he and I fishing and Ann had it framed. I still keep it on my desk today. Sarah seemed happy to see me but both her and Andrew seemed afraid of getting to close to me. I was still sporting an awful lot of plastic tubing and I think they were afraid of hurting me. Kaitlin, however was not afraid, in fact she was even bold. This was Daddy and it didn't matter about all of the lines and stuff, she wanted up on my tummy.
It was about this time that I began to realize that my faith in a God was renewed. There was a centre or controller of all things and he was looking out for us. I found myself praying more often. I prayed prayers of thanks not asking for more but just giving thanks for another chance at life. I found this to be a common thing to happen to transplant patients. Faith was renewed and the world became a beautiful place to live in.
Ann and the kids left after supper and I was alone to watch TV and doze. I was on a pain killer called pentazocine which caused me to be very thick headed. I found that it was bad enough to be stoned but to be stoned and know how stupid you are acting is like adding insult to injury. It may have been a blessing in disguise since all I wanted to do was to get off that painkiller.
Anyway, I can remember being thankful enough that Monday evening wept in the presence of God and thanked him again for giving me this one more chance to live. This time really live, not living to the dollar, living for house payments or new cars but really living. My wife and kids and our happiness would come before money or anything else. The wait for death was over and it hadn't come. "I thank you most merciful God and I promise this I'll not waste this second chance. "

Chapter Ten: The Multi Organ Transplant Unit

The Multi organ transplant unit covers the entire West wing of University Hospital. The floor holds the administrative offices, the ward itself, staff lounges and the out patient clinic. The nurses that work here are special to say the least. They are caring and compassionate but must keep a constant flow of encouragement, almost forcing patients into daily activities. It is their job to put you back on your feet again quickly.
One of the only unpleasant experiences that I had in MOTS was during the first night as a patient there. I was in considerable pain and called for a nurse. I don't remember exactly what I said but the key word was "Sweetheart". I called my nurse sweetheart! Not because she was, but purely because most of the nurses at the hospitals were truly sweethearts. This one wasn't. She came and did whatever I asked and then on the way out the door she snarled "By the way my name is not, Sweetheart, it's 'so and so'." And closed the door. I was stoned on pentazocine and felt like the

biggest creep this side of hell. I apologized in the morning but the damage had been done. This woman hated me and I knew it. I had no right, I guess, to assume the privilege of the name "Sweetheart" but I also felt that she could have been more understanding of a patient just out of a coma and whacked out on a pain killer. It is silly the little things you remember but this nurse cared for me again much later and we were still very uncomfortable around each other.
One my second day in the MOTS, I awoke at seven a.m. for blood tests. They took from seven to nine test tubes each day. It got to be routine. Later, about nine a.m. breakfast came. Still fluids mainly but now called a "soft diet". Cream of wheat cereal, juice and a soft egg. It was all fantastic!
My nurses for the day shift were Shiela and Libby. They became my favourites. Happy, funny and always smiling. They worked twelve hour shifts and looked beat by the end of the day. They came to my room about ten a.m. and said that it was bath time and that they were going to help me bathe. Poor girls didn't know they were dealing with one of the good ol' boys. Ladies don't bath men where I come from. If a man can't bath himself then he'll just stay dirty unless he's unconscious or near death. Anyway, when these two lovely girls offered to help me out of bed and into a chair I informed them that they didn't need to stay cause I'd just do it myself. They persisted and finally I let them help me sit up, just to humour them.
I slid to the edge of the bed and placed my feet on the floor. Slowly I transferred the weight of my body to my feet and slowly I sunk downwards towards the floor. My legs just were not going to hold me. I figured I must have gained two hundred pounds. The girls giggled and soon I had one pretty nurse under each arm pit and they sat me in an easy chair about two feet from my bed. I felt like I'd just walked the Boston Marathon. The nurses got my water, wash cloths, soap and towels ready and then left the room while I sponge bathed. I think they really left to laugh their guts out at me and I don't blame them.
They returned and made my bed and helped me back into it. I was exhausted and slept until lunch.
After lunch I napped for a couple of hours and then got ready for visitors. Ann came in every day.
She kept me updated on the news and I was amazed at her strength and how she just kept on going.
I asked her how our family finances were because I knew they were not good. I told her to put the house in real estate. It wasn't important anymore.
Ann is the family bookkeeper and she had figured that with hospital parking, my TV rental and other incidentals combined with the house and car payments that we would be alright till February, but by April we would definitely lose the house. It would have to be sold. We decided to take care of that right after Christmas.
Then came our miracle. The mail started in a trickle but soon developed into a flood. Get well cards and Christmas cards and visitors, sometimes even just cheques. Some with fives, tens or twenties others with fifties, some with even hundreds and others from service clubs with several hundred dollars in them. One came with a cheque and cash for over fifteen hundred dollars from my fellow employees. I was never so overwhelmed with the generosity of people. Gifts from people I didn't know and even from people I thought disliked me. Some gifts signed only with "From your friends". The Royal Canadian Legion, Optimist Club of Bothwell and my Masonic Lodge all sent gifts of cash. Ann and I wept and thanked God for the compassion our friends showed. It seemed that just when I thought that there was no good left in the world, when it was every man for his own and that the good Samaritan existed only in fairy tales, this little town that I had lived in for thirty years swept my heart away with its' compassion and generosity. I had my faith in mankind renewed and restrengthened in a way that made me a believer all over again. My moral soared! I have since found that if someone in town is hurting it feels good to return the favours I received. It is a most humbling experience.
I was still pretty much wired up, both physically to IVs and mentally to pentazocine. I was on a super immunosuppressant called OKT3. It completely destroys all of the bloods T helper cells so that my immune system could not function at all. This prevented it from attacking my new liver. It may also have caused my coma. I was also on cyclosporine which is the immunosuppressant that I still take orally. It has lots of side effects some of which are loss of appetite, nausea, vomiting, diarrhea, difficulty swallowing, cramps and muscle or join pain, headache, fever and night sweats. It can also cause hearing and visual disturbances, anxiety, convulsions, ulcers, trembling hands, increased hair growth, and swelling of the face and gums. Cyclosporine often causes a depletion of the body's magnesium so I also was on IV magnesium. I was also on IV steroids which reduces the inflammation but has many of the same type of side effects as cyclosporine. Magnesium IVs burn like hell going in even if you run it slowly. After some experimenting I found that if I took a wash cloth and soaked it in very hot water and wrapped it around my IV arm, then wrapped the cloth with a surgical napkin of plastic and taped it tightly at both ends the heat reduced the pain and the plastic wrap acted as an insulator and kept the cloth hotter longer. Apparently the heat causes the blood vessels to expand and allows the magnesium to flow easier. Whenever the cloth cooled though the burning pain came back full and strong.

Little tricks like this made my life easier later on. The OKT3 had a zillion side effects but so did cyclosporine and prednisone so no-one really knew what side effects were being caused by what drugs. I learned to live with them. My strength was returning at a phenomenal rate and by my tenth day I was relieved of my IV lines. I was on oral cyclosporine and could go for short walks without the bother of dragging an IV pole with me. I was still however in considerable pain with the incision and often drugged out on pentazocine.

I have always signed the organ donor card that comes with my drivers license. Ever since I was sixteen I've felt that the cost of dying and being buried was far too great for the enjoyment you get out of it and that if someone could use my body even just for study that would be fine by me. After a transplant one becomes very much aware of the shortage of donor organs and I had vowed to promote this cause when I was well. At that time a television news magazine was doing a documentary special on transplants and donor availability and I was asked if the camera crew and host could interview me in the MOTS ward. I jumped at the chance. Unfortunately I was heavily drugged and didn't get the opportunity to express myself as well as I could have, had I not been whacked out. I still presented myself well and said that I felt that government legislation should play a part in donors and organs. I also felt that the signing of one's license should indicate denial of organ donation not permission. Europeans have had their licenses this way for some time and have much less problem with donor availability. Many people don't sign their licenses not because they are opposed to organ donation but more because they just don't want to think about it. The camera crew came and did a short interview and then left. I completely forgot to ask when the show would be aired and didn't find out till much later that year. I found out quite by accident when Ann's uncle mentioned that he saw an advertisement including me for the following Sunday morning news magazine.

On about my tenth day post op a nurse came in with a pair of wire cutters and a pain killer. I knew somehow that I wasn't going to like this. She gave me the painkiller and said she'd be back in a half hour. On her return she sat down at my bedside and told me that every other suture would come out today and tomorrow we'd remove the rest. The wire cutter turned out to be a set of three fingered pliers. Two of the fingers went under the staple and the other one bent the stitch in the center to pop it out. Sutures of today are not thread but stainless steel staples. They apparently infect less often and don't leave much scaring. The nurse said she would start and give me a rest when ever I needed it. The staples popped out without much problem and not any real pain. I did ask her to stop once just so I could relax since one tenses up during this procedure. The next day she came in with the pain killer and I told her to just get on with it. It was somewhat more painful but we still only stopped for three rest periods in the final sitting. The scar was an ugly thing that required constant dressing and cleaning since it was imperative that it not infect. The right side was much redder in a couple of places but hopefully that would leave without treatment. I was soon capable of dressing and caring for my incision myself.

One thing I became very paranoid about was the chance of infection from other people. I remember, after I could take longer walks, I went down to the hospital gift shop to purchase a magazine. While I was standing at the racks making my choice a man very near to me sneezed without covering his mouth. I dropped the magazine from my hand and literally ran terrified back to the elevator and the safety of my room. Later I found out the that a good deal of your immunities return within hours of being off OKT3. Later yet most all of your immunities return in a couple of months and learn to work around the cyclosporine.

Almost every day after I was free of lines I went down to radiology for x-rays. This involved a trip on a stretcher. Some days young candy stripers or registered nurses assistants would take me. This could prove to be a rough ride. But on the days when the senior citizen volunteers took me the ride was much slower and bumps into and out of elevators were negotiated with care. These older people know what it is like to be in pain and fragile. They were kind, caring, patient people who always took time to visit a bit during the ride. I don't think many of these people knew just what they meant to a patient who was sore all over.

Each room in the MOTS had its own large ceiling mounted colour TV with a wireless remote control. I don't know how I could have made it without the television. I watched it day and night. This was during the time of the falling of the Berlin wall and the Romanian uprising so I had plenty of current events
to keep abreast of.

I had many visitors but the ones who showed most often were Ann and Kaitlin, my folks and oddly enough my brother, John. John and I had never been real close as kids but now he came to see me almost every day. We actually talked for the first time in our lives. We discussed sports, careers, cars and the weather. I found him to be quite an enjoyable fellow to be around and I also found that underneath his hard shell that he cared and worried about me. We have been much closer since then. I like him a lot.

I had asked not to have ministerial service in the hospital and generally wasn't bothered. There was however one man who came in quite uninvited and interrupted a visit with a close old friend Magda Bray. Magda was suffering from Hodgkins Disease and we had been very close most of our lives. We wanted simply to be left alone to enjoy each others company. It had been years since we had been able to talk alone together and we were quite annoyed by this mans interruption. We ignored him till he left despite his attempts to administer prayers and interrupt our conversation. I wish clergy were better at taking hints. There was one other minister, who wore no collar and carried no book. He simply stuck his head in one day and saw me sitting alone. He asked if I'd like to talk and when I said "sure", he came in. He never prayed nor even mention God. He listened to me philosophize, commented briefly and left long before he wore out his welcome. I came to respect him and look forward to his visits. I never did find out his name.

On the outside world a normal winter had turned to an Arctic winter. Sub zero temperatures for days on end had put the area into a veritable deep freeze. Christmas was drawing near and although I had my shopping done there was just a couple of very personal gifts I was hoping to be able to purchase myself. It was Friday December twenty-second when I was given a four hour leave of absence. Ann's sister Eleanor, who also had been a regular visitor, came in that morning to take me shopping. "Dress really warm cause it's freezing out, Jim "she said.

I guess I thought that I was still pretty rugged and didn't want to look like a sissy with a scarf and all but to please Eleanor I dressed much warmer than usual. We left together walking very slowly, since that was the only way I could walk yet and I didn't want to tire myself out prematurely.

As we left the main lobby of the hospital I was hit in the face with the coldest blast of air I had felt since I was a kid. It must have been ten or fifteen below zero Fahrenheit. There was at least a foot of snow on the ground and I found myself being glad I had dressed for the occasion.

We left for downtown London to a place called Novaks. It is an outdoor sporting goods store. We parked and walked arm in arm to the store. This was out of character for me to hold onto a womans' arm for support, especially Eleanor's since she is more like a sister to me. But I was glad for her support, the last thing I wanted to do was fall on these icy walks. We went in and I purchased two Swiss Army knives. One for Brian who had visited me often and called and talked from Toronto for hours sometimes. The other knife was for Reed, I felt as close to him as a father. Knives are men type gifts that are practical yet say "I love you." Real men can't say that!

Next, Eleanor took me to a lingerie store. I wanted to get Ann something sexy although I didn't have the foggiest notion what. Eleanor helped some but basically stayed out of the way. Finally after quite sometime I found something I liked. It was skimpy, but not too skimpy and it was dark blue satin. I don't think she ever really liked that see through stuff. My that type of clothing is expensive for what you get!

Eleanor and I continued on. One thing Elly and I had in common was that we loved junk food. We stopped and ate and then headed back to the hospital. We had donuts and coffee. I wish I could have eaten as much as Eleanor but I just didn't have the capacity. It's a good thing I married her sister because I'm not sure if I could support both Eleanor's and my junk food habits.

By the time I was back in my room I was ready to sleep for days. I thanked Eleanor and she left me to wrap my presents. I had thought of paper but not scissors or tape. The nurses came to the rescue with surgical scissors and dressing tape.

The next day was Saturday and on that evening I was watching the Lawrence Welk Show (something that I used to watch as a child with my Great Grandfather) when I developed a pain over my liver. I developed a fever and it went from mild to raging, at one point reaching one hundred and four degrees. I don't recall being in that much pain for that length of time in my life. The nurses called the docs for permission to exceed standard painkiller dosages. Finally after several hours I fell asleep. During this time several blood samples were taken to determine if I had an infection but none was found. I awoke with no pain and felt no worse for the wear. I became terrified that the docs wouldn't allow me to go home for Christmas that day. I had been anxiously awaiting my first night at home to be Christmas Eve and I hoped the docs would still allow it. Sunday the team came in and after considerable discussion said I could go home for Christmas but not for two nights just one. They would prefer that I stay in for Christmas Eve and I could go home Christmas morning and stay home Christmas night. I was ecstatic!

I went home Christmas morning, with Eleanor and her fiancee Rocco. It was the best Christmas I can remember. We had our families come to our home since we had the largest house and I wanted to stay close to my bed. Everyone brought food and the whole family ate like pigs, which is not totally out of character.

Ann and I watched the kids open gifts in the morning and I couldn't help but cry tears of joy. Life was so wonderful. I had it all, health, healthy kids and a loving family. There is no more than this in when life. My kids gave me a Swiss army

knife. It was something that I'd always wanted and I cherish this gift more than anything. Ann loved her sexy evening wear. Later in the day everyone in the family came over and we ate ourselves into oblivion. During the course of my surgery I had lost thirty or so pounds. My stomach had shrunk and I couldn't eat the way I used to. If I overate it caused me great pain. This happened a couple of times that day. Everyone stayed late and I had to have a nap in the late afternoon, but I enjoyed the company and being home again at last.

When everyone finally left, Ann and I bathed the kids and put them to bed. Then Ann put on her new evening wear and we went to bed. She looked gorgeous. We made love for the first time since my surgery. I don't recall being that happy for quite some time. I prayed to the God and gave thanks for all my blessings.

That night I slept with Ann in our bed but there after I slept downstairs in the den on the couch. I was often up till the wee hours of the morning and needed pain killers to sleep. The last thing Ann needed was to be awakened several times each night when she was under the constant pressure of caring for three children and a sick husband.

Boxing Day we went to Ann's parents and visited and then from there we returned to the hospital. I was not entirely impressed at having to let go of Ann again but we said good-bye and she left to get the kids home and into bed. I was exhausted and fell asleep almost immediately.

I awoke, showered and got ready for the day. The team soon arrived and we discussed how things went on the leave of absence. After further discussion it was decided that I could go home. I was free.

I called our friend, Eileen, who was working in the city that day and lived in Bothwell. She said she'd be glad to give me a lift home after work. I began to clean up my room. I had a zillion cards and Christmas decorations to get off the walls and flowers and some candy to leave with the nurses. And finally clothes and personal effects to pack. The nurses got me some bags to pack with and helped in between patients. I had fallen in love with them all. Maria, a tall girl who blushed beautifully when she was complimented. Sheila a pretty young girl who eventually became transplant co-ordinator. Libby a short pretty girl with a quick wit. Marilyn a gorgeous strawberry blonde. Martha another young single girl who no doubt broke mens' hearts for sport. Patty who was pregnant and ate like I did because of it, she was fun to be with. I have forgotten some I know. I never did learn the head nurses name. She was a soft spoken pretty brunette that everyone seemed to get along well with. Those who I have forgotten will understand I'm sure because that is just the way they are there. I love them all for their compassion and understanding. God bless them and watch over them, they are his angels on earth.

Dr. Sutherland, and Dr. Abujouhi, the fellowship doctors where there twenty-four hours a day and always ready to joke or talk. Not in a hurry to get to the next patient but genuinely interested in me and my well being. Drs. Wall and Ghent (the Masters) came in just about everyday for a minute or so. I was awestruck with these fascinating men. They were so skilled in their trade. The best in the world, in my opinion, yet they were quiet and never wore any badges of honour on their shoulders. They were modest to say the least. It is hard to adequately describe men that you owe your life to.

I had finished my drug and infection/rejection training which enabled me to recognize both infections and organ rejection and to know how to take my drugs properly. I also had taken diet control training and physiotherapy.

I had been in the hospital for a total of twenty-two days. I had met many people in that time and was in one way sad to leave these wonderful friends.

Eileen came in at two-thirty p.m. She helped me load my things onto a cart and then she and a nurse walked me down to the main lobby. We loaded my luggage into the truck, said my good-byes and headed for home. I had made it. I was going to be alright. I was going home. God, thank you. I have never been so content with life. We arrived at Bothwell in time for a late afternoon coffee and supper.

Chapter Eleven: Home For Good At Last

Home life had never sounded so good. I don't think I'm a very good hospital patient ... as a matter of fact some of the nurses called me a hospital impatient. But home was very different from the high tech MOTS ward. I couldn't just buzz for medication, I had to get it myself. Although I'm sure I was a constant source of inconvenience to Ann I tried not to be. Our house had stairs and that was one thing that I could not negotiate well yet. You'd be surprised at how many simple movements involve the use of abdominal muscles and mine had been severed from one side to the other so I limited my trips up and down as much as possible.

I spent my first night at home on the couch in the den. I could watch TV when I awoke in the middle of the night without waking the family and kept drugs downstairs to eliminate roaming the house. These first days I found that I could go all

day without painkillers but at night the pain was just enough to keep me awake. My surgical scar was a large inverted V that spanned my entire stomach just underneath my rib cage. It was still quite red on the right side and required constant care and was very tender all of the time.

There is a time following surgery when one is very highly psychologically charged. "Weepy", they call it. At times I would catch a glimpse of myself walking by a mirror without a shirt on and stop to look at myself. I cried and thought to myself "Look what they've done to me. Why did I let them do this to my body?" I wept when I saw old friends for the first time or when I held Ann or one of the kids. The good thing about this is that I learned that there is no shame in tears.

During the last week of December, Ann and I made the decision to list the house with a Realtor. Even with all of the compassion and love and generosity of our small town friends it was painfully obvious that we would soon lose our house. I was having a hard time with my impaired ability to perform normal activities. It was apparent that I wouldn't be back to work for a while. I guess the hardest fact was that up to the transplant I had never been physically impaired but now I couldn't do anything too strenuous.

The first day I was home we had gotten about three inches of fresh snow. It was light and fluffy and I wanted to be outside so I went out and grabbed a shovel and cleared the sidewalk to the house... I spent the rest of the day in bed and in pain.

Our real estate agent came over and signed us up to a listing. She said our home was extremely saleable and wouldn't last long on the market. All real estate agents use this line, I think it's part of their schooling.

New Year's was upon us and my darling wife decided to have a coming out party for me on New Years Eve. Twenty or thirty of our friends came over and we had the time of our lives.

New Years Day was another day of celebration with both of our families over for dinner. By the time January the second rolled around I was well ready for a couple of days of rest, but on the fourth our real estate lady called with an offer to purchase. We counter offered the same day and accepted the terms on the fifth.

We had sold our house and at a profit that we could hardly imagine. Now we had to find a new one. One that we could afford on lower wages and yet was roomy enough to handle our family. Ann and I had always wanted a big old home but the opportunity had never arisen. There were several in town that we had often talked about but most were either passed down through families or far out of our reach financially. There was a hundred and thirty year old home just off Main Street that had been vacant for three or four years. Ann and I had even stopped one day to look in the windows and admire the Wild Grape vines that covered the whole house. It was in need of a lot of repair but was still fairly straight and laid out beautifully. The owner had died and left it to a close lady friend in her will. The family of the owner had contested the will and thus the house sat vacant until the courts decided who would get it. Late in nineteen eighty nine the will was settled and the lady friend had won. The house was for sale through our real estate agent. Carla, our agent took us to the house and showed us through.

It was a large two story brick home with a full veranda on the front and another on the side at the rear. We entered through the large front door. It was later explained to me that all front doors in these old homes were very wide. They were called "coffin doors" so that during funerals held in the home, the coffin was allowed easy access in and out the wide front door. The front door opened to a vestibule and staircase.

There was a door on the right that opened to the living room with ten foot ceilings and a hall that ended at the doorway to the formal dining room. Just off the dining room there was a three piece bathroom and a small alcove about ten feet square that I now call my office. Back of the dining room was the kitchen. There were no cupboards, no counters or sink. Just a room to eat in. Behind the kitchen was the pantry that contained a sink and small counter top along with a wall of shelves that held all the food, glassware and pots. A small door off the kitchen led up a narrow winding staircase to the maid's quarters. The maid's quarters consisted of two rooms one about ten by ten feet and the other about ten by twelve feet. There was a small step from the front maid's room up to a large bedroom about fourteen foot square. In front of that was the master bedroom of about fifteen by sixteen feet with a six foot square walk in closet. These two front bedrooms both opened to the top landing of the front stair. A third door led to a small room with only a heater and a claw foot bath tub in it. No plumbing, except a drain pipe from the tub if you took a bath here you first carried the water up to the tub. All of the walls needed to be redone. The house would need a new kitchen with cupboards and appliances. All of the floors were white pine board. They too would have to be redone. The roof apparently leaked so it would have to be reshingled. And I definitely was against carrying bath water up the stairs to bathe. We loved it. We had to have it. It had Jim and Ann written all over it.

After finding what the asking price was, and getting over our initial shock, I sat down and obtained some quotes on cupboards, plumbing, roofing, carpets, and a heating and cooling system. Our real estate agent told us to simply ignore

the asking price and bid what we felt was fair on the home considering its condition. We made an offer in the mid twenty thousand bracket and bought our beloved money pit. The woman that we bought it from loved our family and was more like a Grandmother to us than a vendor. She stopped in now and again while we were redoing it to ask how it was going and to wish us well with it.

Since the house was vacant I arranged bridge financing for the month of February so we could live in our current home and work on the newly purchased one. We started to orchestrate sub contractors times and schedules. We decided that we'd hire a close friend, Jim Smith to help with the insulation, new wiring and dry walling of the entire house. Much of the labour we planned to do ourselves.

February came too soon and we found ourselves tearing out walls, rewiring and tripping over the other contractors and the much welcomed help of our family and friends. It was the best therapy I could have had. Not only was it something that I loved to do, but it had to be done on a timetable. We insulated the entire house, put on new roofs, removed three unused chimneys, carpeted or tiled all of the rooms except the hallway and installed and painted or wallpapered one hundred and fifteen sheets of drywall. The contractors installed central heating and cooling, a new upstairs bathroom (we kept the clawfoot tub), new kitchen cupboards and appliances and lowered several ceilings. March the fourth after over thirty days of non-stop rebuilding we moved into our new old home. It was about ninety per cent finished.

I have to give a great deal of credit to Ann, who was at my side slugging each day and never complaining. She did the laundry and took care of the kids after spending every day with me working in the dust and grime. She was a tower of strength and somewhat of an inspiration to every person on the site. We couldn't understand where she got her energy. We also had help from our family and friends. Eileen Smith, Dad, Mike Ross, Ann's Mom Kaye, Eleanor, Rocco, Reed and my Mom all helped whenever they had a spare hour or so. We would never have finished on time without them.

As I said the house was great therapy. It offered the most important thing needed to recuperate quickly and that was motivation. It is important to recuperate quickly for several reasons. One being that a person can quickly get used to being sick and become comfortable with being waited on and making excuses for not doing things that should be done. Another is the sooner you recuperate the sooner you will feel normal and healthy again. And lastly but most important is that if, God forbid, something goes wrong with your new liver and you should have to be operated on again it is imperative that your body is back at its optimum weight and physical best to with stand further surgery. This reason is the prime reason that most second transplant patients die. They are just not physically ready to withstand the rigours of surgery again.

Every Monday and Thursday, I went to the local hospital to have blood drawn and every Thursday I went into the transplant unit out patient clinic. During the first couple of weeks my incision got steadily worse were it had started to get inflamed. This was a steady build up of fluid that hurt to touch. Finally it was decided to lance and drain that portion of the incision. The problem was that the portion of the scar that had to be drained was under pressure of the fluid inside it. This made it impossible to freeze the area. When a freezing needle was inserted the local anaesthetic simply came back out once the needle was removed. Dr. Maroon Aboujoudi had me lie on a table and hold onto the rails. This I knew was not going to be a new favourite past time. Maroon took a scalpel and cut along the swollen area of the scar. My hands tightened on the railing as a searing pain filled my entire being. I began to hyper-ventilate. He cut again, and again I heard bells ringing. The attending nurse, Mary, moved in close to my face and began pat away the beads of sweat with a cool cloth. She winced each time I did. About five minutes and it was over. Maroon said that there had been a great deal of puss to drain out. He had to pack the wound in order for the drainage to continue. I went home with instructions to remove and repack the wound for a couple of days. That portion of the scar healed nicely after that, however I had to have the same procedure repeated on two other places on the incision during the month of January. Other than that my liver functions were returning to normal. I felt great and working on the house helped me regain my physical health also.

March too was incredibly hectic as we struggled to finish the last bits and pieces of the house. Soon however we completed the major tasks and settled down with only minor trim painting and some outside work to do that would have to wait for warmer Spring weather.

I guess during the renovation I let my blood testing slip a little, although, I'm sure that it had nothing to do with my health, it was over a month before the transplant unit noticed that my liver function tests had risen to abnormal levels and then called me into the hospital in April for treatment of acute rejection.

I guess this is what I call the starting all over again!

Chapter Twelve: Rejection (A Disease In Itself)

Things had slowed down somewhat. The hectic pace we'd set in February was now gone and we had settled into a more routine lifestyle. There was more time for the kids and I was starting to look forward to returning to work or maybe even a new career.

I had been considering the profession of teaching for some time. In the early eighties I had gone to school to obtain my high pressure welding licence and this gave me a credential to teach technical courses in high schools. I had sent a resume to the local school board and been hired as a supply teacher in mid February. The only remaining problem was that in order to teach full time or even a lot of supply teaching I'd have to quite my job of fifteen years in the automotive research field. This would mean a loss of my sick and accident benefits, along with my drug plan, hospitalization plan and life insurance plan. It was a hard decision to make. If I got sick or rejected in the next year it would probably mean going bankrupt and losing our home and other possessions. On the other hand, the company that currently employed me appeared to be shutting down their operation and within a year or two I'd be out of work anyway.

All of these questions were quickly answered by a telephone call one April morning. It was the transplant out patient clinic. My latest blood tests showed unacceptably high liver function levels and I was to admit myself to the hospital as soon as I could The doctors suspected rejection. I was told not to eat a thing since my blood sugars were completely out of control also.

My first reaction was fear. I didn't want to get into this rejection thing. It was the prime demise of all transplant patients. Fifty per cent of all transplant patients suffer some kind of rejection within the first twelve months post op.

Ann and I packed a bag and went to University Hospital. I was admitted into the MOTS ward again. I was put on a strict diabetic diet since apparently one of my drugs, prednisone, had caused my blood sugars to soar. An IV was inserted and I was put on massive doses of prednisone. This treatment often stops and rejection before it can really get established. I remember the nurse hanging the bolus of prednisone on my IV pole. She opened the line to my arm and the drip began. Almost immediately I tasted a zinc like metal taste in the back of my throat. The world spun for just a moment and then my stomach started to dance. I was sure I was going to vomit. Ann had left to complete my admission forms and Eleanor was with me. "Elly, get a nurse, I'm going to be sick. "I said.

Eleanor ran for a nurse and returned with one caring a bed pan. Most of the nausea had left but I
still felt very unsure of myself. Prednisone is generally given in ten day courses and by the second or third day your body adjusts to the dose and you don't feel quite as awful as with the first one.

My mind was going a thousand miles per hour. Had something gone wrong? Would I live to see tomorrow? How quickly does rejection kill you? Is death by rejection painful? Why did I allow this transplant business to start at all? I'd be dead by now instead of fearing for my life. I'd have been better off to simply die of liver disease than to live a thousand deaths by rejection every three months, like this nightmare.

The next day I underwent a liver biopsy which proved beyond a doubt that I was in acute rejection. Acute rejection as opposed to chronic rejection. Acute generally the doctors can usually cure with drugs, chronic is a slow steady destruction of the new liver until you die or get another liver. Another biopsy several days later proved that the prednisone treatment was not even slowing the rejection. have to go back to OKT3, the super-immunosuppressant.

So far, I had been in the comfortable surroundings of the MOTS ward. It was quiet there, the nursing care was second to none and all of the rooms were private. However these rooms are vacated as new transplant recipients arrive and I soon found myself on the fifth floor, in a semi-private room with an old man who was senile and talked nonsense some of the day but all of the night. Some of my visitors asked why I put up with the disruption, but someone had to be with the man and I felt sorry for him. Maybe someday I'll be old and infirm and need someone to put up with me. It must be terrible to be old and alone in this fast moving world. This man had a habit of getting up for walks in the middle of the night and the nurses got to depend on me to alert them when he did. I truly wished him well.

The fifth floor was a diabetic and gastrointestinal floor. The nurses here were very busy and often didn't have time to care for patients like my roommate. He was being held at University Hospital
until a bed in a nursing home could be found. The noise on this floor was almost unbearable. Constant paging of doctors, constant jabber of nurses and the only escape from it was a tiny five inch TV with a headset to block out the noise. I hated the change and fought hard to accept it and not be irritable to those who worked there.

On the first day of my OKT3 treatment a nurse came in and hung several pre-medication bags from my IV pole. Solu-medrol, Codeine and Benadryl were the pre-medications. Each one to combat a different side effect of OKT3. OKT3 is a drug that starts out being cultured under the skin of a mouse. It completely destroys all of the T helper cells which are the corner stones of the immunity system. While the T helpers are disabled they can't attack the new liver and the new

liver can repair itself. The body however starts to make new T helpers almost immediately so I had to have an OKT3 shot each day for ten days to re-kill the T helpers. OKT3 is not a predictable drug. Often a cardio pulmonary resuscitator is kept on hand for the first treatment since the drug affects the respiratory system I remember the doctor coming in with the needle and a special filter on the end of it. It looked like a needle sticking out of a film canister full of cotton batten. He tapped into the IV line and slowly injected the drug. Almost immediately my head felt like it was on fire from the neck up. I panicked. My lungs wouldn't work anymore. It felt as though a three hundred pound man was sitting on my chest. I had to fight hard for each breath. The group of doctors surrounding me watched intently for any real abnormal side effects. Slowly, after five minutes or so I could breathe normally again and starting to feel just sickly. Like I'd been hit with a real bad flu. My eyes became sensitive to light and I was given a pair of sunglasses. I laid sick and weak for about two hours. Then as suddenly as it had come it went away and I felt normal for the rest of the day.
I suppose that was part of what was making the whole business of rejection so hard to handle. The fact that I felt good. I didn't feel even the least bit sick until they started to try to cure me. I know that prior to admission at the hospital I was eating two or three chocolate bars a day and could eat a half
dozen donuts at a sitting. These are textbook symptoms of sugar diabetes but I still felt pretty good so I ignored any and all warning signs.
It was Easter time and so I had to spend another holiday season in the hospital. Ann had to do the bunny thing for the kids alone. She video taped it for me to watch later. I don't recall being so depressed. Ann's visits seemed like only minutes long and I longed to be a home with her and the kids. I prayed a lot.
By the third OKT3 treatment I was only mildly reacting for about an hour, so I was given leaves of absence for the afternoons. I would drive home and spent the afternoon and evening with Ann and the kids and leave home again around seven p.m. to make it back into the hospital for the night. That was the way I finished the ten OKT3 treatments, spending the nights in the hospital and the mornings in treatment and the afternoons with Ann.
After the tenth treatment I was released from the hospital and booked for another biopsy in May. The liver functions in the blood testing appeared to be settling back down again and the doctors thought they might have arrested the rejection episode.

Chapter Thirteen: That Summer (1990)

19:21
Later in May I was booked for another liver biopsy. This test showed that although the OKT3 had slowed things down considerably, I was still in rejection. Liver function blood tests indicated that my enzymes had levelled off and were not increasing as they were before. They were still however several times normal and the doctors decided to wait for a couple of months to see if the rejection would subside. My diabetes had gotten steadily worse and I was prescribed a drug called Glibenclamide (“glyburide“). This drug does not cause more insulin to be made but simply directs the pancreas to release absolutely all of the insulin that they produce. The combination of glyburide and a strict diet controlled my diabetes for the time being. The doctors apologized for not being more informative but again they said that there is no text book case in the transplant business, everything is experimental.
The toughest part of this, except from accepting the probability of another transplant, death and all that goes with it, was my diet. People like me shouldn't have to get diabetes. I love sweets, chocolate, donuts, cakes, cookies and almost every sinful food that man has invented. I found that diabetes is not the horrible disease that I thought it might be. It is more of a constant inconvenience. A disruption in my way of life. You'd find it surprising the number of restaurants that don't carry artificial sweeteners or even diet soft drinks. One also gets to the point were you watch what is being served to you in fast food joints. Several times when I had ordered a diet drink I watched as the waitress drew up a regular soft drink and brought it over to me. They just don't seem to realize that what they are doing could kill someone. The only thing that irritated me more than that was the dirty look that you got when you said "I'm sorry but I ordered a diet drink, I'm a diabetic you see.”
Another drink would be poured but not without a tsk or an irritated look. However I did learn to be a
diabetic. I wasn't impressed with the diet but again it beat the hell out of the alternative. There are many symptoms of diabetes that make the disease a real rotten one to have. When your sugar gets out of control you feel like hell, flu-ish to say the least. Your vision blurs. You urinate almost hourly. The needles provide a pain of their own. Your stools

become loose and almost diarrhea like. Once you have gone out of control a couple of times you become very reluctant to let it happen again.
I continued with a normal home life and did some painting around the house, built the kids some monkey bars and even made preparations to go back to work.
I had begun to suffer some side effects from the increased doses of prednisone, imuran (“Azathioprine”) and cyclosporine. Generally the side effects started about twelve thirty p.m. and lasted for two to four hours. They varied in intensity but rarely in characteristics. become weak limbed, my face especially around my mouth and lips would become numb, my stomach would get upset. I experienced a general achiness and flu like feeling.
The first week of August came and the decision had been made for me to return to work August twelfth. Ann and I planned a vacation and we packed up the tent and camping gear and headed North with the kids. We stopped for a night in Sauble Beach where we swam, played video games and generally had a great time. Then we went East to Collingwood where we explored caves and took a chair lift up and a slide ride down a mountain. We continued to Toronto's Ontario place for amusement rides, a gigantic children's play ground and a movie. We finally ended up in Niagara Falls at a Marine park. The kids had a blast at all of the stops and Ann didn't want to come home. It was the first time in my life that Ann seemed unready to come home. She tends to be a wee bit tightfisted (cheap as hell) and I was happy that she was enjoying herself. It was the best vacation on record. It lifted everyones' spirits and set me into the proper frame of mind to return to work.
As far as I was concerned it didn't make much difference whether I suffered the side effects of the drugs at work or at home but my employer decided to start me out on half days. That way I could work in the morning and be home in the afternoons when the side effects seemed to peak. I later discovered that the side effects seemed much less severe if I got physically active in the afternoon and more severe if I laid down. Unfortunately one of the side effects was fatigue. If I laid down in the afternoon I sometimes found that when I woke up my legs would be too weak to support the weight of my body and it took me several minutes to get up again.
Late in August my diabetes became much worse and I finally had to be admitted into hospital to go on insulin and regulate my blood sugar chemically. This upset me a great deal since I enjoyed getting back into a work routine and seeing my friends at work each day. The doctors said it would only take a couple of days in the hospital and I'd be regulated. Unfortunately I lucked out again and spent a full week in the hospital. It seems one diabetic in a thousand is insulin resistant and requires massive doses of insulin to regulate. I was that one in a thousand. Most diabetics inject less than fifty units of insulin per day while I required nearly two hundred. Learning to live with diabetes is a big part of the disease. I had to learn how to give injections, test my blood, control my diet and recognize hypo from hyper glycemic reactions. The injection sites for diabetics are on the buttocks, tops of the thighs, arms, and stomach. I used the stomach more than other areas because that area of my anatomy had no feeling in it due to the nerves that had been severed during the transplant surgery. The key to living happily as a diabetic is to enter a routine. One must balance diet and activity with insulin and sugar intake. You can't just go and split wood for a couple of hours or your blood sugars will fall rapidly causing a hypoglycemic reaction. So if you get active you must also increase your sugar intake. You find yourself constantly making allowances for your lifestyle.
The needles were detail. Maybe after the of needles that I had during my illness I'd become number desensitized to them. I found that they rarely hurt and shouldn't hurt if administered properly. Occasionally a needle can hurt if you happen to get too close to a nerve but chances of this are quite remote. The only other way a needle can hurt is if one does not allow the alcohol that cleans the injection site to evaporate or be wiped off completely. This feels the same way any fresh wound would feel if you poured alcohol on it.
So if you ever develop sugar diabetes don't panic. My experience with it leads me to believe that although I'd far rather live without it, there are much worse diseases to be stuck with.
I returned to work a week later with a glucometer to measure blood sugars, needles and insulin. I was no longer working in the air bag sensor lab but now in the pollution control lab. This lab was much larger and the guys there were a happy crew. I was glad to be back. I started working full time two shifts in October. I enjoyed working, I enjoyed the fellowship of my working cohorts and the routine regulated my life again. I did however find that I was spending my life eating, working and sleeping. The side effects, especially fatigue, were getting worse.
The doctors were getting increasingly concerned about the rate of the degradation of my liver. It was October that Dr. Ghent told me that he had upgraded the rejection to chronic and that this liver would probably only last till July of 1991. This was the first time that anyone had come right out and told me that I had to be re-transplanted. Actually, I think that I had become so accomplished at accepting and dealing with bad news that the idea of a second transplant was more of

a relief that a bother. I'd felt so sick for so long that I would rather risk the transplant, die or be cured, than to go on as sick as I was. The constant fatigue left me wanting to sleep and on anything. I was jaundiced to the point anywhere where kids would stare and comment on my bright yellow eyes. My digestive system was so screwed up that I hadn't had a proper bowel movement for months.

I was doing a little bit of supply teaching on the side. I took the odd day off work or vacation teach technical studies in high schools and sometimes even primary schools. I found the job very enjoyable and planned to take up teaching if I ever got over this liver disease. The kids often asked why I had yellow eyes and had a host of questions when I told them the cause of my yellow eyes and skin. My employment by two school boards as a supply teacher gave me more teaching opportunities than I had time for. I couldn't quit my regular job because of the sick benefits that it had. Supply teachers get paid well but have no benefits.

My family doctor, Susan Munro began to coax me out of work. She was concerned about my fatigue. Eventually we made a deal that if I could just work till Christmas I'd stop in the new year. Dr. Munro is the best of the best. She was kind, sympathetic, compassionate and a pretty good looker too! There is a certain touch that natural born doctors have. It is a soft yet supportive touch. It says something about their self confidence. Susan Munro has that touch and when ever she made contact with me I felt safer, more secure. I could relax because she was there and wasn't letting anything bad happen to me. I shall respect and honour her as long as I live.

My work in the pollution control lab although sometimes monotonous was light and stress free. My boss was a saint and made constant allowances for my trips to the washroom several times per day and my absenteeism for tests and doctors appointments. I didn't work any overtime although we could have used the money. I had decided that life was too short worry about finances, and my life could be especially short. I wanted to spend as much time with Ann and the kids as possible. This might be our last Christmas.

By December I was really quite a mess. My skin had turned a sickly yellow green colour and my eyes almost glowed they were so yellow. Children especially noticed my eyes. The economic climate of the country and of my employer was also a mess. I had long suspected that our company was in financial trouble but now I realized that it was being systematically closed down. One by one, divisions were being eliminated. Even the men at the top were not being spared. I knew that after the second transplant the possibility of me returning there was quite remote. I had invested fourteen years of my life there and could have retired before I was fifty years old. I was hurt and angered by the betrayal. Fourteen years and I would get retirement pension. nothing in return for my service in the manner of a retirement pension.

The kids and I shopped for Ann's birthday and then for Christmas. These were special times for us. We laughed and acted silly in the malls. We ate out at fast food joints and shopped for each other. I had told the kids about the next operation. Sarah accepted it in good stride but this time Andrew seemed old enough to know that his Dad was in big trouble. Kaitlin was three and her interest was in fun and games. That was the way I wanted them to remember me. A fun Dad.

Later in December we had a Christmas hayride. We invited the whole town (it seemed) and went carolling then had chili and hot chocolate. This was what we called a family party with everyone bringing their The kids had a great time of it and so did I. We had friends over several times at Christmas. We decorated the house for the town sponsored contest. We went to the Christmas tree farms and cut our own tree. We always have an artificial tree in the house because it stays up for about a month and won't dry out. The real tree that we cut we put up on the roof of the veranda and covered it with lights and bows. Andrew and Sarah were allowed up on the roof to help and they thought that they were real big cheeses because of it. Everywhere we went we listened to and sang Christmas songs. We went to a couple of Christmas parades. We made Christmas candy and cookies and wrapped presents and kept secrets. We were all silly little children and I guess that's why I love Christmas. The joy and excitement of the season overwhelmed us all.

The excitement dimmed in the third week of December when I went to the out patient clinic. My blood levels were again on the rise. The doctors were becoming very concerned. I went to the hospital on the twenty-second of December for preoperative tests and was put on the official transplant list on December twenty-seventh. This liver was on its way out!

I had three weeks off at Christmas so Ann, the kids and I used them for fun. When Christmas day came my brother had the family over for dinner. We had a wonderful Christmas. Our family seems to have learned how to appreciate these special times. Perhaps it comes from realizing just how precious life is. During the last six months my father had a heart attack while in the middle of bypass surgery. He spent six weeks in ICU and no one expected him to live. His kidneys failed, his liver failed and we all thought that he would die. When he finally pulled through we were all very thankful and overjoyed that Dad was home for Christmas. I guess our family has had more than its share of ill health.

The days between Christmas and New Years we played. We went tobogganing, went to movies, made a snow "person", went ice skating and had a great time. It sometimes took more effort than I thought I had left, but for Ann and the kids it was more than worth the effort. I hope that these times are times that my children will remember.
I had decided to stick to my promise with Dr. Munro and not to return to work in January. This was not a real hard promise to keep since I felt like hell most of the time. I was supposed to return to work on the seventh of January. I made an appointment with Dr. Munro so she could take care of the necessary paper work to allow me out of work as of the seventh. My appointment with Dr. Munro was for the eighth but something came up so that I never made that appointment.

Chapter Fourteen: Retransplantation

During the preoperative testing I talked again to Dr. Wall, the chief surgeon, and Dr. Ghent. They explained that retransplant patients suffer a higher mortality rate. The odds of dying increase approximately fifteen per cent. This statistic is skewed by the fact that many of these patients reject immediately or at least soon after their initial transplant and after being weakened significantly by the first transplant are not physically ready to handle another major surgical procedure. The body is greatly weakened by the new drug regime and the patient is just not ready physically or psychologically for more punishment. The odds are worse even if the patient is ready for more surgery. The previously transplanted liver grows and heals into and onto all portions of the abdomen that it is beside. Thus, when the transplanted liver has to be removed it must be literally cut free of the abdominal cavity. This causes a great deal more bleeding. Also, the liver may adhere to the diaphragm and must be cut away from it too. This causes damage to the diaphragm muscle and can lead to complications with the respiratory system after surgery. Furthermore there are the general odds of any surgical procedure. It is a fact that the more times you go under the knife the higher the probability that something bad will eventually happen. I was not entirely impressed with playing this game of chance but considering the alternatives…
As I said, Monday morning, January the seventh, I was to return to work but instead had made an appointment with Dr. Munro to be formally written out of work for the next day. I had several small chores that I had been wanting to get out of the way at my father's auto body shop. I refinish furniture as a hobby and I had an antique table that was long over due. It had been a thorn in my side that I had been avoiding since it had a finish to it that I couldn't seem to remove. I spent most of Monday getting it and a few other small furniture pieces ready for spray painting. I returned to Dad's early Tuesday morning and cleaned and loaded the paint gun. I was just about to put on a paint mask when my Mom came in and said that I was wanted on the phone at the house. "It's Sheila from the transplant unit." She said.
Sheila Sommerville was one of the first nurses that cared for me in the MOTS ward after my first transplant. She had climbed the corporate ladder to the level of transplant coordinator. She had given me a pager just twelve days ago but I had left it on the refrigerator that morning. Sheila had phoned Ann and when Ann told her were I was. Sheila said "No problem, I'll just beep him."
Ann replied "That would be just fine but I'm standing right beside his pager. It's on top of the fridge."
Ann gave Sheila my Mom's number and I answered the phone to "Jim, it's Sheila, we have a possible donor. Don't get too excited, it's only a possible. Can I reach you at this number?"
"Yes." I answered "I'll be within a hundred feet of here all morning. "
"We should know in about forty minutes if it's a go. I'll call as soon as I know."she said.
I called Ann and told her to get our bags ready and returned to the shop to try to finish my painting chores.
Unfortunately the call back came in about fifteen minutes. They had a donor and the transplant would go down as soon as I could get there.
I kissed Mom and walked back over to the shop. I asked Dad to finish my painting and left for home. When I got there Sheila had already called Ann and she was waiting at the door to go.
One thing puzzled me. Why did I only wait for twelve days for this liver? Was I medically more in need than anyone on the list? Had I simply lucked out and been the next A positive type in line? Did I make good experimental study material? Maybe it was just a large liver and I was the only recipient big enough to house it. Whatever the reason I had to wonder why the docs had set priorities with me.

The organ had already been "harvested" (the docs hate that term) when I left home and it was on its' way from Western Canada somewhere so we were in a bit of a hurry to get to the hospital.
Ann and I dropped Kaitlin, who was not yet in school, off at my Mom's place. We went to the school to say good bye to Andrew and Sarah. When we arrived at the school, the principal acted very nervous and wasted no time in getting our children out of their classes. Going through this for the second time we were much n and at ease and we found other peoples' reactions a bit odd. I hugged and kissed the kids and told them I'd see them in a few days. This is were it became hard to be strong. I told Andrew that he would again be the acting man of the house and to watch that the girls didn't let things get out of control. I thought a silent prayer. He is my only little boy and we are tremendously close in all we do. Sarah had a better grasp of the situation and seemed to be as scared as hell but true to the Weedmark name (her mother's maiden name) she hardly let it show at all. I hope someday she learns to express her feelings. A hug, a kiss, "I love you Daddy" and "Good luck" was all she said. Somehow I think the wait was over for them too!
Ann and I went to the car and drove calmly and quietly, holding hands to London. The second nightmare was about to begin.
We arrived at the hospital and went to admitting. "Your name Sir?" Inquired the lady at the window.
"Jim Kish" I answered.
"Mr. Kish, you can go directly to the fourth floor MOTS unit. Do you know where that is?" She asked.
"Yes, of course." I replied.
"Mrs. Kish, if you could just remain here I'll admit him through you and you can join him in few minutes." She smiled.
I stepped onto the fourth floor and walked down to the transplant wing. I poked my head inside the out patient clinic and said "Hi kids, remember me?"
Karen, the receptionist just about fell off her chair and exclaimed. "Jim, you're supposed to be in surgery."
Wrong door I guess! I left and walked into the unit. I was immediately surrounded by white coats. I donned a surgical gown with no time for a shower and was led to cell number thirteen. "What have you eaten today? Have you had a bowel movement today? Is your throat, ears or nose sore? Have you had the flu in the past five days? What about sniffles or cold symptoms? What medication have you had today? Would you please read and sign this, it's a consent form." The questions came one after the other not letting up for ten or fifteen minutes. Blood samples, urine samples, and a throat swab were taken. Height and weight were recorded. An IV was inserted. These people were in some kind of hurry. Finally all the tests were done and all the questions were answered. Ann had been there for ten minutes or so. We were both relieved when the room cleared out. We needed some time for ourselves.
We held hands and sat quietly talking for about two minutes and a stretcher arrived to take me into surgery. Five minutes later I was outside the surgical theatre doors waiting while an anesthesiologist explained the procedure he would use to put me under. He was a foreign man, very nice but with a thick accent that made him hard to understand. After he had his say I signed the consent and he left. Ann and I waited again, this time for about twenty minutes, two lovers alone together in a busy hospital corridor. Alone for possibly the last time in our lives. Savouring each second, wanting earnestly to show how much we loved each other yet knowing that nothing needed to be said. Alone with our thoughts, praying silent prayers for what was to be. No love was ever this perfect. Both of us were scared to death.
I was glad we'd had the last year. We had learned to live more in the last year that all of the rest of the years we'd been wed. We had been living for each other, simply enjoying each other's company. Loving our children and life's little pleasures. Christmas concerts, and kids plays. We hadn't been to many social functions in the last year because our marriage had filled our spare time. We socialized with each other. I think our friends felt we'd become anti-social. "Don't worry about me." I said. "I won't leave you, I promise."
We kissed softly and rested our cheeks together. No one but Ann and I will ever know how true, how pure, how perfect our love is because of these moments of truth that we've shared. You want to cry and mourn the potential death of your relationship. You dread the thought of being separated forever but you must be brave for each other. There are few people that have the courage to smile and say "I love you, my Darling" when you really want to scream out in fear of what may soon be. But we did. And I was wheeled away into the icy air of a sterile operating theatre.
We skipped pre-op and went to one of the twelve theatres. I remember much more this time. Everything in these rooms is stainless steel. The room is cold, not cool, cold. I was transferred to a cold steel table that had fold away shelves

surrounding it. This allowed them to lay out my arms on these fold out sections and yet gave the doctors close access to my body also. My new found anesthesiologist friend was waiting. He gave me a series of six injections on the inside of my wrist. Only the first one burnt. Obviously local anaesthetic. A black rubber mask was laid lightly over my mouth and nose and I was instructed to breathe slow deep breaths. I can remember not feeling sleepy or groggy but nervous that I wasn't asleep yet. After the freezing in my wrist had taken I looked to the left and saw the next needle that was to go into my wrist. About one eighth of an inch in diameter and three inches long. A barbaric looking tool even when it's shiny much less when it comes out later in a literal spray of blood.
There had been considerable talk before hand about my reaction to the last major general anaesthetic and the coma that followed. All of the doctors we had spoken to, seemed to feel that it was a freak thing and not likely to happen again. "Not likely." That didn't make me feel a whole lot more comfortable.
I continued to talk to the staff that was in the operating theatre. There weren't many of them there. They were all friendly and quite willing to converse. I don't remember falling to sleep quickly. It was like falling asleep at home. Things just slowly faded. I didn't regain consciousness till three days later in the MOTS.

Chapter Fifteen: Recovery II

I remember nothing of ICU. It's not that I'm an ingrate, I just don't remember anything. Jill Smith switched shifts to nurse me. She was the same nurse who cared for me during the last transplant. She is a very special person and I have wracked my mind to remember something of her during this transplant because she was sweet enough to care again but I remember nothing.
Ann says that I talked to almost anyone who came in. Eileen Smith and I had a wonderful conversation about her new car. I wish I could remember it. The comforting thing about this is that Ann told me I usually made perfect sense. I told Eileen that I had once driven a car similar to her new one from Detroit to Chatham and it was a nice car to drive. This had really happened. It was years earlier when that type of car was in its' prototype experimental stages but I had done it and I'm not sure if I could have remembered that in a fully conscious state.
The important thing to me was that I hadn't alarmed anyone too badly. I was awake and cognitive, even if I don't remember it.
I opened my eyes and he was there. My brother, John, sitting quietly in a big arm chair. "Still not feeling to good eh?" He said.
I couldn't talk and the world went black. That was January tenth, my thirty-fifth birthday. My brother and I had spent it, all fifteen seconds together. Apparently I had many other visitors but again I just don't remember them. Mom and Aunt Linda even made a fuss with a balloon bouquet and Ann and Jodi were there with presents. I still feel bad for missing the party.
Again, I opened my eyes to searing pain like fire on the top of my foot. I looked down and two large orderlies had pinned down my legs while a rather frustrated blood technician inserted a needle into the top of my foot to take a blood sample. No pain is quite the same as this. Pure pain, white in colour, omnipresent, and ever embracing. I still cringe at the thought of it. They took blood like this for two days. With an IV line in each arm blood couldn't be drawn from the arms. The blood technician looked as if she was in as much pain as I was.
Later I awoke to a nurse. I looked at her hard and in a very perplexed manner. I knew her, but the name wouldn't come. She was gentle and quiet. Soft spoken and there was a genuine caring and compassion in her ways. I had met her before, she had cared for me before. I fell back into oblivion.
She was still there, although it may have been a different day, when he came in to help her. A short slightly balding fellow with a modest grin. "Good morning, James." He chirped.
I looked at him hard... Tony! My God yes it was Tony! "Good morning, Tony" I rasped and was immediately sorry I had tried to speak. My throat burnt like hell and I was suddenly aware that I was in pain all over. I looked at the girl and spoke softly this time "Maria ".
"Hello, Jim, welcome back." She smiled and continued her work.
After that I knew them all. It seemed that once I recognized Tony, the only male nurse in the MOTS unit, a door to my memory had been opened. Through it flooded all of the names, where I was and most of all that somehow I had done it again. I had twisted the dragon's tail and not gotten burnt.

Although many lines had already been removed I still had lines everywhere. IVs in both arms, a sub hepatic drain in the abdomen, a biliary tree drain also in the abdomen and oxygen at my nose. But the messy ones were gone. No nourishment tube in my nose, the big tube gone from my jugular vein and the urinary tube had all been removed.
My first concern was the date. January eleventh, damn, I missed my birthday. My Mom and my Aunt Linda would have celebrated it without me for the first time in thirty-five years. I was born on their birthday and it had always been a big celebration for the three of us. I later found out that we were all together I just don't remember it. I had presents and balloons and even a cake. Gee I sure would have liked some of that cake.
They made me get up. They made me walk. They forced me to move. I wanted to be left alone. I just wanted to sleep or watch TV but no, they wanted to do stuff. Within days I was well on the road to a quick recovery. I remember seeing patients fresh in from ICU and feeling sorry for them. They had to be pushed into action, just as I had. Every move hurt them. The memory of the pain does not leave quickly.
A wonderful young man by the name of Dr. Vivian McAlister came to see me on a daily basis. We became close friends. I trusted him completely and I am now of the opinion that he is the one of the most sincere and compassionate doctors I have ever had the honour of knowing.
The nurses and other support staff were all terrific. I got the feeling that they were spoiling me because I was a second time around-er. The routine was still rigorous. Just enough time to shower, get dressed, eat breakfast, talk to doctors and have an x-ray before lunch. Then a short nap after lunch and then at least one hour of physio-therapy which had become much more intense since the last transplant.
We had found that I was not allergic to codeine so that became the painkiller of choice. I used it extensively for the first four or five days that I was conscious. Then started to try to wean myself off it since I knew that would be part of the criteria of going home. The incision caused me constant pain even after the staples were removed. I also started to notice that I could breathe much better if I was slightly prone, but didn't mention it to anyone.
Dr. McAlister came in one day and after listening to my chest asked if breathing was difficult and I told him that all I had to do was sit up. I also told him that I had been sleeping in a slightly reclined position also. He frowned and called for a nurse.
"I think we are going to have to drain Jim's chest." He said. "Can you please get us a kit to do that Jim, during surgery there was a lot of adhesion to the diaphragm muscle and that has caused it to dip slightly on the right side. This provides a place for the fluid in your chest cavity to collect. This fluid is always present, it provides lubrication for the lungs as they move inside your chest cavity. However if
given the opportunity it will collect in a place like where yours is damaged and start to accumulate there. Soon there is so much fluid that it begins to restrict the movement of the lungs and eventually your breathing becomes laboured. What I am going to do is insert a drain in your side and remove as much fluid as I can. Your lungs should start to function properly again and eventually take over the regulation of this fluid."
My bed was raised and I laid flat on my back. Vivian froze an area of skin under my right arm pit and made a small cut there. He asked if I wanted something for the pain but since he said there shouldn't be much pain I said no. He inserted the catheter and began to thread it in. The pain started high in my chest and worsened by the second. Vivian ordered some codeine for the pain and continued on. By the time he had the catheter in position it was all I could do to stay on the bed. Ann was waiting outside the room and was soon allowed in to see if she could comfort me some. She did. The fluid began to drain but the pain continued even after I'd had the codeine. After about fifteen minutes I was yelling in pain. Five minutes later Vivian took the catheter out. When it was out I collapsed and prayed never to have to go through that procedure again. In all twenty three hundred cubic centimetres or almost a half gallon of fluid had drained off. Dr. McAlister was amazed. He had been terrific. It must take great courage to hurt someone that you like to make them better. I'm not sure if I could do it.
Immediately, I could breathe much easier. Now I was amazed. I resolved to do my breathing exercises and leave the hospital as soon as possible. I was sick of being sick.
I had been in the hospital about fourteen days but the weekend was only four days away and I decided to try to leave by then. I knew that currently I wasn't ready for home but four days was a long time and I felt sure that I'd be ready by then. I had found that Drs. Ghent, McAlister, Gawley and Wall were all a bunch of softies and I hate to say it but I had them all hand feeding me. They catered to my every whim. I love and respect them all. I began to work on them for the weekend release and on January twenty-fifth, just eighteen days after entering I was released and on my way home.
Ann and Kaitlin came to see me sixteen out the eighteen days. It was a one hour drive each way and Ann said that Kait was always a real good girl. Kait made me laugh and Ann was there for my every other need. I remember on one

particular visit Ann had bought Kait a chalk board in the shape of a teddy bear. Kait sat through our visit drawing happily. At one point she lifted the chalk board and showed us the picture she had drawn. A "U" shaped line across the teddy's middle with stitch marks all along it. "Look Daddy, he had liver transplant too!" She said. I laughed till it hurt.
Dad made it up to see me once too, even after a five month hospital stay of his own for triple bypass surgery in another hospital. Mom and Aunt Linda came up several times as did my sister, Jodi. Brother John stopped in often since he worked in the city. He and I got to know each other again and even became friends. He is really a nice level headed guy. I can't understand why we fought so much as kids. I learned to love and respect him. Hospitals are not his strong point, they make him nervous and queasy. But he came out of a sense of duty as a brother and I shall never forget that.
My drugs had changed slightly from the last transplant. I no longer required imuran and my body was absorbing cyclosporine better than ever. Soon I was down to minimal doses of prednisone, magnesium and cyclosporine. When I was fresh out of surgery I was still diabetic but that too subsided within a couple of weeks. I was sure that this liver and the graft was a good one. Dr. Wall informed me one day that not only had the organ been out of the donor for a near record time but that the donor was a seventy-two year old man. Both of these characteristics were experimental and helped promote the use of the "Wisconsin Solution" that is used to preserve the organ during transportation from one centre to the next and the fact that some of the body's organs do not age in the same manner that the rest of the body does.
There was no sign of rejection and a steady decline in liver function values for the next few weeks
and it appeared that I was well on my way to a full recovery until mid February 1991.

Chapter Sixteen: Not Again

My return home following the second transplant was not as traumatic as the first time. Perhaps I knew what to expect or maybe I had a better feel for how hard I could push myself. I went straight to sleeping in our own bed and only got up a couple of times a night to go to the washroom or take pain medication. I got up and ate with the family and tried to stick to a routine as much as possible.
Every Monday and Thursday, I went to the local at hospital and had blood drawn. One vile of each sample was sent to University Hospital to check for cyclosporine levels and all the rest of the testing was done at, Four Counties General Hospital which was only six miles from my home.
I went to the out patient transplant clinic every other week throughout February and March. My breathing was still somewhat laboured and finally on one trip to clinic the decision was made to drain that right lung again. It had begun to interfere with my sleep and I couldn't climb stairs or exert myself without become winded quickly.
This time Dr. Gauley, another fellowship doctor did the honours. A routine x-ray showed that the right side of my lung cavity was half full of fluid and he said it had to be drained immediately. I sat on a stool in an examination room. Paul Myers, the out patient nurse brought me in some codeine while Dr. Gauley froze a section of skin in the center of the right side of my back. It seems that I have an incredibly tough hide. I don't think I've ever had a biopsy or other minor surgical procedure performed that the presiding doctor hasn't mentioned how tough my skin is to piece or cut. Dr. Gauley was no different. He tried several times to pierce a pilot hole for the catheter that he wanted to insert but was quite unsuccessful. This brings me to the start of this book and the recent past and current events.
The fluid that drained was foggy in appearance and the docs thought that it might be an infection. Instead of going home I was admitted to the MOTS unit for IV antibiotics.
Being back in the hospital was mentally very hard to accept. All I could think of was "not again." I'm
not sure if I could have handled it just then. I was still very sick. I hadn't had the time to get ready for another major procedure. I sat in the hospital for five days trying to get in the proper frame of mind for more bad news. I became the "Prince of Pessimism." Ann once again was my daily saviour, it was times like this that I really needed her. Finally on the fifth day Dr. Wall came in and said that the cultures had shown nothing and that further treatment with antibiotics would serve no purpose. "Let's not fix what's not broken." He said.
I was released the same day and went home feeling a lot better about things. However there was something not right about this, I could feel it. I hoped I was wrong and probably was, but this first flaw in my new liver marred a perfect performance and it was in the back of my mind most of the time.
On March fifth, the clinic called me at home and wanted to readmit me to the hospital for a liver biopsy. My bilirubin and other liver functions had shown marked increases in the last week and I had to be checked out for the possibility of

rejection. I had to go in eight hours prior to the biopsy for a fresh frozen plasma transfusion. This would protect me against the unlikely chance that my liver would hemorrhage after the biopsy since my clotting abilities were below normal. These were all classic signs of rejection and the sooner they knew the sooner they could begin treatment.
I remember my thoughts at the time. "I am tired… I've been down this road before... I don't
want to do this again... For the thousandth time I'm sick of being sick. This kind of luck is called satire in the movies. No one really has this much bad luck. How is it that some people have health and luck and I can't even just have some luck? How can this be fair? No God in the universe not even a really mean one could let this happen."
It seemed obvious that I was not a good transplant recipient. Maybe the docs knew this and refused to admit it. Maybe I really do make good study material. It seemed blatantly apparent that I was slowly dying and there seemed but one solution. Another transplant. The docs said they have one guy that they've done three times. Would this be my claim to fame? James Kish, liver transplant recipient extraordinaire. Spend the rest of my life becoming famous for holding the world's record number of liver transplants? Thanks just the same I'd rather not be famous.
I was incredibly depressed. I knew I was overreacting. But I was enraged. I've served my time.
I've had my share of bad luck. I'm not a bad person and I don't deserve this shit.
I was admitted to the hospital on the eighth, a Tuesday. I was informed that even with fresh frozen plasma my clotting abilities were too low to risk a biopsy through the chest wall. The decision was made to do a trans-jugular biopsy through my jugular vein in the neck. This of course required more time in the hospital. That evening I went to the hospital "quiet room" or chapel and sat alone with God and wept. I was angry at medical science. I felt guilty that I was putting Ann though this bullshit again. She is so fantastic about it all. I was sure God was angry with me. I tried to think of all the bad things I had done in my life so that I could make retribution. I'm not perfect but I still couldn't come up with anything heavy enough to merit the punishment being dealt out. I thought that maybe God wanted me to be a preacher, and that this problem wouldn't go away until I obeyed his wish. But I don't think God works that way. Anyway I wept and it washed away some of the stress.
Later that evening the results of my first blood tests started coming back. A young intern came almost running into the room, frantic at the numbers he had received. My blood levels were at panic values. High blood sugars, dangerously high potassium and high blood pressure had apparently made me a prime candidate for a heart attack. An IV was immediately inserted and I was given sodium bicarbonate, (gee I love when they use real TV drug names) calcium, and insulin via a medication pump. I was closely monitored all night. (That means they didn't let me sleep)
I had been admitted to the fifth floor, which as I said earlier was endoscopic and sugar diabetes floor. I shared a room with two other men. One, a rather nice older guy in for diabetes. The other, an older Jewish fellow who often lost contact with reality. He did however entertain me with Yiddish and I learned a little bit about the Jewish religion from his visitors. He did get a little noisy at night... well maybe real noisy!
Wednesday morning late I was taken down to radiology for the biopsy. I was pre-medicated with the wonder drug Valium. I didn't think I needed it but thank God I let a nurse talk me into it.
The surgeon froze an area of my neck on the left side just over my collar bone. He made a small incision there and inserted a catheter. He began to feed the catheter down the blood vessel to the jugular vein. All was going well when the catheter suddenly crashed into a dead end inside the blood vessel. My right arm jumped about six inches straight up for no apparent reason. Apparently he struck a nerve that controlled an arm muscle. Several times he attempted to go around the obstruction but to no avail. I was perspiring heavily and was in "considerable discomfort", but I wanted this job done so I told him to try again rougher if he had to. The surgeon was frustrated too. "Just brace yourself." He said and tried to force the catheter through the blockage.
I could take no more of this and told him so. He seemed relieved and more than willing to stop. He closed the wound and I was wheeled back up to the fifth floor. I was left with an upset stomach, a splitting headache and a large golf ball sized hematoma on my neck that was sore from my ear to below my collarbone for about a month.
Ann was waiting in my room when I returned and again she held me and spoke softly to me with all her wonderful inanities until she had to leave. I watched TV and listened to Yiddish for the remainder of the night.
Thursday morning I was given one unit of Vitamin K and twelve units of fresh frozen plasma. Dr. Adams, who is, I think, Dr. Ghent's right hand man performed a through the chest wall needle biopsy in about ten minutes. God that man was good. Confident, self-assured, hands that moved with an air of competence. He talked to me about my pet passion, computers as he worked. I hardly knew what he was doing. This guy is a real pro. About two hours later he returned and told me that initial pathological results showed it was definitely not rejection and that there was a lot more results forth coming but for now I could go home. "We have several patients like you, that have been struggling along for

several years with abnormal levels. We don't treat them unless they become real bad. Let's just wait for a bit and see what happens to these liver function levels, maybe it's only a virus. I'm sorry I can't tell you something more definitive." He said. "We all wish it was more text book medicine and less experimental."
I was still very paranoid about the whole episode. My liver function levels eventually dropped back to near normal but I was getting pains just to the right of my navel and a burning pain right over my liver.
On the Saturday evening following my release Ann and I took the kids to a movie. We went to Chatham, a nearby city and spent the afternoon shopping and then went out for supper and to an early show. As the day went by, once or twice or maybe twenty times I had to raise my voice to the children. Along about the twentieth time I did this that burning pain in my stomach hit me full and strong. It was then that I realized that this pain seemed to appear whenever I used my abdomen muscles, but more specifically, my diaphragm, which as I have said was damaged in the second transplant. All during my latest hospital stay this pain had never bothered me. Why? If I didn't yell it didn't hurt. I felt much better immediately and didn't yell as often either. God, ain't life grand?
The following Monday started Spring break and so the family packed our bags and headed for Cincinnati for a short holiday. We had a wonderful time even aside from the scare we got when I thought that I'd left my drugs at home. Ann was furious and refused to leave. "If you've forgotten your drugs mister you have a long lonely drive back home cause we're not leaving this motel." she warned.
I searched again and found them. What a relief. We stayed until I had to return Thursday for clinic. I
still had my bile duct tube protruding from my stomach so I couldn't swim but Ann and the kids had a ball at the hotel pools.
That Thursday I went into clinic. My bile duct tube had become infected, which is a common occurrence, and I hoped that I might have it removed early. This tube is used for a test called a cholangiogram. It is a test to check for blockage in the biliary tree. To do this test without the tube is much harder and is minor surgery. I went in early and Dr. McAlister ordered a cholangiogram right away. It showed no blockage. Then after conferring with Drs. Wall, Ghent and Adams it was decided that my infection was starting to abscess and the tube should be removed. The tube was pulled and the abscess was drained for about a half hour, then packed and dressed. I was finally free of the last tube. The docs told me that my liver function levels were basically unchanged but the bilirubin was up a bit more. I was booked for a Portal Vein Doppler Study to again look for some kind of blockage. Sometimes the portal vein, which is a big vessel, can heal closed with scar tissue at the point that is connected to the new liver.
The next Thursday my liver function levels were about the same but my bilirubin had sky rocketed. During the Doppler study in Ultra Sound they couldn't find my portal vein at all. This meant that the vessel could have blood running through so slowly due to a blockage that the ultra sound couldn't distinguish the portal vein from the surrounding liver tissue. As I left the clinic I was again quite depressed. They talked about a test called an ERCP where they insert a tube down your throat into your stomach and then into the liver. Not very pleasant I'm sure.
I bumped into Dr. Wall in the hallway on the way out of the clinic and he gave me an "in hall" medical. "Lift your shirt. "He said.
He felt my abdomen and asked why I was so glum. I told him about the Doppler Study. He smiled and said "When I connected that vessel I tucked it up into the liver so that it was supported in a manner that wouldn't allow it to heal shut. The way that I did that would make it impossible to see the vein via ultra sound. You go home and stop this worrying. I'll go down to the clinic and talk with the others and we'll find out just what, if anything, is wrong with you. "He said. He squeezed my shoulder and winked.
I don't know how this man can instill trust and confidence the way he can but I immediately felt much better and left for home in high spirits.

Chapter Seventeen: Learning to Live With It

It went away! The dirty damn thing just up and went away. One week the docs are talking about the possibility of a third transplant and the next week… it's all better. Maybe over simplified but essentially that was it. The docs had no idea what caused the liver function levels to take off or level out or even if they could control, it should it return.
One thing for sure is that, yes the liver function levels are heading back down towards normal again and during the next couple of weeks it appeared that this liver had taken and all was well.

Remember the old saying "Cheer up things could be worse so I cheered up and sure enough things got worse." That's me!

During the first week of May, I received another call from the transplant out patient clinic, my liver function levels had again began to rise to panic levels. Reluctantly, I was admitted back into the fifth floor of University Hospital.

One of the rotten things about being admitted to hospital this size is that unless you are an emergency it usually takes a day or more just to get all of the paper work and orders placed. I went in on a Thursday. I laid in a bed feeling perfectly well for two days during which time I had some blood drawn twice. I was going insane locked up so Friday afternoon I hunted down Dr. Ghent before he left and he issued me a two day leave of absence for the weekend.

I don't think there is anything more frustrating than lying alone in a hospital, feeling good, being told you're sick and fearing the worst prognosis. Ann and Kaitlin made the trek in once again and we went home for the weekend.

On my return Monday morning, Sheila Summerville, the recipient coordinator, stopped in with some new blood numbers for me. They were still rising. Sheila was probably the most wonderful caring girl that I met in the transplant business. She took care of details. The details that are so terribly important to those involved in them. She cried with us and laughed with us. She would stay late just to talk.

That morning Dr. McAlister performed a liver biopsy through the chest wall and caused me no harm at all. He is very good with a biopsy needle. Its results showed again, no rejection.

Ann and Kait didn't come in that night but Sheila and I had a heart to heart in a stairwell and I felt better after that. I watched TV late into the night and worked on keeping my mind off my troubles.

The next day the docs had scheduled a cholangiogram to check for biliary tree blockage again. I'd never had this test. It's rather like a needle biopsy only not as traumatic. The surgeon enters through an incision on the right side of the abdomen and inserts a catheter into the biliary tree. Then, there you are big as life on a video screen. Dyes are injected to check for blockages of any type in this bile handling system. If a blockage occurs sometimes the surgeon can even remove it with the catheter. In my case however there was no apparent blockage.

Then again it happened, just as suddenly as they had appeared the liver function levels started back down again sending the doctors off scratching their heads. Dr. Ghent came in the next day and with a hint of a smile he said "James, you've managed to perplex us again. The team has discussed your case at length and decided that we are going to just watch you for a while. I know that must be starting to sound familiar but lets keep our chin up and watch for something to happen." He sent me home.

It is September now, I'm nine months with no rejection yet. My liver function levels jump up and down with no real regularity. Just when I get to the point where a doctor wants to do something the liver function levels plateau and head back down again. It even appears that my levels are stabilizing in the last month or so. I feel wonderful although it appears that I have developed sugar diabetes for life. I can control that with the use of insulin and diet. I haven't returned to work because of the uncertainty of my condition. My company is faltering worse than ever and it looks as if next year at this time it will not exist. Already they have eliminated hundreds of jobs. If I were to go back to work, I'd be laid off in just a couple of months and left without health benefits or pay.

I have started into a new career of public speaking. I love to speak and will hopefully someday become a motivational speaker. I have spoken for MORE the Multi Organ Retrieval and Exchange Program and am scheduled to speak for them again. I last spoke with Mr. Bill Brady a local television celebrity and general manager of a television station. He wrote me and praised my speaking ability. I was overwhelmed with his letter and he even asked to speak again with him in October. I have been hired by two more school boards to supply teach and hopefully in a year or two I can supplement my speaking income with a full time teaching position.

Ann is currently looking for work since Kaitlin has entered junior kindergarten this fall. Our babies are growing up and leaving the nest. Andrew and Sarah are in grades two and five and basically we are all happy.

I have learned to live day by day not worrying about what tomorrow will bring. The Lord has watched over this family and will continue to care for us somehow. Of this I am sure.

Epilogue

There have been many new feelings I have had to deal with in the last couple of years. Some are easily dealt with while others I'm not sure if I'll ever be comfortable with.

I love to use my hands. I have often thought of a job in the construction business since I love to build or re-build homes. Living in a small town I'm sure that I could hack out a living as a carpenter or handyman. But with no drug insurance plan or salary continuance I'm sure that this is out of the question. I have become very much aware of my new limitations. I sometimes think of the consequences of a world war or social system break down. Would I still be able to get my drugs or specialized treatment? I would love to go and travel abroad or live in Australia for a couple of years but this too would require a job with fringe benefits, drug supplies and special treatment centres. I have had to accept a loss of control of my life that most people take for granted.

For now I must limit my life to one with a secure job with good fringe benefits, decent security and a consistent routine. It seems like any taboo. Before I was limited I never thought of wanting such things, but now that I can't have them, I wish for that freedom.

How long could I live without cyclosporine? Would it be painful to die for lack of cyclosporine? Does it hurt to die of organ rejection? It sure hurt to almost die of it.

Everything now is short term. To plan long term is foolish. I still set goals, I still have ideals and dreams, but now they fall into a different priority list that is headed up with simply living today. Living today to the fullest degree. Planning each day just the day before. Enjoying my children's antics and my wife's passing glances. Listening to kids prayers every night and planning their future, not mine. A playful hug from my wife has special meaning and can bring tears of joy for what we might have missed. I have traded long term financial security for short term satisfaction and enjoyment. Maybe, should I live to retirement age, I'll curse the way I live today. I won't have a big nest egg to put me in Florida over the winter months. But for now I'll take that risk…

I've always rather enjoyed the snow anyhow!