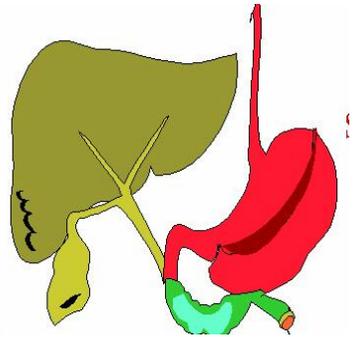


Born Again, and again

Living
through an
Organ
Transplant



Edward G. Van Gennip

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Written: over the period 1998 to 2007, describing the period 1989 through 2007. Most written between 2000 and 2001.

Preface



This book is dedicated to all those people who are facing an organ transplant of one kind or another. It is a very serious and scary operation with many unknowns, many questions. Doctors answer most but someone who has been through the process can help in areas doctors cannot. I'll try to help by relating my own experiences due to by liver transplant June 20, 2000, sharing how I reacted and felt. It's different for each person but many steps, hurdles and feelings are somewhat similar.

I also dedicate this book to the family and friends of a person facing a transplant. I hope by reading you will see some of the feelings, emotions and fears being faced. This will help explain a persons changed behavior. Unless you go through the process you cannot fully understand the feelings but you can sympathize and help.

I'd like to thank so many people for their support in so many ways but I cannot list them all individually as it would be a book in itself. Special thanks of course to the Lord Jesus who alone holds the power of life and death, the power of healing in His hands. In His mercy He has carried me through this ordeal. My wife Nancy, the most wonderful woman in the world for her love, day to day practical support, as well as ongoing emotional support have helped more that I can say. Just taking care of the three young children at times when 'daddy does not feel like playing' on top of all the regular duties to attend to is a lot, but she did much, much more. My wish is that everyone facing such a serious event in their life would have someone as close to them as Nancy is to me.

A special thank-you to my mothers for their continual prayers and support over the years of slowly deteriorating health.

Taking the children for a weekend now and then so Nancy and I could enjoy a little time together was wonderful. Thanks also to fathers, brothers, sisters, aunts, uncles, grandmother and children's prayers and help over the past few years.

The bible says we are all brothers and sisters in the Lord. I've seen how true this is through the countless prayers of friends at church. People like Bob who has been praying almost daily for ten years for my health. I especially appreciated the prayers of people who don't even know me. Mary Ann and John from New Jersey who I met and got to know only a little over a one week period on summer of 1999, who had many people from their church praying for me on a number of occasions. Friends from high school and family members, who have people from their respective churches praying for me, again people who don't even know me. My wife's uncle Ken who has friends in Malaysia, people with many needs of their own yet they are praying for me, a person from Canada who has everything (food, home, job, ...).

Last but by no means the least I would like to thank all the doctors and nurses at Toronto Wellesley and Toronto General Hospitals. Doctor Kortan and Doctor Lilly have both been excellent doctors. They are open and direct, not hiding things from me but telling me what to look forward to as the disease progresses. The nurses and staff I came in contact with were all excellent. Each was friendly, each doing a professional job in terms of taking care of me while in the hospital, but even more I felt that they all truly loved what they did. I was not just their job but they truly wanted to give me the best possible care they could, to make my stay as pleasant as possible. I tip my hat to them for they are a special group of people. I even thank the surgeon's who left a gargantuan scar across and up my stomach. Thank-you all.

The cover shows a decaying leaf from a deciduous tree after the 'skin' has dissolved leaving only the internal structure remaining. This structure supports the leaf and also allows nourishment to flow through it. This looks somewhat like the bile ducts inside a human liver. They are tree like in that there is a trunk which comes from the liver connecting to the

intestines and inside the liver the trunk branches into smaller and smaller ducts. These small ducts carry bile produced in the liver to store it in the gall bladder into the intestines when needed to help digest foods. In some liver diseases these ducts become malformed resulting in improper liver function. Over time this leads to liver failure and death or a transplant. This book is the story of one such case, resulting in a transplant, due to a liver disease named Primary Sclerosing Colongitis.

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Introduction

Introduction

So, you have a ‘disease’ requiring an organ transplant, or know someone close to you who is in such a situation. I was once in that situation. I needed, and have now had, an organ transplant. In fact it was a liver transplant. My purpose in writing this book is to help you understand the process from various points of view as well as many of the experiences you or the one close to you will go through.

The medical process involves many tests, examinations, procedures, education, questions and forms. It can be overwhelming for a healthy person and even more so for someone who is not in optimal health. The experiences include the physical changes of tiredness, sick feeling, weak feeling, weight loss, bloating, skin itching and color change, effects from drugs and many others. The symptoms can be different for each person and each organ type for which a person can receive a transplant. Another side is the emotional changes you will go through. Physical changes inevitably cause emotional responses, and vice-versa. You will question why this is happening to you; what in your lifestyle has caused this problem; what should you have done differently; how can I get over this; must I go through surgery; it's not fair; how will my spouse and children survive; what about my job; and many more questions. Then there is the most important side, the spiritual side. Whether you believe in a God or not, health problems of such a serious life threatening nature will cause you to think about God. Is He real; does He care about me; does He have a plan for all this; what happens if I don't survive; is there another realm; eternity!

In this book I will address all these areas, based on my own experience, my wife's, my children's, those I know who have helped me, and those I have talked to who have had similar

problems and operations. I am not a physician or a psychologist or a minister, so I cannot speak as an expert in any of these areas, but I have gone through the experience of having a liver transplant and thus can speak from first hand experience. Someone once said ‘experience is the best teacher’ and I agree. A doctor can tell you that you will have itchy skin due to increased bilirubin in your blood stream, but they cannot describe exactly how you will feel. Some days your skin is so itchy that it feels better to scratch so hard that you start to bleed and feel that pain, than it is to not scratch and feel the itch. A doctor cannot adequately describe how you feel when your lungs don’t process oxygen and you feel out of breath, or your heart pump blood but not very well, and how that feels.

The flow through the book is basically the flow of events in my life, spanning an eleven year stretch from when I first started having problems until after the surgery and I was home again recovering. I have mixed the events as they occurred with the physical, emotional and spiritual experiences I had as this is the most realistic way I can present it. A lot is liver specific but tests, feelings, processes, operational procedures, drugs, etc. are very similar. So let’s begin, back in October 1989.

1. What's going on?

Chapter

1

*Sooo many visits to the toilet!
Always tired.*

My story begins back in 1989 sometime. Everything was going great. I was married to Nancy, a wonderful woman; we both had good jobs at IBM and Heinz. We were part of a great, loving church as well as loving families. Life was good. At some point, I do not remember exactly when, I noticed that I was going to the washroom for bowel movements more than normal. Also noticed that they were not normal but always either very soft or often times liquid, mixed with a lot of gas. I thought I had caught a virus or ate something bad and it would go away in a week or so. After a while longer I noticed it had not gone away, in fact it was slowly getting worse. I told Nancy about it and started to watch what I ate hoping to find the food causing the problem. At the same time I noticed I was frequently feeling tired. Apparently so many bowel movements take their toll on your energy level. It's hard work going to the washroom 10-15 times per day! I went to visit a 'specialist' in north Toronto to have myself checked out. I do not normally go to the doctor so I did not look forward to this visit but the problem was getting worse so I had to do something.

The doctor suggested I take a powder named Questran mixed with water or juice and see what that does. Questran is some fiber like product which is supposed to bind to stuff in your intestines and thus solidify it. The doctor spent very little time with me, asked very few questions, and did no tests. He did not impress me as a doctor who had any care or time for me.

The Questran did nothing; had no effect whatsoever. Due to my impression of the doctor I did not go back. Shortly thereafter we moved about 45 minutes north of Toronto to rent a basement apartment in the country. While there Nancy became pregnant with our firstborn. She found a new doctor up there. One day she mentioned my problem to her doctor. I went to see him once, talked to him and he immediately referred me to a gastroenterologist (stomach/intestine/colon specialist) in the town of Newmarket. I went to see him one day in his office. We talked for a while then he scheduled me for an ERCP (Endoscopic Retrograde Cholangiopancreatography) the following week. An ERCP enables the physician to diagnose problems in the liver, gallbladder, bile ducts, and pancreas. The tests began.

Tests and more tests

It is now the spring of 1990. The ERCP was the first of many to follow over the years as well as many other types of tests. To prepare for the ERCP I could not eat for 2 days and the second day was only clear fluids. The evening before the procedure I was to drink a four litre jug of gastrolite, a salty fluid designed to flush clean your digestive system from the stomach all the way through to the anus. Instructions say drink one eight ounce glass every ten minutes until gone. Over the next two hours I drank three of the four litres; that's all I could get down as I almost threw-up a few times. Considering the number of bowel movements during that time I think I was pretty clean. The next day was not fun. I did not know what to expect. Two nurses 'held me down' while the doctor inserted the scope into my mouth and down my throat. There was no freezing of any kind, I was wide awake! I assumed this is how it had to be done. I tried to throw up to get the scope out but I found you cannot throw up with something down your throat. The doctor tried to be quick, take a look around and get the scope out as soon as he could. I think it only took about two minutes, but two minutes can seem like

forever. After it was over I went home. Later I learned that usually a patient is slightly drugged so that you are not totally asleep and can respond to doctor's requests to turn or shift your body to help the scope through your system but are relaxed and not feeling like gagging. The good side of no drugs is that I could drive home myself. The only side effect was a sore throat for a few days. Later ERCP's left me with bad headaches as well as a sore throat. I suspect the drugs caused the headaches. Living back in Toronto now I would sometimes take the subway home after a procedure as I felt fine, only to discover the next day that I do not remember the trip home. Nancy did not let me take the subway very often, which was probably a wise thing to do.

First Diagnosis: Ulcerative Colitis

A few weeks after the initial procedure I was back to visit the specialist who did the ERCP. He said I have Ulcerative Colitis (UC). I had never heard of the disease. He explained what it was, that there is no cure, the effects it has on a person, what happens when it gets severe, and how to deal with it. As this book was written to describe mainly the transplant process I will not go into details about UC. The reason I mention it is that it is the precursor to my liver disease, and it is the liver that was transplanted.

The doctor prescribed some drugs, ASACOL being one of them, to help get the UC under control and then to try to keep it under control. Over this period I discovered by trial and error that foods make a huge difference in how severe the UC was. I mention this as it seems to be the case in many diseases. Too much fatty foods tend to lead to heart problems, onions, brown beans, chocolate, milk aggravate stomach, intestine and colon problems. I've heard too much sugar and too much salt lead to kidney problems. So cutting back on some of these foods helped the UC but it is not curable so I continued to have problems, but to a much lesser degree. I would have 3-5 bowel movements instead of the 10-15, or the peak of 20-25 a day.

A while later we moved back to Toronto. Nancy went back to her previous family doctor. She then recommended me to a specialist at the Toronto Wellesley Hospital. He turned out to be an excellent doctor. He took time to explain situations, treatments, tests and I think most importantly the future of how the disease will progress, what the future probably will hold. He also cared about his patients. He asked about the family, how Nancy was handling my problems, how I felt about the problems. All around he was an excellent doctor. I started seeing him in the fall of 1991 and he remained my doctor until January of 1998 when my liver problem became more serious than the colitis, and thus he transferred me to a liver specialist at Toronto General Hospital. He even lent me one of his medical textbooks to read about the disease (this is before the internet was big). One last credit I have for him is that the specialist he transferred me to was very similar to himself; an excellent people doctor who cared for his patients and took time to talk to them. He did not deal strictly with the disease but with the whole person. In the years since I have been to a number of meetings with people with liver and other problems. In many cases people want help and guidance in finding a good specialist who cares about them and takes time to spend with them. I say this to recommend to whoever is reading this book that you seek out a specialist who you feel comfortable with. Not all doctors are the same. Some people want to know every detail and option, others want to know nothing and leave every detail in the doctor's hand. Find a doctor who matches your needs. I never thought about this at the time as I was focused on my problems and not the doctor but looking back I can see how God was guiding me, directing who I talked to, what family doctors Nancy had, when and which specialists I was referred to. The doctors you see make a huge difference in how you deal with problems.

Moving back to Toronto I was working with a new doctor and sent for a lot of tests again. A colonoscopy is a scope from the anus into the colon to get a view of the colon and look for inflammation there. I was injected with some radioactive material and then a bone scan done to check bone density. A

barium enema test is when one drinks a barium solution and then colon is scanned. Lots of tests! I felt sorry for some of the elderly people I saw having similar tests. I found them uncomfortable and sometimes difficult and I think I was young, about 29, and in relatively good shape. After a month of so the tests were finished and everything calmed down for a while.

Back to a normal life, for now

It has been a busy year. Having many tests, being diagnosed with ulcerative colitis, starting to handle it with drugs and diet changes, moving back to Toronto, a new doctor, new tests, and changed drugs. More importantly Robert was born during this time which added additional cares and workload into Nancy and my lives. But now we can get back to normal, tests are done, drugs are being taken as prescribed and the UC is calmed down. I've learned to live with the disease. It's not that serious and only occasionally do I have to urgently have a bowel movement at an inopportune time. Again God was being kind in controlling the timing of all this.

The UC flared up in 1992. The ASACOL was not effective enough so the doctor prescribed prednisone. The good news is that it is cheap and works well. The bad news is it can lead to bone problems like osteoporosis. I was on prednisone for about six months. It takes a while to get off as doctors reduce the amount slowly to reduce the withdrawal effects. Some other effects are facial puffiness, less sleep is needed, some weight gain, hair growth and a general well feeling. These can be good or bad effects depending in the person. For me they were mostly good as I'm underweight, have a long skinny face, much body hair and lots to do so less need for sleep is good. The best news is that the drug worked and my UC was again under control. Over time the weight was lost, the puffiness went away and my sleeping habits unfortunately

returned to normal; I was enjoying the reduced time wasted sleeping.

I mentioned the above incident for two reasons. It's not related directly to organ transplant but has some similarities. First, prednisone is one of the main drugs given to transplant patients after a transplant. It helps your body accept the organ, hindering your ability to reject the foreign object in your body. Prednisone is an anti-inflammatory and anti-rejection drug. Thus it is good to be aware of the drug, its purpose and effects. Secondly, I'd like to point out that problems come and go during extended illnesses. Enjoy the good times when they occur as you never know how long they will last. During the bad times think ahead to when it will be over and focus on the good times to come. Possibly plan some activity to do to celebrate the end of a bad spell. This will help give strength to get through.

2. A Second Setback

Chapter

2

*Why am I tired now, and yellow
tinged?*

Here we go again. I've been feeling well for quite a while now. It's now the middle of September 1992. A great summer has passed but I've noticed lately that I get tired easily. Even after a good nights sleep I feel tired during the day. My family, parents and in-laws are thinking I'm looking a little yellow; my skin has a yellow tinge. Looking at myself every morning in the mirror while getting ready to work I don't notice the gradual change. Likewise Nancy does not either. But now my urine is turning a bright yellow and sometimes a very dark, brownish yellow. I just assume I ate something that set my system off but the color change is not going away. A week or so later I'm looking in the mirror while shaving. As I turn a check to the mirror I need to look out of the corner of my eye to see myself. This is when I noticed the whites of my eyes are also turning yellow around the edges. My ankles and hands have been itching a little lately and it's now getting worse as well. What's wrong now!

I've read some pamphlets about Ulcerative Colitis (UC) and they do not mention anything about yellowing skin or eyes. Neither do they mention the itchy skin condition. So I just live with it for a few weeks thinking, hoping, it will go away. But it does not; it keeps getting worse. Don't be stupid I say to myself, like I was and ignore problems until they can no longer be ignored. The longer you ignore a problem the worse it usually gets and the harder it is for doctors to deal with. Also it takes longer for you to heal.

Second Diagnosis: PSC

I continued to get sicker. I tired more easily, skin and eyes turning darker yellow, skin getting itchier. In fact I sometimes scratch so hard to relieve the itch that my skin tears and bleeds. I feel so bad now that I called the UC specialist to tell him what's wrong. As mentioned previously he is a great doctor. He suspects immediately what's wrong and fits me in to see him the next day. It was a very short meeting as he had to squeeze me between other patients. He looks at me, tells me to look up, down, left, right. He knew the answer but did not tell me right away. He scheduled me for an ERCP. I had already been through this so I assumed my problems were a different kind of problem than previously but still related to the Ulcerative Colitis. Despite the short notice he kindly squeezed me in the following Thursday. ERCP's are only done on Tuesday and Thursdays, both days booked full for the next month, so he told me to come in early the second Thursday and I would be first, before the regular day starts. In total I took two weeks off work. This is the worst I have ever felt, up to this point in my life. I felt worse than when I broke my right leg, clean through, when I was 16. Worse than the recovery from having four wisdom teeth extracted. I think before this the most I had ever been off work for illness was three days.

Thank you Lord for bringing me to a doctor who goes out of his way to help patients like me who are too dumb to take care of themselves in a timely manner. This was a learning experience for me. I'm not suggesting you jump immediately and see the doctor or specialist whenever a problem arises. Use past experience and good judgment to decide when to go. I had the problem for almost a month and it was getting worse all the time, not better. I should have gone to him a few weeks ago.

The Thursday of the following week, the end of October 1992 I had the second ERCP done. This time I was 'relaxed' by drugs as the procedure happened. It was a much more pleasant experience as I did not notice the tube in my throat at all. The other difference was the groggy feeling for the rest of the day and night. I went home and slept for most of the day, then lay on the couch and watched television for a few hours that night.

The following week I was back in the doctor's office. He told me I have PSC, Primary Sclerosing Colongitis. This, like Ulcerative Colitis was a disease I had never heard of. It is a liver disorder where the bile ducts are malformed. In some places the ducts swell and become blocked. In other places the ducts constrict. In either case the bile cannot flow out of the liver. When the bile builds up the liver does not function properly, it does not remove waste products from your body. This leaves the waste in your blood system which then transports it to the skin, eyes, everywhere. It causes the yellowness and itchiness.

A stent, a small tube, smaller in diameter than a drinking straw and about 10 centimeters or 4 inches long was inserted into my main bile duct during the ERCP process. This stretches the bile duct back into a somewhat normal shape. While the stent is in the bile flows through again. After a month or so the stent is either removed or a larger stent inserted to stretch the bile duct further. In my case a second larger and a month later a third larger stent was inserted. A month later the stent was removed. The idea is that after the three months of stretching to successively larger sizes the bile duct will remain open and almost normal for some period of time, hopefully years. Of course each stent insertion and the final stent removal required an ERCP, thus the day off work for each procedure.

PSC is a degenerative disease meaning that it gets worse over time. The time period varies in each individual so the doctor cannot tell immediately how long it will be before I would need a liver transplant. LIVER TRANSPLANT! What's going on here? This is the first I've heard about it. This is getting serious now. A bowel problem is bad enough, now a liver

transplant in my future. I don't like it! The doctor explains the disease quite well, the long term effects, what can be done to treat it, the disease's background such as heredity and racial tendencies of the disease. He also explained the variety of liver diseases, that there is no known cause for this particular type of liver disease and he loaned me a book on the liver and diseases thereof. He also said the ERCP process of inserting stents could be done indefinitely.

My main concern through this time was the thought of a future liver transplant. I was not very educated on the transplant processes and I thought the liver transplant was still in its infancy and thus not highly successful. The doctor assured me that I was young and my liver was still working quite well, especially with the stents. Don't worry he said, you have many years; the transplant process is improving all the time. All I should do is keep myself in the best possible shape. I should eat better; more fruits, vegetables and less junk foods. I should also exercise regularly. I'm thin and in fairly good shape but I do not exercise much, so something to start planning time for. At the time I never realized how important exercise is when going through a transplant of any kind, but looking back now it's clear that the better shape you are in before, the easier the whole process will be and the shorter the recovery time. The last thing the doctor mentioned is that I should have a liver biopsy to get a more accurate idea of how far the disease has progressed. It would also be a reference point for a future liver biopsy to determine the rate of disease progression. Although he says this is an easy procedure I did not like the sound of it.

Getting back to a normal life, yet again.

After this second diagnosis, that I have Ulcerative Colitis as well as Primary Sclerosing Colongitis and now that both are under control, it is time to get back to normal living again. Part of this is the exercise and better eating habits mentioned above. A general note here is that we should all follow good eating and exercise habits but

it's easier said than done. I did well for a few months and I still eat good foods but being thin I can also eat junk food without the weight gain problem, so I did. Exercise became sporadic as life got busier again. I'm taking a second drug now called Ursosalk. This one is designed to stimulate the liver to produce bile. I guess the idea is that if the bile keep flowing then hopefully the bile ducts will remain open. Fortunately I work for a great company with a good drug benefits program. Another blessing or inspiration from the Lord is that I has years previously signed up for the highest level of drug coverage available, so I received the best possible coverage.

As the immediate problems were gone I started to spend some time thinking about life, the future possibilities, the past, everything. Robert was now two years old and Nancy was pregnant with our second child. I wondered the effect the drugs I was taking might have on my sperm and thus on the pregnancy. Thank God, literally, that Matthew was born normal and has been our healthiest child all along. Of course there may be long term effects we will not know about for 20 years, if ever, but for now everything looks good. I also spent time thinking about the future and what would happen if I needed a transplant while still fairly young, still working, and I either died in the process or was disabled in some way that I could not work thereafter. The bible tells us in Matthew 6:34 "Take therefore no thought for the morrow: for the morrow shall take thought for the things of itself. Sufficient unto the day is the evil thereof." Each day has enough problems of its own, don't worry about the tomorrows. This is good advice which I try to follow but it is not always easy to put into practice. I cannot see or control the future, but one can somewhat prepare for it through exercise, good eating, preparing my family in any way possible, spending time with them now, whatever you can think of. The other area I thought about was the past. Even though the doctor said there is no know cause for PSC I still wondered if there was something I did in my youth that triggered it. This again is futile thinking, wasting time, as there is nothing that can be done now, the damage is there. The Bible says in Proverbs 3:5,6 "Trust in the

LORD with all thine heart; and lean not unto thine own understanding. In all thy ways acknowledge him, and he shall direct thy paths.” I need to learn to trust God, leave my problems and worries with Him and realize the truth, that He is in control and He will direct my path.

3. The Cycle continues, then the Bad News'



Tired and yellow again. ERCP cycles.

In the last chapter I was diagnosed with PSC, Primary Sclerosing Colongitis. I remember I was told by my doctor that I would one day need a liver transplant, but not to worry, that was a long way off. I really liked my doctor, he's taken care of me well by keeping me informed of what's going on in my body, first with respect to the Ulcerative Colitis and more recently regarding PSC and explaining in details the nature of the disease, what to expect, how to take care of myself. He has taken time in his busy schedule with many patients who are just as ill as I, many worse, to talk to Nancy and myself and address any and all our concerns.

As my body was getting back to normal the yellow in my eyes cleared up over a few weeks, the itchiness of my skin left, my energy returned, and over a few months my weight got back up to normal. Every now and then I would think about my liver problem and the long term implications but as I was feeling well I did not spend much time focusing on the PSC. Occasionally my Ulcerative Colitis would flare up requiring that I change my diet slightly, avoiding chocolate, pop, ice cream, brown beans, onions, i.e. all the best foods I like. These flare-ups were the most troublesome and took my attention away from the PSC.

In April 1995, about two and a half years after my first encounter with PSC I started to feel tired and weak. Slowly my

eyes started turning yellow. Unlike the first encounter, where I had no idea what was happening, this time I knew exactly what the problem was. I called my doctor who had me come in a few days later. He took one look at my eyes and agreed that the bile ducts in the liver were again blocked. He sent me for blood tests right after our office meeting, got the results the same day and scheduled an ERCP for the following week.

This being my second encounter with PSC, the liver disease affecting my body, got me thinking about the longer term. This is the second time, in two and a half years. Am I going to need this every couple years? If so, then that's OK. It worked last time. My doctor says they can repeat this procedure indefinitely so that was encouraging news. Still, I started to think a little about a liver transplant, and that it may not be as far away as I had thought. Yet my doctor said that it is still a long way off. They can continue to insert and remove stents as needed. This made me feel better in some ways, but still the mind likes to wander and when it does it usually imagines the worst possible scenario. Then you dwell on that and it only gets you down even more. Of course being a man I had to look tough for my wife and family. Also, the news from the doctor that it was still a long way off makes one feel silly if they tell someone they are worried about something that a long way, years and years away. There was no need for my wife to worry just because I was worrying. She tends to be more sensitive to bad news than I, so no need to make things worse. So I kept all this inside, thinking to myself about Nancy possibly having to live and raise our children without me; about our children not having a father figure, or at least not me as the father figure (I expect Nancy to remarry after some time of looking for the right man).

One thought I had was that I should write a letter to Nancy and the kids talking about our family, what I would like for Nancy after I'm gone, in terms of raising the children and her future. Also my understanding of our children's character traits and how I felt they would react in the teenage years to the various social pressures. I then tried to give advice on their strengths and weaknesses and what I felt they needed to know and do.

Although this letter is very personal I have included much of it as Appendix A, just because I feel there are other people out there going through similar thoughts and would also like to leave some advice for their close family members. This letter is very specific for Nancy, Robert, Matthew and Lyndsey, but can be a basis to get you thinking about your spouse and children.

One good thing about worry and mild depression is that it can bring you closer to God. This happened for me. As I thought about these problems starting to flare up in my life over the past few years I started asking God why? What is the purpose of my children not having a father (again I think the worst) in a morally declining society? Just praying to God and reading the Bible was a comfort to me. God did not directly answer me, unfortunately, but through the Bible I could read and learn about many people who went through very difficult circumstances, some far worse than mine. Some survived, some did not. In all cases I learned that God's will, His divine plan, is being worked out in our lives. We often do not understand or like what's happening, but we can know that it is His will, and His will is ultimately for the best.

The ERCP cycle this round was very similar to the first. The doctor performing the procedure inserted a '5 French' stent. The normal recovery process followed where I had a very sore throat for a day and felt weak. Again there was only one day off work, the day the procedure was actually done, as well as a few hours the previous week for the doctor visit and blood tests. About four months later I was back in for another day to have the procedure repeated, but this time it was to remove the '5 French' and insert a '7 French'. Unfortunately this procedure did not go quite as well as the last. The procedure itself went fine and I was home the same day. I slept the rest of the afternoon and dinner hour. I awoke and watched television for a few hours then went back to bed. I started to feel some pain in my chest and could not sleep. Over the next few hours the pain grew worse and worse. Every breath I inhaled caused more pain. It's hard to describe exactly what the pain felt like. It was not heart burn, as I've felt that and it was much

different. It was more like tremendous pressure on my upper rib cage but the pressure was from the inside, not the outside. Finally around midnight as I could not sleep and the pain was still getting worse I decided to go to the hospital. My doctor had told me that whenever an ERCP is done there is always a chance that the pancreas could become infected, which would require hospitalization and strong antibiotics to get the infection under control. I feared this is what had happened.

I went to the closest hospital, which was not Wellesley, where my procedures were done but Centenary in Scarborough. After waiting in the waiting area for a short time I was placed in an overflow area, as the hospital was very busy for such a late hour. I lay there on a bed for an hour or so before a doctor came to see me. They took my temperature, asked lots of questions and then left me to rest for a while. All this time the pain was still there, very strong but not getting any worse. Finally they said it did not look like an infection put probably just sore chest on the inside from where the doctors been working, moving their instruments through my throat, stomach and bile duct. My doctor had said they had difficulty inserting the stent as the bile duct was very tight. The pain started to subside so I went home. By the next morning everything was OK, the pain was gone. There was no infection. A few months later the '7 French' stent was removed and a '9 French' inserted. A few months later that was removed. The doctor again explained that the idea of inserting successively larger stents was to stretch the bile duct over time, then remove the stent and hopefully the bile duct, now stretched would stay at the larger size, thus allowing the bile to flow freely. This had worked well the first time, for about two and a half years. Now I had it all done again, so I was again to wait and see how long it would remain effective.

Before each ERCP, or any medical procedure I believe, the patient is required to sign a medical release form which states that the doctor has explained to the patient the possible complications of the procedure. One item the doctor did mention was that about 20% of ERCP patients develop a complication called pancreatitis. The pancreas gets infected

and antibiotics are needed to clear it up. There is also a possibility of a tear in the pancreas due to the mechanics of the procedure, pushing the instruments down the throat, through the stomach, and further down. Over the few years to follow I have had quite a few ERCP's and never once had a tear or infection. The Bible says in James 5:16 "Confess your faults one to another, and pray one for another, that ye may be healed. The effectual fervent prayer of a righteous man availeth much." I do not remember confessing my faults and know I am not a very righteous man but I do know that many others were praying for me and their prayers, as well as mine, were answered in that I never had a complication.

The 'Bad News'

I quickly recovered from my second round of blocked bile ducts. My strength returned and I felt better. Soon I thought less and less about the long term problems Nancy and I would probably have to face. There are enough day to day issues with work, home and raising children that thinking about unpleasant long term health problems was easy to push out of my mind.

Then in October 1997 it started again. Slowly the tops of my feet and ankles got itchy. Next to itch was the skin between my fingers, my forearms, lower legs, then eye lids and the top of my head. Of course the whites of my eyes slowly got the yellow jaundice look as well. I called my doctor, went in for blood tests and was scheduled for the ERCP routine again. Mid-November 1997 a balloon was inserted into my bile duct, inflated to stretch the duct, then deflated and removed. The normal in and out; a one day procedure. Fortunately this round I did not have the terrible headaches and dizzy spells the following day. This was even more fortunate as Nancy and I had plans to fly to Edmonton Alberta the next day, for a short four day vacation. We went. The first day I was tired all morning but it was all travel anyway. By afternoon I was a little better and the next three days together were great. We

had beautiful weather and a scenic driving to Lake Louise, Banff and then to Calgary. A great time away together.

Shortly after we got back my doctor called. He explained that my bile ducts were slowly collapsing and with each successive ERCP it was getting harder to get stents in to expand the ducts to allow the bile to flow freely again. As the smaller ducts get more and more constricted there will be no way to open them up. When this happens it's possible that a section of the liver may become infected in which case I would need immediate hospitalization and strong antibiotics to get the infection under control. Without this I would die in about two days. This was bad news, really bad and scary news to think your liver could get infected and you die in two days if not treated very quickly. I knew a message like this was coming from my doctor eventually but I did not expect it yet. He also said that it is time to see the liver transplant team at Toronto General Hospital. He had made an appointment with a hepatologist (liver specialist) and gastroenterologist (stomach, intestine, colon specialist). These two special skills were combined into one doctor.

Toronto General Hospital (TGH) was the only hospital in Toronto at that time (the year 2000) which did liver transplants. My doctor had said this was to be an 'initial consultation' so they could get to know me at TGH as eventually I would need a liver transplant there. It was late November 1997 now and the appointment was scheduled for January 26th 1998. No big deal I thought. Nancy and I could go and see what they have to say about my condition and learn a little about the liver transplant process. Little did we know this was the start of a live-long relationship, a relationship which I had hoped would not start for many years yet. I was thirty five years old at that time.

The 'BAD News'

January 26 1998 Nancy and I went to the tenth floor of the Eaton wing; transplant central. All the doctors offices, the various support staff such as dietitian, transplant coordinators, psychologist, the MORE (Multiple Organ Retrieval and Exchange) offices, Step down units and normal care rooms, all dedicated to organ transplants. My doctor from Wellesley had sent over my history. The hepatologist introduced himself, reviewed my information and said 'you will need a new liver within two years or you will be dead.' Those were not the words I was expecting to hear. This was really BAD news, not just bad news like I had earlier at Wellesley but really BAD news. The doctor went on to explain that my case was like many others he had seen. My bile ducts were progressively getting worse, the ERCP's were getting closer together and it would continue to worsen. A part of my liver could die due to improper function with blocked or constricted bile ducts which would cause an infection and require strong antibiotics and possibly a quick transplant. These were not things I wanted to hear, nor did my wife. The doctor said the first step was to send for a few tests and meetings.

Tests and more Tests'

During February and March of '98 I had blood, lung, heart tests as well as a bone scan (due to Osteoporosis from taking prednisone a few years back to control the colitis). I also had a test where I needed to drink a litre of some barium liquid to scan my colon. Some days were one test, some two. Sometimes preparations like fasting were necessary, sometimes drinking various fluids. Included were visits to a psychologist, social worker, nutritionist and an interview with a transplant surgeon. One of the persons, I forget which, asked two questions to which I had to answer YES. If not I would not be eligible for a transplant.

The first question was ‘Will you agree to never drink alcohol again?’ The idea behind this question is that some transplants are the result of alcohol abuse. A transplant is very costly and even more important is the fact there are not enough livers available to meet the demand. People are dying while they wait for a suitable liver. Why should a liver be given to a person who is going to waste it by abusing it? I answered yes. The second question was ‘Will you agree to take the medications prescribed by the doctors for as long as necessary?’ Again due to costs and the shortage of organs the doctors do not want to give a liver to a person who will not properly care for it. This can be very difficult for someone who is not covered by a drug plan. There are aids available for people who have trouble financially. This is described later. I again answered yes.

Steps to a transplant. Am I eligible?

A committee reviews the various tests and interviews over the past few months. They discuss the possibility of success versus failure and what alternatives are available such as drug therapy or some alternative approaches and then decide when and how to proceed. In normal cases the proceed decision means you go on the end of a waiting list based on your blood type. In my case being blood type ‘A’ I was placed at the end of the ‘A’ list. I’m not sure but after having talked to a few people I met in the hospital I believe the procedures are the same for most types of transplants. Some tests are different, some questions will be different, the criteria for being listed on the waiting list will be different, but from a patients point of view the process is basically the same.

In serious cases where a person is going to die in a day or two the above few months of testing will be compressed into a day or less, and many of the tests and interviews skipped. In these urgent cases the doctors need to make an educated guess on how to proceed.

4. Drugs versus Herbs

Chapter

4

Prescribed Traditional Methods

The traditional methods described herein are drugs prescribed by most doctors. The non-traditional methods are the herbs, minerals and vitamins. This is really backwards as the herbs, minerals and vitamins have been around and in use much longer than drugs. Regardless, drugs are now referred to as traditional therapies. There are as many different drugs as there are variations of diseases. Likewise there exist different manufacturers of very similar and possibly competing drugs both of which compete with the generic brands. The generic brands are cheaper and often of the same quality as the name brands but one must beware, especially if they are manufactured outside North America. The main drugs I've taken for colon and liver problems before the transplant are Asacol, Ursosalk, and Prednisone. If these drugs do not work for some patients then others are prescribed. In many cases different drugs cause the same result but enter the body via a different route. Some are inhaled, others tablets or capsules; some suppositories and patches. These are usually just delivery mechanisms to get the drugs into our system. After the transplant a whole different series of drugs are prescribed as there are a whole different series of problems to deal with. In some people drugs are drastically changed even before a transplant as different problems develop. For example your stomach may develop ulcers from taking one type of drug, so the drug is stopped or changed form and a new drug is prescribed to help with ulcers.

In some cases a doctor will say to take as little of a medication as necessary to help with a problem. For example headaches, you take as few or as many aspirin or Tylenol as needed,

which can be different for each person. Similarly for people with colitis or crohn's disease, you take as little Asacol or similar drug as needed to control the disease. In other cases a doctor will prescribe a fixed amount to be taken each day. This is usually to ensure a level of the drug is maintained in your system at all times. This is the case after transplant where the anti-rejection drug levels should be as constant as possible.

Suggested Liver non-Traditional Methods

As mentioned above about the variety of drugs to address the variety of diseases, so also is the case with the non-traditional approaches, often called naturopathic methods. These methods usually include herbs, minerals, and vitamins but could also include other things such as meditation, wearing copper bracelets, changing your diet to avoid certain foods, acupuncture, etc. Depending on your disease some of these methods will help more than others. For example many people with colon problems find that avoiding dairy products makes a big difference in the severity of the problem. Likewise someone with high blood pressure should avoid too much salt.

My specialist at Toronto General Hospital was very good, very open to me taking drugs he prescribed as well as the non-traditional types. He had heard that milk-thistle was very good for helping the liver produce bile and with the flow of bile from the liver. So I took milk-thistle. He encouraged me to find things which helped. He did not feel that this type of action would cure my dying liver but that it would help with the symptoms and possible slow the degradation of liver functions. One word of caution he had which no naturopath or anyone in any health food store ever told me was that some vitamins are fat-soluble, others are water soluble. The body disposes of any excess water soluble vitamins but the fat soluble ones cause extra strain on the liver as it is the organ which produces bile to digest the fat. If you have liver disease as I did then you do not want to add extra strain to the liver. A

word of caution is to research whatever procedures you wish to undertake before proceeding. Some things will help you, some no effect and others can cause further harm.

Some of the types of non-traditional therapies I had heard of for colon/liver type problems are Colon Cleansers, Liver Flush, Fasting, Juice Diets and various types of vitamin/mineral supplements. Considering the fact that I have always been a thin person and over the last few years I've been slowly losing weight I thought that all these therapies except the last one would cause further weight loss. It's very possible that in the long run they would have helped me and I would have regained any lost weight but I did not want to take that risk. When I get a bad cold or a flu I can lose 5 pounds in a few days but take a month or more to gain it back. Also, as my particular problem was liver related and these actions put strain on the liver I did not want to proceed. If a person has a heart problem then a colon cleanser or fasting may not cause heart strain, but they do cause liver strain as the liver must now work to attempt to provide stored nutrients to your system to make up for those lost by the reduced nutrient intake.

One therapy I did decide to try was taking various herbs and vitamins. As mentioned above I took milk thistle, as well as corbicula (made from clam shells) to help with bile production and flow. I also tried bee pollen and a mix of vitamins, at different times to help with energy levels. It is very difficult to tell if they work because they may just help keep you at the same level. One symptom of liver malfunction is reduced energy thus taking something to increase energy levels may result in the levels remaining the same, thus not appearing to work, when in fact they do stop the decline in energy level.

Naturalpath Visits

I have never had a lot of faith in naturopaths, their methods or their suggestions of what to do to help with a persons ailments. As I was running out of options I

decided it would not hurt to try. The unfortunate part is that my company drug plan does not cover naturopathic medicines and they are not cheap. I first went on March 4 1999 for a one hour assessment. Lots of questions were asked followed by a few tests which seemed too simple to me. The suggestions on what to try also seemed simplistic. I had many doubts. To be fair I must admit I had no prior experience and know few people who could testify to great results. Some relatives had taken and continue to take various products but they could not claim terrific results. Another concern is that the non-traditional therapies of all kinds, herbs, vitamins, acupuncture, naturopathic methods, etc. are not regulated and thus no guarantee of any level of consistency or any checks and balances in terms of the levels of active ingredients in each herb or vitamin.

The naturopath suggested multivitamin Ester ACES (Vitamin A, C, E and Selenium). I visited this naturopath two additional times. Each time some kind of pulse check was done and she looked at my tongue. We spend most of the time talking. I felt this was a waste of my money and time so I stopped going. I continued to talk to people I know who take various herbs, minerals and vitamin supplements and I continued to take them. I feel these vitamins did help to keep me stronger, but they did not provide a cure.

I am not trying to discourage anyone from visiting a naturopath or any other type of doctor; I am simply relating my experience. I hope yours is better. My wife takes my oldest son to a different naturopath for his asthma problems. It has definitely been a help to him.

Some suggestions from the naturopath were related to diet, in particular what vegetables I eat. She said dark leafy vegetables are good for the liver, such as spinach and kale. Others which are helpful but not quite as good are beets and artichokes. Unfortunately I only like spinach so that's the one I eat. Common sense tells us that vegetables and fruit are good for us whereas pop, chips, cookies, alcohol, cigarettes are bad. The problem is to change our habits and eat healthier. Different

kinds of vegetables and fruits will stimulate different organs, so depending on your particular ailment you will want to research which to focus on. The key is to eat more of what's healthy and less junk food, in particular eat the seeds, nuts, fruit and vegetables God has provided through nature, not the stuff man has produced in the factory.

One reason the dark leafy vegetables are good for liver related problems is that these vegetables are considered antioxidants. They help the body rid itself of pollutants in our systems due to the junk in the food we eat such as preservatives, the chemicals in the water we drink and the pollution in the air we breathe. The liver is responsible for removing many of these pollutants from our bodies and thus anything we can do to help the liver is goodness, especially for people with liver related diseases. I know there are similar steps you can take which are good for other organs. Another important consideration is that anything you do which is good for your overall health such as eating more fruits and vegetables will improve your overall health. Even if it does not directly help the problem organs it will help the rest of your body which is still goodness and will probably improve the way you feel.

5. Waiting my Turn



Waiting lists

At the end of chapter 3 I mentioned I was put at the end of the 'A' list. 'A' for blood type A and at the end as that's where new transplant candidates always go. When I was listed, the end was position 27. That means there were 26 'A' candidates ahead of me. I was listed in August of 1998. The doctor estimated I would get to number 1 in about 6 months, i.e. 26 people would have a transplant or die in the next 6 months. On that schedule my turn would come in March or April of 1999. That did not seem very far away at the time. It was explained to me that being at the end of the list does not necessarily mean that you are only transplanted after everyone before you is done. It means that if everything runs smoothly with no serious complications then I would be done after the 26 people ahead of me. It's possible I could become very sick very quickly whereas the people ahead of me could all be reasonably well and can wait, so that I would get the next liver available. I would not be moved to position 1; I stay at 27 and the person at 1 stays at 1. After I'm transplanted the person who was 1 is still at 1 and everyone from 2 through 26 is where they were before. But everyone from 28 and on, i.e. the people who were listed after me will all move up one slot. In this manner no person ever moves backwards, only forward, although sometimes transplants are done and a person does not move at all, as in the case of people ordered 1 through 26 in the example above.

Being placed on the waiting list is a big step, almost a life changing step. You now carry a pager so that the hospital can call you if an organ becomes available. You are expected to be able to get to the hospital in a few hours. If you plan to travel

you need to let the hospital know. Another change is in the attitude of people you know when they realize you are on the waiting list. They are always asking if you are feeling all right, 'are you Ok?', 'how do you feel?'. This is especially true of your spouse and family. In reality this is good, they care about you; they only want the best. The problem is that you are sick, getting sicker and you probably do not want all this extra attention. At least if you are like me that is the way it is. But it is very comforting to know people love you and care about you. It is also very comforting to know people are praying for you. This is the greatest comfort of all. Elsewhere in this book I talk about all the prayer support. I truly believe that the prayer is the direct cause as to why I have done so well, both before and after the transplant.

It was a difficult decision to tell my manager that I was on the waiting list. It was difficult because I was afraid it could hurt my career. I could be skipped over for a good job because they would know I may not be around for a few months if I suddenly go in the hospital. At the same time I personally would feel bad if they were relying on me for some critical piece of work and all of a sudden I left for a few months with no explanation and the people there had no time to prepare a backup plan. At IBM the rules are that you do not need to tell you manager, but do tell the Health Services people, who interface to your manager, very vaguely. I decided to tell my him and risk the ramifications because as I said I would feel bad for the people I work with if I suddenly left and it would not be good for the project I worked on. I felt my manager would be fair and understanding and he was. You should determine how you place of employment operates and the character of your employer before you get to the stage where you are on the transplant list. Based on your company guidelines, government laws, and the personality of you manager you will have to decide how to handle it.

When I had tests to be done I would ask ahead of time for a few hours off. My manager was very understanding and that made me feel good. In fact it made me feel more dedicated to my company as they cared enough about my long term

potential that they endured some short term inconveniences. This attitude motivated me to work harder and do the best possible job I could. I think there is a message here for most employers. Employees are your most valuable resource and need to be respected and treated properly. In the long run it will pay off for the company and the employee.

Now that I was on the waiting list I was asked who my support person would be. I picked my wife Nancy of course. I will go into more depth later about a support person and what they should be like. For now I will just say that it needs to be someone you trust and can confide in with anything. Nancy is certainly such a person in my life. At the same time I was told of four lectures being held for all transplant candidates to attend. This is for all, not just liver candidates. They are offered one lecture a week year round except the summer. At least this was the case at my hospital. The purpose of the lectures is to describe some of the processes that will happen. In one lecture former transplant recipients formed a panel, told their story and accepted questions. Another lecture was on the operation itself, the process, the intensive care unit, and a short tour of the ICU. The other two lectures covered various other topics. Attendance was required and a nurse would record who came and to which lecture. The hospital takes this stuff very serious. A transplant is a very costly process. In Canada the patient does not pay for it but we still want to be sure the patient knows and appreciates what's being done for them by the taxpayers. It was at one of the lectures that a nurse mentioned in passing that there are no good books which describe the entire transplant process from pre-transplant, waiting time through post-transplant and recovery. This is what prompted me to write this book. After reading this book the nurse may still be saying the same thing, but I hope not.

Intensive Care Unit tour

I mentioned above about the Intensive Care Unit (ICU) tour. ICU is an amazing and scary place all at the same time. It is amazing what technological advances in the last 30 years allow doctors to now do. It is amazing to see the variety of machinery that the doctors have available to help our bodies function while part of the body is being repaired or replaced. It is amazing to see the variety of machinery to track and monitor a person's various bodily functions. The scary part is thinking how I will be in here soon and these types of machines will be used on me to help keep me alive during and after the transplant. I hope they work more reliably than some of the electrical devices I have at home. A power surge or chip burnout at the wrong time could be costly, to me! I guess a little of my paranoid side is coming through. One of the key ideas in the ICU is to carefully watch a patient to keep them stable, working as best as possible so the body can recover as soon as possible. The sooner the body starts recovering the sooner the patient can come out of ICU, which is a good thing to happen.

With all this modern technology it remains the Lord God in heaven who decides who will live and die. An organ transplanted from one body to another is basically dead when the transplant takes place. Once the organ is placed in the new body it warms up, the blood starts flowing which carrying nutrients and oxygen to the organ. But what makes it start working again? In some cases it does not start. In many cases it does resume its function. Live and death continues to remain in God's control.

After the ICU is the step-down unit. In ICU there is one nurse for each patient. In step-down there is one for every two patients. You are still monitored 24 hours a day and a nurse actually stays right in your room to care for your every need. After the Step-down unit is a regular room. I cannot say much about the nurses in the ICU as I was drugged and don't remember anything but I do know the nurses, male and

female, in the step-down unit were fantastic. They had excellent bedside manners and a great cheery attitude. It can't but help to make you feel better. My hat goes off to these people. It's a very demanding job and they do it well. I say all this now, but at this stage in the game I am still on the waiting list. I'm for-telling here what happens, but it's worth it as these are great people.

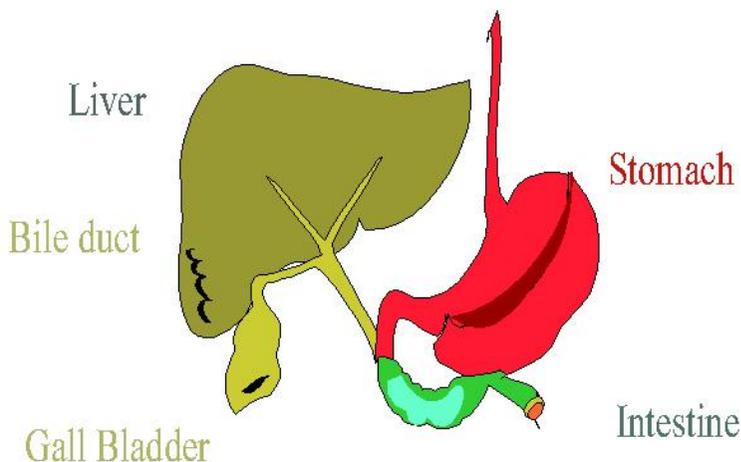
6. Still Waiting

Chapter

6

Organs before the Transplant

The figure below shows the liver and associated organs before a transplant. Compare this to figure 4 on page 43 to see what has changed. Notice something missing?



Diseased liver and bile duct. Bile duct connects to intersection of stomach and intestine.

Figure 1: Pre-transplanted organs

November 1999

November 1999 was not a good month. I'd like to take you through the details of one specific event to show the types of things and events a person with

organ problems can go through while waiting for a transplant. Sometimes these events start unexpectedly and at inopportune times but that's the way it goes. In fact I don't think there is any opportune time for complications.

November 7th at 9pm I was feeling a lot of pain in the area of my liver. It's hard to explain as the doctors say there are no pain nerves in the liver itself so you should not feel pain directly in the liver. So I cannot explain it but I do know the pain was real and it was not fun. At 11:30 it was so bad I went to the local hospital to see if the doctors could determine what was wrong and what could be done to alleviate the pain. After waiting a few hours to be helped I was taken to a room, asked a lot of questions and left sitting there while the nurses and doctor talked. I could hear them in the hallway talking about me. They were discussing the various drugs I take for the colitis and liver problems. After about 1/2 hour the doctor comes back in and asks me what two of the drugs I take are for, what do they do. I explained to him the purpose of each. He then took me to another room where I lay on a bed for another 90 minutes at which time the doctor came back in and said there was nothing they could do. I should go to see my specialist the next day. At 4am I went home. Fortunately I was feeling a little better by this time and being so tired now I could finally sleep. This did not instill a lot of confidence in me, in the local hospital's ability to deal with my particular disease and possible complications which could arise while waiting for the transplant. My wife and I decided that from now on when (or if) problems arose we would go directly to the hospital which does have the knowledge and skills to treat me. A further blessing which I did not realize until later was that God had placed us in a city where an appropriate hospital was close by. One woman I later met was from Ottawa, about 5 hours drive from Toronto. Whenever she has complications it's a long way to travel to see the specialist. TGH (Toronto General Hospital) is one of only two in Ontario which do organ transplants; it is also the closest to Ottawa. Now, in 2007 there are more transplant centers.

In addition to telling the doctor what the drugs I take are for I also had to explain what PSC, Primary Sclerosing Colongitis was. The fact the doctor did not know of my particular disease was discouraging but I cannot blame the hospital or staff. It is not a common disease and this hospital was not designed to deal with this special problem, so the doctors and staff had no need to be able to deal with this particular disease. My wife gave birth to our two youngest children in this hospital and those events went well, so we have no complaints. Even the waiting time was not a big deal. Going in the middle of the night obviously means there are less staff available to deal with the problems that come in. Serious problems are dealt with first and those less serious, or at least those which appear less serious, are dealt with later.

Later that day I called TGH. They scheduled an ultrasound for Nov. 11th. The ultrasound showed no bile duct blockages but that the walls were continuing to thicken and restrict the bile flow. The doctor gave me pain pills, Tylenol #3 and said if they did not help he could give me a stronger pain medication, but there was nothing they could do to 'fix' the liver to remove the pain. It is not uncommon to feel such pain in this disease and sometimes it remains stays until the liver is transplanted. Other times the pain just goes away. The specialist said the pain is caused by the liver swelling due to inflammation of the bile ducts. This swelling causes the liver to press upwards on the diaphragm. This pressure on the diaphragm is causing the pain I am feeling.

By November 12th I cannot lay down; when I do the shift in liver positioning in my abdomen causes so much pressure on the diaphragm that I immediately must sit upright again. The Tylenol pain pills help the regular pain I feel but not the pain when I lay down, thus I do not lay down anymore. I sleep sitting upright or at most about a 45 degree angle. As I am not a very heavy sleeper under the best of conditions so I found this time to be very trying. Walking around, working, dealing with the children can be very difficult when you are in pain as well as constantly tired. The next day I slept half the day making me feel much better.

By Nov. 14th it was getting more difficult to do simple tasks. Climbing the stairs at work from the first to third floor was very painful. Just two flights of stairs cause me to breathe a little deeper than normal walking. By breathing harder the lungs expand and put additional pressure on the diaphragm thus the additional pain. I still cannot lie horizontal. By Nov. 17th I could not bend over to tie my shoes, Nancy had to do it for me. It was hard being around people at work. Someone tells a joke, I laugh even though I try not. I learn the hard way how the laughing causes your internal organs to gurgle around, including the diaphragm causing pain. Tylenol #3 does not help any longer. I don't want stronger drugs as I think they will affect my ability to think straight and thus to work. As the pain increases I feel it spread to my right arm and neck. The doctor says that the right upper body nerve center is all connected thus pain in the diaphragm can also be felt in the right arm and neck. Sometimes my right arm would feel like it was tingling. It was hard to lift and hard to turn my head.

November 18th Nancy and I went shopping for a reclining chair in which I could better sleep at night. The pain and inconvenience was getting worse so we were preparing for the long haul as I was far from the top of the waiting list. With a reclining chair I could find a position where I was not sitting up and also not laying flat; a position where I could hopefully sleep with little or no pain. It is wonderful to have caring, thoughtful in-laws who decided to purchase the lazy boy chair for us as an early Christmas present. That very night I slept better that I had in over a week.

The next day, even after a relatively good sleep I still cannot tie shoes, Nancy came to my rescue again. A new twist today occurred when I tried to lift Lyndsey, my 4 year old daughter. I took her under both arms and lifted straight up. I got her about 2 feet off the ground, lifting her towards my hip to carry her, when a great stabbing pain shot through my side and I had to put her down immediately. Despite the new chair yesterday this was a sad day. It's amazing how little things you take for granted are suddenly missed when you can no longer do them. Be aware of this if you have someone dealing with this type of

problem. It can be very frustrating and having someone offer to help is nice but does not help you get over the feeling of your newly discovered inability to do some simple tasks.

I started to have nose bleeds every 3-4 days. I could be sitting at my desk, watching TV at home, anything and all of a sudden my nose would start bleeding. I would stuff it with tissue and five minutes later it would stop. I told the doctors who checked my blood clotting. It's still pretty good so it's not serious, but a hassle, especially at work. I worry about sitting in a meeting, which are numerous, at work when it starts to bleed. I try to keep a low profile and not draw attention to myself but a nose bleed would draw some. But God has been kind yet again in that it never once happened at an inconvenient time.

Even though I am sleeping better in the reclining chair I am still tired a lot and always in pain on my right side. Pain and constant tired feelings play havoc on my physical relationship with Nancy. Sometimes, when not too tired there is the mental desire but there has not been the physical desire for a while now. Maybe this is where the 'mind over matter' phrase originated! The mind is willing but the body is not is very responsive. I really appreciate the few good days now.

This difficult period is the first time I really look forward to having the transplant done. Up until now I have felt relatively good and healthy so not in any hurry for a transplant. But now I am actually looking forward to getting it over, healing and getting on with life. I think this is a critical turning point in a patient's mental state, where they realize that the disease is real and severe; that an organ transplant is necessary and the sooner the better. This can also affect your attitude, where you look forward to the transplant in a positive state of mind instead of a resigned state, where you know you have to go through with it but don't really want to do it.

By December I had moved to position 12 on the waiting list, from 27 when listed 15 months earlier. At this rate I could expect another year wait. That would be over two years while

the doctors had first estimated about 6-8 months. Can I stand this pain for a year? I've had it for about a month but fortunately now it is gone, I just pray it stays away and my life can get back to 'normal', I can sleep in bed again with my wife. I can lay down but not on my right side, but it is a big step forward. Thank the Lord again that many people were praying for me and the pain never came back!

February 22, 2000 the next specialist appointment. The main discovery was that I moved on the waiting list from 12 in December to 8 now. The doctor now says my turn will probably be around Easter, in April. To me this means it will probably be around the May long weekend, a month later, but in the foreseeable future. There is still a lot of prayer for me. Health is pretty good now, just tired all the time, but still able to work and do some stuff at home and church, but I'm cutting back slowly. Nancy is doing more at home. She is a great woman! I have not been exercising since the November pain and do not really expect to start again until after the operation. I still hope to be able to ride my bike to work and back in the spring. The trip is about 18 kilometers each way.

The changes to my life have been quite significant over the past few months compared to the previous years of problems. The earlier problems were always very short term; I would feel bad for a day or two then be back to normal. But now the problems are lasting longer and leave me weaker when the problem does eventually go away. Nancy and I have decided we will not plan any vacations now until the transplant is complete and I've healed sufficiently. One reason we have decided this is that I am now getting closer to the top of the list. I have been carrying a pager supplied freely by a pager company called LifePage, to the hospital who gives them to patients. The purpose is to allow the hospital to contact a patient at anytime when an organ is available. The downside is that you must remain in a 2 hours driving radius of Toronto. This makes it impossible to travel anywhere except my parents. It really did not matter as our types of vacations are active and I have not been feeling very active lately. If you are dealing with a person waiting for a transplant of some sort

please be sensitive to their constant health problems and thus limited desire and abilities.

April to June 2000

April 15, 2000 has come and the situation continues to slowly worsen with more yellowing of the skin and eyes. Kids and some adults are staring now. A few children at Matt and Lyndsey's T-ball games asked me what was wrong, why my eyes were so yellow. One boy even asked if I was a vampire. I just chuckle and say 'I'm a little sick right now' and they go away contented. I think people at work wonder what's wrong, but say nothing. Some know as I've told them where I think appropriate, i.e. those I work close with. Skin is getting itchier with some scabs from scratching, mostly on my legs. Arms and legs ache a lot by evening. Get pains in my neck and upper right torso but not near as severe as last November.

The next doctor appointment was in May 2000. Easter is past and I'm still waiting. Doc. says I'm now 4 on the list, so probably end of June, missing his April guess and even my guess of the May long weekend. But I am thankful I'm still healthy enough to keep working a regular work week. Some days I'll be very tired and sleep for an hour at lunchtime out in the van, or if it's a really nice day I will lay on the grass and rest. I do not do much at home in the evenings and go to bed very early.

Sunday May 7th, 2000 Nancy and I were interviewed by Patricia, a reporter with 'The Toronto Star' and Andrew a photographer. She was writing an article about transplants. The goal of the article is to educate people of the seriousness of transplant operations and how many people either die while waiting or die during or shortly after the operation. An ulterior motive is to tell people of the importance of organ donation due to the shortage. It's a hard issue for many people to decide on. They have to face the fact that they could die, and decide that even in death they can help some other person or persons.

One person's death which leads to their organs and eyes being donated can help up to seven others to live. To be quite blunt, a dead person has no need of the organs any longer so why not help someone else? Twelve people were chosen by doctors from TGH and the Toronto Sick Kids hospital. I was one of those chosen. There were liver, heart and lung patients, five of which were children. The other liver candidate was a young woman about 20 years old who has the exact same liver disease as I, including the colitis. The difference is that she has been very sick, at home or hospital in bed all the time for the past five months. I feel sorry for her and at the same time use it to again remind me that I have much to be thankful for.

The following week I went for a vitamin K shot. Vitamin K helps with blood clotting, an important process when one undergoes an operation where a lot of cutting is involved. I felt like I had the flu for 2 weeks after. My eyes are really yellow now but the itchiness of my skin has left; strange how it all works. Probably because so many people are praying for strength and endurance until my turn comes up. I am riding the bike to work less now as it's such a draining process. I feel tired already in the morning and riding makes me feel that much more so.

June 6 I went to visit a friend of my mother-in-law who had a liver transplant 9 days ago. She's in TGH, 10th floor, same doctor as me. I also used this trip to the hospital to take in the photography consent form, allowing the newspaper photographer permission to take photographs of me during the operation. I stopped by Dr Lilly office to see where I was on the waiting list. He says I'm now number 2. I just happened to stop by when a new patient was in his office getting prescription for some drugs I take, scheduled for an ultrasound and a few other tests, the same ones I went through. He also has PSC. He did not know anyone who has PSC; he does not know what to expect. He was very happy I talked to him for 1/2 hour about what I've been through. We have many things in common: yellow eyes and skin, itchy legs, upset stomach. We exchanged phone numbers. God's perfect timing kicked in so that I 'just happened' to be there when he was so we could

meet and I could encourage him; I could help him with his fears about the unknown. Little things like this make me feel better; they help me realize there is a purpose to everything that happens, that good can come from something which seems bad.

I meet with the woman mentioned above. She felt she would never get out of hospital for the first few days, being in great pain. Now 9 days later she's very positive, doing exercises for stomach and lungs. It is painful but helpful. She is taking 17 pills for breakfast plus a few liquid things. She does not enjoy the drugs as they screw up your mind. I've already told Nancy to forgive me for things I might say while my mind is mush. Her stomach is full of staples. I thought it would be just normal stitches! Now I can look forward to the pain of having them removed. I guess that will be nothing compared to the operation, except that I sleep through it all. It was great to talk to a person who is just now going through it, remembering first hand what it's like.

I am feeling a little nervous now. Today is June 10th and I realize I'm TWO on the list. It's getting really close; could be any day. The man ahead of me should have been done but missed his pager call, so they took next person. i.e.. he was 1 and I was 3, so they took 2, now he's still 1 and I'm 2. Now is time to make arrangements at work for people to pickup what I'm doing. The biggest concern is my department, most of whom are fairly new. We are going through a heavy work period and they need direction. On the good side is the opportunity for my team lead to pickup the challenge and shine as a person able to take over in times of trouble, or sink and someone else will step in and take over.

Sunday June 12th is the annual Heel & Wheel a-thon. This is a fund raising event for the Crohn's and Colitis foundation, raising funds for research into the cause and cure of these two diseases. This year all of the family except Lyndsey is participating by riding our bikes. Although it was a leisurely ride at a slow pace as Matt is only seven, I still found it very tiring. Later that day I said to Nancy that I would not be riding

my bike again until after the operation. This really surprised her as she knows how I like to ride.

7. The Transplant



*"Mr. Van Gennip, we have a
liver for you"*

Monday June 19th 2000, a regular Monday, work-wise. Not overly busy so I left at 4:45pm. I backed the van into the laneway at 5:15pm. As I was getting out of the van Nancy brought me the portable phone. She said the hospital is calling. "Mr. Van Gennip, this is the MORE office" the woman on the phone said. "We have a liver for you". MORE means Multiple Organ Retrieval and Exchange, which is the group at Toronto General Hospital who are responsible for coordinating the retrieval of organs and ensuring the person to receive the organ is available and in a state they can undergo the operation. "Do you have a cold or flu at this time? Do you have any infections or cuts?" she asked. I answered I was in good health. "When did you last eat or drink something?" I said at lunch time and a drink of pop around 3:00pm. "Can you please come to the hospital in the next hour and a half!" OK I said. This is it!

So it has begun. I picked up the list of people to call to notify the time has arrived. I called a few, Nancy called the rest. Nancy called her parents to come over to take care of the children. I went and had a shower and shave, as I suspect I won't be able to for a few days or a week. On our scale I am now 160 pounds exactly. I packed a few things like toothbrush, socks, pajamas, Bible. Two hours after the call Nancy and I were at the emergency entrance to the hospital, checking in. This was a very rushed time so we did not have a lot of time to worry about what was coming. The hardest part was saying good-bye to the children and in-laws. Robert, nine years old, understood what was happening the best. Matthew

who is seven either did not understand or did not want to face it and ignored what was going on. Lyndsey, only four, knew I was going for the operation and wanted to pray for me. She did and then said she wanted to come visit me in the hospital. Being so young I don't think she really understands the severity but she is the one who realized the most important need at that time was prayer. As this is a very serious operation there are always risks, and it is at the good-bye time that I started to think I may not come through this. I may never see them again. This was a difficult time to face. Trusting in Jesus and knowing He has everything under His control is both the truth and comforting but there is still the unknown from a human standpoint about what's going to happen.

After checking into the hospital I was sent to the 10th floor, home of all the transplant patients, to my room. There an intravenous was put into my arm, although it was not used. Blood pressure, temperature, weight were all taken. The surgeon came in and talked briefly to us. They planned to start at 6am Tuesday morning. A team was out now retrieving the organs. During the night the liver would be checked to ensure it was in good shape. The operation would be from five to eight hours in duration. I would spend tonight night in the hospital.

Around 8:30pm, only about half an hour after I got into the room, pastor Gord walked in. This was very surprising as we had just got there shortly before. His visit was very encouraging; the fact he would drop whatever he was doing to come down on his time to visit was touching. We talked a little and he prayed for us. Gord was very thoughtful in that he did not stay very long; I was not very talkative anyway. This brings up two important points, the first being the power of prayer as mentioned throughout this book. The second is that if you are visiting someone either just before an operation or even after, be considerate of the patient and the patient's wishes regarding how long you can stay. They may not want to talk but just be quiet. They may be tired and want to rest. Try to be aware of the atmosphere and act accordingly.

Nancy decided to go home as there was nothing to do now but wait. If they start at 6am and it takes at least five hours then she would be back until 11am, so that's what we decided to do. She left around 10pm. Just before midnight the nurse came in to clean out my system. I have had no food since lunch twelve hours earlier and nothing to drink for nine hours now. The only thing left was to clean out my colon. So two enemas over the next two hours and a third one early Tuesday morning cleaned me out pretty good. I was ready.

False Alarm, Home again.

Fortunately I did not have to go through a false alarm so I cannot say exactly how it would feel but I am thankful I did not have to go through one. You would spend the night in the hospital, go through the tests, IV, enema's, restless night, calls to friends and family, arrangements for children, possibly for work as well, and then to hear "sorry but the liver is no good, you can go home, we will call you when another is available." This would be a huge disappointment, especially if you were sick and eagerly awaiting the transplant. The doctor had told Nancy and I about false alarms and how stressful and disappointing they can be. They try their best to ensure it does not happen, but sometimes it does.

While I was in the hospital I heard that a person one or two after me on the list got the call to come in for a transplant but was sent home again, then a few days later got the call again and again was sent home, then the third time everything was OK and the transplant done. It's something to be aware of; realize that it could happen and mentally prepared to not let it bother you too much if it does. You are not missing your turn or losing out in any way, it will just taking a little longer. Be patient with the doctors, they are very cautious about the liver they are giving you. The caution is in your own best interest. They only want to do this transplant once so it is best to do it properly the first time, and you probably only want to go

through it once. If you are transplanted with a bad liver, one which does not function when connected to your other organs then you are in serious trouble. You need to receive a good replacement liver in about two days or you will die. Thus it is much better to be sent home again than receive a bad liver.

This is It!

Tuesday June 20th 2000, 6am. After a short restless sleep last night I'm wide awake, waiting for the doctors to come get me. Around 6:45 a nurse comes in and says the operation has been delayed to 8am, they will come for me about 7:30. Around 8:30 I'm taken down to a waiting room where all the people having operations that morning are waiting. There are about twenty patients in beds and family members in this room. I am one of the last ones to arrive.

Over the next hour a whole series of nurses and doctors come by to introduce themselves, ask me questions about tests done, how I feel, when I last ate or drank. They tell me who they are and what they will be doing. I sign the consent form for the operation. Everyone except two other patients are taken away when my turn comes up. I walk with the doctor to the operating room.

In the operating room are about eight people. I remove the hospital gown, no time for modesty now, and lay on the table. They cover me with a nice warm blanket, hook a pulse monitor to a finger and finally connect the IV inserted the night before to some liquid solution. I'm out. I don't remember falling to sleep; I don't remember anything of the operation. The next thing I remember is waking up in intensive care with an incredible thirst. All I can think about is how thirsty I am.

I am liver transplant number forty-five for the year 2000 at the Toronto General Hospital. I am recipient number 854 in the history of transplantation at this hospital.

Figure 2 below shows me in the intensive care unit with all the connections just a few hours after the operation. It's not a pleasant sight for a family member to come in and see but at the same time is amazing at what technology and the medical system can do these days. What's even more amazing is how God has designed our bodies to be hardy enough to endure such severe trauma, heal and continue to function properly at the end of it all. The pink lines were added to the picture to show the incision which is hidden by the bandages. The black circles show the three JP (Jackson Pratt) tubes used to drain fluid from my abdomen. The two outer JP tubes are a few inches long while the in the middle is about six to seven inches long. It goes up over my liver to drain fluid collecting above it. There are EKG pads and wires stuck to various points on my body. An IV line in each arm and one in each side of my neck as well as a heart monitor wire inserted into my neck and down into the chest area. A tube runs through my nose into the stomach and a respirator in my mouth, down the throat and into my lungs. Lastly a catheter is inserted into my bladder as I certainly will not be walking to the washroom in this state.



Figure 2: Ed a few hours after the operation in ICU

What Really Happened

As I was asleep during the entire operation I cannot tell first hand what happened. I will relate what Nancy experienced and what the doctors told her.

The operation actually started at 10am, expecting to be five to eight hours long. Nancy arrived around 11:20am, later than planned due to traffic on the highway; she was not informed of the time change and thus assumed a 6am start. She waited in the 10th floor lounge as it's nicer than the operating room waiting area. At 12:30pm Nancy went to the 2nd floor, where

the operating room is located to ask on my status. At 12:45 a message came out that the operation would not be complete until about 6pm. This is six hours later than expected. Nancy was very concerned about what was taking so long. 1:05pm, pastor Bryan from our church came in told Nancy the nurse would be down soon with an update. 1:20pm a nurse named Anna came out. Nancy's sister Jean was there waiting with her. Jean knows this nurse through a common Christian friend. The nurse is also a Christian. Nancy found this to be reassuring; to have someone known working on me. God is always in control. Anna reassured her that everything was going well. Nancy now found out the operation started at 10am, not 6am, thus the delay. Plenty of time for lunch for Nancy and Jean.

At 2:30pm Nancy went to Dr. Lilly to see if he had any information on my liver from pathology. There were no results indicating the liver had not yet been removed or analyzed. One comment from the doctor is that it is understandable since a PCS patient's liver generally has to be "peeled out" of the body. He looked at my last blood test. The bilirubin count was over one hundred, very high, so it looked like I would have been having more problems any day if I had not been having the transplant. Again God's timing was perfect. Time remains for a little walk in the park.

At 4:45pm Nancy and Jean went back to the second floor waiting room to check my status. No-one from the operating room could come down right now as there were only two nurses and they were busy. They now "expected to be finished at 8pm due to some unanticipated difficulties but everything is going fine now". More anxiety! What's happening? Why the further delays? What unexpected difficulties? Back to the tenth floor lounge. At 6pm Dr. Grant, the main surgeon came up. He had to leave town for an engagement thus turned the remainder of the operation to two other doctors, both well qualified. He said "everything went well but they had difficulty with the portal vein. It had clotted (was blocked). The doctors had to get a new piece of vein from the 'vein bank' to connect the liver to the portal vein behind the blockage." He also

mentioned that I was hard to work on due to my thin frame. There is not a lot of room inside me to work. Dr. Grant said one in fifty livers just don't work after being connected; one in twenty requires additional surgery due to bleeding. I believe Dr. Grant was preparing Nancy for possible complications that could arise due to the portal vein problems. The portal vein is located behind the liver where it is not easily visible on an ultrasound and thus not detected in the tests before surgery.

6:10pm Nancy saw Dr. Lilly in the hall and she asked him about the portal vein. He said this is quite normal in PSC patients. This was unanticipated because it was not visible on the last ultrasound. It is also a possible reason for the pains I had been feeling lately. He also said the chances of the new liver working is very good as the liver was coming from a young person in their 20's and the fact that the MORE team had traveled last night to get the organs (not just the liver for me but lungs, heart, pancreas and kidneys for others). The MORE team is very skilled at organ retrieval without doing any damage to the organs. Again God has provided wonderfully. The reason the MORE team flew to get the organs is that a pancreas was also donated. Only the MORE team is qualified to retrieve a pancreas, and thus they retrieved all the organs. He also said another liver has just come available. So if my new liver does not work by morning then I would get this other liver, before it would be given to anyone else.

At 8:30pm I was moved from the operating room to intensive care unit (ICU), ten and a half hours after the operation started. At 9:10pm Nancy called ICU. They were giving me a bath after hooking up all the machines and hoses. 9:40pm Nancy finally came into the ICU to see me. Nurse Maureen who was responsible for me said I was doing very well, "the better a person is going in the better they are coming out". I had a slight fever, a little blood in my urine; normal, but will be watched. Also some blood in the fluid draining from my abdomen. I opened my eyes while being setup in ICU which is a good sign but they will keep me sedated for a while to ensure I don't try to pull the tubes out. The respirator will also be left

in until morning. During the operation only one unit of blood was needed as some of my own blood was recycled. I could probably be moved to the step down unit tomorrow afternoon, that's Wednesday afternoon. Thank-you Lord for your loving care for Nancy and I during this long, arduous day.

A few days later I realized that Andrew did not take pictures during the operation. I remember him being in the operating room with me when I entered. But then while they were undressing me and getting me ready I assumed he left, to return when I was settled on the table. I found out that he did not return as the doctor's were not aware it was planned for him to be there, so they did not allow him to stay. I guess there was some miscommunication or forgotten communication between the hospital staff who arranged for Andrew to take pictures and the doctors. At least Nancy got a few pictures of me in intensive care. She did it at my request as I wanted to see them. She did not really want to do it, but as I was not going to remember much, if any of it, she indulged me.

The Day After

Figure 3 shows all the tubes and stuff in my body when moved into the intensive care unit. A respirator down my throat to pump air into my lungs; a tube through my nose into my stomach to empty it; four IV lines, two in the neck and one in each arm; a heart monitor in my neck; three Jackson Pratt (JP) drains in my abdomen area to drain away the fluid buildup; a catheter to allow and monitor urine flow.

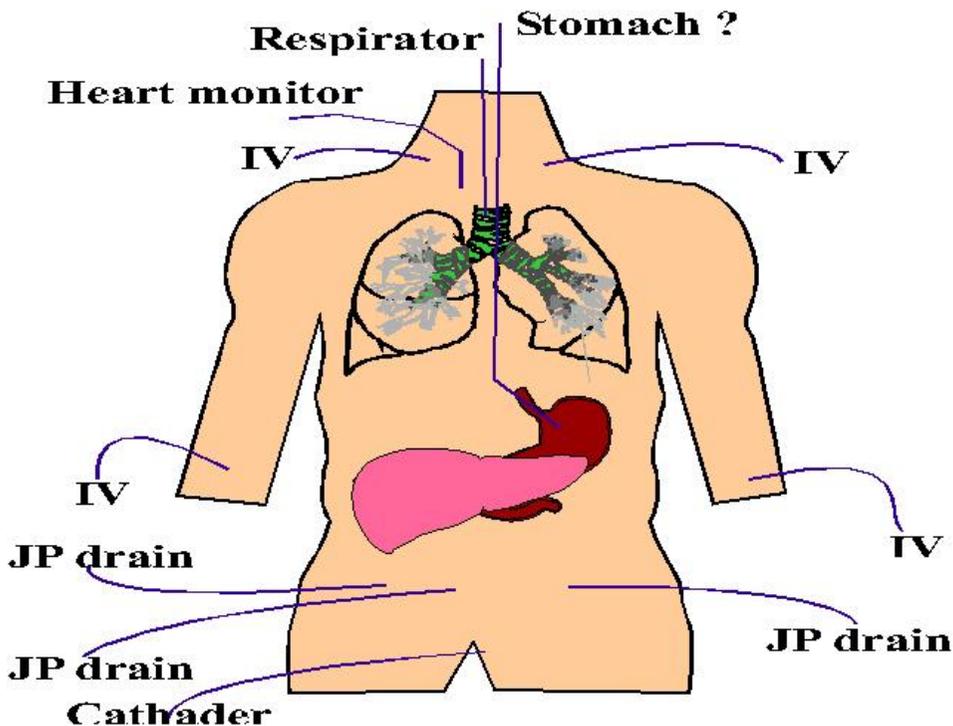


Figure 3: Medical intervention to assist the body in healing

Wednesday June 21st, 2:30am Nancy was home again. She called Maureen, my nurse in intensive care to check how I am doing. Maureen says my fever is gone and clear fluid is now draining from my abdomen, both good signs. She says I am starting to wake up and want the respirator out of my throat. They are keeping me slightly sedated to keep me calm. The tube can probably come out in the morning.

I don't remember anything about the intensive care unit except that I was so thirsty, my mouth and throat so dry. I don't think I was pulling at the respirator to get it out but to signal the nurse that I was thirsty. It really did not matter because I could not drink with the respirator in, so the nurse wet my lips with a moist sponge, many times.

At 11:40am Nancy and Jean were back in visiting. I was still in intensive care but was awake and sitting up talking, the respirator has been removed, hooray! I was still very thirsty

and sucking on ice chips. Brian was my nurse today. He told Nancy that he had never seen a liver take so well. Thank you Jesus, another answer to prayer. At 12:30pm my parents come to visit. My mother cannot believe how well I look and that I'm awake. I start feeling some pain so my morphine dosage is increased. Looking back I do not remember Nancy or my parents visiting; I do not remember Brian or the intensive care unit.

Blood work is being done every four hours and my enzyme levels are looking better. The doctor's start reducing some of the drugs which are hard on the kidneys so they can introduce prednisone which is a little easier on kidneys and helps reduce swelling. Of course it also has side effects but hopefully the lesser of two evils.

The Step Down Unit

Wednesday June 21st, 3:45pm I am moved from intensive care unit to the step down unit. So instead of my own private nurse I now share a nurse with one other patient. I discover later that this patient, Florence had a kidney and pancreas transplant at the same time as I had the liver. We are the same blood type and thus we suspect we were transplanted from the same donor. Nancy says I'm a little apprehensive but I don't remember why. About eighteen hours after I was put in intensive care I was taken out and moved to the step down unit. Nancy called at 10:45pm and talked to me. I started blowing in the air chamber to work my lungs to ensure they do not get congested, infected or collapse. I was pitiful, had no power at all. I could not take deep breaths or hold them. My heart rate is a little faster than normal but an EKG says it has normal rhythm so it's not a big concern. I'm still always thirsty. Nurses are great at getting me water and ice. They say I should not drink too much, and I try not to but I am so thirsty it's hard not to drink. The nurses in the step down unit are great, very friendly and upbeat. Their

presence makes you feel better just because they are happy. They have great personalities for the jobs they do.

I've been thinking about how great is this country of Canada in which I live. I have spend a lot of the time in doctor's offices for almost two years before the operation, for consultations, tests and more tests. Then the operation itself with all the equipment and staff involved. The intensive care unit space and equipment and nursing staff, now the step-down unit are all expensive. Then I consider the future and the ongoing costs of tests and monitoring for the rest of my life. An incredible cost is accumulating and I don't have to pay for any of it. In most countries of the world I would probably have died by now because they could not treat my disease. Other countries which could treat it would do so only if I could afford to pay for the costs, which are probably getting close to one half million dollars over the past two years and these last three days especially. I don't think I will ever complain about our medical system and will defend it against those who do complain. As with any operation there are areas for improvement and ways to reduce costs but from what I've see so far the transplant program is run very effectively and efficiently.

Sleep was terrible, as it will tend to be for a while. I sleep for an hour or two, then wake due to noise or having to urinate or a desire to change positions. It seems that most hospital work such as cleaning and restocking is done at night, thus the noise. Trying to change positions was a constant challenge due to the fact I could only lay on my back and turn a little to the left of right. Even turning was hard with all the tubes in me. A nurse would come by a couple times during the night to take blood pressure, temperature and such, more disturbances. I guess not sleeping well at night makes it easier to nap during the day, which I did a lot.

7:00am Thursday June 22nd I stood on the scale, my first time out of bed. Boy was I ever slow, but at least I got up and was stable enough to stand without losing my balance, even though I did feel a little dizzy. I sat in the chair a few times today and walked to the room's door and back once. I could have walked

farther but I was tired before I even started because I had to stand for three or four minutes while the nurses untangled all the lines in me so I could move away from the bed.

I had some Jell-O, peach juice, ginger ale and soup (liquid only, no solid stuff yet) for lunch. This was a nice change from water which is all I'd had so far. I've gained 5 pounds in weight even though I have not eaten any solid food for three full days, and other than water I have not drank much either. The five pounds was all fluid retention in my abdomen and legs. This didn't look bad on my legs as they were so skinny to start with. Mom and dad came by around noon, Jean about 12:30 and pastor Gord at 2. Lorne was in sometime during the afternoon as well as pastor Cal around 6. A busy day of visiting and fortunately no-one stayed long. I found it difficult to talk, running out of breath quickly. I could say about one half a sentence then had to stop to get a breath and continue. This provides another reminder for visitors to be sensitive to the patient's situation. You may have traveled a long way to visit but they have been through a life and death experience. The patients needs are more important than your feelings. Another thing I noticed which was minor but a discomfort was that I was always hot. All I had on was the blue hospital gown, no sheets or blankets, and even then I usually had the gown off my shoulders, legs and chest; it just lay over my private areas. The others in the room did not seem to find it hot as they had sheets and blankets on, so I couldn't complain. Even at night I was always hot. I'm just a warm blooded person I guess.

Nancy called the next morning, Friday June 23rd. The kids were all eager to talk to me. School was over yesterday so they are home now for the summer. Lyndsey could talk and talk for hours if we let her, Matthew was very quiet, I think he missed me and quietness is his way when he is sad, but he was smiling when he heard my voice. Robert talked a little, he too was quiet, always is, but he wished I get better soon.

Two of the tubes were removed today, leaving one drain in. I'm still oozing from one of the removed tube holes as well as the tube still in. The bandage over the incision is removed. I

have the Mercedes cut, named that way as it looks somewhat like a Mercedes symbol. It's a little scary to look at it and see how long the cut is, from half way around to my back on the right side to almost half way around on the left side and a four inch vertical cut in the middle, just above my belly button to the bottom of my rib cage. Sixty-three shiny staples holding me together! My ankles are a bit swollen today and I have gained three pounds, all fluid buildup. My vision is a little foggy so I'm trying to cut back on the morphine hoping this will help clear it up.

Around 5:30pm Patricia, a reporter for the Toronto Star newspaper called saying I was a 'superman'. She couldn't believe I was already out of intensive care and in the step down unit. To her this is a testimony of my faith in God and His power to heal. She is thinking twice about 'faith'. She was thoroughly amazed. She would like to get some photographs of me and the family but the kids cannot come in yet to see me, especially Lyndsey as she had been exposed to chicken pox a few days ago, so the pictures will have to wait.

Before the operation Dr Lilly had said the record time for a patient having a liver transplant to the time they were discharged was 7 days. My goal was to beat this, to get home in six. Although everything is going very well I'm starting to think I will not break the record. In fact I no longer care if I break the record. I just want to heal properly taking whatever time is needed, but no longer than necessary in the hospital.

I called Nancy at 10:30pm to wish her a good night sleep, to say 'hi' and 'I Love You'. I'm very tired, going to try to sleep myself. I ask for a few things for tomorrow, like toothpaste, razor, shampoo and socks. Now that I can get out of bed a little I think I would feel better if I had a shower and shave. The nurse gave me a sponge bath but it is not the same. Also the one hole from the removed JP tube has been leaking all day. The nurses are very good about changing the gauze and dressing but it's leaking, almost flowing so fast that they cannot keep me dry, so the fluid runs down my side and onto the bed. They have changed the bed a few times as well, but

within an hour it's getting wet again and I have to lay in it. Personally I think they should have left the drain in a day or two longer, just as they have left the other drain in, but they didn't. It's really not a big deal as it's not painful or anything, just mentally it's not pleasant to think about lying in this yellow fluid draining from my stomach.

I sat in a chair for about six hours today; four hours around lunch and two hours after supper. At the time it felt nice to be out of the bed but the next day my abdomen was really stiff and sore. I think I was upright a little too much. One needle was removed from my neck and an IV line was moved from my right arm and connected to remaining IV in my left arm.

There are four patients in the step-down unit. Myself, a woman who had a pancreas and kidney transplant, a woman who had a double lung transplant and a man who had a kidney transplant. Today the double lung transplant was moved out and a young girl, 19 or 20 I'd guess was moved in. Her name is Robin. She had a liver transplant on Wednesday, the day after me. Robin received the liver I would have received had my new liver failed to function properly. I'd never met Robin before but I know of her through a mutual acquaintance. Robin has the same two diseases I do, Ulcerative Colitis (UC) and Primary Sclerosing Colongitis (PSC). The difference being Robin's UC was much worse and she had previously had an operation to remove part of her colon. Now the PSC was at such a serious level that a new liver was needed. She had been in and out of the hospital all year due to poor liver function. She looks so weak and frail. My heart goes out to her for all she's already been through and now she faces the long road of recovery from the liver transplant. I feel so fortunate for the relative good health I have had while waiting for my transplant.

The Floor, out of Step Down

Nancy heard the donor was in their early twenties. We don't know how the person died or whether it was a male or female but we are very thankful for the donor and donor family deciding to donate the organs. Think about what it means. Donating a liver, two kidneys, two lungs, a pancreas, a heart, probably two eyes, with each of these going to different recipients' means up to seven people could have vital organs replaced and one or two people could regain their sight, all from one donor. There can be good come out of any tragedy when we add God's supreme control to this, where he brings the right donor and recipient together at the same time with the right doctors and nurses and everything runs smoothly. So many aspects of the whole process have been prayed about and they have all come together better than we could have wished. For example, most people (80%) have at one point or another contracted the CMV virus. It has nothing to do with how healthy you are. It has flu like symptoms but is not serious. I was tested and found that I have never had this virus. Nancy prayed that the liver I would receive would be from a donor who has never had the virus. If the donor had the virus then I would probably get the flu like symptoms after the transplant and although it's not serious it would make the recovery a little longer and more difficult. It turns out the donor did not have the CMV virus. This is another answer to prayers and demonstrates how God brings the right people together at the right time. As an aside, the backup liver which went to Robin did have CMV, Robin had not had the CMV virus and thus unfortunately she was sick.

I was moved to a regular room Saturday morning, tubes and machines trailing behind me. I took a sleeping pill from the nurse but still did not fall asleep until some time after 3am. I was awake at 6:30 again so the nurse gave me a sponge bath. My stomach is very sore today, but as I've been trying to cut back on pain killers it may be that the pain is the same, I just

feel it more now. The JP is still draining a lot of fluid and one of the holes where there was a JP has not healed and thus is also still draining. Nurses change the dressings frequently but it still keeps leaking through. Nancy and Robert my oldest son came to visit around lunch. Robert has always been interested in machines and how things work and today was no different. He was happy to see me and fascinated to see the staples in my stomach.

Another line was removed from my neck and the IV's removed from my left arm, but the IV line was left in. They are still using this line to give me liquid prednisone injections. It's nice to have the lines removed even if the needle remains. The catheter is also removed today. Boy does that feel nice. I feel more mobile. My meal's now include milk, ice cream and milk-shakes. I think they are trying to get some calories into me. I have to record all fluids going into and out of my body on a chart. I have now gained fifteen pounds since arriving five days ago. The skin on my feet feels really tight and my feet hurt a little when walking. When walking weight is now placed in parts of my feet where there is usually no weight. I starting to feel and hear gurgles in my stomach or intestines, which the doctors say is good news. It takes a while for the intestines to start working again. Five days now and no bowel movement, I suspect that first one, when it comes will be fun!

Very little walking today due to the constant leaking fluid from abdomen. As soon as I get up it start to drip onto the floor. Nurses don't want me walking around leaving a trail of fluid behind me. At 7:30pm a doctor puts a stitch in the one JP hole which is leaking and a nurse gets the idea to put an ileoscopy bag over the other hole. Now the fluid collects in a bag hanging on my side and I can drain it as needed. I feel better now and have my first shower.

There are four videos that transplant recipients are to watch before leaving the hospital. Nancy and I watch the first one today. The videos relate to organ rejection after a transplant, infection, drugs and living a normal life again. I've been inhaling from a lung exercising device. It's amazing how weak

my lungs are after only a few hours on a respirator and how hard it is to take a deep breath due to the strain on the abdomen. I'm getting a little stronger but still not very good. Coughing hurts a lot, so I'm thankful I don't have to do it often. My brother and sister come to visit this evening. My brother being the funny guy he is thinks I would feel better if he makes me laugh. He only did that once as I told him it hurts too much to laugh. It's amazing how every little thing you do seems to have some interaction with your abdomen.

Sunday June 25th, another bad night. I watched a movie and walked from 2 to 4am, then slept until 6:30am. I'm feeling a lot of painful cramps in the lower abdomen. Gas or something is starting to move down there. I now take all the drugs myself except for liquid prednisone which is still being injected once per day through the remaining IV line. The nurse comes in to check what drugs I am taking, preparing me for going home where I have to monitor the drugs myself. I am still hot all the time. Slept this morning from 9 to 11am, now I feel a little better again. My arms and shoulders have become very weak over the past week. I have to put most of my weight on them when I move around and they feel very fragile. Still cannot lay on either side, it's too painful. The one JP hole finally stopped leaking. My lungs are getting a little stronger and walking is getting better. Taking Tylenol regularly for pain so that I can sleep better and feeling less pain makes it easier doing things such as breathing and walking exercises. We watched the second video today.

Walking from my room to the lounge I pass Robin in the step-down unit. She does not look very good so I pray for her improvement. Nancy brought Robert and Matthew in today. Lyndsey had been exposed to chicken pox last week so she still cannot see me. That's sad, but at least I can talk to her on the phone. She has drawn me a few cards saying she loves me. It's very touching, I'm missing her. Matthew was happy to see me. He did not look too good when he saw the staples, but he was OK.

On Monday morning the nurse removed by ileoscopy bag as it was not leaking much anymore. She put a dressing and bandage over the hole. Of course the irritation to the area caused the leaking to increase again, so I was back where I was a few days ago, where the dressing was quickly getting wet and soaking through, running down my hip getting the bed wet. On the good side I had my first bowel movement since last Monday, before the operation! Exactly one week of no movement but thankfully it was not as painful as I expected. My neck bandage was removed. This was quite painful, but only for a few seconds. Having not shaved for a week the adhesive on the bandage was bonding quite well to my neck stubble. It also left lots of sticky stuff on my neck, which did not wash off well, making it hard to shave. At least this is one problem, although minor, which Robin will not have to deal with.

Pastor Bryan was in this afternoon but did not see me. Nancy and I were watching another video in a small corner room where the nurses did not think to look for me. There seems to be a lot of pressure today on my abdomen. The JP hole which was stitched is also leaking. I'm also finding it difficult to breath, probably due to pressure. Still have not had any solid food but Nancy brought in a few fresh picked strawberries, so I had a few of them.

Preparing to go Home

The doctor today said I could probably go home on Thursday, June 29th. A great story to hear! The hospital stay has been good with excellent care but it's always nice to be home. I have a concern about the pressure and pain but it's still two days away. I started taking Tacrolimus and Cellcept today, two immunosuppressant drugs. The ileoscopy bag was removed again and two stitches put in. Also the other stitch which was leaking was replaced with two stitches. The doctor says my body should now be well enough to absorb and get rid of the fluid buildup. The physiotherapy

nurse (or doctor I don't know which) was by. I had to do a few exercises for her including climbing a flight of stairs. She listened to my breathing. Everything went well so I got her OK to be able to go home. I was started on solid food for lunch. A welcome change, even though I still am not very hungry. The food was surprisingly good except for the fact that my stomach has shrunk so I could not eat much. The last IV in my arm was finally removed. Hooray! Both arms are bruised from the IV's as well as needles daily for blood tests, drug injections and fluids. Lastly, as I'm going home soon I met with a transplant coordinator about medic alert and what needs to be etched on it. There are lots of details to finish before being discharged.

Two a.m. Wednesday June 28th the doctor came around checking a few vital signs and then casually says I can go home tomorrow, i.e. after tonight, meaning Wednesday during the day instead of Thursday. I'm still concerned about pressure, lack of bowel movements and something else. This something else is what concerned me the most. It's something I have not mentioned to any nurses or doctors as it's very private. In fact I struggled whether I would include it in this book or not. In the end I decided I should as it is part of the transplant process so others will experience it as well. Preparing for the operation and reading about what's going to happen and talking to doctors did not prepare me for this as no-one had ever said anything about it, so I thought it may be something unusual, happening only to me. As reluctant as I was to talk about it I thought I needed to tell the doctors in case something serious was wrong. So I decided then that when the doctors made their 7am rounds I would tell them about the problem and see what they said. I was hoping there would be no interns or female doctors in the group. I also prayed about going home. I asked Jesus for direction as I was very uncomfortable with it and the possibility of some complication and having to come back in. I really did not want to come back again except for a checkup.

A little after 7am the doctors came around. There were only two of them, both male; thank-you Lord. This put my mind a little at ease. They did their regular checks and asked some

questions. They said I could go home today. I then told them of my concerns and they assured me everything would be OK and if need be I could easily come back in. Finally I told them about my biggest concern, the one I had not said anything about to this point. The problem was that my penis and testicles had swollen up just like my legs, only much more so. My penis felt and looked like a lump of fatty skin, about normal length but five times the diameter, it was huge. Similarly the testicles were about five times as big, equally looking like a big lump of fatty flesh and very heavy hanging down while walking. Of course the doctors wanted to see. They were very good, knowing that this was embarrassing for me. They looked and said this is just normal fluid buildup, just like my legs. It's very common although it's not talked about and that I should not be concerned. I felt relief.

Around 8:30am the nurse who has taken my blood each morning came by. It has always been the same nurse, a big friendly Greek woman with a thick accent. She has been very good in that there has been very little pain when she sticks in the needle, every day, except today. She has a hard time finding the vein and then when she inserts the vial onto the needle there is a little buff sound and no blood goes into the vial, instead my arm starts to bleed a little. So she takes off the vial and removed the needle and puts it in a different spot. Later she said the vial did not have a vacuum in it, thus no blood went in. Very unusual she said. I did not enjoy the process this morning and I took this as God's answer to my prayer about whether I should go home today. The answer was YES, I did not need to be here any longer. Both arms are bruised from IV's and daily blood removal. This little unique incident said to me that it is time to go home.

The rest of the morning was spent preparing to go, getting drug prescriptions filled, packing up cards and clothes I had accumulated, signing a few forms, learning about the EasyPhone system, which allows patients to call the hospital and leave messages for coordinators and also for the hospital to leave messages for patients about drug changes and such. Lastly I went around and said good-bye and best wishes to

those who I had gotten to know over the past week: David my roommate who had the kidney transplant, Robin, the young woman I mentioned earlier with the liver transplant. She was sleeping, as she usually was so I did not actually say bye. Lastly there was Joe, a young man who had been in the hospital for nine months waiting for a heart transplant. He had just had it while I was in. He was so weak after the extended hospital stay that I would walk with him to the lounge and open the door for him as he was not strong enough to open it himself. It's a happy time to be going home but also a sad time to say bye to those who are staying. Florence had a pancreas and kidney transplant the same day as me, came out of step-down the same day, and went home the same day.

Finally I'm home at 4pm, 8 days, 6 hours after the operation, 9 days less one hour since the call. I never realized how rough the roads in Toronto are. I suspect it's the same in every city. Every bump and turn put strain on your abdomen muscles as they work to keep you sitting upright. It's great to be out of the hospital room and get fresh outside air. At home I move immediately to the lazy boy chair and recline similar to the hospital bed. Had a little supper, not very hungry and feeling lots of pressure on my abdomen. Had a small bowel movement, but nothing to get excited about. The happy event of the day was when Lyndsey came home. I hadn't seen her since I went into the hospital nine days earlier. She was all smiles and so understanding that she could not touch my stomach but I gave her a hug and kiss anyway. She was fascinated by the staples and also very happy I was home. That makes two of us!

8. Home and a New Life

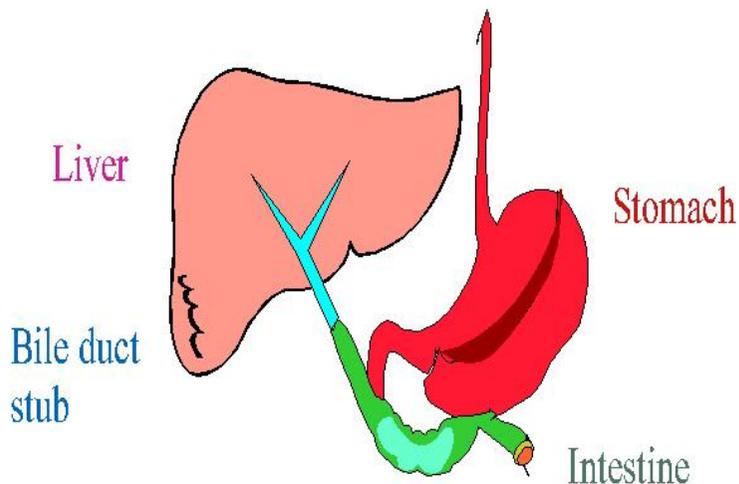
Chapter

8

What do I look like Now?

Below is a representation of a liver and the connections after a transplant. You can see a few significant changes, the first being the lack of a gallbladder.

When a liver transplant is done the existing gall bladder is removed along with the liver and bile duct. As the gall bladder is not a required organ I think the doctors feel there will be less likelihood of complications if the gall bladder is left out. The new liver's bile duct is connected to the small intestine just below where the stomach connects to the small intestine.



New healthy liver, no gall bladder. Bile duct stub from new liver connects to intestine extension at joint with stomach.

Figure 4: Post-transplant organs

A second significant change is the nice pink healthy coloring of the liver. This is the whole purpose of the transplant. The old liver was deteriorating and slowly dying, not doing one or more of its functions, namely the function of cleaning the blood. The new healthy liver starts working immediately and removing the toxins that have accumulated in my system over the past few years. The chart below shows the various components of my blood which the doctors have been monitoring. You can see the dates and levels. Compare the levels twelve hours after the transplant and over the following few days and you see how quickly the new liver gets to work. The normal levels for these components are listed in the last row of the chart.

Date	Blood Pres.	AST	ALT	ALP	Bilirubin
June 21	120/80	1061	991	400	111
June 23	?	262	559	399	150
June 26	135/90	77	247	561	115
July 24	130/100	17	24	144	24
Normal	120/80	10 - 40	5 - 68	40 - 120	0 - 22

The table below describes some components of the blood. It is important to realize that not all of these levels decrease immediately after a transplant. Some level reduce quickly and stay low where others reduce slowly or even decrease and increase again, eventually getting to normal levels.

AST	Aspartate Aminotransferase. AST is in high concentration in heart muscle, liver cells, skeletal muscle cells, and to a lesser degree, in other tissues. Although elevated serum AST is not specific for liver disease, it is used primarily to diagnose and monitor the course of liver disease (in combination with other enzymes such as ALT, LDH, and ALP)
ALT	Alanine Transaminase. Used to determine if a patient has liver damage. ALT is an enzyme involved in the metabolism of the amino acid alanine. ALT is in a number of tissues but is in highest concentrations in the liver. Injury to the liver results in release of the enzyme into the blood.
ALP	Alkaline Phosphatase. An enzyme in all tissues. Tissues with particularly high concentrations include liver, bile ducts, and bone cells. Since damaged or diseased tissue releases enzymes into the blood, ALP measurements can differentiate bone disease from liver disease.
Bilirubin	Total Bilirubin. A breakdown product of hemoglobin, which functions to carry oxygen in blood cells. This is a waste product that is normally eliminated from the body through the liver. As bilirubin levels build up in the body, they give the skin and eyes a characteristic yellow color, called jaundice.

Sore and Tired, first week at Home

Home, hooray, I feel better already, at least mentally. Today is Thursday June 29th, nine days after the operation and my first full day at home. I slept pretty good in the lazy boy chair last night. I even lay on the couch for two hours. I'm feeling very tired today after a busy day yesterday so I slept most of the morning as well. I think the pain killers also make me feel tired, and I have been taking them every four hours because I have been feeling a lot of pain and pressure. It's raining today so I'm not going for a walk which is bad as I'm to walk everyday, but also good as I don't feel like walking today. Nancy told me how much the drugs cost which we picked up from the hospital yesterday. Fourteen hundred dollars, yes \$1400, for about one month's supply. About eleven hundred was just for the two anti-rejection drugs. The others are relatively cheap. Again thank Jesus for the job I have, working for a great company which has a good benefits package. Most of the drugs should be covered by the drug plan. We are not sure yet about the anti-rejection drugs as they are not normally available drugs and may not be covered, but we are hoping. At one time I left IBM for a year to work with my father, which means no drug plan, no disability plan, so I would not be getting paid to recover at home and I would have to pay for the drugs myself. But God was working at that time; He knew the future and brought me back to IBM before I got sick, so that I can now heal and not have to worry about no income and expensive drugs.

My urine is a normal color again, the whites of my eyes are white, not yellow, my dirty yellowish tanned skin is looking healthier and lightly tanned, the black areas under my eyes are clearing up. All in all my appearance is much better. I weigh 167 pounds today, two pounds more than when I went into the hospital. This sounds good to me as I always thought I was too skinny. The trouble is that the weight continues to be fluid which will go away soon leaving me wondering how much I really weigh.

The next few days go by quickly. I'm not sleeping well at night, only one to two hours at a time, then wake up for a washroom break (there goes that fluid buildup) and watch television for an hour or so. My back is always sore as I am always laying on it. I've starting eating a little more now. My stitches on the far right side are still oozing a little. It gets crusty and stops until I have a warm shower which loosens it up, I wipe the loose stuff off and then more fluid oozes out. I'm walking around the school yard now, about one half kilometer, trying to do this two to three times per day. My mouth is always dry, just like it was in the hospital; it must be the drugs that dry it out. A dry mouth makes it very hard to swallow food, making eating less enjoyable.

July 1st I slept for two hours in my daughter's bed as she was at my parents. I tried sleeping flat on my back, something I had not done yet. It was painful at first but I was so tired I fell asleep. When I awoke my ribs were so sore I thought something had split open inside, from stretching out on my back. I could only take shallow breaths as a deep breath expanded my chest which caused terrible pain. I thought about going back to the hospital the pain was so bad, but I put the heating pad on for a few hours and the pain reduced significantly. I don't plan to lay flat on my back again for a while.

Tomorrow is Monday July 3rd, my first clinic at the hospital. They plan to remove the staples, something I would like done but do not look forward to. It will probably hurt and there are sixty three staples. They also want to do an ultrasound which means pushing the probe against my stomach and already sore rib cage. I have not had a bowel movement since I've been home even though I am taking stool softener tablets. So I took two suppositories this afternoon. An unpleasant event to go through but that stuff has to come out sooner or later and the later it is the harder and more painful it will be. After almost two hours of pushing, relaxing, wiggling and more pushing it happened, a huge bowel movement, and it did hurt but it feels great to have done something. Hopefully now things will

starting moving normally again. In fact I had another big bowel movement this evening. Great.

Rejection and Infection. What now?

Rejection is probably the biggest problem a transplant recipient can face, followed by infection. It's a fine balance to take enough anti-rejection drugs so that rejection does not become a problem and at the same time to take as little as possible allowing the body to fight infection and disease as best it can. The immune system is the defense mechanism of the body which causes rejection and also fights infection. Antigens are special markers that the immune system uses to detect and destroy what it thinks are foreign material. The transplanted liver is viewed as foreign material as the markers, the antigens, are unique for each person, just as you finger prints are unique, and thus the body tries to destroy it. Rejection can be mild, medium or severe. For the liver to function properly rejection must be detected early and treated promptly.

Rejection is treated by the anti-rejection medications in three ways. 1) Mask the transplanted organ to appear as part of the recipient's body; 2) disable the immune system so it does not recognize the organ as foreign; 3) suppress the immune systems ability to detect any foreign matter and thus not detect the organ as foreign and thus not try to destroy it. The trick is to allow the immune system to seek and destroy everything except the transplanted organ for you want your immune system intact to fight disease.

Rejection

The average person has one or two episodes of rejection, which is determined by blood work, a biopsy of the transplanted organ or close watching for signs and symptoms of rejection. Rejection does not mean the organ is permanently damaged so you will most probably not lose the organ as long as the rejection is treated promptly. Treatment is done with additional medications or altering existing medications. Many times persons do not feel any symptoms of rejection but if you do they may include:

- Jaundice and / or itching
- Fever of 37.5 Celsius or greater
- Fatigue
- dark urine and / or pale stools
- abdominal pain or an ache on the right side (for liver transplant)
- loss of appetite, nausea or vomiting

If you experience any of the above symptoms you should contact the transplant team immediately. A biopsy is the only way to conclusively check if rejection is occurring. You may continue to feel well and still experience rejection.

Infection

Good oral and personal hygiene are important. Hand washing is key to the prevention of infection. Many problems we encounter are the result of germs on our hands from things we touch and then transfer these germs to openings in our bodies (eyes, nose, mouth) by touching, rubbing or scratching these areas. Good nutrition,

plenty of rest and regular exercise all promote better health and thus the body can better fight infection, even with a reduced immune system. Your skin is a barrier to infection so keep all cuts and abrasions clean and dry. Watch for signs of infection such as tenderness, redness, discharge and pain. Common sites of infection are lungs and urinary tract. Any sores, blisters, lumps, or growths in the armpit, groin, or elsewhere should be examined by your family doctor and then possibly by the transplant team. Signs of infections are:

- Fever of 37.5 Celsius or higher
- Sore throat, shortness of breath, or persistent cough
- change in color or increased production of sputum
- Cold sores around lips and mouth
- pain or burning on urination
- Redness, swelling, drainage, or pain from the incision site.

Any of these signs should be reported to the transplant team.

Letter to the Donor Family

Some province and states have laws about knowing the identity of the organ donor and whether the donor family can know the recipient. You will need to write your letter according to the local rules of where your transplant occurred as the transplant office determines whether your letter will be sent or not. Some things to include:

- Thanks for making the decision to donate the organ(s) and what it has meant to you.
- How long you waited for a transplant.
- How you felt both mentally and physically while you waited.
- How you feel now.
- What you look forward to into the future.

If you need help the transplant office is available. When the letter is ready send it to the transplant office and they will mail it to the donor family.

Nancy and I wrote a letter to the donor family today, about a week after I returned home. This was a hard job, trying to decide what to say to show our thanks and encourage them in their time of grief. Below is our attempt.

We would like to take this opportunity to thank you for the gift of the liver. We are sorry for the great loss you must feel and hope that in some way this note might ease some of the pain knowing that some good has come from whatever tragedy has happened. My husband has had his liver disease for at least seven years and has been on the waiting list for the past twenty-two months. He is thirty-eight years old and we have three young children, aged nine, seven and four.

The Lord Jesus has blessed us since my husband's health was relatively stable during this period but during the operation it became obvious that things were deteriorating. His portal vein was unexpectedly blocked! Maybe things would have gotten worse if we had to wait any longer. God's timing was perfect. Even during the eleven hour operation and over the past eleven days His hand had been evident and has given us peace. My husband is home now after only eight days and is recovering nicely.

There is pain, swelling and discomfort but that's all to be expected. We trust that Jesus will restore him to full strength and health over the next few months. We pray that you might see God's purpose and work in your lives as you too recover from this difficult time.

May God bless you and give you peace.

Tests and More Tests

July 3rd, 8:30am and Nancy and I are at the hospital for the first clinic. These will happen each Monday for a month or two and then gradually get less frequently. I had another bowel movement this morning, boy things are moving now. At clinic they take blood, blood pressure, coordinator asks lots of questions about how I have been feeling, she examines the stitches and my swelling, then I go for two hours to the ultrasound. It takes so long due to the complex work the doctors did on my portal vein. They want to get a good look at it and ensure its all working properly. It is. Back up to the clinic where I expect they will remove the stitches. The coordinator said that because some stitches were still oozing that they would wait a week until next clinic before removing them. That was fine with me as I was tired and it was now 1:30pm. Five hours we have been at the hospital.

Francis, the woman who had the pancreas and kidney transplant was also there for her first clinic. We talked for a few minutes which made me feel better. Many of the feelings, pains, breathing and experiences with eating are very similar to what she has experienced. It is reassuring that everything is going normally. Unfortunately she was being re-admitted today as she had developed an infection in her abdomen. I feel sorry for her and how disappointed she must feel. The doctors say only one or two days are needed so it should not be too bad.

While at clinic I went back to the ward where I was for a week to see who was still there. David, my roommate was gone home as was Robin. This was great news as Robin had been sick for so long. Joe the heart transplant patient was still there, and will be for a while I suspect as he's so weak. I feel sad for him and pray a lot for his recovery. Some of the nurses remember me and say how good I'm looking. As I mentioned before the nurses are really great. They go beyond the call of their job. Even down in the cafeteria one of the coordinators recognizes me and says hi as she walks by. It is really nice.

July 5th, after being home for one week my weight has gone down to 163 pounds. Not bad as I've lost only four pounds. Not a lot of fluid has been absorbed yet. My temperature has been very steady about 36.6 degrees Celsius. This is good as a temperature rise is a first sign of an infection or rejection.

More of this, less of That

Every person is different and thus there is no formula for how much and what types of each drug to give a patient. The goal of the doctors is to prescribe as much medication as necessary to ensure your body does not reject the new organ while at the same time to prescribe as little as possible so as to reduce the likelihood of side effects of the drugs. Combining different drugs can mean that each drug quantity is reduced as the combination of two smaller doses of two drugs has a greater effect than one large dose of one drug, and again the side effects are less. The regular blood tests are to ensure the liver is working but also to monitor the anti-rejection drug levels in my system. My Tacrolimus level was increased from eight milligrams per day to ten after the second clinic on July 10th. The doctors feel the level in my blood sample was too low so early after a transplant. Only two more milligrams, not much, but the next day and for three days since I have felt very lethargic. I am always tired and thus sleeping more during the day. I hope I get used to this and can deal with it soon because it is such a waste of time sleeping so much.

I also take a coated aspirin each day; coated so that it dissolves further down in the digestive system. Usually transplant patients don't take aspirin but I do because of the portal vein work done as part of the procedure. The aspirin helps reduce blood clotting. The doctors do not want the blood to clot in the portal vein where the stitch work was done. This would be messy to have to try to fix. Prednisone is another major drug. I'm taking four milligrams per day. This is one drug they want to reduce as soon as possible due to its side effects. The main

negative effect being decreased bone density possibly leading to osteoporosis. I had taken high doses of prednisone years ago for the ulcerative colitis problem and discovered I already have osteoporosis in my left hip and lower spine. So the sooner I'm off it the better. The coordinator mentioned that in a few months when I'm feeling better they will send me to an osteoporosis specialist at the hospital to help me deal with that problem and start working on preventing it from getting worse. Fortunately I don't feel any effects of it. In the long run, years down the road when my bones become fragile and brittle, is when I will see the effects. There are a few other medications I take to keep stomach acid down, a calcium supplement, a magnesium supplement, a multivitamin, a drug to prevent pneumonia and Cellcept another anti-rejection drug. It has only been two weeks since the operation so I cannot expect drug level to be reduced yet, but hopefully soon they will start.

Second clinic was July 10th. Half of the staples were removed, only half as there is still a lot of pressure and some fluid leakage. I've now lost eleven pounds in one week, since the last clinic. The weight is probably all fluid. Still not eating much this past week; cannot lay flat on my back. Continue taking pain killers but not as regularly and still sleeping two hours at a time but then I fall asleep again quickly after a washroom stop. Breathing is definitely getting stronger but it still hurts to cough or hiccup. On Tuesday I increased my walking route to about two kilometers but then on Wednesday I was very tired and slept most of the day.

Thursday July 13th I was again tired and slept a lot. The swelling in my stomach is going down as evidenced by a wrinkle below my incision that Nancy noticed. Until now is always been bulging out. I slept in bed for five hours last night, on my side with a pillow behind my back. Today for the first time I did all the exercise on the sheet the hospital gives out. They are fairly easy so I need to start using some light weights. My arms and upper body are still very weak. Nancy and I walked around the block again, about two kilometers. The legs hold out well but after a while my stomach feels tender and

tight. I think from the bouncing of the walk. As the organs bind into place and the wounds heal this should go away.

Friday is another tired day. I get up for breakfast, get washed and plan to go for a walk. But I feel so weak and tired I go back to bed after being up only one hour. I sleep until after lunch. Feel much better now but still very weak. I think the increased Tacrolimus dosage is causing the increased tired and weakness as it started when the dosage increased last Tuesday. Hopefully the feelings go away soon as I get accustomed to the dosage or next Monday at clinic they can reduce the dosage again. The days are very unproductive when I sleep half the time. Temperature has continued to stay steady around 36.6 but unfortunately my weight has continued to drop. I'm now down to 149 pounds, 16 pounds less than when I went into the hospital. My normal weight when healthy, eating properly, exercising a little is around 175 pounds. The good news is that this is the same weight as yesterday so maybe this is a sign that it will now turn around and start increasing as most of the fluid is gone and as I continue to eat more each day. Only time will tell.

On a sad note I found out today that Beth, the woman I went to visit a week before my transplant is going back into the hospital. She is having problems with fluid buildup in her abdomen and the doctors think they will need to put a drain in for a while. She has not been feeling well, not eating or exercising. I feel sorry for her problems and will start praying for her recovery again, and at the same time this reminds me how fortunate I have been thus far. Of the five people I've mentioned previously, three are back in the hospital. Only I and one other are recovering well at home.

How can I Help?

Have you ever felt helpless, almost totally helpless? That's how I feel since the operation. In the hospital it's understandable that the nurses do almost

everything. They take vital signs, change the bed, get food and drinks. Initially they even bathed me. But now that I'm home I still feel like others are doing everything for me and I don't like it. I've always been able to care for myself and tried to help others as appropriate. Now I have to accept the fact that it will take time before I can do much. Add a little bit more day by day as I feel able and at the same time willingly accept the help of others who want to help me. It has been said that 'great is the person who humbly helps others but greater yet is the person who humbly accepts the help of others'. So having said all this, what can I do to help? As I'm very weak and due to sore back muscles I cannot lift much, I cannot stand very long as I get tired quickly, so what can I do? I wash dishes occasionally, usually take them from the dishwasher and put them away. I put the children to bed at night, reading a story, singing songs and praying. I watch the kids while Nancy goes shopping or watch Lyndsey while Nancy does something with the Robert and Matthew. I play board games with them and help Matthew with his piano practicing. But as much as they all like to wrestle I cannot do that, yet. It will come in time though. I also help pickup things around the house and put them away, or chase after the children to pick up after themselves so that Nancy does not always have to be the nasty.

Disease and Germs Everywhere

One issue that doctors, nurses and family members seem more concerned about than I do is germs. They are everywhere, can be picked up from almost any surface and can travel short distances through the air. If someone nearby sneezes the germs head my way and I could breathe them in. Due to the immune suppression drugs that transplant recipients take it is harder for their systems to fight off disease, no matter if a virus is breathed in or an infection from a cut or scrape. Everything is probably going to take longer to heal and will probably be felt to a greater extent than a person who is not taking the same drugs.

Washing and Bathing

It is virtually impossible to avoid every possible exposure but it is possible to reduce the chances of catching something with some simple precaution. The first and most important is the frequent washing of your hands. Your hands come in contact with so many things and such a variety of surfaces that they are the most likely to pick up something. Then we put our hands to our face because we have an itchy nose and need to scratch, or a piece of hair falls onto your face and needs to be brushed away, or you need to cough or sneeze so you put your hand to your mouth. This way the germs get in the vicinity of your moist mouth and nose and get access to your inside and thus multiply and you now have caught something. So doctors say washing of your hands frequently is the most important step you can take to reduce the chance of catching something.

Regular bathing is a good habit. A transplant coordinator told me I should shower every day. Don't take baths for the first few weeks until your incision is well healed over on the outside. Sitting in a tub of water in which your whole body is immersed is not really that clean and any bacteria or germs could then get into the incision. A shower is better as the water is flowing over the incision constantly and not just sitting on it. The water helps soften the incision and scabs, helping them to come off easier. It has been just over a month now for me and I still have two small scabs from parts of the incision which have taken the longest to heal over. These are the sections where I had a little bleeding while in the hospital. A few other scabs were loose after a shower so I removed them to discover that underneath they were still attached. After removing them I could see the incision and had a little more bleeding. Obviously I had removed these scabs a little too soon. These are now new areas where infection could set in. The main point here is to not be eager to get the scabs off, they will fall off when ready.

Body Contact

Another activity to avoid, at least for the first few months until you have recovered from the transplant is the hugging and kissing of relatives and friends.

Everyone is happy to see you home and recovering from surgery and wants to give you a hug and kiss to show their love and support. This is all very good and fine except for your unique circumstances. You are just starting a few months long recovery process where your body is trying desperately to heal itself despite the drugs which are slowing it down. The last thing you need at this time is for additional complications due to germs and bacteria entering your system from hugs and kisses. This can be very difficult, if not almost impossible to avoid in some circumstances but it should at least be minimized. My wife asked people at church to not hug me, yet the following Sunday a few did anyway. They do not mean any harm, they either forget or just do not understand the possible implications. So far people other than my wife have only kissed me on the cheek, including my children. I do the same to them. For the first two weeks it was the same with my wife, until I made the move to kiss her on the lips. At this time I felt it was worth the risk, especially considering we have been married fourteen years now so my body should be well accustomed to sharing a few of her germs.

Mouth and Dental Care

The mouth of a human apparently is dirtier than the mouth of a dog! It contains more bacteria and more different types of bacteria, probably due to the wider variety of items we eat. Regular flossing and brushing are very important. Floss at least once per day and brush after every meal and at bed time, using a soft bristled toothbrush. Visit the dentist at least twice per year for cleaning and examination. You need to inform your dentist beforehand that you have had a transplant and that your immune system is

suppressed. You may need an antibiotic drug prior to any dental procedure including cleaning just to ensure no infection get into any cuts or sores. If needed a doctor can send the dentist a letter stating what antibiotics can be used. On top of that for the first few months the doctors will prescribe Nistatin, a liquid you take about a teaspoon at a time, swish it around your mouth, over all your teeth and then swallow. Nurses refer to it as ‘swish and swallow’ when they give it to you a few times per day while your recovering. This is to help prevent thrush, an infection or disease you get in your mouth.

Flu Shots and Vaccinations

Due to the medications taken after a transplant it is important to remember that a transplant recipient is more easily affect by the common flu virus. It is highly recommended that recipients have a flu shot each fall somewhere in the September to November timeframe. If you have received your transplant within the three months before the fall you should talk to a transplant coordinator. If you have an allergy to eggs then do not take the flu shot as it contains protein found in eggs. Your family doctor is the person giving the shot not the transplant clinic. If your family doctor needs a letter then the transplant coordinator can provide it.

These Drugs are Expensive, I'll cut back

See the figure below for the list of the drugs I currently take including quantities and daily costs. Over time some of these drugs will not be needed and hopefully the others will be reduced in quantity thus reducing their negative effects and also reducing the cost.

Medication	Purpose	Quantity	Frequency	Cost
Tacrolimus	anti-rejection	5 MG	2	\$27.34
Cellcept	anti-rejection	500 MG	4	\$18.50
Prednisone	anti-rejection	20 MG	1	\$0.40
Ranitidine	prevent ulcers	150 MG	2	\$1.24
Sulfameth	prevent pneumonia	400 MG	1	\$0.41
Nystatin	prevent thrush	2 ML	4	\$0.62
Magnesium Rogier	magnesium supplement	30 ML	2	\$1.34
Coated Asperine	prevents blood clots	81 MG	1	\$0.19
Total Cost				\$50.04

From the table the total daily cost for the drugs is \$50.04. That translates to \$1,501.20 per month, or \$18,014 per year, a hefty bill especially if you do not have a drug plan. This is where the Trillium Drug plan available from the Ontario government kicks in. This is available only in Ontario but there may be similar plans in other provinces or states. To apply you fill a form stating your family income and other details. Based on family income and any private drug plans you have through your place of employment they will determine the maximum amount you should pay. Any amount over this will be paid for by the Trillium plan. There is also the one time cost of a hospital room, should you be inclined to ask for a private or

semiprivate room. Then there may be costs of traveling to the hospital for clinic tests as well as locally for blood tests.

Based on this excessive cost the transplant coordinator said that some patients without a drug plan or a plan with poor coverage reduce the dosages over time in order to reduce costs. The patient thinks they are feeling well so a small reduction in medications, especially the expensive ones, the anti-rejection drugs, will not hurt. After a while everything still seems OK so they reduce a little more. Over time the body starts to reject the organ as the body's immune system gets up to full strength again. Now the doctors need to get involved and hopefully it is not too late to save the organ. If it is too late a new transplant is needed. This is really bad. It is bad for the person needing to undergo a second transplant, but it's even worse for the next person on the waiting list. That organ should be going to the person, it should not be going to someone who already has received an organ and was careless enough to not care for it properly. So please follows the doctors advice, they have done this many times and know better than you what levels of drugs, especially anti-rejection drugs are needed.

9. Looking Forward



How long to I feel this way?

July 15th through July 22nd were pretty uneventful days. Some days I feel good and can go walking, reading, working on this book and shopping (a little). My voice sounds strong and I feel like talking with people, i.e. my wife and children. Other days I feel really tired and weak. My stomach and back hurt. Sometimes there is pain in the incision, sometimes its inside where the JP drains were, sometimes its lower in my groin area. I don't know what this pain is from. Unfortunately I'm still loosing weight. I'm now down to 146, 19 pounds below where I was when I went into the hospital. I'm pretty well stable now and trying to eat more so hopefully soon I will start gaining. It is nice to have the staples removed so I can turn onto my sides without staples poking me. I'm also now able to lie flat on my back. It hurts for a minute or so when I first lay down but then the pain in my side and chest goes away and I can actually sleep. But I still wake up every time I need to turn over, which seems to be every two to three hours. My body is quite thin but at least is not so noticeable in my face due to the effects of the prednisone. My checks are a little puffy as a side effect of the drug. In my case this is good so my checks are not so hollow from the weight loss. The good days make me feel good about the healing but then a bad day comes and I wonder if I'm really making any progress.

July 24th through August 2nd are also pretty uneventful days as well. At the last checkup the doctor said my blood levels are doing very well. They are thinking of reducing the Tacrolimus levels and cutting off the Cellcept all together. Good news! Hopefully this will help me feel better as my stomach gets upset and my lower intestines have cramps. Still wake up a lot

to go to the washroom and diarrhea still not under control but I have not been losing any weight, struggling to gain weight. I started using small weights with my exercises but the transplant coordinator says to be careful as it's still very early and too much strain on my stomach could cause a hernia or a rip inside and my intestines could be disrupted requiring more surgery. I think I'll listen as I don't want more surgery. I met Florence at the clinic this past week. Remember I said she had to be checked back in due to some complications. Well, she was in for nineteen days, more than twice as long as the original transplant. The reason was that one of her internal connections, stitching, started leaking into her abdomen and this resulted in infection. The doctors had to reopen her incision, search for the leak, re-stitch it, clean out the infection and restaple her closed. I give her credit for the way she has handled the complications, her excellent attitude, looking forward to a better future.

August 3rd I decided to try something I had wanted to do earlier but never felt up to, riding my bike, a bicycle not a motor bike. My wife (and I) were concerned about falling off and my incision popping open again but it seems to be doing well and I'll take it easy. Also the feeling when hitting bumps and such, even walking sometimes sent pains up my side or back when I would stumble over uneven ground. The other main concern is having to bend over to ride. I rode to the drug store and back, a round trip of four kilometers taking side streets to avoid traffic. I found this to go very well, excellent exercise as I find walking to be boring (my personal view not a medical statement). This also worked my lungs much more than a walk, I found out very quickly how weak my lungs were. Legs were like rubber after, a good feeling. Next day was five kilometers to the grocery store and back. Next day was sixteen kilometers down to the lake and back. This should help me get back some muscle tone, now if I could just gain some weight.

Monday August 14th, clinic day again. Today the doctor said he would cut my Cellcept medication in half, from 2000mg per day to 1000. Even better is that this 1000 is divided into

two doses per day instead of the previous four, thus I have more time during the day to eat, i.e. the 7am and 4pm medications no longer are necessary so I can eat during those times. The doctor also said that if things go well, my blood work looks good over the next few weeks they will reduce my prednisone in half as well. This is all good news to me; the less drugs the better. But then on August 22nd David called. David shared the room with me during my hospital stay. He had a kidney transplant. He called to say he had just been checked back into the hospital, he gained six kilograms, 13 pounds in four days. They think he may be rejecting the kidney, so he is in for a biopsy to determine what's wrong. David was the strongest and quickest to recover of all five of us transplant patients I got to know while in the hospital. He's understandably a little depressed today, as I would be. He was doing so well. This now concerns me a little about my drugs being reduced and thus more chance of rejection. It's a fine balancing act of taking enough anti-rejection medications so as not to have rejection problems while at the same time taking as little as possible to reduce the side effects of the medications. If I were superstitious I would 'knock on wood' but to me this is one more showing of how kind God has been to me through all this, in that I have not had any significant problems.

I went to work yesterday afternoon to see my team, my manager, and get some work like reading, to start on at home. Everyone said I am looking very good, better than before the operation. I think I look better because the jaundice is gone, my skin and eye colour is better. Also the prednisone helps fill out my cheeks so my face does not look so thin. As I'm underweight this is good for me. I have been eating a lot and my wonderful wife Nancy has been baking and cooking food I like. As a result I am now up to 154 pounds. It's a long slow climb but progress is being made. It's been just over two months now, one month to go before I go back to work, so one month to continue getting back in shape as much as possible and gain a few more pounds.

August 28th, clinic again. A few minor complaints by me, they check my weight, ask some questions and off to home we go.

Everything is going great so the doctor decides to reduce the prednisone. As the transplant patients are on the same floor Nancy and I decide to see who is there. David my former roommate is back due to rejection of his kidney. High doses of anti-rejection drugs injected intravenously seem to be working. He's not very happy with the situation and I would not either but fortunately he's recovering. David says his veins burn due to the injections. Seeing David makes me realize yet again how fortunate I was in that I am now the only person of the five I know who has not been readmitted. The Lord continues to show His kindness to me.

What can I not do?

The doctors say there is very little a transplant patient can not do, just be cautious. We cannot drink or eat anything with grapefruit as it amplifies the effects of some of the drugs. We should wear a medic alert bracelet or something similar so that if something happens and we are unable to respond for ourselves then a medical team can identify what we've been through and thus are able to help us. Initially we should not drive due to slow reflexes, weak muscles, dizziness, headaches as well as possible pain from the seatbelt against the abdomen and the affects of the drugs on our ability to make quick decisions. When you can drive depends on your recovery time and the ongoing effects of the drugs. The foods and activities a transplant patient can indulge in depend on the type of operation.

Traveling should be planned carefully. It's best to not travel for at least three months for the same reasons as driving. It's also difficult to monitor your state, go for blood tests or clinic appointments, respond to requests from the doctors to change medication levels or even purchase additional medications when away from home. Always let the transplant clinic know your travel plans. Some countries will require vaccinations which you should clear with the transplant clinic before taking the shot. You should also purchase cancellation insurance as

something medical can always come up, but is less likely the longer you've had the transplanted organ. Complications can also happen while away and thus out-of-country insurance is a good idea. If you'll be away for more than a few weeks then you should get a travel letter from a transplant coordinator. This will list your medications and most recent laboratory results as well as emergency contact information. You should always be sure to carry extra medications in event your plans change, which may not be in your control. For example you could get snowed in at an airport for a few days. Another idea is to separate your medications into two sets. One set should always be with you so that it cannot be stolen from a hotel room or lost with your luggage. You don't want to lose everything. With careful planning you can have a relaxed and enjoyable vacation.

The sun is now the enemy. It has been for a while due to increased intensity with reduced ozone levels. With the antirejection medications our system is less able to fight off the effects of too much sun. The ultraviolet rays can cause skin cancer in everyone; even more so when taking immune suppressing drugs. A sunscreen with S.P.F (sun protection factor) of 15 or more will help reduce the risk. Avoiding the peak intensity period from 11am to 3pm will help. Try wearing a hat, long sleeve cotton shirt and cotton pants. If you do notice a change in skin color, or lesions or changes to the color or size of any moles then notify the transplant clinic.

Sexual activity is something that married adults are probably thinking about. When can my spouse and I resume our physical relationship, what can we do, what are the possible results in terms of pain or strain on the incision or internally? First let me suggest that your relationship should resume immediately after you are out of intensive care. This is the touching, comforting type of relationship, not the intercourse type. The doctors say you can resume sexual activity as soon as you feel the strength, but start off gently. Most organ transplants require an incision in the abdomen area and thus the muscles in that area are cut. Be careful not to strain these

muscles too much or you could get a hernia or your intestines pop out through the incision.

Unfortunately with this topic we need to mention the negative side. If you are not in a monogamous, committed relationship you need to consider abstaining or take precautions to try to reduce the chance of catching some disease such as AIDS, herpes, or hepatitis A, B or C. Latex condoms and germicidal contraceptive foam if used properly decrease (but DO NOT eliminate) the chances of disease transfer from one person to another. It's best if both partners use a form of protection to decrease the risk even further. The only 100 percent safe method is abstinence or a committed marriage whereby one has sex with a single partner only.

How Long do I have?

This is a good question for which there is only one answer and its not the answer we want, but it's a question I suspect all people looking forward to any serious operation or life threatening disease will consider. When I was thirty-six years old my wife and I were told by a liver specialist that I probably had about two years to live without a transplant. That means by forty at the latest I would be dead. This did not seem very old to me. The alternative was a transplant. I asked for the statistics of how long transplant recipients survive. At that time, in early 1998 the doctor said the success rate is that eight-eight percent of patients survive for one year after the transplant and eighty percent survive for five years. There were no statistics for longer periods. I believe he said the longest surviving recipient transplanted in Toronto was done seventeen years ago and still doing well.

When in school and I received a mark of eighty-eight percent on a test I thought that was quite good. Now when looking at an eighty-eight success rate I don't feel that it's so great. That means twelve out of every one hundred people don't make it.

That seems high to me. But, considering the alternative of death in about two years, short of a miraculous healing of God, makes the eighty-eight percent look acceptable. As an aside, miracles do happen. I've known and have heard of people who had various diseases and one day, overnight, were totally better with no sign of the disease. Also miracles happen even when surgery is part of the healing process. It's a miracle that doctors can do the extensive surgery they do and that our bodies were designed with the ability to recover. It's a miracle how God works circumstances to bring the right organ to a patient, the nursing staff, and many other events together.

Going through deteriorating health and considering a transplant makes non-believing people start to think about God and usually engage in prayer. It makes praying people pray harder and with more depth. The latter happened to myself, my wife, and I think some relatives as well. You quickly learn to be more thankful and appreciative of everything and every moment you have.

10. What else can I say

Chapter

10

What is in a Support Person?

A person weight training usually has another person working with them to help encourage them along, to yell at them when they are not performing, to say ‘come on, one more, you can do it, just one more, ...’.

The purpose is to push the trainee to perform to their utmost. Similarly a runner may have other people to run with, to help him keep a steady pace, to provide motivation to keep running when the pain comes. A person going through a serious operation such as an organ transplant also needs a person alongside, a support person to help when the going gets tough. The support person needs to have many talents to be effective. Sometimes you need to be tough, tell the patient to smarten up and stop feeling sorry for themselves. Sometimes sensitive to just sit and listen to fears and concerns. Sometimes one needs to provide encouragement and praise when a difficult hurdle is overcome, and someone to come alongside and pray with you. There is tremendous strength that comes from true prayer. That famous psalm of David, psalm 23 says ‘... yea though I walk through the valley of death I will fear no evil for thou art with me, thou comforts me, ...’.

An excellent support person loves you. Not a romantic love or a sensual love but a deeper love of you as a whole person. They desire to take time from their own life and spend it on your life, to help you, even though there is no tangible benefit to themselves when doing such a thing; an unselfish love. Look to your spouse first, if you have one, then a family member or close friend. An excellent support person can make

the journey you are on a much better experience and also lessen the pain by going through it with you.

How to Tell Who's a True Friend

A perfect example of a true friend is the person described above, a support person. You probably only have and only want to have one support person whereas it's great to have a number of true friends.

An acquaintance is someone you say hi to, talk about the weather or last night's sports events. A true friend is someone who calls to see how you're doing and truly wants to hear the answer. A true friend offers to help in small or big ways, even when it is not convenient to them. A true friend offers encouragement and prayer support. A true friend overcomes their own fear of facing someone, talking to someone who is seriously ill, when they may not know what to say. A true friend sticks by in hard times, not just the good times. In times of illness you see who your true friends are as they will be with you throughout it.

A Man Must be Strong, in Control

This is a stereotype if ever there was one. In most cases men tend to be strong emotionally and have a built-in desire to be in control of the situation at all times. But during times of illness, both serious and not-so-serious, the rules should go out the window. Men as well as women have emotional needs and illness bring those needs to the surface more so than any other time. A man must be strong emotionally if his wife or a child is sick but this does not mean cold and unfeeling. Decisions, sometimes hard ones must be made. Sometimes emotions can get in the way of those decisions. At other times the man must be vulnerable and willing to share his feelings and concerns, let it out, let his family know he is human. The Bible says that two are better

than one, for two people together can help each other whereas one person alone has no-one to help.

In summary a man must not always be strong and in total control. Different circumstances call for different sides of our personalities. Also, everything said above about men also applies to women.

Filters

One of the main functions of the liver is to filter bad things from our body. The blood is purified as it flows through the liver. For example, pollutants through drinking water and air pollutants absorbed via the lungs and skin. Many modern foods are processed with various chemicals and preservatives. Our bodies do not like these things so the liver cleans them out. When the liver does not do its job and the junk is not filtered properly then the entire body suffers from the impure blood flowing through it. We do not get the maximum from life that we are meant to get. Likewise the Bible is to be a filter of how we live our lives. The actions we take, the attitude we have, the way we treat others, what we think of as right and wrong. If we ignore the Bible filtering our lives then much junk is allowed to get in. We don't always realize it, just like we don't always realize the food we eat has junk mixed in with it, but never-the-less, it's there. The food may taste and look good but it may not actually be good. Likewise events in our lives may look and feel good but are not necessarily good. Junk in our lives reduces the life we live and we do not get the maximum that God has intended for us.

Let's take a simple example: stealing. What harm is there in taking a chocolate bar from a store, or a few dollars from your employer in one way or another. The Bible says in Exodus 20:15 'thou shalt not steal'. It does not say 'you can steal in certain cases' it simply says 'thou shalt not steal'. Without this filter we can steal, which leads to bigger thefts and then deceit

and hurt feelings and ... where does it end? The filter is gone and our lives have been reduced somewhat, no to mention the lives of those people affected.

Donors

A person must die in very specific circumstances for that person to be an eligible candidate to have their organs considered for use in a transplant. The person must be brain dead having had no trauma to their organs for them to be acceptable for donation. The ideal candidate is someone who is being kept alive via a life support system. The family decides at some point to turn off life support. At this point the doctors are ready to take the organs and tissues when the donor dies. At the same time the patient is prepared for surgery. While the organs are being removed the doctors examine them to ensure there is no damage and they are suitable for transplant. In Canada the donor and his/her family must agree to donate organs. A patient receives an organ and can then live on.

In my case someone had died in some type of accident I believe. I heard the person was around twenty, I do not know if they were male or female. The person had signed their donor card or their family generously agreed to help some unknown people live by donating their loved ones organs. The family made the final arrangements for donation at a time of great grief. I'll call this person my brother as I do not know if it was a brother or sister. My brother dies and thus I can live. What an overwhelming thought. It still chokes me up when I think about it. What greater gift could there be!

This makes me think of another sacrifice. Long ago an innocent man died, gave his life so that other men, all of them sick, very, very sick men might live. Not only did that man die for these sick men, but he died it in an exceptional way. Brother One died for me; he died not out of his own will but due to some circumstances beyond his control. This man two

thousand years ago made the conscious decision to give his life willingly for me, and for you. The Bible says in John 15:13 ‘no greater love has one man for another than this; that a man lay down his life for another.’ This is not what Brother One did for me but it is what Jesus did for me. Brother One died that I may live a few more years on this earth. Jesus died that I might live forever in heaven someday. WOW! Brother One died through no choice of his own, Jesus purposefully came to earth, was willingly tortured, and willingly died for me. Double WOW! Having personally experienced the feelings of one man dying so that I might live I now have a much better appreciation of what Jesus did for me. He died not to give me a few more years on this earth but that I might live forever with Him. What a gift! The ultimate gift, given to me and to you! All you need to do is realize the gift exists and thankfully accept it. It is the only way. John 3:16 says “For God so loved the world that He gave His only begotten Son (Jesus) so that whosoever believes in Him shall not perish but have everlasting life.”. It’s as easy as that.

11. End of the Story, the beginning of All Others.

Chapter

11

Back to Work

I have taken this chapter title from that great author C.S. Lewis. At the conclusion of his book *The Magicians Nephew* he says “this is the end of the story, . . . and the beginning of all the others”. This in fact was true as this was the first book of the seven book series titled ‘The Chronicles of Narnia’. Many things had happened in this book but even more happen in the following six. Book one lays the ground work for the following six. Book one is the beginning. I liken this to my life since the transplant; many things have happened and it’s time to end this story, but I believe there are many more stories to come in the days the Lord will yet give to me.

But before ending this story I’d like to close with a few things which have happened since my last ‘journal’ entry, a few chapters back, on August 28, 2000. It’s now January 1, 2001. Happy New year! I know it is a very happy new year to me; it’s like my first new year, next May will be like my first birthday. Every day is now appreciated more than ever before as I never know how many I have left. But back to the topic: what’s happened from September through December 2000. Please read on to see. I think you will be amazed to see what has evolved in a short three months.

In September, over two months since the transplant and only a few weeks before starting work again I have been doing a little work by reading, to keep up to date on what's going on. As I have done almost nothing over the past year and work will be busy, catching up again, I need to get a few things around the home done now. Minor tasks as my stomach is still weak and tender. A little painting in one room, finish a chair rail in the dining room, a piece of molding on the floor. Remember you are not as strong as you probably once were so we must take work slowly and build our strength slowly. Riding my bike, which I enjoy, is also good exercise. I can work hard if I feel strong or take an easy ride if I feel tired or weak. One day Nancy and I rode 40 kilometers. That's the most I've ever done. My goal next summer, when fully recovered is 120 kilometers, from my house to my parents. Find some exercise or work you enjoy to slowly aid in regaining strength and endurance.

Back to work on September 25th; it's a good thing too, any longer at home and I think I would not have wanted to go back as there is a lot to do at home and lots of volunteer possibilities. But it is good to be back. Many people say how much better I look. Some people did not even know I was away as I don't work that closely with them, but they know me. I was concerned and nervous about how people would react, questions they would ask, if some would avoid me thinking whatever disease I had was contagious (many did not know what was wrong with me). But I was well accepted and welcomed back, a great relief. I do find that working a whole day is tiring, but after a few weeks I'm back to normal again. I take one morning a week for a checkup and blood test but this will slow down soon. Checkups are always good. Thank-you yet again Lord for my great recovery. Thank-you also Lord for the timing of the entire process. Summer is the best time to be home, sitting outside, walking in the warmth and especially as there are fewer germs and illnesses around.

Born Again

The reporter from the Toronto Star paper called in early October. She is working on the stories of the transplant patients and how they are progressing. We talked for a while about how I am doing, what I've been through. She told me how some of the others are doing. Many are either still very sick or recovering but doing so quite slowly. I am again humbled and thankful to God for what He has done for me, His great kindness and mercy allowing so little suffering for me while others, no different than I are going through hard times. She told me she is reporting on 12 people in total. I am eager to read the stories. I had the opportunity to talk for a few minutes at our church one Sunday morning. It was a difficult thing to do but I felt necessary. God put it on my heart to share one main point of my story and although I did not want too He would not let the thought leave my mind. The story I told is included here. Hopefully it has meaning for someone reading this book.

As most of you know I had a liver transplant this past June. I'd like to thank you all for your prayers over the past few months, and in some cases years of prayers. The Lord has been very kind to me, allowing me to recover very quickly with no setbacks.

One day about a year ago I was thinking about my upcoming liver transplant operation, even though I did not know the date. I realized that for me to live someone else would have to die. I really did not want someone else to die for me, but I know that's not my decision. If it's in God's plan for me then He will choose the person and the timing. The important realization is that someone has already died for me, that I might live. That was our Lord Jesus. I've known this since I was a child but it became more real that day.

Something else passed my mind. The person who would 'donate' their liver for me is not really giving it to me because they want to, out of the goodness of their heart or love for me, they don't even know who will be given a new chance for life. The person would probably wish to keep it for themselves, except they have died in some sort of accident. On the other hand the Bible tells us in Jeremiah 1:5 that 'Before I formed thee in the belly I knew thee; and before thou camest forth out of the womb I sanctified thee, and I ordained thee a prophet unto the nations.' If God knew Jeremiah before he was born then He knew and knows me. He knows the number of days of my life. He knows all the events which will transpire during those days. He knows all the evil things, all the sins, great or small I will ever think or do. Yet knowing all this before it ever happened Jesus still died for me. Jesus died not as the person who died and gave me their liver, in an accident, but He died willingly. Not only willingly, but submitting to torture and humiliation before a slow death on a cross. I am very appreciative of the gift of a new liver allowing me to live a few more years here. This has helped me to realize how much more appreciative I should be for Jesus' gift of living eternally!

In November I was asked to talk at Kennedy Lodge, a nursing home. One Sunday a month a group from our church talk there. A guest speaker usually comes and the group sings a few songs. I have again included my topic below in the hope it will be of benefit to someone reading this book. These two stories I have included are examples of how God has been using this transplant crisis in my life to provide a way for me to reach people in ways I would never have been able to otherwise. Doors are opening which I did not even know existed. This book is another example.

Israel and Palestine are fighting, over 100 people killed in the last month or so. Countless people die each year in the continent of Africa due to civil war, ethnic cleansing and Jihad, holy war.

Here in Toronto - gang wars in Etobicoke, two weeks ago a 13 year old slashed the wrist of an elderly woman to get the poppy money she was collecting. How are we to live lives of peace, how do we live in comfort with all this turmoil around?

Almost every family has problems of one kind or another: marriage problems, grown children not living healthy productive lives, young children who have no respect, teenagers who don't care about anything, the stress of such a fast paced society. Financial problems, emotional problems, physical problems. How are we to live lives of peace?

People try, they look many places. Some take drugs or drink to block the stress and worries of day to day life. Some seek pleasures of all sorts to feel some comfort. Some try meditation. Still others travel the world looking for new adventure and distractions. They keep searching as none of these distractions gives lasting peace or comfort. How do we feel peace? Not for the world, but ourselves?

There is only 1 answer: the Bible. Many different people talk about peace and comfort. Different programs, conferences, summits, government initiatives yet crimes get worse, criminals get younger, have less remorse. Psalm 71: 1-4, 18-24, summarized say "Trust in the Lord, hope in the Lord, praise the Lord." It does not say only in good times. Verse 23: says " my soul thou hast redeemed." What a comfort to know God has taken care of my soul.

Read Philippians 4:4-9. It says in part “Rejoice in the Lord, rejoice.” Not only sometimes but always. Care for nothing (worry about nothing). Peace of God will be with you. This does not mean to be careless, we still need to take care of ourselves and children etc. but we do not need to worry/care for the many things we do.

Look at Psalm 139:1-12. Verse 10 say “thy hand shall lead me, thy hand shall hold me”. Darkness cannot hide me from God. God knows everything about us, every detail of how we are made, what we do, what we think. Who better can care for us and guide us than the one who knows us best; the one who loves us most.

Romans 8:28 says “We know all things work for the good of those who love God and are called according to His purpose.” If we love God and are serving Him then no matter what we experience we can know for certain, as sure as gravity pulls things down, that it will work out for the best Also look at Romans 8:35-38. Verse 35 says “Who shall separate us from the love of Christ? . . . ” then the answer in verse 38: “Nothing!”. What more comfort can there be. Nothing, not even Satan can separate us.

In Psalm 50 verse 15 we read “Call upon the Lord in times of trouble and He will deliver thee.” Maybe not physically, but at least bring comfort and peace to your spirit to endure the trouble. A comforted spirit can endure anything whereas a healthy body and sad spirit often cannot. Job had tremendous trouble. Read the first few chapters of Job and see how his children, possessions, wealth and health were all taken away, yet he says “The Lord giveth, the Lord taketh away, blessed be the name of the Lord.”. What peace he must have had to be able to say that.

Finally, consider Hebrews 12:1: “ No chastening is enjoyable, but in the end it yields peace.” As parents discipline children neither party enjoys it, but in the end, if it is proper chastening then it will yield peace and growth in the children. I could go to many other verses, but I’d like to move on.

This is good news and encouraging, but how do we apply this to our daily lives so its real. It is fine to read it but how do I and you use it on a daily basis. I’d like to share my own experience with some physical suffering I went through, and how my wife and I could have peace through the ordeal. In fact many people were amazed at how calm and peaceful we were. Note - there are times when we had concerns and unrest, the devil is always working on our minds to pull us down, but when we turn back to God the devil flees, and our minds are again at rest.

I’ve had a liver disease since around 1992. It did not bother me too much, although I was in the hospital eight or nine times to ‘clean out’ my liver so it would continue to function. In August 1998 the disease got worse and I was put on a waiting list for a transplant. I had the transplant in June 2000 and I’ve been doing great ever since. I thank the Lord for His kindness in bringing me through so easily. There are two things I was reminded of while on the waiting list which directly relate to peace and comfort during difficult times.

First point is faith and trust. The Bible says in Prov. 3:5, 6 “Trust in the LORD with all thine heart; and lean not unto thine own understanding. In all thy ways acknowledge him, and he shall direct thy paths.”

If you trust in God, have faith, and believe He will direct your path then you know no matter what happens that God is looking out for your best interest. It may not be enjoyable, it may be physically or mentally painful but you know God is in control, He has a plan, and that's very comforting.

People who face serious illness tend to think about live and death much more than they do when healthy. This is when God can bring great comfort. You need simply believe in Him and He will care for you and bring comfort to you to carry you through whatever suffering you have to endure.

Second point is the power of prayer. I know I can stand here today because many, many people were praying for me during my illness. I know a few people who have been praying for me daily since I first became sick. Even during my illness I was not really that sick. My liver was weakening but it did not affect my overall health that much; the first answer to prayer. During the operation complications arose which the doctors did not expect but, extra tissue needed to complete the operation was available and the doctors completed the operation successfully; a second answer to prayer. There is a virus called CMV which 80% of people have. I do not have it, but the odds are that the liver I would receive would have this virus and I would get sick from it and be in the hospital up to a week longer. The liver I received did not have the virus and thus I was not sick and was discharged from the hospital in eight days; a third answer to prayer. And there were more. One great benefit of prayer is the peace and comfort of knowing God is there. Talking to Him reminds us He is watching out for us and cares for us. We are valuable to God.

Matthew 10:29-31 says “Are not two sparrows sold for a farthing? and one of them shall not fall on the ground without your Father. But the very hairs of your head are all numbered. Fear ye not therefore, ye are of more value than many sparrows.” EM Bounds says “Prayer in times of trouble brings comfort, help, hope, and blessing which, while not removing the trouble, enable us to bear it and submit to the will of God. Prayer opens the eyes to see God’s hand in trouble.” Prayer is incredibly powerful. It is our access to God; our way of influencing Him to take action on our behalf. I am extremely thankful for the many people around the world who prayed for me.

At one point while I was waiting I realized that for me to have a liver transplant, for me to live someone else would have to die. This really bothered me. I did not want someone to die for me. I was not at peace. One day God told me “don’t worry about it, it is not your decision. I will decide if and when someone should die for you.” This brought back the comfort I had previously enjoyed. But even more importantly He reminded me that someone had already died for me, so that I could live. Jesus died 2000 years ago on the cross so that I could go to Heaven one day and live eternally with Him. This is the greatest comfort there is, knowing that I do not need to pay for my wrongs, for my sins, because Jesus has already paid the full price. A great burden has been lifted from everyone who believes in Him. What peace and comfort this brings.

If you know Jesus then you also know He paid the price for your sins. If you don't have peace in your soul then you simply need to remember that Jesus can give you that peace, just pray and ask Him to be with you everyday. Pray every day for peace and strength to endure whatever that day may hold. God is faithful, He answers prayer, we need simply believe in Him and ask.

Isaiah 26:3 says "Thou wilt keep him in perfect peace, whose mind is stayed on thee: because he trusteth in thee. Trust ye in the LORD for ever: for in the LORD JEHOVAH is everlasting strength."

If you don't have this peace, if you don't know Jesus, if you don't have the comfort of knowing that your sins have already been paid for by Him then you need to get to know Him. Only through Jesus is there true comfort, true peace. Nothing this world has to offer, no amount of money, no amount of power or fame, no amount of drugs can give the peace that Jesus can.

Me, in Print!

Saturday December 10th 2000 was a really exciting day. The three day series of articles about organ transplant appeared in the Toronto Star newspaper, Life section. Saturday was a short introduction about organ transplant and pictures of the twelve people followed. By each picture was our name and a sentence or two introduction to who we are. Three of the twelve had detailed stories written about them. Three more were written in detail on Sunday and Monday was the conclusion. Six of the twelve had detailed stories. The six were two heart, three lungs and one liver transplants. I was chosen as the liver transplant. My story was

on Sunday. Of the six stories only two of us, myself and a twelve year old girl did really well. Three died during or after surgery due to complications. The Lord continually reminds me how He has allowed me to live, for some purpose, while others have been taken. The sixth person is living but not recovering very well.

The Sunday evening, the same Sunday my story appeared in the paper a man from east Toronto called me to talk. He had a transplant a few years ago. It's taken him a long time to recover and even now is not totally back to optimal health. We talk for a while. I told him a little of my story and tried to encourage him. Another opportunity to talk to someone about a common problem, to encourage someone who I would have never had the chance to talk to if I had not gone through all this.

Just before Christmas the reporter called. She told me the sixth patient she had written about was getting really bad. He was rejecting his double lung transplant. The strong anti-rejection drugs which should counteract the rejection were not working. Without a second transplant or a miracle the man would die. She also asked me to ask people at my church to pray for this man. Not only for him but also his wife and five year old daughter. It really hit home as I too have a five year old daughter (and a wife). A few days later there were a lot of people praying for him. The reporter also said that Robin is still sick. I have been praying for her as well as a few others at church. I will do so more often now.

Today is January 1st 2001. The start of a new year, a year doctors had told be three years ago I would not see. At that time I did not really believe them as I felt quite good. Even one year ago I thought I was doing pretty good. My health was going downhill but it was slow. Now, looking back I have no regrets. I know again that God has me in His hand; the timing of every step was perfect. I see now that my health was getting worse, quicker than I thought. I am so thankful for the opportunities I would never have had. Jeremiah 29:11 talks

about God's plan for us. I can see He has a plan for me. I also know He has a plan for you.

I had lunch with the reporter on January 3rd. The man we have been praying for is on life support. Of course I do not know what will happen, only God does. God can do anything, we pray and ask God for what we want, hoping it is also what He wants. I gave the reporter a story, a true story about a woman a few years back who had tuberculosis. Doctors tried various things to help, nothing worked. As a last straw they applied pressure to her lungs trying to get the hole to close up and heal. It did not work and she was going to die. She also happened to get pregnant which was highly unlikely due to her health. As the baby grew inside her it put pressure on her lungs causing the hole to seal up and she was healed. Miracles can happen, they do happen! God can heal where the best doctors in the world are hopeless.

I'm coming to the end of the story now, at least for your reading. I'm hoping my story will go on for many years yet. It is April 4th 2001. My family and I just returned from a Florida vacation. May is my birthday, like a first birthday. June 20th is coming soon, my one year anniversary. Each is a joyous event to look forward to. The Lord has given me a second life on this earth. Many people at church and relatives are still praying, but one great woman told me she has stopped praying as I am healthy and other sick people need her time. Many still tell Nancy and I they are amazed at how well I'm doing. Twelve people of many were followed in the newspaper, only two did well. The two came from backgrounds of faith whereby families and church families prayed. Without discrediting the ability of doctors there is no better medicine than faith in Jesus, the creator and sustainer of the universe and thus each of us. If you remember only one thing from this book then remember that God is life, if this life fails be sure the next one will not. Trust Him, believe in Him.

Appendix A: Letter to my family



To : My Family, whom I love

From: Your father and husband, who loves you,
November 1999

Proverbs 22 verse 6 says “Raise up a child in the way he/she should go and when he/she is old he/she will not depart from it”. Robert, Matthew, Lyndsey, there is nothing more that I desire than for each of you to know “which way to go”. My desire is that your mother and I can raise you so that the way you go is to follow Jesus. If you’re reading this, then probably I have died and your mother is raising you. My hope now that I am no longer with you is that one-day you will join me in heaven, so we can again be together with our Lord forever. The purpose of this letter is to give you some suggestions and ideas to help you through life. I’ve been around a few years now and God has taught me some lessons. If I can pass some of what I’ve learned on to you, then your journey through this world will be easier, and my purpose complete.

Philippians 1:6 says “He who has begun a good work in you will carry it on to completion.” God has begun a good work in each of you. You all have been raised, thus far, to know the Lord, to learn about him at home and in church. God has used your mother and I to start your life on the right foot. As you move into your teenage years you will become more responsible for yourself, and your walk with the Lord. I pray you do not stray, but even if you do, the Lord will carry on to

completion the work He has begun in you. If you stray the road will be rougher, you will have more struggles but God will carry you through. 1 Cor. 10:13 says “you will not be tempted beyond what you can stand. But when tempted, God will provide a way out.” Always go to God for direction. Prov. 3:5 says “Do not lean on your own understanding, but in all ways acknowledge Him and he will direct your paths.” God is in control, at all times, even when you think He is not. Trust in Him, let Him direct you. This is the best way, in the long run it is the only way.

Some times you may miss me. That’s normal. You would like to talk to me, tell me what’s going on in your life, what struggles you are having, what accomplishments you had. Robert and Matthew may need someone to talk to about your girlfriends or Lyndsey to talk about your boyfriend. In these cases, go to your mother. She is very smart, sensitive, and understanding. From the very first day Nancy and I started dating I could talk to her, about anything. She is the only person I’ve ever been able to do that with. Listen to your mother. You may not like what she has to say sometimes, but I think that if you truly listen to what she’s saying, and think about it you find she’s right. You should also go to the Bible. The Bible is full of answers. Sometimes it takes a little digging, but there is a wealth of knowledge and answers. Before reading ask God to open your eyes and mind to His words.

Never despair, never give up hope. Always trust and believe that God is in control. This is hard to do in today’s world where there are so many terrible and evil things going on, people telling you “God does not exist, if he did, he could not let all this happen. He cannot be a loving God.” This is false, totally false. God does not cause bad things to happen, He allows them to happen. People and Satan bring bad things upon themselves and each other. People allow Satan to enter their lives and destroy it. Do not ever blame God for the problems of the world. Do not doubt God, He is real, and is in control, and soon He will set everything right again. Read Job chapter 38 thru 41 or even better the whole book of Job. God

says many things here to which we can only say “your right, sorry for ever doubting you.” He is still in control. He always will be in control.

People will say there is no God because if there was he would not allow all this suffering through-out the world. This is false. False, worldly logic. The Bible shows us in many ways, right from the beginning through the end of the problems man has brought on himself. God created man without sin in the Garden of Eden. Man and woman disobeyed God and thus sin entered the world. All actions and decisions we make have consequences. Man and woman’s decision to eat the fruit from the Tree of Knowledge of Good and Evil was disobeying God’s command to them, and thus they had to pay the consequences. God still loved them, and He loves each of you, but the price for the disobedience still had to be paid. We as Adam’s descendants are still paying that price. Even the greatest people in the Bible, such as Moses and David disobeyed God and had to pay a price, a great price, but they are still listed as great men in the Bible. God’s love is unconditional, we cannot do anything to lose it. That is great encouragement. But, we must accept that God disciplines us. We can take great joy in knowing that soon Jesus is coming back and put an end to all the suffering. When we consider the time of eternity which we will spend with God, the years of suffering we see here on Earth are nothing, they are but an instant in the big scheme of things.

As you get older you will hear in school, on the radio, on TV, at church, everywhere about the problems in the Middle East. Israel and the surrounding nations are always on bad terms with each other. Much of the time the media will make it sound like Israel is the problem. Israel is causing trouble for the Palestine people. Israel is too hard. Do NOT believe it. This is another lie of Satan, working through the news media and peoples ideas. The Jewish people were promised this land 3000 years ago and the Arabs have no right to it. In fact the Arabs nations already have 99.9% of Israel’s land in the Middle East. Even in recent history, back in 1948 the United Nations declared Israel a nation, and given them the land they

now have. This was given to them. The Arabs have no rights to it. In fact, the Arabs attacked Israel many times trying to take the land, and they end up losing. God has His hand upon Israel. Israel has already given up more than half the land they were originally given. The Palestinians will not be happy with the land they now seek. They will always want more. The Arabs will not rest until the Jewish nation does not exist. This is because Satan is working through the Arab people. Israel is far from perfect and goes through much of their problems because they do not accept Jesus as God, but the Bible also tells us that all this must happen in preparation for Jesus' return to Israel. Israel is God's chosen nation, and we need to respect that and help them in any way we can. Do not ever give in to the idea that the Palestinians have any rights to this land. At one time the two lived in relative peace, it was the surrounding nations that caused the unrest.

Speaking of school, you will be taught many wrong things. Unfortunately not all teachers know the truth about many of the social issues or moral issues. They teach the currently popular ideas. They will teach that abortion is OK, that euthanasia is OK, man and woman living together before they are married is OK, man and man having a relationship together is OK, or woman and woman together is also OK. These ideas are all wrong. Again Satan has distorted the truth, and people go along with it. Simple common sense, looking at the facts about life, death, disease, the purpose of marriage will show that all the above accepted things are totally wrong, and this is without even looking at the Bible. If you look to the Bible it is very clear that the above are wrong, and severely wrong. These are the worst kinds of sins. Read Romans 2:24 through 32. God says that our bodies are "holy temples unto Him". Anything we do to one of God's temples is an extremely serious sin.

Each of the above actions does something to one of God's temples, a person's body, and thus is seriously wrong. Do not give in to popular teachings. Do not let anyone say that your thoughts are old fashion, or that you are homophobic. The people are just refusing to accept their own sins and using

fancy words and titles to try to make you feel guilty, when in fact you have done nothing, they are the sinners. Do not buy into their lies, see the truth. Seek answers from your mother, your pastor, the Bible. God will give answers and the words to speak, if you earnestly seek. But always remember “to love the sinner, hate the sin.”

Friendship is one of the most important things in the world. The Bible tells us over and over to “love one another”. There’s a saying that goes “do unto others as you would have others do unto you”. Give people a chance. Everyone, everyone makes mistakes. Also, never judge someone based on what another says. People are great at exaggerating the truth to make their point. As each person exaggerates, the truth gets more and more distorted and eventually its nothing but a lie. Judge for yourselves, and even then do so with grace. Even when you think you know the situation, you probably do not fully understand the background or all the factors involved in the situation. Many people go through trials and struggles we cannot even begin to imagine, let alone think of the impact those trials have on a person. Help others overcome their struggles wherever possible. Think of the story of the “Good Samaritan”. Jesus tells us in that story who our friends truly are. Do not contribute to gossip. “The tongue is sharper than any two-edged sword.” It is true. I’ve heard and seen innocent people ruined by the wrong and harsh words of others. Always talk in such a way as to build others up. This includes correction and pointing out wrongs in a person, but do so thoughtfully, carefully and lovingly.

Friendship or lack of it can be a cause of depression as well. No one is perfect, and friends hurt each other occasionally. This and many other things can cause depression. Many young people these days take a drug called Prozac. This is an anti-depression drug. Please be careful. If you ever get depressed to the point of wanting to take drugs to help, then you need some other type of help. Speak to your mother, pray to God. He alone can help you. Never despair, God is always with you and will help you through any problem that may arise. Your brothers and sister are the best source of friends you could ever

have. Always do your best to keep them as friends. Be quick to forgive and slow to anger and slow judge. Always be open to suggestions and criticism and always assume the best in each other. A gentle and forgiving attitude works wonders. If times get tough, probably your brothers and sister are the ones who will be there for you.

Your mother will probably decide to get married again. She is a very loving woman. I cannot see her spending her years without the love and companionship of a husband. This has nothing to do in any way with not loving you children. She will always love you, but she needs a husband. This new man will become your father. No one is perfect. I was not, your new father will not be also. Please try to work with him. Love him and respect him. He will only want the best for you. Never, never compare your new father to me. We are each different, unique individuals. No two people are the same. I had some good qualities, your new father has some good qualities. We each have some bad qualities as well. Always look for the good qualities.

As you grow older you will start to think about what you want to do with your life. What type of job you want, what you like to do. Do you want to travel, do you want to go to university? I would like to suggest that even if you do not want to go to university that you at least give it one year. Give it a try. Talk to your mother about it. She did not want to go either but after starting she loved it. If she had not gone I would have never meet her. Education is very, very important. As time goes by it becomes more and more important. Almost any type of job these days requires good education. When you are considering what to take at university you also need to consider what type of job you want to do. Don't just consider money, as money does not make a person happy. Your work/job/career will be the largest part of your day, of your live. It is important that you enjoy what you are doing. An eight or ten or twelve hour days will seem extremely long if you do not enjoy what you are doing. Take time to decide what you want to do. Give it lots of thought. Talk to people you know who are in different careers. Go to job fairs. You should start doing this in high

school so that by the time you get to university you know what you want to do. No matter what you decide to do, Ephesians 6:7 says “Serve wholeheartedly, as if you were serving the Lord”. That means do not work to please your boss, but work with integrity and honor to please God. The Bible also says in Prov. 30:8, 9 “it is blessed not to be rich or poor”. Poor people are always struggling just to survive; not much fun. Rich people tend to swell up with pride at what ‘they’ have done, how ‘they’ have gotten rich when in fact, God gave them the riches. Even though a person may work hard to get wealthy, it is still God who gave that person the ability and drive to work hard, the intelligence how to work and make the wealth, it is still a gift from God. In both of these cases, people tend to drift away from God.

Part of your work should be working for the Lord. You should volunteer for charity work, help around the church with the youth group, or ushering. Go on some missionary trip to help out. Sometimes people just want someone to talk to. There are endless needs and few workers to provide for those needs. The Bible says in Matt. 6:19, 20 to “store up treasures in heaven where they cannot be destroyed”. This is the type of activity that will store up those treasures. It does not matter how much or how little you can give to the Lord, it only matters that you DO give. Rich should give a lot, poor can give little, but all can give, whether money or time or talent, it does not matter. I’ve heard of people, who plan to give to the Lord from their great riches, “when the Lord gets them a little richer”. What does God do? He takes away the riches they have. Do not say “next year I will give to God”. No, give this year and next year, whatever you feel is appropriate.

Above I mentioned “build up treasures in heaven”. This can be a little confusing. The Bible says in Acts 16:31 “believe on the Lord Jesus Christ and you will be saved.” It’s as simple as that. Believe in Jesus and you will go to heaven. Ephesians 2:8, 9 say “By faith are you saved, through grace, and this not of yourselves but a gift of God, not by works that no one may boast.” This again says that we must believe, have faith to be saved and no matter how many good works we do, it does not

save us. The Bible also talks about building up treasure in heaven and about rewards. These are for after you get to heaven, they have nothing to do with getting there. Believe in Jesus and you will go to heaven, and once there you will get your rewards. Those rewards are based on your life here on earth. What good you have done. Great people like Billy Graham who allowed God to use them to do great things will receive great rewards. Christians who believe but do nothing for their fellow man will receive few rewards. This is just like the working world, or the way it should be. Those who work hard and do the best job get the best rewards.

I have gone to heaven ahead of you. I know your mother believes and will be joining me some day. I look forward to that day. I also look forward to the day that you, Robert, Matthew, Lyndsey will join us in heaven. That will be a glorious day. For that to happen, you must believe in Jesus. In the previous paragraph it says “believe on the Lord Jesus Christ and you will be saved.” If you do not do this, if you do not believe then you will not go to heaven, and your mother and I will never see you. That is my greatest fear about not being alive to help you grow spiritually. But, God has everything in His control, and has decided to remove me from the scene. You are old enough now to study, search for answers and make up your own mind and heart about whether to believe or not.

Many churches these days are preaching the Bible but with wrong interpretations. Some talk about a “holding place” called purgatory. Some say there is no hell. Some say God is love and could never send anyone to hell. Others say we have God within us. These are all people whom Satan has deceived. Hell is real. Hell will be filled with real people. All the people who believe in purgatory, or God is love, or we have God within us, may also be in hell. Its true God is love, but God is also just, and demands people follow Him. They must believe the truth. If not, they will go to hell. Heaven is an eternal place. That means once one goes there they will stay there with God forever. Hell is also eternal. People who go there will be there forever as well. This seems hard to understand, how someone

could be punished forever, but the Bible says in Rev 14:11 “they will be tormented day and night forever”. Please give God a chance. Believe in Him. Let Him open your hearts and mind so you will believe. There is nothing more that I desire than to see each of you in heaven.

Speaking of heaven, I wonder often how large everything is. It does not matter how much we can envision, how vast our imagination, how creative and intelligent we are, God is far more. We cannot imagine. Read the last 4 chapters of Job. If we think of the earth or even the entire universe, and how vast it is, and place that in the palm of the hand of God, it would be like a speck of dust. The Bible talks about the “sea of glass in front of the throne of God”. Our universe could be like a small air bubble or molecule of water in that vast sea. God is able to listen to the thoughts and prayers of every person on earth, at the same time. God knew everything that did happen and everything which ever would happen even before he created anything. We have no idea of the scope of God. Anything we do He already knows about before we do it. Nothing we do in secret can be hidden from Him. This means no problem we ever encounter is too difficult for God to handle and solve. Corey ten Boom (read the book, or see the movie ‘The Hiding Place’) says “no pit is so deep that God’s love is not deeper yet.” He can see all possible solutions and knows the outcome of each, and which is best for us. We may feel lost and under great stress, but it is needless. We must trust God and seek answers to our problems from Him. Often it will seem as if we did not get an answer. That usually means we need to wait longer, and keep trusting in Him. We must also accept answers which we do not like. Again He knows what’s best, not us.

Nancy, the first year or so after my death is probably a very hard time for you. You will greatly miss my company. Someone to talk to about anything and everything, someone to warm up the bed for you, someone to help with the children, someone to go out with, someone who admires you and compliments you, and many other things we did together. I can provide two points of encouragement. First, the way you feel will pass in time; you just need to give it time. Secondly, I

am still with you. Not physically, but I am in the family pictures and also in your memories. I will always be with you. Things I have said, phrases I used will come back and remind you of me. Try not to feel too sad, and never bitter. Never ask God why, or blame God, thinking He made a mistake, or that you do not deserve to be left alone. I think you would agree that the years we had together were very good years. We were a perfect match for each other. God brought us together at university, and now has seen fit to temporarily separate us. "The Lord gives, and He takes away", but in all cases, "Blessed be the Name of the Lord". Never ask God why, but ask what? What is His purpose in this? God always has a plan. Often we do not see that plan until it is well underway, or even complete. Ask God to show you His plan, or at least help you to follow His plan. Remember the C.S Lewis book "A Horse and His Boy". In it Shasta goes thru troubles from when he is a baby until a teenager. He thinks everything is working against him. It's at this point that Aslan (Jesus) appears to him explaining the events of his life and how Jesus has been there many times causing the events to happen and thus shaping his life leading to the exact stage he was now at. Nothing happens by chance. God is ALWAYS in control.

Nancy, at the beginning of the Bible in Gen 2:18 God says "it is not good that man should be alone, so God made him a helper who was fit for him." You are a very loving woman and thus I think you should have a husband. If you do find yourself lonely especially as the children get older and leave home, if you meet a man and start feeling attracted to him, please try not to compare him to me. Every man and woman is different. I realize it will be hard not to compare, but you must make an effort. I'm sure that the man God provides for you will be an excellent man. He will also be different than me. You must look at those different, good qualities. What else can I say. You have lived with me long enough to know how I think about many things. One last piece of advice is to always pray about anything you are seeking an answer for. Search the Bible for answers, they are there, but often it takes some reading and looking. At other times you just open the Bible

and start reading and the answer is right there before you. Either way, the Bible and prayer are the way to the right answer. I know you have a hard time finding time to read the Bible, but it is important. Through prayer and reading we get closer to God. Spend time reading the Bible. God will speak to you through it. If His plan happens to be to not marry, then I know He has other plans for service for you. I have been very proud of you lately. Since Lyndsey has gone to school you have started to spend time in the Bible, thru Vernon McGee's tapes. That's great. Keep it up, always!

Another last piece of advice is to keep your calm. It is hard to do sometimes, after a long day, when the kids are giving you a hard time. Be sure to have breaks from the kids. Get a sitter. Pray for self control and peace. Try to discipline the kids without anger. Try, that's all I can ask. Best wishes. I've been praying for you in this area before I died, and other areas as well. I've also prayed many times for the children to grow to love the Lord, and find Christian women/man for spouses. I believe God will honor those prayers, but it does not hurt for you to continue praying, in fact it helps.

Robert, Matthew, Lyndsey, I'd like to tell you the history of Nancy and myself. We both went to the University of Waterloo. I lived in an all-male residence. Nancy lived in another residence. We both independently decided to play recreational broomball. We ended up on the same team. I had always been very shy with girls, and still was. But, I decided to introduce myself to someone, and Nancy was that girl. We became friends through broomball. Then one day there was a dance. I attended with some male friends in my residence building. Nancy also attended. We did not know each other was there. At some point she saw me and asked me to dance. That was the start of our dating, during second year of university. One year of dating, then about two and a half of engagement. Just after we graduated we were married. Nancy was the second date in my life, and my first girlfriend. What is my point? My point is that there is nothing wrong with not having a lot of boyfriends or girlfriends. In fact, I think that the fewer you have, the better. If you wait for God's timing, for

everything to be right, then you cannot go wrong. You will not end up doing something you will regret. You will marry the right man or woman and not need to think about divorce. God brought Nancy and I together and He will do the same for you if you let Him. Seek His will, pray and ask for the right spouse and God will honor such a noble request. Society, TV, movies, school will all indirectly teach you that many boy or girl friends is best, be sure what you like, play the field first, and more. It is a lie. The more you play the field the more opportunity there is for an intimate relationship(s), but that should be saved for the marriage bed.

Robert you are a lot like me, a real lot. I hope you don't think this is a bad thing. Each person is unique. Each of us has our own personality, which God has given us. It's like fingerprints, no two are the same. But, at the same time, each child inherits characteristics from their parents, both parents. You have inherited a lot from me, in your looks, your body structure, your mental abilities (you're very logical and mathematical), and your attitude. You take a positive outlook on things, always looking for the good point. This is a very good trait to have. You are very good at math, so you will probably like a job in a field like computers, or science, something technical. You also struggle, as I did, with reading. I was never a good reader. Not until I finished university did I enjoy reading, and now that I enjoy it, I am also getting much better at it. You will probably be like this also, but you can be different. If you realize that you struggle with reading, you can work harder at it, and improve. It will be hard at first, but in the long run you will be better off. The better reader you are the easier school is. Even math and computer courses require reading. You are also the oldest of my children. You are the most responsible. You are thus a natural leader. Matthew and Lyndsey will always look up to you as an example and leader for them. They may deny it but deep down inside they know you are the older brother and they will respect that and look to you for an example. Please try to be a good example. No one is perfect, and I don't expect you to be either, but with God's help and direction you can be a good leader and role model. Sports

activities are probably hard for you. I was never very good at sports. In fact, I dislike most sports. I find I am better at sports like tennis and squash. I like the individual sports. I also enjoyed basketball, probably because I was tall. You too will be tall, and basketball is probably something you will like. Nancy and I have tried to get you into sports younger than I was when I started, in the hope that you will find something you enjoy and be good at. So far baseball and swimming looks good for you. I also enjoyed swimming, and was very good at it. I was the best swimmer in my grade eight class. If you stick with it you also will be good. In all this I am not trying to discourage you from any sport, I encourage you to try and play anything you enjoy. I am simply suggesting some you may like. Whatever you do, just enjoy it. Do not worry about being the best. Each person has different talents and abilities in different areas. There are very few people who are good at many things. Most people are good at only one thing.

Matt, you're the more athletic one. You have a natural God given ability to learn sports and are well coordinated to be good at playing them. You also have the more carefree and risk taking attitude, which helps with sports. Take advantage of your abilities, enjoy sports and be good at them. At the same time don't let your abilities swell your head and think you are so good. Always remember God gives and God takes away. God has given you these abilities, and you should give God the appropriate praise and thanks. Girls are attracted to athletic boys, in high school and university. You must beware. There is nothing wrong with girls and dating but you must learn to control yourself, and what you allow yourself to get involved with. As you are the risk taker, you are more likely to get into serious trouble. Always remember that "for every action there is an equal and opposite reaction". This is one of the laws of nature that God has established, and He always enforces it. Read about David and Bathsheba, read about Moses and striking the rock, read about Jonah and fleeing from Nineveh, read about Samson and Delilah, and there are many more examples. Society these days tells people to be free and do whatever they want. But God says we are all responsible for

our actions. You cannot blame anyone else for your actions. Read about Adam and Eve. They tried to blame each other and the serpent. God held each of them accountable for their actions and each had a price to pay for their disobedience. Self-control and discipline are going to be your problem areas Matt. You will need to learn to control yourself or you will get into trouble with your mother, with the police and with God. Whatever pleasure the action may bring, it is not near the pain that the re-action will cause for yourself, your mother or the girl in the long run.

Lyndsey, it's hard for me to give you much advice as you are still go young. I have some feelings on your personality and I have to admit it is scary. You are an attractive happy young girl. You have your mothers' good looks and generally happy disposition. You also have a stubborn streak that could be the cause of a lot of trouble between you and your mother. I can see already that you are very bright, and know right from wrong. The trouble is that you like to test the limits, to see what you can get away with. The advice I can give you is twofold. First is to realize that no matter what happens, your mother always loves you and wants only the best for you. It may not seem like she is doing the best for you at the time, but believe me, she does want the best. Listen to your mother. Even if you do not agree, at least listen to what she has to say. Do not block out her words, and ignore her. Even if you do not follow her advice, listen to it, and then decide what to do. Remember that you are a big girl, and are responsible for your own actions. As I said to Matthew, there is always a reaction for every action. If the action is bad, the reaction will be equally bad. You need to consider this before you do the action because once the action is done, the reaction will come, there is no way out. Look at David and Bathsheba, they had an action, an affair, which was wrong. Even though David repented to God he still lost his first son and the rest of his live he had family problems. A great, great price was paid for what started with one moment of weakness. Secondly is that you need to loose your stubborn streak. It will be a cause of much trouble for you. Not just with your mother, but with teachers,

with friends both girls and boys, and could get you into trouble. It's very hard to think clearly when you are mad about something. Being stubborn is like being mad, you do not think clearly. You will do things that are wrong, just to try to prove yourself. This is an area you will have to pray about and work on. I think that from what I see in you already, even though you are only 3 years old is that you will be athletic and smart. With this combination you can do great things with your life, as long as you do not make too many mistakes along the way. Lyndsey, always think before you act!

Robert, Matthew, Lyndsey, the last topic I have to give some advice on is sex. This is also the hardest topic to discuss. Not only because most people find it uneasy to talk to their children about, but also because it is something that's best to talk about, and not read about, so that questions can be asked and answered. As I am not around, you will have to go to your mother with your questions. I'm sure she can answer them properly. There is a difference between love and sex. You will probably be taught that the words mean the same thing, and they should, but most people, at least teenage and college boys think of sex as an act that takes a short period of time and then it is done. Young women think of them as the same, and that sex is part of love. This is how it should be, but the love part comes before the sex part, long before. Love must grow and grow and grow over the years of dating, leading to a decision to get married, after which the love that has been growing can be completed with the enjoyment of sex. Sex outside marriage is not true love, no matter what people tell you. The Bible is very clear about sex outside marriage. It says the "body is a temple to the Lord". The Bible talks about many sins but any relating to the body, most of which are sexual in nature, are always looked upon as the worse kinds of sin. They have the worst consequences. I believe the sexual types of diseases such as aids are a direct result of the sexual perversion of men having sex with other men, or women with other women. God does judge and is judging. Sure some people get it from needles or blood transfusions, but that does not negate the fact that the original cause was sexual sin. When a man and

woman are married then Gen. 2:24 says “the two shall become one flesh”. It is also stated in Eph. 5:31. These verses clearly tell us that divorce is not acceptable to God. When a man and woman are married it is for life. Divorce is not an option. Be sure you know whom you are getting married to before you get married.

Your mother and I had never had sex with any person. We had not indulged with each other either until after we were married. This is the best decision we ever made. There is no regret, no one else to compare to, no one else to think was better and thus we miss that person. God gives us laws in the Bible for a reason. He knows what’s best and clearly keeping sex for marriage is best. Giving you spouse your body is the greatest act of giving you can do, other than giving you life. From a purely medical side, if you give someone your body, and that body has been with one other person, and that person with one other, and so on, then you are now joined with all those other people as well. Any diseases they may have had you now have a chance of catching. The few moments of pleasure are not worth the lifetime of problems it will create, or the reduced lifetime you will end up with from some disease. Sexual relationships are very difficult to avoid. Nancy and I were tempted more than once as well, but thanks to God we saved ourselves for marriage, and as a result God has greatly blessed our marriage. Your mother and I have the best marriage we know of, from any of our friends or people we hear about, and I think this is directly related to the fact that we are both now, and have always been totally devoted to each other. We have not, and will not allow any other people to come between us. My prayer is that each of you will look for the long-term benefits of marriage and sex after marriage and not fall for the idea that short-term fun has no long term consequences, because I tell you it is a lie.

I love you. I always have, and always will. I seek only the best for each of you. No matter what happens, you must always know I love you.

Love Dad, Ed.

Appendix B: Drug Side Effects

Appendix

B

All drugs have side effects of one type or another. Some side effect are minor such as nausea, tiredness or bloating (water retention).

Other effects are more serious such as osteoporosis, chance of kidney damage or liver failure. The key is to take the drugs needed to allow you to recover from the transplant and control rejection of the new organ which at the same time minimizing the negative effects of these drugs. Usually doctors will give a variety drugs in quantities as small possible. These drugs are picked as they work together such that two drugs in a small quantity work more effectively than one drug in a large quantity. With the smaller quantity the side effects are also smaller. For example there are currently three main immunosuppressant drugs used. These are Cellcept, Tacrolimus (also called Prograf) and Cyclosporine. Prednisone is also used as an anti-inflammatory and usually used temporarily due to its negative side effects. By giving relatively small doses of two or three of these the desired effects are the same as one drug in a larger dosage while the negative effects are reduced.

Below lists the most common drugs used in organ transplant, their various names, desired function and most common side effects.

Prednisone

Desired Effect	Negative Effects
Cortisone like drug used to prevent rejection. It works by suppressing the immune system which tries to reject the transplanted organ.	Bone disease, infections, cataracts, stomach irritation, water retention, facial puffiness, increased appetite, blood sugar elevation, night sweats, mood swings, bruising hair growth, menstrual irregularities.

Cyclosporin (Neoral)

Desired Effect	Negative Effects
Anti-rejection drug which works on specific cells. It suppresses the immune system thus preventing rejection of the organ.	Increased blood pressure, toxic to kidneys, trembling in hands, hair growth, stomach upset, loss of appetite, nausea, infections, increased risk of cancer, gum swelling.

Tacrolimus (Prograf)

Desired Effect	Negative Effects
Anti-rejection drug which suppresses the immune system thus preventing rejection of the organ.	Increased blood pressure, toxic to kidneys, increased risk of cancer, nervous system (headaches, sleep disorders, mood changes, tremors), diabetes, infection, stomach upset, diarrhea, nausea.

Imuran (Azathioprine)

Desired Effect	Negative Effects
Anti-rejection drug which inhibits formation of white blood cells thus reducing the bodies ability to reject the new organ.	Increased risk of cancer, stomach upset, yellow skin color, dark urine, decreased hemoglobin (tired feeling), bruising and bleeding, infection.

Conclusion – August 28 2007

Conclusion



Today is a warm summer day. I finished work, had supper, and am now just finishing editing this book. Although most of it was written at least five years ago, I have decided now to publish it. I have printed and given away twenty or more copies over the years to people Nancy or I have met who have some kind of serious health problem in the hope this short book will encourage them both physically and spiritually.

I weigh 172 pounds now, about 78 kilograms for the younger group on the metric system. My weight has been steady for years. I continue to exercise, which I started before the transplant to improve my health before it deteriorated too much. I jog and bike ride mostly, but also enjoy tennis.

My three children are now eight years older than when I wrote the letter in appendix A so it is out of date. The Lord has enabled me to spend an additional 7 years with them, so far, as well as with my amazing wife Nancy.

Despite an infection a few years back due to a liver biopsy, checking for rejection, I have done very well. I continue to take drugs to combat Ulcerative Colitis. I find that Metamucil is the most effective. I continue to take Tacrolimus to ward off liver rejection, which was just starting as discovered during the biopsy. Imuran has been added as a second anti-rejection drug to help. I go for blood tests every three months allowing the hospital to monitor my condition. It is pretty stable. Occasionally my creatinine level spikes and my transplant coordinator reminds me to drink lots of water. The water helps my kidneys function better. The kidneys work harder when they need to remove drugs from my blood system. Kidney

failure due to the strain drugs place on it is a common problem. So far my kidneys are handling it well.

As a final note, I was told in my annual checkup yesterday that PSC, my initial liver disease is now attacking my transplanted liver. I have learned that the disease is in fact not in the liver but in my body attacking my liver. Thus the disease exists after the transplant and is now working against my new liver. Fortunately it progresses quite slowly and apparently the disease weakens as a person ages. So it is possible that I will need a second transplant and also possible the disease will calm down enough that it does not damage my transplanted liver to the degree that I need a second transplant. Only time will tell; only the Lord knows. I must live each day as best I can and not worry for I know the Lord Jesus Christ is in control and He always does what is best.