

My Life With Multiple Sclerosis



Learning to live with Multiple Sclerosis

My personal Story

By

ANTHONY VIRGONA

Foreword

I have dedicated this book to myself and all people with Multiple Sclerosis as well as MS Victoria for all the support they have given me over the years.

It's important that we keep on fighting this disease until they find a cure, hopefully in the near future.

I have so much admiration for all people with Multiple Sclerosis and have written this book to raise awareness about this disease and to say never give up and keep fighting. There is always a positive to help you get over that negative, never forget that.

ANTHONY VIRGONA

Acknowledgements

I would like to thank the following people. My mother and father: you have been my inspiration; you have been there for me and love you both.

My sister and family for giving me the courage to keep on fighting, for your love and support and for this I love you all.

All my wonderful friends: knowing your there for support gives me the strength to fight on.

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Professor Trevor Kilpatrick and the staff of the Royal Melbourne Hospital, who have done so much for me. You all have shown support, encouragement, guidance and dedication. Thank You.

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To all the above I thank you from my heart because without you I would not have had the courage to keep on going fighting this disease.

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State Societies

1. The Beginning

The alarm clock is buzzing, the sun is shining and it is time to get ready for another day's work. Only one problem, today I don't feel my normal energetic self. I am feeling very tired and struggling to get out of bed. So I manage to get up, a quick cup of coffee and off I go.

Driving to work, I could feel that my right leg was acting a little strange, a bit stiff and having trouble with the accelerator and brake pedal. When I finally got to work I was concerned as I was feeling very tired and had no energy, when a friend called out are you OK mate. I said I was fine and went on with my job. As the day went on my leg got very stiff and could hardly walk and finally could not go on any further and virtually collapsed.

At this stage everyone was concerned and sat down to rest for a while, but decided to go home. On the way home I was having trouble driving so decided to go directly to my local doctor. On arrival I complained of feeling weak, tired, and had numbness in my hands and feet as well as stiffness in my right leg and losing my balance.

He did an examination on me and said it was best for me to go to the Royal Melbourne Hospital for further tests. This got me very worried as he could not tell me what was wrong. So that afternoon I found myself in the casualty unit. I remember on the way to hospital asking myself am I having a stroke. It cannot be, am too young for that plus never been sick before apart from the common cold.

On arrival to the hospital the doctor on duty asked me to lie down on the bed and asked me to explain what had happened and how I was feeling. I explained the weakness, tiredness, numbness loss of balance and the stiffness in my right leg.

He then explained he was going to use tiny needles to test my reaction response. I lay there for ages and wishing he would move on with it, but seemed like it was taking forever. I then felt pinpricks in my hands and feet and the next minutes he is gone. Must have been his lunch break.

It's now afternoon when another doctor comes in and told me to walk a straight line along the pattern on the floor. Maybe they thought I was drunk.

At this stage I wasn't too concerned, however did not understand what was happening and why. Now the doctor told me he wanted a neurologist to examine me. This time I started to panic as neurologist for some reason reminded me of brain.

My patient friend beside me looked a bit concerned and said Anthony you know that your response was slow when the doctor was sticking those pins in your hands and feet. Thanks mate I really needed to hear that.

I have been here three hours and finally the neurologist Dr Kilpatrick arrives and has a chat with the doctor. Next he does his own examination, so again I go through the same questions but this time he did a test on my eyes. After he had finished I asked him "what's wrong", he told me "guess what" not sure yet but to be sure would like to run further tests and he also arranged for Professor Davis to do a further examination.

So the waiting went on until the professor arrived who also examined me and in his opinion was to admit me and run further tests. At this stage I was in a state of panic as I felt it could be something serious and I could not get any direct answers.

That afternoon I was admitted into a hospital for the first time in my life. What a turn a round, from going to work this morning to being admitted to hospital by late afternoon. Nobody could give me any answers at this stage and I feel so afraid of what the outcome would be. Lying in bed put thoughts through my mind and felt lost and helpless.

After a sleepless night, the day begins when a nurse came in for some blood. As the day went on I became more and more worried. Then a nurse came in and said we will be taking you down for an MRI scan (magnetic resonance imaging) which shows any abnormalities in structures in the brain and spinal cord. That's great I said. This was to be the longest hour of my life. Lying flat on a padded bench which moved in and out of a tunnel shaped scanner made me feel claustrophobic and experienced times of panic.

I felt like I was in a coffin. I could not wait to get out, but was under instructions to keep my head and body absolutely still as this machinery clanked and clattered and took pictures of my brain and spinal cord. My body tense and could feel the terror of being trapped and unable to escape. I remember saying, get me out of here. The hour I spent in there felt like one week and although I went in dry, was soaking wet when I finally got out of the tunnel of horror.

Was taken back to my bed and told tomorrow they would do a lumber puncture on me. What in earth is that I replied? They just need to take some fluid from your spine for testing, the nurse said. It didn't sound very exciting, but hopefully would give me the answers I was looking for.

A doctor and nurse came in the next morning and told me it was time for the lumber puncture. I asked if they could explain the procedure and the doctor said a hollow needle is passed between the vertebrae in the lower part of the spine. A probe from the center of the needle is removed and fluid flows up the hollow channel.

Then I was told to lie on my side with my legs curled up. As I looked I saw this huge needle. At this stage the sweat was coming down, was very nervous and asked the doctor to be gentle. I'm not as tough as I look, you'll be right he replied.



Lumber Puncture

I then felt a needle go into my back at the base of my spine. OOOCH! Was that the needle doctor? No he replied that's the anesthetic. Then I felt the needle penetrate my back. The pain was nothing to laugh about, my eyes were teary from the pain, but could do nothing about it. The nurse was holding my hand for support and holding me in position so I could not move. I just wanted to get up off the bed and run away, saying to myself I do not deserve this. I think I was all confused and could not understand what was happening to me and WHY. Finally it's all over and was told to roll over on my bad and not move for four hours.

So they take me back to my ward and again told me not to move, so I fell asleep. I woke up shortly after and decided I had to go to the bathroom before I wet myself and then went back to bed. Not long after I got back in bed I had this severe headache and buzzed for the nurse. I complained about the headache and she got angry and said no wonder if you go walking around when you're told not to move for four hours that's what happens.

You must keep absolutely still she said. Don't move at all, they have just drained some of the protective fluid from your spine and any movement can cause you pain or possible damage.

Not being a very religious person there I was staring at the ceiling I decided to say a prayer out of desperation and fear of the diagnosis coming. I was so lonely and frustrated lying on the bed unable to move. Next the nurse comes back with something for the headache and put the buzzer next to my hand and said with a smile, "I'm watching you Anthony".

Thankfully my family came in to keep me company as I have reached the stage where I am so scared. Mum and dad would ask questions but could give them no answers. They were also concerned because they are wanting on answers too.

It's now night time, my family has left, the four hours are up and I still have a bad headache. The nurse brings me more tablets and a sleeping pill to help me sleep.

Will now wait for tomorrow morning and hopefully can go home with good news.

2. Diagnosis

“Wednesday 6:00 am”

..... Have not been able to sleep..... Lying in my bed worried and frightened, wondering what’s wrong with me. The numbness and stiffness hasn’t gone. I get out of bed and head for the shower to freshen up.

“11:00 am”

The nurse looking after me comes in and says, “Hello Anthony!” I reply “Hi”, when the doctor comes in and says “hi Everybody” and how are you feeling Anthony. I replied very worried and frightened doctor.

He pulls up a chair and has a seat next to the bed. “I am starting to sweat”. He tells me he has the results of the MRI and lumber puncture. Unfortunately you have been diagnosed with Multiple Sclerosis. Multiple who I replied. How I asked? I have never been sick a day in my life. Is it serious? How will it affect me in the future?

At this stage I am in shock and cannot believe it. He told me it’s not a life threatening. It’s a disease of the brain and spinal cord (central nervous system). Multiple Sclerosis interferes with the brain’s ability to control such functions as walking seeing, talking etc..... Is there a cure? Unfortunately there is no known cure as yet, but MS is not contagious or preventable. GREAT!

The doctor explained that Dr Kilpatrick would be my Neurologist and he will arrange to speak to me regarding where to go from here and the necessary treatment. But for now you will be discharged. The nurse came in and spoke to me, being very supportive and helpful knowing I had just been told of my diagnosis. She could see I was feeling very shocked and depressed and tried to comfort me by explaining about Multiple Sclerosis and told me that life didn’t have to be over. She went out and came back with books to help me understand more about Multiple Sclerosis.

It’s now time for me to be discharged and leave the hospital with thought of “where to from here”.

3. What Happens Now

In a way I feel at ease now knowing what I have and can hopefully start to deal with it. I'll read books join the MS Society and try and educate myself as much about this disease as possible and hopefully this will help me come to terms with it.

My appointment with Doctor Kilpatrick has arrived. He asked me if I had looked into what multiple sclerosis was. I replied that since I had left hospital I have done a lot of research about it and where to get help. Have also contacted the MS Society for help and guidance. He told me that it was the right approach I was taking.

As for a treatment he advised he would put me back in hospital and try a steroid treatment first before attempting any other treatments. You will be required to stay in hospital for 3 to 4 days and receive intravenous Methyl Prednisolone Treatment. I will arrange your admission as soon as possible and you will be notified as soon as a bed is available.

Will I end up in a wheelchair I asked?

Not necessarily he replied, it to early to say at this stage. Let's take it a step at the time.

Admitted to hospital three days later to start the intravenous methyl prednisolone treatment. This time in hospital was very educational and informative as I had the chance to communicate with other patients with multiple sclerosis and exchange different symptoms they were experiencing, how they were coping, their successes and disappointments.

I received calls from friends wanting to know what this multiple sclerosis was. Basically all I could tell them was that it was a disease of the brain and spinal cord or also known as the central nervous system.

I think it is important that I try to get my life in some sort of order so that hopefully I can get through this. I just cannot understand why someone in the prime of his life be hit with this disease which can disable a person for life.

“Very hard to accept”

4. Time to stop work.

After putting in so much time and effort into building a successful fencing business, it's time that I must re-assess my future. After several attempts to go back to work, I found I could no longer work at my full potential and knew it was time to stop kidding myself and finally had to close the business.

The problem I had was that I was on my feet for about 15 hours a day and because my fatigue would not allow such long hours I had to make the unfortunate decision to give it all away. This was devastating for me as I wanted my business to succeed.

I remember after completing my final job which I remember was a picket fence, I was so exhausted it was such a struggle driving home that I said to myself " stop kidding yourself, it's all over ". Multiple Sclerosis has taken control of my life and there is nothing I can do about it. That really depressed me as I knew that MS will control my life from now on.

I remember after I got home doing my book work and reminiscing about the business and what achievements I had accomplished. I got out photo's which I use to take of fences which had special meaning. This might sound strange but to me each fence I would build would have a meaning behind it. Each fence would be symbolic to me. Each fence would remind me of the creativity involved in building a particular type of fence and the meaning behind it on completion.

For example looking at a picket fence would remind me of an ideal family home. It would remind me of a good happy and content family who like to construct that good wholesome image of a happy place. The different size and shape and creativity would have a symbolic meaning. Its colour or colour's give you that sense of come in your welcomed. The picket fence I must say was my favorite because it represented that warm, happy and friendly feeling.

On the other hand you have fences which reminded me of multiple sclerosis. A brick fence for example must have a foundation and built a step at the time brick by brick. The bricks could represent your friends; the mortar represents the bond that holds that friendship together. The purpose of the fence is to keep out isolation and depression. You can always add more bricks and mortar to the fence to keep it growing.

On the other hand being a solid wall reminds me of some of the physical pain I experience. Each brick represents a different symptom which a solid wall keeping out comfort and good health. Because it is solid you cannot see through it and cannot let the pain out.

Then there are fences which are made with iron bars. Although these fences can also look good, they reminded me of being trapped. They make me feel like I am behind bars and they go on forever and never end. I feel like I am caged in and cannot always find the key to get out.

So that night thinking about all the fences I had built made me realize that there are negatives and positives in objects just like there are in humans.



5. Telling Family and Friends

When someone is diagnosed with a disease, the focus is always on them. What we forget is how it effects the people around them, their family and friends, but sometimes it is difficult for them to understand when it's a disease they cannot see.

For a person with MS the disease is like a shadow you live every single day of your life. It is always there but you cannot always see it. It appears when you least expect it but you never know what form it is going to take or how long it is going to last. Also people do not always notice that it is there. It is easy to lie about symptoms when they are not visible. You can tell people you are fine, meanwhile your legs could be tingling, you could have numbness appearing and you could be terrified of the possibility of a relapse.

On the other hand, not everybody believes you when you tell them. I have come across this situation several times since diagnosed. It is so frustrating if people think you pretend to be tired or faking a symptom.

I know that symptoms can be used by some people to manipulate those closest to them; however I could never pretend to have a symptom. Also it would worry my family and friends unnecessarily and I would never play with their emotions like that. I admit that I have in the past lied about my symptoms, but felt that what people did not see or know would not hurt them, especially those close to me. Now I realize that it hurts them more to think I am not being honest. I now tell those close to me about my symptoms. If I have numbness in my leg one day I will keep it to myself, but if still there when I wake up the next morning or it has spread in anyway, then I tell someone.

I believe you must really want to be healthy and strong to live with MS. (Try Too). You must always want to get better. Sometimes things are too much of an effect, but it is important to me to make an effect. I hate being unwell, and hate being stuck at home, but for me MS is like a game of cards. Each player must accept the cards that life deals, but once the cards are in your hands it is up to you how you play the game.

The unpredictability of my disease is by far the hardest psychological burden. I know that if I am well today, tomorrow could be a complete reversal, could it turn into a relapse or will I go from relapsing/remitting MS into the progressive form of the disease. No one can ever tell me in advance.

As much as I need family and friends in my life, it is also important that they always know I am always there for them too, no matter how bad my condition may be. MS does not affect my hearing so I am always there with open ears. I would hate for them to feel they could not come to me for support, just because I have MS and have enough to cope with myself. My family and friends are what keep me going, so nothing is too much to be there for them.

Fortunately I am surrounded by family and friends who are very positive about their views on life. But at times it is difficult to be positive when I am going through another relapse. I do not think at times people have any idea how scared I feel, not knowing which direction the disease is taking me, whether it is going to pass by or will it debilitate me totally this time. It never lets me know, it just does what it like whenever it wants.

Severity is different for everyone, MS is individual, no two cases are exactly the same so each person with diagnosed with MS has to work out for themselves what is best for them, what their limits and capabilities are. If only we could put positive thinking into a bottle.

I have met people with chronic progressive MS who has been totally debilitated by their disease and I stand in admiration at their positive attitude towards their condition. I think that if I ever reach that stage, I would find it difficult to cope.

I fully understand what could happen to me, and I have to live with that fear every day of my life. I have become more analytical about life since diagnosed with Multiple Sclerosis.

Sometime people with MS have chosen to keep it a secret about their condition and they have their reasons. I completely understand as I have been there myself. But for me it was because I did not want to be a label. I did not want people saying, “you know that man has MS”, I am still good old Anthony. I do not want pity, I just want understanding.

It is not yet known what actually triggers off the process of scarring in multiple sclerosis. So nobody can tell me why I have this disease. It is impossible to predict with certainty how MS will affect an individual in the future because you just have no control over MS, it controls you when ever it wants without warning, you cannot control it.

People who are newly diagnosed can feel shock, anger, disbelief and grief when first told they have MS. Their family and friends may share some of

the emotions, because the disease usually strikes suddenly. People have to come to terms with how MS changes their lives in so many ways. It is incurable and this often causes profound anger.



6. Special People

The special people in this world are the most precious
And the most appreciated people of all.
No matter what happens, they always try and understand.
They go a million miles out of their way.

They bring you smiles, when a smile is needed.
They listen and they hear what is said.
In the spaces between words.
They care and share your emotions.

Special people always know the perfect things to say.
They can make your whole day just by saying something,
No one else could say.
Sometimes you feel like they share with you
A secret language that no one else understands.
Special people can guide you, inspire you, and comfort you
And lighten your life with laughter.

Special people understand your moods and nature.
They lovingly know just what you're after,
When your feelings come from deep inside,
And the need to be spoken too by someone,
You don't have to hide from, you share them.

Special people bring sunlight into your life.
They warm your world with their presence,
Whether they are far away or close by your side.

**Special people are gifts that bring
Happiness and treasures that money can't buy.**

7. Save Me

It is so frustrating
That's caused me to change my life.
It makes me angry to see myself
Sliding downhill with nowhere to go.
From positive views on life to negative views.

I feel like someone has punished me
For something I do not deserve.
Robbed me of a future and happiness.
I am tied from fighting this disease
Feelings of emptiness and uselessness.
I try extremely hard
But my legs and body say no.

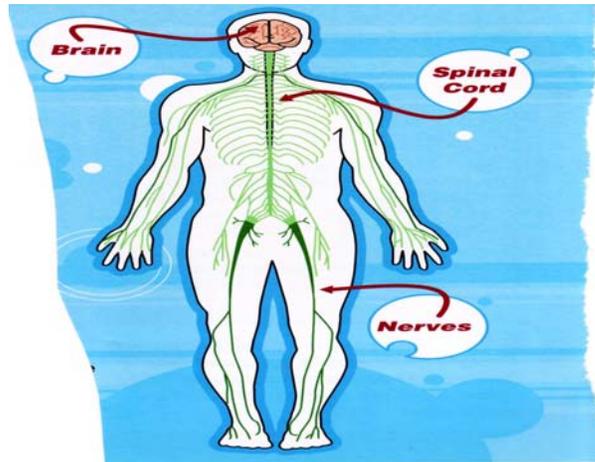
I was so physically active and strong.
Not so now, weakened by this unexpected disease.
How much longer can I keep on fighting?
I know no one is at fault but why me.
How sad it is all this suffering
Yet not one cure is found
To return my body back to its previous state.

I can only try my best
But that is not enough to concur this disease.
I am not a failure
That's for sure.
But hell I am scared
What is in store for me?
Only hopes and dreams and a cure
Can save me from the inevitable.

SAVE ME

8. Frequent Questions About MS?

I. What is multiple sclerosis?



Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system (brain and spinal cord). Its progress, severity and specific symptoms of the disease cannot be predicted. Symptoms may range from tingling and numbness to paralysis and blindness. MS is a devastating disease because people live with its unpredictable physical and emotional effects for the rest of their lives.

An estimated 2.5 million people in the world have the disease multiple sclerosis. In Australia there are an estimated 15 thousand people with the disease.

ii. Who get multiple sclerosis?

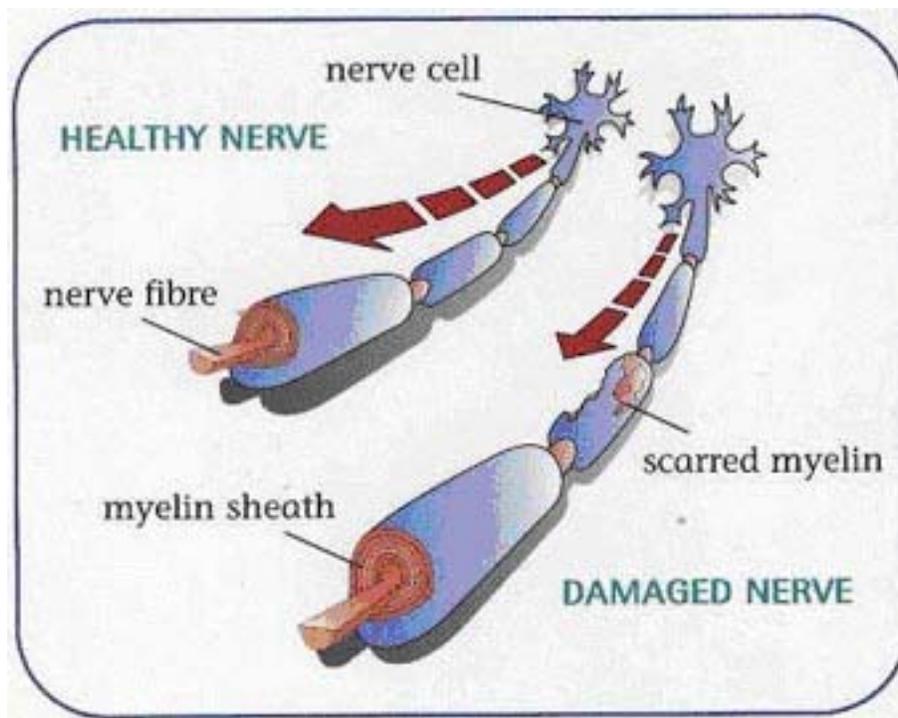
Twice as many women as men get MS, with the onset of symptoms occurring between the ages of 20 and 40 years of age. Studies indicate that genetic factors may make certain individual more susceptible to the disease, but there is no evidence that it is directly inherited. It occurs more commonly among Caucasians, especially those of northern European ancestry.

iii. What causes multiple sclerosis?

The actual cause is still unknown. A healthy body's immune system normally defends the body from attack by viruses or bacteria. In the case of

MS, the body's immune system attacks its own myelin, resulting in disruption or distortion to nerve transmission.

Symptoms result when inflammation and breakdown occurs in the myelin, the protected insulation surrounding the nerve fibres of the central nervous system (brain and spinal cord). Myelin is destroyed and it is replaced by scars of hardened "sclerotic" patches of tissue. Such lesions are called "plaques", and appear in "multiple" places within the central nervous system. This can be compared to a loss of insulating material around an electrical wire, which interferes with the transmission of signals.



iv. What are the symptoms of MS?

Symptoms of MS are unpredictable and vary greatly from person to person.

- They may include:
- extreme tiredness (fatigue)
 - blurred vision
 - loss of balance and coordination
 - slurred speech
 - tremors
 - stiffness
 - bladder and bowel problems
 - difficulty walking

- memory loss
- mood swings and

in severe cases, partial or complete paralysis.

v. Is MS fatal?

No MS is not a fatal disease. People who have MS can be expected to have a normal or near normal life expectancy.

vi. Does MS always cause paralysis?

No the majority of people with MS do not become severely disabled. Two-thirds of people with MS remain able to walk without an aid.

vii. What medications and treatments are available for MS?

Since 1993 four medications (Betaferon, Avonex, Copaxone and Rebif) have been approved for relapsing forms of MS. They have helped lessen the frequency and severity of MS attacks, reduce the accumulation of lesions in the brain and have shown to slow the progression of disability.

viii. Why is MS so difficult to diagnose?

The peculiar nature of MS makes the diagnostic process complex. Elusive symptoms that come and go might indicate any number of possible disorders. Some people have symptoms that are very difficult for GPs to interpret, and these people must wait and see. While no single laboratory test is yet available to prove or rule out MS, magnetic resonance imaging (MRI) has greatly aided in definitive diagnosis.



14. Life Has Changed.

The past twelve months, I have managed to cope fairly well with the Betaferon injections and several doses of Methyl Prednisolone Treatments. However June 2000 I started to see that I was having trouble staying on my feet, so I went to my local doctor who arranged for me to see my Neurologist on Monday 19 June. It was a time of panic for me as I knew something was happening to my body.

Monday 19th June has arrived there I am waiting in the waiting room to be called in to see the Neurologist, but have a feeling deep inside of bad news. The past few weeks I have felt a change in my body which I have not experienced before, which had put fear in my mind. You might ask why? I feel that you get to know overtime and experience when you are heading for a relapse or symptoms are getting worse.

Finally my name is called out and off to the consulting room I go struggling to walk dragging my legs. My Neurologist sat me down and asked how I was, I remember saying to him something is not right. I told him I had experienced MS attacks before, however nothing like what I was experiencing this time around. He asked what was different from previous attacks. My response was all the symptoms previously were nowhere as severe as this time. For example I explained the pins and needles in my hands and feet are now pins and needles up my legs upto my waist and arms upto my shoulders. There is no feeling in my legs, I have blurred vision, my balance and co-ordination are non-existent, memory is doing funny things to me, word's won't come out properly and am suffering very bad depression.

He helped me onto the examining bed as I needed help getting up there. The neurologist preformed his usual examination, which for some unknown reason which I cannot explain why, cannot forget the procedure, but forget most other things not associated with MS. Normally his examination take thirty to forty minutes, however this time it was over in fifteen minutes. Again I asked why, he replied I was to be admitted immediately for more treatment and tests. Why I asked? He told me he did not like what he was seeing and feels that I might have progressed from remitting/relapsing stage of MS to the progressive form of MS. He could not have picked a better day to tell me as my mum was taken to hospital this morning, so I managed to talk him into admitting me on Wednesday, two days later, only for the reason that my dad who is 70 years of age and I was worried of him being on his own.

On the way I had visions of what was happening to me and remember a wheelchair going through my mind. I got home so depressed feeling ill knowing my condition had deteriorated instead of improving or stabilizing. Also the thought of mum being in hospital was not helping my condition.



15. Back in Hospital.

The morning of Wednesday 21st June has arrived, had a sleepless night and arrived at the hospital at 9.30am for admittance. There I was waiting and waiting until finally they told me my bed was ready after a six and a half hour wait, but must admit that once I got to the ward, two lovely nurses Elisa and Louise looked after me as they remembered me from my previous times in the ward last year.

It's good to know that some nurses remember you and are so supportive and caring and show some compassion for their patients. Its now 10pm and am settled in my bed, but getting tired, it's been a long day, but must wait for the methyl prednisolone drip to finish. Have asked for some sleeping tablets as I am having trouble getting to sleep with all these thoughts going through my head.

Day two 22nd June, I awake several times during the night even though I took two sleeping tablets to help me sleep. Nevertheless I got up at 7am, went and had a shower and went back to bed. Doctors and nurses were coming in and out of the room doing their usual thing. I was glad to see that Elisa and Louise were on the morning shift as they were so helpful yesterday. My condition has not altered since yesterday, but is hoping for an improvement in the next few days. I have been told not to go out of the ward unless I have someone with me. This is because my balance and co-ordination is not right.

News of my condition is getting worse and worse by the day. My neurologist Dr Kilpatrick has just being in to see me and has given me the news that I have been trying to avoid since learning about Multiple Sclerosis. He came and sat by my bed and informed me that my MS has changed from remitting/relapsing to the progressive type of MS which means that I have deteriorated since my last attack.

The neurologist has given me a few options to consider in the next month before seeing him again. He told me that the deterioration will continue on or I could consider being involved in one of the research project's which is not a cure. This is something that I must consider even though there are no guarantees, or whether it will be of any benefit to me. Should I take the risk not knowing whether it could affect my life for the worst or should I let nature take its course and hope for the best? It's a decision that no one can make for me so it's going to be a difficult one. Should I or shouldn't I?

It's going to be the most difficult decision of my life, and to make things a bit spooky I have a priest come to see me this afternoon and bless me. It felt like I was given my final blessing.

Well it is now late afternoon and hope I have no more bad news or pins and needles stuck into me. It's been a very stressful day and only hope that tomorrow will be a much better day. I will definitely need some sleeping pills to help me sleep tonight.

I was wrong about bad news, here is some more. Before it's time for me to say good night for today, the last bit of bad news I received today was that once I have finished here at the hospital, I will be transferred to a rehabilitation centre for a few weeks for further treatment like physiotherapy and other therapies. Boy I'm looking forward to tomorrow, it can't get any worse.

The morning of 23rd June, and my day begins at 6am up I get with the help of the nurse and to the showers we go and then back to my bed. Around 9am the physiotherapist came in and took me to the physiotherapy room with a walking frame. I was no longer able to walk with my walking stick because of my balance. So we had a chat about my condition and started on some exercises to try and improve my balance and co-ordination. This went for about one hour and then helped me back to my bed.

Then just before lunch Doctor Fahey came to see me with information about what we had discussed yesterday with the Neurologist. The doctor sat down and explained what the procedure for the treatment I had to consider. He gave me three pages of information and explains to me in plain English that it was going to involve:-

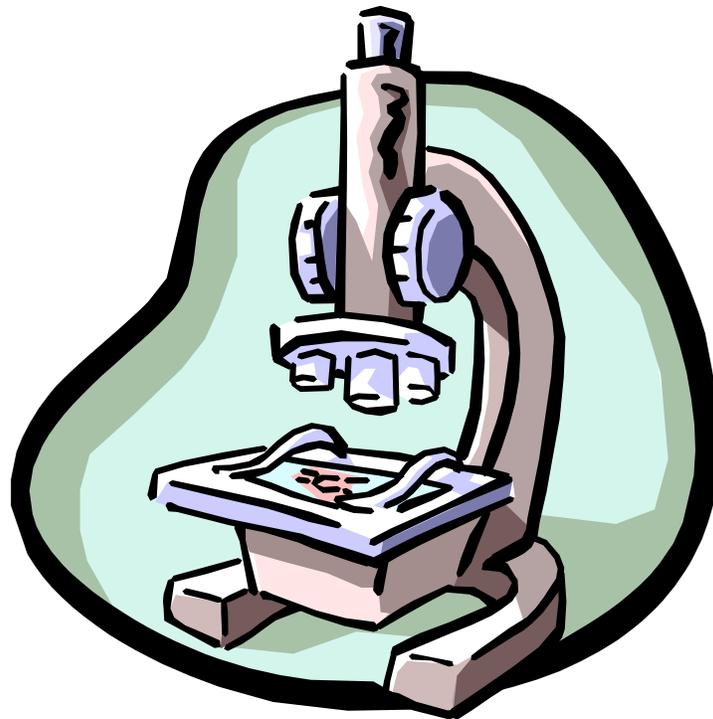
1. Stem cell collection: This is the first step of the collection of a type of white cell called white cells (also called marrow cells) from my blood; these will be used in the last phase of the study (the transplant).
2. Treatment with cladribine: This is the second phase of the study which will begin after the stem cell collection is completed. It consists of 2 courses of treatment with a drug called cladribine. Each course consists of a daily injection, given as a 2 hour intravenous infusion.
3. Repeat collection of stem cells: This is the third phase of treatment which is again another collection of stem cells using the same procedure as in the first phase. The reason for this is as follows: in a normal stem cell collection quite a large number of white cells called

lymphocytes will be collected as well as the stem cells. Lymphocytes are thought to be responsible for some of the damage in multiple sclerosis by attacking the myelin.

4. High dose chemotherapy and transplant: This is the final phase of the treatment which involves the administration of high dose chemotherapy with a drug called cyclophosphamide and a powerful drug called anti-thymocyte globulin. Both these drugs suppress the lymphocytes in the immune system and therefore reduce the severity of multiple sclerosis.

There is a small percentage of dying from this treatment, mainly due to infection or bleeding.

This to me sounded scary but due to my deterioration it's something I will give a lot of thought even though there are risks involved. Dr Fahey has been very helpful with his explanation and information, so it's now up to me to read into it and then make a decision on which way I will go. Will I keep on deteriorating or will I take the chance. Only I can make the choice, no one can make it for me that am the hardest decision I will have to make in my life.



16. Time to call for the Psychiatrist.

In the afternoon I felt like I could not cope with life any longer, so I decided that I needed professional help and asked if I could see a Psychiatrist to help me get through this period of not knowing what to do. So that afternoon Ria the psychiatrist appeared, we had a good discussion about how I was feeling and what I think is causing my depression. I must say that she was great, so supportive, understanding and gave me such satisfaction that made me feel more positive about what I am going to go through. Ria advised me that she was going to put me on medication that should help me get through my days and help with the depression. She thought I should start on the medication immediately. So we left it at that.

My favorite nurse Elisa saw that I was feeling down so she came and sat beside me and spent a good half an hour talking to me. She was so supportive and told me how well I was handling the news I received yesterday. She could see I was down in spirit, but encouraged me by saying how impressed she was with me on my positive attitude and the determination I had in fighting this disease. She gave me hope and said you look too strong to let it beat you. Well there you go Ria and Elisa have really helped so much in putting my mind at ease.

It was also great that Michelle from MS Victoria rang me to see how I was, she is in charge of all the MS Ambassadors and gave me great news that our target for the Ambassador Program had been reached for the year. Michelle also told me that she and MS Victoria are there for me if I need them anytime. It's great to see that my fellow friends from MS Victoria care about how I am going and know I have their support which makes my life easier.

I have made so many great friends through the MS Ambassador Program that I will treasure their friendship for life, especially one particular person named Teresa and her husband David whom I feel like they are like a brother and sister for the support they have shown. Today has been a day with lots of good news, which by far makes up for yesterdays bad news.

I had a fairly good rest last night and today another favorite nurse called Carla is on duty. It's amazing how they remember you from previous stays in the ward and must say Carla is very dedicated in her job, checking up on me very frequently. All my room mate's have been discharged today which

has left me on my own, however it did not take long to fill the beds and make new room mates. At least I have people to talk too again.

The day so far has been ok and will have my last dose of methyl prednisolone later today. Once the treatment is completed, I will spend the next couple of days going through other tests, before being transferred to the rehabilitation hospital. Now it's a matter of waiting, feeling a bit depressed as I know I have to make a decision soon on what happens from here. Will I continue with my current medication or should maybe consider what I discussed with the neurologist. It's going to be difficult, but am in a position where I am not improving and am leaning in favor of the treatment even though there are risks involved and no guarantees. I pray my decision is the right one.

Sunday 25th June, had a good night sleep, however when I got up was having trouble walking struggling to move my legs and cannot push my feet along. Feeling extremely tired and fatigued, so don't think the methyl prednisolone has worked this time because I remember it working within a couple of days on all the other occasions. I am so frightened at the moment because I really don't know which way to go.

Just had lunch, but am feeling lost and depressed, unable to keep any food down. I don't know what to do or say feel weak and have no sense of energy. I suppose the decision I am waiting for is getting me down to the point of anxiety, depression etc. Have been thinking about what to do but am still not in a position to make such an important decision. I have reached a point where I don't know which way to go and need help.

This afternoon I had several visitors, however I have felt uncomfortable as my mind is always telling me "what shall I do". I have asked my family what to do but all they can say is, it's a decision only you can make on your own. It's time I called for Ria the psychiatrist again. Dinner is now over and will try to get some sleep and hopefully tomorrow after seeing the psychiatrist I will feel better.

Monday 26th June, with the help of tablets I managed to get some sleep last night; however nothing has changed since yesterday. Cannot understand why I am dragging my legs, they will not bend, no matter how hard I try. I've had to ring my friend Teresa because I just needed to speak to someone.

The physiotherapist came to see me and took me for some exercising to see if these legs would move. I told her the legs just won't bend and cannot stay on my feet without help; it feels like such an effort and such a strain to get

them to move without dragging. So she worked on me for a while and then took me back to my room.

Not long after I got back, the psychiatrist came in and I told her I need help, my depression is getting worse and worse and am worried about myself. I feel like jumping off the balcony. Ria told me all the pressure is getting to me, but just gave me advice and told me it's not easy what your going through, just take a step at the time and you will get there. She also said that she would tell the nurses' to keep an eye on me as well as the doctors.

Tuesday June 26th, the day begins as normal and cannot see any change in my condition. Had a small breakfast, and off to the physiotherapist I go for a one hour session. It was quite a tiring hour with lots of exercising and stretching. What is so frustrating for me is that the exercises are not hard to do, they are so basic and simple, but my body keeps telling me to slow down. I think that I am trying to hard, because want to see some improvement as soon as possible. But unfortunately it does not work that way with MS. Its so amazing that the harder I try, my body keeps telling me no.

It was time that I started to read the information about the chemotherapy and bone marrow transplant. There are four stages to the treatment and it looks like a long process and by what I have read it will be a very tough time to go through; however for some reason my mind is telling me I have nothing to lose and a lot to gain.

Ria the psychiatrist came in to see how I was going and also told me that they will gradually increase my dosage of antidepressants. We had a good chat for about half an hour and I must say this time she was on time for once, and told her "at least I am not having dinner this time". I got a big smile from her, but seriously she has been great.

Tomorrow I will be transferred to the rehabilitation hospital for who knows how long, but hope it will be of benefit to me. Now I will wait for dinner and then get some rest so I can get ready for the move tomorrow.

17. Transferred To Rehabilitation Hospital.

Wednesday 28th June, Discharged from Royal Melbourne Hospital and taken to Melbourne Extended Care Rehabilitation Centre by ambulance, this was the first ride for me in an ambulance. It's a bit confusing here as I have never been here and don't know my way around yet.

I have met my physiotherapist and was told that I will be here for a while. The people here are very nice and am lucky in being in a room of friendly people. I have a wheelchair next to my bed which is staring me in the face and the thought of me being in one is a bit hard to handle at this early stage, but must face and accept it because its there because I am in need of one.

Am settling in well with my room mates and think we will have a bit of fun here because they are real characters, Peter had a stroke and has been here for a few months Tim has lost half his leg, but they both have such a positive attitude. Just hope I can become as positive as Peter and Tim.

Now for an hour of physiotherapy and then a session with the occupational therapist. The physiotherapy was a strenuous session, but now will wait and see how tomorrow's session goes. Its going to be a long road ahead for me, but am very determined to fight this till the end.

It gets a bit boring at times as there is not that much to do unless you have therapy. They have asked me that if I would like to go on weekend leave and come back on Sunday but feel that it early stages yet and don't think I am mentally ready yet. I am starting to get used to my wheelchair and am coping with the thought of using it much better than before. I think that I have finally realized and come to terms that it has now become a necessity and will need a wheelchair to get around.

Personally I believe that being in a place like this with other people with disabilities is helping me to get my confidence and has made me realize that when in need I will have to use the wheelchair. It's something that I shouldn't be ashamed of. It's a necessity so there is nothing wrong or do not have to be ashamed of my condition.

At first I use to think that it was embracing, but now I do not care what people might think. I have changed my methods of getting around, that's all,

I'm still the person I was before my diagnoses and do not expect to change my personality just because of my disability. I'm still the same old Anthony and that will never change.

Friday 30th June, It an early start with Andy the physiotherapist for another one hour session, still cannot stay on my legs and still no improvement, but will take time to see if any improvement.

The social worker Antoinette had a chat with me after physiotherapy and we discussed what my goals were in life now that my condition is deteriorating. I told her that my goals now that I am a pensioner were to complete writing my book on MS and having it published in the future. Secondly continue with my involvement with MS Victoria and with the MS Ambassador Program which involves speaking engagements and to try and stay as positive as possible.

Later today will spend time with Emily the occupational therapist and then back to Andy for more physiotherapy on my legs. I am thinking of taking weekend leave tomorrow and come back on Sunday as it is very quiet over the weekend; most patients go home and then return. So sometime away from here might help me mentally and will give me a chance to catch up with my internet friends.

Well I think I spoke to soon, I have just been told that I cannot go for the weekend. "why I asked", because they want to keep an eye on me as I am suffering from severe depression. In other words they think it's not safe for me to be on my own. In a way I understand they are looking after me, so not this week.

Have had a restless night, I feel so lost and confused and am afraid for myself. I feel the pressure of making a decision which could be the most important decision of my life. Again I have read all the information on the bone marrow transplant and chemotherapy and know that I must come up with the choice of which way I go, but think am close to a decision.

Am not feeling myself, so to get my mind off things, rang my good friends Teresa and David and had a good talk, told them how I was feeling and their support helped a lot. They are such good people to me and they have assured me when I'm feeling down that they are there for me day or night. They understand what I'm going through, especially Teresa because she also has MS and can understand how I am feeling.

I feel blessed knowing that I have made so many friends through the MS Society that I can count on if in need. They will all go out of their way to help each other. This includes my good friends John and Josie whom I respect not as my friends but as brother and sister. John and Josie have been by my side when I have needed them and not once have they neglected me. Wonderful caring people they are. It means a hell of a lot to people like me to have these people who you know they are always there for me. It's also time like this that you really know who your friends are, and the so called friends who have forgotten about. "Is it because I am now disabled or am I not good enough anymore", so sad but to be honest I am better off without them.

5th July, 2000 have had a bad couple of days, I am very concerned about my depression and also am suffering from very low blood pressure. I have asked for the psychiatrist to come and visit me as I don't know how much longer I can keep on going. The thought of suicide keeps entering my mind and am afraid of doing something silly. The staff here are also concerned, whenever I go out of the ward, I must tell them where I am going and if I go outside I must have supervision with me.

Have had a fairly busy day today with two sessions with the physiotherapist one in the morning and one in the afternoon. As well as sessions with the speech therapist and occupational therapist. I must also see the dentist because of my broken tooth. So I have been in and out of the ward all day, so I am feeling tired, the day has been a long one.

It's also a sad day because one of my room mates Peter is going home after spending three months here after having brain surgery. We have had a good time whilst here and yesterday his wife organized to go out to lunch. It was quite a change; it got my mind free for a couple of hours.

Once again I have asked if I could spend the weekend at home, but unfortunately they have said no yet again because they don't think I am stable enough to be away from here.

6th July 2000, have had a restless night. Started the morning with physiotherapy at 9am, but was having hot flushes and dizziness during the session and had to stop at times.

When I got back to my room, I asked the nurse to check my blood pressure and found that it was a little low. This has been happening for a few days now, so I asked to see the doctor. The doctor came in to see me and I told

her that the blood pressure tablets I have been on were originally prescribed because my blood pressure was high, so the doctor told me they will change my tablets and see if there is any change. Now must go to my final session with the occupational therapist for the day.

18. Want to see My Son:

7th July 2000, have been awake since 4am tossing and turning, so I got up and went to have a shower. Ria the psychiatrist arrived at 8am and we had a discussion about how I was going and how the new antidepressant were working. Ria said she would increase the dosage again and see how we will go in the next week.

She also said that she had contacted my ex wife regarding having my son Tommy brought in to hospital to see me to help with my depression and hope to lift my spirits. However she was unsuccessful. Ria said that in the time she has been a doctor she has never experienced a person like my ex wife, such a cold person and unfair to me as she knows my condition. My ex wife told Ria if Anthony wants to see Tommy he will have to come and see him himself. I wasn't surprised when Ria told me because I expected that sort of reply from her, having no heart and I believe she needs help herself.

Anyway have now decided to think of me first and try and fix my state of depression, so I can have that Experimental Treatment to try and help me with my MS. And hopefully if the treatment goes well, I can get back to Tommy and show her how much I love him and how much he means to me. I pray and pray that all will go well for me so that I can spend time with my son.

The rest of the morning I am busy with physiotherapy twice, occupational therapy and speech therapy, then I will try and relax for the rest of the day. I am not allowed to go home this weekend so it's going to be another lonely weekend, but hope to be allowed at least a few hours at home next weekend.

8th and 9th July 2000, Saturday morning the ward was almost empty, most patients went home for the weekend, but not me. There is not much to do, I can't even watch the football on television as there is no reception on channel seven, so it looks like another boring weekend. I can only do so much writing.

19. Adjusting To The Wheelchair.

I am trying so hard not to use my wheelchair and am trying to use my walking stick as much as possible, but who am I kidding. Unfortunately I can see and feel that it's only a matter of time before I will need a wheelchair more and more. I can only walk short distances with a walking stick and have to keep on stopping and rest. It so hard trying so hard to move my legs, but must now face it and realize I must get use to using the wheelchair. It's not what I want but my MS has just got to the stage when it's telling me you cannot walk anymore. But Anthony will keep on fighting for as long as I possibly can. I have always been a fighter and will fight till I no longer can.

Last night when my family came in to see me, I was so touched by my seven year old niece Antoinette who wrote me a letter. It goes like this:-



Dear Uncle Anthony,
I miss you a lot and I love you.
I hope you get very well soon and come home.
Love Antoinette.

It's moments like this that give me the courage and strength to fight this horrible debilitating disease and believe me I promise to fight it not only for myself but also for my loved ones.

10th July 2000, had a good night sleep for a change and seem to be mentally feeling better. Had a bit of a fall yesterday when using my walking stick, so I think it's time and best for me to start getting use to the wheelchair because my stability is up the creek.

Have a quite morning with the psychiatrist Ria coming to see me, but this afternoon is a busy one with speech therapy, physiotherapy and the social work, which will keep me busy for most of the afternoon.

11th July 2000, had a sleepless night, I missed out on my sleeping tablets last night and have been awake since 2.30am and unable to get to sleep, but still

tired. So I lay in bed thinking and thinking until finally I went for a shower at 6am and then back to my bed.

Just as breakfast arrived I had a group of student doctors come in to examine me, that took about an hour. Finally had my cold breakfast and now wait for 10.30 when I see the physiotherapist and then speech therapy.

This afternoon have the psychiatrist coming to see me at 1.30pm and at 3pm see Emily the occupational therapist. Andrea the physiotherapist has told me that she has arranged for the wheelchair people to come and show me some wheelchairs to trial and choose from, for when I go home. So finally the time has come for me to be in my own wheelchair. I am not excited above it believe me.

12th July, 2000 things are not improving, can see me getting worse day by day. The other day whilst I was outside have a cigarette, I was talking to a group of trainee nurses and told them while talking that I am an Ambassador for MS Victoria and do a lot of talks on MS. They approached me in the afternoon and told me they would appreciate it if I could talk to them whilst in class about multiple sclerosis. I told them it would be a pleasure, plus I thought it might also help me talking about it.

It was very successful, even though it became a bit emotional at times for me to talk about my condition, but overall was pleased with my talk. That afternoon I was surprised to see the trainee nurses come to my room and gave me a card which said:-

Dear Anthony,
Thank you for sharing your story with us,
We found it very inspiring and it was a great
Effort considering how your feeling.
We wish you all the best with the treatment
And luck for the future.
Thank you from
Victoria Nursing Students.

I was so appreciative of them doing this for me that I even shed a tear or two.

Ria the psychiatrist came to see me late in the afternoon, not on time as usual and after a chat told me that tomorrow was her last day because she is being transferred elsewhere. This saddened me so much because she has

been a great help to me with her support. However she said she will still keep in contact with me because she wanted to see how I was progressing and had an interest in my case, which was good to hear. My new Psychiatrist from now on would be Dr Yeatman who she said was highly recommended by her.

13th July 2000, am feeling very unwell and depressed and am not feeling like doing much writing for the moment. I think it's time that I take a break from writing as it is depressing for me to write, so will have a break and take it day by day.

20. Finally a home visit.

18th July 2000, today have a home visit with Emily the occupational therapist which will be a very emotional time for me and my parents. It's 2.30pm and off we go, as we got closer to home I began to get tears in my eyes, but when we got home in a way I was pleased to be there and also were my parents. It's as though they were waiting for a person they had not seen for a long time.

Mum was first out and as I got in my wheelchair she came and gave me a big hug and a kiss. I started to cry because my mother is so special to me. Anyway Emily wheeled me inside and had a look around the house. She advised me on some alterations to be made like ramps for the steps for the wheelchair, shower chair and toilet chair. We stayed for a little while and then went back to the hospital.

19th July 2000, Finally my dental appointment has arrived as I have suffered from a toothache for the last five days. So off to the dentist and off comes the tooth. What a relief, now the pain will go away. Next is the physiotherapist went through a few stretches for half an hour and that's it for the morning.

In the afternoon Ria came to see me much to my surprise and had a good long chat. She is just terrific. She told me "I told you I would keep in touch" with a big smile. Later in the afternoon Dr Yeatman the psychiatrist replacing Ria came to see me and told me that Ria had kept him informed about my depression, but noticed a big change in my attitude and told me that I can now consider some home leave this week, so that I can start to adjust to home life again. That did please me, but told him I would like to take it slowly, that was fine by him he said.



21. Time for My Decision.

A Neurologist from the Royal Melbourne Hospital who works with Dr Trevor Kilpatrick came to see me and I told him I had come to a decision about the treatment they would like me to trial. He said in his opinion I have made the right choice. I told him am starting to look at it in a positive way and am determined to fight till the end no matter what happens.

He told me he would pass on my decision to Dr Kilpatrick and he will now arrange for me to see another Neurologist for a second opinion. Once that is done we can get the ball rolling. I replied the sooner the better because I am sick of watching myself deteriorate and am 100 per cent sure of my decision.

My good friends Teresa and David are coming in to see me today and am looking forward to seeing them. Teresa also has Multiple Sclerosis and is also an Ambassador for MS Victoria like myself. She rang me yesterday and said that she did the speech at Colonial Stadium at the Essendon verses Hawthorn game and also said that she presented the winning captain with the MS Shield. If I was well enough that would have been my job, but must say if I have to pick a person to replace me Teresa would have been the one I would have chosen.

They both brought me an Essendon beanie as I had told them that I had shaved my hair off and my head was always cold. They also brought me a picture of her presenting the MS Shield to the captain at the end of the game. Teresa said that next year we will do it together at the match, which would be an honor for me to make the presentation with her.

Mum, dad and sister with her family are now here, so have a full house at the moment and enjoying the company very much. It's the time of the day that having my family and friends here makes me feel much better. It's now 8pm and visiting hours are over and on my own again. I went for a cigarette and then watched some television before calling it a night.

The last couple of week's have had my ups and downs, but now notice that I am experiencing another symptom of MS, having trouble with the bladder. I get to the toilet and by the time I get back to my room, must go again. It's so frustrating at time as I have got to the stage that I wet myself because I cannot hold on. It makes me feel like a baby at time, I often say to myself this only happens to babies not adults, but again it's not me it's the MS that's making me lose control of my bladder.

The Doctor here has arranged for me to have an ultra sound done to see if my bladder is emptying correctly and also to check my kidneys. Thankfully after the ultra sound they told me my kidneys were fine and the bladder problems were due to MS, which does cause bladder problems.

22. Time For A Second Opinion.

I have just heard from my neurologist to advise me that before they commence with the treatment, because it's an experimental treatment, I would have to have independent assessment done by a neurologist from another hospital. So an appointment has been made for me to see Professor Donavan at the Austin Hospital for his opinion.

So Thursday 10th August, I was taken to the Austin Hospital to see Professor Donavan who after his assessment agreed that I was an appropriate candidate for the Stem-Cell Transplantation Trial. So it's all go ahead now from here. Even though I expected to hear his diagnosis, I remember on the way back to the rehabilitation centre in the ambulance I was frightened and remember thinking to myself, I wish the back doors of the ambulance opened and I go flying out and get run over. It's finally going to happen and by the time I got back to the rehabilitation centre was so scared and got to the point where I had to ring my psychiatrist Dr Yeatman and told him I was in trouble. We had a long discussion over the phone and felt much better after our chat.

It's now been a week of doing a lot of thinking and now know in myself that I have to get mentally right before they start the treatment. It's going to be a difficult time for me but it's a chance I am willing to take and even though I am trying so hard to be positive, deep inside know its going to be a difficult time for me during the treatment.

This week I also lost my good friend Enzo who was discharged, and in a way his presence is sadly missed as we both kept each other in good spirits. He rang me last night and it was great to hear from him. We will remain good friend forever. Enzo and his wife Rosalie have just been great and hope we can continue a close friendship. It's amazing how many friends I have made in the last eight weeks and will keep in touch with them. It's so inspiring for me to share our stories with these patients as we learn so much from each other.

23. Time for my Discharge.

This Wednesday is my turn for discharge after two month and am looking forward to be back home with my family. All the necessary arrangements have been made for me at home and the ramp for the wheelchair will be completed this week, so I am ready to leave this place. However the next couple of month will be difficult for me to adjust to being back home especially now that I am in a wheelchair and also to get ready for the treatment.

I know its not going to be an easy time but I am determined and have complete trust with my neurologist and his team. All I wish is that even though the treatment is not a cure, I am hoping it will stabilize my disability, get out of my wheelchair and hopefully walk like before, if not have accepted the wheelchair could become a permanent part of my life.

Its been a time for me to gather my thoughts and making some tough decisions whilst being at the rehabilitation Hospital and with the help of the therapist and the magnificent nursing staff they have here, especially a few of them who have been by my side from the beginning and helped me get through the difficult times. I can honestly say that if it wasn't for them I don't know where I would be today.

I now fully understand what nurses have to go through with patients and have great admiration for the work they perform. WELL DONE BOYS AND GIRLS.

The doctor spoke to me this morning and told me I would be discharged this week which made me happy to hear. It's been a long two and a bit month's of rehabilitation and am looking forward to getting home this week. It has been a good experience for me being here, but the time has come to move on hopefully to better things. Only time will tell.

Now the scary part starts as I wait to hear from the Royal Melbourne Hospital as to when they will be ready for me to commence the treatment. Will be a nervous wait, but will be glad when it's all over and hopefully all this waiting will be beneficial to me and all worth while. Yes I am scared but will give it my all, because I have so many ambitions and goals to accomplice in life, all mainly to help people with multiple sclerosis. So next week when I see my neurologist hopefully he can give me an idea of how long a wait I have.

It's now 29th August and is my discharge day, so my brother in law picked me up around 12 noon and took me home. When I got home I was so happy to be back with my parents and in my own surroundings.

4th September and time to visit my Neurologist Professor Kilpatrick who told me he knew of my decision and would now start proceedings. He told me that the procedure would take approximately three month because there is so much preparation involved. So now it's a matter of seeing different doctors because it involves a team of different doctors before the treatment can commence.

The next step was to see Dr Grigg an Oncologist who is deputy head of Bone Marrow Transplant Service next week. I went to see him and he explained the procedure in detail and answered any questions I had. So I am feeling a little frightened when I leave his office, but now realize that things are on the move.

Now the final step is to see Yvonne the bone marrow transplant co-ordinator on the 21st September. The day has arrived and there I am in her office. She goes through the procedure in detail and we spent one and a half hours talking and finally I had to sign a consent form for the procedure which I did and she told me that the treatment will commence within two to three weeks.

In a way I am happy now that it is finally around the corner but at the same time am very nervous and scared.

24. But You Look Too Good To Have MS.

When our condition deteriorates to the point where we need help to get around, for example using a walking stick or frame or wheeling yourself around in a wheelchair, this has a profound impact on family and friends and you have to depend on them for help. Previously I might have been able to go out in a public place without attracting attention. But now it has become more difficult as people glance at me when I am in a public place like a shopping centre. And find that when I talk to people, they say you look great and find it hard to believe I have MS. So many times I have been at the supermarket and have heard people say, what's wrong with that man?

Although MS is capable of affecting every part of my body, the focus of MS is on my legs. People notice tremors, spasticity or stiffness in the legs. It's true that the loss of feelings and/or function in the legs is one of the most common symptoms of MS. Since most MS sufferers eventually feel the effects of the disease in their legs, most of us ultimately face the need to use devices like a walking stick or frame and wheelchair to try and keep us mobile and independent.

It gets difficult at times when you have to cross the road. It shouldn't be an issue to start using a walking stick or frame or wheelchair, but in reality, have to use these devices because it's our only source of movement or transportation. This is often so frustrating for me. It feels like I am labeling myself like a crippled or disabled or handicapped person. It means making me vulnerable to the curiosity of everyone who sees me.

At times I feel I am drawing attention when I am using my walking stick or frame and now that I have been unfortunate to be in a wheelchair has made me feel more uncomfortable when I am out for example going around the block or shopping. This is often frustrating and embarrassing, but unfortunately I have now reach this point and there is nothing anyone can do for me. Being in this situation I have found that using a wheelchair helps to let people know that at times I am in need of help. For Example:-

1. I would appreciate if someone would hold the door open for me.
2. Give me some space for my wheelchair instead of getting in the way.
3. I would like help getting to thing's which are to high for me to reach.

It would be nice of people and I would appreciate it if they would recognize my disability and show some effort to help me. I would say thank you. I often find the pros outweigh the cons because there are people out there who have respect for our disability. The challenge is to find what's most important for me and what best works for me, and take it from there. It's not an easy challenge especially now that I must rely on a wheelchair, but it is one that can be dealt with.

Since being in this situation, I keep saying to myself that being in a wheelchair is the least of my worries. If I stop and think it's no good feeling sorry for myself, yes I have an incurable disease but there is always someone worse off than me.

Yes I am sure its going to get harder and harder as the years go by, but this is what life has thrown at me and I know I can get through it with my determination and family behind me.

25. Tired Of Being Sick.

I miss being the old Anthony I was, so much. I am sick and tired of fighting this disease. Have always been the type of person who could manage being ill not that it happened very often, but now I can't deny it. Feeling like I have no control over my MS and feel totally helpless especially now that I am facing the worst stage of MS. This disease as I often say does whatever it wants to me and I have no say whatsoever.

I often sit down on a chair or lay in bed and think to myself that this disease is so hard to live and deal with. Often I wonder if I ever fully accept MS and the losses I have to deal with day in day out. The unfortunate thing with MS is every time something changes, either permanently or temporarily, you have to start that grieving process all over again. The disease comes and goes whenever it wants without warning.

You might feel you are getting better but then all of a sudden it strikes again without warning. It definitely takes time to get use to living with MS. I have now reached the secondary progressive stage of the disease and it has finally got its wish and put me in a wheelchair.

Living with MS is an on going, ever changing process of getting through grief to arrive at acceptance. Every time we acknowledge the presence of MS, even when we're able to view it as it comes and goes, we get a bit closer to accepting that it's here and does not plan to go away, especially now that I have reached the next stage of the disease. Life with MS means going through the stages of accepting I have the disease many times. Even though it's difficult to cope with at times. I find that we are better equipped to deal with whatever it decides to do to us the next time around.

26. Collection Procedure Of Stem Cells

Thursday 21st September, went to see Yvonne who is the Bone Marrow Transplant Co-ordinator. We had a meeting so that she could explain all of the procedure that is associated with the treatment, which took one and a half hours, but was excellent in her explanations. This included the blood stem harvesting called G-CSF. Some of the side effects may include:

- Bone Pain/Ache (as your white cells increase)
- Slight redness around the site of injection
- Slight increase in body temperature
- Flu like symptoms

They expect to commence the procedure next week after I have had the MRI Scan.

The blood stems are collected through a technique called Aphaeresis. This is the process of separating my blood into various components. Basically the process involves drawing blood from my bloodstream, separating out the stem cells, and returning back to me all the remaining cells. This procedure will take approximately five hours every time I am on the machine.

This procedure is accomplished by using a cell separator machine, to which I will be connected. Two intravenous lines are required, one in each arm, one for drawing blood, and the other for returning blood. Anti-coagulant is used in the procedure to prevent the blood from clotting in the lines. There are some side effects to this drug. The main one being that the anti-coagulant binds with calcium in the blood and lowers it slightly.

Your body has between 4-6 litres of blood. The blood is constantly being processed and returned to me. At the completion of the procedure my stem cells are removed from the machine and sent to the laboratory to be frozen and/or prepared for infusion back into myself.

After the collection I expect to feel tired each evening after each collection. This is very common as the procedure, though highly selective, will “skim off” some of the red cells which are responsible for carrying oxygen in the blood. This first stage of the procedure will take about two months as an out-patient and once this is completed, will be admitted as an in-patient for about 4-5 weeks when they put everything together and this time I will go through the chemotherapy. It’s going to be a hell of a time for me, not only because

it's a long process, but because I am to be honest, afraid of what the outcome will be.

Making the decision about taking part in the clinical trial was very difficult, but have reached the stage where I have no choice and will go ahead with the trial even though the treatment is aimed at relieving and controlling the symptoms rather than curing the disease. I thought and hoped that by choosing the treatment and being only the third person to have it done would hopefully help me and if it works would be another step closer to finding a cure for this terrible disease.

I know it's going to be a long four to five month's to complete the trial, but even though it's very frightening for me not knowing whether it will help me, am going to go in with a very positive attitude. God please help me, my life is in your hands. I know that at time's I have stopped believing in you and apologise, but please give me the strength that I need to fight. I have so much unfinished things to do and only you can help me now to achieve these goals.

It's now Monday, 2nd October and my father has brought me in to Ward 5west at the hospital to start the stem cell collection. A tube was placed in each arm and was hooked up to a machine for four hours collecting my stem cells. It was a long uncomfortable time and was glad to have my father with me. It was also great to have my good friend Teresa come in the afternoon and give me support.

So the first stage is now over and will now wait for next Monday, when I start the first stage of chemotherapy. I have now had my week of chemotherapy and am not feeling too well which I expected. Now it's time for me to go home and rest for three week's and then come back for my second lot of stem cell collection.

It is now November, 2000 and have completed stage two which is treatment with Cladribine (chemotherapy) and now await stage three of treatment which will commence on Sunday 31st December with more G-CSF injection, before the stem cell collection on Wednesday, 3rd January 2001.

Since commencing the injections last Sunday, I have had a lot of pain and discomfort and Monday 1st January, 2001 I could no longer tolerate the pain and 2am in the morning had to be rushed to hospital where I was given Morphine for the pain.

Have had a few very uncomfortable days and today back in to hospital for the repeat collection of stem cells which took about six hours. It's been a long day and am glad that stage three is over. One thing I must say is that the service I have received at the hospital is fantastic and thank Tanya, Edith, and Peter for looking after me during my collection.

Now I will wait until 29th January 2001, when I will be admitted as an inpatient for the final stage of the treatment which involves the administration of high dose chemotherapy and transplant.

27. Time for the Transplant.

The fourth phase of the treatment involves the administration of high dose chemotherapy with a drug called cyclophosphamide and a powerful drug called anti-thymocyte globulin (ATG). Both these drugs suppress the lymphocytes in the immune system and therefore may reduce the severity of multiple sclerosis.

The main side effect's of the ATG is an allergic rash and/or temporary arthritis, due to the fact that ATG is derived from horse serum.

Hence after the cyclophosphamide is completed, the previously collected stem cells are reinfused back into the bloodstream (transplant).

It is now 29th January 2001 and after five month of chemotherapy and stem cell collection, I am admitted into hospital and face a very difficult few weeks. This will definitely be my toughest test and even though very frightened and concerned am determined to fight and succeed with any challenge they throw at me.



Bone Marrow Transplant Unit

The past 24 hours have been very tense for me knowing that the time has finally arrived. Last night was very restless and could not sleep, so ended up getting up at 3am and did my washing and cleaned up my room. It was difficult for me to say goodbye to my mum and dad this morning as I left for the hospital because I was thinking to myself will I come back or will I be one of the unlucky one's and not come back home. I know it's a very low percentage that I won't pull through but am quite confident that the team at the hospital will get me back home.

Today the first procedure will be to insert what is known as a Lumen Hickman Catheter which requires a surgical procedure to insert a catheter into my upper body and tomorrow the final phase of the treatment begins with chemotherapy. God I think this is the time where I will need your help more than ever.

Day 2 has begun feeling quite well except for some pain where the catheter was inserted. Today nothing much is happening, so will try to relax and get ready for the commencement of chemotherapy tomorrow. The staff here is great, friendly and very helpful. It's also good to see some familiar faces like Amanda who I remember from the day care centre.

It is now 6am Wednesday 31st January, and I am hooked up to the machine and they started with intravenous drugs before the chemotherapy commences in about two hours. So it's going to be a very long day. This morning the nurse looking after me is Jean and once again I am so lucky in having such great nurse's look after me. My Oncologist Dr Grigg also came to see me this morning to see that everything was proceeding well.

My good friend Josie rang me this morning and so did my other close friend Rosalie. I feel so lucky to know that I have such great people whom I am proud to call my friends. My parents, sister and her family came in this evening and my niece wrote me a get well card which make's me feel much better. It's just fantastic to see my family and friend's show me so much support and this makes my determination to fight on and succeed with any challenge thrown at me.

This afternoon the shift changed and out goes Jean and in come's Danni. Well what can I say but excellent. They are so understanding, supportive and even when I am feeling down, their presence makes life easier for me.

Well it's time to call it a day, am feeling tired, everything is going well for me according to the doctor's and hopefully this continues, so I am keeping my fingers crossed and see how tomorrow develops.

So much that everything is going well, I spoke too soon. It's just before midnight and I rang the buzzer as something is not right, I feel hot, tried to stand on my feet but could not, had very strong body pains and all of a sudden could not breathe. It felt absolutely terrible and thought I was going to die as I had no oxygen. The nurse quickly came in and could see I was having trouble breathing and immediately put on the oxygen mask.

After a while I started to breathe better and all of a sudden I break into this rash which looked like lots of mosquito bites. It really scared me but was told that it was a reaction to one of the medications. Now I will try and get some sleep.

So I managed to get a couple of hours sleep, however another embracing thing happened to me when I wet the bed and that ended my sleep. It is now 4.30am and I wait until the nurse makes my bed and then she can help me to the shower as I will not sleep anymore.

My friends Enzo and Rosalie came in this morning and it was good to see them. All my doctors have come to see me as they have all heard the news about last night. My Oncologist told me that the reaction of the ATG (a powerful drug called anti-thymocyte globulin) which is derived from horse serum is what caused me problems last night. So they are going to change from horse serum to rabbit and hopefully the rabbit will be more effective without the serious side effects of the horse serum.

Josie rang me this afternoon so I could keep her up to date with how things are going. It is now 5pm and the rabbit serum (anti-human thymocyte globulin) has arrived and is connected to one of my intravenous lines. Now I will wait and see what happens.

It is now the morning of 2nd February and as usual am woken up firstly by a doctor at 3am and again by the nurse at 4am for my obbs. I have had a reasonable night, nothing like the night before, so I guess the rabbit serum suits me better than the horse serum. Now I believe I am a BUNNY!

What wonderful friends I have in Josie, John and Rosalie, Enzo who ring me everyday with fail, it means so much to a person who is going through what I am, and it gives me the energy and will to fight.

I am having a bad afternoon with pain in my bones and all over, so will say goodbye for now.

Saturday morning is here, yes they woke me again but at least they let me sleep in until 5.30am. I am feeling a bit better than yesterday, but still have bone pain and am a little light headed which is expected with chemotherapy. Today Amanda one of my favorite nurses is looking after me, who I am please. She sat down with me and we had a chat as she could see me typing on the laptop. I said to Amanda that I was writing a book on my life with MS which I hope will one day be published, great she said as she has an uncle who also suffers from Multiple Sclerosis.

My Oncologist Dr Grigg came in to see me as the on call doctor rang him last night about me not feeling well. It's so good to see how much effort these doctors put in to their patients, no matter which day of the week or hour of the day.

Today I am feeling off colour, experiencing nausea, sweating and just have no motivation to do anything. It was such an effort just to have a shower this morning, but it's important that I don't let go. I suppose the news that they will do the transplant this afternoon is making me tense as I do not know what to expect.

Monday afternoon a doctor and Peter the bone marrow co-ordinator enter my room, one pushing a trolley that had what looked like a milk keg and the other with what looked like a deep fryer. Anyway they open the keg and out come three bags of my previously collected cells, frozen solid. All this looked like something out of a science fiction movie. To my amazement it was all over in no time and the transplant was completed.

The after affect of the transplant is rather embarrassing as the marrow is mixed with a preservative that leaves a terrible odour in your body. I myself cannot smell it on me that much, but people walking into the room really notice the smell. This will normally last about forty eight hours then it goes away. So now all the doctors and nurses are calling me STINKY for a couple of days.

I am now feeling tired and will try and have some dinner. Hopefully tonight I will not have too many visitors as I do not think I am up to having people around me tonight.

Last night was very uncomfortable, tossing and turning and did not sleep very well. The nurse on duty Debbie was very helpful checking in on me. I know I have said it before but these nurses are fantastic people.



Reinplantation of Stem Cells

Today I tried to read the paper but found that was a bit of an effort plus cannot remember reading anything at all. The same with the television I know it's on but don't know what's happening. It is such a strange feeling which is hard to explain.

A change I have noticed this morning is discoloration of the skin especially around my face and eyes. I am now turning yellow, what am I becoming. Still feeling off colour, but will try and motivate myself.

It is now evening and I told the night nurse Debbie that the odour in the room is still around, so the nice person she is, arranged for some peppermint essential oil which has made a big difference. Some people have commented that I smell like dead fish. Anyway the problem is now fixed.

Three days after the transplant and am still struggling with energy. Dr Grigg and his team came in to see me and told me that everything is going well and told me not to worry that I am not feeling too good, it's expected at this stage of the procedure. He also said that things will get worse before they get better. GREAT!

Had a call from my good friend John this morning which did cheer me up and so did Rosalie? Once again I am a very lucky man.

My one incident for the day was when Danni was changing my catheter dressing and splashed me in the eye with one of the solutions, it stung for a while but had a good laugh over it.

This afternoon my blood pressure is up and am feeling feverish, once again it is expected as my blood counts are reaching zero and this causes fever. I am also pleased to see that my weight is starting to drop as it has been worrying me the last few days.

I did not sleep very well last night, was thinking of my son Tommy whom I miss so much. The morning came and decided that I would make another attempt and write to my ex-wife and ask if she could find it in her heart to bring Tommy in to see me. I will await her reply now, but have a feeling the answer will be the same as always. AM I ASKING TOO MUCH!

So my day has not begun very well, feeling depressed plus have noticed a few changes. My throat is very sore and have difficulty in swallowing, so Danni has given me some mouth wash to try and also advised me to stop brushing my teeth as my blood counts are very close to zero and could risk infection with using a toothbrush.

My skin colour is changing to yellowish, I have tremors in my legs, bone pain and that black spot in front of my eyes is back. Parts of my body are showing big dark bruises and cannot look at too much food or coffee without feeling sick.

It's now afternoon and after a light lunch, I complain that my throat and mouth are still sore. So what do they give me now is Cocaine which believe me numbs you immediately. GREAT STUFF!

Anyway will now play some relaxation music and relax for the rest of the afternoon and then wait for my family to visit.

The morning of 9th February, woke up with pain in my bones as well as developing mouth ulcers which I have been expecting sooner or later. My friend Enzo came to see me this morning and spent a good couple of hours together which was great.

I also received a call from Francis who was at Josie's place; we also had a good chat. Later in the afternoon my good friend and fellow MS Ambassador Teresa, walked in to see me. It was great of her to drive all the way here as she has not been well herself, also a multiple sclerosis sufferer. At times I become so emotional knowing that these wonderful people are there when I need them. Knowing I can count on their support and encouragement makes living with this disease so much easier. Having friends like these is what has given me the strength and determination to go through this difficult time in hospital.

Feeling tired, had a full on day with lots of calls and visitors so will now turn in and rest as my bones are aching and my mouth sore.

Had a restless night and am feeling down this morning, plus lots of trouble passing urine. I think I am going to go through a bad patch but will take it as it comes.

I have also received news that my Hickman Catheter is to be removed today as they found that the infection they were looking for is coming from the catheter. So within one hour of telling me it was taken out. It felt like they ripped out my heart when it came out. Now it's back to the intravenous lines. One positive think to come out of today is that I was allowed out of my room for the first time in weeks and managed to take about twenty steps with the help of my walking frame. My other catheter was also taken out today, to see if my urinating problem had improved.

It's now Wednesday and things are getting from better to worse. I had a sleepless night and a hell of a time trying to urinate, have no control, cannot make it in time to toilet and by the time I get there nothing happens. The day has been hell for me and the doctors are trying to figure out how to help me. After a visit from the Urologist this afternoon I have been told to try and hold on until tomorrow and if no improvement they will consider putting in the catheter again. Hopefully I can get through the night without too much discomfort. I was wrong had to call for the night doctor at midnight and told him I cannot take it any longer, the pain is unbearable and to help me. Still had to wait till the morning and see what the urologist suggested.

Daylight would never come and finally when it did so did the doctor who could see I was in a lot of pain and told me we had no other option but to put the catheter back in. So for the second time this week they inserted the catheter, not a great experience but worth the discomfort of it all. My only

worry was that now I know that I will be carrying this bag around for the next four weeks and that includes when discharged.

I cannot help but think to myself, will it be better after the four weeks or is this another downfall of the disease. I cannot believe how unlucky I've been, everything has gone so well, then the infection in the Hickman catheter and now the bladder problem. WHAT NEXT!

Even though still sore, it's now bearable and hope to get a good night sleep. Am very tired.

Friday morning has arrived and after a good night sleep am feeling not too bad, so after breakfast I decided to go for my walk and although it took 45 minutes I was pleased to make it to the reception desk and back to my room, this was my goal by today.

Now Saturday morning, feeling much better and the doctor told me this morning that if all goes well, will most likely be discharged Tuesday afternoon after my last course of antibiotics which has made me a happy man. Cannot wait too get out of here?

Sunday morning and am looking forward to my day leave at home. It's so good to go outside a four weeks of being stuck in a room. Dad picked me up and was glad when I got home. I had a great home cooked meal and then had some fun with my niece and nephew. By late afternoon I was starting to feel unwell, was feverish and having trouble breathing, so was taken back to the hospital.

Monday morning my fever was still high, however it did improve as the day went on. They gave me another two blood transfusions today and it appears it has helped. Well tomorrow is my discharge day and hope that all will be well for me to go home.

Tuesday morning have had breakfast and am waiting for the doctors to give me the all clear to go home. Well it did not happen. I still have a fever and the infection has not cleared up so until all is clear I am stuck here.

Finally Wednesday 28th February, and all is clear, so fingers crossed today could be the day. So as soon as my neurologist and urologist give me the all clear, home I will go. Yes I have received the all clear and by early afternoon am ready to go home. Feels like I have waited so long for this moment.

It's now time for me to complete this story and go public and hopefully by sharing my experience with multiple sclerosis I can give others the strength and encouragement to keep on fighting. It is not by any means a cure, but hopefully people will understand what life with multiple sclerosis is like and remember we have support out there, so don't be afraid to take advantage of the support we have.

Just remember, MS is like a game of cards, each player must accept the cards that life deals, but once in your hands it's up to you how you play your cards.



28. Time has passed quickly

Time has passed so quickly and now I find that four years on, my condition has worsened. From a walking stick to a walking frame to a manual wheelchair to an electric wheelchair.

To make matters worse, life at home was becoming harder and harder. Yes I was getting council help where they would provide me with someone to help me out of bed and shower me every morning, at night a carer would come and put me to bed. Life just got harder and was just too difficult for my aging parents to look after me.

So it was time for me to make another tough decision as to what I should do now. I got in contact with my social worker at the MS Society Coral and started to look for a home where I would be looked after 24 hours a day. As I wanted to go to a home in Williamstown where I would spend several weeks during the year for respite. Unfortunately I was not suitable there because I now needed high level care.

After a long wait Coral rang me and said there was a vacancy in Keilor East which was close to home. I went to have a look at it and saw my room which I liked very much because I would have my own privacy. The other thing I liked about Cyril Jewel Place was that it was a specialised home for people with Multiple Sclerosis.



After a few days I received a phone call from Maryann the Manager and told me I had the room. I immediately said yes and she told me I could move in. In the next couple of days I had taken everything over.

Once again it was hard for me to leave mum and dad, this time for good. One big hug and kiss to mum and dad, with tears in our eyes I got in the maxi cab and off to my new home. I did say to them that every Sunday I

would go home and spend the day with them. It's now been four years and I am still going home every Sunday.

When I got to Cyril Jewell House I was welcome by everyone which was a good start. One of the residence Geoff and I have become close more because we have the same interests in computers.

Been here has also had its ups and downs, I get along well with everyone, but have always liked to voice my opinion when necessary. So I have got into some situations with staff members. My main disappointment with being here is that I find some of the nursing staff here doesn't understand our needs and that is what upsets me.

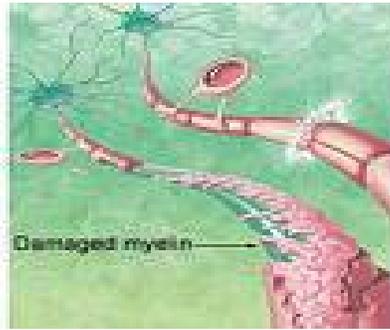
We are people with Multiple Sclerosis and have different needs to the age care on the other side. But its becoming harder and harder to get this through to management. So what I have learned in my time here is do my own thing and that way I don't get involved in the politics here because my health is more important to me. So far this has worked well for me.

Especially now that I have developed other medical problems such as Diabetes, insulin dependent and have also a heart condition. I don't need anymore on top of all I have now. In future I think of Anthony and no one else. My problem has been that I have put others first, but now everyone to themselves. I have followed this and must admit it have work well for me, so now if anyone come up to me for help I tell them to sought it out for themselves.

So to end my story, I hope that whoever reads this story, will get some pleasure out of it and I hope that people with Multiple Sclerosis will get some positives with living this horrible disease. I know it's hard at times but as I said earlier in the book Multiple Sclerosis is like a game of cards each player must accept the cards that life deals, but once in your hands it's up to you how you play your cards.



APPENDIX



What is Multiple Sclerosis?

Multiple Sclerosis is a disease that has puzzled and confused medical science since the late 1800's. The actual name Multiple Sclerosis means many scars, coming from the Greek word Sclerosis meaning scars and Multiple meaning many.

The disease affects the central nervous system, the nerve fibres in the brain and spinal cord have a protective sheath called myelin which is sort of insulation. It helps to conduct electrical impulses between the brain or spinal cord and the rest of the body and prevents them from short-circuiting. When the myelin is healthy these electrical impulses get through quickly and accurately and make our movements easy and co-ordinated. When Myelin is damaged or scarred, the messages become interrupted or distorted.

Symptoms of Multiple Sclerosis depend on where the myelin is damage. It can affect the nerves in the brain, the brain stem and spinal cord. Damage to the motor nerves affects movement, damage to the sensory nerves can alter sensation or cause tingling or numbness.

Multiple Sclerosis can in rare cases disappear altogether after one or two episodes. Or it can progress steadily over many years, bringing a slow deterioration in an individual's capability. It's a disease that leaves a person with Multiple Sclerosis to live a life of uncertainty and unpredictability.

Who gets Multiple Sclerosis?

There are currently two and a half million people across the world with Multiple Sclerosis and fifteen thousand scattered around Australia. Multiple Sclerosis is not inherited directly. It is neither a contagious nor fatal disease. Multiple Sclerosis generally is diagnosed in young people between the ages of twenty to fifty years of age. Multiple Sclerosis affects twice as many

women as men and is more common in Caucasians living in temperate regions of the world.

In Multiple Sclerosis, for some unknown reason which medical science cannot explain, the body misrecognises the myelin sheath as being foreign and sets about destroying the sheath as if it were an invading disease producing such things as bacteria or a virus.

What causes Multiple Sclerosis?

It is not known what actually triggers Multiple Sclerosis. The cause is unknown, no cure has been discovered and as yet there is no way to know who might get multiple sclerosis. There are several theories; one possible theory is that a virus attacks the immune system. In other words, the immune system lets the body's defenses turn on themselves.

Our bodies have a built in defense system which destroys invaders like a virus and bacteria. This defense system can backfire and start attacking the body's own cells. When viruses invade the body, they takeover body cells which might become confused because some viruses take over parts of cells and it might attack both the cells and virus.

What are the Symptoms?

Symptoms of multiple sclerosis vary greatly from person to person. It is possible to have different symptoms at different times. Some are very common but there are no typical set of symptoms that apply to everyone. Also nobody with multiple sclerosis gets all the possible symptoms at one time. They can be mild and last for a short period or severe and long lasting. Some are more common in the early stages of the disease while others occur later. Some may be obvious but others can be invisible, which can be hard to understand for people who don't have multiple sclerosis.

Symptoms might include:-

- loss of co-ordination
- numbness or pins and needles
- loss of bladder or bowel control
- extreme fatigue or unusual tired feeling
- staggering or loss of balance
- dragging of feet

- problems with sight, double vision
- speech difficulties such as slurring
- tremors of arms and hands

Symptoms vary depending on what part of the nervous system is affected. For example, multiple sclerosis in the spinal cord might cause weakness, numbness and paralysis of the arms and legs. Multiple Sclerosis in the brain might cause eye problems, speech difficulties.

Fatigue is one of the invisible symptoms which people with multiple sclerosis find difficult to explain to others. Multiple Sclerosis related fatigue is different to that experienced by people who do not have multiple sclerosis. It generally occurs on a daily basis and tends to worsen as the day progresses; it is often aggravated by heat and humidity, and can come on suddenly and severely. It is advisable for people with multiple sclerosis to manage their stress, sleep and exposure to heat.

Some have speech difficulties, speech may become slurred or it is at times difficult to remember a word. People with multiple sclerosis need to learn what they are suited too and to listen to their body and take notice of what triggers symptoms.

How is Multiple Sclerosis Diagnosed?

Detecting multiple sclerosis can be difficult. Laboratory tests and scanning techniques have made it easier to detect MS. Early symptoms are often so slight that a person doesn't go to get checked out by a doctor. Other diseases of the nervous system have some of the same warnings signs as MS.

Doctors look for two basic signs before confirming MS:-

1. Signs of central nervous system damage. E.g. numbness or tingling of hands and feet and unexplained tiredness.
2. Come and go patterns- symptoms of MS usually appear and disappear without warning unlike those of other nervous system diseases.

Most family doctors will only see a few cases of people with MS in their entire careers. It is felt that this unfamiliarity with the disease can also delay diagnosis. Diagnosis of ms normally occurs after there have been two sudden worsening of MS symptoms (called attacks or exacerbations) within one month and after more than one area of damage to the myelin of the central nervous system has been found.

There are several tests that physicians use to diagnose MS:-

- visual and auditory evoked potentials: - test the time it takes for the brain to receive and interpret messages. Small electrodes are placed on the head to monitor how brain waves respond to stimulation to the eyes and ears. Patients are asked to look at a screen. In a healthy person the response to the images on the screen is almost immediate. If the myelin is damaged (known as demyelination) messages take longer to get through.
- Neurological examination: - This tests for abnormalities in movement and sensory pathways. The neurologist is looking for changes in eye movements, limb co-ordination, balance, sensation, speech and reflexes and signs of weakness.
- MRI scan (magnetic resonance imaging) shows areas in the brain, spinal cord and optic nerves suggestive of the demyelination process that takes place in MS. The MRI scanner is linked to a computer which takes pictures of the brain and spinal cord. It is extremely accurate and can pinpoint the exact place and size of the scars on the myelin. An MRI examination takes about 40 minutes. During that time the patient lies flat on a padded bench which moves in and out of the tunnel-shaped scanner. The experience of lying very still for a long period can sometimes produce anxiety in patients. It can also be very noisy and you are likely to experience panic reactions, noise



intolerance and claustrophobia.

- Lumbar Puncture: - a needle is inserted into the lower back, under local anesthetic, and a small sample of the fluid which flows around in the brain and spinal cord is taken from the spinal cord for testing.



The Physical Changes in Multiple Sclerosis:

The problems that become most apparent to others are caused by a disturbance of motor functions, movement and co-ordination. Leg movements can be affected by muscle weakness or in co-ordination, so that walking may become slow and clumsy. There may be a tendency to stagger or trip in a manner that can sometimes suggest intoxication.

Even people who walk quite well can find they have problems with running, walking or going up stairs quickly. Tremor can sometimes be visible in hand Movements, Extra effort may cause this tremor to become more pronounced.

Speech may also change during the course of MS resulting in slurring or hesitation of speech.

At anytime during the course of the disease, people with MS may experience problems with bladder and bowel functions. This can result in frequency or urgency of urination, both during the day and at night.

Many people with MS find they are adversely affected by rises in temperature that can occur in hot weather, after hot showers or as a result of feverish illness. This may temporarily aggravate symptoms because nerve message conduction is slowed by rises in the temperature of the body.

Fatigue is another common experience of MS and when severe it can be extremely debilitating. People with MS must therefore modify their activity levels and avoid becoming overtired. Energy consumption should be carefully monitored. Rests as brief as five minutes between any activity can serve to recharge the body's batteries.

Psychological Changes in MS:

Psychological experiences that can occur with MS are firstly, the distress associated with the reaction to the diagnosis and the implications of the disease. The diagnosis is difficult and frustrating for either the person with MS as well as relatives and close friends to cope with. Most people experience denial, anger, anxiety, depression, fear and powerlessness before acceptance of the diagnosis.

With **denial** it's easy to assume that the doctors have made a mistake.

Anger as with any bad news, an immediate response is to want to find someone else to blame.

Anxiety with all the unknown issues surrounding diagnosis of MS it is understandable that people's fear of what might happen can become excessive.

Depression When people recognize that MS may have a significant impact on someone's future and life, this could require professional intervention because it could become debilitating in itself.

Acceptance the period of time until a person with MS can truthfully acknowledge the unwelcome news of the disease can be quite extended. It can sometimes take years to reach a point where it can be managed. It can also be a positive experience to share the emotions that can surround this disease with a Councillor.

Peripheral Blood Stem Cell Harvesting

What Are Stem Cells?

Stem cells are very primitive cells from which all blood cells develop. These stem cells eventually develop into specialized blood cells such as red blood cells, white blood cells and platelets. The bone marrow contains large numbers of stem cells and these continuously form, produce and maintain blood cells.

Stem cells can migrate from the bone marrow into the circulating blood, called "peripheral blood". However, stem cell numbers in the circulation are usually very low and therefore need to increase their numbers before they are collected from the peripheral blood.

There is a hormone called G-CSF (Granulocyte Colony Stimulating Factor), which naturally occurs in your body in small quantities. Its role is to aid the production of white blood cells. G-CSF is given in an injection form. The functions of this injection are to stimulate the stem cells to leave the bone marrow and circulate in the peripheral blood.

The injection is usually given in the lower abdomen or upper thighs either every evening or twice a day morning and night for a period of five days prior to the collection.

Side Effects:-

- . Bone Pain/Ache (as your white cells increase)

- . Slight redness around site of injection
- . Slight increase in body temperature
- . 'Flu – like' symptoms

The collection procedure

Stem cells are collected through a technique called Aphaeresis. This is the process of separating your blood into various components. Basically the process of aphaeresis involves drawing blood from your bloodstream, separating out the stem cells, and returning back to you all the remaining cells.

This procedure is accomplished by using a cell separator machine, to which you will be connected. Two intravenous lines are required, one for drawing blood, and one for returning blood. You will need to have good veins in both arms to accommodate the needles used with the machine.

If your veins are not suitable you will need to have a catheter inserted called a “vascath”. A vascath is a temporary catheter inserted in the upper chest area, below the collarbone, just prior to the procedure and is removed on completion of the collection.

You are connected to the machine via a totally enclosed sterile tubing kit, which your blood flows through. Your blood will enter a large bowl that spins, which separates your blood into its components. At different stages during the process, the machine will collect the stem cells when it detects them.

Anti-coagulant (ACD-A) is used in the procedure to prevent the blood from clotting in the lines. There are some side effects to this drug. The main one being that the anti-coagulant binds with calcium in your blood and lowers it slightly.

Your body has between 4-6 litres of blood. Your blood is constantly being processed and returned to you. The maximum amount of blood in the machine at any one time is 200-300mls. The machine will process between 10-15 litres of blood therefore you will have 2 to 3 blood volumes processed.

Side Effects:-

- . Numbness or tingling of the lips (which is a mild reaction to the ACD-A that your blood has been exposed to).
- . Light headedness, sometimes at the end of the procedure.

Sometimes, these problems are due to a lack of calcium in the blood and tests may be performed during and after the procedure, to check your blood calcium levels.

At the completion of the procedure your stem cells are removed from the machine and sent to the laboratory to be frozen and/or prepared for infusion into yourself. A preservative agent called DMSO is added to them prior to freezing and then they are stored until they are required.

Samples are taken from the bag of stem cells and sent to various labs to measure the amount of cells. The numbers present will determine the number of collections you will undergo.

After the collection expect to feel tired. This is very common as the procedure, though highly selective, will “skim off” some of your red cells which are responsible for carrying oxygen in the blood.

What Blood Cells Do!

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| Red blood cells | Their function is to transport oxygen from the Lungs around the body. The normal red blood cell Count is between 120-180. A lowered red blood cell Count is called anemia. The signs and symptoms of Anemia is tiredness, shortness of breath, pale Skin and dizziness. |
| White blood cells | Fight infection, ridding the body of disease causing Microbes and the body’s defective cells.
The normal white blood cell count is between 4-
The most important of the white blood cells are
The neutrophils. A count less than 2 increases the
Risk of infection. |
| Platelets | Form a clot after injury has occurred. The normal Count is between 150-450. A lowered platelet Count increases the risk for bruising and bleeding. |

Chemotherapy

Chemotherapy drugs can be given in many ways, most commonly intravenously over a period of time. When you have chemotherapy there will be a period of treatment followed by a rest.

The chemotherapy drugs must enter the bloodstream in order to reach cells anywhere in your body. The drugs enter the bloodstream immediately if they are injected into a vein or artery. The chemotherapy drugs travel around the body and can enter and destroy certain cells. The cells most affected by chemotherapy are those which multiple rapidly. The rest periods between chemotherapy treatments allow your normal cells to recover before the next treatment.

Side Effects

Side effects vary considerably. Two people on the same treatment may react quite differently and some people will have no side effects. Reactions can also vary from one period to another.

The most common side effects of chemotherapy are:-

- . fatigue
- . nausea and vomiting
- . bowel problems
- . mouth problems
- . nerve and muscle effects
- . effects on the blood
- . hair loss and scalp problems
- . mouth problems
- . bleeding problems

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