

I'm not stupid, just disabled

**Some serious chitchat
about life after a stroke.**

Wolfgang Haufe

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Dedicated to all the people who can't enjoy life as we do. Who don't leave their bed, their home, or are too sick to participate in social life.

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Keep smiling!

Introduction

After a stroke the world out there, the real world, can seem quite daunting, even hostile. Released from the cocoon, the protective microcosmos called hospital, you are like a baby out in the open for the first time, out in the big, wide world. You face reality.

On your own for the first time, even though family, friends and partners don't think so, because they support you. Their support is different from the type you've received in hospital. You feel on your own. Not only do you feel on your own, but suddenly you realise that you have aged by 10-20, or more, years, your emotions are in turmoil, your body doesn't move the way you want it to, and for some reason your voice doesn't sound quite the same as it did the day before. All this happened overnight, from one minute to the next. You can't believe it.

I have met people who didn't even know they had had a stroke during the night, until they got out of bed and fell to the ground. For my part, I felt it violently and I felt as if someone had taken something away from me; a few years. I had aged.

With luck, your partner is still with you, otherwise you'll

seriously begin to wonder whether there will ever be a partner for you again. Whether you are still attractive enough to a prospective partner. Maybe you are. After all, you are still the same person. Well, at least that's what you think. And that's exactly where the problem lies. You think you are normal, but you're not. You just don't want to believe it. You are probably the only person who thinks you are normal. Truly! Ask your friends. And, by the way, you'll find out who your friends are.

You can't blame anybody for feeling uncomfortable around you; it is human nature that anything out of the ordinary has to be approached with caution. Just think of yourself as being extraordinary. Wouldn't you be a little bit intimidated by a disabled person? I would. I actually have been. It happened when a friend of mine came over a few weeks after he had a stroke. It was a relatively mild one, but enough so that I didn't know how to act or react. I was in shock. Me, who had gone through the same thing...only more severe.

Anyone who is face to face with a stroke victim who is just out of hospital, is in shock. Several doctors assured me that this is a perfectly normal reaction. What is not normal is the behaviour that usually follows. One doesn't know what to do. There are so many questions; most importantly: 'How do I not make a fool of myself,

and, the stroke victim?’ Few of us have experience in dealing with people like this.

Which is where this book comes in. It aims to help. No, it’s not a rule book, because there are no rules. Nor is it a guide book, because it would be almost impossible to guide anyone through these numerous situations. Each stroke is different. Each person is different. Each situation is different. There is certainly no recipe for survival of an encounter of the stroke kind! All this book can do, and wants to do, is help; help stroke victims to have a *déjà-vu* experience when they read about a situation, help caregivers to achieve a better understanding, and help people who just happen to come into contact with a stroke victim, to be more relaxed. Included are experiences from stroke victims, caregivers, physiotherapists, nurses, occupational therapists, and doctors. Many people have written to me, I searched the Internet, and corresponded with several stroke clubs and individuals.

So, what makes me the expert? Nothing really. But I happen to have some exquisite credentials. To put these credentials on the table, here is an article, entitled ‘Why not me?’, which was published in the newsletter of the Auckland Stroke Foundation a few months after I got out of hospital.

Why not me?

It was the 20th November 1990. I went to work as on any other day. Around midday I was on the phone to a client. Suddenly my head started to wobble, I said I had to go, I felt dizzy, my head just didn't want to stay straight on my body. Something major was wrong, but at this stage I didn't know what. The secretary who was passing my office heard me yelling "Get me an ambulance, quick!". The next moment it happened. It felt as if someone picked me up by the brain and gave me a good shake. Once, twice, three times. I was frightened and shouted: "I'm dying". As quickly as it had come, it was gone again. For some reason I stayed fully conscious, a fact that surprised the doctors. By now I was lying on the floor with no feeling in my right side. The ambulance had arrived, an officer was attending to me, and soon I was whisked off to Auckland Hospital.

Once there, a scan revealed that I had an aneurysm that had burst, leaving me with severe bleeding, a so-called cerebral haemorrhage. Unfortunately, the aneurysm was situated at the brain stem, which meant it was inoperable, even if it had been detected earlier. It also meant that not only one side of my body was affected, but both. On top of that, I had to have a tracheotomy

(they cut a hole into your throat), because I couldn't breathe (I was on a respirator for some time), and nasal gastric nutrition, (a plastic hose through the nose straight into the stomach) didn't let me see any solid food for almost a month (I couldn't swallow).

Apart from this I had many of the symptoms that normally accompany a stroke. While the majority of strokes are caused by a blood clot which travels to the brain, stopping the blood supply to certain nerves, a cerebral haemorrhage causes bleeding in the brain. Again the blood supply is interrupted. It is much rarer and leaves most people dead, or, if they're very lucky, abominably disabled.

My wife and relatives couldn't believe it! Particularly because I was only 39 at the time and absolutely healthy. Why me? I don't know, but everyone seemed to ask this question, and later, during my partial recovery, I was to ask this question myself.

No doubt every stroke victim has at some stage asked this question. Why me? May I ask the question: 'Why not you?' I'm sure nobody can give me a good reason as to why not. During my four and a half months in hospital I sometimes watched the news. There was a bus in Yugoslavia that went down a cliff with 42 schoolchildren

on board, the Gulf War claimed many victims, hundreds of people died in an earthquake in Russia and entire Kurdish villages were wiped out by Iraq's army.

No, I couldn't possibly sit there and ask myself: Why me? Sure, death is a terrible thing. Something we would rather not talk about; yet it happens all around us, every day. There is absolutely no reason to ask Why me? The question to ask should be: Why not me? Why have I survived? In most countries of the Western World the chance of having a stroke is higher than the chance of winning Lotto. Only, everyone would like to win Lotto. Have you ever heard a Lotto winner ask the question: Why me, why did I have to win? Probably not.

It always depends on how we look at things. On a recent (my 18 months) check-up the doctor told me: "Well, this is it". He said to me that it is very unlikely that there will be any further improvement, and also asked me whether I get depressed. "No," I answered, "I'm just glad to be alive." He told me that many stroke victims get depressed, it is quite normal. "I enjoy life," I said.

Why I survived I don't know, but what I do know is, that we should ask ourselves the following question when depression looms: Why didn't I die? Why not me?

So, that is the stroke part over. Now I'd like to add a

few things that happened while I was still in hospital. This is not intended to be a horror story, it just sounds like one.

One night, after I had enjoyed a few hours of good sleep, I woke up with terrible chest-pain. It felt like a heart attack, even though I don't exactly know how one feels. Nor do I ever want to find out. Anyway, I thought "This is it", and buzzed a doctor. He didn't say much, but gave me a painkiller so I could sleep better. Little did he or I know at this stage, how close I was this night to sleeping really deeply. The painkiller was strong enough that I floated to sleep soon after.

A few weeks later, I had been allowed home for the weekend. As I was entering the house, suddenly there was this pain again. Only worse. The pain was excruciating. I had difficulty breathing. I had difficulty – full stop. My wife called an ambulance that took me back into hospital. After a thorough examination the attending doctor told me that it was pneumonia, and that it was good to have it under control now; they (the doctors) still wanted to observe my pneumonia for a few days. Part of this observation was, of course, to get confirmation that there was actually liquid inside my lung. For this reason a friendly, young, female doctor inserted a not so friendly needle in my back, while I was

sitting on a chair. Missing my spine by only millimetres, she carefully sucked dry the bottom of my lung, and finally extracted a syringe filled with what I considered 'muck', and she obviously considered nothing unusual. The medical profession was facing a puzzle.

Then a few days later, my leg started swelling up and getting hard around the calf muscle. The doctors suspected, quite rightly, a blockage in the vein. I was rushed to get an ultrasound, to have a closer 'look'. The operator who stared at the screen described it in one well known expression – 'chock-a-block'. It was concluded that I had had a thrombosis. Following this, I was transferred to another hospital to have an angiogram. A small camera, inserted into my blood vessels, revealed that there had been a blood clot in my lung previously. The two 'minor' incidents, one of which was diagnosed as pneumonia, were in fact pulmonary embolisms. Again my life had been in danger. Twice.

To avoid another embolism or clot, the blood had to be thinned down. Normally this is easily done by administering an anticoagulant. Normally! In my case, however, a different approach was needed. Because of the haemorrhage a strong anticoagulant was not an option, as it could have caused another bleed. Instead the doctors opted for a mild one (a few days on the

drip). Also, I had a bird's-nest filter (a piece of wire, that looks roughly like a guitarist's discarded B-string) installed in my vena cava. This was supposed to stop blood clots from entering my lungs. And, no, I didn't have much influence over whether or not I wanted a piece of wire to show up every time a X-ray was taken. Of course I was asked, but it was also put to me very bluntly – “Do it, or die”. Naturally, I thought: ‘Who am I to argue?’.

It also was around this time that I had to wear some thrombosis-embolism-deterrent stockings. I can't say that I liked them, and my first reaction was: “What am I? A blimin' cross-dresser?” To my horror I discovered that I, like everyone else who stayed in bed for any length of time, had to wear these not so exciting marvels of modern medicine. In the end I just accepted them as something that was good for me. Like you do in a hospital. You trust whatever someone tells you is good for you. You are not concerned with good looks. On your way out you don't mind a crease in your shirt, do you?

All in all it wasn't much fun. But, anyway, no matter how hopeless a situation seems to be, there is always more than one way to look at things. Sometimes even a way to laugh at things. Well...at least smile.

The official results of an unofficial survey

The following submitted information doesn't claim to be hard facts nor statistics. Indeed any reputable market research company would, quite rightly, question the methodology. Rather than cold statistics, the stroke survivors who contributed to this book tell us how they feel. This is certainly not as accurate as a rational report could be, or some people might expect, but it tells us all we want to know. Surely there are enough organisations who publish surveys each year that delight numerous statisticians. The question is who really needs a cold hard look at reality?

No matter whom I talked to, no matter where they came from, and no matter whether it was a letter, or e-mail, an audio tape, or a face-to-face conversation, there was an underlying feeling of loneliness. The majority of stroke survivors, people from all walks of life, said or gave the impression that they had to fight loneliness. Which is not surprising, considering that on average over half their friends disappear. So do the relatives. They are still there. But they don't just pop in unless they are formally invited or otherwise bribed.

Communication across the board was the most often complained-about reason for frustration. The scale ranged from no voice, slow or barely audible speech, to impatiently listening caregivers. I remember, when I was still in the Intensive Care Unit (ICU) and could only communicate by pointing at a board with the alphabet on it, that it was a very slow, and frustrating process.

Following close on the heels of communication was independence, or the lack thereof, as the second most often mentioned source of frustration. Always having to rely on someone to accomplish the simplest of chores, even getting dressed.

Then there were the little daily tasks which can't be done any more, or can only be performed with difficulty. In no particular order they were –

ON THE FEMALE LIST:

- Knitting
- Preparing for cooking (peeling potatoes, washing vegetables, etc.)
- Cooking
- Going shopping
- Threading a needle
- Doing crochet

THE MALE LIST STATED:

- Chopping wood
- Using tools
- Doing odd jobs
- Going fishing, casting a rod
- Handling and sailing a boat
- Shaving

BOTH SEXES MENTIONED:

- Weeding the garden
- Reading a book
- Going for a walk
- Having a shower
- Getting dressed

I would like to finish this chapter on a positive note. Almost everyone I've had contact with, with very few exceptions, considered themselves lucky. This means, a.) they have seen worse cases, or, b.) they realised that they had a narrow escape from death, and accepted any form of disability as the lesser of two evils. Whatever the case may be for different individuals, they all have one thing in common – they get on with life; and that has to be congratulated. If a stroke strikes, it can't be helped. A disability as a result of it, is without doubt

bad enough. But endless wallowing and dwelling on it certainly doesn't make it better.

Close sesame!

After I arrived at the hospital everything seemed to be a bit hazy. One thing I clearly remember, however, is that I got my new ‘cage’; the ‘cage’ that was to be my prison for the rest of my days. Like ‘life without the possibility of parole’, only I couldn’t even walk to the end of the ‘cage’, because the bars that confined me, went through my body. It was a slow but grim revelation. Slow, because there is, no doubt, a certain amount of denial to grapple with. Grim, because it was quite disillusioning. A new situation; a situation I hadn’t even given myself two seconds to think about, until now. Only now I had to, and I had a lot of time.

By ‘cage’ I mean exactly that. It was like looking out of some dark room or cell, without being able to communicate with anyone. Being conscious, at least semi, I saw and heard the doctors talking to me, but couldn’t respond any longer. An odd experience. There were a few things in this setting that reminded me more of the TV-series M.A.S.H. than an inner-city hospital. First there was this doctor I knew. He talked to me, and it was encouraging to see a familiar face. He was the flatmate of a friend of mine. Then I got a phone call. As ridiculous as it may sound, it is true. A friend

of mine phoned from Hawaii, where he was holidaying with his wife and children. Obviously he had called my office first and heard what had happened, then he'd tried the hospital. The doctor I knew took the call, and held a cordless phone to my ear, as I could not lift my arms. I thought that I talked to my friend, but was later told that I didn't. Presumably I formed the words in my mind, but was unable to speak them. There I was dying and taking a long-distance phone call.

The next thing I remember is some nurse or doctor who prepared me for a tracheotomy, telling me that the anaesthetic would soon take effect, and...

The first thing I saw when I woke up were the monitors and machinery that surrounded my bed in the ICU. What I didn't know, was that 10 days had passed. Ten days spent in the Critical Care Unit (CCU), unable to breath, unable to eat, unable to do anything for myself, just lying there, in a coma. It is, however, this time I want to talk about, because I had the most eerie experience. I'm not saying it was this or that, I'm just saying this is what happened, whatever it was. You judge for yourself.

During that time I had quite a few dreams. I'm sure critics will say: "What makes you think this was not another dream?" Well, it just felt different, but of course

there is no proof. I thought about it a lot, but never could, and still can't find an explanation today. So, you simply have to believe me. Why would anyone lie about an experience like this anyway?

It was a dark space, room or tunnel. I was moving or floating towards a door in the distance, behind which was a bright light. Next to me was someone or something. We had no bodies. I heard our voices, but had no idea who was talking to me. I trusted the voice, nevertheless. When we reached the door, I realised the light behind the door was brighter than anything I had ever seen before. The voice, or whatever it was, invited me to go through the door. Somehow I knew that this was the end, or the beginning of a journey – commonly known as death. Realising what it was, I surprised myself by being remarkably calm. However, I argued that I couldn't leave my wife alone. Not that I was frightened or anything like that. It just was clear to me that I wouldn't be able to come back once I had gone through this door, and this didn't seem fair on the people I left behind,

mainly my wife.

This whole experience was truly beautiful. Of course I would have liked to tell you something along the lines of me meeting Jimmy Hendrix or Janis Joplin and listening to them playing a few songs for me. Nor did I astral travel to Paris to catch up with Jim Morrison, or hang out with Amadeus in Salzburg, or Marilyn in Tinseltown. No such thing happened. Very plain. But magnificent.

Never throughout this entire episode, was I scared or fearful, quite the opposite. Never before had I experienced such warmth and comfort. Whatever it was, it was amazing – and unexplainable. Maybe someone else can explain it to me; someone who knows. I sure don't. It was not until years later, after talking to many stroke survivors, that I realised how relatively common it was. It's just that most people don't like to talk about it. And so I was delighted when I heard the following story from Bob of Port Waikato:

Towards the end of my stay in Ward 10 at Middlemore Hospital I had a life-like dream, and even now I think it may be true. I was in a light blue place. It was not a room, but there was this pale blue all around. I thought to myself that dying

was not so bad after all. I'm sure that I was really dying, but for some reason I thought of my shed at home in Cordyline Road, and that I had to clean it up before I went. Whatever it was, fact or dream, I awoke to find myself in bed and my wife, Irene, at my side. Apparently I had a bad night and it may not have been a dream.

Bob continues:

Another experience I had concerns what I think was a dream, although it was quite strange. I was standing in the fields at Rangiora and looking over the battlefields, sometime during the Maori Wars. The battle had ended, and lying on their stomachs were five or six Maori warriors. They were not dead, but had been shot in the spine while returning to their pa. I went over to them, and none could understand what kept them pinned to the ground. It was a life-like dream, but because everything seemed more precise than life, I knew it was only a dream. The dream was unusual as my grandfather was a soldier in the Maori Wars.

Unexplainable experiences like these are quite common. Maybe Bob experienced, for the first time in his life, that his body wouldn't do what he wanted it to do, that something kept him pinned to the ground. Maybe it was just a dream. Anyway, one can be forgiven for imagining hearing the theme music from the "Twilight Zone" when Bob tells this story.

It happens all too often that we see or hear from past relatives. The next encounter is from Liesje, who saw her deceased mother while on the operating table. She had been admitted to hospital with an aneurysm that could have burst at any minute, so time was of the essence. Liesje went straight into the operating theatre, where several doctors did their best to save her life. Here is what she experienced while anaesthetised:

I remember being in a white room. No, it was more a kind of a space. There was this white, intense light all around me. Then I saw my mother. I thought this can't be possible, because she has been dead for awhile. But suddenly she talked to me: "What do you think you are doing here?" Liesje answered: "I came to see you." Her mother replied: "You better get out of here, you've still got a lot to do."

Later, after the operation, Liesje was told that the doctors 'lost' her for a moment while she was on the table.

Maybe that explains it!

Explains what? An incredible story? As with other stories, I had no reason to doubt the credibility of this one. Sometimes we just don't like to hear what we hear. If we were to see a 'sober' documentary of Saturn, with some of the gas explosions that occur in the ring, the hallucinogenic looking images would bear more resemblance to an LSD trip than a carefully produced TV programme. Consequently we may look for an explanation in the special effects department rather than accepting it for what it is.

There are things beyond our imagination. Maybe we should just accept them.

It's time to face the music

Some time during the hospital stay every stroke victim has to realise that a major disturbance has happened to her or his body. A disturbance that has a major effect on their life. In fact, their life will never be the same again. Some will spend the rest of their days connected to a respirator, others won't ever be able to talk again, others won't walk. This is the time when we are confronted with the truth, a truth we don't want to accept. It is the time when we have to face the music.

Even now, after more than six years, I still believe I'm improving. Is this wishful thinking? Being totally unrealistic? Denial? A glimpse of hope? I remember vividly when I was told for the first time what was wrong with my body. How factually the doctor put it. How gently my wife put it. However, there is no way of putting it pleasantly. Whenever you are told the bad news, it's not something you want to hear. Anytime is a bad time. Maybe that's why we always have hope. Because we don't want to believe it.

Most stroke victims find that accepting that something is wrong is the most difficult part. Many live in denial for weeks, yes months. No matter how much we used

our body, whether someone was athletic or a couch potato, there is still a sense of loss, because one enjoyed a non-competitive walk along the beach, while the other equally enjoyed a walk to the fridge to get another beer.

Now everything happens, if at all, in slow motion. This realisation is particularly difficult for women who have been used to managing an entire household single-handed. Even mundane tasks, such as peeling potatoes, turn into a challenge, while it is equally challenging for men to have to practise bringing that beer or G & T to their lips without spilling half of it before it gets there. The frustration is equally bad for both sexes.

Overcoming this frustration is part of, what the medical profession calls, the 'grief process'. Most people think about grieving only if we lose a loved one, but grief can follow any loss that's important to a person. In case of a strokee, the loss of the function of one or several body parts. When we lie in hospital, after being told what's wrong with us, that's when the grieving starts. As with the loss of a loved one, some people cope better than others. But it is important that we deal with it, no matter how, because denial and unresolved grief can lead to serious physical and psychological imbalance at a later stage. Each individual deals with grief in a

different way. Some signs of grieving are listed here. Even though they are in chronological order, this does not mean that every individual goes through the same stages in the same order, nor necessarily through all the stages listed.

- At first there is a state of shock and denial. The ‘Why me?’ and ‘I don’t believe it.’ expressions are the most common. The denial can extend to loved ones or relatives. I’ve met a woman who had a stroke and her husband totally ignored this fact. When she came home from hospital she placed an advertisement for a housekeeper in the local paper. Her husband told the people who applied for the job that it was all a mistake, and that his wife was quite capable of accomplishing the household chores.
- The emotional phase is often a mixture of positive and negative feelings. Whatever the feeling, it is magnified as a result of the stroke. For instance, the slightest upset can cause a person to cry, while on the other hand the same person might laugh at the news of a death in the family, or at a funeral.
- During these early stages we increasingly experience physical reactions as our natural rhythms are disturbed. This can mean the amount of food or

liquid we consume changes, our sleeping patterns alter, and bowel movement might not happen as easily as before. Also, we are more susceptible to flu, colds, and all sorts of aches and pains.

- The realisation of our loss is, at some stage, followed by depression and panic and this is the time when a counsellor, or even a good friend, can be invaluable. It is a time of doom and gloom; when our world is not only black and white, without any colour or contrast to show us images in a positive light, but grey; when the weight on our shoulders seems almost unbearable; when the stranglehold around our heart is so tight that it prohibits us from breathing freely. Everything seems to be negative. No matter how hard we try, we can't see life for what it is meant to be – fun. This apparently hopeless situation often causes us to panic. Inability to listen or concentrate, absent-mindedness in general are the symptoms. Our minds are preoccupied with our loss. Only time will help us to overcome this situation.
- Another quite widespread feeling is guilt. Again and again we ask ourselves what did or didn't I do. For some reason most questions start with 'If only...', or 'I wish...' In the case of a stroke victim it is 'If only I

had done something about my high blood pressure', 'If only I had stopped smoking,' or, in the case of a loved one, 'I wish I had spent more time with my father.' We desperately try to find a way to blame ourselves.

- Unwittingly we revert to a more primitive state – anger – which is expressed by the most placid of people. This is the stage that prevails longest with many, simply because it is very difficult to channel this emotion. Our society looks at someone who 'lets off steam' with a belittling smirk, totally ignorant of the pain she or he might be going through. We are just not used to dealing with these emotions.
- The 'good old days' take on an unrealistic significance. This idealisation of life and events before the stroke (or the loss of a loved one) is blown out of proportion and is usually followed by a more realistic view. Suddenly there is light at the end of the tunnel. It is the first time we give our future a chance.
- At last we conquer the depression. Gradually, hope comes through. The black cloud that hovered over us begins to lift and let more positive thoughts into our minds. We accept our loss, learn to live with the stroke.

Many experts believe that going through the grieving process and feeling self-pity makes us stronger individuals. When we feel sorry for ourselves, it is important that we spare a thought for less fortunate fellow patients. It probably helps us to improve our outlook on life and to overcome all the negativity around us. It is not really negative, but we immediately associate a hospital with unpleasant things. Whilst in the critical and intensive care units the patient is (in most cases) not aware of what's going on and the family is in shock. Later, in the neurology department, the majority of illnesses have no visible manifestation, which leaves a lot of room for negative thoughts. During this time we appreciate everything and everyone who cheers us up.

Most people who have had a severe stroke end up in the ICU. It is here that doctors examine the stroke patient and determine which part of the brain is damaged. Facing the music starts here. Apart from keeping the patient stable, there is not much the doctors can do. It is up to the stroke survivor to regain control of muscles and nerves.

I recall one day, when Jenny came visiting with a friend, Wendy, while I was in the ICU. They tried to talk to me, but I couldn't say anything. Wendy reminded Jenny that

I was born in Germany, and that I may have forgotten all my English and reverted to my mother tongue. Not a silly thought at all, because with brain injuries all sorts of unusual reactions are possible. So why not with a stroke? At this stage the extent of the damage was not known. Luckily there are no cases reported where a patient forgot an entire language. It is more likely, that a patient slurred something with a heavy accent, and this was interpreted as her/his mother tongue.

It was in the ICU, while I was in a coma, that a young doctor told my wife: "Well, he'll probably die, or he'll be on a respirator for the rest of his life." He had obviously been given the unpleasant task of telling my wife the bad news, and I suppose he had to learn how to do this. Anyway, Jenny marched back into the room where I was lying and said: "Come on Babe," (so I was told later). In a way, one could say I had no choice but to get better. And I did. An understanding and supportive family (sometimes even a bit pushy) is perhaps the most important ingredient in the recovery from a stroke. Later, when, against all the medical predictions, I lived, they told me that I would never leave the wheelchair. Today I walk with the help of a walker. There are however, always more predictions to be added as the patient improves.

For the patient there is no way to anticipate the outcome of the stay in intensive care, because, for most people, the only memory of progress is a hazy one, consequently there is no way of monitoring this progress objectively. Personally I don't remember very much, but one thing sticks in my mind; and that is all the cables and monitors. Fascinating. It reminded me of Mel Brooks' 'Silent Movie', in which visitors to the ICU play a game (I think it's Ping-Pong) on the monitor and every time they change the channel, the patient falls in and out of consciousness. It must have been this memory that made me pull those wires off my chest, because I wanted to see what happened on the monitors. I still believe today that this 'exploration of technology' was the first step in my recovery. In other words, if my body didn't do what I wanted it to do, at least I got those machines to react to what I was doing.

Later, while I was in an ordinary ward (still in neurology), I saw many patients come and go. When I say go, I really mean go! Usually they stayed for only 3-4 days. By that time they were either dead, or their test results had revealed some bad news and they were sent home to die in peace, in familiar surroundings. It's amazing what can happen, when you're in the 'wrong' ward. Not that there is such a thing as a wrong ward, it's just that

many different illnesses give out warning signals like a slight tingling and are consequently first assessed in neurology. During those days, when there was doom and gloom around me, I heard a joke which I very much appreciated, even though I'm not normally that much into jokes. I suppose what made it even better, was the fact that a young doctor (who was himself a patient, waiting for his death sentence) told it. It's a silly thing, and it is possible that some people might get upset about it, but I'd like to share it anyway. So here it is:

One day St. Peter, who stands at the gate to heaven, gave a newcomer a guided tour of heaven. St. Peter explained everything in depth, only to be interrupted by the question: 'Who is that guy over there with the white coat and the stethoscope?' St. Peter answered: 'Oh, that's God, pretending to be a doctor.'

The reason I told this joke, is because I couldn't believe how many people it made laugh, people who really didn't have much to laugh about. It was almost like they were waiting, jumping at the opportunity to laugh. At a time when the future didn't hold much for them, they found refuge in humour, they were ready to laugh.

The world still goes round... just slower

After a stroke life changes: the pace changes. There is, the actual pace, and the perceived pace. Even though nothing has really changed, for the strokee everything seems to happen in slow motion.

It can be years, yes, and for some forever, that the person who has had a stroke is forced to do everything slower, simply because of the inability to concentrate on more than one thing at a time. This slow movement is often wrongly interpreted by the outsider as slow thinking. It is not only the movement, but also the speech. However, these people might, in fact, be thinking very clearly.

This communication breakdown is both, annoying and, at times, dangerous. I call it communication breakdown, because that's exactly what's happening; the muscle does not, or too late, receive the command to move that foot or leg. Or the built-in sensors in the skin don't tell the brain any longer that something is hot. One of the many effects of a stroke can be (as in my case) the loss of hot-cold sensation. In practical terms this means, it kind of hurts when something is too hot or

too cold. But without visual confirmation I'm not able to tell which of the two it is. Only if I stand close to the stove and see my hand near the element can I tell it is hot. I suppose one consolation is that you can always smell it before it gets too bad.

Another factor that influences speed of movement in a strokee's life is confidence. Constant fear of injury makes moving around a very slow ordeal. For me, I've had enough falls to justify slow movement, even if I could walk faster. All these falls did not shatter my confidence, but I now have a healthy respect for Sir Isaac Newton's law of gravity. It is the same thing. The information just doesn't get through to the brain, not in time, that is. Usually I know when I'm about to fall, because my brain tells me that I'm not in balance. The only way to avoid falling is to get visual confirmation early enough.

Visual confirmation deserves some special mention here. Apart from training and increasing the awareness of the two sides of the body, visual confirmation is what is part of Conductive Education, a rehabilitation programme that is enjoyed by many people who have had a stroke or any other form of motor disorder. One such person, Dennis (49), told me:

Besides the standard physiotherapy, I go to Conductive Education. Two, two-hour

*The world still goes round...just slower
sessions a week, with two instructors*

called

'conductors'. He continues: "The recipe for recovery is personal motivation, spiritual and physical development. I've found it has helped my co-ordination and balance immensely.

Conductive Education takes a more holistic approach, looking at the person as a whole. Though some members of the medical profession ridicule Conductive Education, all they really demonstrate is their own inability to accept change. The success stories from people who have had a stroke and engaged in a Conductive Education programme simply can't be ignored.

I asked one of the conductors, Suzy, to tell me some of these success stories.

John was just over sixty when he had a stroke. He was in a coma for a long time and the doctors encouraged his wife to put him into a rest home, saying that he would not be able to look after himself.

His wife persevered and insisted on taking him home. John was discharged from hospital in a wheelchair, with his left side paralysed. He was fully dependent on caregivers to dress him and take him to

The world still goes round...just slower

the toilet. A few months later he started attending Conductive Education classes. At first he was really reluctant to even attempt the tasks requested but he kept attending. His classmates appeared to be good fun, the conductors were very professional, and deep down he knew that his wife deserved some time without him. So there he was, not really willing to give it a go, because he was told by the doctors that he would not improve anyway.

After a month he started enjoying the sessions. The high expectations and safe environment meant that whatever was being achieved was accepted on its merits, which made him feel secure and willing to take risks. He was asked to stand, first with the help of a conductor, then by holding onto bars, and finally all by himself. He was asked to take steps, first with a lot of help, then by pushing on a vertical frame and finally, independently. He tried, and did all these things.

Whatever one tries to achieve takes time and patience.
There is no such thing as seconds or minutes anymore.

Even the smallest task can take hours. In terms of rehabilitation even years. Today, after six and a half years, I'm still improving. They might be very small improvements, but improvements nonetheless. If I have learnt one thing, it is patience. The only thing that can be more important is attitude, positive thinking. I don't think it is particularly difficult to think positively. Maybe not straight after a stroke, but certainly as the years go by. It is the mental strength that often surprises people. Take the case of Peter who worked with Suzy. His positive attitude never ceased to amaze her. She shares his thoughts. He said:

It changed my life to an extent that is hard to comprehend. Before my stroke I never noticed people with disabilities. I had only one worry – money and the things it could buy. After my stroke I became really depressed. Whatever had been valuable to me, all seemed to have disappeared. I could not move freely, I could not talk, I could not make money and I could not spend it on holidays. After I joined Conductive Education classes and started to progress rapidly, my attitude changed. I still could not go out, but doing

The world still goes round...just slower

things at home that my wife had previously done for me gave me much satisfaction and self-worth. I became compassionate when I saw others who had had strokes and whose condition appeared to be worse than mine.

While the medical profession is still discussing the pros and cons, it has to be said that even if only a change in attitude is achieved, it is a step in the right direction. Of course this rehabilitation programme is about more than positive attitude. But I wasn't sure how to describe Conductive Education, so I asked Suzy for an explanation.

Conductive Education was established in Hungary by Professor Andras Peto in the early 1930s. He was an entrepreneur as well as a physician by training. He knew Rudolf Steiner personally and Maria Montessori, Freud and Pavlov, just to name a few. His philosophy was summed up in the following Chinese proverb: 'If you give a hungry man a fish you may relieve him from starving for a day, but if you teach him how to fish, he and his family will prosper.' With this systematic approach,

Conductive Education taught how the disabling symptoms of motor disorders can be overcome by utilising the tremendous residual capacity of the human brain. Peto's approach was revolutionary:

- 1. People with motor disorders were seen as individuals with unique needs and abilities.*
- 2. Their conditions were seen as disorders or dysfunctions that were changeable; as opposed to disabilities that were stigmatising and permanent.*
- 3. The principle is one that everyone is able to learn, and therefore change has since become the cornerstone of modern psychology.*
- 4. The treatment or rehabilitation process was systematic as Professor Peto recognised that one's body and his or her emotions, psyche, spirit and soul are inseparable. Further, one is also an integral part of family and society, connected with complex interactions.*

During my participation in Conductive Education

classes I've seen many people who show the right

attitude. Others, unfortunately, have become resigned

to the fact that they will never catch up with a world

that goes round at a faster speed than they do.

You are not alone

Wherever you are in this world, chances are, you are not alone. In most countries of the western world the number of people who will end up having a stroke each year is about 0.1%-0.2% of the population (approx. 5,500 known cases in New Zealand). This does not seem many, but it is quite a lot if you consider that on average only about 10% of this figure (or 560 people) in New Zealand have a fatal car accident each year, and we think that is a lot, because we read reports in the paper and hear it on the news. It also means, you're not on your own. If you've had a stroke, that's too bad, but it is absolutely no reason to feel sorry for yourself. You can't blame anyone else, and you can't say that everyone else is better off. Because they are not – at least not necessarily. Maybe, physically. But emotionally?

Apart from the body (i.e. physical wellbeing), our emotional wellbeing plays the most important part in our lives. Every psychology student in the first semester has this notion indoctrinated within the first few weeks of study. Most important for our wellbeing is the interaction with other people, that is caregivers, visitors, the postman, etc., any social contact we might

have. Unfortunately the emotional balance is disturbed in most stroke victims, at least for sometime. This can go one way or the other.

While still in hospital, I happened to meet an acquaintance who had also had a stroke. He used to be general manager of a film postproduction company. I'd only known him briefly, and he had come across as what I would call a 'pretty straight' person. Not any more. Now this person, who had always been concerned about his appearance, suddenly burst into tears at any given opportunity, no matter who was around. Whether it was his girlfriend, his son, or a work colleague. More often than not there was no reason for crying whatsoever. When there was a genuine reason to be upset, for example, when he had wet his pants, he hardly reacted. The nurses, there not only to clean up after him, but also as troubleshooters, instant psychologists, yes, friends, did a wonderful job. At least in his case.

In another case the job some other nurses did was not so 'shit-hot'. I'm using this expression deliberately, because it fits the situation that's about to be told. Opposite my bed was a chap in his forties, who could not control his bowel movements one day. Unfortunately he had some visitors arrive shortly after this incident. Although he was able to tell a nurse what had happened

before they arrived, no nurse had attended to him by the time his visitors arrived. It was embarrassing. An unmistakable stench soon wafted over to my bed and the visitors, standing around his bed, were embarrassed as well. Still no nurse in sight. Talk about dignity, or the loss thereof! Finally my wife pushed my bedside buzzer and pointed out the situation to the nurse yet again. Reluctantly she cleaned the man's bed, before this rather unpleasant job could be delegated to a nurse of lesser rank in the medical hierarchy. The man can no longer complain, nor can he feel embarrassed. He's dead now. Just another one of the 25+% of stroke sufferers who die within the first few months. One more reason, I think, to send him off with dignity.

Anyone who has a stroke, has to expect a certain loss of dignity at some stage. Embarrassing? Yes. A reason to be ashamed? Certainly not. Whatever happens to a stroke victim, the same or a similar thing has happened to someone before, or is happening somewhere else in the world right now. It is quite sad to see someone not being in control of their saliva, or worse. Dribbling like an infant is not a pretty sight, and no stroke survivor likes to be reminded of it, even though it is considered 'normal'.

Another 'normal' and quite common occurrence is

foul language. So foul indeed, that children are best kept out of the room. Nurses who I've asked, reported that it is often seen (heard) in sophisticated women. However, in their defence it has to be said that the nurses could not say whether there was any statistical foundation to these findings, or whether it was simply more noticeable to hear the F-word coming out of the mouth of a 'perfect lady'. In any case, relatives and friends should not be surprised to experience some obscene language.

While emotional disorder is at its greatest immediately after a stroke, it can linger on for months, years, and even indefinitely. The most common form would be depression, which is, particularly in the years after a stroke, doctors told me, quite normal. During and after active rehabilitation, which is also the time a stroke victim has to learn to cope with the 'new situation', he or she finds it hard to escape depression. It becomes a question of how to cope with it, rather than whether or not to experience it.

If one looks at the numerous outside influences, the staggering amount of changed situations, the daily reminder of abominable disabilities, it is hardly surprising that a strokee gets depressed at some stage. The 'the-world-is-against-me' syndrome plays

havoc with the mind and while most doctors, possibly quite rightly, argue that deep depression can only be cured with medication, a healthy and positive attitude is definitely helpful in softening the fall into depression in the first place. Here is what psychologist Gwendoline Smith has to say:

As far back as Hippocrates (approximately 460BC-377BC) it was known that change was strongly connected to illness. Human beings will try to avoid change as much as possible, as you will undoubtedly recognise in the way you choose to run your own life. We are especially vulnerable to change that occurs rapidly and without our 'consent' – as it were. Is it then surprising that someone would become unwell, in an emotional sense, in response to change that has left them feeling helpless and despairing? Powerless to change their situation.

It is now acknowledged by clinicians working with depression that the psychology that accompanies helplessness can be a significant contributing factor. A stroke presents the individual and his/her family

with an existential crisis. One that will be with them for an indefinite period of time. As motivation wanes and the sense of optimism begins to erode, those involved will begin to experience a collective sense of helplessness and despair. The dilemma that is posed by the depressed mood associated with such a profound life event, is whether or not it should be treated medically, and in fact will the medical treatments available be of benefit?

The effects of a stroke are both physical and psychological. The neurological damage can of course affect concentration and memory. These are known symptoms of depression but are also side-effects of a stroke. Feelings of despair and helplessness are also symptoms of depression but are also very understandable responses to having your life tipped upside-down. When speaking with Wolfgang he describes not feeling clear enough in his own mind to be able to determine whether or not he was depressed. Hence he did not feel that he would have been able to make decisions

regarding the appropriateness of introducing a medical treatment regime for depression.

I went on to ask him whether or not he felt that it was the responsibility of the family, at this stage, to move ahead with such decisions. He pointed out, and I agree, that the whole family is in shock, they are battling with their own upsets, their own emotions, their fears, their own sense of despair and helplessness. Hence would they in fact be able to make an informed judgment call?

In such a complex life situation there are no hard-and-fast rules. Everybody involved is learning as they go along and making mistakes at the same time. That will involve getting frustrated, feeling angry and feeling sad, with each other, at each other and at the situation. The cloud of helplessness will at times cast its gloom without discretion. So you do the best that you can do – don't be hard on yourselves!

So, the question still remains. 'Do you seek

treatment for the depressed response?' I would suggest that, as the strokee, if you start to lose any last thread of hope and your thoughts become actively suicidal, then you should seek professional help. I have emphasised 'actively' because there is an important distinction between, thinking that it would have been easier on everybody if you had not survived the initial trauma, and engaging in thoughts that involve planning ways to kill yourself. It is the latter that is considered 'active suicidality' and needs to be addressed.

Should the treatment intervention be biological (medication) or psychological (counselling)? Often both will be required, however, this should be assessed by a mental health professional or your G.P. Because so many of the issues involved are the bed partners of a stroke; relationship problems, sexual dysfunction, feelings of worthlessness. I see it more as a both/and, rather than an either/or situation.

I would also like to make the point at this junction, that the points that I have

outlined above also apply to the family members. They are not immune to the stresses that have been discussed, neither are they immune to a possible depression. It is important to take care of the caregivers. You need to be aware of your own emotional needs. Because coping with the effects of a stroke necessitates a certain amount of selfishness, and all the love in the world does not change that reality. The conflicts and frustrations that may occur within your relationship are not a reflection on you or your deficits. It is the reality of what is occurring. So rather than personalise and become a martyr take time out to look after yourself.

In a nutshell, each experience is very unique. What affects one person may not affect another. More resilient individuals may appear to adjust more smoothly, but it is all relative. You should avoid comparing yourself to others, it may well be that genetically you are more sensitive to depression and hence, it is an additional factor that has to be dealt with. Either way,

*judging yourselves is of no help whatsoever.
And remember; "Behind every unrealistic
expectation, lies hurt and disappointment
So don't go looking for them!*

Apart from daily reminders of physical disabilities and the deep psychological problems, there are the emotional scars. Not that the stroke victim wants to deal with it, but he/she has no choice and this is probably the reason why it is so easy for depression to set in. It would be less of a problem if the strokee could deal with it in his or her own time. But instead they can only hope to be able to fight off the attack of depression and accept the inevitable, one's fate; incarcerated for life, with no chance of escape; a prisoner in a body that no longer obeys the simplest commands.

This difficult time can put an enormous strain on any relationship. The support of an understanding partner is essential. For the partner it is a real nerve-testing time, because there is never a certainty as to what is too much or too little. Is the caregiver 'talking down'? Is he or she too helpful, or not helping enough? Often the stroke victim might over react, be totally unreasonable, yet the caregiver still has to stay cool-headed, without being patronising. At any given moment the situation can boil over. Two frustrated minds are only waiting for it!

At this point I'd like to introduce a letter from a woman called Carole, and her struggle with the effects and aftereffects of her stroke. I won't say where she is from, because she isn't always very complimentary about the medical profession.

When I had a stroke, at only 52, with no warning, I was devastated. It effected my left arm, leg, and a few nerves on the left side of my back. I felt my life had been chopped off, as I could no longer do all the activities I was used to up till then. I was taken to the local hospital by ambulance, and then transferred to a nearby hospital. There I was given a CT scan and for two weeks I was not given any physiotherapy or rehabilitation. They told me, that as I was to go back to my local hospital, it would be left till I was there. As my left foot hung loose off my leg, I was given this plastic thing that sat in the bottom of my shoe and up the back of my leg, but it did nothing to support my ankle. I found it very difficult to walk, as my ankle continuously tilted over when weight was placed on it.

I found that a lot of the nursing staff didn't

really have an understanding of how to care for me while lying in bed, and transferring me to and from the bed. I also found I lost some memory of what had happened just after the stroke. What was worse, I could do nothing for myself, not even go to the toilet. I was then taken to begin work in rehabilitation, and got an appointment for the visiting specialist to see me. Unfortunately they didn't send him up to see me when he arrived, to get a proper support made for my ankle. The most frustrating thing was the inability of the staff and social worker to tell us what sort of help we could have at home, and what support there was available for my husband. They were very backward in coming forth with this information, and each time my husband asked what we were entitled to, they continually asked him how he was coping and not what we could have. Finally he got very frustrated with them and said that he felt like punching one on the nose. I feel that they expect too much from the carer at home and there is a need for more back-up and support for them.

Especially as the carer is having to do the job that two people did around the home. They are under a lot of pressure to do all of everything. I find that most people don't know how to treat you, or how to help, and that friends stay away after a while.

Wherever we are in this world, whichever country we live in, unfortunately the medical system may not necessarily provide the care and rehabilitation that is required. Even though, normally all sorts of services are available, often it is a question of asking for the right information. So, insist on your rights as a patient or caregiver, demand explanations and settle for nothing less than an adequate reply.

Talk to me, talk to me, now

‘No matter what kind of disability a person in a wheelchair has, you have to talk to them loudly and clearly. You might not be able to immediately see what’s wrong with them, but, hey, they are in a wheelchair, which probably means they are deaf and a bit slow in the thinking department.’ At least this seems to be a common belief.

As soon as a stroke victim leaves the hospital it starts. People talk about, instead of to, her or him. It actually starts earlier, but it can be excused if it’s done in hospital because there the patient is often under the influence of drugs or, for some other reason, not thinking clearly.

Hospital. It was there, I remember, that I made my first attempt to communicate. My wife, Jen, was talking to me. I could hear her clearly. I could see her standing by my bed. What I couldn’t do was talk to her. I couldn’t hear my own voice. This was just one of many shocking revelations that were still to come. Then I remembered I had had a tracheotomy because I couldn’t breathe. Now, with a hole in my wind pipe there was not enough air to let my vocal cords vibrate. I could see everything. Just not communicate. My voice didn’t work, and both

my arms were too weak to lift. It is a weird feeling, looking at someone you long to talk to, but you can't. It is like being locked in, imprisoned, but worse. The iron bars go through your body. You can't get out.

After a couple of days my voice still did not work, so my wife brought an A3 pad to the hospital. Just as well it was a big one, because otherwise I would have missed it each time I tried to write. Even though my left arm was strong enough by now to lift and write on the pad, I still managed to miss the pad occasionally. This was because I had double-vision. All this and, I suppose, the fact that I'm right handed made my first endeavour to communicate not exactly successful. My second try, however, was much better. Jen had a piece of cardboard with the alphabet printed on it. By pointing at the chart and 'saying' one letter at a time we communicated. It was a slow process, that reminded me of playing charades. A process that required a lot of patience – on her part as well as on mine – but at least I made myself understood.

Finally I was able to communicate. Still, Jenny talked a lot to the doctors for me and about me. But that was alright, because in the ICU patients usually don't make their own decisions. Before that I had spent over a week in the CCU, and was certainly not in a position

for decision-making.

After a week in the ICU I was moved to a single room. The noises I made had improved, and slowly, with the help of a speech therapist, I started talking. There was only one problem – people didn't understand me. Of course I thought I communicated just fine. But not so. After a while, I had to find out that people just pretended to understand me. It must have been as frustrating for them as it was for me. They were embarrassed or didn't want to upset me. No matter what I said, there always came the enlightening answer: "Oh, yes", normally accompanied by a well-meant smile. I could have been downright rude and would still have sparked the same intelligent response. People didn't, or at least found it difficult to understand me. Consequently my wife, Jenny, was to become more and more engaged in interpreting and deciphering whatever I attempted to communicate. People felt more comfortable talking to her instead of addressing me.

It was what I called the 'communication triangle', a pretty rude way of communicating that would fit better into a mediaeval court, than into a modern, 20th century society. Most stroke victims, particularly the speech impaired, experience this way of communicating at some stage of their recovery.

When talking to a fellow stroke survivor about the 'communication triangle', she described the following scene which happened while shopping with her husband. The shopkeeper was very friendly and helpful. She explained every little detail. One could be forgiven for thinking this was a perfectly normal situation. It was, except for one thing – the shopkeeper talked to her husband. No, it was not that her husband showed a particular interest in women's underwear, nor did he have a distracted, 'kinky' look on his face, but his wife was sitting in a wheelchair.

Similar 'perfectly normal' situations like this happen every day somewhere in the world. Nobody in this triangle can be blamed. The outsider can't help feeling uncomfortable and making assumptions, the partner or caregiver is only being polite by answering the person that is asking, and the stroke victim...well, who could blame the stroke victim for being sick of pointing out that nothing is wrong with her or his hearing?

After coming out of hospital, the stroke victim has to establish a new personality, not because their personality is lost totally, it's just that outsiders think it is, and they show it without meaning to. Sadly, adults are not as uninhibited as children. While children unashamedly stare or ask if they don't understand

something, or if something is wrong, adults try too hard to 'act normal', and, by doing so, show how uncomfortable they really are. Not only has the stroke victim to learn how the body reacts, but others also have to learn how they react to a crippled body.

Everyone who's ever seen one, recognises a person who has had a stroke. The sideways and often upwards bent hand, hanging lifeless at the end of an equally lifeless arm. The slow, careful, somewhat grotesque walk. The bizarre expression on the face, caused by muscles not doing what they used to do, but giving way to gravity. And when the person finally talks, you can't help but think that something is wrong with the brain, due to the slurred speech.

It is this slurred speech that often causes the biggest misunderstanding and is why people generally feel more comfortable talking to the caregiver. They don't take the time to listen and consequently, it seems like contents and delivery are being thoroughly mixed up. Like some history books which tell of messengers being killed because they delivered an unfavourable message, so are stroke victims cast aside as stupid, who can't talk, can't think. This seems to be a common assumption.

All the irregularities a strokee encounters are caused

by damaged nerves. The physical effects can be seen clearly. What we don't see is – the effect on intelligence, apart from the odd case that has to be 'put away', because they have a history of psychological malfunctions and are therefore no longer acceptable to society.

It never ceases to amaze me how able-bodied people treat disabled people. The wheelchair sets the tone and intelligence level of the conversation. Not only with people you know, but also complete strangers. It happens almost every time I'm out shopping, that some shop assistant tells me how good I look. A come-on? Probably not. I haven't figured out yet, whether they say that to make themselves feel better, or to make me feel better. Whatever the reason, I must have looked pretty awful before my stroke because no one told me anything like that then.

Another common preconception is deafness. People in wheelchairs do have a tendency to look deaf. Not that there are any rules on how to recognise a deaf person, but a wheelchair, it seems, goes a long way to identifying 'deafness'. If an individual in a wheelchair has the privilege of being talked to by an able-bodied person, it is always with the volume of an amplified singing voice. Why? Nobody seems to know. Often the

culprits themselves are not aware that they are insulting

the wheelchair driver. That will only change if our society

changes.

To do or not to do yourself in, that's the question

Isn't it amazing, how the human brain protects us from unpleasantness. One such unpleasantness is death. We are not used to talking about it, and we don't.

When talking to stroke survivors, I was told by many of them that they thought it would have been better if they had not woken up from the coma. However, none of them said they would commit suicide (at least that's what they said). The fact that they thought it would have been better if they had not woken up from the coma, indicates that they found their new life hard to cope with. However, the fact that they would not take an active part in their suicide, on the other hand, could mean a number of things, including lying, they haven't got the nerve to do it, religious reasons, or maybe they simply think that no matter how bad the disability, life is still worth living.

It is strange – doctors will tell you – that among stroke survivors, it is difficult to find someone who is prepared to freely talk about suicidal feelings arising from depression. Occasionally you find someone who knows something about someone else. Some second-

hand information. But no one likes to talk about their own experiences. One female caregiver I talked to, put it like this: “They think it is contagious. Or maybe they think that just talking about it can make them do it. They are afraid.”

When I found so few strokees willing to talk about suicide it made me feel good, at first. Later I realised that there are people out there who at least harbour these thoughts, but were not willing to share them. That made it impossible for me to expand any further on this very important subject.

Enthusiasm vs professionalism

First of all it should be pointed out that charitable organisations, and the like, do a wonderful job, be they rehabilitation centres, clubs, or support groups for caregivers. Most of them are partly or totally run voluntarily, which can pose problems. Very often these groups are run by amateurs, whereas a more professional approach is often needed. Though this sounds rather harsh, it is, unfortunately, the reality. Care overshadows good management, enthusiasm outstrips professionalism. Again, I have to say, that this is not the norm.

The care given is excellent, considering the person who has had a stroke does not want too much care, anyway. There is always a fine line between too much care and genuine help. One reminds the stroke survivor of her or his disability, the other supports the maintaining of dignity. To understand the influences of professionalism and enthusiasm we have to look at the history of strokes.

Until quite recently stroke victims were regarded as mental patients. Posthospital care or rehabilitation

was virtually nonexistent. The medical profession knew little about strokes; the public even less. Fortunately this has changed in more recent times, even though the old stigma still prevails with many people. Every year more is learned about a stroke and its effects and increasingly people with disabilities are more accepted. However, it was in those 'good old days' that stroke victims were often locked away. Considered something of an embarrassment to society, the only poststroke care given, was by volunteers, mostly family members and friends. Having or building a relationship with the stroke victim, these volunteers, while their work was and is absolutely commendable, all too often got emotionally involved resulting in too much attention, too much caution, and too much care.

Talking with my wife and other caregivers revealed the following observations about amateur caregiving. These are not necessarily my opinions, and certainly not meant negatively.

'Mistakes' commonly made by:

THE CAREGIVER:

- Can't help it, but cares too much
- Not letting the patient fend for her/himself
- Talking for or about the patient

- Allowing other people to talk about the patient
- Sometimes not patient enough
- Taking patient's outbursts personally

THE PATIENT:

- Too confident
- Lack of confidence
- Frustration
- Lashes out at caregiver (totally unjustified)
- Lack of control
- Emotional rather than rational
- Feeling sorry for her/himself

All these misunderstandings can be explained. On the patient's side, it is often denial, frustration, or simply the realisation that they can't get by any longer without engaging outside help. On the caregiver's side it can be impatience or a general lack of understanding. Nobody is at fault.

Let's not forget that husbands and wives didn't ask for, nor were they prepared for this role. They, like the stroke victim, need to learn how to cope with the new situation. Each has to acquire new skills, and control their behaviour. I've heard of women who obtained a driver's licence and men who washed nappies and did other household chores, even though prior to their wife's

stroke, they were a 'flesh and blood' manifestation of male chauvinism.

In all fairness it has to be said that sometimes the strokee demands too much attention. Sometimes people who have had a stroke feel sorry for themselves, even though there is no real reason for it. If the caregiver happens to be the wife or husband, it is probably a good idea to let them have a holiday on their own. Caring for someone can be a 24-hour-a-day job. Caregivers certainly deserve a break from time to time.

Different strokes for different folks

A book about stroke (even though it's mainly about post-stroke experiences) wouldn't be complete without some descriptions of strokes. As I mentioned before, every stroke is different. The stories compiled here are experiences from different people who have had strokes of varying severity. For you it is a chance to read about something that most people prefer not to remember. I do hope it is a good cross section, and provides an insight to the initial steps of recovery and rehabilitation. First there is Bob:

It was the eighth March 1994 and my wife was away at our daughter's place. I walked down the backyard and then it happened – blurred vision and a feeling of not being well. I could see nothing out of my left eye and had to turn to the left to see out of my right eye. I staggered up from the backyard and found the phone. I could barely see the phone and dialled 999 and was told by the operator to dial 111. I think I swore at her and said I required an ambulance. What happened next I do not

know. Whether I dialled the correct number or what. I staggered outside, grabbed hold of one of the house posts, and yelled for anyone of our neighbours to help me. Thankfully a lot of them came and helped me on to the couch. It was about this time that I realised I could not see, and noticed the weakness of my right-hand, side, and limbs. I felt really sick and was thankful when someone produced the bottle of oxygen. Once I got hold of that oxygen, I never went without it for many days. I will be forever grateful to the way our neighbours came to my aid. It felt a long time before the ambulance came. The driver told me what I suspected was wrong – I had had a slight stroke.

Nancy, a retired speech – language therapist from Napier, who's had a stroke herself, writes:

I found out that I had had two minor strokes. The incidents were quite obvious and alarming when they happened and each time I was taken to hospital by ambulance. However, they were diagnosed as heart attacks. When, later, a neurologist

sent me for a brain scan, they showed up as strokes. But fortunately I haven't been left with any obvious aftereffects other than that I sometimes forget words. It is more a delay in recall, as the word I want comes back later.

Strokes can happen anywhere and at any time. This report is from Kirk, who had his in the middle of the night, while on a business trip to Perth, Western Australia, and shows how the unexpected strikes. He had just settled down in his hotel room with a G & T and had finished reading the local paper when it happened:

It was a warm night, so I undressed and got a glass of water from the jug in the fridge. I was standing in the doorway between my bedroom and the bathroom when all of a sudden I fell, dropping the glass which smashed to pieces on the tiled bathroom floor. Although I didn't realise it at the time, I had suffered a stroke.

Obviously my brain wasn't operating properly at this stage because I still didn't think anything was wrong with me although I

couldn't get up off the floor. I tried to pull myself up on the bed but I fell over again. In the end I was so tired I just pulled a pillow off the bed and lay on the floor. During the night I had to visit the bathroom. Not being able to stand unaided the only way was to crawl on my hands and knees, completely forgetting the broken glass on the floor. I was able to pull myself up using the bath and the shower pipe. The only way I could get down was to let myself fall on the floor and crawl back. Back in my position on the bedroom floor I realised how much I had cut myself. I couldn't reach the light switches but could feel myself bleeding like a pig, with pieces of glass still poking out of my elbow and knee. I stayed in this position and soon went to sleep.

Later the next morning I was woken by the ringing of the phone. It was the hotel manager, asking if I was O.K. and offering to send up a doctor.

Finally, I realised that something was seriously wrong with me. A few minutes later a young doctor entered my room and

confirmed that I had suffered a stroke and he called an ambulance which took me to the Royal Perth Hospital.

Another example, from Don, shows how even a severe stroke can seem quite mild at first:

It was an August day. We just had lunch. I had filleted two snapper our friend had brought. I said to my wife that I would bury the waste in the garden. It was raining, so I had my gumboots and raincoat on. I came back at 3 p.m. and sat on the doorstep to remove my boots. There was a feeling of two big circles around my head. This was it. No warning at any time.

Even though his stroke didn't seem that severe at first, Don ended up with a tracheotomy, but eventually made a good recovery. His wife was told like mine, that he would die or later would end up in a wheelchair.

Of course there are many stories that could be told. Instead I hope that every strokee looks to a positive future, rather than the past. Or as Don put it: "It's good. Every day is a bonus."

The days in our lives

When talking to other stroke victims, the question asked most often is: 'How do you spend your day?' A clear indication of the fight against boredom which strikes at some stage or another. Even mundane tasks like getting dressed or cooking a meal take on previously unknown importance. Some able-bodied people say 'they' do it only to fill in the day. Stroke survivors suddenly have a lot of spare time. Time to accomplish everyday tasks, and time for hobbies. Most people I've met spend a lot of time and effort on making themselves 'presentable'. Some physical functions might have gone out the window, their good taste certainly hasn't. However it happens, without fail, that boredom sets in. This might be partly due to the new found freedom from work commitments, and partly to the fact that we can't participate any longer in many sports, or outdoor activities, and some of us have to find a new hobby. No wonder therefore that strokees are interested to know how others spend their time. Mainly it is the little things that are frustrating, the daily challenges. Everyone has to overcome these challenges. Some are the same and others are unique. The following are extracts from letters, in which people have written down their day-to-day frustrations. Apart

from some obstacles to be overcome, the hobbies and favourite pastimes that people have to give up, it's the physical deficiencies that cause frustration. As a consequence there is spare time available which is better not spent in thinking. It might just drive you nuts.

The first report is from Alma:

I had a severe stroke in January 1992 and since then have suffered many minor ones, each leaving me a little more debilitated. My difficulties and frustrations are with me every day. One difficult thing for me to deal with is a new outspokenness. Where once I would have remained silent, now I find, a thought, remark, or comment no sooner enters my mind, than it flows off my tongue and often upsets people unintentionally. Another frustration is always having to rely on others to ferry me from A to B, never being able to be independent of others. Unable to have a day shopping – a walk in the park – or even a visit to a garden centre. Then there are the simple things. Threading a needle, reading a book, hearing without having to ask people to

repeat their words.

There are the sudden noises, or the loud scream of a child, raised voices, fast movement of people running, or traffic flowing, horns sounding and I jump, my nerves are on edge. No longer able to always control my feelings, I find solace in the silence of my room, where I'm often awash with tears. I may long for death but never contemplated suicide, my belief is based on faith, 'the life within me is God given, and only He has the right to take it back'.

One of the most aggravating, belittling and frustrating things of all, is the people, who think because your face is slightly contorted, and you walk with an ungainly shuffling movement, sight and hearing slightly diminished, that your brain has fled and as you are no longer capable of answering for yourself, they address others re your needs.

I had a miraculous cure, which lasted a month, then down I went with another stroke. I would love to be able to conquer

those words that elude me, but they have gone forever. To be able to lie down on the left side of my body without the horrendous pain, for my left arm and hand no longer are sensitive to touch. To be able to weed the garden and so many of the old pleasures one can no longer partake in.

The thing I hate most of all, is my dribbling chin. I am aware of it and constantly wiping my mouth. But among all our likes and dislikes, we must be always aware and grateful for the care of our family or minders. They are often taken for granted. We must acknowledge our love and gratitude for all they do for us. I know I am a tie, a burden, and struggle to help in small ways in sharing their load. Often forgetting to say ‘Thank you’, or, ‘I love you’, yet knowing within oneself a need for a hug, and that a sign of affection makes a difference to one’s day.

Alma managed to put to paper what many stroke victims think. It is difficult for caregiver and stroke survivor alike to determine to what extent there is a ‘burden’ involved. Whether she/he is a burden, feels like

a burden, is or wants to be treated like a burden.

The next letter is from Mrs. Collins, who wrote to me but didn't write her address.

Having suffered a stroke and being paralysed on the left side, unable to walk, talk, or use my left arm, I know how frustrating this loss of mobility can be. I was 76 years old at the time. After five months in the local hospital I was allowed home with a live-in carer, and on a walking frame which I still use. Gradually the help has been lessened. I can shower, dress and attend to myself, except for feeling my left leg. I manage a light meal evenings and weekends. Otherwise I have meals on wheels, which I find a great help. I also have a housekeeper two hours a week and a lawn mowing man once a fortnight.

My husband died many years ago, so I live alone, but I have six children, who all live locally. I attend stroke clubs, diabetes meetings, and belong to an active church group. I always have plenty of company and visitors.

The most frustrating things are having to depend on other people for transport, odd jobs, and not being able to garden. My eyesight is poor so I am unable to knit or do needlework, or much reading.

Otherwise I keep very well, so count myself very fortunate.

One of the most often mentioned causes of frustration, after communication, was independence, or the lack thereof. It is very much on a stroke survivors mind what they can or cannot do. Every day, seven days a week, and of course just about every minute of every day. It starts with getting dressed in the morning. I'm lucky that I can dress myself, even though I never take it for granted. Often the wife or husband has to help. In the next report Joyce from Motueka tells us how her husband, Gordon, makes her life easier, and helps her to get through the day.

Since I was 56 he has nursed me back to recovery that has given me more lives than a cat. Helped me handle all the frustrations that I wake up with each morning. But let's not forget, every waking day is a bonus. Getting dressed is the day's first challenge.

Making sure things are not inside out and back to front. I find dressing and undressing a bit of a hassle. Putting socks and shoes on, tie a lace, if necessary, all sounds so easy...

Guess like most of us I have a little trouble with the balance. The latest incident was last Saturday about noon, when I went to go out the conservatory door to the letter box. I did not make it, did a back somersault, to take full force on my left hand, my stroke side. It took a while before I was able to get to the phone. I really was more concerned about the fish and chips that were cooking for our lunch. Gordon, my husband, up for his Saturday morning at the local RSA, was home in a few minutes, as it is only one or two kilometres away. It took a bit of getting my hulk into standing position, but we were pleased to find I could move and we enjoyed our lunch.

After lunch we were the first in the waiting room at the duty doctor. He strapped up my arm and told me to come back in two weeks. I was entitled to home help, but we

were managing. Have had our moments, though, like two people at the sink to peel two spuds for lunch.

Motueka has a great climate for gardening, and I have a year-round vegetable garden.

Because I lost hearing and sight on my left side, I am not permitted to drive. It was a sad morning when the lovely little blonde purchased my Mini and drove out the drive. Without a car now I still go up to our local shopping centre. Luckily we do not live very far, so I can walk, as I think it is very necessary to exercise as much as possible. I do walk like a wino, but I do not need a stick or a walking frame.

Boredom, or in older people loneliness, is the biggest problem for stroke survivors. Friends tend to stay away, and it is not the right time to make new ones. Most people are not employed any longer. It's not that they don't want to do anything, but because of the associated disability often they simply can't. There are, however, always jobs that can be done, as the following report shows. Helen Wulf, Texan author of [Aphasia, My](#)

World Alone, wrote to me to tell me what she's doing these days. She writes:

I go to a local elementary school to tutor little ones one day a week. The other days children having trouble reading call me and read to me over the phone. So I'm occupied with these dear 2nd and 3rd graders and it is very rewarding.

What an excellent idea. Why are not more people doing that? Helen demonstrates that stroke victims still can play an important part in our society. What is more important than our children? This is one way of combating the low self-esteem, and the niggling negative thoughts that many stroke victims have.

Can 'Political Correctness' make me walk again?

Quite frankly, I don't really care what it is called. And nor do the hundreds of stroke survivors I have talked to (if I believe them, and I do). It really is quite staggering, and yes, even funny, what some representatives of the liberal – sensitive – new age – wishy-washy – politically correct league come up with.

There is, for example, the burning question of what to call people who have had a cerebrovascular accident (CVA), without deeply offending them. Is it 'Stroke Sufferers', 'Stroke People', or 'Stroke Victims'? Well, for some reason 'Stroke People' seems to be the preferred terminology by most (at least by those who haven't had a stroke). Even though the latest findings state that 'People who have had a stroke' are the politically correct buzzwords. However, many people who have had a stroke prefer 'Stroke Survivors'. I've always thought (probably falsely) that accidents produce 'victims', rather than 'people'. Also, 'people' reminds me of films like 'Invasion of the Body-Snatchers' or 'The Night of the Living Dead'. The 'they' syndrome is alive and well. Here 'they' come, the 'people' who've had a stroke. Even 'sufferers' seems better suited, though it

has to be said, that it is probably wrong, in a technical sense at least. You see, after a stroke there is, apart from a loss of dignity, hardly any suffering at least for the majority of people. Most of the suffering that occurs after a stroke is emotional, psychological, and in many cases self-inflicted; a condition the politically correct would probably call 'the manifestation of an inability to cope with a new challenge', otherwise known as 'gone nuts'.

The word 'challenge', of course, signals the arrival of a new, much kinder description for the disabled – the 'physically challenged'. Another one, possibly even more sympathetic, is 'differently able'. Whatever it is called, it doesn't change the disability many people have to cope with. Whoever thought of the politically correct name, most likely hasn't got a disability.

Throughout this book I've used all the different terms but mostly strokee. It seems almost impossible to use one word that pleases all people. So I hope nobody is offended.

Many members of stroke clubs call themselves 'stroke survivors'. A term that at least states exactly what has happened. A cerebrovascular accident that left a (more or less damaged) survivor behind.

A woman in her fifties told me, how much she enjoyed cooking before her stroke. Nowadays it's a chore. Even a simple task, like peeling vegetables, takes hours. When asked how she would feel about a new name for her disability, she answered that as far as she was concerned it was a struggle, and unless someone could take this struggle away from her, she really didn't care. So much for political correctness.

There always are, and there always will be, people who take caring to the extent of political correctness. Very nice, isn't it? They, as much as others, feel uncomfortable talking to stroke victims. Indeed, it is very nice if disabilities are given a politically correct name, it's just a question of whom does it make feel better. Maybe the politically correct brigade finds all these names for their own benefit.

Will the next one be 'The Big One'? No, not earthquake, stupid – stroke.

Everyone who has survived a stroke has got the shock of a lifetime, an experience she or he doesn't want to be repeated. Even though many patients live in denial or simply won't admit it, it could have easily been the proverbial 'Good Night Nurse'. Suddenly it dawns on you 'it could have been me'.

This, let's call it, 'revelation of mortality', is probably the most significant experience in a stroke survivor's life. Not mentioned very often (if at all) during recovery and rehabilitation, the stroke survivor is left alone with the thought of 'a close shave'. Of course we all know, that we will die sooner or later, but this is different. A bit close for comfort. Suddenly it seems so real – too real. Something we are not used to dealing with. Honestly, who likes to talk about death? Who wants to be a party-pooper anyway? We are so preoccupied with avoiding talking about death, that when it strikes, we simply don't know how to deal with it. We are paranoid. Even life insurance is called that because it sounds better than death insurance.

The fear of another (massive) stroke is always with you. Well, at least it is with me. I particularly recall the day when I had a TIA (transient ischaemic attack), often called a mini stroke. The main difference between a stroke and a TIA is that the symptoms, which are the same, or, at least, very similar to those of a stroke, usually disappear within 24 hours. Also, TIAs do normally not cause any long-lasting blackouts. No wonder, therefore, that I remember my attack so clearly.

It was a beautiful afternoon in July and I was not the slightest bit worried that I felt a bit off colour. Even when I had to go to the bathroom and threw up, I was not overly concerned, listing in my mind the food I had consumed recently. When it happened a second time I could only wonder 'Strange, but nothing to worry about'. Shortly afterwards my wife came home, I didn't tell her, so as not to worry her.

Even though I felt pretty lousy, it was not until a quarter past seven, that I knew something was wrong. I stood up and told my wife, that I had to lie on the bed, because I didn't feel that good. Lucky I did it then, because I only just made it. By now I felt extremely dizzy and my balance was affected. I didn't know what was happening, but something was happening. I was on a roller-coaster

ride *par excellence*. My eyes were rolling around in my eye-sockets, displaying distorted images of the room I was in, our bedroom. Meanwhile my wife, Jenny, had entered the room; not surprisingly her face revealed concern. All I could do was wait, to see what this attack would turn into. To see whether this was 'the big one'. Suddenly I felt panic. Anxious not to let Jenny know, I told her that I loved her and that I've enjoyed life with her. I really thought this was the end. Better say good-bye now, I thought, you never know how much time is left. At this moment I was so incredibly impassive. Like someone sitting on a packed suitcase, waiting to go on a journey, but not knowing where the journey leads him, nor whether he will be picked up at all. The uncertainty is probably the most unnerving thing about a TIA. Just waiting for something you don't want to happen. Images of animals awaiting slaughter come to mind.

The attack lasted only about twenty minutes. While I was sitting there, trying to analyse what was happening to me, Jenny was on the phone to our GP. Following his advice, she drove me to the hospital and after intense examination by two doctors, it was concluded, that I had had a TIA. Later that evening I was sitting in the same spot, reflecting on the outcome of the day. I couldn't help but wonder how close it had been this

time.

Since that day, a day I'll never forget, I'm very aware of what could happen if I have another stroke. A fear I share with hundreds, yes, probably thousands of people. The doctors were right, when they told me better not to think about it. Looking back through my medical history, there were several occasions when the doctors told me not to worry about it. A sign that they couldn't answer all the questions I had. But at the same time they didn't want me to keep asking myself these questions because they knew it could only lead to negative thoughts, and who needs negative thoughts?

Of course it could have been 'the big one', as can the next one. It doesn't matter whether it is the second or the tenth. What's more important is that we do not look at the time after a stroke as the disabled period during which our quality of life is somehow diminished, but instead we should accept it as extra time. True, a stroke could have meant death, but isn't this one more reason to enjoy life? It is, because I've had such a close shave, that I could never complain about my disability. If that's what I had to exchange for my life, I've still got a pretty good deal, haven't I?

Why aren't you yourself?

Everyone is somehow intimidated when coming into contact with a stroke victim for the first time. This is quite common. People try to act as normal as possible and have the best intentions. Unfortunately they are so busy being 'normal', that they forget some of the most basic things like – a person in a wheelchair is not necessarily brain-damaged, or someone who has difficulty talking is not always deaf, nor is that person fluent in sign-language. As mentioned before, everyone has the best intentions, but only very few manage to be themselves. To a disabled person all these 'normal' people can seem quite grotesque. It is therefore understandable that the disabled person is tricked into thinking all people she or he comes in contact with have joined the priesthood, because of the tilted head, the squishy handshake, and their often more pathetic than sympathetic tone of voice. The following is an attempt to list those 'normal' people. Any similarities with living persons are deliberate. In case you recognise yourself, don't be upset, just spare a thought for the disabled person who endures this treatment seven days a week, 365 days a year. So, here are several individuals who can improve on their how-to-behave-around-disabled-people etiquette. In no particular order there

are:

The I-don't-know-you, or You've-changed-so-much I-can't possibly-know-you – type of guy or gal.

What does this tell us? The stroke survivor has suddenly, yet inexplicably, undergone a miraculous transformation into Quasimodo?

The minister/undertaker- type.

As mentioned before, to be recognised by a posture, which clearly indicates that this person missed out on some badly needed treatment by a chiropractor.

The I-have-no-idea-what-you're-saying-but-I-smile-and-nod approach.

This can backfire terribly. Imagine insulting a person only to get a nod and a smile as a reply!

Then there is the I-truly-understand-you-mate – type.

This person displays sympathy to the extent of embarrassment. He or she knows every physical strain, every emotional pain and is prepared to share the load.

Similar characters are the Us-two-against-the-rest-of-the-world and the Never-give-up (nudge, nudge, wink, wink) – type.

Unfortunately I've not yet been able to figure out, what this rather strange behaviour really means. Maybe I just don't understand these things.

All types, as mentioned before, mean well. They just happen to be too busy being 'relaxed'. They are trying too hard.

One group of people who were uninhibited and truly themselves were the gays and lesbians I met recently at a party. With so-called normal people it doesn't happen very often that a stranger comes up to you and strikes up a conversation, but it happened that evening. Several lesbians came up and talked to me. In case some of you are wondering, no, there was no underlying kinky, hidden sexual agenda, nor did they approach me swinging from a chandelier. Someone suggested that it was one social minority accepting another. Maybe there is some truth in that, I don't know. Whatever it was, it was uninhibited behaviour usually only found in children who are naturally inquisitive. Over the years it has happened a few times that children have come up to me and asked why I have to be in a wheelchair. I always appreciated this unashamed curiosity. Unfortunately not so our adult society. Many times I have had to watch helplessly when a child's collar bone was almost dislocated by a sudden jerk

from her or his mother's arm, because the offspring was staring, and that, our society considers, is not the right thing to do. 'Improper' behaviour is discouraged from a young age (at least by most parents).

Initially children are quite direct and say things like: "You can't talk", or, "You can't walk". I have heard children say to one another before they entered my room: "Now, don't forget, Wolfgang has broken legs." On another occasion my, then four year old, god-daughter said to me: "Does your leg still hurt?" Maybe it will take a few more generations before adults are relaxed around disabled people, and ask down-to-earth questions. Generally, children are straightforward. You can see on their faces that they are puzzled, looking for an explanation. Puzzled, because it may be the first time they have met a disabled person, and most parents don't talk about it. Children usually make up an excuse for the disability that explains in their minds what's wrong, and they are not too concerned about technical or political correctness. The following report from my 13 year old neighbour Shane, bears testimony to the candid manner and simplicity with which children meet new people, a simplicity that unfortunately diminishes with increasing age. Adults certainly could learn a lot from children.

Why aren't you yourself?

It all started when the person next door yelled over the fence and said: "I've got somebody I want you to meet." So we followed him up a driveway and as we walked around the corner we saw a man sitting on the couch. We went inside to say hello. When he started talking to us I thought he was ill, but then he said he had had a stroke. After that we have been friends ever since and now we go over for dinner sometimes. Everyone is amazed at him because he can ride a four wheeler [farm bike] over the sand dunes and he can type on a laptop. Which the doctors said he could not do. I do not treat him any different than I treat my friends and family. The more I see him the better I understand him. I enjoy his company and I think he enjoys mine.

It's that easy. Well, it can be that easy. For children 'being ill' is a good enough explanation. Very quickly other stuff (like farm bikes or laptop computers) takes over their attention. Nothing is worse than giving the disability too much attention. Children quickly get used to a changed situation and they behave just the way

they like – totally natural and uninhibited. My wife's niece, Melissa, put it this way:

At first it was very scary, but now that it's happened it is fine. For a long time I did not want to go close to him, but now it is just normal and I play on the computer and talk to him.

So far the only people I've met who are themselves were little people. The initial contact decides whether an able-bodied person feels relaxed enough around a disabled person. Most of the time they're not.

Wham, bam, thank you, ma'am

If all nerves in a body can be affected by a stroke, why then is it, that the sex life is not affected at all? Well, it is, or at least it can be. At least in some people. It's just that most people feel uncomfortable talking about it. Why should you talk about it, if you can just lie back and think of 'Mother England'. In all fairness it has to be said, that the feedback I've got, indicated that most people who responded didn't have sex very high up on their list of priorities. Maybe the high average age had something to do with it, considering that members of the older generation, a.) don't like to talk about it, or b.) don't see sex as a priority. However, I must say, I was surprised, when a middle-aged doctor didn't have the courage to talk about it.

It was a Monday morning after I had been home for the weekend. I was waiting for one of the highlights of my otherwise boring day – a visit by one of the many doctors. He finally arrived with a younger doctor in tow. After asking all the usual questions, he asked how my weekend was. That's when I told him that I had had sex, and that it was great. Particularly as it was my first time. No, I was not a virgin, it was the first time

since my stroke. I was flabbergasted by the reaction I got: a sideways glance and silence. He obviously didn't know what to say. I felt sorry for him. At this moment he seemed quite juvenile. He reminded me of the ten year old boys I saw on a holiday in Sweden, myself only sixteen at the time, who looked at a pornographic magazine at a supermarket checkout, and couldn't stop giggling. Maybe not quite the same, but equally juvenile when I really needed someone adult enough to discuss it with. Maybe this doctor should grow up and do at least some window shopping at Hamburg's Herbert Straße or in Amsterdam's red-light district.

Luckily enough I found a person who was not as inhibited as this doctor, but willingly shared her experiences. Her name is Sarah (at least that's what we will call her, as she didn't want to reveal her real name), a 38 year old mother of two (one from a previous marriage). She phoned me one day because she had, as she put it, to get something off her chest. She had discussed it with her husband, but he didn't believe in talking about these things. However she felt, that she could maybe help other women who go through a similar thing, and, here is what she had to say:

I must say my self confidence was shattered after my first marriage. I suppose, that's

why I still find life is a bit hard. My husband, Mark, is wonderful in that respect. He supports me wherever he can. I'm lucky to have him. At the same time it makes me sad that he sticks around.

We had dreamt of a wonderful life together. And now this. It happened at the birth of James, my second child. The fact that we had chosen a hospital birth turned out to be a blessing in disguise. I had just given birth when it happened. It was kind of embarrassing, I thought, with Mark and my mother there. But I don't remember much, as I fell unconscious shortly after it started. The doctors said just as well the birth was over, otherwise it could have affected the baby. That's why I think I was lucky.

Before I came out of hospital, an occupational therapist went to my home and made sure I could get around easily, and had grab rails mounted, where I needed them. After I was at home the Plunket nurse and the community nurse called in occasionally to help me with the baby.

So it was quite good in that respect. Also, Mark, is besotted with our son, James. He doesn't mind getting up at night, when the baby cries, or changing the nappies. That makes things a lot easier, I reckon. One of the consequences of my stroke was that my feeling was affected. Unfortunately this was also the case inside my vagina. At first I thought the stroke had made me frigid, but I talked to my gynaecologist, and she explained it to me. Not that it made me feel much better, this loss of sensation, as she called it, but at least it puts your mind at rest if someone explains it to you.

Nothing worse than waking up in the middle of the night, and your thoughts are going round and round in circles, if you know what I mean. Not a nice thing at all. You keep blaming yourself. Also, I cry a lot. Many nights I cried myself to sleep, because I was depressed and desperate. During those days I thought about faking an orgasm for the first time in my life. Instead, I talked with my husband about it. He understood me and supported me.

I feel much better now. I want you to write in your book, that women out there who feel the same as I should not blame themselves. It's something that men should understand. Something that just happens. Nobody should have to feel how I felt.

BMS – the disability threesome: Balance, Mobility, Sensation

At some stage after a stroke, be it in hospital or at home, you'll have to do some 'damage control'. We know that, in most cases, a stroke leaves one side of the body paralysed. It is this paralysis that is responsible for the three main causes of disability, which are:

- unstable balance
- reduced mobility
- loss of sensation

Of course there can be other disabilities, for example, impaired vision or any of the emotional disturbances, but it is the former three that make stroke the foremost cause of disability in New Zealand.

Balance – Like most stroke related disabilities, the loss of, or at least the disturbance of balance can be short-lived or linger for a lifetime. It can be a few days in hospital, years at home, or forever. Who hasn't seen those characters with a limp arm, lopsided body, twisted hand, hopelessly negotiating the footpath with their walking stick, and sometimes even falling. Any gymnast knows the feeling when you are off balance.

The moment you notice it, it's too late. But unlike the gymnast, the strokee is not able to correct the fall in any way, because one side of the body is often partly or totally paralysed. You just go, and there is nothing to soften the blow. In martial arts, for example, the correct twists, turns, and falls are taught. Almost instinctively we try to correct our falls, and that's when frequently the damage is done. If we could apply martial art techniques we would fall better and many broken bones would be saved.

Mobility – There are a number of methods available for gaining full or partial function of limbs. What they all have in common is that they help to bring back movement and increase mobility. After a stroke joints seize up, tendons contract, and muscles weaken. Whatever exercise programme you embark on, it's good for you. Up to 18 months after the stroke the improvements are most visible, but even thereafter some progress has been reported.

Sensation – Probably the disability that is least noticed by outsiders, it nevertheless influences life a great deal, and can make it difficult and, at times, dangerous. Not being able to feel the caring fondling of a partner, not being able to differentiate between hot and cold when holding a pot on a stove. I have for example a partial

loss of sensation on the right side of my body. There is no difference between something hurting me and someone tickling me. It's just unpleasant. For some people, it is worse. I have heard of a man who had to hold one of those handheld fans in front of his face. He had a burning sensation in his mouth and needed the fan to cool himself down. Our minds trick us into believing something which is not there. The only way of knowing if something is hot or cold, blunt or sharp is visual confirmation (see previous chapter The world still goes round...just slower)

It should be emphasised, that these three causes of disability are only the main reasons, and are often influenced by, or go hand in hand with, other disabilities. Any disability on its own can make life difficult. Unfortunately we often have to live with more than one.

Laughing about disabilities

Q: "What did you do since I saw you last?"

A: "I can't remember."

Overheard at the AGM of the Alzheimer's Society? No, at a stroke club meeting. One member added: "That reminds me of myself, I have to write everything down in my diary, and then I forget to look it up." Admittedly, for some outsiders the conversations heard in a stroke club might seem somewhat comical. But it is this ability to see the funny side of things, that makes members of stroke clubs appear more humane than members of the general public. Members of stroke clubs have one thing in common – they have all had a traumatic experience and they carry the scars. These scars or disabilities, no matter how small, are very visible to the other members, simply because they can relate to disabilities. Not because they necessarily suffer from the same dysfunction, but they know that everyone in this club has some sort of disability. Consequently they are very forgiving. So forgiving, in fact, that they don't mind if someone makes a joke about disabilities. It seems to be the only way to keep sane. A joke someone in a stroke club told me, goes like this:

A few weeks after his stroke a man asks the doctor: 'Will I be able to play the piano, Doc?' The doctor asks the man to show him his hands, examines them and then answers: 'I can't see why not.' To this the man replies: 'That's good, because I couldn't play the piano before my stroke.'

Another reason to smile is the daily situations that often occur when one sees life from the perspective of a wheelchair. Even though not always funny to the politically correct, disabled and able-bodied people should be capable of having a giggle about it. I recently discussed one such situation with a friend who is in a wheelchair because he has multiple sclerosis. I ran [wheeled] into him at a concert. While we didn't have anyone standing in front of us that evening, we started talking about the view that usually greets one in a wheelchair.

Apart from concerts I like to go to art galleries, exhibitions etc. The only unsatisfactory thing is, that wherever people are gathered, you are looking at their backs. I said: "Would you believe it? I am sick of looking at bums. You can only look at so many bums before you get sick of them." He wholeheartedly agreed, nodded, and said: "Nostrils. The other things are nostrils. I usually say: 'You are beautiful, but please sit down, I'm

sick of looking up your nostrils'.”

Funny? Maybe not to the able-bodied, but every person in a wheelchair can relate to it. Besides, it's not a question of how funny it is, but how healing. Psychologically speaking laughing about one's own disabilities can be an important part of the healing process.

Several years ago I had a friend in Germany who had only one arm. He was a printer, working on one of those big four colour machines. These machines can be 20-30 metres long (approx. 67-100 ft) and you can walk between the cylinders. That's what he did. There was a paper jam and he tried to remove the paper while the machine was running. During this operation, unfortunately his arm got caught and pulled into the printing machine. He was lifted off his feet and hung there up to his shoulder, his right arm out of sight, wrapped around the cylinder. These machines are easily capable of ripping one's arm out of its socket. Luckily my friend managed to hit an emergency stop button with his knee. However, the injuries were so bad that he lost his arm.

Years later I saw and heard him taking great delight in explaining the gory details of his accident to anyone who did, or didn't want to hear them. He laughed heartily

at the ‘ohs’, ‘ahs’ and ‘yuks’ of heavily grimacing people and when I asked him about his newly found macabre behaviour, he told me that was what he needed. At the time I didn’t understand what he meant but today I can relate to it – it is therapeutic and part of the healing process.

We have to confront our disability and live with it every day so we might as well accept it. If accepting it means telling jokes, so be it. After all, there is often some truth in jokes, even though the politically correct don’t like to admit it. Very often jokes reflect in a more or less cruel way our daily frustrations.

Jack arrives somewhat distressed at work. When his colleague asks him what the matter is he answers: ‘I just had a punch-up with a disabled guy’. Says his colleague: ‘That’s not very nice. Where was that?’ Jack explains: ‘Right outside the supermarket. The cheeky bugger took my car park, didn’t he?’

Be honest! Who hasn’t taken a disabled car park? Unless the government or local government does something about it, we, the disabled people, can only try not to get too upset about it. For some reason governments manage to draw up more or less questionable laws, local councils encourage ratepayers to hug

trees, our society saves not only the planet but protects any minority group as long as it's fashionable, yet for some reason disabled people still have to argue with able-bodied drivers over designated parking spaces. Is there any argument? I think not. If it wasn't so sad it would be funny.

Whatever the situation we have to try to stay clear of negative influences, as it is bad for the body. It's not always easy. Just try. Keep smiling!

Window to the 'outside world'?

“They just sit there and talk about all sorts of topics, politics, business, whatever. It’s not like other stroke clubs, I’m sure you’ll like it.” And she was right, I did like it. Not only the way Jennifer, a field officer with the Stroke Foundation, introduced the club, but the fact that I met people my age. Having a stroke in common does not necessarily mean similar interests. I had been to a stroke club before, but decided it was not for me. The youngest person there was over twenty years older than I was. We just were not on the same wavelength. This was different. The main difference being, that in the other club every one retired and then had a stroke, whereas here most people were in the middle of their working lives, suddenly had a stroke and were forced to retire. I can identify with that. That’s what happened to me.

Meeting like-minded people, is the reason most often given for attending a stroke club. With increasing age, our interests and priorities change, which makes it even more important to have contact with people in the same age group.

Many people call a stroke club a 'window to the outside world'. I do like stroke clubs for all the right reasons, but a 'window to the outside world'? I don't know. It seems more like an inside world to me. The only time the members of a stroke club have contact with the outside world is when they go on a field trip, an outing of some sort. Normally the strokee encounters adverse reaction individually. The difference is that in a club, this adverse reaction can be encountered as a group. I find it hard to believe that people's attitudes change only because they have to deal with a group, rather than an individual. Unfortunately there is not much information and education about strokes in our society. The this-does-not-happen-to-me attitude prevails. It is a bit like death, we all know it can happen, but we don't like to talk about it.

It is time our society had a change of attitude towards strokes and disabilities in general. When I had my stroke, many of our friends and acquaintances said to Jenny, that they knew of someone, or some distant relative, who had had a stroke. They had never mentioned it before. But it shows how widespread stroke is, yet how little it is talked about. And it won't change. Not unless these people who know of someone go and get some information. Maybe visit a stroke club or a

support group for carers. It sounds ridiculous, but able-bodied people can, even though for different reasons, benefit from stroke clubs as much as disabled people do. I'm a great advocate of intermingling able-bodied with disabled people (Naturally! After all I am disabled). People will change. Attitudes will change. No, I'm not talking about a phenomenon like the Miss Universe contest of a few years ago, where every bimbo wanted to work with disabled children or pursue some other career in social work. But if one compares the new age sensitive guy of the nineties with the chauvinistic, macho bloke of previous years, it becomes increasingly clear that a change is happening in our society.

I talked to Sophia, a volunteer coordinator at a stroke club, about how she became involved as a volunteer and about her impressions. She said:

I hardly understood what stroke was. Actually, I thought it had something to do with the heart but I was to learn very quickly that it involves a clot in the brain causing all kinds of damage and disability. Thus, my first visit to a stroke club exposed me to a whole new area of life I had never even imagined. There were some 10 – 12 men, all aged between 45 to 55 years, all

had been in professional employment, and now they were readjusting to life after a stroke.

My first impressions were mixed. I was like a fish out of water really. How do I speak to these people? What could I say? How could I possibly understand what they were going through? I closely observed each of them, some were struggling to walk, others struggled to make themselves understood, several were confined to wheelchairs.

Very quickly I learned about stroke and the effects on a person's life, and also the family's. It was on another visit to the club that I felt challenged to consider becoming involved myself! These men, and some of their wives who came along whenever they could, were really friendly. They appreciated my efforts and help. Amongst themselves they shared stories of what happened when they had their strokes, their times in rehab, how they were relearning what they had once taken for granted... like walking, or simply driving a car, and how their families were coping...never

mind themselves. As I listened, I learnt more from them. The emotional ups and downs they experienced, the frustrations they suffered because of disability, the uncertainties that the future holds, the developing of necessary new interests they had to find to break the boredom that was creeping in.

Together in this stroke club, there was genuine caring. They would encourage one another and sometimes it was just sad as they talked about the difficulties they were going through. We didn't bother holding back the tears – everyone was being real – they understood each other.

We've also had some hilarious times. Overall there was a great sense of humour and a very positive outlook on life.

The outings we've had as a club have further developed our relationships. Every trip is a challenge but worth it. I enjoy the group and regularly find myself telling people about strokes and the activities we do together as a club.

In closing she says: Our society has become so complex. Life is now at such a fast pace. Everybody is so very busy. I decided to stop and take a look at what I was doing. I opted to volunteer. I'll never look back.

Talking about clubs and attitudes in society brings me to another misconception, 'People with physical disabilities can't work'. Unfortunately this kind of attitude is still quite widespread in our society. Of course, someone who is physically disabled won't be able to do manual labour, nor will someone with a brain injury necessarily possess the cool-headedness required to perform complicated mathematical equations, but there is hardly any reason (except disability related limitations) why someone with a disability shouldn't work. Again, it is the attitude of society. Most people with a disability would like to work. Apart from the prevailing attitude in our society there are only few hurdles to be overcome. Nothing that couldn't be fixed.

This never happens to me

‘Hindsight is 20/20.’ This adage couldn’t be truer than in the case of people who have had a stroke. Of course we would do everything differently if we knew it could avoid a stroke. Many stroke victims thought there wasn’t enough information and education about strokes. Here is only one comment, typical of all the others:

In retrospect, I think that if my doctor in the city had told me what could happen to one with high blood pressure, I would have acted differently. All doctors should explain the consequences of ignoring high blood pressure to their patients, particularly if there is a history of strokes in the family.

The fact is, that all the prevention in the world doesn’t guarantee a thing. Even though there are factors that increase or decrease the likelihood of a stroke happening, nothing is for certain. I asked my GP to spell out the most common factors contributing to a stroke. Like most medical practitioners he listed the following risk factors:

- High blood pressure
- Smoking
- The contraceptive pill
- High blood cholesterol
- Obesity (being overweight)
- High blood sugar

Even one such risk factor is bad enough, but each additional one increases the chance of a stroke. Add even more and the likelihood of a stroke becomes extremely high. With all this information it is still not possible to tell if or when a stroke might occur. The medical profession has, unfortunately, no way of telling. Neither can they fix everything. Not every stroke can be treated successfully. My haemorrhage, for example, happened to be situated in the brain stem, and was inoperable. Even if it had been detected earlier, there was absolutely no way that even the most modern medical techniques could have made it possible for me to be operated on. Which is not surprising, if you look at stories where archaeologists found human skulls in South America, which had holes the size of 50 cent pieces in them. These indicated that complex brain surgery had been done many hundreds of years ago, and today modern medicine doesn't know how it was done. Too many questions, not enough answers – like

stroke itself. Why? How? When? It is up to the individual as to how much care and consideration they give to the general rules for healthy living. After all our bodies react in different ways to different influences. The best example would be George Burns. He was well-known for his cigar smoking. He lived a long and fulfilled life, yet few would argue the fact that smoking is bad for your health.

The human body works in wonderful ways. Ways that are not easily explained. But as the Latin saying goes; 'a healthy mind in a healthy body,' certainly helps. A healthy, positive attitude on the part of caregiver and strokee alike certainly can influence rehabilitation, and, if we're really lucky, our society will change its attitude one day.

Writing about all our frustrations made me realise that every strokee needs the support of a strong partner.

Mine is my wife Jenny.

Bibliography

Broida, Helen, PhD. *Coping with Stroke*, College-Hill Press, San Diego, California.

Dimelow, Judith, *A stroke? Let's cope*, Stroke Foundation of New Zealand Inc.

Griffith, Valerie Eaton, Oetliker, Patricia, Oswin, Prue, *A time to speak*, The Stroke Association, London.

Hewson, Lorna, *Stroke – a Family Affair*, Collins Dove.

Mulford, Prentice, *Your forces and how to use them*, (first published 1885-1890).

Peale, Norman Vincent, *The Power of Positive Thinking*, World's Work Ltd. (A Cedar Book).

Smith, Gwendoline, *Sharing the Load*, Random House, Auckland, NZ.