



[www.strokenetwork.org](http://www.strokenetwork.org)

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Happy New Year. We hope that 2003 brings good things into your life. Living with stroke has been a surprising good experience for many of our readers. We hope this year brings positive energy in your direction. The first issue of StrokeNet for 2003 includes a number of interesting articles.

David Ray's stroke club is taking a winter break, but he shares with us some of his family holiday traditions. Reader Mike Tallinger contributes an inspirational story about his stroke experience. Next find a book review of "Your Mother has Suffered a Slight Stroke" by Kathleen Bosworth, which tells a stroke story from the perspective of a family member. Many will appreciate the helpful hints in the article about G tubes. The website review is of Washington University (St Louis) Stroke Center site. Finally we hope you enjoy the bios of readers David Borer who lives in England and George Murray from South Africa. Happy reading!

Lin Wisman, Editor  
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### Organization Highlights, by Steve Mallory

I want to begin by saying that I hope your holidays have been the best that they could be! The year 2002 was a good one for our organization and I have a feeling that 2003 will be even better. For those of you who are not aware of some of our accomplishments let me bring them up again.

#### o 2002 Recapped

- \* Non-profit status received!
- \* Membership database established
- \* Newsletter enhancements
- \* Search capability added to entire web site
- \* Purchased our own:
  - \* Chat room
  - \* Message board
  - \* Mailing list
- \* Newsfeed on stroke articles
- \* Created our color brochure

- \* Stroke awareness quilts displayed numerously
- \* Golf Fundraiser is extremely successful!
- \* Membership doubled

These are just some of our highlights, but are by no means, all of our accomplishments. We have certainly proven that we are a valuable organization, worthy of non-profit status, and that our on-line stroke support group can make a difference to the worldwide community.

We have finally found someone to fill the Medical Director position. Dr. Shawn Jennings, MD has agreed to fill this position. He will primarily be managing our Expert Panel.

While our new mailing list was being installed last month and during the beginning of December some of you emailed me and informed me of not being able to access some of our web pages. This problem should be corrected now but let me know if it has not cleared up for you.

Unfortunately, the scheduled conference on the Assistive device, the Helping Hand, had to be cancelled at the very last second due to our server being temporarily down. For those of you with hemiplegia this device will be invaluable towards regaining independence in the kitchen and with several other daily tasks. Steve Flaherty, from Welcome to Helping Hand Industries has agreed to reschedule for us and will be at the open-topic chat session scheduled for January 14. I have decided to change the door prize entry to January 10th.

Happy New Year and may the coming year be full of blessings for you and your family!



### Life in New Zealand with a Stroke by David G. Ray

The Stroke Club to which I belong has taken its Christmas break and will not meet again until February. As usual we finished the year with our Christmas lunch. I thought I

would share with you what my wife and I did to prepare for and enjoy the big day.

Although we have only three grandchildren we have plenty of nephews and nieces and we like to give them little gifts. Lists are made of each family member, their age and gender and off we go to the shops to see what is available and subsequently purchase. Also in this pre-Christmas period we have a son who turned 40 a week before Christmas and a granddaughter who turned 12 years old, two days before. (It is, I believe, called family planning.)

It is also the berry season and we travel to nearby (50 kilometers) berry farms to buy strawberries, raspberries and blueberries for making jam or just enjoying with cream. On the route to the cherry farm we pass a chocolate factory beside which our car mysteriously came to a standstill. However it started again after we had walked into the factory shop and replenished our supplies with goodies. This period before Christmas is a busy one, especially for my wife, preparing a variety of food.

Christmas day dawned with gale force northerly winds and driving rain - not the summery day we had wished for. We had invited 16 of our immediate family for Christmas dinner, which, except for potatoes, is a cold meal. Our daughter contributed a green salad, her husband (who is a chef), delightful fruit meat pies, and his parents a tasty fruit salad and a delicious pasta salad. For meat we had chicken and ham off the bone.

Before lunch we exchanged Christmas presents and enjoyed New Zealand sparkling wine and lemonade. As is usual at Christmas we finished with chocolates, nuts and cherries. After lunch the rain stopped and we were able to sit outside in the sun and solve the ills of the world over some festive cheer.

I would think that what I have described would be typical of how many families spend Christmas day. Many people enjoyed their celebrations at beaches and lakes but wherever they spent Christmas it is a time for remember the meaning of the season and having time with family and friends. We cannot forget the troubles in other parts of the world that perhaps are not enjoying the season as we do. We hope and pray that politicians in every country heed the words of Pope John-Paul and the Archbishop of Canterbury.

I would like to finished this report by wishing all readers, in fact all stroke people everywhere, continued return to health and a very happy new year in 2003.

## Stroke Reflections

by Mike Tallinger

Mike Tallinger stroked on March 1, 2000. In this writing he both shares his experiences and offers advise to others. His story is an inspirational one. He has had to relearn many things. He reminds us that the frustration experienced is worth it as the stroke survivor continually relearns various abilities. This edition includes the first few paragraphs. Read the entire article at <http://www.strokenetwork.org/newsletter/articles/mtallinger.htm>.

My goal is to try to impart what I felt and what my caregivers went through. The most important piece of advice is that the stroke survivor will get better. It takes time and the desire to get better. It means that the stroke survivor will have to listen, trust and work along with their therapists, doctors, nurses and other caregivers.

I now drive, talk, listen, write, read, and walk. At the time of my stroke I was unable to do any of those things and I felt that I would never be able to do those things again. My right wrist is weak and I limp slightly but I continue to improve. It's the inside, my brain that was and still is my most important thing to me. The cognitive abilities that I had lost at the time of the stroke was the scariest to me. Being unable to connect thoughts or words sometimes made life unbearable.

My recovery at first was slow, tedious, frustrating. I guess frustrating sums it all up. I couldn't talk or get my wants or needs expressed. And when a stroke survivor can't express him or her self they will increasingly become more and more agitated. It is important to let the survivor know that you want to help to work through the problem and to try to allow the survivor to relax. I found that I was very anxious and demanding. I felt that no one understood me. This is a typical scenario. Caregivers will need to remember this and to try to understand that the stroke survivor is not mad at them, but at the survivor's own situation.

I want to thank all my friends and family who cared about me during my hospitalization and throughout the last two years. Your prayers, calls, letter and concern for me has been the reason I have been able to carry on. Thank you all and God Bless you all!

One thing about the semantics of "stroke lingo". Being very politically incorrect, I was constantly being told I was a stroke survivor, not a stroke victim. Well my friends call it what you want, but I am a victim and I enjoy it. You may as well get as much sympathy as you can, it won't last forever!



**Book Review: Your Mother has Suffered a Slight Stroke, by Lin Wisman**

In her book "Your Mother has Suffered a Slight Stroke" Kathleen Bosworth shares the story of her mother's series of strokes and the responses of the family. Kathy's mother went for a routine medical test and suffered a stroke. She was then one of the small minority of people who react negatively to TPA. She had another stroke, this time a bleed. During the next few months she had several more strokes.

The author's family had a difficult time with medical personnel who they found negative and unable to answer questions to their satisfaction. They quickly discovered themselves having to deal with confusing questions of medical insurance, finances, choosing a nursing home, dismantling their mother's apartment, etc. while dealing with the overwhelming personal experience of their mother's illness.

Anyone who is caring for a loved one who is had a stroke – or other debilitating disorder --will find this book helpful. It is also a good read for medical personnel who deal with families of stroke survivors and would like to hear a story from a family member perspective.

During her mother's illness the author kept a diary. This book is written with the diary as its base. It is not an easy read, but a very helpful one for those dealing with stroke.



**G Tube Care**

Many stroke survivors have a feeding tube when first discharged from the hospital or rehab. Some can eat some foods for pleasure, but there may be a risk for aspiration

pneumonia and it is common that enough food isn't eaten to sustain life.

Many members of the support group were told that their loved ones would never eat normally again and have found that over time, the ability to swallow comes back. The process can be long and involved. Start slowly, under the guidance of a speech therapist. Normally, pureed foods and syrup consistency liquids are recommended. Gradually work up to foods that "clump" (purees, mashed potatoes, etc) because the swallow reflex doesn't recognize small foods (rice, corn, etc) or thin liquids. Drinking with a straw normally closes off the airway and so the swallow get somewhat better. Some studies suggest that carbonated beverages cause the swallow reflex to react quicker than non-carbonated.

As for the feeding tube itself:

They DO wear out (because of stretching, bending, etc). but are fairly easy to replace. A visit to day surgery is all that is involved and, in most cases, the old feeding tube is removed and a new one is inserted. There normally isn't any surgery involved.

Keep a drain dressing taped to where the tube goes into the stomach. This is just a 4x4 piece of gauze with a slit cut in it to accommodate the tube. This absorbs any seepage or weeping that may come out of the tube site. Change the dressing daily. About once a week, leave the area exposed to the air - I don't know if this does any good, but I haven't run into many problems with infections, etc. Sometimes the area around the entry get a little reddened. I don't know if this is due to seepage or chafing. I use a little bit of triple antibiotic cream on the area if I see any sign of redness. Keep the area around the entry point clean with a cotton swab soaked in hydrogen peroxide.

Sometimes the tube itself can become clogged. Forcing a syringe of ginger ale through the tube about twice a month can prevent this and will clean out any residue in the tube

Most medications are delivered through the g-tube. Some are liquids but others are powders or pills. For the pills, buy a pill crusher - only about \$4 and MUCH easier than using two spoon to crush the pill. Dissolve all powders and pills in a couple of ounces of water. Whenever giving anything through the tube, use a syringe to flush it with some water, then put in the meds and then I flush with water again. This keeps the tube fairly clean and ensures that all the meds are in her stomach.

Give at least 1 liter of water through her tube throughout the day. This prevents dehydration. When ever the giving meds or other liquids, drape a towel around the tube to catch spills, etc. Finally (and this is very important), if you have the feeding tube open and you notice your loved one is about to cough, sneeze, or have any other type of sudden movement, pinch off the tube or bend it. Sneezing, choking, and coughing all cause the stomach muscles to contract - sometimes violently! This WILL result in a geyser coming from the tube if its not closed.



## Website Review [www.strokecenter.org](http://www.strokecenter.org) by Lin Wisman

Washington University's stroke site, <http://www.strokecenter.org> is extensive. One section is devoted to Patients and Families, another for Professionals. A third section covers Stroke Trials with information on current and completed trials.

Patients and Family area is geared to provide info for those without a medical background. It focuses not only on basis info but also on data, which can aide the survivor and their family. This section provides general information including an explanation of the different types of stroke. This area is well presented and easy to understand. How strokes are diagnosed is covered. Of particular interest is the section covering the most common medications. An explanation of each drug is given. Links to various medical sites, which provide more information, are provided. Living with Stroke provides general information, suggestions on home modification, suggestions of how to find stroke support groups, and a list of online stroke support resources. Survivor stories and videos are also available.

Whether you are new to stroke or have a lot of experience you are sure to find some new information. There are many suggestions and links which the stroke survivor, family member and caregiver will find helpful.

The professional section includes data on conferences, guidelines and basic science. Diagnosis, stroke management and news are covered.

Washington University is located in St Louis, Missouri.

## Biography: David Borer



I live in a small town in England that is located 30 miles south of London and a similar distance from the coast. We are surrounded by countryside and it is a great place to live.

Waking up on the 6th May 1999 I could not understand why I was not able to jump out of bed as normal. My partner, Maureen, told me to stop playing around and get to work. I worked as a technical marketing manager in the Telecommunications services industry and had started a new job three weeks earlier.

Gradually we realized that I had a serious problem. When my Doctor arrived he decided that I had suffered a stroke. All I knew about strokes was that it was a problem for old people and I was only 59 (my daughter says that is old!) so how could he be right.

During the next few weeks in hospital I learnt about strokes, why they happen and the impact they have on your life. I was unable to use my left side and had lost my sense of balance but fortunately neither my voice nor eyesight was affected.

After a few weeks I moved to a Rehabilitation Centre where the physiotherapists set about trying to restore my body. It was hard work and at times very depressing especially when I was told that I would not be able to walk again although I may be able to "move around indoors". This served as a challenge to prove the experts wrong.

Gradually things improved although I was in a wheelchair for the next four months. I was lucky

that I had friends who took me out so that I didn't lose contact with the outside world. During my stay with the help of one of the therapists we arranged a visit to a restaurant to celebrate Maureen's birthday. A birthday cake and flowers were arranged and during the evening I found the courage to propose to her. I think she was very brave to accept bearing in mind the prognosis from the therapists.

Three weeks before I was due to leave the centre I started to learn to walk again, it was really difficult to remember how I walked before as it is just something that came naturally. A few days before I was due to leave it was decided to extend my stay for two further weeks and teach me how to get up and down stairs. This was very important as most houses in England, including ours, have the bathroom and bedrooms upstairs.

Although I had been home for a few weekends I was very nervous leaving the centre where I felt safe, but with the support of Maureen, my daughter and friends we coped. I was determined that life would continue as normally as possible although I couldn't continue working and my interests such as walking were not possible. Six months after the stroke I passed the special driving test that stroke victims have to take so that I could drive an adapted car, My ex-work colleagues purchased an electric scooter for me which together with the car increased my mobility enormously.

I have always been interested in photography but putting a film into a camera with one hand completely defeated me. I changed it for a digital camera which solved the problem and gave me more interest in computers as an added benefit.

In April 2000 Maureen and I were married and I managed to walk with a stick and stand for the ceremony, which made a great day even better. I was able to drive us to our honeymoon hotel and of course take photos of our time there.

Since then my walking has gradually improved with the help of regular sessions at the gym and a very good physio. I use an electronic stimulator that drives my leg muscles and lifts my left leg forward so although I go very slowly I can walk around shopping centres, etc. Despite all efforts the arm has refused to improve.

I have always liked traveling and we have managed to take a number of holidays the most challenging being the Canadian Rockies and

Alaska. My best holiday memory is walking along a sandy beach which I had been convinced I would never be able to do.

I have recently started to learn to play Bridge which really tests my concentration and memory both of which deteriorated after the stroke. I help a Disabled Access Group by checking all the local planning applications made to our Council to ensure the needs of the disabled are considered. I also manage to cope with some of the gardening and work around the house and spend a lot of time on my computer.

As all stroke victims know it is important to have a positive attitude to get over the many difficulties that arise. I always remember being taught in a management training course that you should try one thing new every month. I started life again after the stroke so I have lots to try.

This months "new" experience is going to the theatre in London to see My Fair Lady, next month it's a shopping trip to France. I personally find it easier to cope if I keep looking forward and making plans for the future.

## Biography: George Murray



My name is George Murray and I live in the Western Cape of South Africa near Stellenbosch, a university town and tourist attraction since it is the oldest village bar Cape Town. I was just over sixty years old on November 23, 2001. It was a beautiful summer morning and my first job of the day at 6 a.m. was to get milk from the farm about one mile away. Driving to the farm, having a chat with the dairy manager about the nice day, and back at home with the milk in the fridge. Waiting for the newspapers to arrive, it was time for a quick look-around and check-off Saturday chores to be done. At 8 a.m. I was off to get the papers and fresh bread some five miles away. On my way out of the shopping center with the papers and bread I felt ... queasy ... and waited for it to go away. I felt better and got in the car and on the way home felt even funnier and funnier, and about one mile from home I stopped the car with a feeling of " I just couldn't care less." Later that day, I woke up in the hospital. I was told I had suffered a stroke and everything was OK. I was not exactly sure what a stroke was, but I couldn't care less and dropped

off to sleep again. Sleeping is about all I remember of that last week of November.

The first week in December I started to surface and I was told what had happened to me, not fully realizing exactly the implications of what I lost. If I had realized then what it means to lose one's right leg, right arm and hand, and half of one's speech capacity, I would probably have done something drastic. Fortunately, my damage was down-played and I was led to believe the damage was reversible, but that I would require serious rehabilitation in terms of muscle tone and speech training. The schedule was six months rehab plus another two months for obtaining a new driver's license. Sounded like a piece of cake...

For the first few weeks at home I had a physio and a speech therapist. I did not even bother to learn left-handed writing -- surely right-handed retraining will be easier with a hand that is used to writing ...? And surely getting special clothes or gadgets for a stroke patient is not necessary--rehab will be done after six months. I exercised my leg and practiced my arm by picking things up. I became skillful in saying "bue moe" and "pooi voo". It wasn't fun, but anyone can suffer anything for six months if restoration is anything to go by.

This status quo went on until June - July 2002 when I could see no improvement in my arm or leg. By now I had realized stroke restoration is not a viable goal. By reading library books about exactly what happened and what lies in my footpath on the road ahead, it became clear that I was laboring under a misconception: There is no reversal. Period. There is no second chance. Period. Furthermore, my right ankle was still giving trouble, and I spent most of my waking

hours in my arm chair-moving about has become too painful. During this time suicide became foremost and uppermost in my thoughts: My wife and children don't really need me any more-I'll be missed for a week or so but life goes on. Also, I couldn't complain-I have had 60 years of fun and tears of which 35 years were happily married. At this stage the psychologist prescribed anti-depressant tablets which had a positive effect.

This past year had gone by without my joining any stroke companion groups (with the exception of StrokeNet) because I still couldn't believe it and I still could not relate something life-threatening happened to me-my right leg also made for error-prone limping with the cane for support. By the time of writing, I have crossed the bridge of accepting my stroke as being with me for the rest of my life, and we have (at last!) located a doctor who is hopeful about fixing my right ankle. So its another three weeks in hospital followed by more rehab, and then, who knows... walking without a cane, getting a drivers' license and doing things!

Looking back over what I have said, it is not so much a biography of my life, but an account of my stroke just less than one year ago and (with few exceptions) the battles with medics and paramedic players. It was not a very good year, but stay tuned in for more information on how I am winning the game against the cards dealt to me. My address is georglm@iafrica.com for mail-letters will be answered.

The Stroke Network is a registered 501(3)c non-profit organization. We are an on-line stroke support organization and are available to everyone worldwide. Since 1996 we have provided stroke support and information to nearly 10,000 people and to hundreds of thousands of visitors to the site. The Stroke Network is the homepage for a network of several other smaller web sites owned by The Stoke Network Inc

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