



<http://www.strokenetwork.org/>

June 2003

Welcome to the June edition of StrokeNet. We hope you find this month's read useful. Steve Mallory asks all members to register for the message board and/or the caregivers mailing list. There is also interest in setting a daily time when anyone interested could meet in the chat room. David Ray describes a trip he and his wife took in New Zealand.

Next you will find an article on Product Websites where you might find just the gadget for which you have been searching. The book "Striking Back at Stroke" by Cleo Hutton and Louis R. Caplan, MD is reviewed. Then the website of the National Institute of Neurological Disorders and Stroke is reviewed. Bios featured are Angelo Leo Carlini and Perryann Davis

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Organization Highlights

By Steve Mallory

We have had somewhat of a slow month primarily due to several issues with my health. It has been nearly nine years since my stroke and that means nine years in a wheelchair without being able to walk. I have central pain over most of my body and now have something like an arthritic condition developing in my neck. This must certainly be a sign of me getting older. I'm only 45 but feel 95!

One significant addition to our organization capabilities is that we now have a Live Help service. Our most recent addition to the volunteer staff and Board of Directors is Perryann Davis. Perry is not only helping me by manning the Live Help area for part of the day but is also making her expertise as a registered nurse available and monitoring our Guestbook. The Live Help button is located on the homepage if you need to talk to someone on our staff. It does not matter what your problem is.

We have over 400 active organization members but only about 50 who are registered message

board stroke support members and another 50 who belong to the stroke caregivers mailing list support group. This means that most of our registered members are not receiving our stroke support services. If you would like to communicate with other stroke survivors or caregivers you just need to join a group.

I need to know if anybody would be interested with meeting in the chat room every day to discuss issues about your stroke or to just talk. You don't have to come every day but just at the frequency you can. Please email me at smallory@strokenetwork.org if you are interested in participating in a daily chat group.



Life in New Zealand with a Stroke

By David G. Ray

Since my last contribution, the Stroke Club to which I belong, has enjoyed a games afternoon and two weeks later, a recital by a group of bell ringers. The games consisted of Indoor Bowls from which a team was picked to represent our club at the district competition between Stroke Clubs, a competition we won last year. Those of us who could not or did not play bowls enjoyed a game of Scrabble. The Bell Ringers were truly magnificent. As Edgar Allan Poe wrote, we enjoyed the "tintinnabulation of the bells." The group, which had enjoyed success in competition with similar groups in Australia, played a variety of classical and easily listening music.

In the later part of March and early April, my wife and I travelled to Invercargill to attend a family wedding and tour the South Island. The first part of the journey was to travel across Cook Strait in the interisland ferry the "Arahura" You will recall the in last month's report I recalled a sinking of a earlier ferry at the entrance to Cook Strait. The day we travelled the sea was absolutely flat calm, the only movement of the ship being forward. Three hours later the vessel docked at Picton in the Marlborough Sounds. The voyage through the Sounds is beautiful with bush covered hills on either side. There are oyster farms in the sounds

besides many holiday and permanent houses dotted about the sides of the hills.

After driving off the ferry we left Picton and drove the 157 kilometres to Kaikoura. The first part of this journey is over a road surrounded with very dry fields. In fact all the upper part of the east of the South Island has been suffering from a severe drought which has had an adverse effect on the flocks of sheep in the area. Driving down the eastern side of the South Island, the fields were extremely dry down as far as south of Dunedin. Returning to our trip, the road continued along the Kaikoura coast. The coast was washed by rolling waves with the colour of the sea a beautiful shades of blue and green. This coast is very popular for surfers and fishermen alike. At Kaikoura we booked into a motel for the night.

Kaikoura is a very popular area for holiday makers. Besides fishing and surfing tourists can also go whale watching, swimming with dolphins and seeing a variety of sea birds. My wife and I went whale watching many years ago. We boarded a launch and sailed a few kilometres off shore. We soon came across a group of small killer whales but the most exciting scene was that of a huge sperm whale sunning itself on the surface of the water. After a short while it raised its massive tail and disappeared under the waves. It was not a sight that you easily forget. You can get more info on <http://www.whalewatch.co.nz>.

The next morning we left Kaikoura for Christchurch, the largest city in the South Island. The drive a distance of 183 kilometres, took us along the end of the Kaikoura coast across some rolling hills and onto the flat Canterbury Plains. Again the dry countryside was evident. The fields supported many flocks of sheep and herds of cattle but many grape vines showed that wine making was becoming very popular. After visiting relations on Christchurch we travelled on to Timaru (160 kilometres away) where I was born nearly 70 years ago. Timaru is a busy coastal port situated about halfway between Picton and Invercargill. I left Timaru to work in Wellington in the New Zealand Customs Service in 1955 and except for 3 years in Belgium have lived there ever since. I suppose everyone has a soft spot for the area they were born and grew up in and I certainly have about Timaru. However we spent the night there and carried on to Invercargill.

Timaru is also a great holiday spot, especially in the summer. The beach there, called Caroline Bay, has a summer carnival with plenty of concerts and other carnival activities. In my youth

my parents and I used to fish off the rock wharf known as the Marine Parade. That was 50 years ago and the harbour and beach area has changed considerably. We spent the night there and carried on to Dunedin and Invercargill the next day.

Next month I will cover the drive to Invercargill and the wedding of my niece.



Product Websites

Several websites have come to our attention, which offer various tools, that could be of help to the stroke survivor. Listed for each site are their product categories to give some insight into items offered. A list of interesting products is also included.

Because each stroke is different, gadgets, which are helpful to one survivor, are useless to another. Be sure to visit each of these sites for ideas. There is bound to be something which you have been seeking or which you would find useful.

Dynamic Living

www.dynamic-living.com

Special needs (like low vision)
Mobility
Unique products (like products that talk)
Around the home
For the kitchen
Bed and Bath
Accessible home
Just for fun (like games and magnifying tools)

Interesting products:

Toilet safety frame
Car caddy – portable handle to help get in and out of a car
Super pole system – simple pole that can facilitate standing up and sitting down
Various gadgets that talk including watches and prescription bottles
Counter top dishwasher
Combination washer and dryer
Implements to help open containers

Gold Violin

www.goldviolin.com

Lifestyles and interests

Reading and writing, travel, sport and fitness, crosswords, cards and games,

gardening
 Comfortable Home
 Bath and spa, bedroom, home office,
 family
 room, kitchen, outdoor living
 See, Hear and Move Better
 Lighthouse Vision Store, magnifiers and
 glasses, Arthritis Store, walking sticks,
 walkers and accessories, large print and
 talking products, ergonomic tools, memory
 enhancers, lightweight accessories,
 hearing devices, pill organizers
 Helpful gadgets
 Items that are not categorized above
 Gift Ideas

There is an option to order their catalog.

Interesting products:

Self-watering rolling planter
 Watering coil
 Ergonomic scissors
 Visually enhanced keyboard letters (4x larger than
 regular keyboard letters)
 Amplified big button phone
 Daypack for walkers or wheelchairs
 Large assortment of walking sticks
 Doorknob extension lever
 Talking thermometer

Senior Store

www.seniorstore.com

This site is focused on gift giving. It is meant to
 aid in purchasing products for seniors. However,
 there are several products worth looking at for
 yourself (whether you are a senior or not). You
 might even find suggestions to give to others who
 might be looking to buy you a present.

Gifts for grandma
 Gifts for grandpa
 Gifts for mom
 Gifts for dad
 Games for seniors
 Low vision products
 Household gifts
 40th and 50th anniversary

Interesting products:

Switch turner knob for lamps
 Milk carton holders
 Back up car sensors
 Large print crossword puzzles

Aids for Arthritis

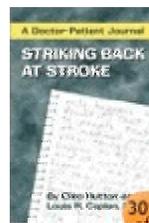
<http://www.aidsforarthritis.com/>

Kitchen
 Dressing and grooming
 Bathroom
 Resting and relaxation
 Household and car
 Comfort therapy
 Foot care
 Communication

Interesting Products:

Sock aid
 Elastic shoelaces
 Key turner
 Pen and pencil grips
 Call for help system
 Long handled sponge
 Safety handgrips

Happy Shopping!!!



Striking Back At Stroke

A Doctor-Patient Journal
 Book Review
 By Lin Wisman

"Striking Back at Stroke" by Cleo Hutton and Louis R Caplan, MD is an unusual book about stroke. Most publications cover either the stroke survivor's story or a medical explanation of stroke. The book combines the two. The first part of each chapter is from Hutton's diary. Through it we are able to learn the survivor's perspective. The second section is Dr Caplan's medical explanation.

Hutton experienced an ischemic stroke in 1992. The book starts with the experience of TIA's, beginning five years before the stroke. Even though Hutton was a nurse the TIA's did not register as a danger signal. The book also covers the event, rehabilitation, and reflections on what she has gained. In addition to standard early rehabilitation techniques, and therapies Hutton devised, her recovery included surgery to correct a hole in her heart.

Caplan's chapter on diagnosing stroke damage and designing a treatment plan is particularly enlightening. He explains the tools of CT and MRI scans as well as the role of history, learning the patient's experience of the stroke and discerning what abilities the patient has lost. He states that physical abnormalities can develop after the strokes first occurring. He also describes other

tools used to discern exactly what happened. These details can inform stroke survivors and their families.

Hutton shares the thought processes, which helped her cope. She documents what it is like to be a hospital patient. Stroke survivors will find themselves identifying. Medical personnel, families, and caregivers will benefit from her perspective.

The psychological effect of illness is covered. Of special interest is discussion of the role of other patients. It was very powerful to see others struggling to improve.

Hutton also explores the role of serious illness in forming a better person. She found herself learning to be a survivor. The key was looking to the future rather than the past. One key element was deciding to attend college. At first she saw it as a coping mechanism. It ended as a goal. She graduated and started a business.

The explanation of factors effecting stroke recovery is successful in showing how multifaceted stroke can be. Hutton's story is a success. She realized that when her official therapy ended she was not through with rehabilitation. Hutton found herself designing therapy.

Reflection on the stress stroke puts on families is included. Families do not receive training in how to relate to stroke survivors. Everyone must take the journey to look toward the future rather than the past.

Dr Caplan's medical observations are extremely helpful. He explains what is happening at each stage from a clinical perspective. Those who have experienced stroke will find answers to some questions.

The book concludes with advice from both authors. Hutton's focus is on what is needed for the survivor to recover to their fullest possible potential. Caplan's remarks focus on current stroke treatment and future trends.

This book is highly recommended for everyone in the stroke family. Hutton and Caplan both share insights which all will find helpful.

[Order the book at Amazon.com](http://www.amazon.com)



Website Review: National Institute of Neurological Disorders

A website of interest is the site of the National Institute of Neurological Disorders and Stroke located at <http://www.ninds.nih.gov>.

This website covers a number of Neurological disorders. On the home page is a list of news. On the right is a list of studies seeking participants. If you would like to consider being part of a trial check this list.

Under the disorders section find stroke under the S's. Of particular interest are sections explaining current research and a list of addresses, phone numbers and email addresses for related organizations.

Also available online are publications of the Institute. Be sure to check out "Post Stroke Rehabilitation" and "Stroke Rehabilitation Information Page."

There is a link provided to MedLine Plus, which contains a good deal of health information. This is a good site to visit for basic information.



Biography: Angelo Leo Carlini

Angelo Leo Carlini, who had a brainstem stroke in December 1999, shares his experiences so far in diary form. Stroke Survivors will relate to many of his struggles. We appreciate Angelo sharing this information with our readers and wish him luck in his continuing recovery.

MEMOIRS OF A STROKE

I suffered a brainstem stroke on the 23rd of December 1999. In this writing he shares the experience of the first 3 years post stroke.

It was a bleed directly to the brain as a result of a weak blood vessel in my head and heightened blood pressure. I could feel it coming on as most of my energy drained and I slumped to the floor; I could not recover. My wife thought I was dying and she called our younger son, Aaron who lived about a mile away. Prior to this experience I did my "morning constitution" regimen: had already taken my daily shower and had just finished shaving. It was just after 6am. Someone called 911 and the emergency team was there shortly. I

fought not to go to the hospital, grabbing the door jamb. But they managed to get me out to the ambulance.

I should have died (more than 60% do) but my wife Deanna would not agree to remove my life support systems. The hospital I was first taken to did not have the necessary skills and equipment. The wait at the first hospital was about 7 hours. I thought I was going to be operated on, but the only operation I had was a tracheoscopy to insure that I did not choke on my own fluids. Although probably induced by the hospital medications (but possibly a result of the stroke) I was completely "out of it". I can remember thinking that I was at the top of the world and I was above the canopy that covers the sky. I could "flip" the "icons" contained in the canopy, and the reality of the world changed. I was in a one-person room. The nurses were very professional and interested.

When I started physical therapy, Deanna was told that we would no longer be able to continue our insurance if we remained in Utah. So we flew to San Francisco, and then by ambulance to Vallejo. At this third location, I was still "out of it" and was placed in a four-person room. I participated in physical, speech, and occupational therapy. About an hour per day I was spent in physical therapy. Therapists were young people (mostly German) from all over the world. They were excellent and very committed. I had some difficulty in swallowing. Finally, I had to undergo some x-ray testing to watch me swallow.

On my first weekend pass I went to where Deanna was staying. Aaron also came. She told him that she had some shrimp in the freezer; and she spelled it out (s-h-r-i-m-p) as if I were a child who could not spell; but I knew exactly what she had in the freezer and thanks to a food processor, I got some ground-up shrimp. Another experience during that same period was a ramp built by our son-in-law, Ryan, which was a bit too steep. Deanna tried wheeling Ryan up the ramp successfully, but I am quite a bit heavier; so, in the rain, Deanna attempted to wheel me down the ramp to the car to go to church. She got me successfully to the bottom (rather quickly). At the bottom, the wheelchair tipped over, dumping me out onto the wet concrete. When I got out of the car at the church, I had lost so much weight that my pants fell down around my ankles. Thank god, no one saw me except Deanna and the missionaries who came out to wheel me to the entry.

The following was recorded at San Diego, 15 May 2002. Since leaving the "rehab" center at Vallejo, California and returning to Utah, I have experienced mouth sensations, which feel like my mouth is re-forming. I can taste with all parts of my mouth, not just my tongue. My left eye still looks across the line of sight of my right eye. Glasses (with a prism left lens), partially correct that.

What frightens me most is my perception of reality vs. non-reality. Things, which I expect to be, often "move" from non-being to actuality. This is the case with reading; those words, which I do not expect, "change" to become those, which I do expect. When I look at anything, I'm not sure if I'm seeing reality or what I expect to see.

Sometime in March 2000, I was released from Vallejo. We spent the next 6 weeks in Grass Valley, California at the home of our daughter, Julia and her husband, Ryan and their children, Michelle, Bradley, Jessica and Julianna. I had the services of a "home-visit" speech therapist, a "home-visit" physical therapist and a "home-visit" occupational therapist. I made some small amount of progress during this time. One day, I went boating and fishing with our son-in-law's brother. I was quite frightened that I might fall into the lake.

Deanna did not pay Julia for our stay, but she was generous in other ways. She bought Julie and Ryan a new hide-a-bed couch and two new dressers; also, she bought a good deal of the food and did much of the cooking. She was also generous with the children. I took us out to dinner for Julie's birthday. We have since given our daughter and son-in-law our electric alternator (after paying-off their electric bill). So, in my mind, we did not "sponge" off of them; I wish we could have done more.

Since coming home, more of my neurons have died (I guess) because of the mouth sensations (described earlier). I have made some definite improvement as I can now talk and with great caution walk. Although my short-term memory is quite poor, my mind seems to be returning.



Biography: Perryann Davis

I am almost 54, and have worked as a RN, since 1970. I always knew what I wanted to do, and found the love of my professional life, when I started hospice nursing in 1998. I loved it, and feel I was the kind of nurse I would want my

loved ones to have. I had a Left hemolytic, cerebellar stroke, and have right side paralyses, which now is major weakness. I drive and can look after myself if things are set up for me, like the chair in my shower. I didn't need any changes in my Camry. I use my left hand and foot; I have always been left side dominant. I don't cook very often, and sadly, I don't quilt, which was my favorite hobby. I was not depressed until about 2 years after the CVA, I was too busy trying to get back the use I had lost. But when I got depressed, I really did! It came about Christmas of 2002, when I realized no one was going to hire me to look after people again. I would apply for jobs and they would be impressed with my resume, but when I told them I had a stroke that was the end. Even if I didn't tell them, when I went for the interview, they would decide that I couldn't do the job, when I knew I could.

I have even offered to work for free, till I proved I could. Everyone seemed to be afraid of the liability. I had already figured out how to compensate (like we all do) to do the job description. And, yes, I could have sued them, but health care is so tough these days, I just couldn't make myself do it. I have that in the back of my mind as a last result, though. I was such a good bedside nurse, and I wanted to stay there, having done management. And we have a nursing shortage! I am still applying and will till I cannot work. But I decide that! End-of-life nursing will always be my love. I volunteered, but it just frustrated me.

Until Steve Mallory whom I address affectionately as, "O'Fearless Leader", asked me. It was a Godsend, and I said yes. I have used this site exclusively since I could use the computer. I reread Ginny's Ford's biography, today, and was thankful, for the loss of my long- term memory. I have always been a voracious reader, and now I can read favorites again, because I don't remember them. The same with movies. It drives Steve, my caretaker, crazy, because he doesn't like reruns. I love what I do for stroke network, I

am an "expert" and I write new people who visit the site and sign the guestbook. It allows me to help people again. I don't understand my inner timetable. I just read Steve's biography again, and this time, it really spoke to me. I realized that the way I got out of past periodic depressions has always been to focus on others. I am thinking about getting my Master's soon, but it will probably be in Social Work, not in Nursing.

My caregiver is my husband Steve, who is 20 years my junior. We have been married 8 years. He is an English Electrical Engineer, and is so patient and kind to me. I tried to give him an out, after the stroke, and he has stuck like duct tape. He is one of the smartest people I know, he writes software from home, but travels some. We are both dog lovers, and have 2 4-legged daughters, Mollie, a 7 year old Golden Retriever, who is spoiled and vain, and Lucy, a 4-year old Rescued Yellow Labrador, who is the best dog I have ever met. She is my soul mate, and is very protective of me. They are my constant companions. Lucy can sense when I feel "unsafe", and will get behind me, to break a fall.

I have a 30-year-old daughter, Meredith, (Merri) who is my finest work. She is beautiful, smart, and a close friend, who has been a support throughout this experience. She sees and mirrors for me, a me as no different than I always was. She has always been the joy of my life. She just got engaged.

I am glad to be among you, my sisters and brothers. We share the same struggles. And frustrations. It takes me sooo long to do things now, which I just did, before. I forget to allow more time! I grew up in Southern Pines, NC, and me moved to SC, in 1998. I am trying to get back to NC-family and friends. The people here, especially Steve Mallory educated me, and supported me.

Thank you all.

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

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