StrokeNet

http://www.strokenetwork.org/ **December 2003**

Welcome to the December issue of StrokeNet.

This month we introduce a new contributor to StrokeNet. Dez Crawford is the assistant director of a municipal animal shelter. She has agreed to write a series of articles of advise for Stroke Survivors about pets. Thanks to Dez for providing readers with her expertise.

Steve introduces new board and staff members. Joe Flasher writes about remedies for mild pain. Dez Crawford advises on how to obtain a pet. She also gives some helpful tips for pet owners. Penny Wohlford shares her experience using the Neuromove. BBC's Stroke Website is reviewed. Steve Sanchez and Violet Lawrence share their biographies.

Have a good read.

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Organization Highlights

By Steve Mallory

The month of November was not quite as exciting as last month but in many ways it was just as busy! Let me start off by telling you a few personal notes before I fill you in on the organization highlights.

I began physical therapy for my neck. Many of you might remember me telling you about an arthritic condition in my neck that has been plaguing me with severe pain. The sessions totaled only about 6 appointments, or 3 weeks worth, which was about all I could stand. Another of the health issues bothering me is a nauseous feeling in my stomach. I think I will finally concede to a stomach scope because it's affecting my eating capability. On some days I am lucky to finish one meal per day. And finally, the last big problem, chronic fatigue! Fatigue is reducing my on-line time from about eight hours per day to about three hours per day. I've been off-line, since Wednesday, which hasn't happened to me, probably ever, in almost 10 years. My wife says I'm a mess and that's exactly how I feel! This brings me to our organization highlights and hopefully the recent changes are enough of an improvement that will relieve me of a lot of the pressures that were keeping me so active in the day-to-day affairs.

The message board and chat room are becoming the on-line stroke support groups that I have always envisioned! I emailed most of you about the end of the mailing list but the previously mentioned groups are definitely picking up the slack. We have a new afternoon chat hostess, Pam Braidt, aka Host Pam. Pam is hosting casual chat sessions every afternoon for anybody who wants to drop by. Her chat sessions consist of social discussion and talk about practical matters for stroke survivors and stroke caregivers. So far the daytime chat sessions are becoming extremely popular with several members attending everyday. Some are attending so frequent that they can be referred to as "Regulars."

In case you aren't sure if anyone is in the chat room you can check the chat room status on the message board to see who is in the room. Anyway, Pam is a young, 30ish, stroke survivor and can almost overwhelm you with her spirit and enthusiastic attitude! She is a breath of fresh air and is a tremendous asset to the organization.

Another major change to the staff is the volunteering of Anne Kenyon. Anne is assuming the position of Stroke Support Director. She is replacing Julianne (Jay) Marken-Bentzen, who is leaving for personal reasons. I want to thank Jay for the years of donating her personal time. Jay is leaving the staff but will remain as a member on the Board of Directors. Thanks, Jay! Getting back to Anne, Anne is a stroke caregiver to her mother, *mum*, and has been a member of our mailing list for years. She is from the island of beautiful New Zealand and is best known for her warm and compassionate spirit. Besides compassion she

brings a wealth of wisdom. If anybody has read any of her mailing list posts or poetry you can easily agree that she is someone who has organized and constructive thoughts. She understands the ups and downs of stroke survivors and *must* be a superwoman, since she is a caregiver and has been successfully juggling everything else in a "married with children" personal life. I definitely look forward to working with her!

We also have a new board member, Kate Anderson. Kate is a long, long time old friend and fellow brainstem stroke survivor. She survived a brainstem stroke, similar to mine, but she was fortunate enough to have made amazing strides with her recovery. She is walking and talking, which is a miracle, since she originally lost her speech and had quadriplegia. She was a spokesperson for the American Stroke Association and has recently written and published a book about her experience with stroke. Katie is one amazing person and will be helping to promote our organization and get involved with fundraisers for our organization. Check out her web site at http://www.katesjourney.com/.

Lastly, we have a new message board forum moderator, Steven Sanchez. Steven is a young, 34, stroke survivor and another welcome sight. Steven will be specifically helping out in the Stroke Survivor section of the message board. His posts are very thoughtful and he will be offering practical advice to guidance whomever posts in the stroke survivor forums. Steven's bio is posted this month at http://www.strokenetwork.org/newsletter/bios/ssanchez.htm.

So, you can see that although my health seems to be hindering my activities with the organization I am confident that Pam, Steven, Anne and Kate will be making sufficient contributions to our volunteers that our organization will continue to grow. Welcome aboard, guys!

Steve Mallory
President & CEO
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Mild To Moderate Pain With Some Aspects In Stroke in Stroke

By Joe Flasher

Pain is a universal experience. The degree to which you feel pain and react to it, are the results of your own biological, physiological and cultural makeup. Past encounters with painful injuries or illness can also impact on how we respond to pain.

When pain persists beyond the time expected for the injury to heal or an illness to end it can become a chronic condition is no longer viewed as a symptom of a disease but an illness itself.

Your peripheral nerves encompass a system of nerve fibers that run through your body. Attached to some of these fibers are special nerve endings that can cause unpleasant stimulus such as cuts, burns or painful pressure. These nerve endings are called nociceptors. You have millions of nociceptors in yours skin, bone and muscles and in the protective membrane around your internal organs.

When the nociceptors detect at harmful stimulus they relay their pain messages in the form of electrical impulses along a peripheral nerve to your spinal cord and brain. The speed of these various messages travel may vary. Sharp pain travels quickly and dull sensations, such as stomach upset or earache, travels on fibers that move much more slowly. When the pain impulses enter the spinal cord they meet up with receptors that act as gatekeepers which filter the pain message on the way to the brain. For severe pain associated with bodily harm the gate may be wide open and an express route used. Other nerve endings may be triggered; such as telling you to pull your hand away from a hot plate so you don not get burned.

When the pain message reaches your brain it responds by sending messages that promote the healing process and two components determine how you respond. The physical sensation, such as a severe pain to a dull aching pain, determines how you will emotionally react. Very severe pain makes it impossible to stand or walk. There is a considerable amount of material available on our emotional response to pain which we can consider in another article if you desire.

I would like at this point to consider the differences between acute and chronic pain. Acute pain is usually triggered by tissue damage. It's the type of pain you usually feel following illness or

surgery. Acute pain can be mild, as from a bee sting, or severe and last a considerable time, as from a burn, muscle pain or broken bone. When you have acute pain you know exactly where it hurts and that it will fade away with time.

Chronic pain hangs on after the injury is healed. Pain is generally described as chronic if it lasts 6 months or more. As with acute pain, chronic pain can span the full range if intensity. It can be dull or sharp, irritating or jolting or it can come and go like migraines that develop without warning. Unlike acute pain, with chronic pain you may not know the reason it's there. The original injury may have healed. Yet the pain remains and may be even more intense.

Chronic pain can even occur without any indication of injury. Years ago people with chronic pain were thought to be imagining the misery or trying to get attention. Doctors now know that is not true. Frequently the causes of chronic pain are not well understood. Sometimes it may be due to a chronic condition such as fibromalygia, which can cause aching in your muscles, or arthritis, which can cause inflammation of your joints.

Occasionally chronic pain can be due to an accident, surgery or infection that damages a secondary, peripheral or spinal nerve. This type of pain that lingers after the original problem has healed is called neuropathic pain. Neuropathic pain can also come from a condition such as diabetes or alcoholism. Once nerves have been damaged they can send can send pain messages that are incorrect, such as burning or itching sensations of pain from diabetes. Little is know about why injured nerves misfire and send painful messages.

Since my topic is mild to moderate pain I am going to limit this discussion to those medications that can be bought over the counter (OTC) and do not need a doctor's prescription. I will cover those medications used for more serious pain at a later time.

Years ago if you had a headache or your arthritis was acting up, you went to the drugstore for a bottle of aspirin. Today, relief from pain means choosing from more than 150 different medications. One product may offer "8 hour relief" or "no stomach upset". or "fast pain relief. Although the package claims may differ they all contain one of these chemicals, Acetaminophen, aspirin, ibuprofen, ketoprofen or naproxen sodium. For pain relief there is not much difference between these products. However, using OTC pain relievers safely is not as simple as you may think.

All of these products are called analgesics (from the Greek meaning no pain). They all relieve pain from headache, toothache, backache, arthritis, colds and muscle cramps. They also reduce fever.

The nonsteroidal anti-inflammatory drugs (NSAIDs) such as Aspirin, Ibuprofen, Motrin, Advil, Aleve and many others reduce inflammation as well as relieve pain. If you have arthritis this ability to reduce inflammation as well as relieve pain is important. NSAID side effects are usually not as serious as the side effects caused by other anti-inflammatory agents. However they can cause dizziness, stomach upset, bleeding, drowsiness or high blood pressure and fluid retention.

Acetaminophen doesn't relieve inflammation. But because it's relatively free of side effects it's a good alternative if you can't take NSAID's for some reason. In general you should not take NSAID's if you are taking blood thinners, have kidney disease, ulcers or a bleeding condition.

Many of us stroke survivors are taking an aspirin a day along with coumadin as a blood thinner which is accepted procedure. However, you don't normally want to add Motrin into the mix. Acetaminophen (Tylenol) has less potential side affects problems.

I am going to attempt to give you a guide for sorting through the amazing array of products. Does adding an ingredient, changing the dose or changing the shape of a product increase its effectiveness? It generally just means paying more.

The following are terms used in some of these products. Buffering, this is adding an antacid to protect your stomach. Whether or not this protection actually works is controversial.

Enteric-coated means adding a coating to the tablet so that it passes through the stomach and dissolves in the small intestine. This may be helpful if you are taking the drug on a daily basis. Because absorption of the drug is delayed it may not work as fast in an emergency situation.

Timed-release, extended release or delayed-release products dissolve slowly and give a more steady and constant relief .Choose timed-release when you don't need more immediate relief.

Extra strength simply provides more ingredients and is more convenient because you will be taking fewer tablets to provide relief.

Combination products such as caffeine with aspirin or acetaminophen actually improve the pain relieving effect. This is not the case with ibuprofen.

Whether you use a tablet, caplet, gelcap, gum or liquid is purely a personal choice; just be aware of the price differences.

Generic pain relievers almost always cost less and are just as effective as the brand names.

If you have questions or need clarification please contact me through the Strokenet Newsletter and I will be happy to help in any way I can. We strokers have to stick together.

Pet-Care Options for Stroke Survivors By Dez Crawford

My husband had two ischemic strokes last year at age 48. Both being able to have "visiting pets" at the rehab hospital and having pets at home has been a tremendous help in his recovery.

I am the assistant director at a fairly large municipal animal shelter, serving close to half a million citizens.
We impound approximately 13,000 animals per year. A big part of my job is managing the adoption program at our shelter, and helping people choose the right pet for their lifestyle and for their family.

I am offering my services to stroke survivors and their families to provide advice on selecting a pet for stroke patients, as well as on the situational changes that evolve for both stroke patients and their caregivers with
regard to the existing pets in your life. Although I have an excellent background with dogs and cats, I also specialize in less common pets like reptiles, birds, fish, rodents and horses. I can provide professional
advice on the care of almost any pet you can imagine. Even tarantulas!

Naturally, I always encourage people to obtain a new pet from a shelter or from a rescue group. Not only are you saving the life of a homeless animal, but you will also likely be free from worrying about the many health and
behavioral problems often associated with the carelessly mated pedigree animals offered for sale in the newspaper classified ads. Just because a puppy or kitten "has papers" does not mean that it comes from a good bloodline or that it will become a good pet. Very few professional breeders run ads in the classifieds. Quality breeders have waiting lists.

If you do have your heart set on a particular breed, seek out a rescue group for that breed. Rescue groups often have a large selection of the pet you most desire, and because the animals have been in foster care with the group's members, they have intimate knowledge of the pet's personality and behavioral traits. This will help you choose the best pet for your needs.

Our shelter works with over 80 reliable breed rescue groups, and I can connect you with many others through the Internet, no matter where you live.

The great bonus of adopting an adult animal is that you know what its adult personality is like, and won't have to go through many of the hassles of raising a puppy or kitten. And if you really want a puppy or kitten,
shelters and rescue groups have them aplenty.

Some issues I would like to cover in future articles include:

1. Visiting Pet programs at rehab hospitals -- what you need to know.

2. Adapting your existing pet's care to the stroke survivor's needs.

3. Bringing a new pet into the household of a stroke patient and much more.

Today's helpful tips:

-- If you have a cat or a dog that gets underfoot and can be easily tripped on, and your stroke patient is alert and has good hearing, attach a couple of little Christmas jingle bells to its collar, along with its ID tag, so the patient can hear if the pet is underfoot.

-- Helping to care for one's beloved pet is important to a stroke patient's sense of independence and self-esteem. If you have a cat, consider putting the food, water and/or litterbox on a countertop where the patient can reach it. Or, for the litterbox, visit your favorite pet shop and purchase a long-handled, stainless steel litter-box scoop with a large scoop basket. This helps a patient who may have problems bending over to scoop a litter
box which is placed on the floor.

-- Use multiple-cat formula litter even if there is only one cat in the household. This reduces odor if the patient sometimes forgets to scoop the litter box.

-- Purchase a large, comfortable kennel cage for your family pet, and kennel the pet at night to avoid a trip hazard when the patient gets up alone to use the bathroom or get a drink of water. Include a litter box if the pet
is a cat. Do this only if there are other responsible people in the household -- it wouldn't be right for the pet to be left in the kennel for long periods if the patient forgets to let the animal out in the morning.

Please feel free to write me at: dezcrawford@hotmail.com with your stroke-related pet-care questions.

I am looking forward to having a regular article in the newsletter.

Neuromove Review

The Neuromove is designed to improve affected limbs. Their website says "The NeuroMove(tm) technique assists in teaching healthy parts of the brain after a stroke to take over lost functionality." It helps to gain lost movements in fingers, hand wrists, elbows and shoulders. It can also reduce drop foot symptom and muscle spasms. The manufacturer, Stroke Recovery Systems, Inc, claims that 90% of patients (6 months and up to 14 years post-stroke) achieved significant improvement with 4 weeks of use.

Penny Wohlford, a StrokeNet reader, has completed six months using the Neuromove. She shares with us her experience:

The Neuromove is a small-computerized device that has a screen that displays muscle activity. It indicates when the person makes the attempt to move. When they reach the threshold they get an electrical stimuli to aid the movement. It works similar to the Pavlov's dog theory. (Feeling and seeing the hand moving. Bio-feedback)

My doctor recommended using it as long as needed to get the response I want. I want to be able to open my hand to pick things up, and put them back down.

I use it only twice a day for about 20 minutes each time. The manufacturer recommends using it as many times as you can, at least four times a day. I don't like to sit that much during the day so I don't and maybe that is why it is taking longer for it to work for me.

I have seen some improvement but not as much as I would like yet. My spasticity has decreased some, but I think because of that it will take longer for the device to help me gain my objectives. I think it may work better for the person who does not have spasticity. The Neuromove is supposed to help both arm and legs gain movement and strength.

My insurance picked up 2/3rds of the cost. You do need a doctor's prescription. For more information see the manufacturer's website http://www.neuromove.com.

All and all I think that it is a good product, however very expensive. The bottom line here is that our recovery is very individual. It's what you are willing to put into it and how much you are willing to accept. I don't want to accept that I may not ever use my left hand again.

Website Review: BBC Stroke Pages

The British Broadcasting Corporation's stroke web pages located at http://www.bbc.co.uk/health/stroke/ are refreshing. The topics are addressed simply. This is a place to go for general information. Items are easy to understand. The site is dived into four sections: About Stroke, Treatment and Rehab, Prevention Approached and Links and Organizations.
The About Stroke section explains what a stroke is and the different types. It is general but the information is a great place to send people who are at the beginning process of learning about stroke.

If someone in your family has had a stroke the first place to go is the Treatment and Rehab section. Basic approaches are explained. This section provides information, which will increase the effectiveness of your questions.

Stroke Survivors will find the section on Prevention interesting. It states that one should look at diet, activity level and lifestyle. If you are looking for ways to prevent another stroke check here to be sure you are following their guidelines. The do and don't checklists are an easy approach.

The Links Sections provides links to other websites, and articles, which the stroke family will find interesting.

A message board and a newsletter are available. These both cover health in general. They are not specifically designed for the stroke family.

This site is a good place to go for information that is easily understood.

Biography: Steven Sanchez

My name is Steven Sanchez. I suffered my stroke at the age of 34. I was a seasonal UPS driver trying to become a full time employee. I worked my bottom off trying to prove to the big shots I could do the job. I would take on loads that were not in my route to prove I was the one for the job. It started to happen during the second to last pickup of the day. I loaded my truck and felt strange. My left arm went numb. As I dug in my pocket for my keys I realized that I was not able to feel them, that scared me I thought I was having a heart attack. I had heard that when your left side goes numb it might be a heart attack. I was able to find the keys with my other hand. I drove off to my last stop. When I arrived there I noticed the back of my truck was open, which you should never do. That scared me even more.
As I was loading the truck I felt strange again. I told the guy that was helping me. He told me to sit down and he would load the truck. He then asked if I wanted some water. I told him yes and he gave me a bottle of water. I tried to grab it with my left hand but I was not able to hold it, it kept falling. Again I told him I did not feel well and I asked if I could use the phone to call my supervisor. He told me where the phone was.
I called my supervisor and told him I was not feeling well. He told me to finish loading the truck and come in. I said ok. My legs felt weak walking back to my truck. I tried to keep up my strength to finish but couldn't. I went back to call my supervisor. I told him I really was not feeling well and was not going to drive back and kill myself or someone else.
He sent out a couple of other drivers. They literally had to carry me out of my truck and asked if I had eaten lunch. I told them yes. They took me back to the hub where another supervisor took me to the medical center. They did not know if it was an aneurysm or a stroke.
They immediately called for an ambulance, which rushed me to the hospital. There they stared to test realizing it was a stroke. I was admitted. My whole left side was affected. I was not able to feel or move anything. I was in the hospital for about two weeks. I was then transferred to a rehab center.
I was down and out didn't know what was to become of my life. Three months earlier we had a baby girl. We also have two boys. I was thinking all sorts of stuff. I did not know if I was going to die or live. I was crying all the time knowing I was not the same Dad I used to be. I was in a wheel chair for about one month. I told myself I had to be strong for my wife and children. I recovered somewhat.
Today I have no feeling in my left hand, little in my face and I am in total pain from the time I wake up to the time I go to sleep. I have had a couple of seizures, some TIA's and I am now seeing a psychiatrist. I am fighting for SSI. I have had a few jobs but it will never be the same. I still have memory problems. I often look for the right word to say. I still get confused and overwhelmed. I have been on State disability for a year now and have exhausted all my funds not knowing where the next dollar will come from but GOD IS good. He always takes care of us. My wife works and that pays the mortgage. I look to God for everything. I have given my whole life to him knowing I cannot do it myself.

Biography: Violet Lawrence

In September 1993 I was making a cup of tea and coffee for our friends and my husband. Next minute I felt dizzy, an irritable aching headache. I tried to soothe the pain from the armchair. I started foaming at the mouth. I was slouching to the left sideways blowing bubbles and dribbling. My husband was frantically rushing around and phoned 111. I was in a state of disbelief. My friend Peter, who passed away last year in July and was then suffering with malignant cancer, managed to calm me down. I was administered oxygen by the paramedics; the ambulance team was thorough, asking a variety of questions. As helpless as I was, my husband James (JR as I have known him) relayed the information. We were transported to the North Shore Hospital, Auckland. Doctors and nursing staff were professional. I stayed until my condition was under control, and discharged. Around 5.30 the next morning I felt unwell so my husband transported me to A&E. The Doctor in charge thoroughly checked out my condition. A series of tests were about to begin. This is where the fun begins.
History: Mrs. Lawrence was admitted to North Shore Hospital on 7 September. The previous day she was seen at North Shore Hospital Emergency

Department with sudden onset of right sided headache, incoherence, right sided lowered facial weakness and weakness of the right arm and leg. Previous history included migraine since age of 5, consisting of flashing lights followed by severe headache, unilateral, nausea and vomiting. The last attack had been six weeks before entry.
One of the medical staff mentioned a lumbar puncture, this happened after transporting me to Auckland Neurology Department. They thought I had meningitis, I had proved them wrong! More blood tests on a daily basis from the problem was unknown, the medical team were baffled trying to find out what is wrong with me. A CT scan performed on the evening of admission to North Shore Hospital revealed a small band of reduced density the right temporal insular region. There was also some widening of three right lateral ventricle, considered to be an old insult and of no current significance. For example, the latter finding could have resulted from an intraventricular hemorrhage at birth, or result of a small intraventricular cyst. The significance the area of reduced density is uncertain, but could represent an old infarct.
Examination
General examination was unremarkable.
Neurological examination revealed weakness in the right upper limb, distal greater than proximal, as well as weakness on right hip flexion. The reflexes are slightly increased in the right upper limb. The remaining neurological examination was normal.

The abnormal signs resolved over the next 24-48 hours while the headache was controlled with a combination of the medications listed above on discharge.
Echocardiogram was performed to rule out an embolic source. It showed trivial mitral regurgitation, and on cardiology review, this was considered to be of no significance.
Mitochrondrial encephalopathy was also in the differential, as a metabolic cause for her disturbance of cerebral function, and to explore this possibility, a serum lactate was performed. The result came back in the normal range, being 1.3 millmols/litre (normal .3-1.3millimols/lllitre for venous sample).
Duplex study on the extra carotid arteries was normal.
It is intended that I am to be reviewed at Dr. Wallis' Our Patient Clinic in 3 months time. Should further problems arise in the meantime, we would be happy to review the situation.
Michael Armstrong Neurology Registrar.
These excerpts are from my medical records This was passed this onto me for future reference.
I hope you will enjoy the saga of my life's history about my condition. This was in September 1993 - ten years as we speak.

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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