

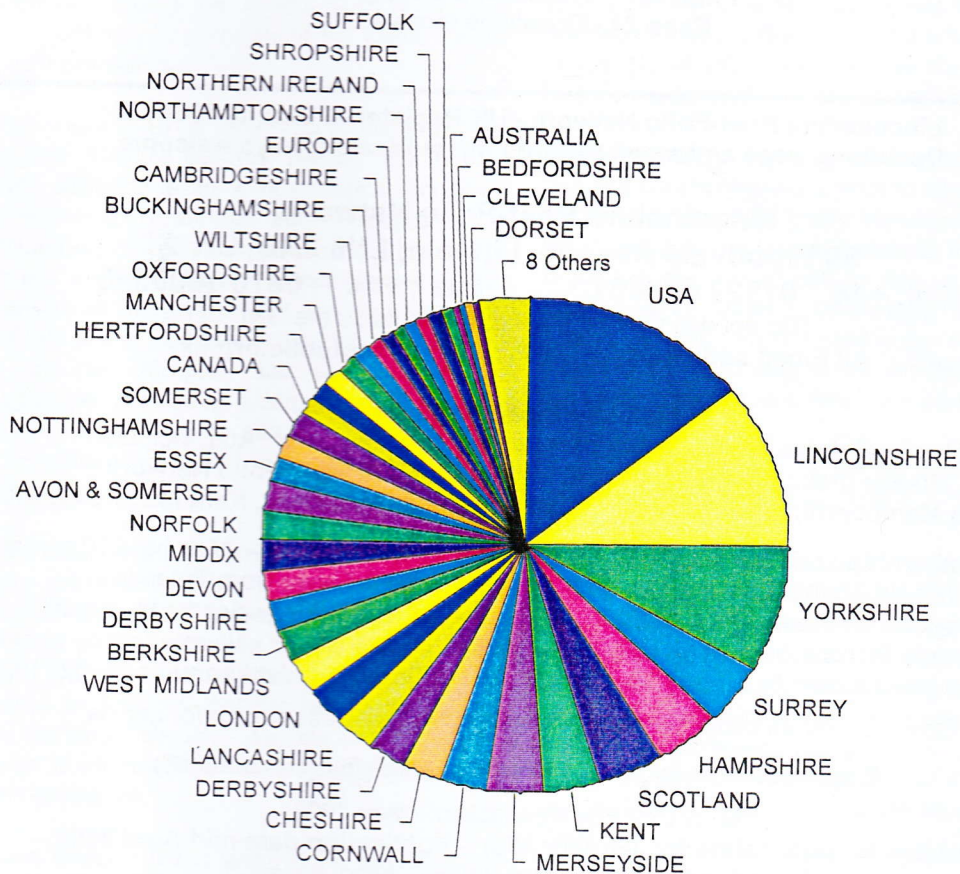


The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 4 - Issue 2 - March 2003

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Lincolnshire Post Polio Network Membership 2003



8 others are Gloucestershire, Herefordshire, Hong Kong, Humberside, Isle of Man, Northumberland, Tyne & Wear and Wales

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Next LincPIN Newsletter - May 2003

Articles for publication by January 25th - Publication date mid April 2003.

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Editorial by Hilary Hallam

Front page - a pie chart of our membership. If you would like to be in touch with people in your county/ adjacent county then let us know.

We are now back in the UK - on average twenty five degrees cooler. Four days after arriving back we were both hit by a virus that is only now two weeks later at last leaving us. Viral fatigue on top of jet lag and fatigue from overuse of energy tokens the month before has taken its toll. Some of our daffodils have opened today so we hope this is a good sign and we will soon have some 'spring' back in our step.

I managed to attend the Lincolnshire Neurological Alliance meeting and am pleased to tell you that Dr. John Bowen, Consultant Neurologist is now in post at the new Neurology Department, Lincoln County Hospital. He will be the guest speaker at our next meeting at 7.00 on April 17th at the County Hospital. Any local members who would like to attend then please contact Hilary on 01522 500134. I look forward to telling you more about his views for the future, next newsletter.

I am sure you will all be interested to know that the Neurological Alliance has now revised their figures of people suffering from a neurological condition from 3 million to 10 million. The UK population is about 59 million so you can see we are talking a huge number and we hope that this increased statistic will at last ensure an improvement in services. However, we have told you in past newsletters that we are at the bottom of the European list for numbers of neurologists per population. Denmark has 100 to our 6. Therefore it is going to take a number of years whilst new neurologists and their ancillary staff are trained.

I will be attending a Neurological Conference in Newberry on March 28th put on by the West Berkshire Neurological Alliance - the Regional Neurological Alliance meeting in Ely on 10th April. 12th April sees me in Exeter where I am speaking at a Conference on ME/PPS that has been organised by member Barbara Tavener. Anyone living in these areas who is interested in meeting up please either email me or ring me.

I have also been invited to speak at the San Francisco Bay Area PPS Support Groups conference on September 19th 2003. More details in next newsletter.

<hilary.hallam@lincolnshirepostpolio.org.uk>

The Phone Team.

Di Brennan - 0151 924 4680 or d.
brennand@btopenworld.com

Since Hilary has been in America three of us having been manning or should I say womanising the Lincolnshire Post Polio phone line!

We three musketeers are Margaret, Pat and Di. We do one week on call and two weeks off and it has been going very well. I started on my first week with some trepidation wondering what was going to happen. Would I have hundreds of phone calls a day from across the world so that I could never venture out of my front door. Would I be expected to know as much as Hilary? Quite impossible! My fears were assuaged fairly quickly as on my first week on duty I had about three calls, asking for help in a variety of ways. One caller thought she had PPS and was due to see a Rehab specialist and wanted to chat and be reassured. My next caller had seen a programme about PPS on BBC East Anglia and wanted more information for her father who was a polio survivor. Nothing I couldn't cope with so a large sigh of relief! Margaret has had similar calls, but Pat was woken at 1.30 am from a caller from America, who hadn't realised the time difference. From what she reported of her phone call I have to say that she sounded remarkably coherent for that time of the morning!

People may leave a message if they would rather so I ring in a couple of times a week to take any messages which have been left. Every Monday morning I alter the message to say who is receiving calls that week. If anyone else would like to join us please let me know. With today's technology it is all quite straightforward. All you need is a sympathetic ear, a pad and pencil to take down details so that Robin Butler can send out an information pack.

Professor René H. Miller 1916 - 2003

René contracted polio in the South of France at the age of nine (1925) and was fortunate that his step-father was able to arrange for a supply of a new vaccine to be flown down to him from the Pasteur Institute in Paris. As a result, the polio was arrested and he was left with a slight limp which did little to hamper his activities throughout his life. In recent years however an increasing lack of mobility in that leg made him think that it could be a case of Post Polio.

He had only been a member for a short time but he was so impressed with your charity's work and enjoyed reading the LincPIN. He was glad that the condition of post polio was becoming recognised by the medical profession.

Maureen Miller, Cornwall.

Polio Survivors Return to Battle

By Julie K Silver MD,
Spaulding Rehabilitation Institute's
International Rehabilitation Center for Polio,
Massachusetts, USA.

"Polio is spectacular, the way it strikes, the way it kills, the way it leaves its trademark." This is the opening line of Robert Hall's memoir, *Through the Storm—A Polio Story*. Polio is, or rather was, a spectacular and wildly uncontrolled disease that occurred in epidemics worldwide in the first half of the 20th century. The World Health Organization expects to eradicate polio worldwide by the end of 2000, and the last reported case of polio in the United States (from the wild virus and not vaccine related) was in 1979. However, there was a time not so long ago that polio was one of the most feared diseases.

Ironically it was through a series of technological advances, including improving sanitation and cleaning up water supplies, that the poliovirus was allowed to flourish. Counterintuitively, the poliovirus primarily attacked middle and upper class families who had improved living conditions but had no immunity (in the past they would have acquired immunity through tainted water supplies). Thus, the number of polio cases reported reached epidemic proportions year after year until the mid-1950's when a vaccine was discovered. Polio will long be remembered as one of the most important and devastating health crises of the 20th century.

Ali Buckley is a 46-year-old nurse who contracted polio when she was 2 years old. Following an initial 2-week hospitalization in which Ali had severe right leg paralysis, she used a wheelchair for more than a year. There were few supports in place for children with disabilities, so Ali reports, "I lost an entire grade and was tutored at home." Ali also recalls that there was such hysteria at the time that she contracted polio that her father's dental practice had to be closed for several months because no one would go to him for fear that he might spread the poliovirus to them. Ali contracted polio in the summer of 1955 and for several summers thereafter, she would endure orthopedic surgeries on her legs to help her regain her ability to walk. For more than 30 years following these surgeries, Ali walked without any mobility devices or braces, but Ali recalls, "I hated summer because it always

meant surgeries."

The polio epidemics were an important social and political issue as well as a public health issue. In part because of Franklin Delano Roosevelt, the 32nd president of the United States who was in office from 1933-1945 and who himself was a polio survivor. FDR was instrumental in promoting the National Foundation for Infantile Paralysis (NFIP) that supported nearly all of the research and treatment of polio. The NFIP later became known as the March of Dimes when all across the country people were asked to leave their porch lights on so that mothers could go door to door and collect money to fight this dreaded disease.

Then in the mid 1950's, both the Salk and the Sabin vaccines were found to be effective and the incidence of polio dramatically declined. The March of Dimes went on to fight birth defects and polio survivors went on with their lives...

Post-Polio Syndrome

Polio was nearly erased from the public's memory by the late 1970's when polio survivors first began to complain in large numbers that something was happening to them that was causing further disability. The most alarming symptom was *new weakness*. Polio survivors, who as a group were remarkably successful both personally and professionally, began en masse voicing complaints about new symptoms that resembled what had occurred during their initial illness (but were generally not as severe).

In 1979, an international journal called the *Rehabilitation Gazette* published a letter from a polio survivor in which he described symptoms of new weakness, pain and fatigue. The magazine was deluged with responses from polio survivors who reported similar symptoms. This coming together of polio survivors who were experiencing symptoms of Post-Polio Syndrome (PPS) began to widely occur. Post-Polio support groups formed in record numbers with more than 100 groups established in the United States alone. These groups became the first real way that information about PPS was described and disseminated.

Doctors and other healthcare providers had learned about polio as a historical footnote. There was a lot of catching up to do now that the majority of polio survivors (more than 60% of the more than 1 million polio survivors in the United

States and 20 million worldwide) would likely develop symptoms of PPS.¹

Symptoms

The primary feature of PPS is **new weakness**. This new weakness may affect muscles that were known to have been involved during the initial polio or muscles that were previously thought to be uninvolved. It is important to keep in mind that during the initial polio infection, regardless of the extent of paralysis, more than 95% of the anterior horn cells in the spinal cord were affected. Thus, often muscles that were thought to be "normal" actually were affected and may now be susceptible to new weakness. Even people who were originally thought to have had the "non-paralytic" type of polio may develop new weakness and other symptoms of PPS.² Sometimes this new weakness is associated with new **muscular atrophy** and one or more of the limbs will appear smaller due to loss of muscular bulk.

David Rubin is a prominent businessman and real estate investor in Boston. He was diagnosed with polio when he was 9 years old and was treated at home. David recalls, "I remember after the onset of the paralysis having my spine tapped on the kitchen table by doctors." When asked about how PPS has affected him, he replies, "The weakening of my legs has been really daunting. I'm used to being very active and independent. It is a continuing difficult adjustment for me to accept the limitations that PPS has imposed."

Another prominent symptom (occurring in more than 90%) is **fatigue**. This fatigue may be muscular fatigue related to overuse or deconditioning of the muscles, or it may be "central" fatigue meaning that areas of the brain that control alertness, memory and concentration are affected.³

Fatigue was the primary reason why 10 years ago, Ali gave up her job as an emergency room nurse. "I couldn't think at 10 o'clock at night." She switched to a part-time nursing position in occupational medicine where she primarily did case management. However, her symptoms of fatigue plagued her and she began to have difficulty with new weakness and pain as well. After 8 years of trying to struggle along, and the realization that "after multiple job accommodations, I couldn't perform my job", Ali made the heart wrenching decision to apply for disability.

Although many polio survivors complain of **pain**, the pain associated with PPS is typically muscle pain (myalgias) that is often related to activity. There are many other reasons that pain may be present including musculoskeletal conditions (e. g., rotator cuff injury, lateral epicondylitis arthritis, etc.) and nerve injuries (e.g., carpal tunnel syndrome, ulnar neuropathy, lumbar radiculopathy, etc.). These problems may be attributable or at least exacerbated by a history of paralysis and muscular imbalances and overuse, but do not fit the criteria for Post-Polio muscle pain.

New respiratory or swallowing problems may occur due to the muscles that control these functions becoming weaker. **Cold intolerance**, particularly complaints of the limbs being cold is a common symptom.

Diagnostic criteria

Post-Polio Syndrome, like all diseases that are classified as syndromes, has no specific diagnostic test. Therefore, it is a *diagnosis of exclusion*. This means that all other medical conditions that may present with symptoms similar to those found in PPS should be considered and excluded if possible. Furthermore, in order to establish the diagnosis of PPS, the individual must fit the following criteria:

- 1 A history of polio (either paralytic or non-paralytic)
- 2 A period of recovery from the initial illness
- 3 A long stable period (generally more than 10-20 years)
- 4 New symptoms that are consistent with PPS and not attributable to any other medical condition

Treatment

Treatment for PPS must be individualized and takes into account the patient's primary symptoms. Treatment may include medications, supervised therapy, injections and in some cases even surgery. It is impossible to present an exhaustive treatment regimen because all treatment is guided by the specific symptoms that predominate.

Rehabilitation protocols need to take into account that individuals with PPS often present with new weakness. This new weakness inevitably leads to an increase in energy expenditure to perform their usual activities. This promotes both fatigue and pain. Thus, PT/

OT should focus on simultaneously preventing overuse and disuse of the muscles. Although this might seem incongruous, in fact, this dichotomy of overuse/disuse is frequently seen.

Consider the polio survivor who uses a manual wheelchair for mobility. This requires an enormous output of energy in order to propel the wheelchair. The arms are exclusively doing the work. But, the workload is not equally shared. Some muscles will be overused and some will be underused. Moreover, the amount of work or "exercise" that the arms must do on any given day may vary greatly depending on the individual's mobility requirements.

Dorothy Aiello, a physical therapist who specializes in treating polio survivors at Spaulding Rehabilitation Hospital often recommends switching from a manual wheelchair to a motorized one. In conjunction with this switch, Aiello recommends a formal exercise program that can be done at home which works all of the muscle groups in a more even fashion.

Without proper instruction and sound advice from skilled rehabilitation professionals, some polio survivors become so fearful of overusing their muscles that they literally barely move about. This promotes disuse of the muscles as well as loss of range of motion of the joints and many other medical problems. The important concept here is to balance activity and rest.

Supervised therapy should address the issues of overuse and disuse of the muscles in order to prevent further loss of strength. Maria Cole, an OT at Spaulding who works on the same team as Aiello, says, "One of the biggest problems is [teaching polio survivors] how to balance energy conservation and work simplification in their daily tasks." Maria reports that a careful analysis of an individual's home and work environment will often lead to identifiable problems that can often be easily fixed. For instance, "ergonomics in the work environment" pose many problems, says Cole. "How they are seated, where their computer is situated and how their desk is set up can be arranged to improve posture and efficiency."

Both Aiello and Cole agree that improving the *efficiency* and *safety* of a polio survivor's mobility is of utmost importance. This may mean recommending lightweight and durable braces, a motorized wheelchair, a handicapped parking placard, a tub or shower seat, etc.

A skilled speech and language pathologist can often help someone manage their swallowing problems by simply teaching them a variety of swallowing techniques. Respiratory problems may improve with BiPAP (bilevel positive airway pressure). Avoiding cool climates and wearing warm layered clothing generally treats cold intolerance.

It is important to recognize that the same treatment plan won't work for everyone. Therefore, it is the job of the rehabilitation professional to meet the challenges of each polio survivor who comes to him or her seeking treatment.

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1. Gawne AC, Halstead LS. Post-polio syndrome: pathophysiology and clinical management. *Critical Rev in Phys and Rehabil Med* 1995;7(2):147-188.
1. Halstead LS, Silver JK. *Arch Phys Med Rehabil* 1999;
3. Bruno RL, Cohen JM, Galski T, Frick NM. The neuroanatomy of post-polio fatigue. *Arch Phys Med Rehabil* 1994;75:498-504.

Error in information in last newsletter page 13 The information on Vaccines for the USA is as follows:-

Reprinted from **Rehab Management**—
January 2000

"The ACIP recommendations for an all-IPV series went into effect on January 1, 2000. They replace those issued in 1997, which, according to ACIP, were intended to represent a three-to five-year transition policy to an all-IPV schedule. The 1997 recommendations consisted of two doses of IPV at two and four months of age, followed by two doses of oral poliovirus vaccine (OPV) at 12 to 18 months of age and at four to six years of age. According to ACIP, an all-IPV schedule is needed to eliminate the risk of vaccine-associated paralytic poliomyelitis while maintaining population immunity."

Protecting Your Arms Will Keep You Moving

by Julie K. Silver, M.D. & Marie H. Cole OTR/L
Spaulding Rehabilitation Institute's
International Rehabilitation Center for Polio,
Massachusetts, USA.

Part 1 of 2 Part series.

This article will cover four common arm injuries that are treatable and generally curable. Keep in mind that many other types of injuries exist and that the treatment is entirely dependent on having an appropriate diagnosis made by a medical doctor.

This article is written in order to encourage prevention of injuries to the arms and to encourage readers who have arm pain, weakness, numbness, or tingling to seek early treatment after an appropriate diagnosis is made by a medical doctor.

Introduction.

Our arms are the keys to our ability to remain as mobile and independent as possible. We need them to bathe ourselves, feed ourselves, and use a telephone, computer or fax. Basically we need them to accomplish nearly everything that we have to do in a given day.

As all of us age, our arms become more susceptible to injuries. For individuals with pre-existing disabilities, these injuries may occur at an earlier age and be more severe because of the increased demands that are required of the arms for day to day activities.

In order to protect our arms from injuries and when they do occur to treat them early in order to heal the injuries, read on...

Tendinitis.

The occupational and/or physical therapist can provide a wealth of information on how to avoid poor techniques and position of our arms and how to avoid re-injury.

Tendons are the structures that are found at both sides of a muscle and are used to attach the muscles to bones. Tendons often become irritated and inflamed through overuse and

because they don't have a good blood supply, can be a little tricky to heal.

Symptoms of tendon injuries generally include pain at the site of the injury. This pain is often worse with activity but may be quite severe at night when resting. Tendon injuries do not cause numbness and tingling feelings in the arms.

Described below are 2 common types of tendon injuries in the arms.

Shoulder Tendinitis.

The rotator cuff is a group of 4 tendons that work together to stabilize the shoulder, especially when moving the arm overhead. The shoulder has more mobility than any other joint in the body, however, this makes the shoulder more unstable than other joints that can't move as freely. Therefore the shoulder (particularly the rotator cuff) is prone to injury because of its inherent lack of stability.

Rotator cuff tendon injuries occur commonly and in the early stages are easy to treat. Long standing inflammation of the tendons can lead to the tendons becoming weaker and in some instances tearing or rupturing. A complete tear of the rotator cuff results in an inability to lift the arm overhead. This may or may not be correctable.

Another potential complication of long standing rotator cuff tendinitis is that the lack of mobility in the shoulder may cause it to 'freeze'. This is commonly called a 'frozen shoulder' and in medical terms is called an 'adhesive capsulitis'. Once again, this may or may not be permanent.

Elbow Tendinitis.

The tendons that attach to the bones at the elbow (medial or lateral epicondyle of the humerus) often become inflamed. In medical terms this is called medial or lateral epicondylitis. These tendons arise from muscles that move the wrist and since the wrist is involved in so many functions, it is not surprising that tendinitis frequently occurs in these tendons.

Tennis players who use a lot of forceful wrist movements often have tendinitis of the tendons that control wrist movement that attach to the elbow. Therefore, this medical malady is commonly termed 'tennis elbow'. However, tendinitis at the elbow can occur in anyone who uses his or her wrists (and hands) routinely. In fact, this injury is often seen in office workers

who spend their days using the phone, fax and computer as well as filing and other repetitive activities. Elbow tendinitis can also occur when individuals place a lot of pressure on their wrists such as during transfer or when using mobility devices such as canes and crutches.

Nearly always, elbow tendinitis is treatable and usually curable.

Medical Treatment for Tendinitis.

Medical treatment generally consists of rest from activities that provoke the symptoms of pain. Using ice on the inflamed tendons can be very useful (the authors recommend using an ice pack or ziplock bag of ice water applied directly to the elbow or shoulder for 20 minutes at a time, 2 - 3 times a day.) A doctor may prescribe anti-inflammatory medications. Injections of local steroid medication (similar to 'cortisone') can also help heal these injuries. Occasionally surgery is necessary and if recommended is generally successful.

Rehabilitation Management of Tendinitis.

Since tendinitis can impact our ability to perform everyday activities, the goal in rehabilitation is to reduce pain, increase flexibility, strengthen, and most importantly restore function.

Therefore the initial goal of the physical and/or occupational therapist is to evaluate and individual's strength, posture and flexibility as well as to determine which activities may be contributing to the injury and causing pain. The therapist then can give expert advice on how to reduce the stress placed on tendons that will generally include proper seating and posture instruction as well as providing tips on making simple adjustments at home and at work in order to avoid aggravating activities.

As part of the treatment, the therapist may use treatment 'modalities' such as ultrasound that provides deep heat to warm the tissues - improve blood flow and relieve pain.

An exercise program is usually initiated on the first visit, but is recommended in a very specific manner. Most often, the exercises include only a stretching program because strengthening is not recommended until the tendons become less inflamed and less painful.

In the case of tendinitis at the wrist, either the physician or the therapist may recommend a splint for the wrist. The splint provides rest for

the tendons and relieves the pressure from the overworked muscles.

If the symptoms persist despite treatment, surgery may be an option. In the case of post operative rehabilitation, the focus again is on reducing pain and restoring strength, flexibility and function.

Part 2 of 2-part Series.

Our arms are the keys to our ability to remain as mobile and independent as possible. This part is how to prevent injuries in the arms and how to treat them once they do occur. This article will cover nerve injuries - carpal tunnel syndrome and ulnar nerve injuries at the elbow.

Nerve Injuries.

There are several nerve injuries that commonly affect the arms. Two of these are discussed below. Keep in mind that the symptoms of nerve injuries often present with pain (similar to tendinitis) but are generally in a different location and frequently have associated symptoms of numbness and tingling or an electrical or 'hot' feeling.

Nerve Injury at the Wrist.

The most common nerve injury at the wrist is compression of the median nerve in the carpal tunnel (hence the name Carpal Tunnel Syndrome). The carpal tunnel is a band of tissue that surrounds the end of the wrist underneath the skin. Through the carpal tunnel run a number of tendons that control the hand and one nerve - the median nerve. It is the median nerve that becomes compressed and causes carpal tunnel syndrome in some individuals.

The symptoms of carpal tunnel syndrome may include pain, numbness and a tingling or electrical feeling in the thumb, index finger, long finger and sometimes the ring finger. Often the symptoms are worse at night. Untreated, prolonged compression of the median nerve can lead to permanent hand weakness and loss of sensation.

Nerve Injury at the Elbow.

The ulnar nerve is very vulnerable to injury from pressure at the elbow when it becomes superficial as it passes through a groove called the cubital tunnel. This injury is common in the general population because of the pressure the

insides of their elbows when they sit and rest their elbows on armrests. For individuals with disabilities who spend a lot of time seated, particularly in wheelchairs, ulnar nerve injuries can easily occur and may be quite severe.

Symptoms of an ulnar nerve injury are similar to those found in carpal tunnel syndrome except that it is usually the little and ring fingers involved.

Medical Treatment for Nerve Compression Injuries.

The medical treatment for both median and ulnar neuropathies as described above is first and foremost to try and relieve pressure on the nerves. The pressure can be direct, such as with resting the elbow on an armrest or wearing a watchband too tight around the wrist, or may be indirect generally involving repetitive movements of the wrist or elbow (e.g. typing, knitting, working with tools, etc.) Activities that produce either direct or indirect pressure on the involved nerve should be avoided.

Using ice on the elbow or wrist can be useful (once again, no more than 20 minutes at a time for 2 - 3 times each day). A physician may recommend anti-inflammatory medications. Injections of local steroid are sometimes done for carpal tunnel syndrome, but not for cubital tunnel syndrome. Finally, surgical release of the nerve may be the best way to heal the injury - depending on its severity and the response to more conservative measures.

Rehabilitation Management of Nerve Compression Injuries.

The rehabilitation management of nerve injuries first and foremost involves protecting vulnerable nerves from further injury. Physical and occupational therapists who treat these injuries are experts in teaching people how to prevent further injury by protecting the vulnerable nerves. Therapists are also experts in providing assistance with pain management as well as recommending appropriate stretching and strengthening exercises.

Although nerve injuries are treated differently than tendon injuries, many of the same principles apply. These include avoiding aggravating activities (e.g. anything that causes pain or other symptoms such as numbness and tingling).

Also similar to tendinitis, the rehabilitation

management of nerve injuries may include prescribing splints to reduce pressure and relieve pain. Typically, for carpal tunnel syndrome wrist splints are worn at night. Elbow pads can be worn during the day to minimize direct pressure on the ulnar nerve and to provide a reminder to avoid leaning on the elbow.

Treatment modalities such as ice, heat or electrical stimulation may be used to decrease inflammation and pain. Once pain is reduced, the therapist will generally recommend strengthening exercises.

If symptoms continue despite treatment, surgery may be recommended. After surgery the treating physician prescribes a specific rehabilitation program that generally includes wearing a splint, pain management techniques, and gentle range of movement exercises. Stretching and strengthening exercises are gradually incorporated into the rehabilitation program as healing progresses.

Conclusion.

All of our arms are susceptible to injuries, because of the demands we place on them. For individuals with disabilities, these demands may be unusually high due to compensating for weakness elsewhere. Although not all injuries can be prevented, many can with a little knowledge and forethought. For those unavoidable injuries, an appropriate diagnosis and early treatment can be the key to a complete recovery.

www.wheelchairsonthego.com

Wheelchairs on the Go: Accessible Fun in Florida

is a hot new travel guide for Florida's visitor and resident with a physical disability or handicap. If you plan to vacation in Florida and you are mobility impaired such that you use a cane, walker or wheelchair or simply can't walk far, this 424-page book is for you! *Wheelchairs on the Go: Accessible Fun in Florida* lists wheelchair-accessible and barrier-free accommodations, tourist sights and activities from the Panhandle to Orlando to Key West. With attention to detail and respect for the range of readers' physical challenges, *Wheelchairs on the Go: Accessible Fun in Florida* describes potential barriers and how to overcome them to have fun! Additions and updates to the book will be posted on the web site.

When your Home is Not a Safe Haven

by Laura A. Ryan, OTR/L,
Maria H. Cole, OTR/L
Dorothy D. Aiello, PT,
Julie K. Silver, MD

We think of our homes as havens--places where we are safe and secure from the unpredictable, mercurial and sometimes downright hazardous "real world". More often than not, however, this security is unfounded. In fact, most of us live in homes that are fraught with hidden dangers that could potentially cause us serious injury. Indeed, studies show that accidents are the 6th leading cause of death in persons over sixty-five years of age and that falls account for two thirds of these deaths. Moreover, at least 1/3 of falls that result in someone getting hurt occur in the home or in other familiar surroundings. The good news is that research also shows that modifications to make your home safer can dramatically decrease your risk of falling.

HOW TO MAKE YOU SAFE

In order to minimize the chances of falls and subsequent injuries you must first rule out any health issues that may contribute to your risk of falling. In the medical literature, these factors are often called *intrinsic factors*. Intrinsic factors are those things that affect how your body works. Examples of intrinsic factors include, but are not limited to, blood pressure abnormalities, poor vision and/or hearing, the effects of medication and overall weakness and/or inflexibility. In order to optimize your safety you should ideally have an annual physical examination by your doctor that includes an assessment of your vision, hearing, balance and strength. It is also important to have your doctor review your medications. Simple changes in medications, eyeglasses or even a little physical or occupational therapy to improve balance and strength can have an enormous impact on your personal safety both at home and in the community.

HOW TO MAKE YOUR HOME SAFE

The medical literature also focuses on *extrinsic risk factors* for falls. These are things that may affect your ability to move about safely, but don't have anything to do with your personal health. For example, the presence of throw rugs or slippery bath mats, clutter in your home, poor lighting and the lack of grab bars in the bathroom are all considered extrinsic risk factors that contribute to people falling. Because these risk factors have to do with the environment, they are

nearly always correctable.

THE GAME PLAN

Since most of us have difficulty viewing our homes objectively, it may be worthwhile to have a physical or occupational therapist come to your home and make specific recommendations about how to make your home safer. This is generally covered by medical insurance if your doctor recommends a "home visit". However, regardless of whether a therapist is available to come to your home, there are some basic guidelines for home safety that you can use to improve access and safety in your home:

Stairs/Entrance - Stairs and entrances are notoriously dangerous areas in home. It is critical to keep entrances free of clutter and to eliminate doorway thresholds and scatter rugs as much as possible. Outdoor walkways and stairs should also be clear of clutter and need to be shovelled and sanded when inclement weather occurs. A railing on both sides of indoor and outdoor stairs greatly improves safety. Nonskid tape and colored tape on the edge of the stair (a good visual cue—especially if you have poor vision) are also helpful. If you have difficulty going up and down stairs, consider installing a stairlift indoors and a ramp outside.

Kitchen - Ideally, a gas stove is safer than electric because you can see when it is off and it cools quickly after being turned off. However, an open gas flame can be a real hazard, too. It is important to avoid cooking when wearing clothes that are loose or may get in the way of your heat source. When cooking, keep commonly used items within easy reach. Items that you use daily (e.g., pots and dishes) can be placed on the counter. For those things that are stored in cabinets it is best to keep them at waist height and toward the front of the cabinet in order to avoid stooping and reaching. There are many commercially available compartment accessories that you can use on your counters or in your cabinets to both improve how the space is organized and how attractive it looks.

Bathroom - Bathrooms can also be high-risk areas because of the slippery surfaces and often small rooms. Many people fall when holding onto a towel bar or pushing on the sink in order to stand from the toilet. This obviously is not safe to do. Instead, professionally installed grab bars, particularly next to the toilet and in the bath or shower, will make negotiating your bathroom much easier and safer. Generally a short bar (12") vertical on the wall as you enter the tub and, ideally, a right angle grab bar on the far wall is recommended. Another simple and inexpensive option is to use a tub rail that clamps to the side of

the tub—these can usually be installed without professional assistance. Moreover, this rail can be repositioned and provides a grip for both entrance and exit to the tub.

Shower chair recommendations will depend on how much you weigh and how you move about. The features of the chair (e.g. armrests, surface type) should be considered as well as width, depth and height of the chair. A hand-held shower offers more control over directing the flow of water and adjusting the water temperature. This also allows you to get into the tub without having to step directly into the stream of water thereby reducing your chances of slipping. To improve safety when exiting the shower, a nonskid bathmat cut to a narrow width can be utilized.

Getting on and off the commode can be a real challenge, and it is important to do this as safely as possible. A raised toilet seat can make a dramatic difference. The ideal height is typically 17-19 inches from the floor, but may vary depending on your height. Raised toilet seats can be purchased in many retail stores and recently there have been some very nice options that may make this more aesthetically pleasing than those available in the past. These seats also offer a variety of options, including armrests, adjustable height and different seat surfaces. If you use a wheelchair, the height of the toilet seat should equal that of the wheelchair to allow for a level lateral transfer. Another option is to elevate the entire toilet from the floor. A plumber needs to install this, but it does not significantly change the toilet appearance.

Bedroom - Bedrooms should be devoid of clutter and have adequate lighting, particularly for night-time purposes. Light sensitive nightlights that automatically turn on can make getting up in the middle of the night much safer. Ideally you should sleep on the side of the bed closest to the bathroom or doorway. Minimizing clutter and ensuring ample space around the bed is also important. Comforters or blankets should be well fit so they are not dragging on the floor, as this is a tripping hazard.

Living Room - Living rooms often have many tripping hazards including small tables, magazine racks, stacks of newspapers, raised carpets, etc. It is important to make your living room clutter free and with adequate room to move about.

Seating should include a firm, supportive chair (with arms is preferable). If the seat is too low, a carpenter can increase the height by adding wooden blocks under the chair legs; however, this must be done so that the chair is secure and the blocks don't stick out potentially causing you

to trip. If the seat is too soft, adding plywood under the cushion can make it firmer. A lumbar support cushion can be purchased in many retail stores and often will provide additional support and comfort.

For machinery such as lights, radios and televisions, remote controls will help you to avoid getting up and down unnecessarily. Lamps should be easily accessible or when possible, activated by remote control switches or auditory cues.

Computer Station - If you spend time using a computer, it is important to make sure you are safe and comfortable when doing so. The computer station components should be easily accessible and wires and cords should be removed from walking areas and tacked down. The chair you use should be a good height for you and you should be able to sit and stand safely.

WHAT TO DO IF YOU FALL

Not every fall can be prevented. So, it is wise to have a plan in place that will work if you do happen to fall. Perhaps the most important safety consideration is emergency response. There are specific emergency response services—most of these have you wear a pendant or bracelet with a button that you can press to summon help if you fall. Home alarm companies also offer emergency response services that work by a similar system (e.g., pendant or bracelet with a button). If you have a home alarm system, you can often add this service. Another security measure is to carry a cordless phone with you during the day.

If you can't easily get up from the floor, either a physical or occupational therapist can teach you the best way for you to do this in the event that you do fall. Obviously this would be a preventative measure and the goal of learning a "floor transfer" would be so that if you ever fell, you would know the easiest and safest way to get up.

The statistics on falling and sustaining a serious injury are sobering indeed. However, it is comforting to know that there are some simple things that we can do to make our homes much safer in order to protect our loved ones and ourselves.

Reprinted from Accent on Living—Summer, 2001

Active Isolated Stretching.

Last newsletter I wrote about AIS following three sessions of therapy. Its now three months later and in answer to questions that I am being asked I hope the following will explain how this form of stretching can help everyone to function in a healthier way. Note I said, everyone, not just polio survivors.

When we are born we have a range of movement for each joint. If we don't stretch our muscles regularly then as we age we lose some of the range. We can all remember babies sucking their toes but I doubt many of us can still do this. As we become less able the range can decrease further and our joints become stiffer. Circulation of these joints is impaired and many of us experience the results of this.

The basis of active isolated stretching is to isolate each muscle or muscle group in turn and then gently stretch them in their range. An easy way to see this for yourself is to lay your hand flat on a table or even your knee and try and raise your fingers one by one. They will go to a variety of different heights. So how far do you think your fingers could go? 45 degrees, 60 degrees, what about 90 degrees? Surprisingly the answer is 90 degrees, that's how far we could move our fingers when we were babies. How often do we lift our fingers up in this plane now? Rarely. We use our fingers the opposite way and curl them but rarely do we lift them up. So part of the muscles in our hands are never being stretched.

Take our feet. How much of your foot and toes moves now compared to what it could do when you were a baby? Can you lift your toes up? Can you curl them? Do you ever stretch them apart except when cleaning them? Mine hardly move and have got worse over the last ten years. Remember a recent newsletter when we learned that our foot muscles are the pump to get the blood back to our hearts..... are all your foot muscles getting a workout? Is your 'foot pump' working to its optimum level? Mine certainly were not.

If we look at the rest of our body, especially now that we are having new problems of functional decline, do we have other parts of our bodies that have muscles that are never stretched to their full potential? Yes, we do. Moving them ourselves or having them moved for us will improve circulation. Improved range of movement lessens injuries.

A simple way of seeing how stretching little by little works follows. Keeping your hand flat either on the table or on your knee, lift your first finger and with three fingers of your other hand gently lift that finger up a little bit higher for no more than one and a half seconds and put it go back down again. No more than eight to ten ounces of pressure. You can try this on a set of kitchen scales. Repeat lifting this finger up to ten times. As you lift each time you will notice that your finger is going higher and higher. Do the same for each finger on each hand.

You can do the same for your toes - those that are not arthrodesed (fused). Some of us will have had foot surgery that prevents us moving some parts, but there are likely to be parts that could still do with a bit of help. OK, our feet are a long way away and its not easy getting them up high enough to work on them. If you can't reach then maybe you have someone who could give you a hand. Take that foot and gently stretch your ankle up and down and turning in and out. Now take each toe one by one and lift it up and then curl each toe joint down and up. Stretch the web of each toe. You may be interested to know that you have 2000 nerve endings in each foot - compared to 200 in each hand - and therefore you might find more pain when doing this. When you have stretched each foot then put your feet up four inches above your heart and rest them. Do your feet feel warmer, are they pinker? This increased circulation should make a difference - I have noticed a considerable decrease in muscle twitching.

This is the way active isolated stretching works. First you isolate the muscle or muscles that you want to stretch and then you lift them yourself and the therapist/or someone helping you will just take the limb that bit further for a second and a half. Anywhere you have limited power to perform the lifts required the therapist can do the whole action for you. This is called Assisted Active Isolated Stretching. Even if you can't do the lifting think yourself doing it. Therapists will normally repeat the actions ten times, however this is not set in stone and five repeats may be the optimum for you. Five repeats on one side and then five on the other. There is a protocol (sequence) of exercises for each area of the body.

Ideally we could all do with being stretched but how possible this is in the UK will depend on the type of training any therapist you see has had or has the time to learn.

When you start therapy there are always

exercises to do at home. How many and how much will depend on what else you have to do in the day and your physical ability. The therapist will show you the actions you need to do and you work out when is the best time for you to do them and how many. Record what you do. Personally I have found that three repeats of each arm and neck exercise sitting on the side of my bed/on the loo every day is possible and helping me retain what I have regained. It takes one of my available ten energy tokens for the day. I have considerably less ability to do the actions for myself with my legs and need assistance. [My daughter flew to Florida and learned AIS so that she could help when we are in the UK. Every day in Aaron's Clinic patients partners/family members are taught how to help at home].

What has the increased range of movement done for me? Instead of having a stiff body that was getting stiffer, its now loose, my spine moves again. All actions are easier. Turning over in bed is easier now and I do not have to wake to such a high a level of wakefulness. I am therefore sleeping better. Driving is more comfortable as I can turn my neck further to see at junctions. Dressing puts less strain on my joints as I can now reach behind me, doing and undoing my bra from behind, no more twizzling! For some years I have not been able to drain a can of drink due to lost neck extension, I can drain the can again now that I have +30 instead of -10 neck extension. Getting up and down out of a chair, in and out of bed, in and out of a car. All these actions are easier. Less pain, and more importantly far less strain. I still have muscle fatigue and central fatigue and have to pace and rest and use my aids and assistive devices. However, seeing an improvement in my ability to do tasks after all these years of decline has made a considerable difference to how I feel about myself.

All the latest medical articles on pps recommend exercise starting with stretching and then strengthening where possible.

Speak with your health professionals and ask about this form of stretching. Fully illustrated workbooks and videos are available from www.stretchingusa.com.

I have already passed the information to the Hospital Trusts in Lincolnshire. I will let you know the outcome.

<hilary.hallam@lincolnshirepostpolio.org.uk>

the RESPITE association.

Providing a helping hand to those who care

What do we do?

The Respite Association became a registered charity on May 16th 2001. Our main aim is to provide assistance in the funding of appropriately qualified respite care for disabled, sick or elderly persons in order that their regular carer can be allowed to take a much needed break.

Who will we help?

Many of the people who are at home caring for a loved one are forced to live on very limited incomes. It is these people that we are working to assist.

What does it cost?

Providing suitably qualified carers in the home or a temporary place in a residential care centre is obviously an expensive business. This is why so many carers find themselves unable to take a holiday to re-charge the batteries. The Respite Association will try to meet all or part of the cost according to individual circumstances and need.

Many of our clients are referred to us by other Charities or Social Workers who do not have the funding to assist.

An idea of cases they have helped is
a carer for one night a week,
a carer for one evening a week,
relief carer for one day a week
funds towards the cost of two weeks
and another several weeks
of residential care

**The Respite Association,
Leadenhall Manor,
Leadenhall Road,
Holbeach St. Marks,
Nr. Spalding,
Lincolnshire
PE12 8HA.**

Tel. 01406 701079

MEETING OF THE MINDS
A Vehicle Conversion Gone Bad
By Larry Rosenthal

From: Abilities Magazine,
vol. 43, Summer 2000, page 72

When a dealer recently equipped my van with a wheelchair lift, he installed a motor to open the van's sliding door and lower the platform. One day after work, the motor ripped the van door off its hinges, and threw it onto the ground. "Gosh, would you look at that," I said, adding several colourful adjectives for emphasis. My brother Steve rescued me. It took him an hour to detach the battered door from its cables and wrestle it into the back of my van.

The next day, I drove down to the dealer, whom I will call The Weasel. Lest any offence be taken, let me assure you the dealer looks nothing like a weasel. The dealer is very big and smooth, while weasels are actually quite small and furry.

After carefully surveying the damage, The Weasel explained my warranty. The warranty covered the motor, because it was a new part. The warranty covered the platform because it too was a new part. The door, on the other hand, was an old part. The warranty, declared The Weasel, stated very clearly it didn't cover any damage done by the new parts to the old parts.

"Help me to understand," I implored him earnestly. "You, an authorized dealer for the Reliable Lift Co., installed not six months ago a power lift for the princely sum of \$4,000. Now the motor runs amok, attacks my door, and I must pay you \$225 to have the door repaired?"

"That is exactly right!" said The Weasel, obviously impressed with my perspicacity.

"You see," he explained, warming to his subject, "there is a little rubber stopper, an old part, that is supposed to prevent the sliding door from opening too far. That stopper became missing. However, I am certain the motor we installed has come through unscathed."

"That is indeed wonderful news," I exclaimed. "And my brother says there is a sensor switch which, once the door is fully open, directs the motor to stop pulling on the door, and start lowering the platform. Pray, might it be that this sensor switch alas faltered in its supervisory

duty, thus allowing the hoodlum motor to pull my door off?"

"The damage," clarified The Weasel, "occurred because the stopper was missing."

"Perhaps," I volunteered helpfully, "you should have checked the stopper when you installed the power door. And wouldn't you agree, the stopper would not even have mattered if the blankety-blank sensor switch had told the blankety motor to stop blankety pulling on the blankety-blank door?"

"The damage," clarified The Weasel, "occurred because the blankety-blankety-blank-blank-blankety stopper was missing."

After lingering but a few short moments to exchange final pleasantries centering upon, though not limited to, family heritage, I took my leave, and was soon conversing with a Consumer Affairs official.

Mr. Consumer Affairs was very sympathetic. He was prepared to mediate. If that didn't work, he was absolutely prepared to mediate some more. Reluctant to subject my good friend the dealer to so harsh a remedy, I decided to call my lawyer instead.

My lawyer opined that, regardless of any self-serving animal blank the Reliable Lift Co. might have included in a warranty, no court in California would absolve my local authorized dealer of liability for damage done by the motor so soon after it had been installed.

The next day I reached The Weasel by telephone. "I have been speaking with my legal people," I revealed, "and they tell me my position is most solid. As a faithful customer and fellow human being, I ask you to open your heart to reason and do the right thing, lest I be forced to have the door repaired elsewhere and sue your blankety posterior for damages including, but not limited to, repair costs, missed work, emotional distress, etc."

"As a responsible member of the business community, I will fix your door without charge," replied the Weasel, "and I also suggest we sever our association, thereby preventing any future misunderstandings. There is a perfectly good adaptive equipment dealer in Far City to the south, and an equally competent dealer in Furtherville to the north. There is also a dealer not 10 minutes from where I speak, who unfortunately is totally incompetent."

"I appreciate your new-found honesty," I told The Weasel. "A lower life form - a tarantula, for example - might not have warned me that blanking off my local dealer might in the long run cost me considerable time and difficulty."

"I am nothing if not helpful," declared The Weasel. "And I want you to know I feel in my open heart that a \$225 payment for repair of the door would restore our relationship to its former excellent condition."

"Thank you for sharing," I replied. "Please fix the blankety-blank door for blankety free, and I'll take my blankety-blank chances."

And he did, and I will.

Larry Rosenthal is an American who exaggerates a little but not a lot.

From Member Jann Hartman

Dietary advice.

I would suggest that you might want to read or get a copy of: "Power Nutrition for Your Chronic Illness" by Kristine Napier, MPH, RD, 1998. This is a very informative and helpful book with easy, tasty recipes for those dealing with a variety of chronic illnesses.

Basic information and links can be found on my WebSite.

<http://www.geocities.com/arojann.geo/ppsnutrition.html>

Grace Layton Sandness and Polio Artists.

Grace Layton Sandness was born to Richard and Edith Harriet Layton at Valley City, North Dakota.

In 1950, just after completing her Freshman year at Cottey Junior College, Nevada, MO, she was stricken with polio. She was in an iron lung for several months and in hospitals for a year.

Her natural artistic talent gave her a much needed outlet for her ambitions and her active mind, as well as aiding in her therapy. Being a quadriplegic, she held the pencil in her mouth; working hard to improve her drawing she soon was designing a Christmas card for the family's use. This was followed by the production of "Grace Notes." [And a notecard collection called, "Sugar and Spice"]

The business flourished and for fifteen years Grace used the money to finance a foster child, sending her through the eighth grade and buying her a

sewing machine.

With the help of Roy Lund, a local radio "ham", Grace was enabled to pass the examination for a license as a "ham" and she became known as the "brown-eyed Angel" by all the radio hams. She met her future husband through her radio contacts, as he too, was a "ham" by the name of David Sandness.

Grace graduated from the State University of Iowa with a B.A. and David with an M.A.; and later he received his Ph.D. from the University of North Dakota. Their love for children has led to the adoption of seven children.

Source: Barnes County History 1976 Page 212
http://www.webfamilytree.com/grace_layton_sandness.htm

Other Polio artists include Mexican artist, Frida Kahlo, as well as our own Bob Mauro (KZ2G):
<http://www.geocities.com/ram9872002/Polioart.htm>

And, these are some artists I have found who painted and sketched with their mouths:

Ann Adams (1937-1992), Jacksonville, FL, USA
Great story here:
<http://www.nmia.com/~paulos/annadams.html>

Richard Bauer (Polio, Sept. 1949) USA

Ganesh Kumar: Kerala (India?)

Earl Bailey (1903-) Nova Scotia, Canada

Nyla Thompson, postcards, Austin, TX, USA

Elizabeth Twistington-Higgins, MBE (1923-1990), UK

Peggy McCormack, Oral Artist of the Ozarks, Arkansas, USA

Lynda Hamilton, San Diego, CA, USA

A. E. Stegmann (1912-1984): Germany, Founder and first president of the Association of Mouth and Foot Painting Artists of the World.
<http://www.amfpa.com/>

I am interested if anyone knows of any of these people or other artists who had Polio (especially those who were mouth painters).

I would be pleased to hear from anyone who wants to tell their story to others whether they are artists or not...Jann (WB3FXH) -arojann@yahoo.com

<http://www.geocities.com/arojann.geo/poliopeople.html>

INTERESTING MEDICAL FACTS

Optic neuritis vs. multiple sclerosis

What's the difference between multiple sclerosis and optic neuritis?

Optic neuritis (retrobulbar neuritis) is due to inflammation of one or both optic nerves. This inflammation may be a result of a viral infection, autoimmune disease or multiple sclerosis (MS). Signs and symptoms of optic neuritis may include:

- Loss of vision in just one eye
- Pain on movement of the eyeball

Vision usually improves or returns to normal within 2 to 3 weeks without treatment. Optic neuritis may occur as a single, isolated attack or may signal the beginning of multiple sclerosis. Not all people with optic neuritis develop MS. Likewise, not all people with MS experience optic neuritis.

Multiple sclerosis is a chronic, potentially debilitating disease that affects your brain and spinal cord (central nervous system). In MS, your body directs antibodies and white blood cells against the myelin sheaths surrounding nerve structures in the brain and spinal cord. This causes inflammation and injury to the sheath and impairs nerve function. The result may be multiple areas of scarring (sclerosis) in the central nervous system. The damage may impair muscle coordination, affect vision or interrupt other nerve signals.

Neurotoxin Discovered in Chronic Fatigue Syndrome

Needham, MA November 17, 2002 – Research sponsored by the National CFIDS Foundation was formally announced at the International Symposium on Toxins and Natural Products in Okinawa, Japan on November 17-19, 2002 by Dr. Yoshitsugi Hokama. The research, for the first time, discovered ciguatoxin, a potent neurotoxin, in the blood of Chronic Fatigue Syndrome patients.

"Chronic ciguatera poisoning has already been suggested as a scientific model for Chronic Fatigue Syndrome (CFS)," stated Dr. Hokama. Ciguatoxins are potent, heat stable, non-protein, lipophilic sodium channel activator toxins and are recognized as some of the most potent biological toxins known. They produce dramatic neurological manifestations, such as peripheral

sensory or motor symptoms (including paresthesias, pain, burning, tingling, numbness), central symptoms such as headache, autonomic dysfunction and also affect multiple body systems (gastrointestinal, immune, hepatic, cardiovascular) and the muscles.

Many CFS patients in the study had higher levels of the toxin than the patients with cancer, hepatitis or acute ciguatera poisoning.

Quantitative assay results range from 1:5, the lowest toxin level, to 1:160, the highest toxin level. All CFS samples gave titres of at least 1:20, with the majority of titres from 1:40 to 1:160.

Dr. Hokama presented his preliminary findings in a lecture titled "Acute phase lipids in sera of various diseases: Chronic Fatigue Syndrome, ciguatera, hepatitis, and various cancer with antigenic epitope resembling ciguatoxin as determined with Mab-CTX."

Dr. Hokama is a Professor in the Department of Pathology at the John A. Burns School of Medicine at the University of Hawaii at Manoa. He is a world expert in the area of fish toxins with hundreds of peer reviewed publications to his credit. Hokama developed the Membrane Immunobead Assay test for patient sera, using a specific monoclonal antibody for ciguatera toxin (Mab-CTX). His current research into Chronic Fatigue Syndrome and a ciguatera toxin connection was funded by the National CFIDS Foundation's research grant program.

Gail Kansky, President of the National CFIDS Foundation, said, "We believe this to be a significant breakthrough. CFS, which has come to include myalgic encephalomyelitis, is a very severe illness that has not received adequate funding or appropriate medical attention. Although there are still many unanswered questions and much work to be done, research efforts will ultimately turn the tide in the understanding of this disease and allow patients to receive appropriate medical therapies.

We are indebted to Dr. Hokama and his colleagues for providing this monumental first step." For more information on this study please contact The National CFIDS Foundation

The following article is about M.E. There is a huge overlap of symptoms experienced by people with neurological conditions. Some of our members in the Trent region have been diagnosed with 'PPS of the M.E. variety.'

TIME TO PUT THE EXERCISE CURE TO REST?

by Betty Dowsett, MD

There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion [1]. And, on follow up over decades (rather than weeks or months), the average person so disabled is found to be functioning (as a student, employee or parent for example) dangerously near their energy limits. The prescription of increasing exercise in such a situation (or in the early stage of the illness when the patient desperately needs rest) can only be counter-productive.

WHY DO SUFFERERS FROM M.E. FIND ENERGY IN SUCH SHORT SUPPLY?

Although the brain comprises less than 2% of total body weight it requires 20% of the available body energy and a constant supply of glucose and oxygen to sustain its exceptional metabolic work load. Apart from maintaining sufficient chemical and electrical activity to keep millions of nerve networks constantly charged for action, the brain is a power house which initiates and synchronises all out physiological functions [2]. The brain stem and mid brain contain (like the bridge of a ship) all the necessary switches and dials for the passage of information to and from the spinal cord and higher intellectual centres. However, recent research using sophisticated brain scans (PET and SPECT) [3] which measures metabolic activity generated during brain functions, have revealed a paradox. Whereas in healthy controls or people suffering from depression metabolism increases with exercise, in patients with ME it is diminished for a considerable period following exercise. Diminished metabolism in the brain stem (which also houses a nerve network, the reticular activating system, charges with keeping us awake and attentive) explains one of the

most disabling symptoms of this illness - the unpredictable onset of central nervous systems exhaustion following minor physical or mental activity. Not only are sufferers unfairly assessed for disability benefits by tests (such as the distance walker or the time taken, for example) which take no notice of these prolonged after effects but they are categorised as psychologically disturbed and expected to respond positively to exercise which might only benefit normal people or those suffering from depression.

DO PATIENTS WITH M.E. SUFFER FROM SPECIFIC MUSCULAR PROBLEMS IN ADDITION TO GENERAL EXHAUSTION?

There are two answers to this question

1) Most patients with M.E. complain of malaise and some experience severe generalised pain. This is related to the disturbance of metabolism in the co-ordinating centres of brain previously described, whereby the appreciation of pain becomes distorted and the supply of natural pain killers (encephalins and endorphins) diminished. Muscle, joint and bone pain in M.E. may therefore have central origin.

2) Some 30% of patients have a local abnormality in their muscles, when tested for electrical activity (EMG) for the metabolic effects of exercise (the sub anaerobic threshold exercise test) or by biopsy or serological tests (for evidence of persistent or past enterovirus infection) [4]. Whether the individual with M.E. comes into one of these two categories or neither, undue muscular pain or exhaustion following exercise is an indication for rest and some modification of activity. Those who advocate exercise as a cure for M.E. have failed to notice that Nature decrees that we must all spend at least 1/3 of our lives resting in bed. This is necessary for running repairs to the brain and to damaged muscles or other tissues. Some reparative hormones (e.g. Growth Hormone) are only produced during this essential period of rest.

WHAT ADVICE CAN BE GIVEN ABOUT ENERGY MANAGEMENT?

There being, as yet, no specific medical treatment that can be recommended for this illness (a statement recently supported by the Department of Health [5.6] despite a contrary view from the Royal College of Physicians that patients for all ages should be offered the 'psychological benefits' of exercise, drugs and

psychotherapy), so the first principle of management still remains CONSERVATION OF ENERGY! Being in short supply for all M.E. sufferers, who mainly function in a range of 40%-70% of normal, energy is more valuable than gold dust and must be conserved as such for two essential purposes.

1. To accomplish the essential chores of life, which are not necessarily enjoyable. These can possibly be delegated, made simpler by mechanical means, postponed or omitted if not vital. Why waste this precious commodity?

2. The greater part of any energy available must be reserved for the things most important to you and which you love to do for, without something to look forward to however small, life is not worth living. NB. A great many people love their work, DIY and domestic tasks and for them paragraph (1) will seem like gold dust well spent. For others, even the most housebound, joy can come from a variety of different pets, undiscovered or long forgotten talents (art, writing poetry, music or computer skills) or for occasional outings and carefully planned holidays. Happiness is the finest therapy and will provide distraction even from pain and disability. Postpone ambitions or holiday plans if necessary but never totally relinquish them - life is full of surprises!

CONCLUSION

Every sufferer from M.E. differs slightly from others in terms of symptoms, life style and stage of illness. No doctor can dictate an activity programme without a clear understanding of the cause and limitations of energy supply in any particular individual and the patient is almost always the best judge of this. It is a good idea to keep a very simple diary to guide the process but don't waste energy on it! Use a few coloured pens and mark on the calendar the percentage of energy (EG 5/10) remaining daily at bedtime. Mark, in other columns, adverse factors (such as visits to the dentist or menstrual periods) saving a big star for pleasurable activities and things to look forward to. If you love athletic pursuits and can't be happy without them, try your own modification but stop before pain and exhaustion set in. Remember that muscles remain constantly in tone if you only move between bed and bathroom and that you can always devise and monitor your own programme at home.

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5. Letter from GILLIAN MARSH, NHS Executive Headquarters to patient with ME in Leicester, May 1998.

6. Letter from Baroness Jay, Health Minister to Mr Tim Yeo MP on behalf of a patient with ME in Suffolk, April 1998.

Question posed on our Members Email list.

**How does your spouse/partner/family member handle your disabilities?
What have you done to help them through any problems they may have had?**

This is a very important issue. It is not just the polio survivor who is affected by the onset of PPS. Everyone that we regularly come into contact with in our daily lives will most probably have noticed a difference in us. Sometimes it is very hard for them to bring up the subject, sometimes it is hard for us. If its hard for both parties then you can see it is likely that problems, that could be overcome, can arise.

Maybe you are the Polio Survivor or maybe the carer or a family member reading this. I know that we wish we could continue to do everything that we have done in our pasts but we can see that some tasks are just beyond us now. This can be particularly hard when we have elderly parents that we expected to be helping.

If you have any hints of tips on how to broach the subject of asking for/offering help then please write to us for the next newsletter.

LEGS by Laurie Mitchell

It's 4 a.m. and I'm curled up in my favorite chair sipping a steaming cup of coffee.

Relaxed, gradually coming awake, my eyes drift across the room and focus on legs – I count four, then four again, to come up with a total of twelve. These twelve legs belong to my dinette table with two chairs. Funny, it has never occurred to me to consider legs as a topic, either of conversation, or as a subject to write about.

As I enjoy my coffee, I ponder all the different types of legs in our universe: fat or thin, plain or fancy, straight or crooked, ugly or pretty, knock-kneed or bow-legged. There are jogger's legs, dancer's legs, and skater's legs. The list grows.

Legs have been referred to in many ways. During World War II, beautiful movie stars' perfect legs were called "gams." I remember when Betty Grable's gams were insured for a million dollars. It is not unusual for professional dancers to insure their legs these days, often through Lloyds of London.

Most of us take our legs and feet for granted. We were born with them, have lived with them, and we don't spend much time worrying about them, unless of course, we suffer from bunions or ingrown toenails. Loss through surgery or accident adds another dimension. Women probably spend more time on their legs and feet than men do. They shave them, anoint them with lotions, and painstakingly paint their toenails. I've heard it's fashionable to add glittery toe rings, too.

Pretty shoes enhance nice-looking legs. High-heeled shoes on beautiful legs are certainly sex symbols. Men appear to come in two flavors: they are either Leg Men or the blank-and-blank kind. Where does this mystique regarding women's body parts come from? Do women pay the same attention to men's physiques?

I remember when my then-husband, who, by the way was a Leg Man, told me that he never dreamed he would marry a woman who didn't have pretty legs. I often wondered if this was a back handed compliment or a put-down.

Due to early childhood polio, followed by many corrective surgeries, my legs are far from perfect. But they still function, and when I think of the alternatives, I'm very happy to live with both of them, such as they are.

I think about the different numbers of legs people, animals, or furniture have. This list begins with zero and ends in infinity. I begin with five.

You question a 5-legged something? You're probably visualizing a broken-down coffee table with four legs, held upright by a 5th leg in the middle. Not quite.

Once, my mother was coerced into chaperoning seven little Girl Scout Brownies to the county fair. These children were innocent city-bred girls.

The Los Angeles County fair was held each year east of L.A. in Pomona. It had permanent structures that housed exhibits, as well as outbuildings for animal displays. After touring the buildings, ooh-ing and aah-ing at the wondrous displays, the girls were led out to see the prize animals. There were fuzzy bunnies, crowing roosters, timid goats, raunchy rams, crooning calves, plus many more.

When the girls came to the pen that held stud horses, one little girl blurted, "Oh, Mrs. Mitchell, look at that five-legged horse!"

She didn't exactly whisper and when the surrounding audience heard her remark, they burst into laughter. My mother was so embarrassed; she immediately led the children outside and returned home. So much for five-legged animals.

Now, to move on to the subject of four legs. No need to identify all four-legged critters. We know what they are. They've been on the planet for zillions of years, and we hope will last another gazillion.

Three-legged species are not natural species at all. They usually emanate from four-legged animals that have lost a leg through accident, disease or abuse by another.

I've seen domestic dogs and cats that have lost limbs due to accidents that necessitated surgical removal. They appear to be happy and functioning, almost as well as if they still had the original four. But, since most of us are not animal psychics, we have no idea what they really think.

As for two-legged creatures, we naturally think first of human beings. Then birds. Maybe dinosaurs. There are probably others, but let's keep it simple.

Of these, human beings have managed to change the Earth forever. At times our behavior is far worse than bird-brained. In terms of ecological management alone, we've barely got a leg to stand on!

I've watched one-legged birds hopping as they forage for food. Sometimes, people also end up with only one leg, either through accidents, war injuries, diseases or genetics.

I am always touched by images of Siamese Twins born with a total of one or two legs.

When an article I wrote about my Polio's Prison was published, a woman wrote to me about losing a leg at seventeen. The doctors couldn't find a cure for her complex Polio-related condition.

Even as she lay on a hospital bed, she somehow managed to graduate from high school and went on to lead a productive life.

I've met many unusual people in my life, but one who stands out as the most unforgettable is a man named Bob.

He was married, had a beautiful seven-year-old daughter, and was the owner/operator of a 24/7 home-based business. Before the days of computerized equipment, he ran a 30-line, manually operated switchboard telephone answering service. I came to know him as one of his clients, as I'd just begun a business of my own.

What was most unusual about him was that he had no legs. Never had any. Was born without them.

Remember the years of Thalidomide babies who were born with missing limbs? His birth predated this drug, but something interfered with his physical development.

He owned a torso, buttocks and arms with small appendages that ended just below the elbow joint. He had no fingers.

What amazed me was how he functioned in life, accomplishing far more than what many full-bodied people do.

He was in his early 30's and had modified his telephone switchboard so that he could operate it himself. He held a pencil in his mouth, or slipped it through a leather strap on his arm. He

wrote messages. He switched the phone lines and plugged them into correct slots.

He also authored a book on how to set up and operate a home-based business.

When he and his wife and daughter went out to shop or to eat at a restaurant, his wife pushed his wheelchair. He appeared to be at ease with his disability, if we dare call it that. He never held back from anything he wanted to do and never seemed self-conscious when people were rude enough to stare at him.

One day, when I had occasion to stop by to discuss a business matter with him, his wife answered the front door and directed me to their backyard.

I found him scooting along on a little square skateboard mounted on casters. Extended from under the leather strap on his arm was a paintbrush dripping with green paint. Bob was peacefully painting his patio furniture.

During my lifelong struggle with the residual effects of polio, when I felt diminished, his maximizing his potential left me chagrined.

Here I was, with two legs, two arms, a complete torso, and a head on my shoulders. And here was Bob, accomplishing much more without complaint. At that moment I decided to never again feel sorry for myself.

It bothered my then-husband to watch Bob eat at the local restaurant when we would happen to be there at the same time. My spouse's lack of compassion for those less endowed was actually his disability, one only he could overcome.

Inwardly, I praised Bob for having the fortitude to face his challenges and operate in our world like a role model. Outwardly, I was quiet, until many years later.

I've thought of Bob over the years and wonder how he is or what he is doing now.

I grew up with mostly different children and attended schools for the handicapped until I reached adolescence.

A neighborhood friend was a victim of Down's Syndrome. She wrote to me with lovely, 3rd-grade-level handwriting. She was another acquaintance in my life who overcame her disability and functioned far beyond other's expectations.

The sun has risen. My coffee is cool. I stretch, grateful for the strength to start another article.

My four-legged Cassie dog comes up to my side, wagging her tail of inspiration.

In this moment, I know that it's not important whether we have two legs, five legs, or no legs at all. It's only where our hearts carry us and what we do with what we have that matters.

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Letter to the Editor,
From Beverly Bucellato
<bb_dutchess@yahoo.com>

Hils, I leave my ceiling fan on even during the cold winter months here in Michigan. There is something about the moving air that comforts me, and the gentle breeze drifting across my face makes me breathe much easier. At first I used a fan to drown out noise when I had to work midnight shift. Wouldn't you just know that the farmer next door bought a mule at the same time I was bumped to midnights. Anyways it worked and I missed the air currents when I eventually went back to my regular shift so I had the ceiling fan installed.

Hey, whatever makes life more comfortable!!

Beverly

Hint or Tip from another PPSer.

Try using thin washing-up type rubber gloves when putting on support stockings. It helps.

Margaret in Arkansas.....

Chocolate

Pronunciation: ['chahk-ê-let] note the "addictive" caution.

Definition 1: A drink, paste, or candy made from the fruit of the cacao plant, roasted and ground to a fine powder, then mixed with sugar.

Usage 1: The noun is now used adjectivally as a color, a rich brown one, as a chocolate suit or chocolate soil. There is an adjective, "chocolaty," which can mean rich in chocolate or resembling chocolate in color.

Suggested usage: Use chocolate with caution (it can be addictive) but the word you may toss around with abandon, so long as you keep in mind that it always connotes the ultimate in edibility: "The chocolate make-up on her mouth and eye-lids made it difficult for him to keep his lips to himself." Ladies, please use make-up of this color judiciously, less you encounter a chocoholic (someone obsessed with the taste of chocolate).

Etymology: English borrowed "chocolate" from Spanish but it ultimately comes from the language of the Aztecs, Nahuatl: "xocolatl." This word is built on xococ "bitter," a drink made by a sugar-free people from cacao, itself from Nahuatl cacauatl "cacao". The same language gave us "coyote" from "coyotl" and "chili" from "chilli." It is also the source of ahucamolli "avocado soup or sauce," from which Spanish "guacamole" derives, and ahucatl "avocado," from which guacamole derives. The Aztec "ahuacatl" sounded so much like the old Spanish word avocado "lawyer" (currently abogado), that the Spanish made the slight folk etymological change before lending the word to English. (Thanks to Luis Apiolaza and Grant Hutchinson, frequent conversants in the YD Agora, for suggesting the rich, dark source of today's word.)

MALE OR FEMALE?

SWISS ARMY KNIFE - male, because even though it appears useful for a wide variety of work, it spends most of its time just opening bottles.

SHOE - male, because it is usually unpolished, with its tongue hanging out.

HAMMER - male, because it hasn't evolved much over the last 5,000 years, but it's handy to have around.

TIRES - male, because they go bald and often are over inflated.

HOURLASS - female, because over time, the weight shifts to the bottom.

REMOTE CONTROL - female... Ha! You thought I'd say male. But consider it gives a man pleasure, he'd be lost without it, and while he doesn't always know the right buttons to push, he keeps trying.

Ah, yes....I remember it well.....

Next time you are washing your hands and complain because the water temperature isn't just how you like it, think about how things used to be.

Here are some facts about the 1500s. Most people got married in June because they took their yearly bath in May and still smelled pretty good by June. However, they were starting to smell so brides carried a bouquet of flowers to hide the body odor. Hence the custom of carrying a bouquet when getting married.

Baths consisted of big tubs filled with hot water. The man of the house had the privilege of nice clean water, then all the other sons and men, then the women and finally the children -- last of all the babies. By then the water was so dirty you could actually lose someone in it -- hence the saying, "Don't throw the baby out with the bath water."

Houses had thatched roofs -- thick straw -- piled high, with no wood underneath. It was the only place for animals to get warm, so all the dogs, cats and other small animals (mice, bugs) lived in the roof. When it rained it became slippery and sometimes the animals would slip and fall off the roof -- hence the saying, "It's raining cats and dogs."

There was nothing to stop things from falling into the house. This posed a real problem where bugs and other droppings could really mess up your clean bed. Hence, a bed with big posts and a sheet hung over the top afforded some protection. That's how canopy beds came into existence.

The floor was dirt. Only the wealthy had something other than dirt. Hence the saying, "Dirt poor." The wealthy had slate floors that would get slippery in the winter when wet, so they spread thresh (straw) on the floor to help keep their footing. As the winter wore on, they kept adding more thresh until, when you opened the door it would all start slipping outside. A piece of wood was placed in the entranceway -- hence a "thresh hold."

In those old days they cooked in a kitchen with a big kettle that always hung over the fire. Every day they lit the fire and added things to the pot. They ate mostly vegetables and didn't get much meat. They would eat the stew for dinner, leaving leftovers in the pot to get cold overnight

and then start over the next day. Sometimes the stew had food in it that had been there for quite a while -- hence the rhyme, "Peas porridge hot, peas porridge cold, peas porridge in the pot, nine days old."

Sometimes they could obtain pork, which made them feel quite special. When visitors came, they would hang up their bacon to show off. It was a sign of wealth that the man could "bring home the bacon." They would cut off a little to share with guests and would all sit around and "chew the fat."

Those with money had plates made of pewter. Food with high acid content caused some of the lead to leach into the food, causing lead poisoning and death. This happened most often with tomatoes, so for the next 400 years or so tomatoes were considered poisonous.

Bread was divided according to status. Workers got the burnt bottom of the loaf, family got the middle and guests got the top or "upper crust."

Lead cups were used to drink ale or whisky. The combination would sometimes knock them out for a couple of days. Someone walking along the road would take them for dead and prepare them for burial. They were laid out on the kitchen table for a couple of days and the family would gather around and eat and drink and wait to see if they would wake up -- hence the custom of holding a "wake."

England is old and small and local folks started running out of places to bury people. They would dig up coffins and would take the bone to the "bone-house" and reuse the grave. When reopening these coffins, one out of twenty-five were found to have scratch marks on the inside and they realized they had been burying people alive. They would tie a string on the wrist of the corpse, lead it through the coffin and up through the ground and tie it to bell. Someone would have to sit out in the graveyard all night (graveyard shift) to listen for the bell, thus someone would be "saved by the bell" or was considered a "dead ringer."

.....and that's the truth...whoever said that history was boring.

Author unknown.

Treasurer's Thoughts

In my last article I said I would tell you how the day to day costs were met and controlled. Hilary added a postscript that the next issue would include details of how the organisation is run.

Sitting in the chair of treasurer I'm not involved in anything to do with:

- the Health Service,
- attending conferences,
- giving talks or
- taking telephone calls from potential members

and I will have to leave others to tell you about that aspect of our work

As treasurer I am a trustee of the charity so do my bit contributing to the discussions on

- the constitution (it is unfortunately necessary to revise it again),
- the way we want to move forward and
- the costs of what we do.
- as well as paying the bills,
- banking the membership money (remembering to tell Robin who has paid)
- and worrying over our financial commitments.

Membership

Robin (the membership secretary) is currently encouraging all members to keep up their membership, and he appears to be being successful; in addition the committee is considering ways of approaching lapsed members to see if they wish re-join. Membership is important not just because of the fees it brings in (the annual fee of £10 or \$25 just about covers the newsletter), but increased numbers also give the organisation more "clout" when dealing with the NHS and other official bodies.

The Newsletter

With respect to the newsletter the last two copies of the magazine have been 24 pages long, and you have probably noticed that they are now printed, rather than photocopied, and have become more colourful. The cost of the last newsletter, including the postage envelope etc, was an average of £1.69 per member. The newsletter has a long journey before it reaches you.

As you know Hilary is responsible for the editorial content, once complete this is sent to the printer via Robin. Once printed the newsletter is despatched from the printer in Kent (who invoices me), to Skegness where members Barry and Olivia put them all in envelopes (Robin pre-prints sticky labels from the membership list) Barry and Olivia get the envelopes to the post office (don't ask me how - approximately 260 were posted out in January). Barry buys

the stamps from the cash float he carries; hopefully he gets from the counter staff in sticking the stamps and postage labels on. He sends me the receipt from the post office and I reimburse his float. Every other issue he goes out and buys fresh supplies of envelopes. After all of that it lands on your door mat, and if you're anything like me you ask Hilary why it was late this month.

Expenses

I do encourage all committee members and helpers to put in expense claims, but all I can say is that expense claims are conspicuous by their absence. I even tell them that if they let me know what their costs were but didn't claim them I could treat it as a donation - but they all ignore me.

Gift Aid Donation

So far I have received 31 signed declarations. Thank you to those 31 people, for other members who haven't filled in the form (copy available in the October newsletter), but do pay tax I would be very grateful if you could complete it and send it to me. When April 5th comes I am currently able to claim £250 from the Inland Revenue so far this year. Between us we can make it more.

Donations

At the time of writing this (19th February) we have received £1,104.07 and \$330 in donations from 27 individuals including over £400 given in memory of John Bowles. Thank you to all of you we do rely on donations.

Your comments

I would be grateful to hear any ideas you have

jenni.paulger@lincolnshirepostpolio.org.uk

Jacob and Rebecca to Marry.

Jacob (92) and Rebecca (85) are all excited about their decision to get married. They go for a stroll to discuss the wedding and on the way go past a drugstore. Jacob suggests that they go in. Jacob addresses the man behind the counter: "Are you the owner?" The pharmacist answers "Yes." Jacob: "Do you sell heart medication?" Pharmacist: "Of course we do."

Jacob: "How about medicine for circulation?" Pharmacist: "All kinds." Jacob: "Medicine for rheumatism?" Pharmacist: "Definitely."

Jacob: "How about Viagra?" Pharmacist: "Of course." Jacob: "Medicine for memory?" Pharmacist: "Yes, a large variety."

Jacob turns to Rebecca: "Sweetheart, we might as well register our wedding gift list with them."

Thankyou for the donations towards our work received from

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