



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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Editor's Corner

As I write this column a highly successful (Post) Polio Awareness Week has just concluded. Thanks to the generosity of our members we received a lot of publicity; a report on this is given on page 4. The Week culminated with a picnic at Pecky's Playground, Prospect. The weather was perfect and a great social day was enjoyed in a peaceful bush setting. Being a more relaxed affair than our Seminars, it gave people the opportunity to catch up at length with friends over a leisurely lunch, while listening to the *Bush Bandicoots* play lyrical music. Member Tony Marturano was fortunate enough to win the well-stocked Christmas hamper raffle put together by Alice.

Our Annual General Meeting and Seminar: **Post-Polio and Urinary Problems** will be held on **Saturday 29 November**, commencing at **11:00 am**. Full details are given on page 2. The Network's 1996/97 Annual Report and Financial Statements, and the last AGM's Minutes, are enclosed. Please try and attend the AGM. We need members to participate in this important meeting where the Management Committee is elected for the next year. Come and have your say.

Copies of the **Proceedings** of the November 1996 Conference *Living with the Late Effects of Polio* are still available at a cost of \$29. Also on sale at the AGM will be our Network T-Shirt (which features a colourful graphic of a polio virus particle) at \$15, and Christmas puddings at \$10.

Membership Renewals - Please Read This Important Message

The Network's membership year runs from 1 July to 30 June, in line with our financial year. This means that everyone's membership is due for renewal on 1 July each year. At any time, however, some members are yet to pay for the current year, some members are financial for the current year, while still others are financial for the next year (or even later). So that you are aware at all times when your membership is paid up to, the following is printed across the top of your address label: "Renewal due on 1 July XXXX" where XXXX is the year that your membership is paid to. For the majority of you, the date on your label will read "1 July 1998", while a few members are paid in advance beyond that date. **However, if the date on your label is "1 July 1997" you have not yet renewed for this current year, and your membership subscription is overdue. In this case you will find a Membership Renewal Form included with this Newsletter.** Your early return of this form with the subscription amount due will ensure that you continue to receive the Newsletter. Remember, if you have already discarded your address label before you read this, you only owe money if you have received a Membership Renewal Form.

Merle Thompson has asked me to pass on her thanks to all those members who took the time to complete the **Member Questionnaire** which was distributed with the last Newsletter. We had a very good response which Merle will shortly start to analyse. It is not too late to return the Questionnaire, so if you've been meaning to fill it out, please do so now!

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Annual General Meeting

Date: Saturday, 29 November 1997

Time: 11:00 am - 12:00 pm

Agenda: As previously circulated

Venue: The Independent Living Centre
600 Victoria Road, Ryde

Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking spaces for members who are only able to walk or wheel short distances.

Lunch: Bring a packed lunch to eat from 12:00 pm.

Afternoon Tea: As this is our Christmas meeting, you are requested to bring a plate to share after the AGM Seminar concludes.

Drinks: Cordial, tea and coffee will be available all day.



Seminar : 1:00 pm

Post Polio and Urinary Problems

There are few things more distressing than recurring urinary problems, especially if polio limits your mobility and makes the problems harder to tolerate. Well, you don't need to put up with such discomfort. For example, the rehabilitation specialists at the Post-Polio Clinic at Prince Henry Hospital recognise that polio's late effects can impact on urinary function and they refer polio survivors to specialists in this field.

Following the Annual General Meeting, we are very fortunate to have Urologist/Gynaecologist **Dr Andrew Korda** speak on this important topic. Dr Korda is Chairman of the *Sydney Incontinence Forum* and treats both men and women in his practice. Most importantly, he has treated polio survivors and understands their particular and differing difficulties. After his presentation, Dr Korda will answer questions from the floor.

As usual, afternoon tea will follow. Please stay on and celebrate the festive season with us at the last Seminar for 1997. If you are a new member this is a great Seminar to attend to meet people, as we always get a good roll-up at Christmas.

Meet the Management Committee

This month we are continuing our profile of Management Committee members. Network Librarian Tony Marturano took these photos so that you can get to know the Management Committee, and be able to recognise Committee members at meetings. More next issue.



Merle Thompson is a very active member of the Management Committee, even though she works full-time and commutes from the Blue Mountains to the City for work and to attend Network meetings. Merle has taken on several projects for the Committee, including collating and publishing details in the Newsletter of all NSW rehabilitation facilities, making and maintaining contact with Area Health Services and Divisions of General Practice, assembling an Immunisation Information Kit, and developing a Hospital Admission Fact Sheet and Wallet Card.



Allan Quirk has been a keen supporter of the Network and its Management Committee for many years. He brings to meetings a wealth of knowledge from his active involvement in the disability sector. He also brings potential issues to the notice of the Management Committee. Allan has special interest in access for people with disabilities who walk rather than use wheelchairs, the move of the health industry towards a "casemix" model and the implications this may have for polio people, and companion animals.



Bernie O'Grady is the popular Convener of the Blacktown / Blue Mountains Support Group. In the second half of this year Bernie has also been acting as Support Group Co-ordinator after the resignation of Nancye Bonham due to ill health. Bernie has represented the Network at several forums, particularly those discussing health issues. Whenever a mail-out needs willing hands, we can always count on Bernie and his wife Irene (an Associate Member) to assist.

Report on (Post) Polio Awareness Week: 2 to 8 November

This year we supported the Commonwealth Department of Health and Family Services' *Immunise Australia Program*. Our poster depicted people who have disabilities resulting from polio. We distributed 1000 of the posters to interested members, early childhood centres, Area and Regional Health Services, Divisions of General Practice, and many community and government organisations throughout NSW. Posters also went to the interstate Post-Polio Networks to keep them informed of our campaign, while Librarian, Tony Marturano, placed a copy of the poster and related materials on our Internet home page to reach an even wider audience. We had good feedback about the poster, with some suggesting it should be displayed year round.

In addition to posters, all members who had offered to do media interviews were sent copies of *A Short History: Post-Polio Network (NSW) Inc*, a Fact Sheet on *The Late Effects of Polio*, and the booklet *Understanding Childhood Immunisation*, as background information.

Publicity for the Week went very well. Janet and Alice were kept busy organising members to speak to reporters all over New South Wales. Full details are still being collated, but to date we are aware that six interviews were aired on metropolitan radio stations, four on regional radio, one on regional TV, and twelve stories appeared in local newspapers. We also received many mentions in newspaper *Community Noticeboard* columns. Janet has asked me to pass on her heartfelt thanks to all members who so willingly participated in media interviews to ensure that the Week got a lot of coverage.

Immunise Australia Program Receives A Boost

The following update was provided to us by the Commonwealth Government.

First launched in February 1997, *Immunise Australia* has now stepped up a gear with a new community education program designed to boost Australia's low level of full immunisation.

Community Education Program

The Community Education Program was launched at the New Children's Hospital in Sydney by Federal Health and Family Services Minister, Dr Michael Wooldridge in July. A confronting television advertisement featuring a seven-week old baby coughing violently as a result of whooping cough was unveiled as the latest weapon in the Government's bid to lift immunisation coverage. Other advertisements later this year will focus on measles.

Dr Wooldridge said it was amazing that only just over half of the children in Australia are fully protected from vaccine preventable disease. "This year in particular there has been an alarming number of cases of whooping cough in children too young to be immunised who have caught the disease from older unimmunised children", Dr Wooldridge said. The Minister also confirmed that Immunisation Awareness Days will be held on Saturday 4 October and Saturday 6 December at locations where immunisation coverage is low.

Non-English Community Education Program

A collection of multilingual information resources has been specifically designed to ensure the immunisation message reaches Australians from diverse cultural and linguistic backgrounds. Advertising will appear in non-English press and radio and a public relations program will be supported and driven by the use of bilingual health professionals. Printed materials have been produced in 12 community languages.

Community Education Program - next steps

The Immunise Australia Community Education Program will continue until December and will consist of: TV and print media advertisements; supporting public relations program to provide more complex information to the community and providers; a 1800 information line; a regular editorial column in *Australian Doctor*; development and distribution of the Immunise Australia Program update newsletter; and development of the Australian Childhood Immunisation Charter through which health professionals and community groups will commit their support for immunisation.

Polio's Legacy: An Oral History

by Edmund T Sass

Book Review by Mary Westbrook

Edmund Sass, a polio survivor, found himself captivated by a book of first hand accounts of Vietnamese people's experiences during the Vietnam War. It occurred to him that, "Polio survivors also have stories to tell. We received no purple hearts or even belated recognition for the wounds we received" at a time "when there was no concern for handicapped rights or accessibility, a time before political correctness, when a person with a physical disability was just a 'cripple'".

Sass gives as a rationale for his book the fact that "Polio survivors are an endangered species... There won't be any more like us and no one will mourn the fact. When we are gone, so are our stories. And the loss will be more than ours, for these stories tell us much about coping, the resiliency of the human spirit, and living a good life in spite of adversity". In his conclusion he states that the stories in the book "should give optimism to parents who are currently raising a child with a disability or chronic illness".

The book consists of interviews with 35 American survivors who were asked to "Describe their recollections of the day they were diagnosed with polio; their initial stay in hospital; the types of therapy, surgeries and other treatment they received; the impact of polio on their childhood, their family, their relationships and their adulthood; to describe any post-polio symptoms" and in addition to tell their best polio related stories. Sass comments that most participants had "stories bottled up inside them just waiting to be told" but had rarely related them.

The book commences with a twenty page history of polio written by Richard Owen, a rehabilitation specialist, polio researcher and polio survivor, whose personal story is also included. Owen notes that the development of the polio vaccines brought "research on the disease and its treatment to an abrupt halt... Knowledge about the epidemiology and pathology of polio is essentially frozen at a mid-1950's level". Many mysteries and enigmas regarding the disease remain. Owen sees Roosevelt's attack of polio as "a stroke of luck, not only for polio victims, but for those with other disabilities as well". Not only did Roosevelt affect attitudes toward people with disabilities but he "played a crucial role in raising millions of dollars for the treatment of polio patients and polio related research". Owen comments on polios' denial of fatigue. He says that the only three groups who work their muscles to total exhaustion are weight-lifters, race horses and polios.

Sass organised the 35 histories into ten chapters based on the major themes emphasised by the story tellers. Thus the first chapter "She carried herself like a queen" contains the autobiographies of three survivors personally treated by Sister Kenny. Almost all thirty-five participants were treated by the Kenny method and tales of hot packs (one survivor still has scars from them), stretching and manipulation of limbs occur in most stories. Fifteen survivors report having surgery (40 operations in all) and many of their stories occur in the chapters "Under the knife" and "Scoliosis: The abnormal curve". One teenager found that "a mistake had been made when they put me in the cast. They had set my left foot at the wrong angle, and after being like that for six months, it stayed that way".

Because the doctor "forgot" to place small sponges at pressure points such as the heel, "when the cast came off, a lot of skin and meat came off with it". Twenty-five years later this woman still experiences great pain and has trouble walking. Some other operations were also badly botched but no one brought malpractice suits.

Survivors are now finding it difficult to find follow-up care. One woman who had undergone spinal fusion for scoliosis saw the specialist who performed it shortly before the doctor's retirement. "When I asked him for a referral to another orthopedic specialist he just said 'All I can say to you is that I really don't have anyone to whom I can refer to you.' " Eventually she hurt her back and visited a scoliosis clinic. One of the doctors tested the reflexes in her knees. "He discovered I didn't have any. He looked over at the other physician in the examining room and said 'She did walk in here, didn't she?' The other doctor looked at him and said 'Yeah, but I'm not sure how.' "

Other chapters also have treatment oriented titles such as "Of lungs and wheelchairs" and "Braces, crutches and canes". Some chapters are titled according to the time of onset, "Adult polio" and "Old Timers" (people who contracted polio before 1940, none of whom were hospitalised). The final three chapters relate to outcomes: "Complete (or almost complete) recovery", "Active lives" and "Late effects".

The format of the questions asked has contributed to many of the autobiographies being recitations of facts with little indication of how these events affected the person. While the medical care differed from that received by most Australian survivors many of the experiences are similar. Participants speculate as to why they were the only person in their family or neighbourhood who developed paralytic polio. The problems associated with lack of access at school, the loneliness and lack of dates in adolescence, the determination to walk again (preferably without irons) despite what the doctors said, the refusal of doctors to acknowledge the reality of post-polio symptoms, are experiences that most survivors will relate to.

The survivors who admit to having late effects from polio seem to be franker about their feelings. One woman recounts that it was only in adulthood that she appreciated how her early hospitalisation had caused her to be the only member of her family who suffered from separation anxiety. "My homesickness prevented me from enjoying overnight visits with my friends and resulted in humiliation, embarrassment and of course teasing." Those who report that they have no post-polio symptoms often attribute this to leading very active lives. Some who have post-polio symptoms conclude that they are "paying the price" for pushing themselves too hard.

However, many participants who deny having post-polio symptoms go on to mention their increasing fatigue, pain, falls etc. Sass himself says that he has read of " 'Babying your motor neurons' and 'listening to your body' ". But if I listened to mine, I'm afraid that all I'd do all day is sit on the couch and complain... . Instead, I intend to keep on exercising and living my life basically as I have always done." Another participant who says that she is "alert" for symptoms but "have certainly felt none", is nevertheless feeling fatigue, is limping more and falling over often, though "I never hurt myself". She was offered a handicapped parking space at work, "But I said it was silly to hold down a handicapped parking spot for eight hours a day. There must be somebody else who needs it more than I do, and I think I'd feel guilty if I parked there. I just need to get close enough to get in without falling". Fortunately her boss has provided her with a non-marked reserved parking space. One respondent says that even if he had post-polio symptoms "I don't think I'd admit to having them". It makes one wonder about the accuracy of post-polio research in which the researcher attempts to establish the prevalence of post-polio syndrome by sending questionnaires to, or phoning, all the people in a particular area who contracted paralytic polio. As this book demonstrates, denial is rampant.

A theme raised in most of the accounts is, what would my life have been like if I hadn't contracted polio? Some people speak only of the negative effects. For example, "I believe that my life would have been much more enjoyable because I would have been able to take walks, run, ride horses, dance and not have to worry about falling or whether I could get

into or out of a place". Some feel disability has hindered their career advancement. Inability to take part in sporting activities led others to concentrate on study thereby gaining access to careers they would not previously have contemplated. A doctor and a social worker found that their disabilities have led to better rapport with their clients. Several comment that their children have very positive attitudes toward people with disabilities and other minority groups as a result of their parents' disabilities. Others feel they are better people because of having polio. For example, "It has made me a much more sensitive person, not only to other people's physical disabilities, but possibly to any differences or challenges they might have". Some report being selfish or immature during adulthood as a result of their upbringing following disablement. Mary Ann says that it would be great if she could run and dance, "But if I had to go back and not have the same life's journey I think I'd say 'No thank you'. It's been 45 years, and I like where I've gone and where I am. I don't like the disability, but I do like my life and the life's journey that I had".

Many participants appreciate the improvement in attitudes toward people with disabilities, "You're no longer some oddity or a freak", and today's greater access. Bill however does not. Bill came from a working class family none of whose members had attended college. His widowed mother managed to obtain an extremely generous rehabilitation scholarship which enabled him to attend a prestigious university. As a result Bill has had a successful career as a university administrator. Today he reacts negatively "to so-called disabled or physically challenged people. I often use the term derisively. I have made cracks about 'crippled' people parking spaces... I get angry. Maybe it's because nothing like that was done for any of us when we had polio. After all, I had to manage without any of those things when I was in a wheelchair".

One contributor concludes that "Polio is a particularly cruel disease. It steals your childhood, gives you 20 or 30 years to adjust to the disabilities which you were left, and then threatens to return to complicate your life again". This return is exceptionally difficult to cope with according to Jennifer (another participant who won't get a disabled parking sticker as she always has someone who can push her chair through parking lots) because polio survivors feel guilty. "Our parents told us we were just like everyone else, and if we wanted something we could do it. It might be harder for us, but we could do it. I think we just got that in our brains, and it's hard for us to accept that we have limitations now." Sharon comments "In this part of my life, I have to find a way to accept that if I don't work from seven in the morning to midnight, I'm still valuable. And that's the hardest lesson of all, because so much of my life has been serving and living up to people's expectations". After experiencing much grief Jennifer has found that "If I live within those boundaries my life can be like a well framed picture, and that picture can be filled with beauty and joy. I can do a lot of things that fit within that picture frame, but if I try too much, then it all spills out and ruins the most important things, the beauty and joy I've put at the centre of the picture ... accepting those limits helps me to see the possibilities within the limits".

Overall this is an interesting book. While it is intriguing to observe the range of ways in which people reacted to polio and its problems there is a certain repetitiveness as each participant answers the same set of questions. Some of the contributors have views on the causes and treatment of post-polio symptoms that are counter to research evidence. Thus this is not a useful book on how to cope with post-polio symptoms. You will identify with some participants and sigh and smile over their recollections. Others may remind you of how you used to feel before you decided to change your lifestyle by taking major steps such as applying for a disabled parking permit. Unfortunately the book is so overpriced that I would not recommend buying a copy.

"Polio's Legacy: An Oral History" was published in 1996 by University Press of America. Its ISBN number is 0-7618-0144-8. A copy may be purchased as a special order (takes three or four months) through the Co-Op Bookshop, Cumberland Campus, University of Sydney, phone number 02-9351 9484. It costs \$70.

Pain in Post-Polio Syndrome

Anne C Gawne, MD

Anne Carrington Gawne, MD, received her medical training at the Uniformed Services University in Bethesda, Maryland, and did her residency at the National Rehabilitation Hospital in Washington, DC. Before moving to Spain Rehabilitation Center at the University of Alabama in Birmingham, Dr Gawne treated polio survivors at National Rehabilitation Hospital for nine years. She co-authored "Post-Polio Syndrome: Pathophysiology and Clinical Management" with Lauro S. Halstead, MD, National Rehabilitation Hospital, which was published in "Critical Reviews in Physical Medicine and Rehabilitation", Vol. 7, Issue 2, pages 147-188.

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Symptoms of post-polio syndrome include fatigue, new weakness, and pain in muscle and joints. Chronic pain is the second most prevalent symptom reported and frequently is the most difficult to treat. Improvement in the evaluation and treatment of pain can significantly improve comfort and restore function. The differential diagnosis is extensive, but many of the problems appear to be related to overuse of weak muscles along with abnormal joint and limb biomechanics.

To facilitate the diagnosis and treatment of pain, a classification that divides the pain syndromes into three classes has been developed: 1) post-polio muscle pain; 2) overuse pain; 3) biomechanical pain.

Post-Polio Muscle Pain occurs only in muscles affected by polio. It is described as either a deep or superficial aching pain, which many survivors say is similar to the muscle pain they experienced during their acute illness. Characterized by muscle cramps, fasciculations, or a crawling sensation, it typically occurs at night or the end of the day when one tries to relax. It is exacerbated by physical activity and stress, and cold temperatures.

Overuse Pain includes injuries to soft tissue, muscle, tendons, bursa, and ligaments. Common examples are rotator cuff tendonitis, deltoid bursitis, and myofascial pain. Myofascial pain in post-polio is similar to that in others. It occurs most frequently in the muscle of the upper back and shoulders and is characterized by bands of taut muscles and discrete *trigger points* that elicit a *jump* response when palpated. These occur due to poor posture or improper body biomechanics.

Fibromyalgia (see box on page 9) with its associated symptoms is another cause of muscle pain that has been recognized by other investigators and has similar symptoms, but is distinctly different from post-polio muscle pain. The classic *tender points* are uncommon with post-polio muscle pain.

Biomechanical Pain presents as a degenerative joint disease (DJD), low back pain, or pain from nerve compression syndromes. Weakness induced by polio affected muscles, as well as poor body mechanics, makes the joints more susceptible to the development of DJD. Survivors who walk develop degenerative joint disease in the lower extremities because years of ambulating on unstable joints and supporting tissue increase the chance of developing further pain and deformity. Those who use wheelchairs or assistive devices such as canes, crutches, or walkers are prone to DJD, or overuse syndromes, in their upper extremities, especially the wrist and shoulders. The joint pains are only rarely accompanied by swelling and/or inflammation, but do demonstrate tenderness and abnormal range of motion. X-rays of painful, weight-bearing joints may show degenerative changes proportional with the amount of stress the joints have sustained.

Nerve compression syndromes, including carpal tunnel syndrome (CTS), ulnar mononeuropathy at the wrist or elbow, brachial plexopathy, and cervical or lumbosacral radiculopathy, are syndromes that can cause pain as well as neurological deficits in the post-polio individual. Risk factors for the development of focal neuropathies of the median and ulnar nerves include use of an assistive device such as a cane, crutch, or wheelchair. These neuropathies can be detected on electrodiagnostic tests (EMG/NCS) before the individual has the characteristic symptoms of CTS.

Diagnostic Criteria : Fibromyalgia Syndrome (FMS)

(according to the 1990 American College of Rheumatology)

To meet the criteria, patients must have:

- widespread pain in all four quadrants of their body for a minimum of three months
- at least 11 of the 18 specified tender points

Although the above criteria focuses on tender point count, a consensus of 35 FMS experts have recently determined that a person does not need to have the required 11 tender points to be diagnosed and treated for FMS. This criteria was created for research purposes and many people may still have FMS with less than 11 of the required tender points as long as they have widespread pain and many of the common symptoms associated with FMS. Commonly associated symptoms include:

- fatigue
- sleep disorder (or sleep that is unrefreshing)
- jaw pain (TMJ dysfunction)
- post-exertion malaise and muscle pain
- numbness and tingling sensations
- skin sensitivities
- irritable bowel
- chronic headaches (tension-type or migraines)
- cognitive or memory impairment
- morning stiffness
- menstrual cramping and PMS
- dizziness or impaired coordination

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The evaluation of post-polio individuals with pain requires careful investigation of all aspects of their pain. Among the questions asked are typical ones such as "What makes the pain better?" and "What makes it worse?" The way pain interferes with the survivors' ability to sleep and work is noted. Which treatments are helpful and by whom they are given is also documented.

Pain management in post-polio is based on a few basic principles, supplemented by class-specific recommendations. These basic principles include efforts to: 1) improve abnormal body mechanics; 2) correct and minimize postural and gait deviations mechanically; 3) relieve or support weakened muscles and joints; 4) promote lifestyle modifications; 5) decrease the abnormally high work load of muscles relative to their limited capacity.

Treatment for Post-Polio Muscle Pain includes decreasing activity throughout the day, applying heat, and stretching. Stretching has a role in maintaining the extensibility of muscle and connective tissue; however, it must be performed judiciously because there are

situations in which a polio survivor may derive greater functional benefit and be safer with tighter tendons and reduced joint range of motion.

A variety of medications are used to treat post-polio muscle pain, but the most common ones - such as nonsteroidal anti-inflammatories (NSAIDs), Tylenol, benzodiazepams, and narcotics - are of little use. The use of tricyclic antidepressants (TCAs), especially amitriptyline, can help with pain and also with fatigue.

Treatment for Overuse Pain includes modification of extremity use, followed by modalities such as ice, heat or ultrasound, transcutaneous electrical nerve stimulation (TENS), and occasionally NSAID medications. Treatment for myofascial pain consists of myofascial release techniques, including spray and stretch and trigger-point injections. Often rest is not possible since many rely on upper extremities for both locomotion and self care. In rare cases, steroid injections or surgery may be needed.

Treatment for Biomechanical Pain includes posture and back-care education and decreased weight bearing through use of assistive devices such as braces, crutches, wheelchairs, and scooters. Abnormal biomechanics can often be modified with fairly simple and practical interventions such as cervical pillows, lumbar rolls, glottal pads, dorsal-lumbar corsets, and heel lifts. These pains are usually improved by conservative measures aimed at reducing mechanical stress - pacing activities, supporting weakened muscles, stabilizing abnormal joint movements, and improving biomechanics of the body during common daily activities. Anti-inflammatory agents are used sparingly, and then only in low doses to supplement conservative measures. In particular, efforts should be directed at improving routine daily activities such as sitting, standing, walking, and sleeping, as well as any repetitious activities at work. Weight bearing with the wrist hyperextended and radically deviated should be avoided.

For those with carpal tunnel syndrome who must use a cane or crutch, an Ortho-ease or pistol grip is prescribed to place the wrist in a more neutral position and spread out the weight-bearing surface on the palm. Providing adequate support for weakened muscles and unstable joints can often be a difficult challenge; however, the basic orthotic principles are similar to those used in the management of other neuromuscular diseases. For individuals with low-back pain, lumbosacral corsets, a shoe lift, or pelvic lift can help improve biomechanics. For genu recurvatum (back knee) or genu valgus (knock knee) due to quadriceps weakness or ligament instability, a long-leg brace (KAFO - knee-ankle-foot orthosis) with a free ankle and an extension stop at the knee is used. Polio survivors with dorsiflexor weakness or ankle instability can benefit from an athletic ankle splint, high-top shoes, or a short leg brace (AFO - ankle-foot orthosis).

Many individuals need an orthosis that combines strength and lightness. The new plastics and lightweight metals can often be used alone or in combination. Frequently, survivors prefer to repair and use their old braces rather than start over with new ones. Others may resist using any kind of brace for cosmetic and psychological reasons. Orthotics are recommended for the following indications: 1) to improve safety by reducing the risk of falls; 2) to reduce pain; 3) to decrease fatigue by improving gait speed and symmetry.

Pain can be reduced by altering biomechanics and by changing to a lifestyle that reduces physical activity. These strategies may be difficult to accomplish, however, because they often require developing behaviors unlike the old, familiar ones. Altering the pace and intensity of discretionary activities and learning new ways to gain more control over when and how activities are performed is essential. Restoration of function as well as relief of pain can be accomplished by an inter-disciplinary team that includes the polio survivor, physical therapist, occupational therapist, psychologist, rehabilitation engineer, and physician.

Surfing the Net!

I'm presenting two quite dissimilar articles this issue from my Internet browsings. I hope you enjoy them. The first focuses on fatigue.

Post-Polio Fatigue

How It Can Change Your Mind

Mavis J. Matheson, MD

February 1995

One of the most frustrating late effects of polio for me was the awareness that I could not concentrate and a feeling that I wasn't thinking clearly any more. For many of us who have compensated for our physical limitations through intellectual pursuits this is a terrifying feeling. Is it not bad enough that our bodies are giving out? Must we undergo the indignity of losing our minds as well? Studies show that in spite of marked impairments of attention, polio survivors are within the high normal or superior range on measures of higher-level cognitive processes and IQ. [1] They also show that if we allow ourselves to become fatigued we do lose our ability to focus our attention and to rapidly process complex information (requiring 23 to 67 percent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no fatigue or mild fatigue). [2]

Polio survivors experience two kinds of fatigue. One is physical tiredness and decreased endurance. The other and often more distressing kind is "brain fatigue". Brain fatigue describes problems with attention, alertness and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration (96%), memory (85%), attention (82%), word finding (80%), staying awake, and thinking clearly (70%). [3] Tests indicate that an impairment of selective attention (related to damage as a result of polio) results in feelings of fatigue and cognitive problems. [2]

The poliovirus damages the anterior horn cells of the spinal cord but that is not all it damages. It also damages parts of the brain stem. Findings indicate that poliovirus consistently and often severely damaged the brain areas known as the Reticular Activating System. [4],[5] These areas are responsible for activating the part of the brain involved in maintaining voluntary attention, memory, spontaneous interest, initiative and the capacity for effort and work, and for preventing feelings of fatigue. This is the area that keeps us awake and allows us to focus our attention. [5]

Polio survivors report that they are most disabled by the visceral symptoms of fatigue. These are feelings of exhaustion, passivity and an aversion to continued effort that generate an avoidance of both mental and physical activity. [5] Dr RL Bruno suggests the existence of a Fatigue Generator in the brain. [5] His findings suggest that there is a close relationship between impaired attention and fatigue. There would be survival value in a brain mechanism that promotes rest when attention and information processing ability are impaired. An area of the brain (the Basal Ganglia) may generate mental and physical fatigue. When the Reticular Activating System is damaged, the Fatigue Generator takes over and produces problems with focusing attention and with physically moving without significant conscious effort. Damage caused by the poliovirus chronically reduces the firing of the nerve cells in the Reticular Activating System. Rest or sleep would increase the firing of the brain activating system nerves, restore activation and once again allow motor behavior. [5] [Ed: An article by Dr Bruno detailing his work in this area was obtained from the Internet and reprinted in PPN Newsletter Issue 24, June 1995.]

The damage would explain why polio survivors have no difficulty concentrating after the original infection but why are we developing problems thirty or forty years later. One theory is that the age-related loss of nerve cells combined with an already abnormally small number of nerve cells as a result of the original poliovirus infection may impair the brain's activating system enough to produce impaired attention and fatigue as polio survivors reach mid-life. [4]

The first step in treating the disorders of concentration, memory, attention, word finding, staying awake, and thinking clearly is to deal with the fatigue. Energy conservation, work simplification and the proper provision of rest periods throughout the day are the treatments of choice in dealing with post-polio fatigue. [6] Stress management is also critical in the treatment of post-polio fatigue. [7] Dr Bruno et al are currently studying the use of a medication (a post-synaptic dopamine receptor agonist currently used in the treatment of Parkinson's Disease) in the treatment of post-polio patients who do not respond to conservative treatments. [1] They caution that there is a real danger that treatment with medications will allow Polio survivors to resume their hyperactive Type A lifestyles and further stress poliovirus-damaged, "metabolically vulnerable" neurons in the brain stem and anterior horn. [7]

As with any treatment strategy we must try to find the most effective treatment that will do the least long term damage while helping us to deal with our current problems. Certainly reducing physical and emotional stresses in our lives and getting adequate rest make sense for everyone, even polio survivors. The good news is if you can get rested, you will find your ability to concentrate, pay attention, remember words and stay awake will improve. You may even find that you can enjoy reading and thinking again!

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The second Internet article tells a story of polio and survival from a perspective that not many of us would have experienced. The article was posted on the Internet by Paul Cone, whose opening remarks indicate he is a polio survivor himself.

Friends

The following article, from the San Francisco Chronicle (16 April 1995), tells the story of a Vietnamese-American polio survivor whose hardships are difficult to imagine. Yet she has maintained balance and developed compassion. After reading it my troubles seem small. I am posting with some deletions from the original.

Paul Cone Be kind to yourself and others.

Vietnam

Pamela Burdman, San Francisco Chronicle Staff Writer

Thirteen year old polio survivor Ly Vo had never been on an airplane before, but the moment the cargo door popped out, she knew the C5A Galaxy was going to crash.

It was the spring of 1975, and the Viet Cong were advancing on Saigon. The military plane was just minutes out of Saigon's Tan Son Nhut Airport, on a mission to carry 13-year-old Ly and 242 other children from Vietnamese orphanages to safety in the United States.

Sitting in the cargo hold and staring at blue sky as the wind rushed in, Ly began to feel faint. "I knew I would probably end up dying", she recalls 20 years later. "Living through the war, we knew that most likely we were going to die. We just didn't know how or when."

The pilot tried for an emergency landing, but as the jet skidded along the ground, its bottom half tore off and burst into flames. When Ly awoke, she was lying on her stomach in the muddy waters of a rice paddy. Ly suffered severe internal injuries, and her legs were broken in six places, but she survived. Within a week, she was on another plane, on her way out of the country again.

For Ly, the C5A's crash was just another detour on a remarkable odyssey that has taken her from a bombed-out village in the Vietnamese countryside to orphanages in Danang and Saigon, and eventually to the San Francisco Bay Area, where she now owns a home, works two jobs and is raising a child of her own.

Ly can vividly recall the harrowing days that forever changed her life. Crippled from polio at a young age, Ly spent her early years by her mother's side. The slight peasant woman carried her everywhere. All that changed one morning when Ly was six.

Ly and her mother were eating dinner when they heard the familiar rumble of bombs exploding, but the sound seemed far off, so they did not bother running for cover. Suddenly, a foot-long piece of shrapnel flew into the hut, ripping through her mother's thigh. That night, while her father searched for a doctor, Ly watched her mother bleed to death.

"During the war" says Ly "you could die within seconds. We were faced with that really early."

The attacks, by American bombers, eventually destroyed Ly's village. Ly's father took his four children to the nearby city of Danang, where they were split up to live with different relatives. Ly remembers the day her uncle took her to the orphanage. She was never sure why.

"After my mom died, nobody cared for us" she says. "I thought I'd live in an orphanage in Danang forever."

Because of her polio, Ly was at first grouped with retarded children. To convince the nuns that she was worth sending to school, she spent two years doing chores around the orphanage. When she finally made her point, she still had to get there on her own -- putting thongs on her hands and crawling alongside the other children. Her knees grew thick from calluses.

"I had to challenge a lot in my life at a young age to get things I wanted", she says. "Education was one of them."

From the orphanage, Ly was transferred to a Saigon hospital for an operation on her legs. She was still recovering from the surgery when she was carried on board the C5A, pleading to be left in Vietnam. When she arrived at the home of her adoptive parents, the DeBolts, she was encased in a body cast from chest to toe.

Her new family was large -- Ly was the 19th child to join Bob and Dorothy DeBolt in their spacious home. Most were handicapped kids from Vietnam, Mexico and other countries.

Ly had no trouble convincing the DeBolts to send her to school. She was expected to study hard and help care for the seven kids younger than her. She was outfitted with braces and crutches and, in 1976, walked for the first time.

But Ly never stopped wondering about what had happened to her real family. Each time she heard about somebody returning to Vietnam, she would send a letter with them in hopes it would somehow reach those she had left behind. When the war finally ended, Ly's father, Minh Vo, took his other children back to the countryside. They and their neighbors found the spot on the Vu Gia river where the village had been, and began to rebuild their homes.

Three years later, in 1981, when village officials came to his hut with word of a daughter in America, Minh Vo was dumbfounded. "I had a daughter named Ly", he told them. "But I believe she has died." The officials handed him Ly's letter -- it was the tenth she had written in the previous six years. Although she could not name the village where she was born, she accurately described its setting on the river's edge, as well as nearby villages she remembered passing on the way to the bomb shelter. She wrote about her childhood, her mother's death, the orphanage. Her eighth-grade picture from Piedmont High was attached.

Five years passed before Ly saved enough from baby-sitting and other odd jobs to visit Vietnam. She went back with Anh and Tich, two of her adopted brothers who were also going to see their families for the first time.

At her native village, Ly received a hero's welcome. Her overjoyed family and fellow villagers kept her up night after night asking about her new life half a world away. They could scarcely believe how active she could be in America as a disabled person.

On her second trip, she met a farmer named Thanh, and two years ago they were married. Last year, Ly gave birth to their son, Kaimi. Thanh remains in Vietnam, awaiting a US visa

so he can join his wife and son. An arc-shaped scar on Ly's left cheek is the only visible reminder of the airlift 20 years ago.

Seventy-eight children died when the C5A went down. All had been sitting in the plane's cargo hold. According to *Friends for All Children*, the relief organization that brought Ly to Saigon for surgery and later to the US, she was one of only three children in the cargo hold to survive.

Despite two years of nonstop headaches from the crash, the nine years it took to get a settlement from Lockheed and the 12 years she was separated from her family, Ly was never bitter about being put on the plane against her wishes.

"I took it as part of life", she says. "I accepted the war so well because I accepted anything else that happened to me."

Every morning, Ly kisses Kaimi goodbye, then leaves him in the care of her adopted brother Anh. She heads off in her wheelchair for the BART ride to Longfellow Elementary School in Oakland, where she is an instructional assistant for bilingual children. In the afternoon, she's off to her job as an office assistant at the state Regional Water Quality Control Board.

Ly says she couldn't be happier with how her life turned out -- for a disabled person in Vietnam, going to work, getting married and raising children would have been virtually impossible.

She's doing what she can to change that. She and Anh have founded *Ablenet*, a nonprofit organization that is teaching disabled people in Vietnam to use computers so they can break with tradition and lead more independent lives.

Sitting in her Berkeley home after work one evening, with one-year-old Kaimi busily crawling all over her lap, Ly marvels at the circuitous path her life has taken in the last 20 years.

"I always feel I must have a purpose why I survived through so many things", she says with a smile. "I'm not sure what it is, but I think for one person to go through so much pain and suffering, there must be a purpose."



Post-Polio Seminar Program 1998

At this time of the year I usually announce the dates for next year's Seminars, so you can note them in your diaries well in advance. With the change in our financial year, the Annual General Meeting is now held later in the year. Until the new Management Committee meets after the AGM to discuss the Seminar program for the following twelve months, the details cannot be finalised

However, so that you can plan now to attend the first Seminar, the tentative date of 7 March 1998 has been set. Confirmation of this date (with venue and speaker details) as well as all other dates for 1998 will be advised in the next Newsletter. As in previous years, you can expect that four Seminars will be held throughout the year, with the final one coinciding with our Annual General Meeting.



Member Brian Nash, Springfield, has forwarded his polio story to share with our readers.

I look forward to your newsletter and when I have finished with it I pass it on to my Doctor to read, as he was surprised with what I have showed him so far.

I contracted polio in 1943 at the age of 7 years. I was put into Fairfield Infectious Diseases Hospital in Melbourne, and it was really scary for me not being allowed anyone in to see me, as they could only look from the windows. I was in there for 6 months, I was one of the lucky ones. I had it down the right side, but I got better and did not need calipers like some of the kids on my ward. But later on, everything that happened to me happened down the right side. At one stage when I was speaking to an Orthopaedic Specialist I told him that I had had polio and could these symptoms with my muscles be attributed to it, and he laughed and said no.

Since then I have had a knee reconstruction, now awaiting for both knees to be replaced and have had my right hip replaced. I was getting these muscular feelings in my right thigh and I spoke to my Doctor and he thought it was because I had pulled a muscle so sent me to see the physios but they did not get rid of the pain. I then received the two booklets from you and when I opened one of them with the drawings of the pain area I showed it to my Doctor who then said I will have to find out more about this because I do not know enough about it.

My specialist now does not insist that I have a full anaesthetic. I have an epidural and when I am back in the ward I do not suffer with the after effects of a full anaesthetic.

I have a print-out of my medical history which I have given to the Hospital to go into my records, but the Card that you have on page 15 [Ed: Issue 33] I think is very good because it is something that we should carry around with us in case anything does happen and then the medical staff know how to treat us. Hoping to hear more about this Card as I would like to have one for my wallet.

All the very best in your work.

Member Gwen Giles, Glenbrook, asked that the following offer be published in the Newsletter.

Gwen wrote to tell us that like a lot of us she has to buy two pairs of shoes to get one pair because of her different-sized feet. She wonders if there is anyone interested in numerous pairs of new shoes: right foot size $7\frac{1}{2}$ - 8 and left foot size 6 - 7. Gwen says she will be glad to pass them on to anyone who has the opposite feet to hers. To take Gwen up on her kind offer, simply give her a call on (02) 4739 2416.



The Management Committee wishes you a
Happy and Holy Christmas
and a
Healthy and Peaceful New Year