



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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Editor's Corner

Welcome to the Christmas edition of the Newsletter. You will have noticed that your address label now contains the statement "Renewal Due:" followed by a date. This has been introduced as a service to members to keep them informed as to the currency of their membership. In this regard, subsequent to many of you paying your subscription for the current year, an amendment to the Network's Constitution has changed our financial year from 1 April - 31 March to 1 July - 30 June. This means that this year all members' subscriptions have been extended by three months, with renewals each year now not being due until 1 July. A renewal date of 01/07/97 or later on your label means you are financial.

While I'm on the subject of Constitutional amendments, all proposed amendments were approved by members at the Special General Meeting held on 7 September 1996. The number of members both attending the meeting in person or voting by proxy was very encouraging. Thank you for your interest in, and input to, this most important aspect of the Network's management.

Please note your diaries now with these **1997** Seminar dates, which all fall on a **Saturday**. Information on topics and venues will be provided as soon as it is available.

1 March	7 June	6 September	29 November
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Please note that the **Annual General Meeting** will be held in conjunction with the **November** Seminar.

Early next year, probably commencing in February, a new history series will be screened on ABC TV, in the evening. We understand that the series is named *Timeframe*. One of the episodes is focussing on polio and contains interviews with Network members. At this stage the producers are unable to tell us exactly when it will go to air. If we get enough forewarning, details will be included in a Newsletter or Information Bulletin. Otherwise, watch your TV program guide.

There are lots of goodies in this issue, something for everyone I hope. See the last page for a bit of frivolity - it is the silly season after all! Until next year ...



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



Nola Buck From the President's Desk

As President of the Network I have asked Gillian for this opportunity to convey my heartfelt thanks to you, the members, for your support of our activities over the past few months. We have staged the (Post) Polio Awareness Week, and International Conference *Living With The Late Effects of Polio*, both inaugural events. This is the first time that all members throughout NSW have had the opportunity to participate together in a Network activity.

(Post) Polio Awareness Week

(Post) Polio Awareness Week is now firmly established on the NSW Health Calendar. This year, the event was held 3 - 9 November 1996. A full report is given on pages 3 and 4. The aim, developed eighteen months ago by the Management Committee, was to bring the Network and its activities to the attention of those many people who contracted polio and who were now experiencing its late effects. As people who have had polio, we wanted to promote a positive image of our achievements. Our poster reflected this.

This, our first Awareness Week, was a great success due to the efforts of the Northcott Society and you, the Network members. Your response to Northcott's invitation to speak to the media and/or distribute posters was greater than we had anticipated. This was very encouraging to the Management Committee. I would like to thank every member who contributed for your participation in and support of our first (Post) Polio Awareness Week. It was very successful with wide media coverage and more than 60 enquiries. We hope that next year the Week will receive national recognition.

International Conference : *Living with the Late Effects of Polio*

After eighteen months of meetings and planning our Conference was held. It is a little difficult as a member of the Conference Committee for me to give an objective opinion but from what those who attended have said, I believe the Conference was very successful.

During the period 7-10 November 1996, 168 people attended the Conference from New Zealand, Japan, Korea, Western Australia, South Australia, Victoria, Queensland and, of course, New South Wales. For many, it was the first time they had experienced a Post-Polio Conference and some found it a little overwhelming to be among so many people who had had polio.

A summing up of the conference appears on pages 5 to 7 in Mary Westbrook's paper *Post-Polio Syndrome - Where Do We Go From Here?*, but on behalf of the Management Committee, I would like to thank all members for their support of the Conference through their letters of encouragement, their best wishes and their attendance. I know that for many attendance was impossible. I hope that through this and future newsletters, and the availability of Conference Proceedings and audio tapes, you will gain some of the knowledge imparted by the various speakers and experience the "buzz" of the Conference.

In upcoming newsletters we will report on outcomes from the Conference, such as greater co-operation between the different state Networks and future Seminars to expand on topics raised by conference presenters and participants.

On behalf of members of the Management Committee I would like to wish you and your family a joyous and Holy Christmas and good health for the New Year. During this year a numbers of our members and friends passed away. Perhaps we could pause a moment to remember them and their families while we celebrate Christmas.

Report on the NSW (Post) Polio Awareness Week

In early 1995, the Management Committee agreed to have a Polio Awareness Week included on the NSW Department of Health Calender. The week chosen was 3-9 November, 1996, as it was thought this would be a fitting build up to the International Post-Polio Conference which we were staging in Sydney 8-10 November 1996.

Because of the close relationship between The Northcott Society and the Network, and the fact that the Society attributed its establishment to the thousands of children affected by the polio virus in the early decades of this century, Northcott agreed to assist the Network to promote this Awareness Week.

Poster

To convey the message that many people who have had polio are leading successful, adventurous and fulfilling lives, a poster featuring Allan Grundy, who has had polio and who is a regular crew member in the Sydney to Hobart yacht race, was printed. This poster also gave a brief description about the late effects of polio, alerted people to the International Conference, and promoted the Network and its contact number.

Network members received a questionnaire informing them of the Awareness Week and its objectives and requesting them to assist in promoting the week by giving interviews to the media (for example, newspapers and radio) and/or distributing the poster within their local community. Response was good with a number of members generating media interest by approaching the media themselves.

Eight hundred posters were distributed to Department of Social Security offices throughout the state, the NSW Health Department, and the State Library as well as to Network members who displayed them in pharmacies, doctors' surgeries/waiting rooms, clinics, shopping centre notice boards, libraries and community health centres around New South Wales.

The Network received many calls seeking further information in response to the poster.

Fact Sheet / Short History

In response to requests for extra information from reporters and other organisations, a *Fact Sheet* about the late effects of polio was produced and the Network's *Short History* document was revised and expanded.

Newsprint

Two news releases detailing the late effects of polio and the international conference *Living with the Late Effects of Polio* were distributed to all Sydney papers and radio stations via *Medianet*.

The Sydney Morning Herald reported on the late effects of polio with a story featuring Dr Mary Westbrook, a member of the Network. This article also was also featured in Melbourne on page 2 of *The Age* on 6 November 1996.

Suburban and regional newspapers carried stories during the Awareness Week and contacted people in their area who had expressed a willingness to speak to a journalist about their experiences.

To ascertain the success of the news releases, the clipping service *Media Monitors* was requested to clip articles for two months that mentioned polio and/or post-polio. To date, twenty articles and/or mentions have been published in various newspapers.

In direct response to the newspaper coverage, there have been numerous calls from people who have read articles and stories in their local papers. In fact, more than 60 people have made enquiries; some of these also registered for the international conference held at the end of the Awareness Week. All callers were keen to learn more about the late effects of polio and were relieved to learn of a possible cause of their health concerns which previously had gone undiagnosed.

Radio

Two interviews on ABC Radio 2BL took place. The first was with Professor Simon Gandevia, a leading researcher on the late effects of polio from the Prince of Wales Medical Research Institute. The second interview was live-to-air from the Conference venue with Dr Elizabeth Dean, an international guest speaker from the University of British Columbia, Canada.

Regional ABC and local FM radio stations interviewed Lillian Vickers, a well-known Tamworth resident and a member of the Network.

In response to the article published in *The Sydney Morning Herald* and *The Age*, ABC Perth and Hobart conducted interviews with Dr Westbrook.

The Network would like to express its appreciation to The Northcott Society for making this (Post) Polio Awareness Week so successful. Their generous donation of their expertise and facilities enabled a far greater coverage of the Week to be achieved than was originally envisaged.



A Christmas Surprise For Merv

On Wednesday 11 December 1996 a draw took place at the Prince of Wales Medical Research Institute to find a lucky new owner for late member Dorothy Hull's car which came to the Network from her estate. The car was advertised to members in Issue 11 of the Information Bulletin. The draw was necessary because the Network received a number of worthy requests for the car, and this method of determining who should get the car was considered to be the fairest to all. The decision to have a draw was not taken lightly and in no way trivialised the great need for the vehicle that each person had expressed. Every applicant was invited to be present at the draw.

Professor Ian McCloskey OA (Executive Director of the Prince of Wales Medical Research Institute) officiated, in the presence of Jane Ellams (Public Relations Officer of the Institute) and Stephen Ryall (Manager, Administration and Community Relations, Children's Medical Research Institute), and Network representatives Nola Buck, Gillian Thomas and Peter Garde. The lucky recipient was Merv Tindle from Leeton who was over the moon when told of his good fortune. We are sorry that there was only one car. Perhaps other members might like to emulate Miss Hull's generosity and consider the Network and its members when updating their wills.

Post-Polio Syndrome - Where Do We Go From Here?

Mary T. Westbrook, PhD

Dr Mary Westbrook presented this paper at the final plenary session which wrapped up the International Post-Polio Conference, held in Sydney 8-10 November 1996. The Conference Committee had asked her to give participants her impressions of the weekend and to provoke some thought and discussion on the way ahead.

The task I have been assigned in this final session of the Australian International Post-Polio Conference is to present an overview of our activities over the last three days. I have attended previous post-polio conferences in Australia and overseas and I consider that this conference is the best in which I have ever participated.

As usual the major focus of this conference has been health care for people with post-polio syndrome. We have had excellent information and advice from our international speakers, Dr Yarnell and Dr Dean. Australian health practitioners from a range of professions such as medicine, physiotherapy, occupational therapy, speech pathology and podiatry have presented lectures and workshops.

An interesting innovation at this conference was that polio survivors were more involved in the presentation of health care sessions. In two of the workshops a health practitioner and one of their PPS clients gave the two sides of the story: an orthopaedic surgeon and his client discussed hip replacement surgery and a speech pathologist and her client discussed swallowing problems. There was also a workshop in which attendees described what they had found helpful in dealing with post-polio symptoms.

A major innovation at this conference was that while there were five plenary sessions there were also four sessions during which four parallel workshops were presented. While this presented dilemmas of choice it also meant that each workshop session, which lasted 75 minutes, could present a topic in depth and allow more opportunities for participant involvement than is possible in plenary sessions. Interestingly, 11 of the 16 workshops were presented or co-presented by polio survivors. Although they were often speaking in a professional role they really understood the experience of post-polio and this enhanced their presentations.

It was apparent from reactions in the health care sessions that a major concern of survivors is accessing health practitioners who are knowledgeable about PPS. Some support groups have been active in collecting and passing on information about such practitioners to their members. There is clearly a need to increase the clinical knowledge of health practitioners regarding PPS and to encourage research in the area. We need to liaise with health professional schools regarding the inclusion of PPS in their curricula. We should suggest that they encourage some of their honours and post-graduate students to do research in the area of PPS. Such tasks seem daunting but remember that the post-polio clinic at Prince Henry Hospital and the associated research program have their origins in the efforts of the NSW Post-Polio Network. One inducement that we can provide is willing research subjects.

Another innovation which added to the success of this conference was the wider perspectives from which the PPS experience was explored. The conference had an international perspective both in terms of speakers and participants from overseas. These visitors helped participants to view disability from a cultural perspective as did the workshop by Gayle Kennedy, an Aboriginal Australian who contracted polio. Videos on the situation of people with disabilities in other countries were shown including one on the elimination of people with disabilities during the Third Reich. An historical perspective was introduced by sessions

which explored attitudes in Australia at the time that we contracted polio and how such attitudes shaped our initial treatment and our future lives. Disability rights and the problems of women with disability were discussed.

One overwhelming impression I have from the conference is that we polios are opening up with each other in ways that did not happen in the early days of our support groups. We are acknowledging that dealing with PPS is difficult. We still too frequently downplay our problems and criticise ourselves for not coping more effectively. As one participant said, we need to learn to ask for help and to say "No" to demands that overtax us. One of the main messages of this conference has been that we need to be caring of ourselves and that we can gain much through mutual friendship and support. I recently read the following comments by Kitty Stein (1) who has multiple sclerosis. They also apply to polio survivors. She says that we need to nurture ourselves or as she expresses it, "to develop a nurturing voice".

Acquiring a nurturant voice means entering into a mutual, loving relationship with yourself. It means being empathic with yourself when things are hard. It means tolerating your shame, soothing yourself when you're disappointed, off balance or disoriented, uncertain, and so on. It means giving yourself enough time to adapt, protecting your use of energy so that you can do the things that are important to you. It means providing limits for yourself in an understanding tone. It means appreciating that you are more than your illness. It means being able to reach out for and receive collaborative support when you need it. It means appreciating all that you do for yourself that you wouldn't have to do if you weren't chronically ill or disabled. It means advocating for yourself both internally and externally when needed. And it means understanding how difficult it is to do all this and being supportive with yourself when you make mistakes and get upset (pp. 117-118).

Finally, I'd like to talk about where we're at, what we have achieved, before we rush on in typical polio style, to where we are going. Earlier this year *New Mobility*, an American magazine aimed primarily at people who have a spinal cord injury, ran an editorial entitled *Polio, PPS and Beyond* (2). In it the editor, who has a spinal cord injury, wrote:

The polios, above all else, were our (disabled people's) pioneers. We owe them our lives. They survived into a strangely divided land that was, by definition, friendly to them and hostile to their disabilities. Instead of caving in, they invented rehabilitation, independent living and disability rights. Now they've survived into the bizarre world of post-polio sequelae, and they're faced with national indifference. Will they do as well?

The polios once showed us - the non-polio crips - how to live in the world with a disability. They showed us what it is to be disabled and proud and to survive and sometimes have a good time doing it. Now they may teach us how to grow old with our disabilities.

Long live the polios (p. 6).

Some health practitioners regard PPS as the last rattle of a group of dinosaurs about to depart in the last ark off the rank. But our struggles are beginning to have significant effects on rehabilitation theory and practice. As you know post-polio symptoms have two major causes; the neurological changes that are unique to PPS and the overuse of compromised body systems interacting with the ageing process. As a result of publicity about PPS this second set of late effects is now being recognised as occurring in a wide range of disabilities previously considered to be stable e.g. spinal cord injury, cerebral palsy, spina bifida, congenital and early amputation. In 1995 Dr Christopher in his presidential address (3) to the

American Academy of Physical Medicine and Rehabilitation called for a new life-span approach in rehabilitation which incorporates this late-effects model. The late-effects model is beginning to be applied to disabilities acquired later in life such as stroke and those long recognised as progressive such as diabetes and multiple sclerosis. Indeed this late-effects or life-span perspective is now considered relevant to all disabilities. Okamoto and Yang (4) pointed out that, "Ageing with a disability begins at the time an individual acquires a disability and ageing infers a dimension of time to the disability that is changing, not static as once believed" (p.2). People ageing with a disability have been described (as we know from experience) by the American Congress of Rehabilitation Medicine (5) as "orphans" in the health care with "no system of post-rehabilitative primary care, acute care, or long-term care that is responsive to the particular constellation of health care problems commonly experienced" (p.S8).

The recognition of the late effects of disabilities has led to some critical evaluation of initial rehabilitation. Mottos such as "No pain no gain", "Use it or lose it" and "Independence at any price", which encourage super-crip behaviour are beginning to be questioned and replaced by mottos such as "Conserve it to preserve it" (6, 7). A handbook for consumers entitled *How to Live Longer with a Disability* has also been published (7). One of its authors has spinal cord injury and the other, of course, has post-polio syndrome.

LONG LIVE THE POLIOS!

References:

- (1) Stern, K. (1996) In *The voice of shame*, (eds.) R. G. Lee & G. Wheeler. San Francisco: Jossey-Bass Publishers.
- (2) Corbett, B. (1996) *Polio, PPS and Beyond*, New Mobility, Volume 7, No. 30, June, p. 6.
- (3) Christopher, R. P. (1995) *Physical Medicine and Rehabilitation across the Life-span*, Archives of Physical Medicine and Rehabilitation, Volume 76, pp. 1-3.
- (4) Okamoto, G. & Yang, H. (1993) *Aging with a Disability*, The Rehab Journal, Volume 9, pp. 2-3.
- (5) American Congress of Rehabilitation Medicine Committee on the Social, Ethical, and Environmental Aspects of Rehabilitation (1993) *Addressing the Post-Rehabilitation Health Care Needs of Persons with Disabilities*, Archives of Physical Medicine and Rehabilitation, Volume 74, pp S8-S14.
- (6) Whiteneck, G. C. et al (1993) (Eds.) *Aging with Spinal Cord Injury*, New York: Demos.
- (7)* Becker, E. F. & Mauro, R. (1994) *How to Live Longer with a Disability*, Bloomington: Accent Special Publications.

* This book is published by Accent Special Publications, Cheever Publishing, Inc., Post Office Box 700, Bloomington, IL 61702, USA. It sells for \$11.50 (US) in the USA. I asked the University Co-op Bookshop, Cumberland Campus of the University of Sydney, phone number (02) 9351 9484, to order it for me as a special order. It cost me \$18.95. To assist with ordering the ISBN is 0-915708-38-8. The chapters are entitled: becoming disabled, social aspects, physical aspects, psychological aspects, from one disabled person to another (personal accounts), prevention of late effects, tips to make your life easier, sexuality and disability, the medical community, benefit programs (American focus), and on death and dying.



Look Great in a Post-Polio Network T-Shirt!

The Conference Committee was looking for a symbol for the Conference, and for the Network. Some creative thinking took place and it was decided what more relevant image could we come up with than a graphic design of a polio virus? The design appeared in black and white on the cover of the Conference Program and is shown below. The design in striking colours (red, yellow, green and blue) features on Conference bags and Proceedings, and on white T-shirts which the Network has available for sale at \$15 each plus postage.

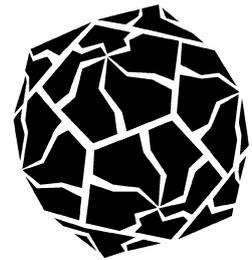
The graphic design on the Post-Polio Network T-shirt is a three-dimensional schematic representation of the external shape of a single poliomyelitis virus particle. The particle is symmetric, like a soccer ball (but ten million times smaller!) constructed from five-sided segments (pentagons). The pentagons are differentiated artificially in the graphic by their different colours. On each pentagonal face of the virus particle there is a symmetric "hill". To graphically depict these hills, the design shows five jagged "paths" which extend from the pentagonal sides and traverse the hillsides to each hill peak.

The outer layer of a poliomyelitis virus particle is a thin shell constructed from proteins. The shell protects a molecule of ribonucleic acid (RNA) which resides at the centre of the particle. The virus particle readily reproduces itself and so a single virus particle is infectious.

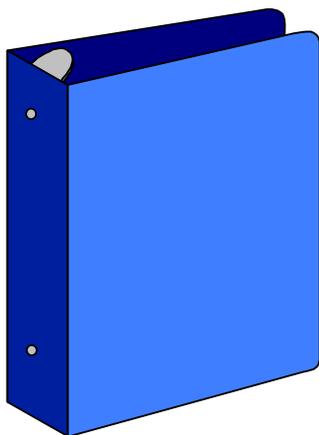
Concept and original design: Peter Garde
Virology consultant: Dr Peter Robertson
Final design: Billy Blue Design and Writing

Graphic and description © Post-Polio Network (NSW) Inc 1996

T-shirts may be ordered from:
Post-Polio Network (NSW) Inc
PO Box 888, KENSINGTON NSW 2033
using the enclosed order form



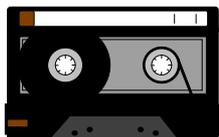
Post-Polio
Network (NSW)



Post-Polio Conference Proceedings

All participants at the Conference *Living With The Late Effects of Polio* received a folder of Proceedings. Although substantial (more than 80 pages), this folder was incomplete in that some important papers had not been received by the time the printing deadline was reached. Outstanding papers are now being collected together. Once we have them all, every Conference registrant will receive a set of the new papers to insert into their folders at no additional cost. We are keeping our fingers crossed that the papers will go out in February.

If you were unable to attend the Conference, don't despair. Proceedings will also be available for sale. At this stage we anticipate the cost will be around \$26 plus postage. A final costing will not be available, however, until we know how many copies we need to have printed. To assist in our planning, please indicate on the enclosed form whether you would like to purchase the Conference Proceedings when they are available. We will let you know the cost as soon as possible and will at that time send out an order form for you to return with your payment.



Audio Cassette Tapes from the Conference: *Living With The Late Effects of Polio*

Audio cassette tapes of all the plenary sessions and some of the workshops are available now. The enclosed order form gives details of the tapes which cost \$12 for a single tape or \$11 each if two or more are purchased. Postage is extra, or you can arrange to collect them at an upcoming Seminar. These tapes have been professionally made and the quality is very good. Don't miss out on hearing what the speakers had to say simply because you couldn't get to the Conference.



And The Winners Are

Your support of this, our first state-wide fundraising raffle, was magnificent. The effort realised over \$7,000, from which costs need to be deducted (for example, the scooter, the printing of the tickets, and some costs for the holiday). We were very fortunate to have three of the prizes donated and received an almost 50% discount on the price of the scooter.

Thank you for your support of the raffle through ticket sales and donations. We are now better placed to work towards our goal of providing training and support for local groups. The raffle was drawn on the last day of the Conference. The winners (all Network members) were:

Prize	Won By	Drawn By
Shoprider Scooter	Ken Chalker, Albury <i>Ticket No: 4650</i>	Sue Kinsler Korea
Return Coach Travel Voucher plus Seven Nights Accommodation	Jan Burgess, Carlingford <i>Ticket No: 1806</i>	Mika Kitagawa Japan
Original Painting by Margaret Greig	Neryle Elmer, Blacktown <i>Ticket No: 2072</i>	Audrey Richardson New Zealand
Hamper of Assorted Goods	Dorothy Iles, Lalor Park <i>Ticket No: 2060</i>	John Smith Western Australia

Congratulations to all the winners! The two \$20 meal vouchers donated by Pizza Hut went to members Jean Davis and Maura Outterside for selling the most raffle tickets.

A final thank you to all those sponsors without whose generosity the raffle would not have been possible: Peter Fraser from Scooters Australia, McCafferty's Coaches, and Margaret Greig.

Surfing the Net!

Just a reminder that the Network now has a home page on the Internet, thanks to the efforts of Tony Marturano, the Network's Librarian. The address now appears on the front page of each Newsletter. Tony tells me he is getting about 60 people a week looking at the page, and the number is increasing all the time. He has already been contacted by several overseas polio groups. If you can't access the Internet but would like to receive a disk of polio-related documents (in IBM format) that Tony has downloaded, simply forward \$5 to the Network and Tony will send one off to you.

Tony has sent me many interesting articles from his Internet browsings. There is such a lot of material (with more coming from Tony all the time) that I'll have no trouble filling up Newsletters for a long time to come.

This issue, the three articles I'm including are all fairly topical considering the content of our recent Conference.

Exercise - What is Right for You?

Mavis J. Matheson, MD

April 1995

Many people with a history of polio can improve muscle strength and cardiovascular conditioning with an exercise program [1], [2]. One of the problems that people with Post-Polio Syndrome face is how much exercise they should be doing. We have all been told to conserve our energy. We know that too much exercise will further damage already weak muscles. We also know that if a muscle is not exercised it will lose strength. So what should we be doing?

Determining how much we should do isn't easy. We must learn to recognise fatigue. We must learn which pains mean overworked muscle and which are part of normal aging. We need to pay attention to our bodies and use pain and fatigue as signals. We have to let go of the "no pain, no gain" philosophy we learned while we were recovering from polio. We must also learn to use how we feel today to assess yesterday's activity and plan for tomorrow. Dr Agre and Dr Rodriguez have shown that polio survivors can assess their own muscle fatigue [3].

The key to exercise for people with Post-Polio Syndrome is to suit the activity to the amount of damage to the muscle. This damage may be a result of the original polio and from post-polio overuse. Different researchers use different methods of determining just how much a muscle or group of muscles is damaged and what exercises are appropriate [1],[4]. After consulting with our doctors to assure ourselves that we don't have some disease process other than PPS causing our problems, we must decide how much to do. What can we do when we don't have a Post-polio Clinic and physicians willing and able to do four limb EMGs? Without using EMG, we can still look at our histories and we can feel how we are doing now. Using this information we can try to set up or get the physiotherapists (many of whom have little or no knowledge of post-polio syndrome) to set up appropriate exercise programs for us.

I suggest you try to figure out what each of your limbs should do based on your experience with that limb. For each limb, ask yourself "Which is the most severely involved muscle in this limb?" "Is that muscle weak?" and "Am I noticing signs of increasing weakness in that muscle?" Increased pain in the muscle, twitching, decrease in quality of movement, being able to walk shorter distances, having more trouble with stairs, more difficulty standing, muscle wasting, difficulty holding your arm up, driving, dressing, and tiring with fewer and

fewer repetitions during your regular exercise routine are common signs of increased weakness in a muscle or limb. Do you know of any reason other than PPS why that muscle may be weak? For example has the muscle been immobilised recently?

A limb that does not have any weakness is classed as *no clinical polio* [1] and you can use it like any normal limb. These are the limbs you can use to get a good workout for your heart and lungs (cardiovascular workout). Be active 3-4 times a week for at least 20 minutes getting your heart rate up to 60-80% of maximum. You can exercise these limbs like normal limbs. It is also sensible to do gradual exercises to maintain strength and flexibility. If you notice any signs of increasing weakness, you must re-evaluate your limb and your exercise program for that limb.

If your muscle is mild to moderately weak but shows no signs of increasing weakness, the limb would be classed as *clinically stable polio* [1]. You can exercise these muscles with care. They should probably not be significantly fatigued. Try exercising 3 times per week for periods of 10-20 minutes with frequent rests. Progressive resistance exercises (also called non-fatiguing strengthening exercises) with gradually increasing weights may be used to maintain and possibly gain strength. Monitor yourself carefully while you exercise and if you notice any signs of increasing weakness, you must re-evaluate your limb and your exercise program for that limb.

If your muscle is severely weak, the limb is probably appropriately classed as *severely atrophic polio* [1]. Active exercise of the limb is likely impossible. Passive range of motion exercises may be used to maintain flexibility.

If your muscle is weak and showing increasing weakness, ask yourself "Am I doing too much or too little?" Unless the limb has been immobilised recently (for example, in a cast or on bed rest) you are probably doing too much. The limb should be classed as having *clinically unstable polio* [1]. You should try decreasing the amount of activity that limb is doing, use energy conservation, and get your rests. These are the muscles that are being damaged by overuse. You must not fatigue them. It is probably a good idea to stretch to maintain flexibility and range of motion. If the limb has been getting too little activity, you can try a carefully graduated program of non-fatiguing exercises. Monitor yourself carefully while you exercise and if you notice any signs of increasing weakness, re-evaluate your exercise program for that limb.

Whatever your exercise program, continue to make changes to help you conserve energy. Pay attention to fatigue and rest when you are tired (before you are exhausted). If you are overweight, you need to lose weight. Dr Peach and Dr Olejnik found that patients who successfully control the factors responsible for neuromuscular overuse did not lose muscle strength [5].

- [1] Gawne AC, *Strategies for Exercise Prescription in Post-Polio Patients*, In Halstead LS, Grimby G (eds.) *Post-Polio Syndrome* (1995) pp. 141-164.
- [2] Fillyaw MS, Badger GJ, Goodwin GD, Bradley WG, Fries TJ, Shukla A, *The Effects of Long-Term Non-Fatiguing Resistance Exercise in Subjects With Post-Polio Syndrome*, *Orthopedics*, (1991) vol. 14:1253-1256.
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- [4] Feldman RM, *The use of EMG in the differential diagnosis of muscle weakness in post-polio syndrome*, *Electromyogr. clin. Neurophysiol.*, (1988), 28, 269-272.
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L-Carnitine and Post-Polio Syndrome

Mavis J. Matheson, MD

September 1994

Between 1991 and 1993 Dr Thomas Lehmann from Switzerland treated 27 persons with post-polio syndrome with 1000 (-3000) mg/day of L-carnitine. The results were:

	Better	Worse	No effect	No response
Endurance	18 (72%)	0	7	2
Fatigue	6 (30%)	0	14	7
Sleep	7 (29%)	3	14	3
Standing up	12 (48%)	0	8	2
Strength	17 (68%)	0	8	2
Pain	14 (58%)	0	10	3

Appropriate double blind crossover studies still need to be done.

L-Carnitine - from "meat" (Latin: carnis) has been known for a long time. It is found mainly in the meat and liver of sheep, lambs, rabbits, in milk and in yeast. L-Carnitine is a prescription drug in Europe and is marketed in health food stores in the United States. It is available in health food stores in combination with aminoacids in Canada. It was originally classed as Vitamin BT but can be produced in the body from methionin and lysine (with the aid of vitamin B6, vitamin C, niacin, pantothenic acid and iron) in the kidneys and liver. It is stored in muscles and liver. It is excreted by the kidneys. There is no known L-Carnitine toxicity. It has been reported that acetyl-L-Carnitine is more effective than L-Carnitine. D-Carnitine inhibits the action of L-Carnitine.

The theory of why L-Carnitine works in post-polio syndrome is as follows. The paralysed or weakened muscles of the polio survivor are atrophying or atrophied as a result of the late effects of polio. Because there is less muscle, there is less possibility to store L-Carnitine. When tissues become acidic (lactic acid from overuse) or there is desaturation of oxygen (due to respiratory insufficiency or bad vascularisation) the concentration of L-Carnitine is lower in the blood, tissues and cells. The (over)use of muscles (whether atrophied or overused in compensation) has been shown to cause a local fall in levels of L-Carnitine. L-Carnitine improves the metabolism of oxygen, fat and glucose and inhibits the use (abuse) of muscle proteins for energy production. The deregulation or decompensation of the metabolism of fatty acids, glucose, oxygen, and energy (necessary for good muscle function) because of a lack of L-Carnitine could result in fatigue and weakness of the muscles.

More studies need to be done and the results published. Research on L-Carnitine is currently being done in Europe and Australia. A strict vegetarian or vegan diet is very low in L-Carnitine and could accelerate weakness. I do not recommend that every polio survivor take L-Carnitine pills because we don't know about toxic side effects yet. While we are waiting for the final answer, it would make sense for polio survivors to keep meat in their diets.

Resources:

- [1] Simon, Roberta and Darien, RN, *What's Happening with Research Medications*, 1991, Polio Network News.
- [2] Lehmann, Thomas, MD, *L-Carnitine and Post-Polio Syndrome*, 1994, Handout - 6th International G.I.N.I. Conference.

Sex and Polio Survivors

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Last January I got a brand new Macintosh computer that came with a modem. Ever since, I've been "surfing" the Internet, hardly stopping for food or sleep. You'd be amazed at what I'm finding on the disABILITIES bulletin boards: Sex. Yes, unbridled, undiluted and unimpeded discussions about sex among people with all kinds of disabilities, from high-level quads to quadruple amputees.

However, there is one place where I've heard no discussion of sex: the Post-Polio bulletin board. There are lots of questions about PPS that you had the answers to years ago: Do I have ALS; does exercise make you weak; where can I get a scooter? But, not one question or comment about sex.

I guess I shouldn't be surprised. Many of our patients at Kessler don't mention sex, either. Some mention that spouses do not believe that PPS symptoms are "real". But most often, spouses are very supportive about the need for their post-polio mate to slow down and take care of themselves, even if that means a new brace, crutches or a scooter. So, if spouses are so supportive, why is there no mention of sex?

ALL'S TOO QUIET ON THE SOUTHERN FRONT

There are probably several reasons for the lack of talk about sex:

* Many polio survivors grew up in the 50's when discussing sex was the same as walking down Main Street without your pants. Also, 40 years ago, even more than today, people with disabilities were thought not to be fully human, let alone sexual beings.

* Also, it was vital back in the dark ages that anything not "normal" (that is, anything not seen on Ozzie and Harriet) be hidden. So, if a polio survivor expected to have a relationship with someone the disability had to be hidden. Since the polio residuals were often hard to hide, the disability was often just ignored or denied. It amazes me still how many survivors tell me that they have never, ever discussed the fact they had polio with their spouse, let alone the experience of having had polio or - God forbid - their feelings about it.

The process of hiding, denying or ignoring the reality of what's happening in one's body caused problems. Many people just turned off any awareness of their bodies and any feelings they have below the neck. Others have turned off ALL feelings, both below and above the neck. Since you can't turn off pain without turning off pleasure as well, an inability to feel will make sensuality or sexuality nearly impossible - or as appealing as eating dry toast.

Also, walling off one's feelings also cuts off the ability to be intimate with oneself and with others. And, intimacy is the gateway to sexuality.

* Having a visible disability at an early age can result in other barriers to intimacy and sexuality. There is a disturbingly high frequency of physical, emotional and sexual abuse among polio survivors. Nearly one third of the patients we treat have been physically or emotionally abused, and 25% of the women have been sexually abused. Not surprisingly, those who have been abused are much less likely to risk intimacy or be interested in sex.

Also not surprisingly, the more obvious the assistive device people used following polio, the more likely it was they had been abused. No wonder polio survivors discarded their braces

and crutches and don't want them back - ever! Now, 40 years later when PPS symptoms start and braces, crutches and wheelchairs are appearing again, the painful memories of the past and the reality of disability can no longer be hidden. Old fears of unacceptability and new fears of rejection surface and cut self-esteem off at the pass. And, the old vicious Rules of Society also come screaming back:

Rule #1: If you're disabled, you're not attractive;

Rule #2: If you're not attractive, you can't be sexual;

Rule #3: If you can't be sexual, you shouldn't have sexual feelings;

Rule #4: Wear flannel pyjamas and sleep on the couch.

"IF I THINK I'M SEXY, AND I LIKE MY BODY..."

Well, sexy is as sexy thinks. One of the disABILITIES bulletin boards is actually called, "Sex is 99% Mental". Sure you may not look like Cindy Crawford or Mel Gibson. But, how many non-disabled people do? What counts is how you feel about yourself, not how you look to others. If you're not acceptable to yourself, you won't be sexually available to, or even intimate with, others.

The first step to intimacy and sexuality is recognising and dealing with the emotional reality of the original polio and any abuse you have experienced because of it. Next, you need to identify your own negative feelings about yourself and stop projecting them into the heads of potential friends and lovers. Since a whopping 77% of polio survivors are married, it's your spouse's head that you're filling with your own negative thoughts about yourself and fears of rejection.

Finally, if you turned off your body to stop feeling physical pain, you need the experience of good physical feelings. You need to decrease your PPS fatigue, muscle weakness, and pain by decreasing physical and emotional stress. Then, you need to start sending pleasant physical sensations to your brain. Try long hot baths, a whirlpool or, best of all, a massage. When you make nice to your body and good feelings start travelling to your head, other good physical sensations (like the erotic ones) will follow that "stairway (or ramp) to heaven".

For those who are single, get a computer, a modem and start "surfing the net". It is actually possible to meet hundreds of people without leaving your living room. Whether you decide to let them into your life (or your bedroom), the safety of the computer gives you the freedom to be yourself and even practice being intimate with others, without worrying that everyone is looking ONLY at your brace.

When all is said and done, here's the Golden Rule for being an intimate and sexy polio survivor (with apologies to Nike):

Turn off your thoughts, turn on your body and JUST DO IT!



Help Wanted! Tell Your Community About our Network

A new poster to promote the Network and local support groups has been developed thanks to the efforts of Central Coast convener Shari Brewster. A copy of the poster is included with this Newsletter, and further copies will be distributed to all Support Group conveners. If you are able, please put the poster up somewhere in your local community such as a pharmacy, doctor's waiting room, clinic, notice board, library or community health centre. If you are a member of a support group, please fill in the details at the bottom of the poster.

Pulling Your Leg!

Member Tony Marturano recently forwarded me this article which he thought might be of interest to members experiencing difficulties similar to his. I repeat his disclaimer, though, that if you wish to consider trying Tony's solution, only do so in consultation with your regular health care givers.

I was looking for a new place, the present one had too many stairs and would not be suitable for a wheelchair. My right leg (good leg) had just about had it, I could not lift it off the accelerator to the brake in my car (it would hit the brake on the side sometimes instead of the top of the brake). I could not sit, stand or lie down in any manner of comfort.

The problem had been getting worse over the last 5 years even though it had been with me as my guide or governor since I was young. I was getting desperate and last year went to a local hospital Rehabilitation Department without much help. Then I went to a sports medicine specialist I knew a few years back and told her of my problems. She sent me for a CT scan of my lower spine to rule out any problems there and also referred me to an immunologist for the fatigue who then referred me on to a respiratory specialist who then referred me on to a sleep specialist. Now this was getting silly. I stopped this roundabout and made another appointment with the sports specialist. In the meantime I was talking to a nurse I knew and mentioned my problem. She told me it was my sciatic nerve and the only way to fix it was with traction.

By the time I got home I was ready to make a simple device to see if it would help. This was a pulley system with a weight suspended from it. My leg was attached to the device by a "collar" (made from an old boot) around my ankle. This stretched my leg lengthwise. It took me a couple of hours to make. I set it up across the end of my bed and was ready to try it out. The results were immediate; after two hours the burning sensation had gone, the weakness too. I had not felt so good for a long time.

I was able to sleep right through, my short term memory problems went, and most of all I can walk further and longer than for a long time without the loss of power in my good leg.

I have found with the bad gait posture that the polio has given me, this problem will not go away. I have been maintaining a once a week self-treatment for an hour, and after 3 months have not looked back. This pain made me tired, fat and nearly lose my mind. All these effects have reversed in the last three months.

If you have this problem and want to try my solution, please do it in conjunction with your Doctor's advice as to its suitability for your needs.

Bits 'n' Pieces

- Qantas has replaced its BL50 airfare for visually impaired travellers with a **Carer Concession Airfare** for passengers with severe disabilities who cannot travel without the assistance of a carer. This provides a 50% reduction off full fare Economy, Business and First Class domestic airfares for the passenger with a disability and their nominated carer, and is available to holders of a *Carer Concession Photographic Identification Card*. The distribution and administration of the Card is being handled by the National Information Communication Awareness Network (NICAN), the Canberra-based national information service on recreation, sport, arts, and leisure activities for people with disabilities. Call NICAN on 1800 806 769 to obtain an application form for the Carer Concession Card, or for more information.

Is There A Santa Claus?

Being that time of the year again, one may ponder the perennial question "Is there a Santa Claus?" This question has now been the subject of scientific investigation by Anon in the very reputable and authoritative journal *Spy Magazine*, January 1990. So that you can be as enlightened as I was, I now present the findings.

 No known species of reindeer can fly, but there are 300,000 species of living organisms yet to be classified, and while most of these are insects and germs, this does not *completely* rule out flying reindeer which only Santa has ever seen.

 There are 2 billion children (persons under 18) in the world. Since Santa doesn't (appear to) handle the Muslim, Hindu, Jewish and Buddhist children, that reduces the workload to 15% of the total - 378 million according to the Population Reference Bureau. At an average (census) rate of 3.5 children per household, that's 91.8 million homes. One presumes there is at least one good child in each.

 Santa has 31 hours of Christmas to work with, thanks to the different time zones and the rotation of the earth, assuming he travels east to west (which seems logical). This works out to 822.6 visits per second. This is to say that for each Christian household with good children, Santa has a thousandth of a second to park, hop out of the sleigh, jump down the chimney, fill the stockings, distribute the remaining presents under the tree, eat whatever snacks have been left, get back up the chimney, get back into the sleigh and move onto the next house. Assuming that each of these 91.8 million stops are evenly distributed around the world (which, of course, we know to be false but for the purposes of our calculations we will accept), we are now talking about 0.78 miles per household, a total trip of 75.5 million miles, not counting stops to do what most of us must do at least once every 31 hours, plus feeding and so on.

This means that Santa's sleigh is moving at 650 miles per second, which is 3,000 times the speed of sound. For purposes of comparison, the fastest man-made vehicle on earth, the Ulysses space probe, moves at a poky 27.4 miles per second. A conventional reindeer can run, tops, 15 miles per hour.

 The payload on the sleigh adds another interesting element. Assuming that each child gets nothing more than a medium-sized lego set (2 pounds), the sleigh is carrying 321,300 tons, not counting Santa, who is invariably described as overweight. On land, conventional reindeer can pull no more than 300 pounds. Even granting that "flying reindeer" (see the first point) could pull *ten times* the normal amount, we cannot do the job with eight, or even nine. We need 214,200 reindeer. This increases the payload, not even counting the weight of the sleigh, to 353,430 tons. Again, for comparison, this is four times the weight of the Queen Elizabeth.

 Over 353,000 tons travelling at 650 miles per second creates enormous air resistance. This will heat the reindeer up in the same fashion as spacecrafts re-entering the earth's atmosphere. The lead pair of reindeer will absorb 14.3 *quintrillion* joules of energy. Per second. Each. In short, they will burst into flame almost instantaneously, exposing the reindeer behind them, and create deafening sonic booms in their wake. The entire reindeer team will be vaporised within 4.26 thousandths of a second. Santa, meanwhile, will be subjected to centrifugal forces 17,500.06 times greater than gravity. A 250-pound Santa (which seems ludicrously slim) would be pinned to the back of his sleigh by 4,315,015 pounds of force.

In conclusion - if Santa ever did deliver presents on Christmas Eve, he's dead now.

Footnote from Santa: It's amazing how some people can get things so wrong!