



Editor's Corner

There have been some developments since Part 1 of this issue was released. At the Seminar to be held on Saturday 6 August, there will now be two major presentations. As previously advised, Elizabeth Hastings will address Network members about the Disability Discrimination Act. Her talk will now begin half an hour earlier, at 1:00 p.m. Commencing at 2:30 p.m., Professor Simon Gandevia will provide an update on his post-polio research. Afternoon tea will follow. For your convenience, I have included the updated full program on page 2. This Seminar should not be missed.

New Zealand Conference

The registration form for the Post Polio Support Society NZ (Inc) National Conference which will be held at the Auckland Airport Travelodge, Friday to Sunday 23-25 September 1994, was enclosed with Part 1 of this issue. This is a reminder that a late fee of \$30 applies to any registrations received after 1 August 1994. Your President and Editor will be attending the Conference and should be bringing back lots of information for future editions of the Newsletter. It would be good to catch up with some of you over there.

Raffle Result

You might recall that member Mrs Yvonne Stone from Kindee kindly donated a home-made knee rug from wool she had spun herself. The rug was gratefully accepted by the Network Management Committee and subsequently raffled at the Annual General Meeting/Seminar in May. The rug proved very popular and the raffle brought in \$47.50 for Network funds. The rug was won by long-time member Cec Schmitzer of Leichhardt who went home a very happy man. I'm sure he or his wife will put it good use especially during this cold weather.

Walkabout Scooter

Also at the AGM/Seminar in May, David Happ of Total Mobility Pty Ltd demonstrated the Walkabout Electric Scooter, the Nordic Reclina-Lift Chair, and the Adjust-A-Matic Bed. A lot of members took the opportunity to test what technology can offer. David has now contacted the Management Committee with the following offer: for each scooter purchased by a Network member, his company will donate \$100 to the Network. The Network is most grateful for this offer. If you are interesting in trialing/buying a scooter, please ring David on (02) 873 1935 or mobile 018 265 439 and indicate you are a Network member.

Farewell Shirley

Those of us who know Shirley Roach well will be aware that she has been talking of going to sunnier climes in Queensland for quite a while. Well, the time has finally arrived to pack her bags and she will be leaving us next month (after a farewell appearance at the 6 August Seminar). For a number of years Shirley has filled important positions on the Management Committee. Her enthusiasm, hard work and willingness to lend support will be sorely missed by her fellow committee members. We wish her well in her new home and are sure she will stay in contact.

Seminar Topics : Saturday 6 August 1994

The Disability Discrimination Act (1992)

followed by

Post-Polio Syndrome - New Ground in Research

- Time** : 1:00 p.m. - 2:30 p.m. (The Disability Discrimination Act)
2:30 p.m. - 4:00 p.m. (Post-Polio Syndrome Research)
- Place** : The NSW Society for Children & Young Adults with
Physical Disabilities
2 Grose Street, Parramatta
Ample on-site parking is available - follow the signs
- Lunch** : 12:00 p.m. - 1:00 p.m.
Please bring your own lunch - tea and coffee provided
- Afternoon Tea** : 4:00 p.m.
- RSVP** : Please phone Nola on (02) 636 6515 by 4 August 1994

The Disability Discrimination Commissioner, Elizabeth Hastings, will be our first guest speaker. Details of Ms Hastings' talk were given in part 1 of this issue. The Network is very pleased that the Commissioner has found time in her busy schedule to travel up from Melbourne to speak to members.

Our second guest speaker is Associate Professor Simon Gandevia, Senior Research Scientist, Prince of Wales Medical Research Institute. Professor Gandevia, who is a leading researcher in the role of the brain and nervous system in the control of human movement, muscle force and endurance, has forwarded the following outline of his talk.

A request two years ago from two colleagues who had contracted severe polio in childhood prompted Professor Gandevia to start researching post-polio syndrome. His special expertise in human muscle force and endurance and in the very difficult investigatory technique of microneurography, enabled him to apply this knowledge specifically to the muscle deficits which develop in polio survivors which we now know as Post-Polio Syndrome. His first study revealed an interesting finding: the polio survivors' muscle weakness (measured by their ability to voluntarily "drive" their arm muscles) was the result of an impairment in the central nervous system, rather than specifically in the nerves that drive the muscles. This finding is a world first and has important implications for current and future therapies.

Professor Gandevia will explain the techniques he uses in his research at the Prince of Wales Medical Research Institute. Many of the testing procedures have been developed in the Institute's laboratories and would be available in few others in the world. Also, the database of test results is likely to be the most detailed of its type in the world. Professor Gandevia will also talk about * the aims of his research * why research needs to be stepped up * why the assessment of breathing muscles is an important priority * the establishment of a dedicated post-polio muscle testing laboratory and * the development of new therapies.

Please don't delay confirming your attendance at the 5th Anniversary Luncheon. The venue (The Huntley Parramatta) holds seventy comfortably (including a number in wheelchairs). To make sure of your place, we need your deposit. Just complete the invitation sent out with the last Newsletter and return it to the Secretary as soon as possible. For your convenience, forms and money can be handed in at the August Seminar. In case you are wavering about coming or not, I've reproduced the menu below to whet your appetite. The afternoon will feature an entertaining talk and a musical interlude - something to please all tastes. A lucky member will also win a lucky door prize which is being provided courtesy of The Huntley. Numbers are limited, so get in early.

Tea or coffee will be provided but drinks are extra

Sleep Apnea and the Post Polio Syndrome

The diverse array of symptoms that have been reported associated with the Post Polio Syndrome include fatigue, increasing muscle weakness, excessive daytime sleepiness, non-restorative sleep, swallowing and breathing difficulties. However, a number of these sleep and respiratory symptoms may also be reported by individuals without previous polio, who have been referred to a sleep disorders clinic for a condition known as Sleep Apnea. It is important that both clinicians and individuals realise that these two conditions may occur concurrently. The development of sleep apnea in someone with a past history of polio may simply be part of the natural prevalence of sleep apnea in the general population, or sleep apnea may be a direct or indirect consequence of the distribution of muscle weakness associated with previous polio. In this article I will briefly outline what sleep apnea is, who is likely to suffer from it and where to seek advice. High risk individuals with sleep or breathing problems should consider the possibility that some of their symptoms are related sleep apnea, and seek the appropriate advice.

What is sleep apnea?

Sleep apnea is the failure to breathe during sleep. However, there are various types of apnea as well as varying degrees of severity. (Figure 1)

Obstructive Sleep Apnea (OSA)

This is most common type of sleep breathing abnormality seen. A recent Australian study found that 10% of men and 5% of women in the 40-65 age range had obstructive sleep apnea. In OSA, there is loss of control or "tone" of the muscles of the throat. As a person attempts to breathe in, the throat closes, preventing air reaching the lungs. Over the next few breaths, the individual tries harder and harder to suck air in. Eventually this abnormal breathing, along with the fall in oxygen level which accompanies it, causes the person to awake briefly, possibly only for 5 or 6 seconds. However this arousal will restore activity to the throat muscles, opening the throat up and allowing air once again into the lungs. This cycle of abnormal breathing followed by arousal may occur just a few times a night in a certain body position in some people or as many as 500-600 times in a single night for those with a significant problem. The most common symptoms reported by people with this problem are snoring, daytime sleepiness, episodes of choking during sleep, waking up unrefreshed and restless sleep. Reports by a bed partner of pauses in breathing during sleep is the clearest sign of the presence of the obstructive sleep apnea syndrome.

Central Sleep Apnea

Less frequently seen than obstructive sleep apnea, central sleep apnea is a condition where breathing also ceases, not because of throat closure, but because of a reduced effort or even no effort to breathe. Pure central sleep apnea is most commonly seen in people with heart failure or those who have experienced a stroke affecting the breathing centres of the brain. In such cases the brain is either slow or totally fails to recognise changes in the level of oxygen and then

overcompensates, causing the individual to breathe quickly between apneas. A "waxing and waning" of breathing is produced, and snoring is not usual in this condition.

More commonly seen in people with previous polio and significant chest wall muscle weakness is a condition known as nocturnal hypoventilation. During sleep, people with this problem simply do not breathe deeply enough. Any condition which causes weakness of the muscles of the chest wall, and in particular, weakness of the diaphragm which is the major muscle of breathing, will be susceptible to this problem. During wakefulness and most stages of sleep, all muscles of the chest and abdomen can be called upon to assist with breathing. However, during Rapid Eye Movement Sleep there is normally a generalised relaxation of all muscles of the body, so the burden of breathing falls entirely on the diaphragm. If the diaphragm has been weakened or is in an abnormal position because of a significant spinal curvature, breathing effort may be less than that necessary to keep oxygen and carbon dioxide levels within normal limits. Over time this abnormal breathing during sleep will extend into daytime breathing. However, this process may take years to become apparent, much like the post polio syndrome itself.

Partial Upper Airway Obstruction

This recently recognised syndrome is the result of relaxation of the muscles of the throat and tongue. A narrowing of the airway is created which only partially reduces airflow and usually produces snoring through vibration of the tissues of the airway. In some people this partial obstruction will cause arousal from sleep and significant daytime symptoms even though there is no drop in oxygen level, nor will breathing grossly abnormal as in OSA. This breathing abnormality is often very subtle and can often be overlooked. In some cases its presence can only be confirmed by a good response to treatment.

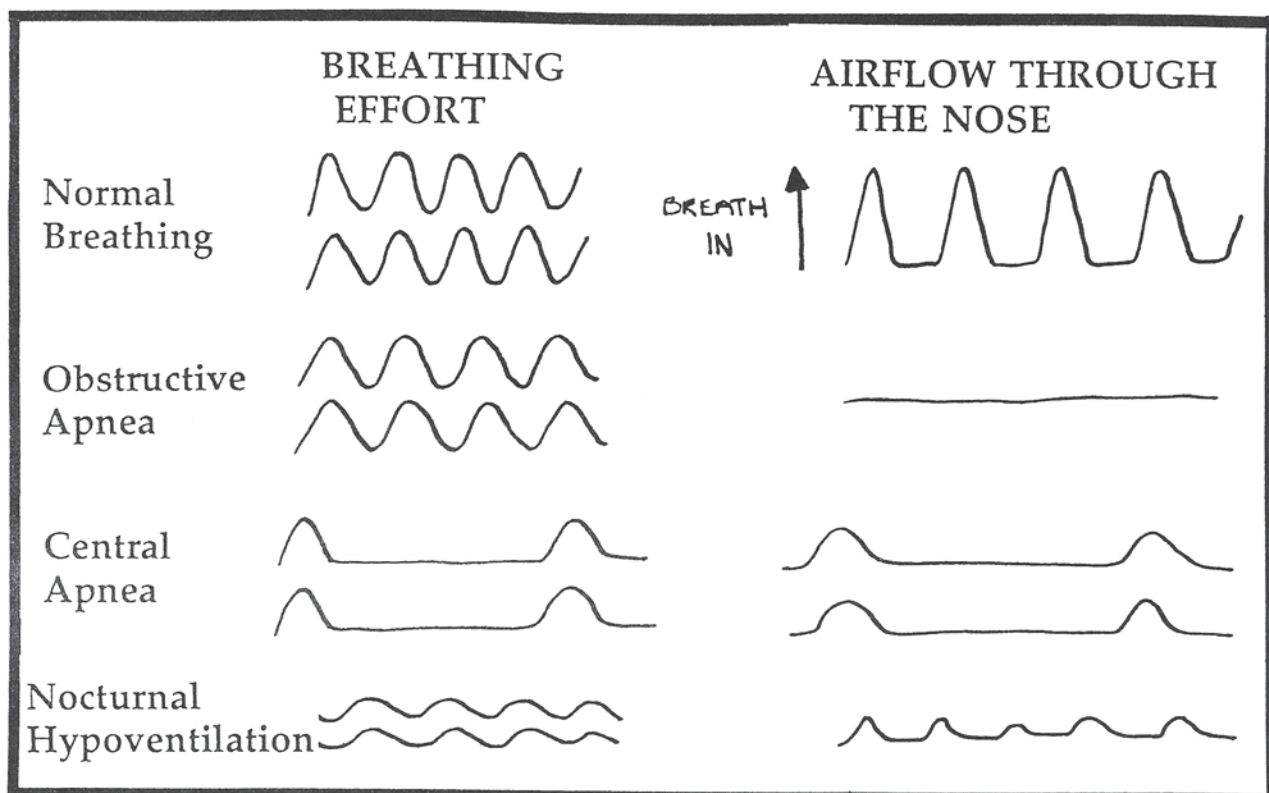


FIG. 1

What is a sleep study?

In order to correctly diagnose a sleep breathing problem and its severity, a sleep study is necessary. The first step is to talk to someone who specialises in the assessment and management of sleep disorders. They will take a thorough history and examination, and if there is a strong likelihood that daytime symptoms are related to sleep breathing problems a sleep study will be organised.

A full sleep study involves the monitoring and measurement of electrical signals from the brain and a number of muscles of the body. Small electrodes are placed over the skull and on several muscles of the face, chest wall and legs to pick up electrical activity and movement. These electrodes are attached to the skin with a simple glue, and the procedure is not a painful one. In addition, probes to measure oxygen levels are also used, along with a nose mask or prongs to measure breathing. Many laboratories will also monitor the movement of the chest wall. This detailed recording of sleep and body movements permits the detailed assessment of just how abnormal sleep is, and the cause of any abnormality. In addition, other tests such as blood and breathing tests may also be performed if it is felt necessary.

If an abnormality is identified, the problem will be discussed and treatment options explained. Depending on the problem and its severity, treatment may range from diet and lifestyle modification (including smoking and drinking habits), medication (for nasal congestion or abnormal leg movements) to mechanical devices to assist or unload breathing (nasal stents, CPAP or ventilators). Nasal CPAP (continuous positive airway pressure) is a mechanical device which produces a flow of air through a nose mask which acts to splint the airway open during sleep.

Who is likely to suffer from Sleep Disordered Breathing?

Unfortunately, there is no simple daytime test to detect the presence of sleep apnea and its nature. Since snoring is very common in the general population, not everyone who simply snores needs further investigation. The key symptoms indicating the likelihood of sleep apnea appear to be heavy snoring and excessive sleepiness during the day. However, many people have lived with their symptoms over a long period of time and may not notice their problems. A history of restless sleep and witnessed breathing pauses reported by a sleeping partner tends to better reflect the presence of the disorder.

Overseas reports and our own experience, suggest that individuals with muscle weakness affecting the throat or the chest wall are the group most susceptible to developing serious sleep related breathing problems (Figure 2). Significant curvature of the spine, the use of ventilatory support during the acute infection and bulbar involvement appear to be strongest factors indicating a late onset

deterioration in respiratory function and breathing control. Both polio sufferers and treating clinicians need to bear in mind the possibility of abnormal sleep breathing developing many years after the acute polio infection. This abnormal breathing can disrupt sleep and affect daytime function, with symptoms overlapping those seen in the Post Polio Syndrome.

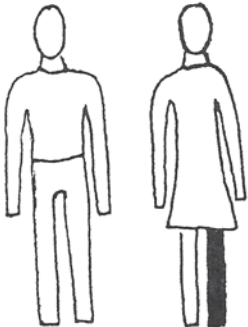
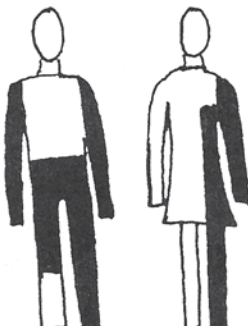
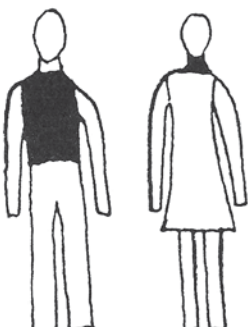
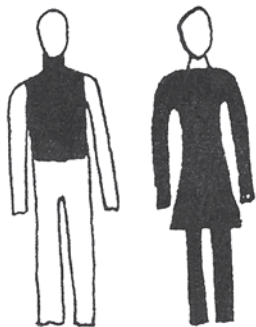
Region of paralysis/muscle weakness	Comments (Most likely findings on sleep study)
	<ul style="list-style-type: none"> * No significant sleep abnormalities detected. * Presence of sleep apnea associated with normal occurrence in the general population.
	<ul style="list-style-type: none"> * No sleep-breathing abnormalities detected. * Any apnea likely to be associated with the incidence in the general population. * Disrupted sleep may be related to muscle/joint pain, skeletal problems such as back or shoulder pain, and an inability to find a comfortable sleeping position
	<ul style="list-style-type: none"> * Presence of apnea likely to be a direct or indirect result of polio based on the distribution of muscle weakness. * Weakness of the throat or chest wall muscles promotes either partial or complete closure of the throat during breathing in. * Changes in the shape of the skeleton may further contribute to the problem eg. kyphosis ("round shoulders") or scoliosis (lateral curvature of the spine) may alter the shape of the airway.
	<ul style="list-style-type: none"> * Significant muscle weakness affecting the chest wall muscles, and in particular the diaphragm, producing reduced effort to breathe during sleep. * Some degree of obstructive sleep apnea may also be present.

FIGURE 2.

Where are Sleep Laboratories located?

There are a number of both public and private sleep laboratories located in NSW, primarily in the Sydney area. The following is a list of Sleep labs associated with public hospitals and their contact numbers. Most laboratories require a referral from your local doctor or specialist.

- Concord Hospital (02) 736 7064
- Royal Newcastle Hospital (049) 26 6833
- Royal North Shore Hospital (02) 438 7111
- Royal Prince Alfred Hospital (02) 565 1137
- Westmead Hospital (02) 633 6797

Annual General Meeting Report

At the Annual General Meeting held on Saturday, 7th May, 1994, the following General Business was discussed.

- ORTHOTICS Alicia Lee has completed her report based on answers received to her Orthotics Questionnaire (see Pages 10-12).

As the Disability Council of NSW is supporting a Task Force to look into the issues of cost, quality, standards, co-ordination and availability of orthotics, the Network felt it was appropriate to cease its investigation and give its support to the Task Force by having a representative on it.

- POST-POLIO CLINIC In reply to the Network's letter dated 10 April 1994 regarding the rumour of possible closure of the clinic in 1995, the following reply dated 2 May 1994 was received from Professor Richard Jones:

"Firstly, let me reassure you that it is our intention to continue on the work of the Post-Polio Clinic in 1995 and for as long as it is required. With the Government and Area decision to ensure that The Prince Henry Hospital is a centre of excellence for Rehabilitation & Spinal Injuries, it would be untenable to think that the very services which are so required could be curtailed in any way."

- POST-POLIO RESEARCH Following a statement made by Senator Graham Richardson, in his capacity as Minister for Health, during a radio interview when he stated he would like to see more research into "unfashionable diseases", the Committee wrote to Professor Richard Jones on 10 April 1994, who replied as follows:

"A research project was carried out by Dr. S. Gandevia of Prince of Wales Hospital and his report is to be published in the journal "Brain".

Research funding for the Rehabilitation Unit has been discontinued and I will be seeking funding elsewhere. Support by the Network to assist the Rehabilitation Unit to obtain funding through Government or Charity would be most helpful." (*The Network is currently looking at ways it can assist Professor Jones in this regard.*)

- PARKING PERMITS Network member Alan Quirk raised the issue of parking permits for people with disabilities. From a situation where it was difficult to obtain a parking permit, the present one where they are freely issued for a relatively non-disabling illness, is causing great difficulty to those people with severe ambulatory disabilities. It was agreed that the Network form a sub-committee to investigate the problem, and to make recommendations as to how it can be overcome.

May Seminar Report

During the short break for lunch Mr. David Happ of Total Mobility Pty Ltd demonstrated an electrically operated bed and reclining chair. Later in the day, several of our members had a 'hands on' look at the Walkabout Scooter.

After lunch the Seminar got underway, with four Network members taking the floor to talk about their lives and demonstrate aspects of their work. It was fascinating to gain an insight into what these people are achieving.

Margaret Greig began by giving a short resume of her life and how she undertook the challenge to paint by mouth, being prepared to accept the artist's lot of "living on a shoestring" until her work was recognised. Today she is a renowned artist and member of the Paint by Mouth or Foot Society. It was riveting to see the development of a "very alive" kookaburra as Margaret deftly wielded her brush held in the mouth. Following this demonstration, Margaret played a video produced by the Paint by Mouth or Foot Society, in which the artistic gifts of people who are unable to use their arms was demonstrated. This video also showed a man driving in London controlling the car by a wheel on the floor, and a sculptor producing intricate work with a welder operated with her feet.

Suzanne Rangi read her poem "My Left Leg" which was recently featured on radio. This poem expressed Suzanne's feelings as a teenager who had contracted polio and touched a chord with a number of members. I understand our Editor is seeking permission from Suzanne to publish the poem in our Newsletter so that members who were unable to attend the Seminar can have the opportunity to read Suzanne's work.

Rosemary Shepherd who is a lace specialist at the Powerhouse Museum commenced her talk with a series of slides, showing the development and use of lace over the ages. This was followed by a demonstration of bobbin lacemaking during which Rosemary answered questions from the crowd gathered around her and talked about her life. Her book on the subject proved very popular as did the examples of her work she had brought along.

Alan Quirk gave a most interesting talk about his selection and training of Zuga, his dog. Zuga assists Alan with a whole range of daily living tasks and has got his master out of a sticky situation on more than one occasion. Zuga's job requires him to be happy to lie around "conserving his energy" while remaining ever alert to Alan's requirements. Throughout Alan's talk, Zuga patiently lay at his master's feet and displayed exemplary behaviour.

It was a very happy and interesting day and it was great to hear what four of our members are achieving in their lives. The day was well attended with several new members from both city and country.

Janet Malone

Next Issue

The next issue of the Newsletter will contain the following reports:

- "Danish Polio Society" by Kay Johannsen, an Australian polio survivor now living in Denmark. Kay spoke at a Network seminar in December 1993 and, after her return home, has written an account of her talk for the benefit of members who were unable to attend the Seminar.
- "What is Dysphagia?" by Monika Kaatske-Macdonald from Concord Hospital. Monika co-ordinates the Concord Swallowing Clinic. Monika addressed our March seminar on her work and has now forwarded the text of her talk for the information of members.

Orthotics Survey Results : Dr Alicia Lee

Some time ago, an article and questionnaire (written by Dr Alicia Lee) appeared in the Newsletter asking members to provide details of their experiences with orthotics. Dr Lee has now analysed the results of members' input and prepared the following report. The report has also been passed on to the Orthotics Task Force being sponsored by the Disability Council of NSW.

Nine letters were received in response to PPN's first enquiry about members' problems with orthoses. These letters were open ended.

Twenty-nine questionnaires came in response to PPN's second enquiry. Eleven of the questionnaires were from members who did not use orthoses (members having been asked to say if they did not use them in order to allow for some indication, however inadequate, of the proportion of members using and not using orthoses). They were also asked to report satisfactory as well as unsatisfactory experiences. There was thus a total of thirty-seven responses.

Questionnaires asked for information under the headings *fit* (which includes comfort and general function), *availability* (including delay), and *cost*. They were also asked if the supplier was *private* or *public*.

Summary questionnaire responses are given first. Responses for the second table were judged as generally satisfactory or unsatisfactory on the basis of at least two out of three headings. Respondents total to 18 since non-users are not included.

Questionnaires N = 18

Table 1 : Specific

	Satisfied	Unsatisfied	Totals
Fit	6	11	17
Availability	9	6	15
Cost	6	9	15
Totals	21	26	47

Table 2 : General

	Satisfied	Unsatisfied	Totals
Private	5	3	8
Public	5	7	12
Totals	10	10	20

Not surprisingly, letters all contained complaints. Because open ended, they are harder to summarise. Where possible, statements relating to questionnaire headings were extracted and are given below.

Table 3 : Specific

	Satisfied	Unsatisfied	Totals
Fit	0	9	9
Availability	0	6	6
Cost	0	4	4
Totals	0	19	19

Table 4 : General

	Satisfied	Unsatisfied	Totals
Private	0	8	8
Public	0	3	3
Totals	0	11	11

Although members were not asked about shoes, these were often spontaneously mentioned. Shoes are also an urgent problem, so these comments are included.

N.B. Totals do not always equal N because some people have used both private and public suppliers, or did not give the information.

Adding these tables together, the overall picture is as below.

Table 5 : Total Specific

	Satisfied	Unsatisfied	Totals
Fit	6	18	24
Availability	9	12	21
Cost	6	13	19
Totals	21	43	64

Table 6 : Total General

	Satisfied	Unsatisfied	Totals
Private	5	11	16
Public	5	6	11
Totals	10	17	27

It is interesting to note a higher degree of satisfaction with public than with private suppliers.

In a study like this it is often most useful to look at qualitative aspects of members' responses. Below are some main points from individual, often long, letters.

- (1) Difficulty in identifying problems with orthoses and getting adjustments; user ended up making own adjustments; delay; lack of sympathy; pain; cost of shoes.
- (2) Staff not qualified; poor assessment; poor workmanship; no quality control; user blamed for complaints of bad fit; high cost; long delays.
- (3) Bad falls from bad fit and breakage of callipers, leading to concussion and bleeding; waste of money; is using callipers 30 years old because new ones unsatisfactory.
- (4) Cannot get new leather jacket, through cost and not finding anyone to make it.
- (5) Brace doesn't fit; callipers too long; shoes no good, causing pins and needles; lives in country and had to send equipment back to North Shore Hospital where long delay due to lack of staff; inadequate consultation and rushed work; no female staff.
- (6) No concern with aesthetics; punitive attitudes of orthotists; no tax relief; no interest in maintenance.
- (7) Staff rude; would not believe user's complaint callipers too heavy; when got light-weight callipers elsewhere could not get PADP payment because user refused to accept first callipers.
- (8) Lack of staff; cannot get properly fitting callipers.
- (9) Two callipers cost \$1,300 each and shoe build-up \$50 each; insurance doesn't cover cost; delay to see specialist for referral and further delay to get callipers made; needs referral each time to get repairs; callipers too heavy, badly fitting, uncomfortable and unaesthetic; no quality control: doctor did not even want to look at finished callipers.

Many questionnaire respondents added comments, of which two are given here:

- Doctors take little interest in making of orthoses. Clients are therefore left to the mercy of individual orthotists, who may not know what is best to do. "I do not like being meat in this sandwich, as well as the victim, at mercy of experts."
- "Has taken some 15 years to train my orthotist who has persistently upset me by insisting any troubles with the gear has been due to either my strange shape or my misuse of equipment."

These comments, and many of the letters, apart from their factual complaints, are notable for their highly emotional tone, indicating how much distress, resentment and sheer anger is caused by lack of suitable equipment. This merely shows the enormous importance of adequate orthoses, not just for such important considerations as comfort, but for users' ability to gain employment, and for the maintenance of day-to-day living.

It is not possible to get representative figures in such a study as this. There seems no reason, however, why the questionnaire results should have been biased in any one direction (though letters specifically asked members to describe problems). Moreover, the consistency of responses is reason to suppose they may not be untypical. Therefore, while these results can be seen only as suggestive, they certainly give a picture of a most disquieting situation, urgently needing rectification.

My Encounter with Polio

When the following article written by Joan Colquitt crossed my desk recently, I found myself identifying with parts of her account. I was also struck by the similarities between the Texas Polio Survivors' Association and our own Post-Polio Network in NSW. We share like origins and philosophies and undertake the same type of work on behalf of our members. While our Network is just turning five, TPSA is celebrating its tenth birthday this year, both significant milestones. I thought other members might enjoy reading Joan's story. (The article is reprinted from TPSA Tips, Vol. IX, No. 1, First Quarter 1994, with kind permission from Texas Polio Survivors' Association, PO Box 35688, Houston, Texas USA 77235-5688).

My encounter with polio began in early January of 1946 when I was two years old. I lived in Bryan, Texas, and it was a mystery as to where I contracted the virus. Some of my earliest memories centred around my struggle and "recovery". I remember the long hours spent lying on the couch with my right leg swathed in hot towels. Exercise became a major part of my existence. My mother worked diligently with me, encouraging me to exercise and raising my leg and bending it when I could not do it myself. I lived with a leg brace and orthopaedic shoes, and though I was considered one of the "lucky ones", I always felt that I was different.

Many polio survivors like myself, who for years have disguised our polio limitations, have to face the most severe life style changes. Today, most people do not realize that I have a problem. I am often asked, at TPSA functions, why I am there. I am forced to explain and defend my right to be there.

We who have hidden or minimized our limping and continued to work at full speed to meet life's challenges, must now severely curtail our activities. We find we must start to relinquish the load to others and slow down; use a cane, put on braces again, climb into a wheelchair or three wheeler, use breathing machines and even go on disability status.

I have not yet learned how to properly use my cane. I bought one some time ago and have tried it unsuccessfully at home, but I am not yet ready to walk out in public with it. However, occasionally I wish I had that cane with me.

Polio patients were taught that the only way back was by way of strenuous exercise, every day. We worked as hard as we could and then worked a little harder still. Back then it worked. Depending upon the type of affliction, most of us were able to regain the use of most of our muscles and continue our lives. Of course, there were the braces and wheelchairs, walkers and iron lungs that had to be dealt with. There were the families who also struggled with polio and learned to care for their loved ones who needed assistance.

Studies have proven that polio survivors are some of the most intelligent and hard driving individuals in our society. We all adjusted, maybe some with more difficulties than others, but we coped and put polio behind us. We thought we had it licked.

But no one prepared us for what lay ahead. As we advanced into maturity, we became resolved to the fact that polio was a nuisance, but one that was forever in the past. Then, many of us began to notice that something was once again happening to our affected limbs and bodies. Something insidious and frightening was occurring. And we had no one to turn to.

When I began to notice weakening and atrophy of the muscles in my right leg, I immediately began the only way I knew to make it better. I started a new exercise program to "build up" my leg and once again overcome any taint caused by my polio.

My exercise program continued for a few months and I was very proud of my progress. I gained two inches in my thigh, something I had never been able to do before.

Then the muscle cramps and spasms began. I ceased my exercise program and began to question what was happening. I had never had the opportunity to know another polio victim, so I had no one to consult. The physician who treated me and monitored my therapy had long since died. And I didn't actually think my problem was serious enough to consult my family doctor.

Then one day my husband picked up the newspaper and pointed out an article describing a meeting which was to be held to discuss the late effects of polio. I went. The year was 1984.

I found myself in an auditorium with hundreds of people who had survived polio. It was a very emotional experience for me and I found myself near tears just being in the same room with so many people who had experienced polio. We sat and listened as several speakers described what was becoming known as Post Polio Syndrome. Dr Lauro Halstead, now director of the Post Polio Program at the National Rehabilitation Hospital in Washington DC, described his confrontation with the late effects of polio and explained the seriousness of the situation that most of us faced. None of the speakers had any good news.

After the meeting, people gathered into small groups to discuss more intimately their own experiences and symptoms. I gathered a handful of printed information from a table and joined a small group of three or four people. We talked and exchanged names and phone numbers and vowed to contact each other for support and further discussion. I never saw any of them again.

The Texas Polio Survivors' Association (TPSA) grew out of that first meeting. TPSA was formed by people who faced up to their problems and wanted to spread the word to others who had not yet heard about the dangers posed by polio. We have the encouragement and support of the Texas Institute for Rehabilitation and Research and regularly receive referrals from the staff.

After the initial shock of learning about post polio problems, I put it out of my mind. I was on the mailing list to receive further information and even though I did not attend any meetings for quite some time, I avidly read the literature that came to me. I also ceased my strenuous self-prescribed exercise program. In 1988 I began to tentatively test the waters of TPSA. My symptoms had continued to change and I could no longer deny that something was actually happening to me. It wasn't long before I dove in and immersed myself in learning all I could about the progression of post polio symptoms.

I believe that if I had not overworked my leg with my initial rejuvenation program, I would not be having the difficulties I currently experience. Maybe I could still walk up stairs without muscle spasms or pain. I could be using my right leg to push on the accelerator instead of reaching over with my left to handle both the accelerator and the brake. I could walk the length of the mall and back without limping in pain. I could turn over in the night or wake up and get out of bed in the morning without pain in my back. I would not experience the incredible fatigue that overcomes me by the end of the day.

At times I find it difficult to accept my limitations and am tempted to continue to be the hard driving person that I have always been. When I was a child, my mother always told me, "Can't never did anything". Today, I find it tough to say "I can't" when I still "want to". TPSA helps me to interact with other polio survivors and keep my perspective about my own situation.

What polio survivors save today, they will have tomorrow. We must learn to reduce stress on weakened limbs, we must cast aside our denial and accept the fact that we must work with our post polio symptoms, not against them. Conserving our strength, not depleting it, must become our goal.

TPSA also encourages inoculation against polio. Recent statistics indicate many children are not receiving polio vaccinations. This situation could prove disastrous if steps are not taken to ensure that every child receives the vaccine.

TPSA offers much needed information, support and assistance and provides a continuing presence for many individuals experiencing the late effects of polio. We also provide information to health care professionals. Most medical professionals have never seen a case of polio, nor do they know or understand what is happening to polio survivors. The numbers of people asking for help continue to grow as more and more individuals recognize the root of their problems.

The March of Dimes, which was formed to serve polio victims, has shifted the major emphasis of its services to preventing birth defects. They still provide some assistance to TPSA, but we must seek the major portion of our support from other sources.

Every year the Board of Directors, staff, members and supporters of TPSA strive to continue to provide TPSA's much needed services. TPSA is there to help those who say "I have a problem, please help me deal with it". Help us to help others. We can't do it all alone. Polio is not gone from this earth. It continues to haunt the lives of many. We would appreciate your help in continuing our fight against the ravages of polio.

Joan Colquitt

President, TPSA Board of Directors

Support Group Report

Hi, by now you will have received my introductory letter. Thank you to all those convenors who have replied. I look forward to hearing from you all when time allows.

Firstly I would like to thank John Jackson of Northern Inland support group for representing the Post-Polio Network (NSW) Inc at the Narrabri Disability Expo where he received several enquiries. Thanks John for the time and effort put in on our behalf. The convenor of this very successful support group, Barbara Chapman-Woods, has a new address and telephone number - her new details are given in the updated list below.

I would like to take this opportunity to welcome John Burns as the new convenor of the Roselanders support group. At the moment John is making telephone contact with members.

Liverpool-Sutherland convenor Robyn Robinson is planning a Christmas in July get-together for her group.

ACT support group convenors Maureen and Brian report that their April meeting with Dr Jill Middleton was a great success. It was their group's first anniversary and everyone enjoyed speaking with Dr Middleton over a long afternoon tea when her talk was over. Twenty-four members were present, including five new members. Congratulations.

Ermington support group convenor June Brown reports that although membership of her group may be small it is very successful.

Hunter Area support group convenor Barbara McCormack has much to report. A responsible authority has given assurance that the Hunter area will definitely have its own post-polio clinic. Barbara will let us know when details have been finalised so that we can publish the information in the Newsletter for the benefit of all Network members living in the region. The support group's recent visit to the Independent Living Centre at Ryde was a great success and Barbara feels many could benefit from a similar visit. Thanks also for the copies of the Kenny Clinic photos from 1939.

The current list of Support Groups and convenor contact details is given below for the information of members. If you would like to join one of the groups why not give the convenor a call?

Best wishes to you all.

Suzanne Rangi **Support Group Co-ordinator** **(02) 554 4204**

Support Group Listing

ACT

Maureen Kelleher	30 Erldunda Circuit HAWKER ACT 2614	(06) 254 9288
Brian Wilson	5 Hussey Cove BONYTHON ACT 2905	(06) 293 2747

ALBURY

Neil Von Schill	358 Jacinta Court LAVINGTON NSW 2641	(060) 25 6169
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BASS HILL

Andreana Salopatis 88 Lowana Street VILLAWOOD NSW 2163 (02) 727 7508

BLACKTOWN-BLUE MOUNTAINS

Jeanne Parkes 2 Chelsea Place ST MARYS NSW 2760 (02) 623 4989

CAMPBELLTOWN

Brian Toby 23 Bowerbird Avenue INGLEBURN NSW 2565 (02) 618 2279

CENTRAL COAST

Barbara Merrington 41a York Street EAST GOSFORD NSW 2250 (043) 25 2532

COFFS HARBOUR

Anne O'Halloran 20 Crescent Street East URUNGA NSW 2455 (066) 55 5204

Nancye Bonham 51 Gallipoli Road COFFS HARBOUR NSW 2450 (066) 52 5083

ERMINGTON

June Brown 4 Woodward Street ERMINGTON NSW 2115 (02) 638 1392

GRAFTON

Jacqueline Bishop 8 Aries Road JUNCTION HILL NSW 2460 (066) 44 7483

GRIFFITH

Meryl Blanchard 136 Kookora Street GRIFFITH NSW 2680 (069) 62 5341

HAWKESBURY

Irene Alexander 12/32-38 East Market St RICHMOND NSW 2753 (045) 78 1010

HUNTER AREA

Barbara McCormack 4 Englund St BIRMINGHAM GARDENS NSW 2287 (049) 51 1647

INNER WEST

Joan Mobey PO Box 91 GLEBE NSW 2037 (02) 660 8769

KELLYVILLE

Carole Turner 4 Jerilderie Avenue KELLYVILLE NSW 2153 (02) 629 1501

LIVERPOOL-SUTHERLAND

Robyn Robinson 168 St Georges Crescent SANDY POINT NSW 2171 (02) 771 4176

NORTHERN INLAND

Barbara Chapman-Woods 100 Court Street MANILLA NSW 2346 (067) 85 1172

NYNGAN

Marion Wardman PO Box 107 NYNGAN NSW 2825 (068) 32 1350

ROSELANDERS

John Burns 22 Graham Road NARWEE NSW 2209 (02) 534 2751

SHOALHAVEN

Judith Orford 70 Sheaffe Street CALLALA BAY NSW 2540 (044) 46 5346

UPPER NORTH SHORE

Barry Palmer 7 Beryl Avenue MOUNT COLAH NSW 2079 (02) 457 9959

WELLINGTON-DUBBO

Hugo Orro "Tabletop" WELLINGTON NSW 2820 (068) 46 7272

YOUNG

Jean Robinson 32 Nasmyth Street YOUNG NSW 2594 (063) 82 4337