



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

Welcome to regular readers and new members alike. Our next **Seminar** will be held on **Saturday 10 July**. We again have two excellent speakers lined up - full details appear on page 2. In this issue of the *Newsletter* you will find articles on post-polio, book reviews, the opportunity to participate in a Re-evaluation Counselling Course, Support Group Reports and Post-Polio Post.

It is membership renewal time. With this *Newsletter* you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 1999 (as indicated on your address label) you will find a **Membership Renewal Form** enclosed, for the period 1 July 1999 to 30 June 2000. Could you please confirm, complete or amend your details as given on the form, and return it with your subscription to the Treasurer at the above address. If you are already financial beyond 30 June 1999, you will instead receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. Again, please check your details and amend as required, and then return the form to us as soon as possible.

This year's **Mini-Conference** and **Support Group Conveners' Workshop** will be held **21-22 August** in **Coffs Harbour**. Preliminary details are given on page 3. Look out for the full **Program and Registration Form** which will be included with next *Information Bulletin* to be **posted in July**.

Raffle books will also be sent out in July. An exciting array of prizes is being assembled with the raffle to be drawn at our **Tenth Anniversary Lunch** to be held on **Saturday 6 November**, during *Post-Polio Awareness Week*. The raffle is our major fund-raising exercise and deserves your support. As an unfunded organisation, we have to fund-raise in order to provide the extensive Network services we do, and to enable us to outreach to polio survivors in rural and remote areas.

The Management Committee is currently putting a lot of time and energy into seeking out **funding sources** to ensure the ongoing viability of the Network. You can help our efforts by writing in to say how valuable the Network's services are, and how much the Network has helped you to understand and manage the late effects of polio. We would also appreciate it if you could keep an eye on your local papers for notification from Councils of funding available to community groups. If you can send details to the Network we can apply for grants to assist local Support Groups and to help us undertake activities in regional areas.

The book *Managing Post-Polio* edited by Dr Lauro Halstead is now in stock and all orders received to date have been filled. Order your copy today - the cost is \$25 post free throughout Australia.

Finally, we have very exciting news to report. **Elizabeth Dean** [Associate Professor, School of Rehabilitation Sciences, University of British Columbia, Canada] who was a keynote speaker at the Network's Conference *Living with the Late Effects of Polio* in 1996, will be in Australia in October and has graciously accepted our invitation to speak at this year's **Annual General Meeting**. The AGM will be held on **Saturday 30 October** as originally scheduled, at **The Independent Living Centre, Ryde**. Please make sure this date is marked in your diaries - you won't want to miss this Seminar. Full details of Elizabeth's presentation will appear in the next Newsletter.

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Post-Polio Network Seminar

Date: Saturday, 10 July 1999

Time: 1:00 pm - 4:00 pm

Bring a packed lunch to eat from 12:00 noon and catch up with friends before the Seminar, and afterwards at afternoon tea.

As usual, fruit juice, tea and coffee will be provided.

Venue: St Paul's Anglican Church Hall
57 Princes Highway, Kogarah

Please note that the Hall is on the left-hand side of the Princes Highway as you drive towards Sydney, between Gladstone and Regent Streets. If you are driving from Sydney down the Highway, you need to turn right into Regent Street, left into Gladstone Street, and finally left back onto the Princes Highway. St Paul's is then a short distance along the Highway, on your left. Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

This Seminar will again feature two guest speakers.

Members may recall that our Spring 1998 issue of the *Information Bulletin* carried an article on customised clothing for those who have difficulty in dressing. At **1:00 pm, Jill Roy** from **Flinders Clothing**, which markets this range of garments and shoes, will speak to us and present a display of many of the items now available.

It should be remembered that this is one of the few companies that provide a full range of clothing for men as well as women.

While Flinders Clothing is a Sydney based company, they provide a mail-order service and can also be contacted via Email on the Internet at <royz@bigpond.com>. Nonetheless, joining us at the Seminar and seeing first-hand what is available would undoubtedly be the best way to make an informed decision on what may be of benefit to you.

Our second guest speaker from **2:00 pm** will be **Christine Dunnell** who is a member of **International Training in Communication (ITC)**. Christine is currently the co-ordinator for the ITC speaking program with the Sydney Paralympic Organising Committee. She became involved with the Paralympic speaking program 18 months ago when ITC were asked if they would provide speakers to community groups to raise awareness of the Paralympic Games and encourage spectators to attend.

Christine will give an overview of the history of the Paralympic Games, how and why they started, and how they have developed. Christine will also tell us about the sports we will see at the Games and how participants are categorised. She has particularly promised to do some research into the involvement of polio survivors in the Paralympics. As a highly-skilled communicator, her presentation promises to be both informative and entertaining.

As usual there will be a question and answer session after each presentation.

If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there.

Mini-Conference and Support Group Conveners' Workshop

This year our country *Mini-Conference* will be held in Coffs Harbour on Saturday 21 August 1999, in conjunction with the Network's long-established and active local **Support Group**. The venue is the well-appointed and fully accessible *Catholic Recreation and Sporting Club*, 61A West High Street, Coffs Harbour. As the Club is all on one level you won't need to negotiate any steps or lifts. Parking is readily available.

We are currently finalising speakers and topics. Full details of the Conference Program and a Registration Form to attend will be sent out with the *Information Bulletin* in mid-July to all members and other interested people. In the meantime, if you have any questions, please contact Gillian on (02) 9663 2402.

Ken Dodd from the *Coffs Harbour Support Group* has generously offered to look after all local arrangements. If you would like any information about the Coffs Harbour area including travelling times, how to get to the venue, motel/hotel accommodation and accessibility issues, please give Ken a ring on (02) 6655 1112.

Our second annual **Support Group Conveners' Workshop** will be held on **Sunday 22 August 1999**, following the Mini-Conference. Last year's inaugural event was adjudged a great success by all who were able to attend. For the first time Conveners and Co-Conveners were able to meet face to face and learn about how the different Groups operate. This year the Workshop will be facilitated by the Network's respected Support-Group Co-Ordinator, Bernie O'Grady. Following valuable feedback from Conveners after the first Workshop, this year's event promises to be even more worthwhile. If you are currently a Support Group Convener, or are thinking about becoming one, you are urged to try to attend. For further information, and/or to register your interest in attending this most important event, please ring Bernie on (02) 9688 3135. A Registration Form for the Workshop will be sent to Conveners and interested members in mid-July.

Use of Medication in People with Post-Polio Syndrome

Susan Perlman MD

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Susan Perlman MD is Associate Clinical Professor of Neurology and Director of the Post-polio Clinic at the University of California Los Angeles (UCLA). Since 1988, the clinic has evaluated and treated 600 polio survivors, with an approach combining neurological assessment, neuro-rehabilitation techniques, medication intervention, and consultation with associates in orthopedics, medicine, sleep disorders, psychology, and alternative (complementary) medicine. The clinic coordinates with the dedicated support groups in southern California and offers educational outreach to the health care community.

Post-polio syndrome is a constellation of new symptoms (fatigue, weakness, pain, cold intolerance, muscle atrophy, or new problems with activities of daily living), occurring in survivors of definitively (by history, exam, or electrical studies) proven acute poliomyelitis, after a period of at least 15 years of stable recovery and performance, and in the absence of any other medical or neurological condition. It is felt to result from the weakening and loss of previously recovered lower motor neuron connections to muscle, possibly due to aging, greater fragility of the recovered nerves, or immune system dysregulation. Onset can be insidious, progression is usually slow, and treatment is most successful with rehabilitation strategies.

Until we better understand the causes of post-polio syndrome, we will have no curative medication. At best, we can use medication to treat the symptoms and to improve the quality of life, and we can avoid using medication that could make the symptoms worse. Certain other diseases (elevated blood cholesterol levels, high blood pressure, heart disease, and cancers) require use of medications with side effects that can exacerbate symptoms of post-polio syndrome. These should be used, but with careful monitoring of the polio survivor's functioning.

Symptomatic Medication

The three primary symptoms that we can treat with medication are weakness of muscle, fatigue (individual muscle and generalized), and pain, that is, post-polio pain, overuse pain, bio-mechanical pain, and bone pain (Gawne, AC, 1995).

Drugs to reverse muscular atrophy or to improve muscle strength by stimulating motor nerve endings to reconnect with muscle fibers (*nerve growth factors*) are all still experimental. They are currently being tested for use with other motor nerve diseases. Only insulin-like growth factor type 1 (IGF-1), also known as myotrophin or somatomedin-C, has been tested in people with post-polio syndrome (Miller, RG, 1997) (see chart on page 6). It brought no change in strength or fatiguability, but did improve recovery from fatigue after exercise. Human growth hormone has been given to increase a person's natural level of IGF-1, but showed little or no improvement in strength (Gupta, KI, 1994).

Another approach has been to develop and test drugs that would protect the nerve-muscle connection from new damage in the first place (*neuro-protective agents*). Again, several have been studied in other diseases, but only selegiline has been tested in post-polio syndrome, bringing some improvement in symptoms but no clear stabilization of the disease (Bamford, CR, 1993). Although many people use over-the-counter anti-oxidant preparations of various types, these have never been formally tested to prove any ability to slow down the changes of post-polio syndrome.

Anabolic steroids, often used by body builders to improve muscle bulk and power, have been tried by polio survivors and other persons with neuromuscular diseases, but *The Medical Letter on Drugs and Therapeutics* reports the side effects (risk of prostate cancer in men, masculinization in women) greatly outweigh the potential benefits. *Metabolic stimulants* (L-carnitine*, L-acylcarnitine, coenzyme Q), used to improve the ability of muscle to make energy and possibly reduce fatigue and improve strength, have also been tried by polio survivors, but have been associated with rare allergic reactions and insomnia (Lehmann, T, 1994; Nibbett, JI, 1996).

Specific *anti-fatigue* drugs can act either in the brain itself (on pathways controlled by dopamine and noradrenaline) or by improving communication at the nerve-muscle connection. These are, respectively, central and peripheral agents. Centrally-acting anti-fatigue medications include amantadine, bromocriptine, selegiline, pemoline, ephedrine, and certain antidepressants (selective serotonin re-uptake inhibitors, which may also have nonadrenaline activity). All have been tested in other fatiguing neurologic illnesses, but only the first three have been studied in post-polio syndrome. Amantadine provided no reduction in fatigue (Stein, DP, 1995), but bromocriptine (Bruno, RL, 1996) and selegiline (Bamford, CR, 1993) did. Several studies have been done using pyridostigmine, a peripherally-acting drug, (Trojan, DA, 1993, 1995; Seizert, BP, 1994; Trojan, DA, 1997) that reflected variable effects on fatigue, possible mild improvement in strength in very weak muscles, and notable side effects (primarily gastrointestinal) .

When contemplating the use of anti-fatigue drugs, we first treat any concomitant problems (other medical or neurological illnesses, sleep disorders, depression) that could be adding to fatigue.

When rehabilitation techniques have not given adequate *pain relief* and medications must be used, we determine where the pain is coming from before choosing the most specific treatment agents. In our experience, for true post-polio muscle pain, centrally acting, non-narcotic drugs work best (serotonin-stimulating medications, for example tricyclic antidepressants, clonazepam tramadol; central nerve relaxants, for example baclofen, tizanidine; nerve stabilizers, for example anticonvulsant drugs like carbamazepine or gabapentin).

Fortunately, we have no drug for overuse pain. If we did, using it would be like taking the batteries out of a smoke detector because it is noisy at night. This pain makes polio survivors aware that they are overdoing and need to cut back.

Biomechanical pain resistant to non-drug strategies may respond to short-term use of non-steroidal anti-inflammatory drugs (NSAIDs). Some survivors may experience the side effect of gastrointestinal problems.

Joint-related pain may require cautious long-term anti-inflammatory therapy. When a true analgesic is required, whether it is as simple as acetaminophen or as strong as a narcotic, it should be taken in moderate amounts and on a schedule, not just when the pain is so severe that a higher dose is necessary. If taken together, mild anti-histamines or anti-anxiety medication may make pain-killers work better and at a lower dose, but do have their own side effects.

Acupuncture, electro-acupuncture, acupressure massage, and possibly magnetic therapy may work on painful muscle areas along the same pathways as narcotics, and all have been tried in post-polio syndrome. Pain caused by fibromyalgia may respond to low, bedtime doses of amitriptyline (Trojan, DA, 1994).

Cautions about Medications

Many drugs may have drowsiness as a side effect or may increase fatigue within the general population. (Always check the label or ask the pharmacist or physician.) These include central nervous system (brain) depressants, for example narcotics, sedatives, tranquilizers, sleeping pills, and alcohol; antihistamines; antidepressants; and anti-anxiety agents. Polio survivors who take these medications may experience an increase in polio-related weakness and fatigue.

Diuretics (water pills) and laxatives may deplete the body of essential minerals required by nerves and muscles for normal functioning. Many other drugs (antibiotics, chemotherapy agents, even mega doses of some vitamins, for example B₆) can contribute to nerve damage. Muscle relaxants and drugs similar to them in chemical structure (quinine, quinidine, procainamide), as well as other medications used for heart or blood pressure problems (beta-blockers, calcium channel blockers), may add to polio-related weakness and fatigue.

Anecdotal evidence suggests that cholesterol-lowering medications of the "statin" family may also increase polio-related weakness and fatigue. Polio survivors, particularly those with a lesser muscle mass, have reported fewer and less dramatic side effects from some medications when taking a lower dose.

Polio survivors and their physicians should scrutinize all medications - current and newly added - used to treat various medical problems to be assured that related conditions, such as fibromyalgia, elevated cholesterol, high blood pressure, etc., are appropriately treated, but with minimal effect on polio-related symptoms. .

* A placebo-controlled study, as yet unpublished, recently done in Germany showed no significant difference between placebo and L-carnitine.

Table. Pharmacology of Post-Polio Syndrome: Recent Trials

Drug	Category	Type of Trial	N	Results in PPS
Amantadine	Anti-viral	Randomized, placebo-controlled trial	25	No significant improvement in fatigue ¹
Prednisone (high-dose)	Steroid, anti-inflammatory	Randomized, placebo-controlled trial	17	No significant improvement in strength or fatigue ²
Human growth hormone	Hormone	Open trial	5	Little or no improvement in muscle strength ³
Bromocriptine	Dopamine receptor agonist	Placebo-controlled, cross-over trial	5	Improvement in fatigue symptoms in 3 patients ⁴
Selegiline	Neuro-protective agent	Case studies	2	Improvement in PPS symptoms ⁵
Pyridostigmine *	Anti-cholinesterase	Open trials	17, 27	Improvement in fatigue ⁶⁻⁷
		Placebo-controlled, cross-over trial	27	Improvement in fatigue, strength ⁸
Insulin-like growth factor 1 (IGF-1)	Growth factor	Randomized placebo-controlled trial	22	Improvement in recovery after exercise, change in strength, fatigability ⁹

- 1 Stein DP et al. *A double-blind, placebo-controlled trial of amantadine for the treatment of fatigue in patients with the post-polio syndrome.* Ann NY Acad Sci 1995;753:296-302.
- 2 Dinsmore S et al. *A double-blind, placebo-controlled trial of high-dose prednisone for the treatment of post-poliomyelitis syndrome.* Ann NY Acad Sci 1995;753:303-313.
- 3 Gupta KL et al. *Human growth hormone effect on serum IGF-1 and muscle function in poliomyelitis survivors.* Arch Phys Med Rehabil 1994;75:889-894.
- 4 Bruno RL et al. *Bromocriptine in the treatment of post-polio fatigue.* Am J Phy Med Rehabil 1996;75:340-347.
- 5 Bamford CR et al. *Postpolio syndrome response to deprenyl (selegiline).* Int J Neurosci 1993;71:183-188.
- 6 Trojan DA et al. *Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue.* J Neurol Sci 1993;114:170-177.
- 7 Trojan DA, Cashman NR. *An open trial of pyridostigmine in post-poliomyelitis syndrome.* Can J Neurol Sci 1995;22:223-227.
- 8 Seizert BP et al. *Pyridostigmine effect on strength, endurance, and fatigue in post-polio patients (Abstract).* Arch Phys Med Rehabil 1994;75:1049.
- 9 Miller RG et al. *The effect of recombinant insulin-like growth factor 1 upon exercise-induced fatigue and recovery in patients with post polio syndrome (Abstract).* Neurology 1997 (in press).

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* An article detailing the results of the *North American Post-Poliomyelitis Pyridostigmine Study (NAPPS)* has been submitted for publication.

A Family Affair: The Impact of Post-Polio on Family Relationships

Dr Adam Gruszczynski

This article is excerpted from the Ontario March of Dimes' *Solutions for the Future Conference Proceedings* (publication pending). The article was first published in *PoliOntario*, January 1999, Volume 6, Number 2, and reprinted in *Sappling's*, March 1999, Newsletter #29. It is presented here with permission of *Saskatchewan Awareness of Post Polio*, Canada.

One of the difficulties of being in a relationship with a person who has a chronic illness is the belief that we are alone. Everything is directed toward the person with the chronic illness and while that is fair enough, it is important to remember that the partner is also having to make adjustments to the illness.

In today's discussion I am going to outline my situation when my partner, Dr Mavis Matheson, began having problems with post-polio, and how we managed our relationship as her post-polio progressed. Mavis and I met in Regina as interns in 1985. Early in our relationship she mentioned she had had polio and had recovered. She led an active life, had swum competitively and enjoyed hiking and skiing — all the things that I enjoy doing. She hadn't yet heard of post-polio syndrome, so it never occurred to her that she might experience problems in the future. We had two children and worked together at the same clinic for five years. We were travelling and enjoying life together — things were working pretty well. She was one of those active, Type A people — always doing five things at the same time. In 1991 we decided to form a clinic of our own. This required a lot of organizing and Mavis did all of the detail work. She was finding herself increasingly tired, needing to sleep more and becoming irritable. I was also becoming irritable and we found ourselves pulling away from each other. We thought the changes in our relationship were due to the stress of setting up the clinic and expected things to right themselves when we opened. Things did settle down. We shared the practice, I was working 3 days a week and Mavis worked 2-1/2 days a week. This gave us more time with each other and the children. In early 1993, I found Mavis becoming emotionally distant. She was tired, going to bed more frequently and having more aches and pains. She was limping more and found herself spending the weekends recovering from the work week. Over the spring her symptoms got worse. Mavis began reading about post-polio syndrome and quickly realized that what she was reading was describing what she was experiencing. Her family doctor was not helpful as she had no familiarity with post-polio. Mavis knew she had to start making some changes in her life. She cut out a half hour from each work day and, rather than running to work, started using her car. She found that she was ending the day in better spirits but was uncertain whether she was going to be able to get going the next day.

Things came to a head in 1993 when I got a call from the receptionist at the clinic saying that Mavis was taking medications from the drug cupboard. I cursed myself for not realizing that things were getting so bad. I was in denial and not paying enough attention to the realities of Mavis' illness. We reorganized our responsibilities at the clinic, Mavis took some time off and I began to work full time. She did a time/energy study while she was at home and found that she was taking over 300 steps a day — while she was trying to cut down and rest. We lived in a four level split with the bathroom on one level and the kitchen on another. I realized that we needed to move to a one level home. During one short month we went from having an equal relationship working together, to Mavis not working, me working full time and the family having to change our home. We also had to try to explain what was happening to the children who were 3 and 6 at the time. As time went on, Mavis found that she was able to do less. She was not recovering and was becoming

increasingly fatigued, even with her modified schedule. She began to get more depressed. I was becoming stressed and irritable as well and did not know what to do to make things better. I found myself staying up later and letting myself get more fatigued, thinking — if she's tired, I should be tired too. It's not very rational but when people are under stress they're not always rational. Eventually Mavis insisted that I seek counselling. This was useful because when I was growing up my mother suffered from severe depression. It was like living with a chronic illness. There were times when I would come home and not know what situation I would be facing. When I left home I figured I had left the chronic illness and not have to deal with it again. Now here I was in the same situation only it wasn't going to be a couple of years and I wouldn't be able to leave. That was very hard to deal with.

Our situation continued to deteriorate throughout the fall and just before Christmas Mavis went into the hospital because of other health concerns, perhaps ALS or Multiple Sclerosis. She was in the hospital for a week and had all the tests done. The doctors said "this is just a psychosomatic thing". By that time I had read enough, knew enough and observed Mavis enough to know that this was not the case. Mavis was depressed and I had to support her through that psychosomatic nonsense. In January I started to keep a journal of my feelings, especially the feelings you don't want to share with your spouse. You don't want to tell them that you are tired of dealing with the problems, that you are tired of not being able to do things, and you are angry at them. It's not their fault but those feelings are still there and the journal provided an important outlet.

Mavis went to see Dr Rubin Feldman in Edmonton. He did a few simple tests and diagnosed her a classic case of PPS. He counselled her about changes she would need to make to maintain her health. She learned that many of the lifestyle changes we had gone through already were the things that she needed. While she was in Edmonton I continued my journal, exploring my goals and values. I realized that the things that I found important in my life were still available to me in our relationship. It was important to me to have challenges, to grow personally and to have satisfaction. Our relationship provided a situation where I could have all of this. I didn't have to run away to be fulfilled. It was also at this time that I realized one of the things Mavis was working through was the fear that she was going to be abandoned, that I was going to leave her. I found that the reason I wasn't running away was that I was meeting my needs in the relationship. The realization that Mavis felt that I might run away gave me a chance to show my commitment to the relationship. We hadn't married yet and I thought this was an appropriate time to propose to her. This was an important step in her realization that I was not going to leave the relationship.

Things were still unsettled though and we both needed a lot of separate time. Mavis needed time to come to terms with herself and to develop ways to rest and get her energy back. I needed time for myself to come to terms with what was happening with her, to grieve through the losses and to get comfortable with our recent changes. In May 1994 things came to a head. Mavis got so tired and so distressed that she checked herself into the hospital. While in the hospital, she developed a routine of sleeping in the afternoons and resting and she felt much better. It was at this time I realized that either this relationship is going to work or it's not. Interestingly enough, while Mavis was in the hospital she had come to the same conclusion. We started settling into the routines of a more regular relationship. We discovered that there were ways of travelling with a disability. We discovered there are ways to conserve energy. We got a housekeeper. We found through trial and error that we were able to build our relationship again. We realized that we had some losses but there were new challenges that keep it worthwhile and exciting.

I have read many books about family relationships and chronic illness and through them, have learned some very good advice. Be aware of your attitudes about chronic illness. If you have had previous exposure to chronic illness, there may have been some very positive or really negative events which could colour your perception and your relationship. My previous exposure had been a very negative experience and I assumed that the current situation would be negative as well. It is useful to be in the present and not dwell on what might happen tomorrow or grieve about things that have changed. Instead, concentrate on what is happening today. Worry about tomorrow tomorrow. Getting worked up about things that might happen is a big waste of energy.

Know your values and goals and be honest with yourself. Take ownership. Acknowledge the situation and acknowledge that you want to be in the relationship. It is also important to maintain boundaries and give yourself some separation. I live with an illness but it is not my illness. I am affected by it but I don't have to suffer from it. I can do things that I enjoy doing without having to feel guilty that my spouse is not able to do them. This separation gives me the energy to come home and do things together and deal with the stressful parts of the relationship when they arise. All of these things are factors in taking care of yourself and your relationship. If you don't take care of yourself, you probably won't be helpful to your spouse. Sometimes you might need to acknowledge that at least things aren't getting worse and might even improve. Occasionally Mavis and I find there is another loss we did not expect. We find ways to adapt and get around the hurdle. We have found that our relationship is working because we've been through this challenge together. We each had to work on separate parts and were able to use the things that we learned to work together.

Opportunity To Expand Your Life Through A Re-evaluation Counselling Course

Joan Mobey (02) 9660 8769

This opportunity to learn Re-evaluation Counselling (RC), also called Co-Counselling, should attract smart, effective people. Some of you may be suffering the late effects of polio or have other difficulties in your life; others may not.

I have been involved with this movement for 15 years and have been a teacher of the fundamental theory and practice for about 12 years. This involvement has made a tremendous difference to my life and I would like to give other polio survivors the opportunity to share this experience.

RC is a grass-roots movement that began in Seattle, USA, approximately 50 years ago, and at this time has spread to over 80 countries. Some countries have just a few co-counsellors, while in others there are thriving communities. Australia comes into the latter category. In Sydney there is a community of more than 200 people.

You may wonder why you have never heard of Re-evaluation Counselling before. Up until now we have kept a low profile, and the community has grown by word of mouth. But we now feel it is the right time to show a more public presence, and to share our theory and practice more widely.

Let me tell you some things RC is not. It is not a New Age movement, and not part of, or a substitute for, the mental health system. It will not cure the physical effects of post-polio, nor be able to provide information about treatments and aids (we are so fortunate to have the Network to fulfil this role). If you take up my offer, you will not become a professional counsellor. You need no academic qualifications to become an excellent co-counsellor.

However, RC is useful for empowering people to take up their current challenges, broaden their horizons and enrich all their experience. It may well lessen the fatigue that we suffer by freeing us of the tension from old polio memories and current frustrations. (That part of the fatigue which is physically caused will remain, but RC may help there as well by making it easier for us to be more sensible about pacing ourselves.) And if you persist it will be a means to improve your quality of life and your ability to deal flexibly with (among other things) the many frustrations of the late effects of polio. If a number of Network members and their friends take it on, they could make up a special network of support for each other in which the telephone could play a key role. If they choose to become involved in the larger RC community, they would have access to a wide variety of co-counsellors of different ages and life situations. There is no charge for individual co-counselling sessions.

In a fundamentals class there are two roles to be learned: the role of client and the role of counsellor. Each role informs the other. It is not possible to be a Re-evaluation Counselling counsellor without also engaging in depth in the process of being a client.

The counsellor needs a knowledge of the theory, but the greatest tool an RC counsellor can have is a growing freedom from the rigidities that hamper not only our ability to be awarely there for another person, but also our ability to respond spontaneously and appropriately. The theory is also important to the role of client, enabling clients to work effectively in their turn. In a session, both people work together, as collaborating peers.

We are able to be freed from our rigidities by natural processes, including laughter, shaking, tears and talking without interruption. Polio survivors have generally been strongly conditioned to manage their feelings without releasing them and no good can come of trying to force release. The class would start off very simply just by talking about ourselves and our lives, while others listen awarely and without interruption. The process would deepen naturally as trust was built up, inhibitions dropped, and knowledge of the theory expanded and deepened through reading, thinking and talking.

Being a Re-evaluation Counsellor does not mean focussing your attention on the difficult experiences of the past or the present. It does mean getting on with your life with your attention on the goodness of people and the beauty in the world around us, while having agreed upon time-out to clear away the hurts of the past.

If I receive a response from this article, I will present an introductory session so that people can make a decision as to whether they want to continue.

Local Support Groups Get Together

On Saturday 5 June the Network's *Central Coast* and *Hunter Area* Support Groups held a very successful combined meeting at the *Kincumber Multipurpose Centre*. More than thirty members, family and friends attended, including Management Committee members Gillian Thomas, Alice Smart, Bernie O'Grady and Allan Quirk who travelled from Sydney, accompanied by Irene O'Grady and Peter Garde.

As Lynne Ellis from the *Central Coast Support Group* writes: "We had a lovely 'get together' and our Guest Speaker was local author Carol Mara whose book *Iron Cradles* (about a child who got polio in 1951 ... a lovely book, very well written and well worth reading!) has just been published. [Ed: See *Mary Westbrook's* review on the following page.]

Carol gave us a most interesting insight into the research required to write a book like this, and 'question time' turned into a lively discussion of conditions in hospitals and country towns in the 50s. We all got together over lunch and afternoon tea, and got acquainted with some of the people we hadn't met before."

Anyone who wishes to join either of these Support Groups, please contact **Barbara Tunnington** (**Central Coast**) on (02) 4369 2397, or **Wendy Chaff** (**Hunter Area**) on (02) 4957 5254.

Iron Cradles : Childhoods Lost to Polio

Mary Westbrook

Most accounts of the polio experience have been written by people who contracted polio. However many polio survivors have only limited knowledge of how polio affected other members of their families. Some Network members had parents who refused ever to talk about polio, a few even denied that their child ever had the disease. In our Newsletter of May 1996 we published *Family reflections: A dialogue with my mother*, in which Sunny Roller and her mother discussed for the first time what had happened to them both when Sunny contracted polio over 40 years previously. Now Australian author, Carol Mara, has written a novel *Iron Cradles* which tells the story of a country family in the 1950s whose baby, Beth, contracts polio. The novel is beautifully written and will be of interest to general readers for its vivid portrayal of country life and attitudes in mid-century Australia and its treatment of the universal themes of a family in crisis, a child's separation from its mother and community prejudice. For polio survivors the book will have profound relevance. It deals with what was for many of us the most defining event of our lives: there was before polio and after polio when our lives had been changed forever; not only our bodies but our relationships with others.

The main focus of the novel is the mother, Nettie, who loses her child to an uncaring hospital far away in the city and who eventually brings her daughter back home. But the enforced separation has left scars that prove difficult to heal. At night Beth often wakes, "her face a silent scream, her breath coming in hectic gasps. I don't know where she is, in some unutterable dark world that will not release her from its thrall. I gather her up ...make warm milk and play 'This little piggy went to market...and this little piggy cried wee wee wee all the way home.' And in that moment she is my daughter again." The reader is privy to the mother's thoughts but the feelings of the other members of the family are apparent from their behaviour. The elder brother is ashamed and jealous. The father gradually softens and becomes more supportive of his wife. The difficult grandmother grudgingly provides some assistance when Beth returns home learning to walk and clinging to her mother. The aunt in the city visits Beth in hospital but finds it difficult as her neighbours are too frightened of possible infection to mind her children. The needs of the new baby become secondary to Beth's problems.

Polio survivors will be interested in the details of hospital life, finding similarities and differences between King's Hospital in the novel and Royal Alexandra or Prince Henry etc. I talked with the author and asked about her connections with polio. She told me they had been few. The trigger for the book's polio theme was having a friend who had polio as a young child. Carol observed the effect of this experience on her friend's relationship with her mother. However the events in the book are entirely fictitious although Carol spoke with a number of polio survivors to gain insight into life in a polio ward.

Polio survivors will find reading this book a worthwhile experience though it could lead to a few tears. For most it will be a walk down memory lane. It may also give new insight into our families' experiences at that time and could lead to better communication with siblings and parents who are still alive. The book is published by Allen and Unwin and retails at \$16.95. The Network has organised a special deal with the publishers for Network members. You may purchase the book for \$15.25 and have it mailed to you post free by filling in the flier in this *Newsletter* and posting it to Allen and Unwin.



BLACK BIRD FLY AWAY

Hugh Gallagher's Story of Living with Polio in an Able-Bodied World

Mary Westbrook

Hugh Gallagher has been described as the hidden architect of the Americans with Disabilities legislation. After writing several books and many articles on disability he has now written his own story of forty years as a polio quadriplegic and his participation in, and observation of, the disability revolution. "The world has changed and so have I" he says in the introduction to his book (3).

Gallagher contracted polio in 1952 at the age of 19. His hospitalisation was painful and traumatic. He comments that he is glad he was not treated by Sister Kenny, as he required an iron lung and she considered such patients too far gone to save. Many child survivors might regard his hospital experience as relatively benign, with constant visiting from family and friends. Nevertheless Hugh describes events which permanently affected him both emotionally and sexually. He is certain that the "torture" of the pain inflicted by his physiotherapist "gave her a significant degree of pleasure. This woman is now dead. I can only hope that she is roasting in hell, roommates with that Nazi woman who made the lampshades out of the skins of her concentration camp victims." Returning from evening engagements she would stop by the hospital and if Hugh were asleep turn off his respirator and time with a stopwatch how long before he woke from suffocation. At that point she would laugh, turn on the respirator and leave. He still hates being woken suddenly at night by the phone. "For a second I am trapped, paralysed, mute, and dying." The horrible and humiliating treatment of his constipation was experienced as violation and rape. As expected by his family, Hugh was a constantly cheerful patient until the day that the doctor told him he would never walk again. Hugh became hysterical and his father "repulsed by it, repelled by it, retreated from the room. He did not reach out his hand, he did not hold me, he did not weep with me --- he left me alone. I learned again that day that an expression of my honest emotions and feelings was not acceptable. There was something disgusting about them and, thus, about me. My honest feelings must be hidden from my family, and those who loved me. If I showed even a fraction of the depth of my feelings, they would abandon me." How many children with polio were told, "Don't cry", "You're spoilt/naughty", "Your parents won't visit if you cry"? Against his wishes Hugh was sent to Warm Springs, the rehabilitation centre for polios established by President Roosevelt. "It was the best thing that ever happened to me I found that I could have fun again."

Hugh spent three years at Oxford University in the late fifties. He went to Trinity, the only college to have a bedroom, bathroom, dining room and a chapel on the ground floor. The bathroom was not accessible so he did not have a bath or wash his hair for a year at a time. The accessible toilet "was a block away, down a ramp, up a ramp. In the rain --- it rains all the time in Oxford --- the ramps were slippery the doors opened inward so I had no privacy. The WC was not heated and its windows were kept open year long, no matter the weather." On his return to the US Hugh worked in Washington as assistant to a senator. The access that had been provided in the city for President Roosevelt had been removed after his death. As at Oxford, Hugh was the only wheelchair user around Congress. With the help of Senator Bartlett, he began his life work; "the search for equal access and equal rights for disabled people. I conceived and drafted what became the Federal Architectural Barriers Act of 1968. This is, to my knowledge, the first legislation anywhere to treat the equal access of disabled people as a civil right." During the sixties Hugh was instrumental in making Washington's public buildings and monuments accessible as well as the nation's parks, hospitals and airports. There was considerable opposition from officials and often they had to be blackmailed by fear of losing funding. "It was for their own good." While Hugh worked on behalf of disabled people he did not

associate with them. Once when he had to stand in for the senator and speak to a group of people with disabilities, "I found it was an agony. I was rigid with anxiety and hyperventilating. I thought I was going to pass out right there at the podium. It would be several more years before I understood something about the angry, passionate feelings this appearance caused me. These feelings were not about their disabilities they were about mine."

By the age of 40 Gallagher was director of the Washington office of British Petroleum. "If people asked me --- and many did --- how I felt about my paralysed body, I would reply, 'Why I never think about it at all, not at all'. And I honestly believed I was telling the truth." Then the black bird flapped its wings and Hugh plunged into a major depression. He struggled for a year before seeking psychiatric help. Painfully he came to understand that he had never accepted his physical disability: "So deeply did I despise my body, that I searched for additional ways to burden and humiliate it I had denied it all --- rest, nourishment, care, and pleasure No matter how spectacular my achievements might be, there was no pleasure in them I was unworthy, like a leper in exile; I was an outsider. So awful was my inside, I could reveal it to no one. I deserved no love, no comfort, no affection, and I refused all." It was only after the resolution of his depression "that I learnt to accept the fact that I was severely disabled and couldn't do what the able-bodied could, that I had limits. It was only after dealing with my denial that I came to identify with other disabled people and share my feelings with them. And that was the beginning of my new life." After his recovery he found that when addressing disabled groups, people who came up to talk with him would, for the first time, touch him.

The last two decades of Hugh's life have been productive and far happier. He wrote a book on the impact of polio on Roosevelt, one of his heroes (1). He found that FDR dealt with his paralysis by total denial. He never spoke about the negative feelings generated by his loss to any member of his family or to his doctor or probably even to himself. If anyone referred to his disability FDR would cut him off with a cold fury. Hugh discusses the harm this "courage" and self-control wrought on FDR and those he cared for. He considers FDR "a magnificent leader on a world scale, but he was no longer my role model. He was Super Crip; I opted for human." Another book described the euthanasia program in which over 200,000 disabled people were eliminated during the Third Reich because they were judged to have "lives not worth living" (2). Hugh writes: "the German physicians, with their mad efficiency and arrogant confidence in the infallibility of their judgment, did no more than act out in grotesque fashion the feelings towards the disabled that are widely shared, albeit unconsciously, by many in our society." I recommend that you look for these books in your library (1,2).

These are some of Gallagher's final thoughts. He believes strongly that disabled people "should not confuse the struggle for an accessible world with a need for emotional well-being. A handicap has emotional as well as physical components, and both must be acknowledged and tended. It is appealing and straightforward, but wrong, to say: if only we had kneeling buses and accessible subways, then our self-esteem would be restored. In fact, something like the reverse is true. The better we feel about ourselves, the more healthy our self-esteem, the more effectively we can work to make the world accessible to all." He compares living with polio to running a marathon. Long distance runners "force their bodies to a level of strength and endurance far beyond their natural capacities Our muscles are paralyzed or partially paralyzed. Our muscular systems are able to function at only a percentage of normal strength. They have but a fraction of normal endurance. Nevertheless we have taught them to perform marvellous feats. With exercise, ingenuity ... we have found ways to make our muscles perform what for the able-bodied are the ordinary, easy tasks of daily living. And, often enough, we have found ways to make the way we do these tasks look normal, even easy." Age, Hugh says "comes earlier and with greater impact to the polio. What is no more than annoying to the aging able-bodied can

be totally disabling to the polio.” He warns, don’t waste your time being a Super Crip. “Since I bombed out of Super Cripdom, I have continued to have an exciting, reasonably productive life. The difference is that I now enjoy it.” Coping with post-polio is “a matter of economics: cost/benefit analysis. How much expenditure of limited energy for how much satisfaction. Minimize the exertion; maximize the pleasure.”

The book is a collection of recent essays and past writings including diary entries, rather than a biographical narrative. Although linked by the author’s comments there is a certain discontinuity and at times repetition, while some aspects of his life are barely touched on. For example, at the end of the book Hugh writes that over years “with the help of analysis, religion, and, for me, the great art that is available in Washington, I have become my own self, a person in his own right, and that person is a writer” but the reader is told nothing else about the role of the last two factors in his life. It is a book anyone interested in disability issues and polio survivors will enjoy. As Hugh says, “There is nothing in the world polios love more than talking about polio with other polios.” The book is unlikely to be published in paperback and as it is American, is expensive to buy in Australia. Ask your library to buy it. It is cheaper to purchase over the Internet than to ask a bookseller to order it.

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1. Gallagher, HG, *FDR’s Splendid Deception*, Vandamere Press, Arlington, VA, 1994.
 2. Gallagher, HG, *By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich*, Vandamere Press, Arlington, VA, 1996.
 3. Gallagher, HG, *Black Bird Fly Away: Disabled in an Able-Bodied World*, Vandamere Press, Arlington, VA, 1998. My copy was purchased by credit card from an Internet bookshop (<http://www.Amazon.com>) and cost \$US21.95, postage \$US5.95, altogether about \$A44 depending on the exchange rate.
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IDEAS Expo '99

Report by : Neil von Schill

Our Network was represented at the IDEAS Expo held in Albury from 20 to 22 May 1999. The Expo featured products and services for people with disabilities, carers and health professionals living in southern NSW and northeast Victoria.

There were over 50 sites displaying the latest products to assist people with disabilities, with a range of providers offering a variety of services to different groups. Approximately 1,200 people visited the Expo over the three days and the event enjoyed good media coverage.

The Post-Polio Network (NSW) site was set up and manned by *Albury Support Group* Convener, Neil von Schill, who was very ably assisted and supported by members Ken Chalker and Margaret Bennie. Polio Network Victoria helped by providing some excellent photos for display, as well as printed material for distribution. Members of the *Wangaratta Support Group*, Margaret and Frank Goodman, Jan Ellis and Nick Lindsay, helped staff the site on Thursday and Friday, while Polio Network Victoria Community Officer, Jeanette Marshall, joined the team on Saturday.

Enquiries were received from a range of people including people who had a mild case of polio with no evident late effects, polio survivors who sought out the stand with a view to joining the Network, university students, home carers, relatives of polio survivors, PPN members, employment agencies, and interested younger and older members of the public.

Neil von Schill gave a short presentation on behalf of the Network outlining details of the late effects of polio and the activities of the Network which was very well received generating comments and questions.

The involvement of our Network at the Expo was a very worthwhile venture. It was a valuable public relations exercise in bringing the existence of the Network to the attention of the community as well as providing a focus for potential new members.

Support Group Report

Bernie O'Grady
Support Group Co-ordinator

Phone: (02) 9688 3135

Blacktown - Blue Mountains Support Group

Convener : Bernie O'Grady

Our Support Group has been operating since 1992, and meets on the third Monday of the month (except January and December) from 11 am to 1 pm at the Kingswood Community Centre, Corner Bringelly Road and Baden Powell Avenue, Kingswood.

Over the last couple of years some members have left the Group either because of health problems or because they are moving away from the area. We are in need of members to join the Group. If you are looking for a happy and jovial atmosphere, yet very fulfilling in helping one another in coping with their individual problems, come to one of our meetings to see what we are all about. You will be made very welcome.

If you are interested in joining us please telephone me on (02) 9688 3135.

Northern Rivers Support Group

Convener : Rosalie Kennedy

Our Group met on 20 February at the Ballina Hospital Meeting Room. Five members attended, including a new member.

The group is hoping to have a guest speaker at the next meeting, and have asked me to explore the possibility of engaging a person knowledgeable about pharmaceuticals and a physiotherapist. I have made contact with two people in the local area and hope to pin them down to dates in the next two or three months.

We are meeting in both Ballina and Lismore so that we can be accessible to members, as we cover a large geographical area. If anyone in the Northern Rivers region would like to join us when we get together every second month, please give me a ring on (02) 6620 2329.

Northern Inland Support Group

A Farewell

Barbara Chapman Woods has been the Convener of this Support Group since 1992, and has done a wonderful job in organising regular meetings for members who live in and around the Tamworth region, and operating a very successful *Round Robin* contact system for members who live long distances from Tamworth and can only stay in touch by mail.

We are sorry to say that due to health problems Barbara has had to resign as Convener of the Group and move back to Sydney. The Network and all the members from her Support Group would like to express their thanks and gratitude to Barbara for all the hard work she has done, and wish her well for the future. Barbara has advised the members of her Group of her retirement, and we would like to join her in encouraging someone to take over as Convener, so that this successful Support Group can keep going.

Support Group Update

Since the February *Newsletter*, the Network has been successful in having another member indicate an interest in starting up a Support Group. As a result a new Group will soon be operating in Griffith, convened by Dawn Beaumont-Stevens. Please contact Dawn on (02) 6962 4249 if you would like to join this Group as it gets underway.

We still need Conveners for the Eastern Suburbs, Canterbury / Bankstown, and Sutherland / Sylvania areas. If you can help we'd love to hear from you.

POST-POLIO POST



Member Agnes Castle, Coffs Harbour, recently approached Australia Post seeking to have polio survivors remembered through the "Face of Australia" series of stamps.

Dear Gillian

Enclosed is a copy of a letter I sent to Australia Post. Don't know if I will get my face on a stamp - but it was worth a try.

This is the letter which Agnes wrote to "Face of Australia" at Australia Post. Let's keep our fingers crossed that Agnes' photo will make it onto a stamp commemorating polio survivors.

I send this photo on behalf of the hundreds of people who were afflicted with polio during the 1950-51 epidemic.

I was one of those Australians who, at the age of 13, was hospitalised for 12 months, with very little known about the treatment of the disease. We all shared very cramped and antiquated hospital facilities, with families travelling long distances to spend a little time with us.

Recognition of our struggle and survival would be a great boost to us all.

Thanking you.

The Network has recently been invited to join the "National Approach to Access Working Group". This Group is exploring issues associated with creating and maintaining accessible environments. To help us gain a better understanding of problems you face accessing your community, Management Committee member Allan Quirk is seeking Network members' input. Allan has been active over many years advocating for the needs of polio survivors and is now seeking to enhance the Network's knowledge of members' concerns with all access issues. These include ambulant or wheelchair access to public transport, parking, public buildings and toilet facilities, as well as negotiating slippery surfaces and other safety issues. Planning authorities are often unaware of the differing requirements of people with walking difficulties and as a result their needs may be overlooked in the design of public facilities. Allan is looking forward to hearing your personal experiences.

As many of you will be aware, work is continuing on building and transport standards which are aimed at making the community more accessible to people with disabilities.

Do you have any serious concerns relating to access to buildings and surroundings, and/or transport which need to be recognised in future design and standards work and which might assist other members as well as yourself. Please indicate how and why your access is affected. It would help if you could state what cost-effective improvements could be made in new developments for you to gain better access and safety.

Remember, because "the system" is largely beyond our control we can only try to draw attention to such needs - in other words, don't expect a magic fairy to set everything right overnight!

You can send your contributions either by mail to the Network, clearly marked to Allan Quirk, or you can Email Allan directly at <alq@fastlink.com.au>.

