



POST-POLIO SYNDROME: WHERE DO WE GO FROM HERE?

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

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

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

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

It was apparent from reactions in the health care sessions that a major concern of survivors is accessing health practitioners who are knowledgeable about PPS. Some support groups have been active in

collecting and passing on information about such practitioners to their members. There is clearly a need to increase the clinical knowledge of health practitioners regarding PPS and to encourage research in the area. We need to liaise with health professional schools regarding the inclusion of PPS in their curricula. We should suggest that they encourage some of their honours and post-graduate students to do research in the area of PPS. Such tasks seem daunting but remember that the post-polio clinic at Prince Henry Hospital and the associated research program have their origins in the efforts of the [NSW Post-Polio Network](#). One inducement that we can provide is willing research subjects.

Another innovation which added to the success of this conference was the wider perspectives from which the PPS experience was explored. The conference had an international perspective both in terms of speakers and participants from overseas. These visitors helped participants to view disability from a cultural perspective as did the workshop by Gayle Kennedy, an Aboriginal Australian who contracted polio. Videos on the situation of people with disabilities in other countries were shown including one on the elimination of people with disabilities during the Third Reich. An historical perspective was introduced by sessions which explored attitudes in Australia at the time that we contracted polio and how such attitudes shaped our initial treatment and our future lives. Disability rights and the problems of women with disability were discussed.

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

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

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

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

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

Long live the polios (p. 6).

Some health practitioners regard PPS as the last rattle of a group of dinosaurs about to depart in the last ark off the rank. But our struggles are beginning to have significant effects on rehabilitation theory and practice. As you know post-polio symptoms have two major causes; the neurological changes that are unique to PPS and the overuse of compromised body systems interacting with the ageing process. As a result of publicity about PPS this second set of late effects is now being recognised as occurring in a wide range of disabilities previously considered to be stable e.g. spinal cord injury, cerebrial palsy, spina bifida, congenital and early amputation. In 1995 Dr. Christopher in his presidential address (3) to the American Academy of Physical Medicine and Rehabilitation called for a new life-span approach in rehabilitation which incorporates this late-effects model. The late-effects model is beginning to be applied to disabilities acquired later in life such as stroke and those long recognised as progressive such as diabetes and multiple sclerosis. Indeed this late-effects or life-span perspective is now considered relevant to all disabilities. Okamoto and Yang (4) pointed out that, 'Ageing with a disability begins at the time an individual acquires a disability and ageing infers a dimension of time to the disability that is changing not static as once believed' (p.2). People ageing with a disability have been described (as we know from experience) by the American Congress of Rehabilitation Medicine (5) as 'orphans' in the health care with 'no system of post-rehabilitative primary care, acute care, or long-term care that is responsive to the particular constellation of health care problems commonly experienced' (p.S8).

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

LONG LIVE THE POLIOS!

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This book is published by Accent Special Publications, Cheever Publishing, Inc., Post Office Box 700, Bloomington, IL 61702, USA. It sells for \$11.50 (US) in the USA. I asked the University Co-op Bookshop, Cumberland Campus of the University of Sydney, phone number [\(02\) 93519484](tel:0293519484), to order it for me as a special order. It cost me \$18.95. To assist with ordering the ISBN is 0-915708-38-8. The chapters are entitled: becoming disabled, social aspects, physical aspects, psychological aspects, from one disabled person to another (personal accounts), prevention of late effects, tips to make your life easier, sexuality and disability, the medical community, benefit programs (American focus) and on death and dying.

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