



Thoughts on the Retreat

by Ann Buchan

(Polio Australia's Health & Wellness Retreat
– 18th to 21st April, 2013)

When I was asked last year by a physio student (commissioned by Mary-ann Liethof), to consider being involved in the retreat in 2013, I didn't really realise what I was in for.

I first became interested in the work as a teenager, meeting as a girl guide and in the school hall at Yooralla Crippled Children's Centre in Balwyn, Victoria. The room was full

of standing frames and braces and callipers. My sister had a friend who was also a Girl Guide (Julie), who had been partly disabled by polio. Then I had a physio visit the house to treat my sister for asthma, so I then knew I wanted to be a physio (and that same physio, Pat Cosh, ended up being the head of the physio school.

I have been working as a neuro physio now for 45 years. In my private practice work, I have seen people with the late effects of polio for 30 years and am still learning.

I have been to a few polio conferences and was on a panel helping to edit the two late effects of polio handbooks with Charlotte Leboeuf (1991).

Contact with Mary-ann by e-mail certainly inspired me to see this retreat as something rather special.

I have never given a formal plenary talk before, so the job was quite daunting - there are now so many references available and increasingly more evidence and guidelines for effective care. So where was I to start?

And so to **Thursday evening:**

The opening sharing of hopes for the three days ahead were very special, such as . . .

- We thought we had it licked.
- Learning to be better for the carer, in spite of pain and lethargy.
- Hearing other peoples' stories - and goodness, did that become quite confronting!! But exciting too when one person shared that he felt 100% better after the last retreat!
- Issues of surgery being offered without really considering the whole of the body!
- Some had had no contact with others with PPS.
- Others could have run the whole weekend on their own experience and knowledge of the bigger picture!
- One had "blanked it all out till now"!
- Some saw it as a new chance, some looking for practical tips.
- One had been in an iron lung for 2 years, yet did national service and worked for 30+ years!
- One had been a tap dancer.
- Carers wanted to learn more.

What a great starting point for the weekend and not a bad setting either!!

The plenary talk was hard to keep short yet relevant, not too complex and yet not oversimplifying or minimising the complex range of features in Post-Polio Syndrome (PPS) and the difficulty in diagnosis.

The 'Falls' session could have gone on for two hours - I certainly appreciated people's honesty in telling their falls story. How do you keep a balance between keeping active and not being too fearful of falling, using a crutch or stick and a splint (to effectively 'come out' and admit that there are some problems!).

Having a student, Ben, with me to demonstrate what normal balance is in the 23 year old versus a 60+ year old was helpful. And I hope that getting up off the floor will now be easier for the frequent fallers amongst the participants.

Having the opportunity to see people and a carer in the consult room was a rare treat. Too often a local pain concern is only treated locally - a painful neck may be from over activity and muscle imbalance. For some people, no one has really looked at this or the windup phenomenon of pain. Panic and fear it may be like linked to those early traumas.

Splints need regular checking or secondary nerve compression can cause more disability. It was great to have the other University of SA physiotherapy graduates, Alex Daniel and Vivienne Maxwell, present as volunteers. Let's hope that the next generation of allied health practitioners does really **get it**.

I have some research questions:

- Were there more miscarriages amongst women who had polio?
- Is there a greater risk of bowel cancer for people in a wheelchair?
- What is the incidence of Parkinson's features later in life in people who had polio?

My thanks go to Lorraine, Esther, John and Fay, Pauline, Douglas, and Kate and others for raising further questions and challenging a traditional therapeutic model.

I have provided various handouts including Richard Bruno's "10 Commandments", a the Challenges of Post-polio syndrome presentation, and a list of points as a background to the Falls session.

In my sorting of polio and post-polio notes, I came across notes given out (when I was a student) on the callipers, splints and support systems available. I was sorry not to hear Adam Holden's session on "To Brace or Not To Brace". There is certainly a greater variety of designs and supports now. But we still need to be careful as too many modern ones end up in the back cupboard. One person I saw was getting a neuropathy from the callipers being too tight.

It was a "treat" to be able to attend.

Suggested additional reading:

- [Explain Pain](#) by Dr David S. Butler and Prof G. Lorimer Moseley (Noi Publications, Adelaide Australia, 2003)
- [Clinical Neurodynamics](#) by Michael Shacklock, published by Elsevier, 2005.
- [The Late Effects of Polio](#): Introduction to Clinical Practice by Polio Australia, 2012
- [The 10 Commandments of PPS](#) (Richard Bruno and Nancy Frick)