

## Polio Particles 20

Mary Westbrook

### Ageing with polio.

*'Aging with a disability'*, a book edited by Bryan Kemp and Laura Mosqueda, has been published by Johns Hopkins University Press, 2004. Although aimed at health practitioners (It is subtitled *'What every clinician needs to know'*), people who live with disabilities acquired earlier in life will find it interesting and informative. Of the 16 chapters, four are concerned with specific disabilities. Dr Jacquelin Perry wrote the chapter on polio. I found the facts about the early course of paralytic polio and its typical recovery pattern interesting eg 10% of patients regained normal function within 2-4 weeks, patients attained 93% of their eventual recovery within one year, and on average, affected arm muscles recovered more than did leg muscles. There are chapters on ageing with spinal cord injury, cerebral palsy and developmental disabilities. The rest of the book covers issues common to all disabilities and polio survivors' experiences are frequently referred to. Chapters include: *'A consumer's perspective on living with a disability: How change in function affects daily life'*, *'Family members' perspective on aging with a disability'*, *'Quality of life, coping and depression'*, *'Family and caregiver issues'*, *'Maintaining health and function'*, *'Secondary conditions'*, and *'Barriers to care: the provider's and the consumer's viewpoints'*. The introduction points out that we are among *the first generation of people with early-onset disabilities to live into middle and late life. Consequently we [the authors] know very little about how they might age. However information...has been accumulating for the past twenty years [and] what has emerged is a picture of atypical aging; these people frequently undergo substantial and even profound changes in health and functioning in midlife. These changes were neither anticipated or planned for in earlier generations. The usual practice in rehabilitation was to urge people to do all they could and to push a little (or a lot) past normal limits to maximize their abilities. Professionals in rehabilitation paid little attention to the long-term consequences of disability or the issue of aging...The first group to notice that aging was not going well was the population with polio. While PPS is unique to polio survivors we share some late effects with other disability groups. People with cerebral palsy develop inordinate rates of orthopedic problems and falls. Those with spinal cord injury develop osteoporosis. The authors remind us that: Aging is not the same as being aged. People begin to age long before they begin to notice the changes normally associated with being aged. This means that the best time to influence how you age is when you are young. Small changes early in life have a major impact on later life...What are the long term consequences for joints of continuing to walk despite pain?...How long should a person with a disability plan on working? Dr Mosqueda comments that, Olympic athletes are among the small proportion of people who push their bodies to their highest possible level of functioning. Perhaps people with disabilities share this characteristic with elite athletes; but instead of pushing their bodies during training in the quest for a gold medal, they must do so every day just to accomplish their daily activities and fulfil their social roles. She says that able-bodied people have physiological reserves that enable them to accommodate much of the decrease in capacity which occurs with ageing but people with disabilities have a much reduced buffer zone. Dr Kemp discusses depression and quality of life of people with*

disabilities. He says that while depression is more common among the disabled population there is little association between depression and severity of disability. For example, one research study found no difference in the occurrence of depression rates among paraplegics and quadriplegics. Kemp, who has researched polio survivors, found that having social and community activities was strongly linked with feeling happier. The moral is that if fatigue limits the number of activities you can do, choose social activities with friends and have the groceries delivered. If you are on the Internet you can order them online. The book can be purchased from Amazon.com for \$US24.95.

### **Some positive aspects of PPS**

Norwegian polio researcher Anne-Kristine Schanke has published a study titled '*Never second best? A narrative perspective on shaping and reconstruction of identity in twenty polio survivors*', in the *Scandinavian Journal of Disability Research* (2004). These survivors, all of whom were experiencing late effects of polio, told Schanke their life stories. She says that in childhood and youth survivors inhabited a *dual world; the internal one, feeling different, and the external world, behaving as non-disabled. As adults, before the onset of the late effects of polio, they were all somehow in the 'normal mainstream' by confirming important aspects of their normal identity on par with other non-disabled people by means of marriage, parenthood and paid work.* Schanke found that for many the onset of PPS led ultimately to a changed and more favourable view of themselves. One woman began her story '*I've gone through such a big change. You know, before I was affected by the late effects, I was polio-Beth. Now I am the woman Beth.* Beth's story is similar to the experiences of many Network members. She contracted polio aged five and was in hospital for two years. *My mother was over-concerned about appearances, she only wanted to talk about 'nice things'....I was not satisfied with myself. I always had to show endurance and prove myself.* Beth worked, married and had a child. Like a number people in the research she was helped by counselling when she developed PPS. Survivors also found that becoming friendly with other survivors, often for the first time, contributed to this personal growth. Beth describes beginning to empathise with her five year old self. *It was like the woman-Beth started taking care of polio-Beth...I do not regard myself as disabled as before, my self-image has changed [although] I use a wheelchair permanently now...some women get more mature and secure as they get older. So did I...I think [PPS] has made me grow as a human being. I think my curiosity and interest in others has developed. In spite of the fact that that my disability complicates my daily life and also makes me feel tired and sometimes depressed, I feel richer and more complete as a human being than before. Without polio I think my life would have been a more ordinary and boring one.*

### **Work lives of women with disabilities**

Mary Grimley Mason, a polio survivor, has written '*Working against the odds: Stories of disabled women's work lives*' (Published in 2004 by Northeastern University Press). Mason tells the stories of the working lives of 18 disabled women, two of whom had polio, that she interviewed. In America 73.9% of

women with work disability status are unemployed, compared with 24.7% of women without work disability status. The employment figures for polio survivors are much higher than for other disability groups. Mason says that she, and many of those she interviewed, had for many years denied the discrimination they experienced in the workplace due to having disabilities. Like most of us they felt alone in their struggles and devised strategies to overcome workplace obstacles of gaining and maintaining employment in the days before disability rights were heard of. Sally, a food technologist and polio survivor, used a walking stick until she had unsuccessful back surgery for her scoliosis at the age of 46. *'The operation didn't stop my work', Sally says. 'I worked from my hospital bed. I never lost pace. I never lost any pay'*. She now needed to use a wheelchair which led to greater discrimination at work. *'They would think you could not make a presentation because you were in a wheelchair...I knew I absolutely had to change my image. When I used to go to work I wasn't required to look like I was highly successful—you know to wear expensive suits and dresses. But when I was in a wheelchair I made a decision. I was going to dress for success because I realised that people thought that if you were in a wheelchair, you were really not as professionally competent as someone who wasn't...So I totally changed my image'*. The book is \$US20 on Amazon.com.

### **Famous polio cases**

Jack Nicklaus contracted polio when he was 13 at the same time as his sister. Jack recovered within a few weeks but his sister was not so lucky. Network member, Ian McKenzie, sent me information about Manon Gropius who contracted polio aged 17 in 1934. Manon's mother Alma was married to the composer Mahler. While writing his Symphony no.10 Mahler discovered that Alma was having an affair with the architect, Walter Gropius. He died before the symphony was complete and Alma and Walter married. Their beautiful daughter Manon was described as *an angelic gazelle from Heaven*. She had wanted to be an actress but after she got polio she used a wheelchair. She died unexpectedly in 1935. Alban Berg wrote his violin concerto *'To the memory of an angel'* in her memory.

### **Preserving polio shoulders**

A 31 page booklet titled *'S.O.S. Save our shoulders; a guide for polio survivors'* is available as a free download from the web at [www.einstein.edu/polioandmobility](http://www.einstein.edu/polioandmobility). It was produced by staff at the Moss Rehabilitation Research Institute in Philadelphia. Most polio survivors experience some shoulder problems. Even if the polio virus did little damage to our shoulder muscles most of us with weak leg muscles have overused our shoulders to compensate eg to push ourselves up from chairs, to pull ourselves up stairs. The shoulders of most people with PPS have started to show symptoms such as loss of strength and pain at a time when they are now more dependent on their shoulders than ever. This booklet tells you what you can do about shoulder problems and how to avoid further problems. There are lots of useful illustrations. You can see what the rotator cuff (the muscles that support the shoulder joint) looks like and positions to assume when exercising shoulder muscles. The booklet points out that most polio survivors do

not realise the stress and strain they are placing on their shoulders. It gives many tips on how to avoid making your shoulder problems worse eg put your shirt or jacket on your painful arm first, do not sleep on your painful shoulder, keep items used most frequently in cabinets below shoulder level. Here are several suggestions not included in the booklet. Purchase a higher toilet seat. They fit over the existing seat and you can try them out in the display bathroom at the Independent Living Centre, now located in the new Northcott building at North Parramatta. I found that nursing baby grandchildren exacerbates shoulder pain so I now place a pillow on my knees and rest the baby on that, laying an arm across the baby to provide security. I have a small chair that two-year-olds use to climb onto my lap. Dr Julie Silver in her book '*Post-Polio Syndrome*' reminds us that our *arms are the key to independence...if you cannot use your legs at all, you can still remain totally independent—living alone, bathing yourself, feeding yourself, driving a car. But if you cannot use your arms at all you immediately cease to be independent.*

### **New polio cases in 2005**

From time to time during the year there have been brief reports in various newspapers about an increase in the number of polio cases in various parts of the world. From a wide range of sources I have put together this picture of the state of play in early July. In 2003 a year long boycott of the immunisation program occurred in northern Nigeria due to fears of the vaccine. The numbers of cases of polio in Nigeria increased sharply but are now decreasing since vaccination recommenced. In the two months from early April to early June 2005 there were 144 cases in Nigeria compared to 217 cases in the same period last year. At the time northern Nigeria stopped vaccination polio was endemic in six countries but polio has now spread to at least sixteen other countries that had previously been declared polio free. Many of these countries were in Africa eg Burkina Faso, Chad, the Central African Republic, Mali, Sudan and the Ivory Coast. The Nigerian polio virus has spread to Yemen and Indonesia, both of which had been polio free for some years, possibly via pilgrims to the Haj. As of 22/6/05 Yemen had had 243 cases of polio this year. This is almost half the 533 new cases of polio so far in 2005 worldwide according to WHO on June 22. New cases of polio in Indonesia are being reported regularly; as of July 2 there had been 66. Massive increases in vaccination are occurring in these two countries to stamp out the epidemics. In early July Angola reported its first case of polio for four years; the genetic composition of the virus indicated that it came from India. There are signs of improvement in India, one of the counties where polio is still endemic. There have been only seven cases of polio in Uttar Pradesh to June 25 this year compared to 1200 in the same period three years ago and only 18 cases in India overall this year. Cases are down in Pakistan; 10 cases this year, 40% less than in that period last year. Even though the number of cases worldwide is up this year remember that in 1988 there were 350,000 cases.

This issue of Polio Particles was first published in Post-Polio Network (NSW) Inc Network News Issue 67, July 2005. Reprint requests should be forwarded to Mary by email at [AskMary@post-polionetwork.org.au](mailto:AskMary@post-polionetwork.org.au)

