

Marion Kosseck's Story



Growing older is something we all have in common, we feel the effects of aging in various ways; getting puffed out with over-exertion, sleeplessness, joint stiffness, tiredness, aches and pains, etc. For years I seemed to have signs of 'early aging' and an inability to cope with normal everyday activities. Fortunately, with the help of medical staff, caring people and support groups, I have recently found the answer to many questions I had throughout my life. I learnt that "It's not all in my head", "I'm not going mad", "I'm not the only one" and "Others have the same symptoms and similar problems". I would briefly like to share my story in the hope that it may help someone else as I have been helped.

I was born in England and lived there with my family until we immigrated to Australia when I was thirteen. When I was four years old, I contracted paralytic polio, spending many, many months alone in a glass isolation room in an Infectious Diseases Hospital without visitors. I remember being very ill, unable to move and wondering why everyone deserted me, except the strange people dressed all in white. Sometimes I would see my parents on the other side of the glass cubicle, Mum always cried a lot. I was allowed to have my blue rabbit she had made for me, he was my friend and I could talk to him. Not everyone survived, but with treatment, exercises and perseverance, in time, I recovered. Learning to walk again, first with and then without callipers was difficult, the doctors were very strict and demanding – "Ignore the pain, you will walk again" "Come on get up and get going" "You must keep going – forget that your legs hurt". This constant striving to be 'normal' became a pattern for my life - I learnt not to listen to my body and just always kept pushing harder to achieve anything. Although I realised that I couldn't do all the things other could, I got on with my life and led a fairly normal childhood and adolescence. I worked hard at being normal; eventually forgetting that polio had even existed.

Years later I married an Australian dairy-farmer and enjoyed a very wonderful yet busy life raising a family and working our farm together. I was happy to support and lend a hand to our church, schools, family, friends and neighbours. Although I had many periods of serious illness, operations, constant fatigue and was frequently unable to keep up, after long recovery periods, I would just get up and keep on going again. It was hard to understand, but I didn't think about it too much; happy, loving years are how I like to remember them.

Trying to get fit, ("use it or lose it" they said) I took up walking and water aerobics, I improved for a time, but after a few years the tiredness and weakness became constant. I was always struggling for breath and exhausted after any slight activity or exercise, so I stopped a lot of activities. Finally, 'overuse abuse' took its toll and my body told me it had enough and I collapsed; I was diagnosed with Chronic Fatigue, which meant *complete* rest and a *big* change in diet and lifestyle.

After many months without much improvement, my Doctor referred me to the Post Polio Syndrome Clinic at the Rehabilitation Centre at Grace McKellar in North Geelong where I found out about the '*late effect of polio*', which can occur ten to fifty years after the initial Polio attack. It was a shock, both mentally and physically; I had forgotten that word '*polio*' and all the problems and emotions that were associated with it. I hadn't talked about or thought about that part of my life for years, now it was here again, with all the memories of isolation, paralysis, pain, loneliness, callipers, trying to fit in and be normal. But I needn't have feared I've found others who have similar or worse symptoms and caring people who understand and are very supportive, positive and helpful in assisting us to deal with our individual needs.

It is easier to understand these late effects if the original effects of polio are understood first. Briefly in layman's terms, polio is a virus that enters the mouth, affects the lining of the gut causing gastro problems, then can enter the blood stream giving pneumonia or flue-like symptoms and then for some it invades the central nervous system and the nerves that control muscles and movement, thus causing muscle pain, weakness and/or paralysis. The late effects of polio are usually due to "overuse abuse". Surviving nerves that were damaged by polio had re-nervated, but have been and are now doing extra work for those nerves that were severely affected and unfunctional. So too, overworked muscles ache and joints hurt after decades of doing too much work with too little muscle support.

As my story explains, I eventually found an explanation for many unanswered questions about my poor health, now and in the past. I have learnt that most *polio survivors* (not victims) tell a story of struggle and triumph; the sudden random onset of paralysis, the gradual restoration of strength seemingly as a result of individual willpower and finally, for many, resumption of an active productive life, which leads them to believe they have put polio behind them.

The story, for most, is made possible by denying their disability and the reality of what was lost and the life that might have been. We seem to display self-deception or denial and later in life, when polio survivors begin to experience the new weakness of the late effects of polio (PPS) the denial usually is still intact, which makes understanding and accepting the new changes all the more difficult. As they begin to accept the fact that they are disabled again, they are often overcome by feelings of anger, bitterness and despair, as well as coping with the changes in the health abilities.

With the help and wonderful caring support of doctors, my physiotherapist, occupational therapist, naturopath, hydrotherapy polio class, the Polio Network, our PPS Support Group and sharing a common bond with fellow polio survivors, I am learning 'self help' and together with my caring husband, most days I am learning to cope with these mental and physical changes to our lives with a positive, bright attitude and trying to 'CONSERVE TO PRESERVE' not 'USE IT OR LOSE IT'.