

## **Case Studies of Polio Survivors with Late Effects of Polio/Post Polio Syndrome from Queensland**

### Ms B:

Ms B contracted bulbar poliomyelitis in 1961 at four years of age. On admission to hospital, she initially spent 3 weeks in an iron lung then remained in the hospital for a year. She was in an institution for her years of primary education and could not attend high school because no support workers were available in schools at that time. She did attend the Taringa Rehabilitation Centre and began working in the Commonwealth Public Service in 1983. At that time, she was relatively self-sufficient but needed some help with washing her hair, grocery shopping and housework. In addition, she could never use public transport and had to rely on taxis for transport.

In the early 1990s, Ms B began to experience the Late Effects of Polio with increased muscle weakness and excessive fatigue. She also developed depression. Whereas previously she could walk several blocks in a street, she now needed a wheelchair to cover a distance of more than one block and she required personal assistants to help with the activities of daily living. She was invalided out of the Public Service and employment generally in 1998 because of LEOP.

Ms B now requires a wheelchair for travelling distances of more than 3 or 4 metres. Her balance is severely compromised and she needs a personal support worker for 6 to 7 hours every day. She must use a bi-level CPAP machine to assist her breathing during sleep and suffers from chronic depression for which she receives medication. She endures bladder leakage for which she also receives medication. She has increasing postural collapse and scoliosis, gross muscle weakness and extreme physical and mental fatigue.

In 2002, Ms B underwent abdominal surgery which resulted in 4.5 weeks in an Intensive Care Unit due to respiratory failure. This occurred despite her alerting the Anaesthetist and the Nurse in Charge of the increased sensitivity of polio survivors to anaesthetics, especially if the polio survivor has spent some time in an iron lung. She was prescribed statins to control cholesterol levels by a General Practitioner and suspects that the

medication further increased her muscle weakness, which is a recognized side-effect of this class of therapeutic drugs in polio survivors with paralysis.

Ms B states:

**“I currently have little or no access to doctors or other health professionals who have knowledge of the Late Effects of Polio. I am 54 and I am more physically dependent than is my 91-year-old aunt. Where do I go? What do I do?”**

Dr G (non-medical):

Dr G was a six-year-old boy when he contracted poliomyelitis in 1951 but it was not until 2005 that he developed the symptoms of Post-Polio Syndrome. Apart from fatigue, some pain and some loss of muscle function, he also experienced swallowing and speaking difficulties.

He describes the diagnosis of PPS in his case as a ‘hit-and-miss affair’ based finally on exclusion of any other recognizable complaint by the collective input of himself, his General Practitioner, a Medical Specialist and a Physiotherapist. He now has reduced functionality generally and seriously reduced levels of fatigue which he needs to carefully self-manage. Dr G laments the double-whammy effect that PPS adds to the normal burdens of ageing.

**Dr G comments that a standard assessment scheme for PPS, run by a national or state reputable medical agencies, would greatly improve the current piecemeal approach to PPS diagnosis.**

Dr T (non-medical):

Dr T is aged in her mid-60s. She is a retired academic and self-funded retiree with private health insurance. Dr T contracted polio in 1950 at the age of 5 years and required the use of an iron lung initially. After 18 months in a home for ‘crippled children’, she

made a reasonable recovery but required the ongoing use of aids – full body brace plus callipers on both legs.

Twenty five years ago, she started to experience unexplained knee pain and greater fatigue. She subsequently required a manual wheelchair for mobility. Prior to this, she started to fatigue and to fall more frequently. She had to relocate and modify her new home extensively. Dr T has always used a car fitted with hand controls but needed to add a hoist to lift the wheelchair on to the roof of the car and a transfer board.

Dr T required considerable surgery as a young person to maintain her mobility, e.g. muscle transplants and bone fusions, including three spinal fusions, as well as bilateral surgery for carpal tunnel syndrome. She maintained an independent lifestyle for some 35 years and worked full time until about ten years ago, when she found that she could no longer continue due to fatigue with the onset of Late Effects of Polio. Her fatigue has since increased and is compounded by weight increase with no formal exercise program. She also has arthritis and urinary incontinence.

Recently, the Queensland Medical Aids Subsidy Scheme (MASS) provided Dr T with a motorized wheelchair but she has been unable to transfer successfully into it so cannot make use of it. The services that she does receive are 90 minutes of home care every fortnight, biannual respiratory testing, annual endocrinologist consultations and biannual BMD testing. She receives treatment for high blood pressure and osteoporosis ('Fosamax') but she describes her symptoms of LEOP as being 'basically untreated'.

Eighteen months ago, Dr T fell out of her wheelchair which resulted in extensive facial bruising and knee damage that required weeks of private physiotherapy and left her unable to transfer independently. Twelve months ago, she partially dislocated her thumb and that has not completely healed.

**Dr T considers that, because she started the Post Polio Support Group in Queensland, she was better informed than many to manage her health quite well,**

**despite the paucity of current healthcare providers with a sound knowledge of the chronic nature of LEOP. She hopes that, in the future, professionals with better knowledge will be able to manage her health needs.**

Mrs R:

Mrs R contracted polio in 1954 aged almost 15 years and spent nine months in hospital. Her left leg was completely paralyzed from the hip. She was fitted with a full-length calliper which she wore until soon after she married in 1963, when she also learnt to drive a car which greatly increased her mobility. She made a good recovery and had two children.

Mrs R developed knee pain in the early 1990s and started using a walking stick after arthroscopy on her left knee. In 1995, she began to wear a full-length calliper again when out of her home to give her better mobility and to help relieve back pain. In the last nine years, Mrs R has suffered fatigue and pain in her back and 'good' right leg, which has made her more dependent on her husband. She has also torn both rotor cuffs, one as the result of a fall. In 2007, she was diagnosed with breast cancer and was subjected to six weeks of radiation therapy. Since then, she has experienced even more fatigue and more pain and finds life significantly more challenging.

Mrs R worked part-time from 1979 to 2000. She has Private Health Insurance and receives a Government part pension. In 2003, she and her husband moved into a home that was built to cater for her specific needs. She has been a member of the Brisbane Post Polio Support Network since its inception in 1991 and values the information and help that she gains from membership. Her main frustration has been the time taken to upgrade her callipers and replace her custom-made medical footwear. She has received some financial assistance from the Medical Aids Subsidy Scheme (MASS) for this purpose three times in the last 17 years; but, each time, the supply of calliper and compatible footwear has taken more than a year.

**Mrs R believes that she has been fortunate to have gained knowledge and support from the Post Polio Support Network that has enabled her to seek out relevant health service providers. However, the time taken to obtain some services has been frustrating for her.**

Mr B:

Early in December 1945, Mr B was showing the symptoms of influenza – high temperature, sore throat, aches and pains. He left his bed and moved to the verandah to watch his father and brothers erect a tent in preparation for a Christmas camping holiday; but, after a few minutes of standing, his legs collapsed from under him. A local ambulance officer was called and immediately diagnosed Mr B’s illness as polio.

Shortly after admission to the isolation ward of the Royal Brisbane Hospital, Mr B became totally paralyzed. However, with a program of physiotherapy, hot packs and hydrotherapy based on the Sister Kenny method of treatment, he gradually gained some strength in most of his body. After three months in hospital and with bed availability in short supply because of the polio epidemic, patients who had shown some progress, including Mr B, were discharged to continue their treatment as outpatients.

Unfortunately, Mr B was discharged without the aid of a calliper on his weakened right leg and later required surgery to straighten the limb.

As a 14-year-old boy whose main ambition in life was to excel on the sporting field, Mr B was devastated about his future and he experienced some months of remorse and self pity. Mr B entered the workforce as a clerk but soon moved on to sign writing and ticket writing which used his artistic flair. Employment gave him confidence and the conviction that walking with a limp was better than not walking at all. A job as a part time ticket writer in a hardware store led on to a position in hardware retail. He then took on the responsibility of overseeing the development and expansion of a group of 105 hardware stores. He later appeared on television as a promotional presenter and became a publisher of a hardware trade magazine. Mr B’s working life provided him with total satisfaction.

In 2008 at the age of 77 years, Mr B became increasingly aware of the toll taken on his body by Post Polio Syndrome and he retired. Polio had left him with obvious weakness in one leg but Mr B was now experiencing progressive weakness in most of his body with muscle shrinkage, joint pain, breathlessness, difficulty with swallowing and lack of energy. Ten years ago, Mr B walked with the aid of a stick but he now requires a wheeled walker when moving outside the house.

In 1991, a meeting of polio survivors including Mr B led to the formation of a support group under the auspices of the 'Paraplegic and Quadriplegic Association' (now the 'Spinal Injuries Association'). Like others, Mr B was concerned about the lack of knowledge of PPS among medical professionals. Polio survivors with PPS were often told by their General Practitioners that their symptoms were "just part of the ageing process". Mr B has been the Convener of the Brisbane Post Polio Support Network for the past ten years and only relinquished the position early this year (2012). During his tenure, he worked diligently to raise awareness of PPS through contact with health professionals and by the use of the media. He has also promoted the Post Polio Support Networks in Queensland which provide peer support through regular meetings and newsletters. He regularly communicated by phone with those who could no longer attend the meetings because of increasing mobility problems. Mr B also supports the establishment of a rehabilitation clinic in Brisbane for PPS and related chronic conditions.

The death of his wife two years ago means that Mr B is more dependent on assistance with house cleaning and the provision of meals by service organizations. The recent changes to his lifestyle have eroded his confidence and restricted his ability to take part in social and community activities.

**Mr B regards his ten years as Convener of the Brisbane Post Polio Support Network as most rewarding to him personally since it enabled him to provide support and comfort to polio survivors who, like himself, have also been affected by Post Polio Syndrome.**