

Dear Liz,

The people below are all quite willing to discuss their cases individually with representatives of the Government if it was deemed advantageous in gaining extra support for the polio community.

Ms N

Ms N is aged in her mid 60's, she live alone. Ms N is on a part pension and has maintained private health insurance. She contracted polio in 1947 aged 3 years. Like many she made a good recovery and did not require the on-going use of any aids. She maintained an independent lifestyle and worked full time until about 10 years ago when she was no longer able to work full time due to fatigue and pain which was related to the later effects of polio. In 2010 she was diagnosed with ovarian cancer, has undergone surgery and two sessions of chemotherapy. During her first set of chemotherapy her thumb became numb she is fortunate her oncologist recognised that this may have been related to prior nerve damage and changed the dosage. Her oncologist is not consulting with a polio specialist her main concern is that apart from her physicians, nursing staff seem unaware of the extra levels of fatigue that she has to manage due to late effects of polio. One a recent hospital visit she was asked to transfer herself unassisted from the trolley to a bed. Even after the embarrassment of explaining her polio related fatigue on top of chemo the staff still asked her to transfer herself. She fell and need assistance into the bed. Ms N is a proud woman and has been self-sufficient all her life, she lives on a part pension and between chemotherapy she is able drives her car she does not use any mobility aids. She has fallen at home and due to exhaustion needed to crawl across the floor to climb in a chair. Polio survivors seem to succumb to cancer more that the general community this may be due to being more vulnerable due to fatigue and the late effects of polio.

Ms N does not believe that she would qualify for assistance from the multipurpose taxi program. Her life would be made so much easier if there was greater understanding of later effects of polio and chemotherapy. Perhaps a national advisor could be appointed to advice on a set of procedures for polio survivors undergoing chemotherapy.

Mr A

Mr A is aged is 82 years of age, his wife is his primary carer she is 81 years of age. Both are of small stature, their home has been extensively modified at their cost.

Mr A contacted polio in 1938 aged 7 years. Mr A made a reasonable recovery and for a time did not require the use of mobility aids. In 1995 Mr A returned to using callipers on both legs. Mr & Mrs ran their own clothing business and are partly self funded retirees and have private health insurance. Over the last 20 years many modifications were made to make their lives easier. Until 3 years ago Mr A used a mobility scooter and had a hoist to lift the scooter in and out of the car. The car had been fitted with hand controls so Mr A could maintain his independence. Doorways in their single level house had been widened to enable Mr A to get around the house in an indoor scooter. The bathroom had been modified as much as possible to enable better access. Outside areas had been paved to provide for easy maintenance.

In 2008 Mr A lost the control of his legs after surgery to reduce back pain. After further treatment in 2010 he was hospitalised for over six months and at a time it was not expected that he would survive. In 2010 it was recognised by Mrs A that he would be better off in his own home. Although a detailed plan was prepared by a senior rehab specialist it was not followed through. Over a four week period Mr A was trialled first overnight then 2-3 days at time in his own home. Mr A replaced his electric bed with a model that could be lowered and raised, a lifting machine was delivered (instruction did not take place for 8 days) and a motorised wheel chair was purchased. A personal carer with co-contribution provided one visit per day. After a short period of improvement, Mr.A's health once again deteriorated. It was identified that he was suffering from a lack of physio.

After much intervention he was included in a physio program at a local rehab Hospital. His health improved, but unfortunately due to the type of the program he was accepted into assistance was only able to be provided for 3 months. No other ongoing program was available for someone with a chronic illness whose condition would not doubt continue to deteriorate. During this time **Mrs A's** health started to suffer. Several times a day she would use the lifting machine to transfer Mr A to and from his bed, his wheel chair and his toilet chair. Mr A's is now being accessed for his third motorised wheel in 18 months. The first had a fixed chair back and was hired as Mrs A was told that Mr A did not qualify for the State Wide Equipment subsidy as he had spent so long in care at the Kingston Centre but after six months an application could be placed (I have spoken the SWEP this is not strictly correct). The second chair provided with SWEP assistance had a fixed seat and required extensive modification to the back rest and the foot plates need modification to enable the lifting machine to get close enough to provide a safe lift. Hopefully chair to be delivered in the next few days the third will have a tilt seat and be more appropriate for someone requiring full time use of a wheel chair.

Mr A and Mrs A are a long last receiving some of the services that enable Mr A to enjoy reasonable health. They include respite, a nurse Monday to Friday to provide bathing assistance, 11/2 hours a week home care from the local council. Mrs A is currently managing neck and shoulder pain. Mr A & Mrs A have spent over \$55,000 in the last two years on a wheel chair accessible car, and paying for the balance of aids and equipment after the SWEP contribution. Added to this Mrs A has paid a further \$1800 for three periods of respite care in the last 18 months. Mr A is currently in reasonable spirits and part of their living room is being modified to accommodate his bed and a new person hoist. Their main sadness is that they no longer will be sharing the same bed. Mr A has been troubled by the thought of his wife suffering health problems and not being able to assist.

Mr A's health would have been better managed by nurses and occupational therapists with a sound knowledge of the chronic nature of later effects of polio. Mr & Mrs A hope is that in the future someone with that knowledge can manage Mr A's future health needs, they are after all in their four decade and she is tired, extremely tired.

Mr W.

Mr W aged in his early 60's contracted polio in 1954. He recovered well and became a very physical active and competitive. In his late 40 and early 50's he started to experience unexplained fatigue. In 2002 he had an operation for prostate problems and experienced some problems with the anaesthetic – longer to recover. The problems with fatigue seemed to increase after that operation, even though his general health had improved. In 2005 he was diagnosed as suffering from the later effects of polio. He was been extremely fortunate and has had considerable help managing chronic health problems. He uses a VPAP at night and uses a scooter, crutches and manual wheelchair as required. In 2010 he had a colonoscopy. Mr W made sure that the anaesthetist was aware of his childhood polio and his respiratory condition. After discussions with his respiratory physician the anaesthetist decided that it would best that the procedure was done under an epidural. Mr W spent 9 hours in recovery due to the slow and uneven process of feeling returning to his legs. His "polio" leg regained feeling about an hour before his "non polio" leg.

His current dilemma is the long wait times for assistance from SWEP. He is on the **urgent** wait list for a brace for his "good" leg, so far he has been waiting 4 months. He is also on the wait list for shoes so far 12 months. He wears a brace on his polio leg. In the last 4 years he has contributed in excess of \$10,000 to his health needs, being purchase of his scooter, wheelchair, crutches and medical costs associated with non-claimable orthotic devices.

Mr W believes that he is fortunate in that he has the knowledge and support to negotiate his health needs with services providers, but is concerned that as he ages he will be less able to do this.

General Recommendations

Benefits of removing disabling factors has untold benefits. This requires specialist assessment and has proved to provide both an economic saving to state and an increase in the individual's well being and self sufficiency. For Polio survivors this may mean greater assistance with

- **Orthotics can reduce fatigue and assist with falls prevention** (Orthotics consultations are not covered by Medicare and only partially subsidised (Max \$2,200) by SWEPP in Victoria)
- **Greater assistance with home modification/relocation.** Through a lack of realistic support and education and it being considered "too hard" most polio survivors do not appreciate the health advantages of living in a home with fully accessible facilities. Many live in homes with multiple steps and have bathrooms that are not disability friendly.
- **Specialist advice and ongoing support** from a health organisation such as Polio Services that has an understanding of the chronic nature of late effects of polio to assist with the management of the on-going loss of function. (Currently due to staffing restrictions Polio Services is only able to provide support to a small number of people each year)
- **Greater availability of wheelchair friendly retirement villages / nursing homes.** Few nursing home rooms are designed for people using **motorised** wheelchairs. Many polio survivors require the services of supported living earlier than the general population. A greater number of **motorised** wheelchair friendly rooms probably require legislative encouragement.
- **Support for Post Polio Survivors undergoing Chemotherapy.** The side affects of Chemotherapy can be best managed with an oncologist consulting with a post polio specialist. Though there is little published material in this area, it is well recognised that the polio survivors will require extra support during periods of treatment. More research into this area is required with the view to increasing greater awareness of the needs and support required for polio survivors undergoing cancer treatment.

NB I am following up stats with ABS - According to the Australian Institute of Health and Welfare (AIHW) and the Australasian Association of Cancer Registries there were 100,514 new cancer cases registered in 2005 perhaps other data was collected at the same time.

- **Inclusion of number Polio Survivors and whether they live with LEOP and PPS on an ABS Chronic illness Survey**

The last survey on the chronic effects polio was conducted as a part of the "1968 Survey of Chronic Illness and impairments". Extrapolations from this survey projected that there were some 7,800 Australians in 1968 whose lives were affected by the chronic condition of their childhood polio. This survey **did not include** Victoria, N.T. or the ACT and if included it is likely that this number would have been in excess of 12,000. (1 in 1000 of population) Few of these individuals surveyed would have been survivors of the 1950's epidemics and few would have been affected by what we now know as the late effects of polio. The definition used in 1968 for those surveyed was "late effects of acute poliomyelitis" defined in 1968 a condition of which was residual paralysis* Either way it is a very significant number of people living with the severe affects of residual paralysis, who in 1968 would have been in the minority of polio survivors.

**International code number 044 is listed in the 1965 Revision (Revision 8) of the International Classification of Diseases and the meaning of the "Late effects of acute poliomyelitis" is not what is meant by that term today. It was not until the mid-1980s that the Late Effects of Polio were widely recognized and acknowledged and the term Post-Polio Syndrome was also coined. International code number 044 in 1965 really meant residual paralysis after acute poliomyelitis, the actual degree of residual paralysis being irrelevant. Not all polio survivors with ongoing residual paralysis will develop what we know as LEOP or PPS today anyway. - Margaret Peel*