

House Standing Committee on Health and Ageing Roundtable on Late Effects of Polio/Post-Polio Syndrome

Polio Survivor Case Studies from New South Wales

A. The acute illness: Children

Poliomyelitis is a disease requiring notification and, in the majority of cases, requiring infectious disease isolation. The common name of "Infantile Paralysis" is, to an extent, a misnomer as not all cases were children. However, children predominated. In research carried out by Polio NSW (then Post-Polio Network (NSW) [PPN]), 7% of the polio survivors surveyed were babies under one year and 64% were children aged 1 to 10. The major polio epidemics in Australia occurred between the late 1930s and mid 1950s. At this time hospitals had very restricted visiting with parents being limited to one visit per week. Thus all hospitalized children had limited contact with family, and not only when they were in isolation.

The following accounts convey the experiences of some polio survivors who contracted polio as children. These experiences continued to impact on many of them as adults.

CS-01

In late 1939 I began getting constant headaches, extreme pain in my body, especially my left side, left arm and hand, left leg and spine. My mother took me to the local doctor on a few occasions and finally the GP told mum he thought I had contracted the dreaded Infantile Paralysis, at that time an epidemic across Australia.

An ambulance was called and I taken to the W base hospital and placed in the isolation ward. I cannot recall much about the other children there. I spent approximately 3 months in the isolation ward. I had no contact with my family whatsoever, it was a very traumatic experience for an 8 year old.

CS-02

In 1954 I had just turned 6 years old and resumed back at school after summer holidays, when I went into 1st class.

I came home from school one day with a violent headache and high temperature. My parents put me to bed and gave me something for the pain. The second day I was worse and could not get out of bed. The doctor was called and he said I had polio and rang for the ambulance. I was taken out to the Prince Henry Hospital at La Perouse where most of the polio people were taken. This was a very traumatic time for me as they held me down to put a lumbar puncture in my spine to make sure it was polio. I had "bulbar polio" which affects the muscles controlling swallowing and breathing. I became worse and lost my speech and all body movements. That night the police came to the house and told mum and dad I was dying and didn't think I would make it through the night. Mum and dad raced out to the hospital leaving my two brothers with a neighbour. My parents were put into a small room where they waited for many hours to see if I would pull through.

That would be the last time any one would help our family out. No one would come near the house. The washing was still on the line, and had to be dried by the fire at night. Everyone that we knew was frightened they would contract polio.

My older brother had to mind my new-born baby brother in the car while mum and dad visited me, as no children were allowed in the hospital.

This was a terrible place for a 6 year old and I still remember to this day the children in iron lungs, and dying all around me. I pulled through but was very sick. I couldn't sit up and lost the power in my arms and legs. I remember being spoon fed brains and tripe and still can't stand the smell of them.

I stayed at the Coast Hospital for a few months and was then sent to Margaret Reid Crippled Children's Home. They took me there by ambulance and I remember seeing beds on wheels with red blankets on. This frightened me – I had never seen red blankets on beds and all the children were dressed in clothes, not in nightwear. I cried and cried and wanted to go home.

My parents were only allowed to visit on Sunday. The journey to the hospital took a long time for my parents and they had to bring lunch and dinner for me because the hospital didn't have cooks working on Sunday. I always cried when they left.

CS-03

I was 6 years old when hospitalized. The most vivid and lasting memory I retain from hospital is the iron lung. Wafted nightly into an azurine Stygian cavern I eventually turned this nightly ritual into a game and pretended to be at Luna Park enjoying a magical boat ride. Yet I don't recall staying in the iron lung for long periods, so I may have been sedated beforehand as I think I spent the night in this hellish machine.

Restrained in a stiff cot, a metal cage that hung above the cot had an easily reached monkey bar which allowed us to shift about a little, though the nurses regularly moved us about to prevent bed-sores and such.

CS-04 (aged 10)

Mum was allowed to visit me when I was in isolation and she was fully covered like the nurses. The only way I could tell it was her was by the sound of her voice. I only saw my family, aunts and uncles when they pushed my bed over to the louvered windows and they were standing outside in the cold wintry weather. What a heart breaking scene it must have been for everyone. I know my family was in a state of disbelief; how could this happen to them?

An aunt told me of a time when she came to visit and spoke to me through the window. She said I told her that I could now sit up. After much struggling, huffing and puffing I said, "Look I can do it". She was shocked to see that all I had done was lift my head off the pillow but I was just so proud. I had a long way to go to get better but I guess that was a start.

B. The acute illness: Adults

CS-05

I developed a sore throat. It just didn't heal and then I developed a temperature. I then found I couldn't swallow and so B arranged for me to be taken to hospital. In a deep haze I was questioned as to whether I'd had the polio injection. "No" was my reply.

I could hear frantic talking in the background and I was to be taken to another hospital – all that part is simply a fuzz now.

My first recollections were seeing B at the entrance as I was in an isolation ward and even the nurse would have to scrub up and put on full gown and gloves. I'd feel such a nuisance asking for anything.

First of all let me explain that because I had bulbar polio which affected my breathing apparatus and my legs were OK I was placed on my stomach on a bed with feet tilted up and initially I had a nurse with me which I'm sure was almost all the time with a tube sucking saliva out of my mouth so that I wouldn't swallow it. I was told that if I swallowed it could spread to my legs. I find this hard to understand and believe but it is so clear in my mind. The most painful thing was having to have my neck turned around every 4 hours or so. They could only move it the tiniest fraction at a time and then I had to rest. I used to scream at the slightest turn but I kept being told that it was absolutely necessary to keep it rotating. It was a slow and laborious task to just turn it from one side to the other and I would absolutely dread the moment and no doubt the nurses did as well.

It wasn't until I accidentally read the chart on the back of my bed that I found out that I had polio. When I came to my senses and was able to sit up in bed I was not able to swallow anything more than a teaspoon of stewed apples for some time without it causing a cough that kept going for about 15 minutes and almost caused me to choke. I was not able to lift my arms hence could not comb my hair and my tongue was half paralysed which caused my speech to be badly affected. Apparently my mum and dad were notified but told not to bother coming over as they didn't expect me to live for more than 4 days.

I'll never forget the first day I was able to have a bath. Firstly I was absolutely exhausted by walking about 10 steps and when I got into the bath and completed my wash I was unable to lift myself out as my knees and legs had become so weak. Once again, by the time I eventually got to bed I felt I'd run a marathon.

I had to be very careful when eating as if anything, even the tiniest bit of saliva went down the wrong way it would almost choke me. When I eventually arrived home and mum and dad were driving me over the bridge I can recall eating a section of orange and all of a sudden a little juice went down the wrong way and it started me off. I just couldn't get breath and actually watched my body collapse and could do nothing about it and didn't want to frighten my parents. Some miracle then enabled the smallest amount of air to enter and very slowly I watched myself come to life again. I was too frightened to eat oranges for years after that episode.

I was then taken to some type of rehabilitation institution where there were a lot of polio victims recuperating. There was a pool and all types of equipment to exercise on. I can recall seeing all these toddlers who just

didn't want to do any exercises. I was so glad that I was old enough to be aware and understand that this was my only way back to health.

I so wanted to cry but each time I did they would send someone along to try and cheer me up. I just wish I'd have been allowed to do this as I don't feel I was ever able to grieve properly.

I often wonder – and this to many people would seem like a crazy question – whether if you had to get the virus whether you are better off getting it as a baby when you don't know anything else – rather than being a totally whole person one day and quite disabled the next.

CS-06

At first I was diagnosed at home by a doctor in the morning with a sore throat caused by a virus. By the afternoon I said to my wife there is something wrong, she rang the doctor who said he would call in the morning. Through the night I got up very dysfunctional and tried to have drink of water and could not swallow, and managed to get to the toilet. The doctor arrived at 9 am and saw my condition, apologised for not coming earlier. I was now drowning from my saliva, an ambulance was called and raced me to hospital. After two hours I was fortunate an ear, nose and throat specialist diagnosed polio of the throat.

As it was in the middle of a polio outbreak I was raced by ambulance to an isolation unit at Prince Henry Hospital, on arrival I was put on a bed at about 50 degrees, hoping the fluid would run out. By now I was quoted as being 95% drowned, and my family were called as I was not expected to live. I was told they would have to put a tracky in immediately. When I came to after the surgery I had this monstrous rubber tube sticking out of my neck and nurses would come every half hour with a catheter and push it down into my lungs and suck the fluid out. By now they had stainless steel trackies with a cuff which when filled with 10cc of air would act like an inner tube sealing off my windpipe and I was allowed to have jelly and fluids at meal times, but after meals they would let air out and of course what was sitting above the trackie and my mouth would go down to my lungs and they would have to suck it out again. This ritual went on for about two months. By now I was allowed to go to the bathroom by myself. During this time people in their late twenties were coming in in prime physical condition and within a week carried out in a box.

C. The recovery phase and early years: Children

CS-07

The big positive of life at C was that the Department of Education ran a one-teacher school in a cottage in the grounds. At first, I was wheeled into the classroom in my bed. The standard of teaching must have been reasonable because, though I had only been at school for three weeks before falling a victim to the polio virus, when I returned home after two and a half years I came third in the class and thereafter topped my year. For some years after returning home I had a masseuse visit me twice a week, but otherwise I walked to the nearby convent school, joined in playground games with the other children, suffered terribly from chilblains during the winter and hit a tennis ball hard against the church wall every morning before school.

Polio affected me in my legs, principally the left one. Beginning with full-length callipers these were gradually reduced until, when I was twelve, I was allowed to wear ordinary shoes (though never the "tippy-toe" ballet shoes I aspired to) and was told by the doctor to "go and live my life", and that is what I have done.

CS-08

After my discharge I was treated as an outpatient. I had regular, perhaps twice weekly, home visits from physiotherapists, then called masseuses, who checked my progress and administered exercises

Transport was a real problem. A special wedge shaped pram was built to accommodate me in my Y-shaped splint. Both splint and pram had to be enlarged as I grew. The pram would not fit through the door of a railway carriage and I was always put in the guard's van. Carriage by bus or tram was simply not possible. I was taken on family outings in the family car, but with my splint strapped on the back to be used immediately on arrival at our destination. During the journey, it advised onlookers that there was a polio person on board, perhaps not an unusual event in those days.

The pram was my conveyance when I started school at R Primary. My mother hired a couple of the more senior students to push the pram to school and to bring me home. My recollection is that this arrangement worked quite well.

My enforced confinement and immobility and my inability to join in the activities of other children my age must have encouraged development in other directions. For instance, I was reading and writing before I began school and when I did begin I was promoted through the infant school in a matter of months.

CS-09

When I was released from hospital I was not at first allowed to return to school. Mum had to take me three days a week to H Hospital for exercises. In those days we did not own a car so mum used to carry me from our house about half a mile uphill to the bus stop, then swap buses at H station to get to the Hospital. Remember I was six years old and no baby. After a couple of weeks of this a crippled girl who lived just up the road loaned mum her old wheelchair so she could push me up to the bus stop and back which made it a little easier for her. I only found this out a couple of years ago when we were going through some old papers and found the receipts for where she and dad had paid off the hospital bills and ambulance bill in weekly instalments.

When I was first allowed to go back to school I only went for a half day until I was gradually allowed to return full time. I seemed to catch up the missed schooling okay and went on to complete my leaving certificate

CS-10

The year 1959 loomed and I was going to the A High School in the New Year. I was very apprehensive about the whole thing. Not only was I disabled but a year older than the other girls in my class. I had to repeat 6th class as I wasn't well enough to go to the High School the year before. Also I was going to have to travel by train as we lived about 48 kilometres out of A. My parents would have to pay for a taxi to pick me up from the station and deliver me to school and take me back to the station in the afternoon. No social services to help them then.

The big day arrived and it is one day that has been imprinted on my mind for time immemorial. After the interview with the headmaster where my condition was explained, the time had come to face the class room.

The classroom was on the ground floor and they only had wooden floors then. The noise from my calipers and sticks were bad enough but I was carrying a suitcase which thumped loudly every step I took. Every eye in the class was pointed directly at me. Out of nearly one thousand pupils at the school I was the only one disabled, physically that is. How on earth did I walk around carrying a suitcase with a brace on my right thumb and using sticks? I will never know. I think they thought I must have come from Mars.

I know I was called names and one of them was "ironsides", which did really hurt. There were no special privileges for me at all. I had to walk up and down the stairs with my calipers bent and hanging on to the railings for dear life, also carrying my sticks and suitcase.

D. The recovery phase and early years: Adults

CS-11

I was able to leave hospital and return to my family and farm life. Crutches weren't much use in paddock and wet ground. Using an old farm ute I was able to repair fences, shift stock, and complete many small tasks, mostly kneeling (no chance of falling). I later rigged an electric start of the diesel milking machine engine. Also a set of ropes and pulleys to work gates and lift 10 gal milk cans. I think all these were a challenge that helped greatly to enable me to gradually resume a reasonably productive life style. I have managed with lots of help from my family and friends to have a pretty good life and achieve all I wished. Dairy farmer to store PO, school bus and agencies to woolgrower, lambs, grain, then retirement.

CS-12

I was fitted with a new 'lightweight' caliper. It had joints at the knee with locks and a leather lace up bucket at the top, much more comfortable and I could sit down with both knees bent. It made travelling on buses much easier. Always the optimist I felt life was now beginning to improve.

All this time I gradually gained more strength in my arms and left leg and my mobility improved, eventually I threw away the caliper and found I could manage very well. I never considered myself disabled, just someone who couldn't run, bit of a problem sometimes when late for the bus. This problem became less and less as I progressed in my career, bought a bike, then a scooter then to a motorbike and graduating to my first car in 1958, an Austin A35.

All this time I do not remember being bitter or resentful, sure I was depressed sometimes when I acknowledged there were certain things I would never be able to do, but ever the optimist my glass was always half full. Physical sport was one area I was unable to take much part in, however this was no big deal as I was pretty hopeless with the bat and ball or football and I preferred to watch.

E. The onset of the late effects

CS-13

When I was 6 years old I lost the use of my left arm. We were told I had Infantile Paralysis. I was not in an iron lung or hospitalized, and initially my left arm was put into a firm metal brace (similar position to a Traffic Cop stopping traffic!). I was eventually released from the brace and I received constant physio on my arm. I do remember a lengthy stay in bed, and my legs being very feeble after that inactive period. As far as I, and my family members, can remember, I recovered fully within 1-2 years.

Since that time, the only reference I have ever made to the polio problem was that my left arm was very slightly weaker and thinner than my right. I have always led an active and busy lifestyle.

Approximately 4-5 years ago I found I was tired after my weekly Tai Chi class and instead of coming home and practicing the moves I had learned that day, I found I was tired and had to sit down and recover. I also started a Yoga class 4 years ago, but found I was absolutely drained of all energy after a session. At first I just put it down to age and perhaps I was not as active as before, so had become a little unfit. Approximately 3 years ago I visited my Dr for my usual 2 yearly check and she noticed my leg and arm muscles had deteriorated, so suggested I do weight bearing exercises to build up my muscles. She showed me a "press up" and I told her I would have difficulty doing that exercise as I had had polio as a child and that arm would not take my weight comfortably. She immediately told me I had Post Polio Syndrome and told me to contact our local clinic. I had no idea what she was talking about, having not even given my previous polio problem a thought in 58 years or so. She did extensive tests to eliminate any other cause of the dreadful fatigue.

My Dr also sent me to a neurologist for further tests. My left arm is thinner than my right and about half strength. We also found that my leg muscles were originally affected by the polio (although I was unaware of that fact all my life).

It has probably taken me at least 2 years to accept that my lifestyle had had to change and I do not have the energy that friends of my age have.

CS-14

At boarding school I played tennis, basketball and volleyball. I thought I had to do everything everyone else did and would not admit defeat.

After leaving school I worked full-time for 34 years, but about 35 years after I had developed polio I was having a lot of trouble keeping on with my job.

For some years I had been having increasing pain and difficulty walking far or standing for long, until finally, after a process of elimination of other possible causes I was told that it was caused by Post Polio Syndrome.

During the day, as soon as I tire, I leave that occupation and do something else because I have found it is very bad to keep pushing myself.

I use a walking stick if I go to crowded places where I could be bumped and perhaps fall, but otherwise I don't use it. People are surprised at how mobile I really am, in fact, sometimes it is difficult to make them understand that I can't do what they think I should be doing.

CS-15

I contracted polio in M in 1953 at the age of 19. Both of my legs were affected resulting in five months in hospital, however, after rehabilitation I made a full recovery improving sufficiently to play sports, while I maintained good health for many years.

It was nearly 30 years later that I visited a local doctor as I had begun to experience some leg weakness so I was referred to a physiotherapist who prescribed an exercise program. Symptoms of leg weakness and back pain continued over the years to fluctuate, eventually I was referred to various specialists for further assessment and tests.

When I heard about post-polio syndrome I saw Dr A a rehabilitation specialist who diagnosed my muscle weakness as due to Post-Polio Syndrome, and suggested a management strategy. However, by 1993 I developed further muscle weakness, and debilitating fatigue. At this stage I found it necessary to reduce my work hours, but a short time later I decided to resign altogether.

In more recent years I have learned to pace myself more, and I also began using an electric scooter for shopping and taking our two Australian terriers for their daily walk!

Management of my problems continues to be the key to coping with my ongoing symptoms.

The hardest part of having Post-Polio Syndrome is having to deal on a daily basis with a problem which I thought I had put behind me fifty years ago.

CS-16

I peaked in my physical improvement in the late 50's and early 60s, actually walking without a stick for over five years during which time I met my wife and helped to rear our three children.

Then gradually things started to come unstuck, from the age of fifty onwards. A regression which is still continuing - first pains and frequent falls, then legs that progressively bowed backwards. By the time I consulted a Bone Specialist, I was beginning a long slow regress back to where I started in 1951.

Through the 70's and 80's my condition worsened, necessitating early retirement from work, back into long callipers and crutches. Now, however, I am older and my arms and body are weaker, my posture is all out of whack. Not able to do very much of a physical nature, easily exhausted, daunted by challenges. I spend a few days in bed most weeks.

I can honestly say I have never met anyone with polio who improved so much and then declined so severely as I have. However, I still value my lifestyle, being able to drive my car with hand controls - I can fly with wheels under me!

CS-17

About Post Polio – for about twelve years now my muscles have been deteriorating, beginning with a numbness in my left leg (the good one!) and muscle pain in the same leg. It was impossible to get proper diagnosis in C – both specialists I saw insisted that there was no such thing as post polio syndrome. They were unable to suggest any other cause for my symptoms, though!

Membership of the Post Polio group in C gave me access to much information, and now I do not try to exercise too often (I used to do aqua aerobics three times a week) which seems to control the pain in my leg, which only surfaces if I do too much. I have just taken up Pilates, which I feel will help my balance.

Of course, the lack of exercise leads to other problems. I have been diagnosed with glucose intolerance, and advised to exercise – but I don't see how I can exercise enough to make any difference. I control it through diet and natural supplements.

CS-18

I had been suffering from depression over the relapse in my condition, and not knowing what was happening to me physically led to me feeling quite suicidal at times, even to the point of trying to push myself from the hospital to the highway to push myself under a truck, and I was very angry at doctors who dismissed my pain and spasming as psychosomatic and not a medical condition at all and therefore they just dismissed me as psychosomatic. To try and find out what was going on my own. I demanded a referral to a Rheumatologist in T who then referred me to the rehabilitation clinic at T Base Hospital. Where the day after my admission the nurses and the Gerontologist referred to my condition as Post Polio Syndrome, this was such a relief to me that what was wrong with me really had a name, and that I no longer was suffering alone, there are approximately 45,000 other people in Australia with this condition.

CS-19

More than 30 years later, I noticed a return of symptoms I thought she had left behind. Used to working up to 20 hours a day in my successful catering business, I found my arms were getting so weak I could not lift a tray of food. I suffered headaches, could not dress myself and had difficulty sleeping. Now I must use a wheelchair if I need to be mobile for a long time.

CS-20

Around 1993/94 I began to notice I couldn't walk very far without a rest and my leg muscles became very painful. Then I started avoiding steps and stairs, using lifts and ramps wherever possible, I began to worry about what was wrong, my eldest daughter suggested post polio syndrome which she had read about, but I poo pood the idea. My doctor wasn't much help, he sent me to a neurologist who ordered biopsy's on my leg and arm muscles. After much muttering and many dollars he said I did not have PPS. After I gave my Doctor some of the PPN literature, he is now converted and very supportive.

Comments from polio survivors who participated in Polio NSW research:

My biggest problem at the moment is difficulty using my hands which has never been a problem before – can't sew any more for instance; writing etc difficult – even typing. This is great stress!

Fatigue much increased.

Often feel tired – but may be due to what I try to do each day.

Often hoarse or lose voice suddenly.

My husband often remarks my voice has softened very much during the last 3 years. People can't hear me on the phone.

F. Living with the late effects

Comments from polio survivors who participated in Polio NSW research:

Ten years ago I had no problems with household tasks; now in bed - they are all impossible.

I get a lot of back ache and tire quite quickly.

I cannot bend or pick things up – no strength in back or legs – very good balance when standing straight up; have to lift myself up by hand to vertical position.

Do not vacuum – too fatiguing and dangerous; meals: usually ask for help; supermarket: prefer help – too fatiguing and dangerous.

What I can't do doesn't get done.

My need for maintenance and gardening assistance has only been a factor in the last 8 years but I feel daunted needing help at “only” 38!

Gardening, shopping, laundry, housework are hard to fit in when I have to rest periodically and pace myself in physical activities throughout the day. Entertaining and mixing socially can be very tiring (though enjoyable too).

I do not like living alone and when I fell twice last year it was very difficult to manage on my own.

Can't hold arms up for long; have to lay down after I have a shower to rest.

Lift myself out of bath with arms; it is the getting up and down or out of bath – have to be very careful.

I am using my right arm to lift my left hand when eating but I don't consider this a difficulty as I have always used my right arm to help out in many situations all my life.

Sometimes very difficult with food – often unable to cut up food.

Avoid writing where possible.

Problem with writing does vary from day to day.

Writing – often unable – have to pick day/times.

Everything an increased level of difficulty from ten years ago.

I find that everything takes me longer to achieve being so much slower in movement. Still manage to have interests – library, computer, friends.

Retired more than 10 yrs ago because of polio-related difficulties.

Have not worked for 15 yrs – had to stop due to PPS.

Early retirement due to increased mobility problems and fatigue.

Off sick past 6 months – polio related.

When I finished work 29 yrs ago it was on account of polio difficulties; voluntary work had to be decreased because of polio difficulties; now in things I've been involved in, no new ones.

G. Medical and allied health professionals and polio survivors

CS-21

One of the biggest problems facing polio victims is it is such a condition of the past many doctors have had no experience of treating it. A lot of doctors are younger, they haven't seen polio and they will call it arthritis, or headaches or chronic fatigue. At the same time you feel like they are putting it down to hypochondria.

CS-22 (recounting ambulance and hospital experiences following an accident)

The medical and para-medical professions aren't always aware of what is good for us old polios. When the ambos arrived, one of the first things they did was give me a dose of morphine despite my exhortations that this was a bad idea. I wasn't in agony and I was concerned about the respiratory depressant effects of the morphine on my breathing. Because of my physical deformity, my lung capacity is very low. Anything that further compromises my breathing should be considered as risky. I guess because the ambos are trained to follow a uniform protocol, they ignored my request. This needs to change.

I won't go through the details of the ensuing sequence of events but I ultimately woke up in the netherworld of an intensive care ward with an endotracheal tube down my throat attached to a ventilator to support my respiration. I was completely paralysed and could barely open my eyes. The paralysis was due to effects of repeated doses of neuromuscular blocking drugs, which are necessarily used to assist the intubation process. Old polios are particularly sensitive to these drugs and lower doses than normal should be used as it may exacerbate muscle weakness for days. This, most assuredly, slowed down my recovery.

The third issue arising from the accident relates to the way that old polios are adapted to their existing physical condition. My fall resulted in broken ribs and a haemo thorax or bleeding within the lungs. This accumulation of blood means that the lungs can't function normally and gas exchange; uptake of oxygen and blowing off of carbon dioxide can't take place as efficiently as it should. Hence, the need for artificial ventilation until the blood can be drained from the lungs. To evaluate this process, the intensive care physicians regularly measure the blood gas concentrations and when they're back, close to normal, they take out the endotracheal tube. In my case, as a result of pre-existing chest deformity and respiratory muscle weakness my blood gases especially carbon dioxide were already "abnormal" before the accident. However, my body was well adapted to this apparently abnormal situation and able to function perfectly well. The intensivist, unaware of this situation was unwilling to remove my tube. This is dangerous because the longer one remains on artificial ventilation, the more difficult it becomes to wean the patient off the artificial support. The problem arises because intensivists work "by the numbers". If those blood gases aren't by the textbook then you ventilate until they are. For old polios, this is plain wrong. Luckily my old friend and colleague Prof G made a special trip to C to explain this to the intensivists and the tube was pulled.

Comments from polio survivors who participated in Polio NSW research:

No support whatsoever from family or doctors. No understanding of polio.

The doctors don't seem to know much about it.

Only [consult health professionals] when something comes up – haven't much confidence in them

9 yrs ago I found myself unable to cope with this problem. I had to resort to wheelchair but I moved towhere I found support in a hydro pool with a lady who understood my problem and got me moving. I then started to walk a bit and with this exercise I started back and then I found a massage clinic that I now go to weekly. My doctor can't help me but does support my effort. I now think of my improvement as a miracle.