

Jill's Polio Story



1946 - Introduction

I was born 8th December 1946 in England. Two years later a sister came along and we lived with my parents above the dental practice where my dad worked as a dentist.

1955 - Hospitalisation & Poliomyelitis

I contracted Poliomyelitis during 1955 when nine years old. I was admitted to an isolation hospital in a single room. Each room had one outside glass wall and glass walls the length of the inside corridor so we could see other patients in their beds. My parents visited me by waving through the glass walls from outside the building. I remember my legs and arms getting weaker over the next 24 hours and having a bad headache. The next few days were hazy with fever and I surfaced a week later. I had full length plaster casts bandaged on my legs for the first six weeks but was able to sit up at times. In the seventh week I moved into a three bedded room and started the 'road to recovery' program, commencing with sharing a room with two other children.

A week later I was moved to The Rowley Bristow Hospital about 10 KMs from my home. The hospital was surrounded by trees, grass lawns and fields. My ward had stable doors by each bed and the top half was kept open all the time. We knew when cold weather was expected as a trolley was wheeled down the ward and each patient issued with a thick warm Red Blanket. Luckily for me it was spring when I was admitted. During summer our beds were rolled out into the sunshine at every opportunity as fresh air was considered good for us. My physiotherapy consisted of daily, leg and arm gently stretching and gradually learning to walk again. The long wooden rocking horse on the lawn play area that held 6 children became my daily challenge. I remember the thrill of finally walking to the rocking horse after weeks of crawling to it and pulling myself up onto a seat.

Many of us polio's spent months in the rehabilitation hospital so with our new found friends we set about things children do, including getting up to mischief. I often had my crutches pinched if I was on the rocking horse too long and had to crawl to where they had been thrown. I also remember one evening when the whole ward ganged up and locked the two staff nurses in the supply room. Two school teachers would take classes each week day, and we took great pleasure in sliding our comic's in-between our text books to read.

The highlight of each week day was a ride on a flat cart pulled by a tractor that took us on a ten minute trip to the main building where we had hydrotherapy. I loved the warm water and found it a great way to increase my limb control, walking pattern and lung capacity.

Six months after my admission my parents took me on a car drive. The drive was cut short as I became frightened each time my dad tried to go over 15 kms an hour! However all was ok by about the third drive I was taken on.

1956 - Rehabilitation

After nine months I was discharged home, walking on crutches and able to dress and toilet myself. Three days a week for 18 months my parents took me back to the hospital for mobilisation therapy and the hospital school lessons. During this period I remember going on a stretching machine to try to improve my back scoliosis. The stretching 'rack' consisted of a thick belt round my hips and straps attached to the couch bottom and another belt around my waist/chest or neck with straps attached to the couch top. The top straps were then winched up to a given pressure and I had to lie there for 30 to 60 minutes. This treatment continued once a week for six months, and hurt!

1957 - Early Teenage Years

Two years three months after I contracted Poliomyelitis I started back at my old school and my parents arranged for an hour's private physiotherapy at home two days a week. I then did what polio's do and got on with my life. My parents encouraged me to do everything I could and felt I adapted well to my new life. I started horse riding lessons and eventually learnt how to mount a horse unaided. My parents arranged to cost share with a neighbour's horse and I enjoyed six great years of riding 'Roger' a steady black Dales horse.

1965 - Career Training

My next memory was starting a three year diploma course at St. Loyes School of Occupational Therapy in Exeter, about 250 Kms from my home. By then I was getting around on a small 50 CC Suzuki motor bike, called Josephine. and learning to drive a car. It took me about 6 hours to ride 'Josephine' from my home to Exeter as her cruising speed was around 25 MPH (40km/h). I covered over 20,000 miles (32,000) on Josephine and a piston engine re-bore. Luckily there was less traffic on the roads then, I'm not sure I would have had such fun on today's busy roads. On one bike ride to Exeter, I had a large joint of well hung venison meat tied on the back. Every town I went through dogs followed me trying to get a bite. On the long journeys I used to eat my sandwiches going up steep hills as Josephine's speed dropped off dramatically under load. One English winter I stopped at a garage for petrol on Salisbury Plain. So cold, I could not get my legs to the ground in time to avoid Josephine falling over. Only my pride was hurt. The garage owners took me inside, gave me a cup of tea and wisely insisted I continue my journey by train, which I did.

1970 - Emigrating to Australia

It was because of Josephine I immigrated to Australia. In England I joined a motor car maintenance evening class and met up with Janet. Janet & Marion were immigrating to Australia around the time I wanted to travel overseas. So to cut a long story short, I flew to Melbourne, Australia a month after Janet & Marion and we shared a 2 bedroom flat for 4 years in Richmond. The rent was \$21 per month, probable \$160 a month in today's terms.

I had Josephine shipped to Melbourne and continued riding her around as our only means of transport for the first 2 years. Josephine lived under the stairs in a corner of the flats. I found work as an Occupational therapist (OT) in 'The Repatriation General Hospital' in the Melbourne suburb of Heidelberg. This hospital was a great starting point for life in Australia as the OT department had many different work areas that staff were rotated through. I made lasting friendships that continue to now.

After two years I saved enough to buy my first car, a 'round tail light' Cortina. I was so nervous when it was time to drive off, the car salesman offered to go for a drive round the block with me, however the suggestion spurred me on to take the plunge, and I've not looked back since. My parents joined me in the flat for 6 weeks when my flatmates were away. It was a new experience to have my parents as guests in my home, instead of me being in their house. We had a wonderful time together, tripping around locally and then to Alice Springs, Brisbane, Whitsunday Islands and Sydney together. I still recall very fond memories of that trip and our time together, even after so many years.

1974 - My working Career

After 4 years at Heidelberg I moved to 'Coonac', a Commonwealth Rehabilitation Centre that provided Rehabilitation & treatment for working age people. Coonac specialised in particular on work simulation training for disabled teenagers and young adults who had problems learning to cope with authority, taking instructions or the grind of daily work. At Coonac the OT staff were also rotated around the different working areas. I found 'Work Re-training' very satisfying so decided to 'specialise' in that area as an OT. This was my most physically active period. I was still young, had no Post Polio Symptoms, was well established in a different country to where I grew up, had plenty of friends, a car to drive, rode horses, visited England every few years and felt life just rolled along. This was also the era of one working career with perhaps 3 jobs and long term stable job employment. However the winds of change eventually came to Coonac and for a while I worked as a 'Team Leader' with a multidisciplinary staff team, before Coonac, as a Centre, closed. Its patients, now called clients, were then managed from small regional offices. I was looking for change and found a desk job in the newly established 'WorkCare' system (later called WorkCover and then 'WorkSafe'). This was my most job challenged period, both physically & mentally. It was a real adrenaline rush to be part of a new and rapidly evolving system. I used my OT skills in an office job as part of a multidisciplinary team of staff establishing rehabilitation policies and procedures for work injured people. Never a dull moment!

1985 – The start of Post Polio Syndrome (PPS)

However after a few years working for WorkCare I began to notice walking on soft carpets a problem, and that I was getting tired more easily. This was my first inkling of PPS. With hindsight PPS probably began when I was attracted to the less physically demanding role of 'Team leader' at Coonac.

1991 – PPS Diagnosis

As my problems progressed, I felt confused as I had always thought my Polio recovery would remain stable. Fortunately a friend put me in contact with the ParaQuad Polio Community Officer and I began reading their regular newsletters looking for more background in the new term 'Post Polio syndrome' (PPS). I soon heard of Robert Adler, a specialist with expertise in Post Polio, but had to wait 3 months for an appointment. This 3 month wait was very hard. By now my weak leg was so painful and swollen I needed crutches to get around, then my shoulder deteriorated and I my throbbing knee made sleeping difficult. I often cried, even at work as depression set in. By the time my PPS appointment arrived I was a mess and cried through the very detailed assessment. The results went to my GP who was relieved to have such a thorough assessment and practical recommendations to follow up. I began depression medication and counselling, was fitted with a calliper on each leg and some general physio.

After 3 months the depression subsided, the callipers relieved my swollen knee and aching shoulders and I had a much better understanding of how to manage my PPS. Life returned to a less mobile 'normal' but one I could adapt to and plan for the future with.

1992-3 The Big Trip

As soon as I was diagnosed officially with PPS, I decided to take a year off work to travel around the world while I still had enough physical capacity to enjoy it. I still recall the moment I sat in my local library, pouring over a large atlas and said to myself 'where in the world shall I go? !! I eventually decided to select several locations to spend a few weeks in rather than keep moving every day or so. Due to my reducing mobility I had found that the biggest energy depletion was moving from one place to another, i.e. packing, carrying luggage/taxi to bus/train/boat etc, then finding accommodation at my new location.

The schedule I decided upon was to: Fly to East Asia and backpack by bus/boat around Indonesia, Thailand & Malaysia. Fly to Africa and join a 6 week camping coach trip visiting 6 countries in central Africa. Fly to Egypt and stay in a hostel for 3 weeks, then join a 2 week coach/camping trip. Fly to Greece and backpack by train/bus/boat around Greece, Italy and Switzerland. Train to Belgium where I stayed with family friends, boat/train to my parents house in England. Fly to South America and join a coach/camping 10 week trip starting at Rio De Janeiro in Brazil then travelling through 6 countries; Brazil, Paraguay, Argentina, Chile Bolivia, and ending in Peru. Fly back to Australia.

I actually returned one week overdue because of last minute unscheduled flight changes. I knew my workplace was downsizing by a massive 75% and the remaining 25% would be reabsorbed within the parent organisation in a new building. I asked a friend to track down someone to say I'd return a week late. My friend collected me from the airport and told me he could not leave a message at work since no-one he spoke to knew my name! I found the old work office empty so went to the parent Office. Of all the names I previously knew, only one manager knew me. I then went through a rapid identity change moving from the rehabilitation area to Investigations/fraud as it was the only area to offer me work. To my surprise, this new job was most interesting and proved to be a great learning experience.

2000 – Disability retirement

I had a few more years of uninterrupted work, before succumbing to a bad bout of PPS with 2 months off work resting. I returned to work for a year before suffering another PPS downer. This time I returned to work 3 days a week & alternating with 2 days a week formal sick pay for another year. With yet another PPS downer I finally accepted reality and retired on a disability pension during the year 2000. Being utterly exhausted & again depressed, I took to my bed for a few weeks. I then gradually reintroduced one activity at a time, careful not to overdo things like before. After 6 months I was back to doing a few hours pottering around the garden, shopping in my electric wheel chair and even had the occasional meal out at night. I had toilet/bath/shower rails installed and sorted out a travel package of folding toilet seat that doubled as a commode/shower seat. I also purchased a light weight mobility scooter that lives in the car boot and enables me to get around from where ever I park the car. More recently I've added a Boot Hoist.

2003 – Living with PPS

Although I never missed the daily routine of work, I soon missed the company of working with others. Fortunately I was able to find one day a week voluntary work at ParaQuad Victoria, helping the Polio Information Officer. The voluntary work I do is very rewarding, especially as I regularly use the skills I had acquired in OT and the WorkCare system. After trial & error experiments I found ways to conserve energy and minimise 'attacks' of exhaustion that would often stop me in my tracks. My way of balancing rest and activity was to rest flat in bed 12 hours every night, as this gave me quality 'up time' during the day. I consciously chose to be active during the day as I enjoyed outdoors/day activities. I still continue this routine and have learnt to cope with the long periods lying in bed, awake, but recharging my batteries. I have been able to adapt PPS management to most hobbies I previously enjoyed, including the horse riding.

My Hobbies

Camping

I first went camping with my family on holiday in France and England and have continued to enjoy camping ever since. Soon after arriving in Melbourne I bought a 2 person canvas tent, basic cooking equipment and sleeping bag. The only concession to my disability was to use a light canvas camp stretcher since lying on flat/bumpy ground was uncomfortable.

Horse riding

I learnt to ride a horse during my Polio Rehabilitation program. Then became a mad horse riding teenager and continued to ride all through my college days. After immigrating to Melbourne, I continued riding on a regular basis and even bought a saddle & bridle with my first Australian tax refund. I soon discovered the extra support that an Australian Stock Saddle vs. an English flat saddle gave me. After about 10 years I found my left ankle was twisting in the stirrup with metal against bone, so for 20 years I threw my energy into flying light aeroplanes. About the time I had to stop flying because of PPS weaknesses and exhaustion I had a major left ankle reconstruction and found I could ride again with a correctly aligned ankle no longer banged against the stirrup. Luckily the right leg full length calliper I now wear sits comfortably on the saddle.

I ride by balance, falling off about twice a year because my right leg cannot grip the horse, so I never ride alone. For safety, I designed and use a toe cap for each foot. The toe cap prevents my feet sticking in the stirrup during a fall and so avoids the risk of being dragged along the ground. I made a leather set for Aussie rides and folding canvas sets for riding overseas (GB & NZ so far). I also am careful to ask for a beginner's horse every time I ride at a new place, and a stock saddle of course.

Flying

Soon after I began work at 'Coonac' Rehabilitation Centre I read a book called 'Flight Into Danger' which told of an airliner where all the crew and all but 2 passengers were stricken with severe food poisoning. One of the 2 unaffected passengers had a private Pilots Licence and flew small planes for fun. The story told how the Private Pilot contacted Air Traffic Control and via instructions landed the plane at an aerodrome. Inspired, I made inquiries, and found I could finance flying lessons on a tight budget, spread over a 2 year period. Flying was great compensation for not horse riding due to ankle pain.

I found each flying lesson such a 'high'. To feel the responsive plane controls in my hands and change direction with the lightest touch was a mind freeing bonanza. After 2 years I gained my 'Restricted' Private Pilot's licence which allowed me to fly passengers in a local area. During the next 6 months I learnt to navigate around Australia, and gained my 'unrestricted' licence. My first major flight was to Adelaide to visit friends, unfortunately I could not find anyone to fly with me so went alone, probably the best thing I did as it really set me up for long distance flying as Pilot in Charge. I went on to fly to places such as Queensland, South Australia, Northern Territory, and Tasmania in addition to Victoria.

Trekking (horses/Camel)

After a few years of appreciating how much more I could do with the freedom of an electric wheelchair/mobility scooter, I realised I could also cadge a ride other ways. Such as horse trekking over Mt. Bogong, Mt. Feathertop and around Mt. Buller. Not limited to horses, I then tried a 5 day camel trek walking nearby Lake Eyre, then a year later an 8 day camel trek in the Flinders Ranges. Wow! each trek is such a buzz, I feel as though I am bush walking on an 'All Terrain' live scooter, covering ground my mobility aids could NEVER take me. Who knows, I may have been a bush walker if I'd not had Polio. In Egypt, during my year away travelling the world I rode a horse around the Giza Pyramids & Sphinx, then a donkey around the tombs in the Valley of the Kings. In Peru I rode a horse for one day of the Inca trail and camped overnight on the Trail – breathtaking. Next morning I rode the horse onto a station platform to take a train to the base of Machu Picchu where I rejoined my group as they completed their three day walk along the famous Inca Trail.

The Future

Who knows what the future holds for any of us. For myself I plan to keep doing as much as I can, while I can, and thank God for each day I enjoy. Future action hopes include donkey trekking and expand horse & camel treks to other regions of Australia. Possible even ride a donkey down the Grand Canyon, provided I can stomach the breathtaking narrow ledges the donkeys walk along. On the practical side I am adjusting to hard PPS facts that in time I will need to make my home more wheelchair friendly and ensure the routine aspects of living can be done by others while I save my energy for selected interests as long as possible. For me the key word to minimise PPS decline where practicable is to ADAPT.

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