

Polio then + now

The average age of a person who had polio is 71 years, according to an informal 2010 survey of 388 New Zealand polio survivors. Of course there are those who are older and surprisingly some who are younger.

By the early 1960s mass polio immunisation throughout the country saw the elimination of polio epidemics.

People now living with the late effects of polio were born prior to the 1960s, though a small number of children and young adults are immigrating to New Zealand with existing polio.

New Zealand experienced polio epidemics in 1916, 1925, 1937, 1948–49, 1952–53, and 1955–56.

Effective polio vaccines were developed in the 1950s.

Jonas Salk's inactivated vaccine of 1955 was followed by Albert Sabin's weakened live virus oral vaccine in 1960.

Here, use of the Salk vaccine delayed the reappearance of polio between 1956

and 1961. After this a mass immunisation campaign using the Sabin oral vaccine achieved high population coverage and eliminated the polio virus from New Zealand.

These epidemics were a frightening time for families who saw their infants and healthy toddlers stopped in their play, stricken down by polio.

It was even more terrifying for the victims who faced isolation, separation from families, and long periods in hospital.

Some patients with polio flu and those less affected recovered at home.

In wider society schools were closed, and sports events, movie theatres, and public swimming pools were also shut down.

Wherever there was any large gathering of civilians there was a risk of contracting or carrying the invisible polio virus.

There was a regimen of intensive rehabilitation by therapists determined to see their patients back on their feet and returned to their parents as 'near normal' as possible.

Day in and day out the mantra was "you can do it, try harder, push yourself a bit more", and the patients' willingness to please their therapists moulded independent and resilient polio personalities.

No matter what the level of paralysis in

the body, there was no paralysis of the spirit in the small survivors of poliomyelitis.

Human nature being what it is and children being children, there were happy times of getting up to mischief, outdoor play, picnics and caring, kind nursing staff who eased the painful days.

Adults with polio formed lifelong friendships and connections with those they met in the hospital wards.

Better Times

Society was anxious to forget the polio epidemics.

As children with polio were discharged from hospitals and rehabilitation homes (the Wilson Home in Takapuna and the Duncan Home in Wanganui) back to their own homes, an uneasy denial began to settle upon the nation.

The children fitted in at school as best they could, often discarding leg irons, special shoes and crutches.

Sure, they may have walked with a limp or dragged their feet or flapped their polio arms or struggled for breath with weakened lungs, but they were determined to 'join in', 'be normal', 'not miss out'; slowly the initial terror of polio faded.

Parents, teachers and even the children themselves rarely spoke again of those ➤



Edith recovering from polio at Auckland's Wilson Home.





Edith and another young patient with the Wilson Home's massage therapist.

polio years. It was pushed deeper under the surface of daily life.

Education, marriage, children and careers followed in the peak years of physical stamina for polio survivors.

Some climbed mountains, travelled the world, became doctors, nurses, teachers; "if I could beat polio I can beat anything" was the unspoken motivation to prove 'we' were as good as everyone else.

If anything was a challenge, it was there to be overcome by sheer willpower.

For many it took huge amounts of effort to 'fit in', sometimes doing 150% more than a normal person to complete the same task.

Always the person with polio pushed themselves beyond what was required, drawing on some inner standard rather than the expectations of others.

Was this trait an echo of a parent or therapist saying "if you want to be just like everyone else, push harder, do better"?

Second Time Around

The nightmare of an invisible enemy slowly crept into the recovered polio person's life in the mid 1980s: something was going wrong.

Survivors of polio, by then almost forgotten, were visiting their doctors' clinics with fatigue, weak muscles, and new pain in bodies that had compensated for so many decades.

Doctors and medical professionals had no answers, and many patients wandered from doctor to doctor seeking help.

Post Polio Syndrome was the new name for a condition affecting up to 60% of

OF THE PEOPLE WITH POLIO SURVEYED IN 2010, 78% CAN WALK. THIS TRANSLATES TO WALKING WITH CRUTCHES, BACK INTO CALLIPERS (ONCE DISDAINED), AND PUTTING ON STURDIER SHOES AGAIN.

people who had contracted polio 30 or 40 years previously.

This was a blow. It meant picking themselves up to face the late effects of polio. But this time there was little understanding. Few doctors knew about Post Polio Syndrome, nor did many people with polio.

Soon support groups and organisations to educate polio survivors sprang up around the globe, and within a decade Post Polio Syndrome was an acknowledged condition. But even today many doctors, physiotherapists and health professionals in New Zealand have low awareness of the condition, or are willing to consider it an issue when polio survivors mention it.

Ageing with Polio

Is there a difference when a person with a long-term disability such as polio ages, compared to a so-called 'normal' ageing person? I believe there are several factors which emphasise that difference.

There is an advantage of living a lifetime with some limits on mobility.

People with polio have learned to

figure out ways of doing things to help themselves as they age.

Many live with spouses who already accept that teamwork is necessary.

The spouse may already be carrying in the shopping, hanging up the laundry, loading a wheelchair into a vehicle, and parking closer to the doors of buildings.

A lifelong positive and 'can do' attitude continues to strengthen the polio survivor's resolve to enjoy life to the full and to find ways of doing just that.

But what happens when the abled bodied spouse becomes frail, or the polio person becomes ill?

Who does the running around then?

This is becoming a serious situation for the feisty polio person who has been able to control the environment in which they live. The 'fixer' is no longer able to fix the ageing or illness of their spouse or of themselves, and the once independent, stubborn and capable polio person is faced with asking for help.

For some this is the last straw.

All their life they have shunned help by saying "no, I can do it myself. I'm OK. I can manage, thank you."

Now they can no longer manage, but



who do they ask for help?

For some, their adult children are overseas or living far away. For others a gradual isolation creeps in as social connections lessen.

For many the information about available help isn't known.

Where to go for respite for the able bodied spouse, and how to put home care, shopping, cleaning, transport in place, is often not sought by the person with polio who is used to "managing just fine".

A suspicion and distrust of medical procedures and personnel still lingers for some polio survivors who have unpleasant memories of treatment decades ago.

The thought of having to go to hospital or face surgery is put off as long as possible.

The smells and sights of hospitals can sometimes trigger anxieties.

Because polio has largely gone from the national psyche, including the medical world, there can be some misunderstandings and confusion surrounding Post Polio Syndrome.

Often a health professional will assume a polio person has had a stroke, or that the affected limb doesn't have any feeling.

An assessor may overlook that a person with polio has made adjustments all their life and some suggested solutions may not work.

They can be reluctant to accept new ideas.

The need to listen is important.

In fact it can happen that the polio client is the one to educate the caregiver or health professional about their condition.

Or they give up and say few people understand about Post Polio Syndrome, so why bother?

Post Polio Syndrome

There are three main symptoms of Post Polio Syndrome.

Fatigue: Body fatigue, mind fatigue (brain fog), hitting the limit and not being able to continue in a physical or mental activity; energy is often recoverable by rest.

Weakness: Polio affected muscles become weak, with atrophy and decrease of muscle bulk, all of which eventually weaken the 'good' muscles that have compensated for decades.

Pain: New pain can be experienced

in muscles and joints. And there are other symptoms: difficulty swallowing, breathing, sleep apnea, headaches, emotional and depressive events (can be caused by flashbacks to the original polio), osteoporosis, weight gain as mobility challenges lead to a sedentary life style, and a variety of individual health issues.

A person with polio is also at risk of illnesses that come with the ageing process: diabetes, high blood pressure, cholesterol, and so on.

Ongoing Health Issues

Polio can complicate the treatment of many diseases. For example if exercise is recommended for weight reduction or osteoporosis, it takes a skilled therapist to put together a plan when the client has a fear of falling or uses sticks or a wheelchair for mobility.

Of the people with polio surveyed in 2010, 78% can walk. This translates to walking with crutches, back into callipers (once disdained), and again wearing sturdier shoes. For some, mobility requires a scooter, a wheelchair or a walker.

Regardless, there is a determination to keep the mobility gained so long ago.

While the outlook can feel bleak for some ageing polio survivors, it isn't the case for most. The driving desire to be included, participating and contributing members of society, to make a difference, to maintain mobility by any means, shows their capacity to cope and to enjoy life.

Polio NZ Inc

Twenty-four years ago the Post Polio Support Society of NZ Inc was established. In 2012 the name was changed to Polio NZ Inc to include all people who had polio as well as those who have Post Polio Syndrome. The Society is dedicated to offering support through its quarterly newsletters, pamphlets for health professionals about Post Polio Syndrome, 20 regional support groups, national conferences, its information line 0800 476 546, and its website, www.polio.org.nz



Edith Morris is the president of Polio NZ Inc and a well known disability advocate, writer, and radio personality. She lives in Hamilton.

Coral and Ted

We hope you enjoy **Judy Walker's** touching tribute to her parents and memories of supporting her Mum, who contracted polio as a newlywed in 1952.

This is a story about my parents.

My Dad played an integral role in the continued wellbeing of my Mum, who contracted polio in November 1952, seven months after they married.

Mum was whisked away and placed in isolation.

Dad wasn't allowed on public transport after visiting her, such was the general fear of this disease.

With no visitors, Mum felt sheer terror as to what was going to befall her, and fear of being half conscious, paralysed from the neck down, and not being able to breathe properly.

The iron lung was already in use!

Those were dark days.

Now the treatment: she started to exercise her arms, as she hated being manhandled.

Hours and hours of cruel treatment, forcing the paralysed limbs to move, was beyond endurance.

One nurse used to force Mum to bend across her body and touch her toes, a physical impossibility.

When she failed, which of course was every time, this woman used to push Mum's spine forward until she *did* bend.

Mum's screams used to fill the ward.

She couldn't get up and run away, she could only lie there and wait for her turn as the screams of others got louder and closer to her room.

This was how polio was treated at the time.

Then came a visit to the public hospital of a representative of the Duncan family, who were bringing a revolutionary treatment for polio to New Zealand, much frowned upon by the established medical community.

They only took the 'hopeless cases'.

Bill Bell and a lovely nurse trained in the Kenny treatment, Sister Vera Ellen, changed things, and Mum's healing began. Talk about right place, right time!

The Duncan Hospital changed everything and at last there was progress.

Staff were properly educated and treated their polio patients with dignity.

Mum had to teach her legs to move again, just like a baby.

All this time Dad was holding down a job and spending weekends wheeling Mum all over the hospital to give her a change of scenery.

Mum and Dad often talked of the day when staff held her up as he was approaching the Hospital to visit, and she 'staggered' into his arms as a surprise.

Of course I have only learned recently that despite all care she crashed onto the floor badly soon after.

Having their children presented its own challenges.

Medical staff anaesthetised Mum and pulled us out with forceps.

Ouch!

I love to tell my friends that I'm a miracle, as my parents didn't think they would be able to have a family at first.

Of course, being the eldest of three girls, it soon dawned on me that I had a role to play in supporting Mum, so I learned to cook, doing things step by step, running from the kitchen to the bedroom where Mum would be resting her legs.

Savoury mince was my speciality!

I also used to chop wood and mow the lawns from a young age, not to mention 'fetching and carrying'.

The saying in our house was "what's the matter, are you paralysed or something?"

This was a catchphrase at the Duncan Hospital, too, I discovered later.

Our life was pretty normal, though, and Mum was keen for us to participate in everything.

I can remember her (with a couple of library books, a flask, blankets and a hottie) waiting at the bottom of Mt Ruapehu while we climbed it, and went tramping or sliding on plastic bags in the snow.

We girls soon learned how to lift Mum and to help her in various ways. This was normal for us, although a fall often put Mum out of action for days afterwards.

I recall once we were in a department store and she was having difficulty as usual in the toilets.

When helping her in the bathroom, my sister and I would try to hold Mum up, saying stupid things and giggling



and being silly so as not to make her feel embarrassed. Who knows what the department store staff thought of the noise going on in the toilets? Who cares?

My Dad taught us to show affection and concern, to do our chores and, most importantly, he set the example of always being available to Mum for emotional support.

I think this is amazing as he came from a background which was lacking in this.

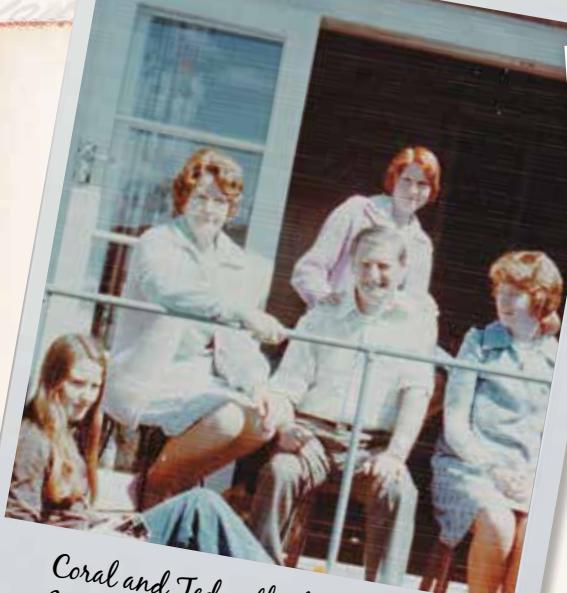
One of things my parents also taught by their example has been to adjust to your circumstances and do your best.

This is a hard thing to learn but necessary when life forces you to confront things you don't want to face.

After such a battle to gain mobility, which took months, it wasn't easy to when Mum lost it again after a 'normal life' for 30 years when she developed Post Polio Syndrome.

Mum was a redhead, and fought to stay as mobile as she could right up until she died in 2011.

We miss her, but we don't miss the pain and suffering and dependence of her final five years. Dad struggled with the large



Coral and Ted with their daughters Judy, Barbara, and Pauline.



gap left behind, but has coped very well (he is now 83).

Since Mum's death, a book has been published dedicated to the Duncan family who subsidised the polio hospital in Wanganui and where the Kenny treatment helped so many people.

Mum is not mentioned in *Otiwhiti Station* but was there when the hospital relocated to Wanganui, and was a patient of Bill Bell, whom she spoke of often with fondness.

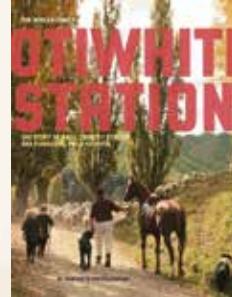
She was a fighter like most of the polio people, and considerably more disabled than many.

Mum had no balance so swimming, walking, stairs, and crowds (she was often knocked over) all required quite a balancing act. All this even though at 20 she was a netball rep for Rangitiki, a marching girl, and sports mad.

I know this story can be told over and over with disabled people and how they face their challenges head on.

But hey! This was my Mum, Coral, and of course she was an 'extra special' Mum and friend.

Judy and her husband Rob live in Rotorua. They also supported Rob's father, Cecil, who lived with them for many years until his recent death.



You'll find
Otiwhiti Station
at public libraries
and bookstores.

Judy's suggestions for family carers

- ✿ One thing my parents taught me was that you have to accept what you can't change.
- ✿ I never really knew what help was available and I was afraid to ask for it. This was a mistake. The cost has been high.
- ✿ Tell your doctor how things really are. I should have done this many years ago when I was supporting my father-in law, who lived with us until he died in July.
- ✿ Education about the condition you are dealing with is essential. You may be thinking the person you support is being difficult, but this might be due to their condition, or a side effect of pain or strong medications.
- ✿ A sense of humour is really hard to keep at times, but can diffuse embarrassment or awkwardness if it is appropriate.
- ✿ Accept all the help you can get. Join groups and forums with others in similar circumstances.
- ✿ Get out of the house as much as you can. If a friend offers to help, accept their 'relief care' for an hour or two and treat yourself to a normal activity like shopping or coffee. The person you support might love the change of company too, and if they don't, too bad! You need regular breaks and so do they, so you can manage for the long haul.
- ✿ Get as much support from family as possible, especially if you need some time away.
- ✿ Don't neglect your kids and grandkids. They need your love too. And, they give the best love and hugs ever!
- ✿ It's hard to show love when you're stressed, so you must look after yourself well. Your family member will benefit.
- ✿ Then there's the different challenge of helping to care for your spouse's parent. This can be stressful, as you may not know them well at first, or understand their thinking.
- ✿ Good communication between partners supporting elderly parents is therefore essential!
- ✿ Women tend to inherit these situations and they really need a supportive partner in order to cope with any challenges.
- ✿ Families of carers need to express their appreciation often to those providing intensive support. Good and supportive friends are great too.
- ✿ Reading *Family Care* and being part of helpful organisations will relieve stress as well. It does help to know you are not alone! FC