

we're still here!

Many New Zealanders who had polio in their younger years are living with the effects of Post Polio Syndrome in older age. By **Edith Morris**

I was six months old when I got polio in an epidemic sweeping the country.

My mother was 19 years old and living at home with her parents.

Her two teenage sisters were at school, and two young adult brothers were at work.

This was a three generation family with lots of coming and going, and polio in the house was devastating.

There was a social stigma surrounding the family, and for three weeks everyone was quarantined.

Isolation

The house was fumigated with sulphur.

Neighbours were in dread of 'catching it' off our family, and avoided contact.

Schools, swimming pools, theatres, sports events and church services were all closed for varying lengths of time during the epidemic peak.

Immediately after the diagnosis I was put in isolation for three months.

This meant no more breastfeeding from my mother, no cuddles from Granny, or piggybacks from my young uncles.

Isolation meant a 'nothingness', a separation which has left its emotional scars to this day.



My father was in New Guinea fighting in the War when I got polio. The bouncing, bonny baby he left behind was a floppy little rag doll on his return.

I was unable to move, and needed daily trips to the hospital for treatment and therapy.

Recovery

When I was 18 months old I was admitted to the beautiful Wilson Home for Crippled Children, where I stayed until I was about five years old.

I was institutionalised in paradise. Set high on the cliffs of Takapuna, the Wilson Home had sunny verandahs to lay the children on, and healthy, fresh sea breezes.

The big windows in the massage rooms were open most of the time.

Meals were taken outside in highchairs for the babies, and in beds wheeled outside for older children.

Schoolwork and play was done outside in the colourful garden

overlooking the sea.

Hydrotherapy treatment was in the damp basement pool, and then the little patients were again laid out for more therapy in the sun.

Culture shock

Skilled and caring nurses become like family over the years.

No matter how much my parents wanted to visit, they only came once a month from a long distance.

They were strangers to me, and when I was sent home ready to start school, 'outside' life was a culture shock.

I had sisters I didn't know, a mother I had never bonded with, and a father who was determined I was going to walk.

He diligently massaged my weak legs and stood me up every time I fell down.

To him I owe my stubborn streak.

As a child I came under the care of the Crippled Children's Society, as it was then known (but don't use those words now, will you!).

I attended regular school but didn't do well with my lessons.

CCS arranged for me to do extra classes, and I graduated from Seddon Memorial College with secretarial skills.

Global epidemic

I walked with leg braces and crutches, and didn't look like the usual young elegant office girl anyone would want to employ, and was told so.

This was in the 1960s; the Equal Employment Opportunity statutes didn't exist back then. Buildings didn't have ramps, and there were

no mobility parking places, or accessible anything.

CCS again helped, funding a car and driving lessons, and I became mobile.

I put polio behind me and got on with life.

Marriage, children, a career, and a life worth living followed; no matter that I still wore braces and walked funny.

Epidemics of polio raged through New Zealand. Early records show the initial major outbreak in 1914, epidemics in 1916, 1924-25, 1936-37, and 1947-48, with smaller outbreaks between these years.

Common experiences

Regular polio 'seasons' followed in 1952-53 and 1955-56. The last outbreak was in 1961.

Salk and Sabin's vaccine discovery brought a dramatic stop to epidemics in New Zealand as the mass immunisation campaigns began in the late 1950s.

But we are still here.

My story has similar elements to those of most people who had polio.

We are all in a time capsule of common experiences.

Paralysis, isolation, hospitalisation, years of rehabilitation, plaster casts, splints, hot blanket wraps, muscles being pulled and pounded, massages, water exercises, special shoes, braces, sticks, and crutches were all part of our early lives to some extent.



Survivors

Somewhere in the polio experience, an unusual personality trait was being nurtured in those who survived these epidemics.

We had come through the gruelling rehabilitation.

Our collective self-talk went something like this: "We must recover, we've got to pass for normal, we must make more effort than anyone else, we need to do 120 percent more than is required of us. If we achieve a lot more than others, maybe we will be considered normal."

The so-called A type personality that often marks polio survivors has become our own worst enemy.

We tried so hard (too hard) during



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our years of activity: school, sport, jobs, marriage, children.

Polio seemed to be behind us.

We didn't talk about our early struggles and we certainly didn't ask for help. Why should we?

We can cope, we can do it ourselves. Self-reliant, stubborn, and driven are some of the words used by many polio survivors.

I often say, "We are not victims of polio, we are survivors."

Once, a friend said, "It sounds like you've survived a war when you use that word."

That's it exactly!

What is it?

We have soldiered on regardless of exhaustion, weakness and pain.

We have dragged around our polio bodies on sticks to prop us up and braces to hold our legs, backs and necks upright.

By sheer determination and drive we have pushed ourselves to the limit.

But something's gotta give.

Around the mid 1980s, people with polio began to complain to their doctors and therapists that they were having strange new symptoms.

They said "we are so tired, we can't cope, we are falling over, we are in pain and we don't know what to do about it."

The usual answers were "you are just being lazy, do more exercise, you are getting old, it's all in your head, just buck yourself up".

New diagnosis

Polio survivors all around the world were experiencing similar problems. Already weakened muscles that had been overused for decades finally rebelled.

Slowly the medical world realised that these complaints had several things in common: new pain, new weakness, lack of stamina, and extreme fatigue.

These collective symptoms define Post Polio Syndrome, or The Late Effects of Polio.

In the initial epidemics it was roughly estimated that there were 10,000 people who had polio in New Zealand. As the decades have gone by it is unknown how many of these are still alive, and might now be affected by Post Polio Syndrome.

Support Society

We do know that those who are members of the Post Polio Support Society of New Zealand are only the tip of the iceberg.

Hundreds more who are living with pain, weakness and fatigue could be helped if our Society can locate them. We assist with information for their doctors, education about Post Polio Syndrome, and offers of encouragement from one of our

Philippa Werry's children's book *Enemy at the Gate* will appeal to all age groups. Published in 2008 and a Junior Fiction Finalist in the New Zealand Post Book Awards, it revisits the terrifying polio epidemic of 1936 through the eyes of a young boy as polio's shadow comes closer and closer to his Wellington community.

Who in the neighbourhood will get polio? How will everyone cope?

The story moves along at a steady pace, building curiosity right up to the last page.



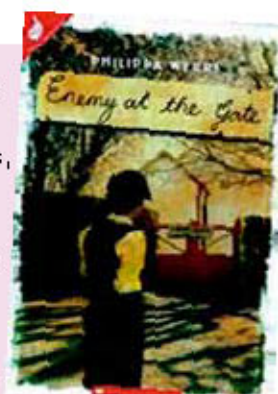
23 support groups throughout the country.

We share a common bond of being part of a unique time in history that has all but been forgotten in the nation's psyche.

Edith is the President of New Zealand's Post Polio Support Society, (0800) 476 546.

Above, Edith and her sister visit Auckland's Wilson Home, where Edith spent several childhood years recovering from polio.

Previous pages, Edith with medical staff at the Wilson Home, and other young polio survivors.



Philippa Werry has included historical events, and typical lifestyles and language of the time, to portray a truly New Zealand setting.

For most people polio is a forgotten disease, and this story subtly shows a new generation what it was like to live through that extraordinary time.

I can wholeheartedly recommend this book.

Reviewed by Edith Morris

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