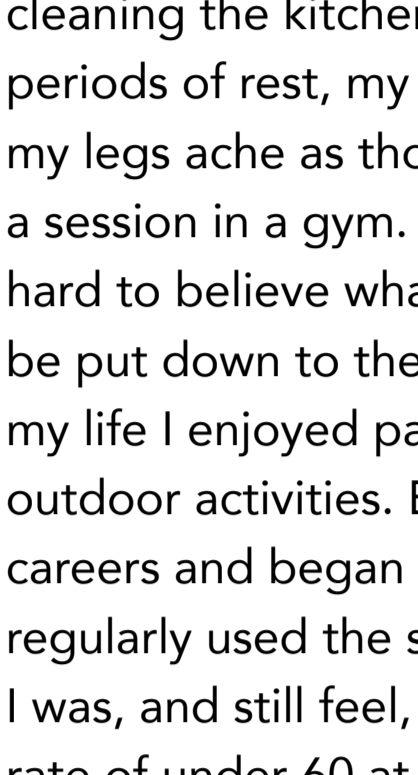




Living with Late Effects of Polio

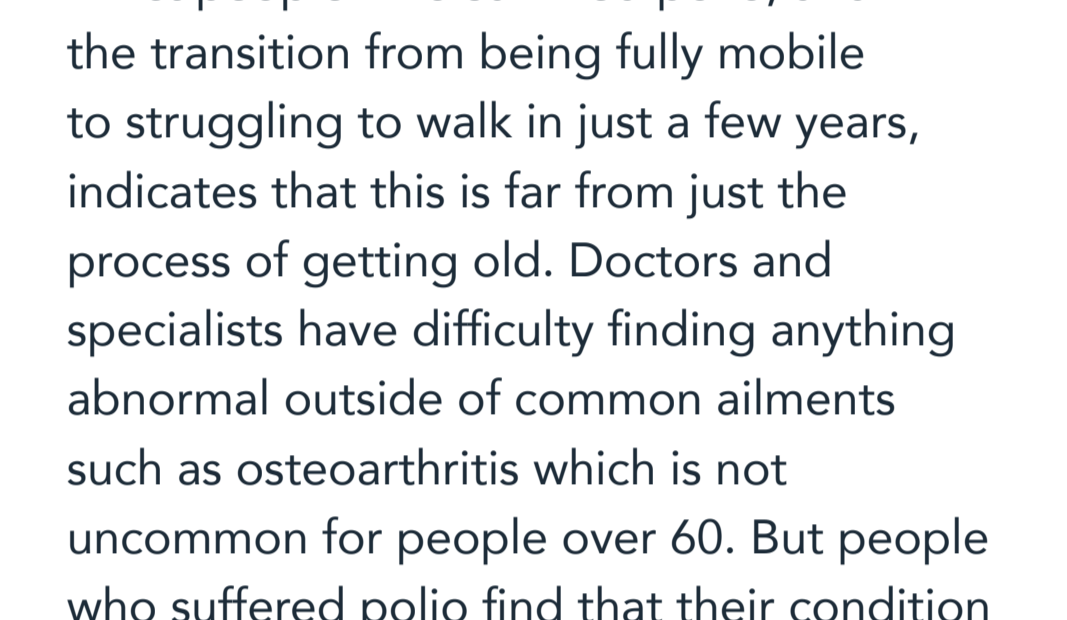


WRITTEN BY
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A personal account by Lonnard highlighting his experience of living with Polio.

It is 11 AM. I sit back in a lounge chair exhausted and in pain. There were no overly strenuous activities in my morning, just a short walk, making breakfast and cleaning the kitchen afterward. Even with periods of rest, my body feels listless and my legs ache as though I had just finished a session in a gym. In my early 60s, it is hard to believe what I experience can just be put down to the aging process. Most of my life I enjoyed participation in sports and outdoor activities. Even when I changed careers and began working in an office, I regularly used the stairs rather than the lift. I was, and still feel, fit with a regular pulse rate of under 60 at rest.

I contracted Polio as an infant, but apart from some weakness and atrophy on my left side, I thought as most Polio survivors do, that the worse was behind me. With no other obvious answers, I approached Polio New Zealand, who in turn, put me in contact with the Duncan Foundation who support people with neuromuscular conditions.



Through these associations I met many other Polio survivors, and the similarities in our stories are startling.

The speed in which the fatigue and pain inflict people who survived polio, and the transition from being fully mobile to struggling to walk in just a few years, indicates that this is far from just the process of getting old. Doctors and specialists have difficulty finding anything abnormal outside of common ailments such as osteoarthritis which is not uncommon for people over 60. But people who suffered polio find that their condition continues to deteriorate rapidly.

Most people who had contracted and recovered from Polio, looked forward to a healthy long life ahead. But for about 60% of Polio survivors, that reality changed dramatically. And we must accept that for us, this is life with the Late Effects of Polio (LEoP).

The most accepted explanation for the onset of LEoP is the overuse of the remaining motor neurons that were not destroyed by the Polio Virus. These remaining motor neurons sprouted new axons to reinnervate the orphaned muscles. Over time, the reinnervation no longer keeps pace with normal degeneration through aging.

There is no actual diagnosis for LEoP and therefore can only be determined by eliminating other possible causes.

Common Symptoms include:

- Chronic Fatigue
- Muscle weakness
- Pain
- Breathing and swallowing difficulties
- Interrupted sleep
- intolerance to cold temperatures

A number of these symptoms are experienced by many people going through the aging process, but for those who survived Polio, the onset is often more pronounced and at an earlier age than for the general population. Not all people living with LEoP experience the same symptoms. However, weakness and fatigue are two that we all generally share.

Fatigue is not tiredness. Everyone experiences sleepiness at some point through lack of sleep or lifestyle, but by changing sleep patterns this is most often managed. Fatigue on the other hand can never be alleviated by such changes. Fatigue is that feeling of body weariness beyond just being tired.

“**Fatigue is not tiredness**”



For my own experience, day-to-day activities like mowing the lawn and vacuuming would tire my legs and result in aching as if I had completed a training run after a six-month layoff. My arm muscles would also feel heavy, and my whole body feel weary. Most days I live with the feeling of pain and exhaustion beyond anything I experienced as an active sports person and outdoors person.

Managing fatigue requires a change in lifestyle and acceptance in the reality of what is happening to your bodies. For me, it involved hiring a contractor to mow my lawns, and have someone call regularly to clean and vacuum my house, to go for shorter walks and work from a home office to avoid the strains of commuting.

For me and others with LEoP, acceptance of how our lives have changed is probably the hardest part. For the thousands of us who thought Polio was a horror of our past, reality did not creep up on us, it ambushed us.

Polio New Zealand's Vision is that all people who have survived polio in New Zealand have affordable access to appropriate health care and the support required to maintain independence and make informed life choices.

www.polio.org.nz

