

My Polio Experience (Anonymously provided)

I am a 75-year-old woman. I had polio when I was 18 months old in the 1949 epidemic, before there was a vaccine. I don't remember getting ill or being in hospital.

I grew up with a paralysed left arm and a slightly impaired right leg. My parents were told to put my arm in a sling. When I was four, I had an operation on my leg and a doctor decided I should be strapped into a plastic support to hold my paralysed arm bent at the elbow. The support required many tedious trips to hospital for measuring and replacements when it got cracked or I grew. I hated it so much. It prevented me from doing all the things I wanted to do, which, at that age, was playing with dolls, dressing-up, clambering about on climbing frames in the park etc. Unknown to me, my parents were very concerned about how I'd cope at school while wearing the support. Nevertheless, the rule at home was, 'You must wear the support. Doctor says'. Fortunately, one day, when I was taken to hospital for a check-up, I saw a different doctor. He had the empathy to inquire about how I found the support. When my mother explained how obstructive it was, he surprised her by saying that its sole purpose was to help me. If it didn't help, I didn't need to wear it. We threw it in the bin and life improved no end. I started school able to join in everything.

At university, I used my experience to write my undergraduate dissertation on relationships with physically disabled people. This was long before anyone had thought about disability studies. There were few relevant texts to consult. I married, but sadly, was widowed. I was left with a two-year-old son. I brought him up on my own, became a teacher and later left teaching to work in the voluntary sector. In the 2000s I did a diploma in disability studies, which I enjoyed immensely and it gave me a fresh outlook and a knowledge base from which to campaign.

I always fell over occasionally, but thought nothing of it. By the time I reached my 50s, it seemed to me it happened more often. About 15 years ago, I found that I couldn't get up by myself when I fell. It has led to some difficult situations. I realised it must be post-polio syndrome. My walking had become a bit limited. Following several bouts of infection in my leg, originally due to an infected cut, I was sent to hospital for intravenous antibiotics. On leaving the hospital, I found I couldn't walk back to the car park. My GP sought the advice of a neurologist who said that the infection could be exacerbating the post-polio syndrome. It would probably get better on its own. It did improve a bit. Now I have had a number of recurrences of the infection and each time I'm left unable to walk as well as I could before. I use a stick and can only walk about 30 metres, with my leg getting imperceptibly weaker with every step. I have to be very careful. I have not found any references, in general information about post-polio syndrome, to infections having this effect.

I have been lucky enough to enjoy much good health. Of course, women need the services of health professionals even when they're well. As I get older I've had to consult health professionals more often. I continue to be surprised and disappointed by their attitudes. It is my experience that, whatever my reason for using health services, the professionals think that, without asking any questions about my circumstances, because I have an impairment, I must be 'informed' that I 'can't do' various tasks that I've been happily doing for over 70 years and, in the guise of 'helping', they actually make life more difficult for me.

So far, I've led a fulfilling life. In my retirement, I pursue my interest in politics, support community projects and campaign, particularly around equality and disability access.