

Book

Surviving polio with disabilities

In 1988—the year when a global drive for eradication of polio began thanks to the initiatives taken up by the World Health Assembly—350 000 children a year worldwide were paralysed for life by polio. According to WHO, one in 200 cases of polio resulted in irreversible paralysis, and, among paralysed patients, 5–10% died as a result of progressive immobilisation of their respiratory muscles. At that time, polio was endemic in 125 countries, and many children who ultimately survived the infection despite paralysis subsequently had substantial, lifelong disabilities, mostly affecting their legs.

Although the current global situation regarding polio has changed over the past three decades, eradication of the disease is proving much more difficult than expected. According to WHO, with global initiatives, the number of reported polio cases yearly has decreased by 99%, from 350 000 in 1988 to 22 in 2017. WHO reports that “More than 16 million people are able to walk today, who would otherwise have been paralysed. An estimated 1.5 million childhood deaths have been prevented, through the systematic administration of vitamin A during polio immunization activities”.

The global scenario relating to polio has improved. However, for most people who contracted the virus more than three decades ago and suffered disabilities as a consequence of the disease, life has been a struggle. In *A Certain Loneliness: A Memoir*, Sandra Gail Lambert—a survivor of polio who has fought lifelong against the disease—shares various aspects of her life, including her loneliness, and physical and mental challenges. The book is an engaging and honest memoir-in-essays that unfolds how Lambert, now 66 years old, grew up after having polio in childhood. The author also describes her struggles with isolation and independence as a survivor of poliomyelitis.

Although her adulthood was spent in various places throughout the USA, much of Lambert’s childhood was spent in Norway with her military family. She was fond of nature; when she was 6 years old, she loved the Norwegian forest down the hill from their house. During early childhood, she underwent two surgeries because of polio. In her memoirs, Lambert speaks of “the pain of the contraption put on [her] legs at night that was supposed to untwist [her] bones”. She also describes the social isolation that she faced as a survivor of polio, and her confusion about where to sit on the school bus and why no one sat with her.

The disabilities caused by polio can place many limitations upon an individual during their life. In her memoirs, Lambert talks about the agony caused by several

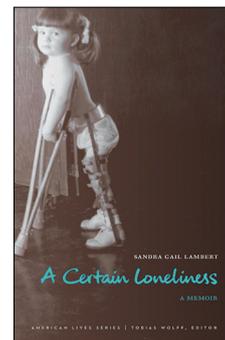
of these limitations, describing how she dealt with a life of uncertain tomorrows—with braces, crutches, and manual and powered wheelchairs. Lambert was told by doctors at a Norwegian military hospital that her spine was “too curved” to do exercise, and was put in a “plastic corset”. Doctors suggested that she should undergo surgery, as soon as her family were moved to the USA, “to insert steel rods”, followed by bed rest for 6 months. She also recalls advice from a doctor at a post-polio support group that she should not to do anything that leaves her with pain or muscular fatigue, or that results in a sense of weakness that persists for more than 10 minutes.

However, aside from describing polio-related disabilities and limitations, *A Certain Loneliness* also includes accounts of enjoying a life with disabilities. Lambert recalls taking her first plane journey in 20 years, on which she spent US\$2000; there was no good reason for the trip, she writes, except fun. When boarding the plane, she found that there was no difference between old-fashioned wheelchairs and the boarding chair for people with disability; so, to sit on the chair, she simply needed to slide from her wheelchair and perch on top of it. In another note, Lambert says, “Six hours of paddling and a chilly day for South Georgia mean the only reason I know my backside is there is because it always has been. I’m back in the Okefenokee, but I have my own kayak now. There was no one to stop me from getting out on the water, no one to caution me about the cold”.

Lambert’s writes, both frankly and intriguingly, of a love of nature, and of frustrations, challenges, and triumphs. As she approached 60 years of age, she says, the changes, rearrangements, and sorting-throughs of her life, which took place over several years, made her consider herself a learned and wise person. For her friends who do not have disabilities and are getting older, she has her “words to offer”; she cites examples from her life and offers solutions to her friends, advising on “learning the paradoxical dance of limitations that lead to new horizons and unexpected joys”. She writes, “I chirp with an unrelenting cheer about how my life has turned out”.

A Certain Loneliness explores various angles of the life of a person with disabilities due to poliomyelitis. The anecdotes expressed through various essays reflect the joys and sorrows of a polio survivor who handles the challenges of life despite the various hurdles attributed to the crippling disease. The book is a must-read, not only for polio survivors, but also for people with disabilities, health-care providers, and others.

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