

Caring & Planning for the Future

PPV made the decision to gather real and current data of the experience and future needs of those who are suffering from Post Polio Syndrome. We received 53% response rate from our members

A key finding is that our people have experienced isolation and loneliness from a young age. There has been a prevailing sense of having to work harder all their lives and now face uncertainty about future health needs - availability access support

Here's a summary of the survey results:



Contracted

- 89% were under the age of 10 when they contracted polio. 80% had paralytic polio requiring calipers and aids



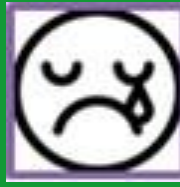
Hard work

- Most had to work harder all their lives to make up for their physical disability and high family expectations



Impact on family & friends

- People reported being socially isolated, unable to visit family due to accessibility issues or unable to participate in activities



Loneliness

- All experienced severe loneliness and isolation and were scared and confused. As were their parents who could not see them.



Treated differently

- Most were treated poorly or differently because they contracted polio before vaccination was available
- As disabled, couldn't secure work and some had to leave their profession as their health worsened



Greatest fears

- Worry about their future health needs and access to support, including funds to cover aids and assistance
- Being treated in the health system by people who no longer understand post polio symptoms

WHAT WE NEED IN THE FUTURE



More aids and assistance

- We are denied aids and assistance because of age
- most needs will not be funded adequately under My Aged Care



Access to NDIS regardless of age

- Most have struggled on without complaint and now extra help is needed but is not available
- "We got it very young, and it had nothing to do with age."



Medical knowledge

- we need improved professional understanding, knowledge and support :
- "They are ill-trained to assess my needs when I have had so many years running my own life as a disabled person."



Improved physical, emotional, social health

- Support needed includes knowledge of help, psychological support, and improved (health) services
- "Employment discrimination all my life, and now banned from the NDIS. I feel unfairly punished"

"Sadly, we are the forgotten people."