

## Congress of Older People's Voices from the Margins

This story was documented for the #Embolden2023 *Congress of Older People's Voices from the Margins*. A full report on Congress is available at [celebrateageing.com/margins](https://celebrateageing.com/margins)

Congress is an initiative of Celebrate Ageing Ltd. Thankyou to our 2023 Congress Principal Partner, Elder Rights Advocacy and our other partners, the Australian Government Department of Health and Aged Care, Older Person's Advocacy Network (OPAN), Australian Association of Gerontology, ADA Australia, The Older Women's Network NSW, QueerSpace Drummond St and Council on the Ageing.

### Polio survivors, by Shirley Glance OAM

President of Post Polio Victoria

Email: [shirley@postpoliovictoria.org.au](mailto:shirley@postpoliovictoria.org.au)

Web: <https://www.postpoliovictoria.org.au/>

My name is Shirley Glance and I am the President of Post Polio Victoria – I also am a Polio Survivor.

Poliomyelitis or Polio was one of the most feared diseases in the world, paralysing hundreds of thousands of children every year and causing permanent muscular damage. The epidemic peaked with around 70,000+ Australians diagnosed between the 1930s-1960s. Most Polio Survivors are now aged 50+.

Children diagnosed with Polio were told they didn't have a disability – or wouldn't have one unless we were lazy. There were few support services, so we just had to get on with living as best we could. People wanted Polio to go away – so we were taught to say nothing. We were silenced. We hid our disabilities and tried our best to live 'normal' lives.

But Polio didn't go away. Many Polio Survivors continue to live with symptoms and chronic conditions attributable to their original polio infection. Others can develop Post-Polio Syndrome 40 years after contracting Polio. This is a degenerative disease causing muscle weakness and atrophy, chronic fatigue, pain and respiratory problems, sensitivity to cold, difficulties with swallowing and poor sleep. It has a significant effect on overall health and wellbeing, and the capacity for older adults with PPS to age well.

Few Australians understand these legacies of Polio -and the voices of people ageing with Polio have not been heard.

After almost 60 years of silence, our voices are beginning to be heard. Our President is undertaking a Fellowship with Celebrate Ageing's Elder Leadership Academy to help promote Polio inclusive services and communities.

In 2021 the Australian Association of Gerontology supported a preconference workshop on Ageing with Post-Polio Syndrome and produced a paper from the workshop – and supported the development of three short films sharing the stories of Polio Survivors. We have entered an edited version into the Focus on Ability Film Festival because we want to be recognised as people living with disabilities and people who are ageing.

In 2013 one of our members Robyn Abrahams became a member of OPAN's National Older Person's Reference Group and we hope this will help make sure our voices are heard. We are also working on a learning module for Elder Rights Advocacy, Victoria to educate their advocates about outreach to Polio Survivors who find it difficult to ask for help.

Several of the current issues we have stem from the lack of recognition of Polio as a disability. This has meant that many Polio Survivors have not accessed NDIS because they don't have a disability. It has also meant that Polio Survivors are not accessing the supports they need to stay at home and are at risk of premature admission to residential aged care.

Service providers need to understand that we were hidden from the public and so were our disabilities. So many of us were not 'allowed' to have a disability – and so even though we walk with a frame or callipers we may not see what disability and aged care services have anything to offer us.

People are not aware of it because it has been eradicated but they forget the legacies polio has left behind and they need to advocate for polio inclusive communities and services.

What's one thing people can do now? We want you to watch our film and then go to the AAG webpage and download our preconference workshop report.

Workshop report: <https://www.aag.asn.au/Web/Stay-Informed/Latest-News-Articles/AAG-report-on-Post-Polio-Syndrome.aspx>