

Ageing with Post Polio Syndrome, Shirley Glance OAM

Fellowship with the Elder Leadership Academy

Title: Ageing with Post Polio Syndrome

Fellow: Shirley Glance OAM

Date: 2022 – 2023

Context

Between the 1930-1960 there were around 40,000 cases of polio in Australia. Many polio survivors have had a disability since childhood, were quarantined and isolated from family for long periods of time, were bullied at school and experienced workplace discrimination. Most are now older people.

It is estimated that a minimum of 20,000 – 40,000 people had paralytic polio in Australia between 1930s and 1960s. Actual figures for the number of people infected with the virus are up to a hundred times greater, **2 – 4 million** Australians. While polio no longer threatens Australian society today, it is not forgotten.

There is a misconception that Polio is 'gone'. In reality, most polio survivors experience Post Polio Syndrome (PPS), which includes weakness, fatigue, pain, temperature sensitivity, insomnia, swallowing disorders and muscle pain. These symptoms and the experiences of people living with PPS are not understood.

Furthermore, polio survivors were often told they would not have a disability unless they were lazy. Consequently, some survivors don't acknowledge their disability, don't access disability support services and are at risk of premature admission to residential aged care – because of their reluctance to access support services to stay at home.

In 2021, Shirley Glance OAM, President of Post Polio Victoria met with Celebrate Ageing to raise awareness of the experiences and needs of people living with PPS and to promote inclusive communities and services for people ageing with PPS.

Aims and objectives

The Fellowship aim is to build inclusive communities and services for people ageing with PPS by:

1. Documenting the experiences and needs of people with PPS
2. Document a model for inclusive communities and services

3. Engaging key services in listening to the voices of people living with PPS
4. Promoting inclusion of people living with PPS in key aged care sector policies, events and meetings.

Activities

1. Produced three short films documenting the experiences of people ageing with PPS
2. Delivered a pre conference workshop on Ageing with Post Polio Syndrome to the Australian Association of Gerontology (AAG) Conference in 2022 including:
 - Film message of welcome by Lady Marigold Southey AC and Kim Beazley AC, leader of the Australian Labor Party (ALP) and polio survivor
 - Presentations by polio survivors including Dr Peter Freckleton, Shirley Glance and Robyn Abrahams
 - Presentations by clinicians including: a medical rehab specialist, social worker, physiotherapist, neuromuscular orthotics, and an occupational therapist
 - 50 participants in the room, 20 online
3. Disseminated a media release to promote the pre-conference workshop
4. Worked with AAG to write up a policy paper from the conference
5. Produced a collection of speaker papers from the workshop
6. Became an Elder Rights Advocacy Ambassador
7. Made contact with OPAN to seek partnership opportunities

Outputs

- 200+ views from the three short films
- 1 preconference workshop
- 1 policy paper (in progress)
- 1 collection of papers (in progress)
- 70 workshop participants
- 1 Ambassador role
- 1 article in Australian Ageing Agenda:
<https://www.australianageingagenda.com.au/features/services-falling-short-say-polio-survivors/>
- 1 article in The Senior Newspaper
<https://www.thesenior.com.au/story/7990945/polio-crusaders-set-sights-on-ndis/>
- 1 article Aged Care news <https://agedcarenews.com.au/2022/11/18/forgotten-post-polio-syndrome-generation-front-and-centre-at-aag-conference-2022/>
- 1 forthcoming workshop with OPAN
- Elder Rights Advocacy ERA

Outcomes

- Increased awareness of the experiences of people ageing with PPS
- Increased links between Post Polio Victoria and State and National Aged Care Advocacy services

Links: tbc