

21st May 2018

Hundreds turn out for free public information session

'The Late Effects of Polio', hosted by Polio Australia's Clinical Health Educator, exercise physiologist Paul Cavendish, was held at Tea Tree Gully Library. As well as the expertise being shared during the presentations, many enjoyed the chance to meet with fellow members of the polio survivor community, exchange stories, and chat over a cup of tea.

The late effects of polio (LEoP) refers to the decline in function in later life by polio survivors, after a plateau period of improved function – sometimes of decades – that follows an acute episode of polio. Some survivors may be diagnosed with Post-Polio Syndrome (PPS) a neurological condition associated with significant decline in functional capacity.

More significantly compared to the general ageing population, polio survivors may experience a loss of motor units (polio survivors have fewer motor units available after their illness, so their bodies need to work harder to move); sarcopenia (a loss of muscle mass and function); reduced proprioception and coordination, creating a falls risk; and a decrease in respiration capacity (1.9% decrease per year for polio survivors, compared to 1.1% per year for the average population).

Pain, muscle weakness, post-exercise fatigue, cramps, joint pain, and heat and cold intolerance can also be experienced as late effects of polio. In addition, the revival of upsetting childhood memories relating to the disease, a sense of losing independence, and the prospect of returning to rehabilitation, can all have negative psychological impacts.

Compounding these factors is that some medical practitioners have limited understanding of LEoP, attributing these symptoms to simply ageing. Providing polio survivors with information about LEoP and the supports available to them within the medical system, and empowering them to share this knowledge with their medical team, was a key objective of this session.

Mr. Cavendish highlighted the benefits of learning to navigate the health system to identify potential avenues of support. "Seeking assistance can be challenging," he said, "but medical professionals have knowledge and skills that can help."

These avenues include:

- The National Disability Insurance Scheme (NDIS) – those under 65 years should register
- Aged care funding / My Aged Care – those over 65 years should register
- Private health insurance – ask your fund what is available
- GP Management Plans, including the Chronic Disease Management Plan and Mental Health Care Plan - funded by Medicare, these plans are coordinated by your GP so you can see other health professionals at a subsidised rate
- Rehabilitation physician interventions such as assessments of secondary medical conditions and management of conditions such as pain and fatigue in liaison with the GPs
- The Department of Veterans' Affairs
- Orthotists who provide more specialised treatment than podiatrists
- Dietitians for healthy weight management - extra weight means extra force needed for mobility, which puts extra strain on muscles
- Speech pathologists for speech and swallowing difficulties
- Occupational therapists for strategies to manage fatigue, considering planning, pacing and prioritising what you do with your day, and practising good sleep hygiene
- Aids and equipment.

Pain management, respiratory issues, musculoskeletal health, and orthopaedic management (including anaesthetic sensitivities) are also common medical considerations for those living with LEOp that can be improved with the support of an informed medical team who are prepared to identify suitable new methods and strategies.

Attendees were encouraged to explore the Health Professionals Register, compiled by Polio Australia and [accessible on its website](#), to locate health professionals who are experienced in and informed about treating polio survivors.

“Plan ahead and future-proof your life,” said Mr Cavendish, “even if you feel you don’t need this support now.”

Dr Nigel Quadros, Senior Medical Staff Specialist from the Department of Rehabilitation Medicine at the Queen Elizabeth Hospital, also presented during the session. He is currently undertaking a longitudinal research study, *Understanding the ‘polio survivor’ and promoting healthy ageing*, with his fellow principal investigators Dr Kandiah Umapathysivam (Dr Sivam) from the University of Adelaide, and Dr Anupam Datta Gupta from the QEH.

The study is non-invasive, measuring loss of muscle mass, strength and function of polio survivors aged over 65 years, on an annual basis. It is aimed at promoting understanding among the health professional community about the situation of polio survivors, and where necessary, develop models of care to assist polio survivors to age healthily.

This study will form the basis for the establishment a comprehensive registry of polio survivors, monitor their general health and medical status in a dedicated clinic to be established at The Queen Health Hospital.

Dr Quadros told the session that the key aspects of physical ageing experienced to greater extents by polio survivors compared to the general population, sarcopenia and frailty can be reduced by the right exercise plan, good nutrition, and falls prevention. Medication has been trialled but has not yet been proven effective.

To enquire about Dr Quadros’ study, please telephone (08) 8222 7322 or email nigel.quadros@sa.gov.au

Attendees were invited to ask questions of the presenters. These covered topics as diverse as non-disclosure of polio survival status to medical professionals, fatigue after exercise, lack of symptoms of LEOp in later life, medications that are contraindicated for polio survivors, and negotiating with medical teams about the level and type of anaesthetic provided during surgery.

The session presented a valuable opportunity for polio survivors to come together and share experiences and information with each other and the presenters, in the hope of improved outcomes for those living with LEOp. “You are all resourceful, independent people – but please don’t under-emphasise the situation,” Mr Cavendish concluded. “Find out what supports are available to you.”

Polio survivors are encouraged to join Polio SA, and direct their health professionals to the website to subscribe to updates about professional development workshops, clinical practice resources, and the latest research about polio: www.poliosa.org.au/health-professionals

ENDS

For further information, hi-res photos & interviews please contact:

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ABOUT POLIO SA:

Polio SA is a not for profit organisation operated by volunteers. All staff and members have had polio or have a family relative diagnosed with post-polio syndrome (PPS). PPS is the late effect of polio, usually occurring 20 to 40 years after the initial infection. Not all people who previously had polio will experience new symptoms.

Our aim is to:

- provide information about the late effects of polio and PPS to members and the greater community
- provide a supportive network through consultations, referrals and social gatherings, and
- ensure that Polio SA members are aware of their rights regarding their disability.

We provide the following services:

- mutual support through group meetings
- access to discounted health services including massage and hydrotherapy (see our website for details of current services)
- newsletters keeping members up to date with local and international developments
- access to a wide range of relevant information, and
- connecting people with similar interests.

Country groups previously there were polio support groups in rural South Australia, however to our knowledge these are no longer active. All Polio SA resources are available to our rural members, including books, fact sheets, past newsletters, and personal stories.