

2017 Committee:

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President's Report



We continue to advocate on behalf of the polio community with a particular focus so far this year on transport issues and polio services. Articles in this edition provide more detail.

Our ongoing meetings with Polio Services Victoria aim to ensure that the voices of clients are heard and are taken into account in the design, delivery and review of services.

In February 2016, St Vincent's published an online document "Anaesthesia & Surgery - A guide for people with a history of polio". We publish page 8, a questionnaire about your polio history. PPV advises polio survivors to complete copies for all their medical practitioners.

W.H.O has extended its warning of polio as epidemic. This reminds us of that the poliovirus is still a live issue while Post Polio continues to expend the health, financial and support resources of polio survivors, their families and their communities.

PPViews No.17 April 2017

Continuity of Support Program

This essential program is intended to assist people who are not eligible for the National disability insurance scheme because they are aged 65 years and over. They also need to have been receiving state or territory funded disability support packages.

The Continuity of Support program will be rolled out in stages across Australia as the NDIS is also rolled out. The dual rollout will continue over the next two years.

As with consumer directed funding, the continuity of support program will mean individuals will be allocated funding via an individual support grant. The grant can be managed through an existing service provider you currently use or through a financial intermediary of your choice. Some service providers may not be able to provide appropriate programs. In that case individuals can access support to find appropriate assistance.

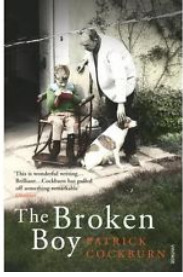
The importance of this is that people with substantial disabilities won't be pushed into aged care facilities. Although My Aged Care will provide much support to older people it is unable to provide the same number of hours of disability support as the state governments currently do.

Aids and equipment will not be funded under The Continuity of Support Program, unless you have been getting this as part of your state funded disability support package, however funding will still be available in Victoria under the State Wide Equipment Program.

People needing assistance Under the Continuity of Support Program will need to check that their current service provider

More information available about the dates and programs on this website <https://agedcare.health.gov.au/programs/commonwealth-continuity-of-support-programme/implementation>

Review of "The Broken Boy" By Patrick Cockburn



This autobiography is Patrick Cockburn's story about growing up with polio. He caught polio in September 1956. He was 6 years old, living with his family in County Cork, Northern Ireland. At the time polio was spreading

throughout Northern Europe, but unlike previous outbreaks this was uncurtailed, and unpredictable.

"The Broken Boy" took 17 years of research. It is based on recollections of patients and staff from hospitals where Cockburn was an inpatient, health records, announcements from Public Health Authorities and Public Institutions. He concludes that the 1956 polio epidemic was the longest in modern history. It overwhelmed health services. Public authorities were contradictory in their response, querulous in closing public places and publishing little about the numbers of patients admitted to hospital; perplexing for a time when the aetiology and the way the polio virus spread was well known, and trials of a successful vaccine had already taken place in the U.S.

Both Patrick's brothers caught polio. It was known to spread by contact during the incubation period; but hospitals refused to release the names of patients," to protect patient privacy and avoid panic."

Parliamentarians in London wanted to avoid the idea of a pandemic. The Irish regarded this as a particular form of British autocracy and censorship. The first published name of a British polio victim came from New Zealand. "A Dr A. McFarland, a twenty-six-year-old doctor from Belfast, had been on his way to take up a medical appointment aboard the liner "Rangitoto" when he was found to have caught polio." He died on board, and Cockburn concludes that "the local papers were happy to write detailed stories about victims of polio so long as they were struck down far from Ireland.

Chapter 14, the last, begins by Cockburn naming the first patients of the 1956 epidemic, and ends with polio having a legacy "more menacing than when it was finally brought under control in the 1950s and 1960s." Polio patients of forty years past, suddenly experienced muscle weakness and exhaustion. 'The motor neurons controlling a particular muscle for it

begin to lose its' strength." This is Post Polio Syndrome, "the return of old disabilities or the development of new ones."

"The Broken Boy" is a must read for Polio advocacy workers.

Susan Shaab

Extending Polio Warnings

WHO Committee Recommends Extension of Polio as Public Health Emergency of International Concern Feb 15, 2017

WHO

(<http://www.who.int/mediacentre/news/statements/2017/poliovirus-twelfth-ec/en/>): Twelfth meeting of the Emergency Committee under the International Health Regulations (2015) regarding the international spread of poliovirus "The twelfth meeting of the Emergency Committee (EC) under the International Health Regulations (2005) (IHR) regarding the international spread of poliovirus was convened via teleconference by the director general on 7 February 2017. ... The committee unanimously agreed that the international spread of poliovirus remains a Public Health Emergency of International Concern (PHEIC), and recommended the extension of the Temporary Recommendations for a further three months..." (2/13).

This seems to have followed 2 cases of polio last year in a war-torn region of Nigeria, a year after it was thought polio had been eradicated there. As a response to these new cases the Government announced that they would mass vaccinate 5 million children against polio.

****APPLY FOR YOUR CONCESSION BEFORE NEXT SUMMER****

Medical Cooling Concession

Fact sheet

Medical Cooling Concession

The Medical Cooling Concession provides a 17.5 per cent discount on summer electricity costs for cardholders where a member of the family has a medical condition that affects the body's ability to regulate temperature. This concession is available from 1 November to 30 April each year. The concession is given in addition to the Annual Electricity Concession.

Qualifying conditions include:

- multiple sclerosis
- lymphoedema
- Parkinson's disease
- fibromyalgia
- post-polio syndrome/poliomyelitis
- motor neurone disease.

Applications for other conditions must be approved by the Department of Health & Human Services.

To be eligible cardholders must hold one of the following cards:

- Pensioner Concession Card
- Health Care Card
- Veterans' Affairs Gold Card.

How to apply

Phone your electricity retailer for an application form or contact the Concessions Information Line on 1800 658 521 (toll free).

The application form needs to be completed and signed by your doctor confirming your medical condition. If your condition is one of the pre-approved conditions, forward the form to your electricity retailer. For any other condition, forward your form to the Department of Health & Human Services for assessment.

Your electricity retailer will check your concession card details with Centrelink and apply the discount to your bill.

More information

For help in your language call the Concessions Information Line on 1800 658 521 (toll free) and ask to speak to an interpreter.

For more information contact the Concessions Information Line on 1800 658 521 (toll free) or visit www.dhs.vic.gov.au/concessions

Polio Australia

Improving health outcomes for Australia's polio survivors

The Late Effects of Polio: Do you know the signs?

Pathophysiology of the Late Effects of Polio (LEoP)

Acute poliomyelitis (polio, also known as 'infantile paralysis') is a viral infection affecting the nervous system. It can infect both the central and the peripheral nervous system, but the most common infection is in the anterior motor horn cells, resulting in flaccid paresis of the muscles. This can present as a widely variable distribution of weakness in skeletal and bulbar musculature, with residual impairment and paralysis ranging from minor muscle weakness to total paralysis requiring intervention such as ventilation.

After motor-neuron destruction during the acute polio phase, surviving motor units sprout axons to reinnervate the denervated or 'orphaned' muscle fibres. This process of denervation and reinnervation is ongoing over the muscle lifespan. As a consequence, polio-affected muscles have oversized motor units and increased muscle-fibre density. It is thought that these large motor units result in increased weakness as they 'drop out' due to ageing and/or overuse. Due to this process, people with LEoP may have experienced a prolonged period of stability of physical symptoms such as weakness and pain, often lasting several decades, before presenting to their primary care provider with what can feel like a resurgence of polio-like symptoms.

LEoP can present as a unique cluster of biomechanical and/or neurologic features in each individual, which can be moderated if properly assessed and managed. The LEoP are essentially a 'diagnosis of exclusion', but should be considered for clients/patients who are known to have had polio themselves — or other members of their family (which may indicate undiagnosed sub-clinical damage). The LEoP refer to any of the following features.

Musculoskeletal features

- Decreased muscle endurance and muscle fatigue
- Overuse of compensatory muscle groups
- Muscle pain and/or spasms
- Joint pain and/or degeneration such as arthritis
- Biomechanical deformity such as kypho-scoliosis
- Muscle contracture
- Osteopenia or osteoporosis

Neurological features

- New muscle weakness
- Muscle atrophy
- Preservation of sensation irrespective of muscle loss
- Muscle twitching/fasciculation
- Compression neuropathy

Respiratory features

- Shortness of breath due to chest deformities
- Respiratory insufficiency due to sleep apnoea
- Weakening respiratory muscles
- Hypoventilation due to early damage to the respiratory control centre

Bulbar features

- Impaired thermoregulation
- Dysphagia/swallowing problems
- Dysphonia/vocal dysfunction
- Dysarthria/unclear speech
- Chronic fatigue, headaches, poor concentration

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The Late Effects of Polio: General Information

Additional considerations

- Biomechanical problems
- Bladder dysfunction
- Weight gain due to decreased mobility
- Oedema
- Psychosocial concerns due to increasing disability
- Pre and post-planning for surgical procedures

Comorbidities

- Cardiovascular disease
- Endocrine and metabolic diseases
- Chronic pulmonary disease
- Hip and limb fractures due to falls

Supporting factors

- Actual or suspected history of poliomyelitis
- A period of partial or complete functional recovery after acute infection, followed by an interval of stable neurologic function
- Symptoms persist for at least a year
- Exclusion of other neurologic, medical and orthopaedic problems

Factors NOT supportive of the LEOp condition

- Resting tremour of limbs or head
- Worsening peripheral neuropathy
- Dizziness or vertigo
- Numbness
- Problems with sensory organs
- Primary altered sensation

LEoP Health Team

- General Practitioner
- Rehabilitation Specialist
- Neurologist
- Physiotherapist / Occupational Therapist
- Orthotist / Podiatrist
- Respiratory / Sleep Specialist
- Speech Pathologist
- Dietitian / Nutritionist
- Osteopath / Massage Therapist
- Psychologist / Social Worker

More information

Polio Australia's www.poliohealth.org.au website contains resources for health professionals including clinical practice publications, post-polio research papers, and the Health Professionals Register for referral or further consultation.

Contact Polio Australia:

PO Box 500, Kew East, Victoria, 3102
Email: office@polioaustralia.org.au
Phone: 03 9016 7678

Name: _____

Date of Birth: ____ / ____ / ____

Information about my Polio History

This form provides some information regarding how polio affected me in the acute stages and some information about how it affects me now - including my current abilities.

For further information about polio in general, please contact Polio Services Victoria on

03 9231 3900 or 1800 030 324 or psv@svha.org.au.



**POLIO
SERVICES
VICTORIA**

**ST VINCENT'S
HOSPITAL
MELBOURNE**

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

THEN	Acute Phase	I contracted polio when I was _____ years old. I was living in _____ (location) at the time.
		I was hospitalised / treated at home* for _____ weeks / months / years*
		I needed to be fed through a tube in the initial stages: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
		I was on a ventilator (iron lung/tank): <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
Rehab	Regions of my body that were affected during the acute phase of polio infection:	<input type="checkbox"/> Right arm <input type="checkbox"/> Left arm <input type="checkbox"/> Right leg <input type="checkbox"/> Left leg <input type="checkbox"/> Trunk (spine or abdomen)
		I finished rehabilitation in _____ (year).
		After rehabilitation, I was still had weak muscles (or paralysis) in my:
		<input type="checkbox"/> Right arm <input type="checkbox"/> Left arm <input type="checkbox"/> Right leg <input type="checkbox"/> Left leg <input type="checkbox"/> Trunk (spine or abdomen)

Today I have weakness in these areas of my body:

☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg ☐ Trunk (spine or abdomen)

At the moment I experience the following complications from polio:

☐ Respiratory/breathing problems ☐ Weakness ☐ Pain ☐ Cold intolerance

☐ Swallowing difficulties ☐ Fatigue ☐ Sleeping issues ☐ Urinary problems

☐ Falls/near-misses ☐ Sleep apnoea ☐ Bowel problems

I also struggle with these related issues:

☐ Stress/hopefulness ☐ Weight control ☐ Exercise tolerance ☐ Other:

☐ I have required **respiratory review** in the past. My Respiratory specialist is: _____

I use the following equipment / aids / orthoses:

☐ CPAP machine ☐ AFO (short calliper) ☐ Walking stick ☐ Manual wheelchair

☐ BiPAP machine ☐ KAFO (long calliper) ☐ Crutches ☐ Powered wheelchair

☐ Hoist ☐ Modified footwear ☐ Frame/walker ☐ Other:

☐ Transfer board ☐ Other orthosis/brace:

I am able to walk _____ metres **OR** _____ minutes before needing to stop.

My walking is limited by: ☐ Weakness ☐ Breathlessness ☐ Other:

☐ Fatigue ☐ Pain

My ability to perform the following tasks / activities:

Task:	Independently capable	Supervision required	Assistance required	Equipment needed
Transfer on/off bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transfer on/off chair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transfer on/off toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Showering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

I live in a: ☐ House ☐ Flat ☐ Supported Accom. ☐ Homeless

☐ Unit ☐ Public housing ☐ Aged care facility ☐ Rooming house

I live with: ☐ Family ☐ Others ☐ Alone

I receive support at home with: ☐ Personal care ☐ Cleaning ☐ Other:

There are _____ steps at home. ☐ Rails located at the steps ☐ Ramp access available

I have had the following modifications performed to my home environment:

Update on our meetings with Polio Services

Two meetings between PSV, represented by Manager Allied Health and Community Programs, Kathryn Bailey and Coordinator Claire Formby, and polio community representatives from Bayside Support Group, PPV and PNV - Liz Telford, Margaret Cooper, Ron Exiner, Peter Willcocks, Bev Watson and Mary-Ann Leithoff from Polio Australia have taken place. This is the key consultation for PSV.

These meetings focus on service issues, discuss feedback and the feedback process for clients with the overall aim to improve the experience of clients attending the service as well as the process of giving feedback.

The concept of patient-centred health care, care that is responsive to the needs and wishes of the patient and treats the patient with dignity underpins our discussions.

Over the years many people have spoken with PPV about their experiences with PSV, both positive and negative. Some have asked us to pass on the feedback for them, others have been concerned about this impacting on funding. At these meetings these stories have been discussed in a constructive process of examining what makes for a good health service experience.

Client feedback is necessary to improve any health service. PSV funding will not be withdrawn because of concerns raised by users of the service. If you have concerns or suggestions about how the service could be improved, it would be great if you provided them. You can contact the Coordinator Claire Formby, or contact us if you prefer.

If you would like to know more, or to discuss these meetings contact PPV.

Standing together against transport cuts

Some changes to the mobility allowance and multi purpose taxi programs have been suggested, although it is as yet unclear what is being proposed. PPV has contacted Ministers to argue the case that people with disabilities need more support with transport not less, whether they receive the NDIS or not.

PPV is concerned both for members who are getting older, while living with post polio syndrome, and a younger immigrant group who have had little or no treatment in their home countries where polio has not been eradicated.



Those who have survived polio, with some paralysis, have to face life with disability. Every day the individual with full or partial paralysis has to use all her/his strength to get through all the ordinary tasks of life. We are not alone in fighting these cuts.

Below is an excerpt from the People With Disabilities Australia media release. (PPV is a member of PWDA).

"Over 25 different groups, from across Australia, are united in opposing these cuts to vital transport funding for people with disability," said Ms Samantha French, Advocacy Projects Manager, People with Disability Australia and representative of DPO Australia.

"The Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016 will restrict access to transport funding to only those eligible for the National Disability Insurance Scheme (NDIS). There are approximately two million people with disability of working age, but only 460,000 will be transitioning to the NDIS. This means that this Bill will impact many people with disability who will not have access to the NDIS, including people over the age of 65.

"People with disability need more access to transport, not less. Until the Government can provide a public transport system that is accessible for all people, transport support for people with disability who are forced to use other means is essential. The current allowance should be increased, not cut as this Bill proposes."

The full joint statement is [available on the PWDA website](#).