

Issue 130
Winter 2018

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From the President

Wow, what a great turn-out at the Late Effect of Polio (LEoP) Information Session at the Tea Tree Gully City Library. There were over 120 members, friends and most importantly new members in the meeting; listening to Paul Cavendish tell us all about our life with the LEoP.

Paul was able to cover a very broad range of subjects, at least some of which affect all of us Post Polios. Discussing how ageing and LEoP can be a very debilitating combination, but how with help and information from Polio Australia and Polio SA improvements in lifestyle are possible. All in all, a very successful afternoon. I must extend my gratitude to all Committee Members of Polio SA for conducting this information session in a professional way and apologise for my lack of attendance, thank you all.

While speaking about successful functions I would like to remind you all that the Polio Australia Wellness Retreat will be held from the 11th-14th October 2018 in the Stamford Grand Hotel in Glenelg. As part of the program a "Walk With Me" event will be held on Thursday 11th October at 3:00pm and finish at approximately 5:00pm, we will be walking along the Glenelg Foreshore. We will be looking for sponsors and walkers to take part in this event, if you are interested please contact me. Every little bit you can do will help make this another successful occasion for Polio Survivors in South Australia.

Brett Howard, President, Polio SA
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Polio SA

*The post-polio support group
for South Australians*

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Hilton SA 5033
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- 📌 poliosouthaustralia

Save the date – Annual General Meeting

All members are warmly invited to attend this year's Polio SA Annual General Meeting.

When: 1pm, Sunday 19 August 2018

Location: 302 South Road, Hilton

Please bring a small plate of food and join us for afternoon tea following the meeting. Tea and coffee will be provided.



Disclaimer: Polio SA Inc. assumes no responsibility for any treatment undertaken by readers of this newsletter. Any advice, either explicit, or implied is not intended to replace qualified medical advice.

Letters of general interest will be published in future issues as space permits. We reserve the right to edit all letters for reasons of space and clarity. We will withhold your name upon request, but no unsigned letters will be accepted for publication. Opinions expressed in letters do not necessarily reflect the views of Polio SA Inc.

Polio SA inc. does not express or imply endorsement of physicians, products, seminars or services that are mentioned in this newsletter. They are mentioned simply as a public service to polio survivors and those interested in them. Articles do not necessarily reflect the views or policy of Polio SA Inc.

Hundreds Of People Attend Late Effects of Polio Information Session

A wealth of information about the physiological and psychosocial experiences of polio survivors later in life, and available supports and strategies, was shared at a free, public information session on the afternoon of Saturday 12 May in Adelaide.

'The Late Effects of Polio', hosted by Polio Australia's NSW Clinical Health Educator, exercise physiologist Paul Cavendish, was held at Tea Tree Gully Library and attended by more than 120 people. As well as the expertise being shared during the presentations, many enjoyed the chance to meet with fellow members of the polio survivor community, and chat over a cup of tea.

We all know that the late effects of polio (LEoP) can include pain, muscle weakness, post-exercise fatigue, cramps, joint pain, and heat and cold intolerance. 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. LEoP affects up to 40% of polio survivors.

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.



NSW Clinical Health Educator Paul Cavendish (left) with Dr Nigel Quadros (right), Senior Medical Staff Specialist from the Department of Rehabilitation at the Queen Elizabeth Hospital.

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 Umamathysivam (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.

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. Attendees also took the opportunity to become members of Polio SA and take advantage of the \$15 membership, accessing free weekly hydrotherapy (valued at \$50 per week) and 12 free massage session (valued at \$40 each). If you were unable to attend or attended but didn’t complete a form, you can become a member by visiting the Polio SA website.

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.”

Newsletter contributions

Do you have a story to share? Write a letter to the editor.

Articles can be sent to us via email or post.

✉ poliosa.office@gmail.com

📍 The editor, Polio SA, 302 South Road, Hilton SA 5033

Articles for the next issue are due by 1 August 2018.

Polio SA Inc office

We love hearing from our members. Whether you have post-polio symptoms or if you require information, call us on:

☎ 0466 893 402

Please keep in mind that our office hours are currently unpredictable. If you wish to visit our office, please telephone ahead. Our office phone is redirected to a committee member.

Summary of Anaesthesia Issues For The Post-Polio Patient

by Selma H. Calmes, MD, Chairman and Professor, (retired) Department of Anesthesiology, Olive View-UCLA Medical Center, Sylmar, California

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anaesthesia care. No study of polio patients having anaesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.
4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anaesthesia at the incision plus PCA, etc.) helps.
5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anaesthetics are given.



6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.
7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralysed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.
8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

For more info: Review "Postpolio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of Anesthesiology (Vol.103, No.3, pp 638-644). This article reviews polio, postpolio syndrome and anesthetic considerations for this patient population.

Article first published:
<http://post-polio.org/edu/hpros/sum-anes.html>

How A House Sale Sign Helped Me Play Golf *by Graham Daish*

I was stricken with infantile paralysis (polio) at the age of two and had my last tendon stretching operation at about eleven, after that I tried to forget about it and get on with my life.

About five years ago I started to collapse forward and realized that the time had arrived when I needed some support in walking.

I first paid for a brace to be made for me but it was not successful, so decided to have a go at making one myself.

This, of course was all new to me so it was a matter of starting from scratch.

My first attempt was made from an old metal "House Sale" sign. When finished and painted black it looked terrific and was a tremendous help in walking. Unfortunately it suffered constantly from metal fatigue and became heavier with the required additional strengthening. So I arranged for another brace to be made for me from another source, however I was informed it would take some time because they were very busy and short staffed.

So in the mean time I continued to refine and use my home made brace. The result after quite a number of modifications was, I thought, quite good. It weighs around a kilo and is now constructed of stainless steel. I made the knee joint adjustable so that I could keep the angle up to just behind the falling forward stage. The lower pressure pad is behind the non-existent calf muscles and the pad above the knee is at the front of the barely existent thigh muscles. I drilled holes in the pads to vent the heat and lighten them, and also pivoted them in the centre so they maintained even pressure over the whole area. I had found that when they were in a fixed position it was extremely hard to stop pressure being exerted on the top or bottom of the pad. I can honestly say that in the years I wore it I never had a pressure sore, and that includes playing eighteen holes of golf each week. The ankle joint is flexible and the foot section fits all of the shoes I wear, including my golf shoes.

The main problems were still maintenance issues due to my lack of understanding of the materials used, lack of access to suitable screws and fittings, and my constant effort to reduce the weight which contributed to a few structural failures along the way. One little refinement I am very proud of is my guard over the knee joint to stop my trousers being caught in it and being ruined when walking and sitting.

The new brace being made for me was finally completed after three years so I changed over to that and I have been using it now for a number of months. It is extremely well made and is constructed from the new materials available and moulded on a cast of my leg.

I suppose one needs to actually wear a brace for some time to really understand the problems that are faced, and I found that I needed to make a few changes to it to improve its comfort and usability. I have no criticism at all of the makers, it seems a very well-constructed item, but I think that the positioning of the top pad on the back of the leg is not as comfortable for me and doesn't allow the knee to fully bend to the squatting position. It can also give the wearer a painful pinch on the back of the leg when sitting on a chair. The fixed pads also make it hard to avoid pressure points and I have had to put extra padding in a number of places. There wasn't any adjustment at the knee joint so I inserted wedges to stop the knee going back too far, and also a guard to stop my trousers being pinched. I didn't take it back to the manufacturer for alteration because they are so busy with more worthwhile cases and my wacky ideas might seem a slight on their achievement. They were very helpful when I was making my own brace, so I am extremely grateful to them.

My old brace is at present in pieces on the work bench awaiting more modifications. Because my leg has shrunk even more I am considering constructing a standard brace with straighter side struts that are adjustable between knee and ankle. The pads will still be free floating and will be moulded to the shape of the leg. This means that when my leg shrinks even more I only have to modify the pad and not have the whole brace remade. I enjoy tinkering in my workshop, but with many other interests it may take some time to get around to the modifications. I also read about new innovations, such as robotic contraptions coming on to the market! And dream that one day I will be able to try one and compete in a Marathon! Of course, at seventy eight this is very much wishful thinking, but it doesn't hurt to dream does it.

I hope other brace wearers find my article of interest

Polio SA – Subscription Renewal Form

(due on July 1st for 2018/19 membership)



Annual subscription cost

\$15 Individual Member / \$20 Member and Carer / \$20 Organisation

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Please sign below to meet Government Privacy Act Requirements.

I consent to Polio SA Inc. retaining the above details until I cease to be a member of this group.

Signature required: _____

Methods to Pay for subscriptions

1. Personal cheque made out to Polio SA Inc. to accompany this form.
2. Postal order made out to Polio SA Inc. to accompany this form.
3. Bank Transfer at your local branch or on the internet (subscription form must still be returned)

BSB Number: 105-084

Account Number: 326443840

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I have enclosed a subscription of \$_____ I have enclosed a donation of \$_____

Please post this form to: Polio SA - 302 South Rd, HILTON SA 5033

NOTE: No receipt will be issued unless requested and self-addressed stamped envelope is enclosed.

Let's face it - English is a crazy language.



There is no egg in eggplant, nor ham in hamburger; neither apple nor pine in pineapple. English muffins weren't invented in England or French fries in France. Sweetmeats are candies while sweetbreads, which aren't sweet, are meat. We take English for granted. But if we explore its paradoxes, we find that quicksand can work slowly, boxing rings are square and a guinea pig is neither from Guinea nor is it a pig.

And why is it that writers write but fingers don't fing, grocers don't groce and hammers don't ham? If the plural of tooth is teeth, why isn't the plural of booth, beeth? One goose, 2 geese. So one moose, 2 meese? One index, 2 indices? Doesn't it seem crazy that you can make amends but not one amend? If you have a bunch of odds and ends and get rid of all but one of them, what do you call it?

If teachers taught, why didn't preachers praught? If a vegetarian eats vegetables, what does a humanitarian eat?

Sometimes I think all the English speakers should be committed to an asylum for the verbally insane. In what language do people recite at a play and play at a recital? Ship by truck and send cargo by ship? Have noses that run and feet that smell? How can a slim chance and a fat chance be the same, while a wise man and a wise guy are opposites?

You have to marvel at the unique lunacy of a language in which your house can burn up as it burns down, in which you fill in a form by filling it out and in which, an alarm goes off by going on.

English was invented by people, not computers, and it reflects the creativity of the human race, which, of course, is not a race at all. That is why, when the stars are out, they are visible, but when the lights are out, they are invisible.

Funny signs from around the world

Cocktail lounge, Norway:

LADIES ARE REQUESTED
NOT TO HAVE CHILDREN
IN THE BAR.

Doctor's office, Rome:

SPECIALIST IN WOMEN AND
OTHER DISEASES.

Dry cleaners, Bangkok:

DROP YOUR TROUSERS HERE
FOR THE BEST RESULTS.

A Nairobi restaurant:

CUSTOMERS, WHO FIND OUR
WAITRESSES RUDE, OUGHT
TO SEE THE MANAGER.

On the main road to Mombasa:

TAKE NOTICE: WHEN THIS
SIGN IS UNDER WATER, THIS
ROAD IS IMPASSABLE.

On a poster at Kencom:

ARE YOU AN ADULT THAT
CANNOT READ?
IF SO, WE CAN HELP

In a city restaurant:

OPEN SEVEN DAYS A WEEK
AND WEEKENDS.

In a cemetery:

PERSONS ARE PROHIBITED
FROM PICKING FLOWERS,
FROM ANY BUT THEIR OWN
GRAVES.

Location unknown:

"TO DO IS TO BE" - Nietzsche
"TO BE IS TO DO" - Kant
"DO BE DO BE DO" - Sinatra

Polio Australia

Representing polio survivors throughout Australia



Polio Health and Wellness Retreat

Body / Mind / Spirit

Stamford Grand in Glenelg, South Australia

Thursday 11, Friday 12, Saturday 13 and Sunday 14 October 2018

Expression of Interest Only

Polio Australia will once again be facilitating its 4 day / 3 night Polio Health and Wellness Retreat for polio survivors and their partners/family members from Thursday 11 to Sunday 14 October, 2018 in beautiful Glenelg, South Australia. The holistic 'Body / Mind / Spirit' theme will continue and may include sessions such as:

- ◆ Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- ◆ Hydrotherapy and exercise options
- ◆ Latest orthotics, aids and equipment displays
- ◆ Seated Yoga and Meditation Sessions
- ◆ Activities To Keep The Mind Active
- ◆ Creative Workshops

See details of previous retreats at www.polioaustralia.org.au/retreat-2017/

Polio Australia's Health and Wellness Retreat

11th—14th October 2018

Approx. cost of registration fees for 3 nights accommodation, all meals and most activities \$450 pp double and twin / \$500 single.

Mix of ocean-view and mountain-view rooms available. All fees yet to be confirmed.

Please provide me with more information on the Polio Health & Wellness Retreat when available.

Name: _____

Address: _____

Phone/s: _____ **Email:** _____

Return to: Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or
Email: office@polioaustralia.org.au

Member Services

If you are interested in any of these services, ring our office on 0466 893 402 and ask for vouchers. There is a limit of twelve vouchers per person, each with a maximum value of \$40.



Remember you must be a paid up member to receive vouchers.

City

PhysioXtra

115-117 Pirie Street,
Adelaide SA 5000
Phone: (08) 7221 9110

Eastern suburbs and Hills

TOORAK GARDENS

The Physio Clinic

Godfree House,
2 Moore St, Toorak
Gardens SA 5065
Phone: (08) 8342 1233

NORWOOD

PhysioXtra

Suite 1/39 Clarke Street,
Norwood SA 5067
Phone: (08) 7221 9289

PhysioXtra

110 Magill Road,
Norwood SA 5067
Phone: (08) 8331 7586

NAIRNE

John Kirkwood Polio Practitioner

17 Carmen Court
Nairne SA 5252
Phone: 0410 779 159

Nothorn suburbs

PROSPECT

The Physio Clinic

177 Prospect Road
Prospect SA 5082
Phone: (08) 8342 1233

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Aromatherapy, Foot
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Mobile: 0409 097 080
Phone: (08) 8390 1206

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Golden Grove SA 5125
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Fax: (08) 8289 1255

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handicapped person.

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MARION

PhysioXtra

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Marion SA 5043
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Morphett Vale SA 5162
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Centre Complex,
Reynella SA 5161
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160 Unley Road,
Unley SA 5061
Phone: (08) 8373 2132
Car parking off Mary Street
is accessible. Facilities
include a disabled toilet
and wheelchair access.

WOODCROFT

Bruce Harrison

14 New England Drive
Woodcroft SA 5162

Mobile: 0402 337 382
bruce_harrison@aapt.net.au

Western suburbs

HENLEY BEACH

Lori Brittle – Massage Therapist, Pilates & Physiotherapy

506 Henley Beach Road
Fulham SA 5024
Phone: (08) 8356 1000

WOODVILLE SOUTH

The Physio Clinic

2/95 Findon Road
Woodville South SA 5011
Phone: (08) 8342 1233

Outer metro

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Physio-Wise

Phone: (08) 8522 6611
Australian Physiotherapy
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LYNDOCH

Physio-Wise

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Change of address

If you have changed your address recently, please fill out the following and mail to the office at:

**Secretary
Polio SA
302 South Road,
Hilton SA 5033**

Please supply your email address if you would like to join our database and receive email newsletters in future.

Old details

Name _____

Street _____

Suburb/Town _____

Postcode _____

Phone number _____

Email _____

New details

Name _____

Street _____

Suburb/Town _____

Postcode _____

Phone number _____

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If unclaimed, please return to:

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AFFIX
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Please send all mail to:

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Polio SA
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Hilton SA 5033**

Membership fee reminder

It's time to pay your membership renewal fee. If you have not yet sent your renewal, please forward payment to

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302 South Road
Hilton SA 5033.**