

Issue 148

Summer 2022

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Polio SA

*The post-polio support group
for South Australians*

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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.

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Welcome to the Summer Edition of the Polio SA Newsletter

IT'S THAT TIME OF THE YEAR TO BE WISHING EVERYBODY A JOYFUL CHRISTMAS AND A GREAT NEW YEAR.

So do we reflect on the past year, remember those who have passed on, or think of those just arriving and of course "WHAT THE HELL" we are doing in the next year.

I am sure we all have something planned!!! A holiday, a new home, car, more plants for the garden, paint the front door, A cuddly puppy to annoy us with!! So many things to keep us all occupied and honest!!

And amongst all that we have to keep our self as healthy as possible so to embrace the future year, and that's the goal of POLIO SA to keep our members informed and to alter them to any new ideas, services and supports that might pop up over the next year that will benefit a stress-free year as possible.

Big BUT, MEMBERS have to be involved as possible if we are to keep this little SELF SUPPORT GROUP called POLIO SA going, sadly the two events held to date had only 14 members attend, it does not give my fellow committee members much encouragement to press on without our 250 odd members to support them.!!

So NEW YEAR RESOLUTION I WILL TRY AS HARD AS POSSIBLE TO SUPPORT POLIO SA EVENTS AND COMMUNICATION AS MUCH AS POSSIBLE!! There you've done that.... great job!

So, before I leave you to a nice cup of tea and 3 chocolate biscuits, our congratulations to our life members Charles, Trevor, Ron, Maureen and Maria, great stuff over 150 years of support between them to POLIO SA.

Many thanks to my committee for turning up each month and planning our future, most of all Helen who despite being unwell has held the Fort and the phone and the laptop to keep the communication on track, she is always there to answer your questions, VERY BEST FOR THE NEXT YEAR.

TO ALL A HAPPY NEW YEAR
KYP President Polio SA December 2022



HELLO
Summer



Life time member awards presented to Ron Blackwell, Trevor Jessop, Charles Greeneklee , presented by Nat Cook MP.

At our recent AGM in October lifetime member awards was presented to Ron Blackwell, Trevor Jessop, Charles Greeneklee , Maria Harding, Maureen Kowalick. (Maureen and Maria was not able to attend).

To congratulate them on over 20 years of volunteering to Polio SA. We thank them for their service and loyalty, awards were presented by Nat Cook MP many thanks for attending.

Afterwards there was a Q & A session by Michael Jackson Clinical Health Educator for Polio Australia we thank Michael for attending as it was also World Polio Day 24th October 2022.

Brief summary of questions

- Access to physiotherapy who is polio informed- members also pointed out one listed had retired.
- Once again polio awareness lack of knowledge by GPs was expressed by several. Michael gave a clear explanation of difficulties the GP face.

Encouraged them to take the pamphlets/books to help.

- Is it known if polio sufferers have any pronounced difficulties re Post Covid .
- Can we catch polio twice-of the 3 strains of polio .Type 2 and 3 are gone, but type 1 is still wild in Pakistan and Afghanistan.
- Brief mention made of water analysis in New York and London.
- Fatigue, pins and needles, cramps, restless legs were discussed. Some discussion re help from Magnesium which might help. Carnitine was queried- some doubt, no real test. Vit D recommended for overall help. Basic exercises as per Polio Aust sheet can certainly help. (See page 3 & 4 of this newsletter)

After formalities everyone got to enjoy afternoon tea which was served by the ladies from Rotary Holdfast Bay we thank them for volunteering to help on the day.

Thank you also to Dianne Woidt Polio SA member for volunteering to help at AGM, and committee members.

Exercising Muscle Groups with Giant Motor Units in the Presence of Partial Paralysis

Specific guidelines for exercise in those with Late Effects of Polio:

- 🌐 Polio survivors should be encouraged to exercise to benefit their health.
- 🌐 Exercise in post-polio patients should be prescribed and monitored.
- 🌐 The expertise and guidance of LEOP-informed therapists should be used.
- 🌐 Avoid LEOP fatigue and pain rollercoasters by careful prescription.
- 🌐 When initiating exercise programs think: low-strain, slow, conservative.
- 🌐 Assess safety (fall, fracture, temperature) in each exercise mode choice.
- 🌐 LEOP weakness can be stabilised or slowed, but never normalised.
- 🌐 The goal to articulate, is to "stabilise function" NOT to "get stronger".
- 🌐 Avoid unnecessary "extra" stress and strain on all muscle groups.
- 🌐 Educate survivors on moderate consistent exercise and risks of disuse.

STRENGTHENING

- Any strength gains will emerge slowly; progress exercises gradually.
- Only exercise muscle groups that test as 3+ or greater out of 5.
- Fibre type, fibrosis, atrophy, and vasomotor tone affect muscle function.
- Low resistance (intensity), moderate repetitions, ensuring frequent rest.

CARDIOVASCULAR

- With whole body modes, exert only to the capacity of the weakest limb.
- Modes that support weaker limbs should be prioritised (e.g. aquatics).
- Shorter moderate bouts with rest (intervals) may be tolerated best.
- Environment and clothing planning help reduce heat loss after exercise.

JOINT RANGE AND MUSCLE LENGTH

- Stretching must appreciate surgical history and any limb bracing in use.
- Stretching can reduce pain, reduce asymmetry, and stabilise posture.
- Stretching intrinsically affects muscle control - this can present risks.

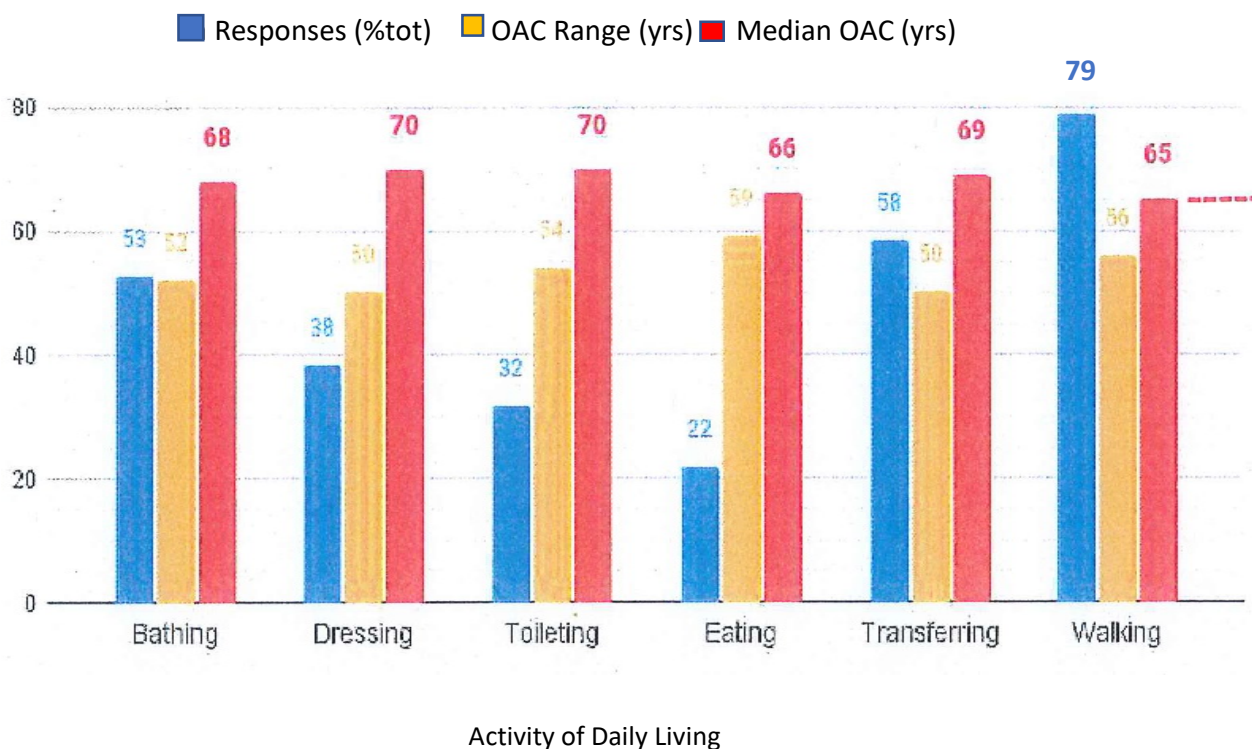
BALANCE AND CONTROL

- Skill and balance activities should adhere to the above constraints.
- Reducing fall risk using a multifaceted approach should be a priority.

Polio Australia
Representing polio survivors throughout Australia

Reported Onset Age of Change (OAC) in Functions of Polio Survivors

(n=180 Australians, SD +/- 10 TO 13 , except eating 16)



Australian polio survivors were surveyed in 2020 by Polio Australia. One survey, covering topics on Health and Health Professional Use, asked polio survivors to recall the age where they detected a change in their previous ability to perform activities of daily living (ADL).

The chart above shows the responses to the questions about ADL changes.

When working with polio survivors it is important to understand the following aspects related to ADL change:

- The most common (79% of respondents, **blue**) ADL change experienced was a change in walking ability. This aligns with published post-polio research - walking ability change is an indicator of LEO/PPS onset and is multifactorial.
- While changes in toileting (32%) and eating (22%) are less common, they can indicate reducing capacities within bulbar and autonomic neural networks.
- The OAC across ALDs ranged 50-59 years (**orange**), from survivors' early thirties to late eighties. Both young and elderly polio survivors report change in ADCs. Post-polio literature asserts that ageing is not the primary reason for functional changes in polio survivors - changing body system capacities is.
- The median OAC reported was 65-70 years of age (**red**) - an age frustratingly close to but beyond NDIS eligibility (red dotted line). Clinical questioning of the polio survivor may reveal that ADL changes were noticed prior to age 65 but were dismissed or denied. Those <65 years old should obtain NDIS assistance.

Further functional context is important to obtain from each individual polio survivor.

It is prudent for each member of the multidisciplinary health team to understand the variability and extent of the ADL and function changes experienced by polio survivors.

In case you missed it this story was covered in The Senior Magazine for December 2022

Story by Rowan Cowley The Senior Thursday December 01 2022. www.thesenior.com.au



Post Polio Victoria vice president Peter Freckleton says many Australians who are living with post polio syndrome—or long polio—will be prematurely placed into aged care if eligibility for the NDIS is not expanded.

“We have been fighting all our lives to get the support we need, and we are still fighting now.”

Peter Freckleton's words echo the sentiments of many Australians living with polio-related disabilities whose care needs are not being met. And he says it is just not good enough.

He is one of a group of polio survivors calling on the federal government to expand eligibility of the NDIS, which is inaccessible to many people living with serious disabilities as a result of the disease.

Australians must be younger than 65 to access the scheme.

The group fears many people living with post polio syndrome will be prematurely placed into aged care if this does not change.

Mr Freckleton, a barrister and vice-president of Post Polio Victoria, said the group was considering launching a class action against the federal government if eligibility was not expanded.

The group has encouraged those who are eligible to apply while there is still time.

"Some people with polio denied their disabilities and didn't apply for the NDIS," Mr Freckleton said.

"Now they are struggling to get the support they need through My Age Care." Others were already too old to apply when the scheme was put in place.

Mr Freckleton said the lack of NDIS support for people 65 and older should be of concern to all Australians because disability can occur at any time.

(continued page 6)

Diagnosis

Diagnosed with polio at the age of six, at first his symptoms resembled those of the flu. "I was in bed, Mum was giving me lots of orange juice, then I woke up one morning and I couldn't move my right leg," he said.

His symptoms got progressively worse, to the point where he couldn't move a muscle. "Luckily I never got to the point my breathing didn't work, I never needed an iron lung, but my muscles were completely knocked out."

He spent months at the Fairfield Infectious Diseases Hospital, in what he described as a "very harsh and scary experience". Parents were discouraged from visiting because it might upset the other children.

"They tended to keep us out of sight and out of mind. My father had to go to a local lawyer and get a written habeas corpus to compel the hospital to release me."

Long term effects

Mr Freckleton was left with several serious life-long disabilities. He is paralysed in both legs, and both hips are contracted, meaning he can not straighten his back when standing. He can't walk without steel leg braces and crutches, and prefers to get around in a wheelchair these days, as it is quicker and more efficient.

In addition to his physical difficulties, he has also encountered a lot of societal barriers due to his disability, including employment discrimination.

"My disability, I couldn't hide it because I was constantly leaning forward," he said.

"Sometimes I'd put in a job application and it was good enough that they would invite me interstate for an interview, but as soon as I walked in, I saw their shutters coming down."

postpoliovictoria.org.au

Peter was recently also involved with a recent post polio workshop held in Adelaide

The workshop

The Australian Association of Gerontology (AAG), Post Polio Victoria and Celebrate Ageing will host a workshop for people with post polio syndrome at the Adelaide Convention Centre on November 22. The workshop will take place during the 55th AAG Conference, and the NDIS won't be the only item on the agenda.

The workshop will feature a number of expert presenters from various medical and health related fields, including pain rehabilitation, physiotherapy and mental health support. It aims to push for more inclusive support and services from the wider community - from employers, to physicians.

"The other thing we're trying to get across is disability is not a death sentence - you can have a good life, provided you get the right sort of support," Mr Freckleton said.

The vaccine

The workshop also aims to raise awareness of the importance of parents vaccinating their children, with the recent resurgence of the disease in New York highlighting the danger of under vaccination.

"The vaccine was brilliantly effective. When it came, suddenly (new cases of) polio was a thing of the past, it was only long polio that was a problem," he said.

"I think it would be very foolish of people not to vaccinate their kids."

Life With Polio — Graham Daish

I was born in England, at Seaview on the Isle of White on the 11th of February 1936.

At the age of two mother entered me in a baby competition and I came second. The judge was a well-known actress of the day called Cicely Courtneidge who said she picked me for my well-shaped legs. Then I came down with Infantile Paralysis (Polio) and that was the end of my lovely legs, but at least I have a photograph of them to proudly show people how they used to be.

I was taken over to the mainland for treatment. The method used in those days was for the patient to be immobilised. That meant being tied down in the cot to stop movement. I suppose when the affected limbs were well and truly atrophied, you were allowed to go. Now, in my advancing years and having to give up golf, I no longer get recurring breakages, so it is a while since doing any repairs. The new braces have come a long way and they have rectified most of the inadequacies inherent in the old ones, but I will persevere with my old faithfuls and hope they last the distance home. Later the preferred treatment involved exercise which proved more beneficial.

I was told to exercise at home which was rather awkward in a small house with six children. Later I had a number of operations to stretch the tendons then was allowed to leave school on set times during the week to have electric treatment. Not sure if it helped, it certainly didn't help my school exams after missing the same lessons every week. I can imagine the report saying that this child is very weak in maths and should be kept down a grade until he catches up.

The family came to Australia in 1947 and I had my last operation in Adelaide. I then stayed in the city for after-surgery treatment. The result being I missed a year's schooling due to the boat trip and operation, so was put down a class anyway when I finally attended school in Australia. I am writing this to demonstrate how the illness can affect a life in so many ways.

I managed to go through most of my working life avoiding medical treatment on my legs but finally in middle age had to look for a brace for my right leg. I had one made for me which was fixed at the ankle. I was told it would take a while to get used to but if I persevered it would help me enormously. Soon after I started wearing it, I was just coming out of a building which had a very small step at the door less than twenty-five mm in depth. But that was enough, the heel of my foot was on this step with all my weight on it and because of the fixed ankle I was pulled forward heading for the ground. Being used to falling I swung around to take it with the shoulder but finished up on my back and there was an almighty bang, just like hitting a base drum. The back of my head should have been split open by collecting the stone wall, but instead it put a large dent in the metal door of the power box. You can be lucky! That was the only time I ever used that brace and I said, if that's the best they can do, I will make my own.

I found an old metal 'For Sale' sign and with the tin snips fashioned a brace, with knee and ankle hinges. It was heavy and soon suffered from metal fatigue, but it worked and from then on, I made my own brace. After many refinements it finished up with adjustable pressure pads which allowed the pressure to be all over the area instead of cutting in at the top and bottom edges. I could adjust the knee joint, so the knee was just behind centre. I could also lock the knee if I wanted, however I found it a pain to walk, having to swing the leg out and around, and sitting down. I put guards over the hinges to stop holes being punched in my trousers and made an anti-foot drop with quick disconnect to stop fatigue when I drove long distances.

(continued page 8)

Being a golfer, I was experiencing quite a lot of pressure on the brace and always breaking struts. I realised I could just increase the size of them for better strength, but the challenge was to keep the weight down to around a kilo. Despite shopping around, I was never able to find suitable aluminium, so tried alternative materials such as stainless steel. I finally went to another maker which after two years finally came up with a brace which was very well made from the newer materials. But I still had to heat the thing up to stop it rubbing then fit adjustments to the knee hinge and stop my trousers getting holes in them. Despite having the stronger material struts they still broke, and I needed to make new ones.

Now, in my advancing years and having to give up golf, I no longer get recurring breakages, so it is a while since doing any repairs. The new braces have come a long way and they have rectified most of the inadequacies inherent in the old ones, but I will persevere with my old faithfuls and hope they last the distance.

In my seventies I found I was getting slower in moving my right leg over to the brake pedal, so I purchased a new car with all the safety features such as emergency braking etc. I still brag about getting from Sydney to Newcastle on the freeway without touching the accelerator or the brake. Just sit in behind a vehicle doing the speed limit, if he slows down just swing out and carry on. I also taught myself to use my left foot on the brake and keep my right one for the accelerator, so I didn't have to move my legs at all and found it much quicker.

I am now having to use elbow crutches, one in the house and two on uneven ground outside so I am not good for long walks.

To overcome my problem of unable to walk any distance, I have an old gym exercise bike that I can sit on the saddle and peddle, the handlebars are connected to the pedals so I can use my arms as well. It has a belt tensioner so I can also adjust the tension. I set the timer for 10 minutes and perform neck and arm exercises as I move my legs, so I get a good workout. The last 30 seconds I go flat out and make out I am trying to reach a young child before it runs on the road. My friends say I will have a heart attack and I say I would much rather have it at home than outside actually trying to save someone. You never know when you might be called upon to have to move fast to get out of the way of a pushbike or stop being mugged etc. I have a smart watch so I can monitor my heart rate at rest and after flat out, so have a pretty good idea how the old ticker is holding up.

I have dependent edema in my withered right leg and must have vein restrictions, so I put my legs up when watching TV and have an air pressure pad set up to strap on the legs when sitting for a while doing my fine art paintings, playing my beloved flight simulation or processing emails and avoiding scams.

That's my life so far and reading back I don't think I have suffered too badly. Of course, I regret getting polio and am sure if I had dodged it, I would have married Marilyn Monroe and been a world champion of some sport (ha ha).

Any suggestions to further improve my health and wellbeing would be appreciated. (But not digging up Marilyn)

All the Best,

Graham Daish

Hydro and massage vouchers update as you may or may not know , funding for hydro and massage vouchers ceases at the end of June 2023.

A new Government Grant was approved after that date but only to cover advocacy and information services a grant of \$20,000 a year for 4 years.

In regards to Hydro I have been in contact with Seamus Smith at the Repatriation Health Precinct Pool at 216 Daws Rd , Daw Park 5041.

They are reopening the Community Pool Access Program on the 5th December 2022 if you did want to use the pool for The Community Pool Access Program it is for independent aquatic exercises. You will be supervised by pool attendants for safety purposes, but you will not have any guidance from a Physiotherapist.

Session Times and Cost

30-minute sessions for community pool access are available at the following times:

- Monday - 1:00pm, 1.30pm, 2:00pm
- Tuesday - 1:00pm, 1.30pm, 2:00pm, 2.30pm
- Wednesday - 12:30pm, 1:00pm, 1.30pm, 2:00pm
- Thursday - 1:00pm, 1.30pm, 2:00pm, 2.30pm
- Friday - 12:30pm, 1:00pm, 1.30pm, 2:00pm

Payment - \$5 per visit, or \$50 for an 11-visit pass. They only accept EFTPOS for payment – no cash.

Existing passes with credit will be honoured. These are the details I received from Seamus there is also other paperwork you would need to complete to attend you can call me to send it out or you can contact direct Seamus at Repat Pool 7117 5054.

Also wanted to share a link with you about accessible accommodation Shirley from Post Polio Victoria shared with us.

<https://www.accessibleaccommodation.com/>

Kind Regards

Helen

Polio SA Community & Membership Officer

0466 893 402

poliosa.office@gmail.com



- How did the reindeer know it was going to rain?
Because Rudolph the red-knows-rain, deer!
- Why doesn't Santa eat junk food?
Because it's bad for your elf!
- Which one of Santa's reindeer has the best moves? Dancer!
- What do you call an apology written in dots and dashes?
Re-morse code.



**Merry Christmas
Happy New Year
from Polio SA**

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

 To the editor, Polio SA, 302 South Road, Hilton SA 5033

Articles for the next issue are due to the editor by 2nd March 2023

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.



Dr Nigel Quadros

Queen Elizabeth Hospital
Level 8b, Woodville Road
Woodville SA 5011
Phone: 8222 7322

nigel.quadros@health.sa.gov.au

Dr Nigel is Director of Rehabilitation Services at the Queen Elizabeth Hospital and St Margaret's Rehabilitation Hospital and also a Senior Clinical Lecturer at the University of Adelaide Healthcare. He is a Fellow of the AFRM (RACP). His areas of interest include stroke and general neurological rehabilitation, amputee rehabilitation, pain management, management of post-polio syndrome, and Continuing Professional Development.

A referral from your local GP is required for appointments. Dr Quadros can arrange assessment by their physiotherapist and orthotic department and any tests as required. If you have any specific questions you can email him directly.

When visiting Dr Nigel, take the lift to the 8th floor in the main building and follow the signage for 8b.

Member Services

If you are interested in any of our services ring the office 0466 893 402 and ask for vouchers
There is a limit of 4 vouchers per person with a maximum value of \$40 per voucher. Remember you must be a paid up member to receive vouchers.

City

PhysioXtra

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

Toni Stubing Massage

9 Hackney Rd
Hackney SA 5069
Phone: 0432 937 799

City North

PROSPECT

The Physio Clinic
177 Prospect Rd
Prospect SA 5082
Phone: (08) 8342 1233

Eastern suburbs and Hills

BLACKWOOD

The Physio Clinic
238 Main Rd,
Blackwood SA 5051
Phone (08) 8342 1233

MARRYATVILLE

The Physio Clinic
222 Kensington Rd
Marryatville SA 5068
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
19 Federation Way,
Nairne SA 5252
Phone: 0410 779 159

Northern suburbs

ELIZABETH

Richard Barker Physio
2 Burgate St Elizabeth
Grove SA 5112 & 3 Tolmer
Rd Elizabeth Park
Phone:0438826517(state
from Polio SA when book-
ing)

GOLDEN GROVE

Golden Grove Family
Health – Diane Preston
Massage Therapist
205 The Golden Way,
Golden Grove SA 5125
Phone: (08) 8289 1222
Fax: (08) 8289 1255

NORTH EASTERN SUBURBS

Mobile Massage

This can only be done on
certain days and takes
around 3-4 clients a day.
Preference given to house
bound and the more handi-
capped person.

Arrangements to be made
with Reeva Brice
Phone: (08) 7423 7162
Mobile: 0412 866 096

PARALOWIE

Wax on wax off by Gen
10 Airdrie Ave
Parafield Gardens SA
5107
Phone: 0430 867 248

Southern suburbs

HALLETT COVE

PhysioXtra
1/1 Zwerner Drive,
Hallett Cove SA 5158
Phone: (08) 8387 2155

MARION

PhysioXtra
724 Marion Road,
Marion SA 5043
Phone: (08) 8357 4988

MORPHETT VALE

Hands on Health
Massage – Jimmy
Kucera
Shop 7, 20 Taylors Ave,
Morphett Vale SA 5162
Phone: (08) 8325 3377
Plenty of car parking.
Flexible times.

MORPHETT VALE

South Side Health Care
Unit 4 /232 Main South Rd
Cnr Bains Rd Morphett
Vale SA 5162
Phone: (08) 8382 2255

UNLEY

Unley Medical Centre
Unley Physiotherapy
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.

Western suburbs

HENLEY BEACH Massage Therapist, Pilates & Physiotherapy

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

SEMAPHORE

Bruce Harrison
100 Semaphore Road
Semaphore SA 5019
Mobile: 0402 337 382
bruce_harrison@aapt.net.au

WOODVILLE SOUTH

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

Outer metro

GAWLER

Physio-Wise
3 Murray St Gawler 5118
Phone: (08) 8522 6611
Australian Physiotherapy
Association Member

LYNDOCH

Physio-Wise
Phone: (08) 8524 5094
Australian Physiotherapy
Association Member

Regional

PORT ELLIOT

PhysioXtra
39 North Terrace,
Port Elliot SA 5212
Phone: (08) 8554 2530

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 _____

Name _____

Street _____

Suburb/Town _____

Postcode _____

Phone number _____

Email _____

New details



If unclaimed, please return to:

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

AFFIX
STAMP
HERE

Please send all mail to:

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