

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

Editors: Nola Buck and Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: (02) 9890 0946

Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

Our popular **Country Conference** is back! This year we are returning to Canberra where we held our first such event in 1998. Join us at an **informal dinner** on **Friday, 17 October**, and then attend the **Conference** on **Saturday, 18 October**. A lot of work has gone into lining up a wonderful array of speakers and topics, so please show your support for the organisers and the speakers by coming along – see further details on page 2. As usual, everyone is welcome, not only those within easy reach of Canberra. **A Registration Form is enclosed – please RSVP by Friday, 10 October**. The very reasonable \$35 cost for the day includes morning and afternoon tea and lunch – we look forward to seeing you at what promises to be a great day.

Meanwhile our **Mid-Year Seminar** held on Wednesday, 23 July, was a very successful meeting and we are pleased that members are taking the opportunity to attend our new-look Seminars which now each feature a range of informative topics. Sue Ellis has done her usual sterling job of writing up the presentations for the benefit of members unable to be present. You can read her comprehensive Report on pages 7 to 21.

On Friday, 12 September, Polio Australia's annual NSW "Walk With Me" fundraiser was held in Parramatta. Once again Northcott invited NSW walkers and wheelers to participate in their Western Sydney event. The small but enthusiastic "Polio Power NSW" team and friends raised over \$12,000 which will be shared equally between Polio Australia and Polio NSW in the provision of information and support services to polio survivors and their families. This was a record result and we give a huge thank you to Northcott, to everyone who donated and, of course, to the participants who all worked so hard to raise these vital funds. It's not too late to donate to the **2014 Walk With Me campaign**. Donations can be made until 11 November 2014. Just go to this page to donate to Polio Power NSW: tinyurl.com/polio-power-nsw. All donations (which are tax deductible) are very gratefully received and will advance the support efforts of both Polio NSW and Polio Australia.



Polio Awareness Month will be celebrated nationally in October. Polio Australia is again inviting "polio heroes" to join in a visit to Parliament House in Canberra on Wednesday, 29 October, to bring our need for support services to government decision makers. For further information, please visit www.polioaustralia.org.au. At a state level, we are including posters, flyers and bookmarks with this *Network News*. We will greatly appreciate you distributing and displaying these resources to help promote Polio NSW and our work.

Finally, a reminder that this year Polio NSW celebrates **25 years of support** for polio survivors and their families. We are holding a **special anniversary lunch** in conjunction with the Annual General Meeting on Saturday, 29 November, at Burwood RSL Club. Please come along and celebrate this milestone with us.

Unless otherwise stated, the articles in Network News may be reprinted provided that they are reproduced in full (including any references) and the author, the source and Polio NSW Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of Polio NSW. The views expressed in this publication are not necessarily those of Polio NSW, and any products, services or treatments described are not necessarily endorsed or recommended by Polio NSW.

Country Conference 2014

Gungahlin Lakes Golf Club (www.gungahlinlakes.com)
Cnr Gundaroo and Gungahlin Drives, Nicholls, ACT



Conference Dinner: 6:30 pm Friday 17 October 2014

Program: 9:00 am to 5:00 pm Saturday 18 October 2014

The Country Conference allows all Polio NSW members, especially those from the ACT and south-east NSW, to find out about issues and services relevant to people with the late effects of polio. Spring is a wonderful time to visit Canberra so we look forward to seeing you there!

Speakers include:

- **Mary Durkin**, ACT Health Services Commissioner and Disability and Community Services Commissioner, ACT Human Rights Commission, will deliver the opening address.
- **Dr Geoff Speldewinde**, Head of Rehabilitation Calvary John James Hospital, Canberra, will speak about rehabilitation for people with post-polio syndrome following surgery.
- **David Halpin**, an Accredited Exercise Physiologist, will speak about his experience working with people in Ghana who have had polio, providing an insight into how it affects people's lives in this developing country. David will also provide some information about exercise DO's and DON'Ts for people with the late effects of polio.
- **Randolph Sparks**, Clinical Psychologist, will present on the psychological impact of chronic illness, including the emotions people might experience, psychological strategies that can assist in coping with these emotions, and the impact on other people such as carers and families.

There will also be presentations from:

- Health Care Consumers Association ACT
- Technical Aid to the Disabled ACT
- Independent Living Centre
- Nican, an information service on recreation, tourism, sport and the arts for people with disAbilities
- Wheelies with Wings

Please return the enclosed Registration Form with your payment to the Polio NSW Office by Friday, 10 October 2014

Transport Assistance for Polio NSW Members

On page 4 of *Network News*, Issue 89, March 2014, was an article advising members that Polio NSW had received a Government grant to provide \$20 fuel cards to volunteers who drive polio survivors to Support Groups, Seminars and other activities.

Few members have so far availed themselves of this opportunity to show appreciation to their drivers' generosity by driving them to polio events. With a number of events still coming up this year, including our Country Conference and 25th Anniversary Celebration Lunch, please be sure to apply to us to help defray the petrol costs incurred by your volunteer driver, whether he/she be husband, wife, daughter, son or friend.

We also know that many attendees at our Support Groups and Seminars are driven to and from by volunteer drivers, so please contact the office on (02) 9890 0946 to make arrangements to have fuel card(s) sent to you.

Vale, Roger Smith

by **Brian Wilson, ACT Support Group Convenor**

Roger was an esteemed and valued member of the *ACT Post-Polio Support Group*, being a foundation member from our Group's start in 1993. He enjoyed his role as Co-Convenor, managing our Guest Speaker co-ordination for which we had many and varied speakers over the years. Roger also was a major contributor to our Christmas party, by way of funds for gifts, but also for entertainment with his clever and well written poems and limericks. Every year we had the "*Roger Smith Door Prize*"; he so enjoyed presenting the gifts.

Roger was born in 1932 and was 18 when he contracted polio, a real tragedy for a strapping young farmer who loved rounding up the sheep. We had many discussions about the for and against of being a baby or an adult when contracting polio.

Roger passed away on 20 August 2014 after many months of illness and hospitalisation. His funeral service was held on the 28th August.

Convenor Brian Wilson has received many condolence messages from the Group's members who stated how much they respected and admired his attitude and fun loving personality, he was a true gentleman.

Member Sylvie Sampson stated "*... Roger was such a well-loved member of our group. To say that he will be sorely missed seems so inadequate. His loving personality and his big smile, as well as his poetry and limericks were always fun and entertaining. ...*"

And President Gillian Thomas wrote "*... Roger was a great supporter of Polio NSW and, I know, of the ACT Support Group. I enjoyed the chats we had over the years. ...*"



Pain Management Network Website

Reprinted from the Newsletter of IDEAS, June 2014

A new website has been launched by NSW Agency for Clinical Innovation – called “Pain Management Network”. It has been designed to assist people with chronic pain.

The site contains information to enable people to develop skills and knowledge in the self-management of their pain in partnership with their healthcare providers. It has a series of ‘episodes’ you can watch which features stories of people living with chronic pain as well as advice and information from clinicians. Some of the topics include:

- Introduction to Pain
- Getting help from your Healthcare Team
- Pain and Physical Activity
- Lifestyle and Nutrition
- Role of Medications
- Pain and Thoughts
- Pain and Sleep

There is also a section of the website focusing on spinal cord injury pain – which is still in development. To find out more visit: <www.aci.health.nsw.gov.au/chronic-pain>.

You can also call one of the Information Officers at IDEAS on 1800 029 904 for further information on any of these services.

The Rural Disability Network Becomes Official

Reprinted from the Newsletter of IDEAS, June 2014

Fourteen years ago, Lori Grovenor recognised the need for people with disability to have more access to information about what is available out there: *“Until someone told me, I had no idea what opportunities were available to me. I was struggling on my own with kids and a disability in a little town. I was beginning to feel isolated.”*

Recognising that she was probably not alone, Lori decided to do something about it. The Rural Disability Network of NSW (RDN) was born.

Since that time, RDN has been bringing together and connecting people with disability who live in rural and remote NSW. RDN gives people with disability opportunities to share ideas and information. It is also a forum for people to find out more about what’s going on for people with disability and to have a voice on the unique issues facing people in the bush.

“And now we’re excited to announce that we’ve become an Incorporated Association!” says Lori. *“This gives us the chance to have more choice and control of what happens for our Network. It helps us to be more official and to be taken more seriously. It also gives us more control of our opportunities for funding and donations and how and where we use it.”* Says Lori: *“It is about time that people with disability in the bush have our own voice. We’re more than just a single rural member sitting on a Board in a city-run organisation where we are often too easily out voted, or just not heard.”*

RDN has been formed and is run exclusively by and for people with disability who live in rural and remote New South Wales.

If you would like further information on the Rural Disability Network you can email <rdn.nsw@gmail.com> or call one of the Information Officers at IDEAS on 1800 029 904.

Accessible Cruising

Reprinted from *Spinal Injuries Australia* magazine, *The Advocate*, May-June, 2014



Cruising season is all year in Australia. With so many of our members going on cruises we thought it would be great to look at the accessibility of some of the more popular cruise ships.

Carnival Cruises

General Access: Carnival has made substantial modifications to enhance the ability to move about the

ships. The ships feature accessible elevators at each elevator bank with tactile controls within reach of guests who use wheelchairs. Accessible routes are available throughout most areas of the ship and signs are posted to assist you in locating these pathways.

Modified Cabins: these cabins are designed for guests who may utilise a wheelchair and include features such as grab bars and shower seats in the bathrooms.

Accessible Cabins: these cabins are designed for guests with highly limited or no mobility who utilise wheelchairs or other similar assistive devices and include features such as turning space; accessible routes throughout the cabin; and accessible bathrooms.

As with all Carnival reservations, staterooms within each category are assigned on a first come, first serve basis. Therefore, it is advisable to reserve an accessible or modified stateroom in advance. Carnival Cruise Lines bases Carnival Spirit year round in Sydney and Spirit will be joined by sister ship Carnival Legend in September for seasonal cruising from Sydney this year and again in 2015.

Princess Cruises

Accessible Cabins: Today, the Princess fleet offers more than 350 wheelchair-accessible cabins. Each vessel features up to 31 accessible cabins across a variety of stateroom categories. These rooms are designed for wheelchair manoeuvrability, with widened doorways into both the cabin and its bathroom; wheel-in showers, hand-held showerheads and bath distress alarms; as well as lowered closet railings, sinks, and handrails; and removed or revamped thresholds. Additional equipment is also available on request, such as toilet seat raisers, shower stools and bed boards. Wheelchair users will find access-friendly design across most of the Princess fleet, making it easy to enjoy each vessel's restaurants, theatres, spas, lounges and open deck space. Elevators have generous wide doorways, and wheelchair seating is available in show lounges and other public spaces.

P&O

P&O Cruises operates three cruise ships – Pacific Dawn which is home ported in Brisbane and Pacific Jewel and Pacific Pearl which operate in the main from Sydney.

Ports accessed via ship's tender: It is important to note that access to tender ports may be restricted. Don't worry if you can't get off the ship, there are plenty of fun activities for you on board! Many of the Shore Tours are suitable for people with limited mobility. Access to some tender ports may be restricted. The Shore Tours staff will happily suggest suitable tour itineraries to accommodate your mobility needs.

Accessible Cabins: There are accessible rooms on all ships, subject to availability at the time of request.

There are also a limited number of specialised kits for hearing impaired guests available upon request at time of booking.

Supportive measures

Reprinted from NZ Polio

The goal of a support group is to empower its members with the tools to make adjustments to continue a life of dignity and independence.

Contrary to the image sometimes portrayed in the media, healthy support groups are not 'pity-parties' and do not promote the idea that 'misery loves company'.

During the original illness, many polio survivors were hospitalised for extended periods and established a spirit de corps. After successful rehabilitation, they lived active, integrated lives. Many of today's successful groups have rekindled this sense of belonging to a unique group.

Also contributing their perspective to support groups (though maybe with some hesitation or even resistance) are individuals who never were part of a group based around having polio or a disability.

Support groups provide a forum for people to learn from each other about how to enhance the quality of their lives. Historically, support groups related to a common health condition developed to help people resolve problems with bureaucracies. For this reason, groups are encouraged to operate with minimal structures and rules.

Spending excessive time on organisational details detracts from the primary goals of providing personal support and advocating for systems' change.

Successful support groups promote personal empowerment to overcome personal adversity by encouraging members to become active, assertive managers of their health care, challenging attitudes of helplessness, hopelessness, and victimisation. Successful groups create a confidential environment for people to share their feelings safely. Healthy groups balance a time for 'me', a time for 'us', and a time for 'you'.

Communication is vital in a support group.

Members should be encouraged to own their ideas and reactions by using 'I' statements, such as '*I think ... I feel ... I suggest ...*'

Participants should avoid speaking for the group without consultation, generalising by stating, '*all polio survivors ...*', or telling others what to do, such as '*you should ...*'

Equally important is listening to whoever is speaking by not interrupting or engaging in cross-talk. Sometimes distressed members digress on tangents and tell detailed stories rather than staying focused on the topic. To minimise these situations groups should develop ground rules for the meeting time and recognise the limits of the group's role by encouraging persons who experience continuous or intense distress to seek professional assistance.

Effective leadership is also vital. Most groups function successfully with co-leaders or a committed core team.

Excerpted from the "Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors", Editors: Joan L. Headley, and Frederick M. Maynard MD. Post Polio Health International (1999).



Mid-Year Seminar Report - 23rd July 2014

by Susan Ellis

Anne O'Halloran, who took on the role of Seminar Co-ordinator after joining the Management Committee following the 2013 AGM, organised a very successful mid-year Seminar which was attended by 40 members. The three guest speakers presented interesting topics which generated numerous questions from the audience. Many thanks also go to the Office staff for their organisation of the venue and food and the associated administrative tasks. Long-time Committee member, Alice Smart, provided morning tea and a raffle which always attracts a lot of interest from members vying for first prize!

Ms Jenny Ly is currently the Senior Health Promotion Officer at Arthritis and Osteoporosis NSW. Her role involves educating groups in the community and is largely focused on the range on Healthy Lifestyle Programs for people with arthritis or osteoporosis. Jenny is a pharmacist by profession and has a special interest in complementary medicines and health education. **Arthritis NSW Health Information Service 1800 011 041**

Complementary Medicines and Alternate Therapies

Over the last few years, there has been an increased amount of interest in complementary medicines to treat a range of health conditions.

Arthritis is a painful chronic condition that causes pain, inflammation, muscle weakness, fatigue, reduced quality of life (these may also appear in post-polio) and it is not a surprise that people seek complementary medicines.

It is important to remember that people respond differently to treatments – what works for one person may not necessarily work for another. It is very much a case of “try it and see”. In the presentation some of the more common complementary medicines were covered, such as fish oil, krill oil, glucosamine, chondroitin and what research has been done as to their effectiveness and, more importantly, any side effects.

What is Arthritis?

- “arthros” = joint, “itis” = inflammation, so **arthritis** = inflammation of a joint or joints
- A joint is the point at which two or more bones meet
- Almost any joint in the body can be affected
- There are over 100 different forms of arthritis
- **Osteoarthritis** is the most common form, cartilage thins out
- Inflammatory forms, where the body's autoimmune system starts to attack itself – eg **rheumatoid arthritis** which generally affects women between 30-50
- Osteoarthritis may affect one or many joints – joints most affected are the hands and weight-bearing joints
- Rheumatoid arthritis often starts in smaller joints such as those in the hand and wrist
- The hand and wrist are common locations – eg osteoarthritis, rheumatoid arthritis, psoriatic arthritis and can include lupus, gout and JIA (juvenile idiopathic arthritis)
- Can affect hands symmetrically or asymmetrically
- Any joint in your fingers, thumbs, knuckles and wrists can be affected by arthritis

Statistics

- 1 in 5 Australians has arthritis
- Almost half the population aged over 65 have some form of arthritis
- Not just a condition affecting older people
 - 2.4 million people of working age
 - 1-4 in 1,000 children are living with JIA
- Prevalence will increase to around 7 million by 2050
- Total cost of arthritis is around \$24 billion per year

Why do people choose Complementary and Alternative Medicines (CAMs)?

- Used throughout history for thousands of years
- Thought to be natural, gentler and therefore safer for the body
- Also thought that if multiple ingredients are working together they must yield a better result
- Concern for side effects, eg on stomach or blood pressure, or lack of pain relief with mainstream medicines so they then seek an alternative by selecting CAMs

Potential problems with CAMs

- There is a lack of regulation
- No dose standardisation, different brands have different doses which can be difficult to determine if it will work
- CAMs may be diluted when added to other supplements or other ingredients which might make them less effective
- People may put off taking more effective main-stream therapies
- Potential for side effects and drug interactions
- Many people do not inform their doctors, always tell your doctor about CAMs you take

Regulation in Australia

- TGA (Therapeutic Goods Administration) is the regulatory organisation in Australia that evaluates products (eg over the counter medications, prescriptions) for safety, quality, and effectiveness. They control product recalls as well.
- Two-tiered system of regulation: Listed and Registered

Check the Label!

Listed Products are labelled as **(AUST L)**, next to the barcode

- Contain low-risk ingredients that relate to non-serious health conditions
- Are assessed for quality and safety but **NOT** for effectiveness
- Examples: most complementary medicines

Registered products are labelled as **(AUST R)**, next to the barcode

- Contain higher-risk ingredients, or are used for more serious health conditions
- Assessed for quality, safety and efficacy
- Examples: prescription medicines, some over-the-counter products as well

Note

Regulation of products – CAMs are assessed on toxicity, potential for side effects, and potential for harm with prolonged use, before they are sold.

Do Complementary Medicines actually work?

- Little scientific proof available, very little research in this area
- Many poor quality small studies with inaccurate or exaggerated results and trials
- Benefits may vary depending on the type of arthritis
- There is a need to make sure that the benefits have been clearly proven

Jenny stated that there is definitely a need for more scientific research on a larger group of people over a longer period of time before it can be proven that CAMs actually work.

Jenny has used statistics and research from Arthritis Research UK who produces an evidence-based report every 2-3 years. It is based on the use of complementary and alternative medicines and therapies for arthritis and musculoskeletal conditions to determine whether they are effective and safe and if there are any side effects that we need to be wary of.

Arthritis Research UK have developed a **rating scale** based on elements such as improvement in pain and function, increased movement, and improved general well-being.

1 indicates that there is no evidence, or little evidence, and

5 indicates that several studies show that the complementary therapy is effective

**** Remember: what works for one person
may not always necessarily work for other people ****

Safety rating

Red indicates serious side effects

Amber indicates side effects serious and more common

Green indicates mainly minor side effects

COMPLEMENTARY THERAPIES

Acupuncture: A traditional Chinese medicine technique where fine needles are inserted into the skin at certain 'trigger points' to reduce pain and inflammation. The research has shown that in OA small improvements in pain and function were achieved after 8 weeks (rating scale **5**) and for RA trials have failed to show improvement in pain (rating scale **1**). The safety rating is **GREEN**, side effects being mild bleeding or bruising, and rarely – nausea, dizziness, fainting, vomiting.

Precautions: Anyone with a bleeding disorder, or who takes blood thinners such as Warfarin, check with your doctor. It is also advisable to find out how qualified and experienced the acupuncturist is as this is not regulated. Does the therapist have other polio clients?

Copper Bracelets: Very popular years ago. The thought is that the copper has anti-inflammatory properties and can help with pain if worn on a certain area – the wrist. Research shows no improvement in pain, stiffness or function giving a rating of **1** for OA and **0** for RA with a safety rating of **GREEN**, indicating no serious side effects but only mild side effects such as rash, skin discolouration or irritation.

Massage: Very popular, some people stating that they do wonders for them, this depends on the massage therapists, check if they are a member of the Australian Association of Massage Therapists (AAMT). Massage targets soft tissues such as muscles, tendons, ligaments and is used to relieve muscle tension. There have been limited studies on massage and it is not recommended for already inflamed joints. Massage was not evaluated in the Arthritis UK report.

COMPLEMENTARY MEDICINES

Fish Oil: There are two types: Fish body oil and Fish liver oil (cod liver oil). Fish oil is rich in Omega-3 fatty acids which have anti-inflammatory properties. Omega-3 Fish oil supplements are available as capsules or in liquid form. Fish oil is recommended by rheumatologists for rheumatoid

arthritis to help reduce joint pain, morning stiffness, swollen joints and also symptoms of fatigue that come with the condition (rating scale **5**). There is less evidence that fish oil is effective in osteoarthritis (rating scale **1**).

Recommended dose in RA = 2.7 grams daily

- 14 standard fish oil capsules (1 tablespoon of liquid fish oil)
- 7 capsules of fish oil concentrate
- 15 ml of bottled fish oil
- It may take 2-3 months before benefits are noticed
- About half the above dose of Omega-3 fish oil for OA

The safety rating for fish oil is **GREEN** with possible side effects of stomach upset, heartburn, nausea, diarrhoea, flatulence; these side effects can be minimised by using the odourless variety or by storing the product in the fridge and taking with food. There is also concern with Cod Liver Oil which contains Vitamin A; high doses of Vitamin A can cause liver toxicity and hair loss. Can also interact with other supplements and medication eg Warfarin, causing risk of bleeding (fish oil may need to be stopped 1 week prior to surgery).

Krill Oil: A more concentrated source of Omega-3 which is absorbed much better than standard fish oil products resulting in fewer capsules needed per dose eg 1 Krill Oil capsule is equivalent to 6 Fish Oil capsules therefore much more convenient. Only limited research has been undertaken, only one trial in Canada. Krill Oil has similar side effects, precautions and drug interactions as Fish Oil. It is very expensive, however.

Glucosamine: Derived from shellfish (eg crab, lobster, shrimp) or prepared in a laboratory, it is a nutritional supplement. It is available in capsules, liquid and cream (arthroid). Glucosamine is found naturally in the body, it is the building block of joints, tendons, ligaments, cartilage and synovial fluid. There is also a vegan type made from corn for people who are allergic to shellfish. Glucosamine sulphate may slow down or repair cartilage breakdown – this has not been proven yet. Glucosamine hydrochloride is less effective.

Recommended dose:

- Glucosamine sulfate: 1500mg daily
- Glucosamine hydrochloride: 1500mg daily
- May take 8 weeks to 3 months to be effective

The safety rating for glucosamine is **GREEN** with possible side effects of headaches, skin reactions (rash) and stomach upset; it is recommended to take with food. Precautions: those with shellfish allergies and diabetics, it may increase sugar levels. Drug interactions: Warfarin, chemotherapy, cholesterol-lowering medicines.

Chondroitin: Is found naturally in the body and is a vital part of joint cartilage. Chondroitin supplements are made from cow or shark cartilage and are often used in conjunction with glucosamine. A small study (2008) found that the combination of chondroitin and glucosamine reduced pain in moderate-severe OA. Research from 2010 showed that Chondroitin alone showed no improvement in joint pain.

Recommended dose in OA = 800-1200mg daily

- May take 8 weeks to 3 months to be effective

The safety rating for chondroitin is **GREEN** with possible mild and uncommon side effects of stomach upset, headaches, diarrhoea, rash. Precautions: may worsen breathing problems for asthmatics. Drug interactions: Warfarin.

Green-lipped Mussel: Is a type of mussel native to New Zealand; coastal Maoris have less osteoarthritis and it was thought to be due to their diet of mussels. It is now available as a supplement in capsule or powder form and contains Omega-3 fatty acids which have anti-inflammatory properties. When combined with paracetamol or anti-inflammatory medicines, it can

reduce pain, improve function and improve quality of life. The exact dose needed is unknown; it is very expensive.

The Arthritis UK report gives an effective rating scale of **3** for OA and **1** for Rheumatoid arthritis. The safety rating is **GREEN** with possible side effects of nausea, flatulence. Drug interactions: Warfarin.

Reliable information sources

- Be careful what you read on the Internet, or what you hear from family and friends
- Arthritis NSW
- NPS Medicines Line: 1300 633 424
- Your health care team
- www.quackwatch.com
- National Institute of Health (US): National Center for Complementary and Alternative Medicine (NCCAM): <http://nccam.nih.gov/>



Summary

- Arthritis is an individual disease and what works for one person may not work for another
- Complementary medicines can take time to be effective
- Choose your complementary therapist carefully and make sure they have the right qualifications
- Treat complementary medicines like any of your prescription medicines
- Complementary medicines can have side effects and interactions
- Don't stop using your prescription medicines without speaking to your doctor or specialist



REFERENCES:

- Arthritis Australia. Information sheet: “*Complementary therapies*”
- Arthritis Research Campaign (2007). “*Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia authoritative report*”.
- Arthritis Research UK (2013). “*Practitioner-based complementary and alternative therapies for the treatment of rheumatoid arthritis, osteoarthritis, fibromyalgia and low back pain report*”.



Mr Robert McLeod has had many years as a banking and finance executive. He has been with Sydney Cochlear Implant Centre (SCIC) for six years, the last four as Chief Executive. SCIC is the third largest cochlear implant program in the world. Robert has an 18 year old son who was born profoundly deaf and who has bilateral cochlear implants. Robert said this is a special reason for his involvement with SCIC.

The Work of SCIC and the Cochlear Implant

Sydney Cochlear Implant Centre supports **choice and opportunity** – opportunity for children who are born deaf, and adults who acquire deafness, to have the choice of becoming part of the mainstream world.

Sydney Cochlear Implant Centre is a comprehensive clinical program for diagnostic services, cochlear implantation and related services. SCIC is a not-for-profit registered charity. The adult Cochlear Implant Program was established in 1984 by founding surgeon Prof William Gibson and the paediatric program commenced in 1987. Prof Gibson is the world leader in cochlear implants, also known as a bionic ear. The original cochlear implant was invented by Prof Graham Clark who is now using the technology to develop a bionic eye and is also working with paraplegia. The device was initially meant for adults who had lost their hearing. Prof Gibson thought it would be beneficial for children born without hearing. It was very controversial at the time. Now in 2014 SCIC is probably the 3rd or 4th largest program in the world having performed 3½ thousand cochlear implants to date of which Prof Gibson has performed about 2½ thousand.

SCIC provides a full lifetime service for recipients of all ages from pre-surgery right throughout their life. SCIC's philosophy is to provide a free service to all ages. Services are offered throughout the state of New South Wales with 50% of all clients living outside of Sydney. SCIC's services are also available to interstate and international clients. Research conducted at SCIC underpins the clinical program. SCIC is recognised as a benchmark program that provides training services by Dr Gibson to other organisations both interstate and internationally.

The Main Clinic and Administrative Centre is located in Gladesville

A referral from your GP is required to make an appointment.

Permanent Sites

Gladesville
Newcastle
Canberra
Gosford
Lismore
Port Macquarie
Penrith
Darwin

Visiting Sites

North Rocks - RIDBC
Parramatta – Garfield Barwick
Westmead Hospital
Wagga Wagga
Dubbo
Orange
Tamworth
Wollongong

Clinical Team

- 10 x Ear, Nose and Throat Surgeons
- 23 x Audiologists
- 8 x Habilitationists/Therapists for development of speech and language
- 3 x Family Counsellors, support parents through the journey
- 2 x Biomedical Engineer, technicians
- 4 x Research Audiologists
- Students

Supported by

- Management and Administrative team
- Community and Corporate philanthropy
- Board

Industry Partners

- Government – Department of Health
- University – Sydney University
- Non-Government Service Providers

WHAT WE DO

Pre-surgery diagnostic and assessment services

- Counselling

Ongoing care and maintenance for life

- 24 hour on-call help line for when devices are lost or damaged
- Replacement parts and loan speech processors which will have the individual's program downloaded onto it, posted out within a day
- Mapping review; children 6 monthly, adults annually
- Speech perception testing annually
- Speech and language assessment at 1 and 2 years post switch-on

Outreach Services

- As determined by client needs SCIC provides outreach services to centres across the state

OUR GOALS

For Children

Close to normal development
Opportunities such as mainstream schooling

For Adults

Return to pre-hearing loss
Functioning including continuation of employment, telephone use etc.

WHY IS IT IMPORTANT?

For the Children

- benefits of speech, language and educational development
- up to \$400,000 education cost savings per child
- decreased social isolation
- decreased dependence on social welfare and special funding
- significant increase in educational opportunities

For the Adults

- return to the workforce
- increased self esteem
- social independence
- decreased dependence on social welfare

For the Community

- educational savings
- decreased demand on social services
- reduced special need services
- contributor to society
- Australian icon service

CAUSES OF DEAFNESS IN CHILDREN

(Robert has identical 18 year old twins, one was born profoundly deaf, it proved NOT to be genetic but rather caused by being in contact with the Rubella virus during pregnancy.)

Genetic = 33%; Meningitis, Rubella, Mondinis, Waardenburgs, Ushers (deaf and blind), LVAS = 42%; Unknown = 25%.

CAUSES OF DEAFNESS IN ADULTS

Generally, adults lose their hearing as they age OR it can be caused by industrial deafness. Usually hearing aids are sufficient but when an adult can no longer hear, even with the use of hearing aids, then a cochlear implant can be the answer.

SOME INTERESTING FACTS

- Over 3,000 implants have been performed at SCIC
- All children today are screened at birth for hearing and vision defects, early intervention is critical especially in relation to learning speech
- 95% of our vocabulary is learnt by the time we are 5 or 6
- The birth rate of deafness for children has not increased
- 120 children have surgery each year for cochlear implants
- Two-thirds of all surgeries are performed on adults
- 15% growth rate in adult surgeries each year
- World's first congenitally deaf child implanted in 1987
- Youngest congenitally deaf child implanted at 3 months of age (usually performed between 9 and 18 months)
- Oldest adult implanted at 95 years of age
- 373 surgeries performed in 2012/13
- A cochlear implant costs \$25,000 but private health insurance will cover the cost or it can be

subsidised by government – SCIC’s philosophy is for a free service for all ages (see more below)

- The doctors at SCIC do not charge any gap fees
- Cochlear implants are produced in Australia

AGE OF CHILDREN RECEIVING THEIR FIRST IMPLANT

47% were 0-2 years, 32% were 3-5 years, 16% were 6-10 years and 5% were 11-17 years.

SYDNEY COCHLEAR IMPLANT CENTRE

- We give the gift of hearing to children and adults who are born deaf or acquire deafness later in life
- We teach deaf children and adults to learn to listen using their cochlear implant
- We provide the means for adults to resume their life in a hearing world
- We provide the opportunity for children to be part of our mainstream hearing world
- We teach deaf children to talk

SO HOW DO WE DO ALL THAT?

Public Funding via NSW Health – uninsured clients

- 62 child recipients – CI device only
- 80 adult recipients – CI device only
- the annual allocation is reviewed each year but not guaranteed
- SCIC surgeons do not charge a gap fee

Public Funding via ACT Health – uninsured clients

- 22 adult or child recipients
- SCIC surgeons do not charge a gap fee

Private Health Insurance

- funds approximately 50% of non-public funded implants
- private health insurance covers cost of device, hospital and surgery
- private health funds differ on provision of upgrade devices

Charity Funding

- made available by a Charity, Trust or Foundation and generally covers the cost of the device only – generally about 20 per year



Emeritus Professor Barry Baker graduated MBBS from the University of Queensland in 1963 and doctor of philosophy (DPhil) from Magdalen College in the University of Oxford in 1971. He has specialist qualifications in anaesthesia (FANZCA and FRCA) and in intensive care. He was reader in Anaesthesia, University of Queensland 1972 to 1975. Foundation Professor of Anaesthesia and of Intensive Care, University of Otago 1975 to 1992, and Nuffield Professor of Anaesthetics, University of Sydney 1992 to 2005. He is currently the Dean of Education for the Australian and New Zealand College of Anaesthetists. Barry also has a keen interest in the history of medicine. He has more than 200 publications in the academic and scientific literature on anaesthetic, physiological and historical topics.

The Part Polio Played in the Formation of Intensive Care Units *and* Current Management of Ageing Polio Patients Particularly During Surgery



Polio has been around for a very long time and recorded as far back as the Egyptian times as evidenced on tablets from 1403BC.

Dr Baker spoke of his encounter with poliomyelitis from his childhood years and during his medical career. He first became aware of poliomyelitis as an 11 year old boy in his hometown of Brisbane when an epidemic caused the cricket season to stop for the summer. It turned out to be the worst epidemic on record for Queensland. The seriousness of the epidemic came home to him personally when a 9 year old boy who lived 100 meters from his home contracted poliomyelitis and was dead within the week, this event quickly focused his mind on the whole issue of poliomyelitis.

Dr Baker then spoke of his own mother talking to him about Sister Elizabeth Kenny, who in fact had had NO nursing training, but garnered information from nurses. Sister Kenny lived in Nobby on the Darling Downs west of Brisbane and got involved in nursing people in the district, not just polio patients but anyone who was sick and needed help. She had no nursing training and did not charge for her services. As a child she had fallen off a horse and broken her arm. She was sent to Toowoomba and was treated by a GP, Dr Aeneas McDonnell, who not only fixed her arm but had her into his household for about 6 weeks while she was recovering and this was when she got interested in his medical books and his skeletons and lead to her interest in nursing (it was not common for women to train as medical doctors at that time).

Sister Kenny went back to Nobby and got involved in this ad hoc nursing practice. During this time she was called to a very sick child and she contacted Dr McDonnell who told her that the child had infantile paralysis and that there wasn't anything she could do for it. She asked "*What should I do?*" His advice was to treat what you can, treat the symptoms. So she treated the child with hot compresses and stretching. The child was known to say to Sister Kenny, "*Please I want them rags that welled my legs*". This was how Sister Kenny became involved in the treatment of poliomyelitis; it was prior to the first World War.

She was intensely controversial both in Australia and America but particularly in Queensland. Dr Baker felt a link to Sister Kenny. She opened her first hospital in Clifton (where Dr Baker was brought up), on the Darling Downs. Two medical people who supported her in Queensland were Dr Abe Fryberg, Director of Health, and Dr Aubrey Pye who was Medical Superintendent of the Royal Brisbane Hospital, both of whom Dr Baker knew in the early days of his medical career.

Looking at figures of polio cases in Australia, Dr Baker has been unable to find decent statistics that record cases accurately, in some years (eg 1951) statistics were completely missing. New Zealand statistics are better. They show that roughly one in ten who contracted polio died. In the 1930s there were 592 deaths recorded, in the 1940s the figure was 480 and in the 1950s there were 871 deaths.

His next interaction with polio was as a first year medical student in 1958 when he had to be vaccinated against polio as well as other infectious diseases. It was the Salk vaccine. Dr Baker stated that he has never seen an acute case of polio in his career. It had died out as a disease in our part of the world. When he was in third year medicine he was vaccinated with the Sabin oral vaccine.

Dr Baker's next contact with polio was as a trainee specialist in the Brisbane General Hospital, where he met two polio patients, one who was incarcerated in the hospital and was in an iron lung. This patient did foot-painting and never left the hospital.

As he worked in intensive care he came across a second patient, Fay Cottrell, who had had polio from the 1947-48 epidemic and now had pneumonia. Fay was treated for pneumonia and then sent home; she had very limited mobility, was fairly severely handicapped and in a wheelchair most of the time, she was not on any ventilation, she had not previously had any breathing issues until this pneumonia episode. Within a week she was back with recurrent pneumonia, she was treated again then sent home and within another week she was back. It obviously was not as simple as it looked and each time she came in she required assisted ventilation and was put into a **Both respirator (iron lung)**. She didn't want a tracheotomy as she was an occupational therapist at the Spastic Centre in Brisbane and didn't want to lose the ability of speech. She wanted to be treated in a Both respirator which had to be retrieved from the hospital basement (the only one left from the polio epidemics) for her use.

In the middle of the night this machine failed, Dr Baker was called and he spent the night repairing the leather bellows as she slowly deteriorated. It was eventually decided that she needed to take this respirator home, which she did. She worked during the day and in the evening she went to sleep in the respirator. When she slept her breathing collapsed and this caused her to get pneumonia; the respirator solved this problem.

Interestingly, Fay's blood oxygen levels taken during the day were very low (35mm of mercury tension), which normally would mean the patient would be fairly incapacitated, yet she could do mental arithmetic with these levels (normal levels would have been 140). Doctors were always taught that this low level of oxygen would be incompatible with life yet here she was functioning at a high mental level. This demonstrated to Dr Baker that there is a vast variation of normal, and of what levels you can function within this range of normal. She continued to use the Both respirator at night. She continued working until retirement and lived to a reasonable age.

In the early sixties post-polio syndrome didn't really exist, it did exist but nobody really knew about it, it was thought that once you recovered from polio that was it. However, as we get older, as indeed everyone gets older, we lose a lot of our neuro-muscular function and if you initially had respiratory involvement then your respiratory function can be affected quite badly in the post-polio stage. This is how Dr Baker got interested in post-polio.

Edward Both was an Adelaide engineer who invented his respirator in 1938, it was made of wood and cheaper, quicker and easier to make compared to the 'iron lung' which was made in America and was made of steel (Drinker respirator). Both respirators were used in Fairfield Hospital in Melbourne during the epidemics and filled entire wards.

During the largest European epidemic of 1952-53 (which coincided with Australia's largest epidemic of 1951), Denmark found that they didn't have enough respirators to deal with the huge influx of new polio patients so only a very few people were treated with them. The rest went to the infectious diseases ward under physicians who didn't really understand the problem of respiratory function in the polio patient which led to them being treated incorrectly. A build-up of CO₂ resulted and caused an acid in the blood stream which made the physicians think it was a metabolic problem rather than a respiratory problem and these patients were dying.

Eventually an anaesthetist, Dr Bjorn Ibsen, was consulted and immediately saw that the problem was similar to those patients who had too much anaesthetic and were not breathing properly. He identified the problem and decided that he could provide a quick and easy solution. Most of these patients already had a tracheotomy and so he just connected up a tube and a pump as a means to get the gas in and the gas out. This is what is now called a ventilator but without the mechanical pump. The bag had to be squeezed constantly so he recruited medical students to perform this task, each patient required three medical students doing 8 hour shifts for up to six weeks. The patients then survived in much higher numbers. Prior to this, the death rate of the patients in the wards was nearly 90% and afterwards it was 10-15%. This increase in survival rate and the continuing arrival of new cases saw the need for a mechanical 'hand' to be invented that could mechanically squeeze the bag.

*That was the beginning of major **ventilator** production all over Europe. This was the beginning of saving polio patients. It was also found that many other respiratory problems, that is, those not related to polio, could be saved by the advent of the ventilator. It was also how **intensive care** started.*

It took longer for the ventilator to be used in Australia. In 1956 Dr John Forbes, a very famous infectious diseases physician and Australian Medical Superintendent at Fairfield Hospital, Melbourne, stated that "*This hospital, with experience of all methods of artificial respirations, considers that the tank type of respirator or iron lung is still the most efficient machine*". This was 3 years after the big change was made in Europe on how to treat respiratory failure. This was partly because the ventilator was a bit more complex than a 'box that had big bellows' (the Both respirator). The Both respirator pumped the air in and out, making the patient breath in and out.

In Copenhagen, Dr Ibsen realised that if polio patients could be treated with ventilators then many other patients with respiratory problems could benefit from this type of treatment as well. So he started up a special ward for respiratory treatment of patients who needed this artificial ventilation or respiration. In the first four years he treated 121 patients with respiratory insufficiency after surgery, 60 patients after trauma, 34 patients with primary lung disease, 19 patients with neurological disease and 25 patients from other conditions such as poisoning. Of these 259 patients in total, 93 died.

*So, this ward was what we would regard now as an **Intensive Care Unit**, it was the very first ICU anywhere in the world which evolved solely from the treatment of poliomyelitis patients.*

Medicine can be very conservative and new ideas can sometimes take many years before they will become accepted as shown with Dr Forbes who was an infectious diseases physician, not an anaesthetist, and who was very resistant to any new treatments. Eventually Fairfield Hospital had an ICU attached to it and he did change but it took a while.

Acute Polio Phase

Destruction of anterior horn cells (motor cells)

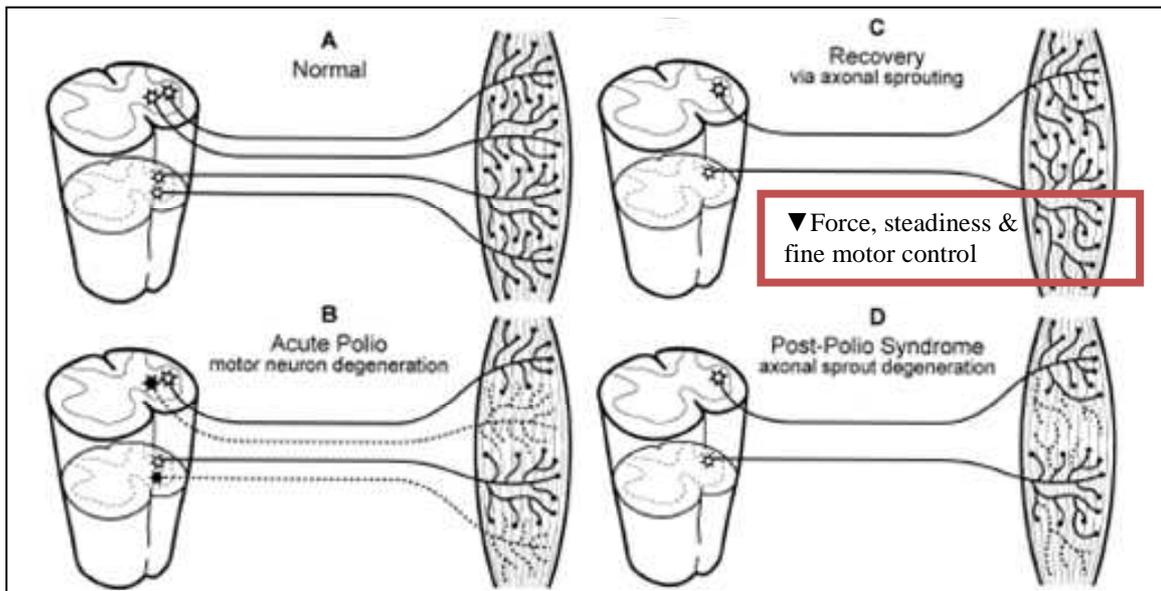
Brainstem cells

- **reticular formation – motor, cardiovascular system, respiration,**
- **swallowing, pain, sleep**
- **vestibular nuclei – balance**

Cerebellum – roof nuclei – ataxia (lack of co-ordination of movement)

Recovery starts after 2-3 weeks and will plateau after 7-10 months, it is a long time then before things start going downhill again.

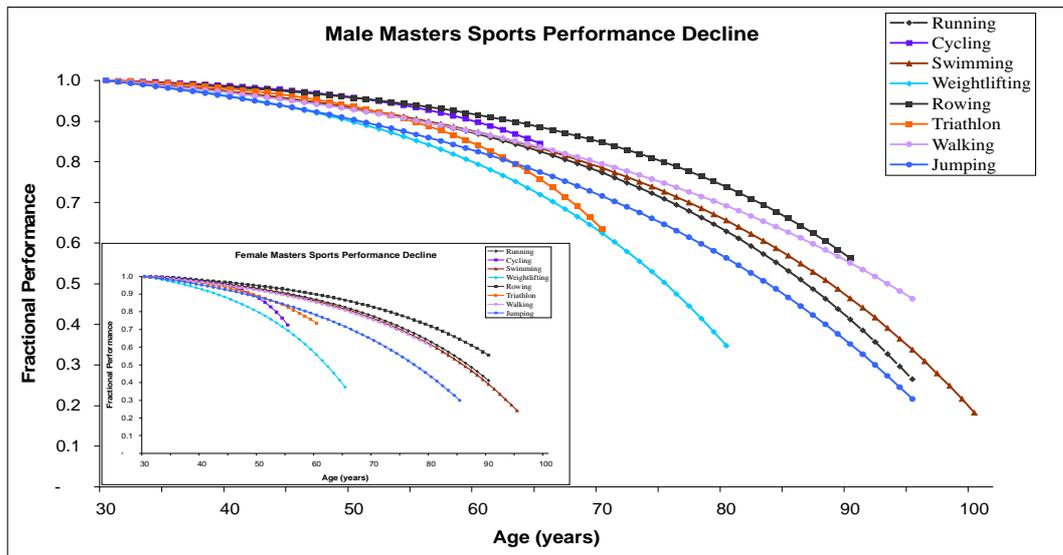
Acute polio is the destruction of motor neurons but the more important ones are the brain stem cells; these are the ones that catch up with you particularly at the acute phase but also in the post-polio phase. They are probably the ones that cause the most difficult problems to deal with such as those experienced by Fay Cottrell.



Anesthesiology 2005; 103: 638-644

The Poliomyelitis virus knocks out some of the motor neurons (**B**), then in the recovery phase the remaining neurons sprout extra 'branches' and link up so you start to compensate a little bit and you get some recovery (**C**). Then over time these extra branches start to become less (**D**) and they drop off. As we age, everybody experiences 'drop off' not just polios, but in post-polio syndrome (**D**) we can see that we end up in a phase that is similar to the 'acute polio' phase (**B**) and this is not so good.

The symptoms of post-polio syndrome (PPS) are fatigue, somnolence (a strong desire to fall asleep), poor concentration, muscle weakness, pain (muscle pain, for example: bursitis, tendonitis, overuse pain, joint and back pain), dysphagia (difficulty swallowing) (10-20%), cold intolerance (65%), and respiratory dysfunction problems (40%). Respiratory dysfunction can be associated with scoliosis/kyphosis, sleep apnoea, and hypoventilation but can also be due to brain stem cells being 'knocked out' during the acute phase.



Baker and Tang
 Experimental Aging Research 2010; 36:453-77

Dr Baker also has an interest in how we age; we are all on a deteriorating phase from the moment we get over the 20-25 year stage. Mostly people are pretty good up until 60 and then things start to fall off at a faster rate. At 60 you are 15-20% less than what you were at 20-25 and then after that it goes down. Then between 50-70 it is 35-40% of what you were at 20-25. If you are post-polio you can be okay up to say 50 or 60 and then you start to fall off. Unfortunately, with post-polio you have to remember that you haven't got as many of the motor neurons to work with as non-polio people. And this is why late middle age is a critical time for post-polios.

Motor neurons drop off in everybody but in post-polios the problem is that we have already lost some at the acute polio stage. So as we all age there is a gradual decrease in anaerobic and aerobic systems, a decrease in muscle mass, strength and power, a decrease in reaction time, co-ordination, joint mobility and skeletal size.




PPS & Anaesthesia

Preop Assessment

- VC < 1500 ml or < 50% predicted – needs full pulmonary function tests
- SRDB may have cor pulmonale or pulmonary hypertension

Periop Management

- No reports of adverse effects with regional anaesthesia
- More sensitive to anaesthetic drugs – “low & slow”
- Do not use suxamethonium if possible
- Care with non-depolarising neuromuscular blocking drugs – “low & slow”
- Care with opioids – “low & slow”
- Slow discharge from Recovery or PACU – more monitoring
- May require sleep apnoea assistance or even ventilation

Polio – Acute to Chronic
Barry Baker 2014

The common problem with polio people that Dr Baker has spoken to in relation to anaesthetics is that their doctors won't listen. So if you are a polio patient and about to have an anaesthetic you should NOT assume that the doctor knows even if he has performed anaesthesia on you before, you need to remind him that you are a post-polio patient and that there might be problems.

Pre-operative Assessment: Initially you should have basic respiratory function tests performed to decide if you need more extensive tests to assess your respiratory function. Regarding a respiratory function test – if the results are less than 1500 ml or less than 50% of what is predicted then you should have a full set of respiratory function tests so that the doctor can see exactly what the problem is and how bad you might be.

Respiratory disability issues are made worse if you have got other problems such as scoliosis/kyphosis, sleep apnoea, and these respiratory issues will affect the heart also. If you have a problem getting air in and out of your lungs this then obstructs the way that the blood flows from the right side of the heart to the left side of the heart. This causes the right side of the heart to get more energetic so it can drive the blood flow through and causes the development of hypertrophy (enlargement) of the right side of the heart or cor pulmonale or pulmonary hypertension, that is, the blood pressure in the pulmonary artery is higher, whereas cor pulmonale refers to right sided heart insufficiency.

Peri-operative Management: There are **no** reports of problems with regional anaesthesia (local), it is better than having a general anaesthetic.

You will be almost certainly more sensitive to anaesthetic drugs (general) and so Dr Baker says – “low and slow”, that is, a low dose and give it slowly. This will help the doctor become aware of how it is affecting you. The drugs take time to work, so if you inject them then wait for them to take effect, you can then decide if you need to give a little bit more. Low dose and slow, repeat doses are the way to go.

DO NOT use suxamethonium which is a short acting neuromuscular blocking drug (a depolarising drug) which has been shown to have some prolonged effects for post-polio patients. Most anaesthiologists will know this. It is the “low and slow” technique that really needs to be enforced to the anaesthiologist.

Care should be taken with non-depolarising agents which block the neuromuscular junction, effectively putting a blind across so the transmission cannot occur from the neurons to the muscles. So again, “low and slow”. Post-polios have fewer neurons to work on fewer muscles, and if you get a big dose the drug is going to hang around for a lot longer. Low and slow, give it time to work.

Care should also be taken with post-operative analgesia, opioids particularly, again low dose and slow. If you have respiratory problems that come from the mid brain then you have fewer respiratory neurons that are working and if you knock them out with a big dose it is going to lie around a lot longer before you get back to normal. Ask to be kept in the recovery area or the post anaesthetic care unit until everybody is sure that you are breathing fine, or if there is a problem you can then be sent to an ICU. If you have sleep apnoea issues then you may need sleep apnoea assistance. Sleep apnoea is when you actually have periods where you stop breathing, stop and start, stop and start. The stopping periods can be quite prolonged.

During question time when members related some of their experiences and concerns, Dr Baker stated that we should make the doctor listen to our concerns about anaesthesia. It is in our interest to try and remind the doctor we are post-polio patients and that they need to be extra careful.

Pat Featherstone stated that she always starts by asking the doctor what he knows about post-polio. She then has to tell them the basics and finds that most have been receptive. It is very hard to get past the attitude of people and doctors that there isn't any polio around and that they know very little about it

Dr Baker reinforced that if we are going to have surgery then we must firstly talk to our surgeon about our concerns with anaesthetics and that most polio patients have problems with anaesthetics and you want to be sure that the anaesthetist is aware of post-polio. Try to be diplomatic.

Nola Buck asked why when she comes out of an aesthetic she is shivering. Tell the nursing staff, everyone not just the anaesthetists, and remind them again at the latest possible opportunity, that is, just before the commencement of your surgery "*Don't forget that I'm a polio patient*". Communicate with everyone who is involved in your care. Don't think that everyone has read your notes. Tell them that you have paralysis in your left leg or arm or that you have back issues or lung issues or cold intolerance. Keep communicating.



My Polio Story - by Madeline Coelho

I contracted polio in 1954 at the age of 2½, before the Salk vaccine was invented. In 1954 I was living at Chullora, the migrant camp, when I was struck by a log at the bottom of a pile of logs. It cut open my ankle. I was taken to hospital for stitches. It was at the hospital that I contracted the polio virus. Hospitals can be dangerous places and are not always germ-free. For six weeks while the virus incubated, I was very ill and could not stand on my right leg. Mum took me to numerous doctors. They said I was 'bluffing'. It was only after the six weeks was over that Mum was told I had polio. By that time it was too late to do anything. They told me I was lucky to have a 'clear' chest - I didn't need to go in an iron lung. My right leg was the most affected. I had a drop foot (where I had had the stitches), my right leg was 1½ inches shorter than the left leg, and there was wastage in the muscles of my right leg. They put a calliper on my right leg and for a time I was taken to Royal North Shore Hospital for physiotherapy. A sponge was put under my right knee and wrapped in a rubber band. I think this was the treatment Sister Kenny had initiated. After a while they stopped the physiotherapy. They told Mum they could do no more for me. They took away the calliper and I had to walk without help. I remember suffering with shoes that did not fit my right 'drop' foot. I always had blisters. I could not do sports. It wasn't until I reached the age of 8 that I was able to hop on my right leg. It was quite a triumph, like Alan Marshall in "*I Can Jump Puddles*".

When I went to school I excelled academically. Sports was another matter.

My life has certainly been a challenge living with the after effects of polio and now, in my early sixties, with Post-Polio Syndrome. I have always been a Type A personality, always achieving, overexerting myself. Academically I was an overachiever and I was not always interested in my personal or social life. I did not get married young, indeed not until the age of 39. I missed out on having children.

My husband passed away over 11 years ago from leukaemia at the age of 43. I was now alone. I have been battling with my various disabilities (bipolar disorder, Type 2 Diabetes) ever since. I have learnt not to push myself these days. I need a 'nanna' nap in the afternoon. Sometimes I find it is better to isolate, as being around other people can be stressful. I have had special orthopaedic shoes from my twenties. Unfortunately they are very expensive. Meanwhile I have to live with the after effects of this terrible disease as do many others.

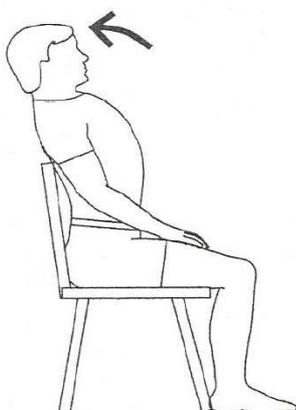
Proper Stretching Techniques by Liz Pike

This article is reprinted from the Atlanta Post-Polio Association's newsletter, APPA News, Fall/Winter 2013/2014.

Liz Pike is a physiotherapist from the Shepherd Center. Most of these stretches can be done by everyone in APPA. You may not be able to perform them all but there is huge benefit in doing even one of them on a daily basis. Like many things, after years of neglect, stretching for a day or two won't produce miraculous results, but you will see a big difference after a week of daily stretching. Of course, be careful, especially at first, to not over stretch anything. After a long period of inactivity there will be muscles that are pretty tight and will need a while to loosen up. One real advantage to these stretches is that many can be done sitting down which makes it easy to do them while watching TV!

Exercise Program For:
APPA

Date:09/05/2013
Page:1



Stretch cerv ext w/chintuck

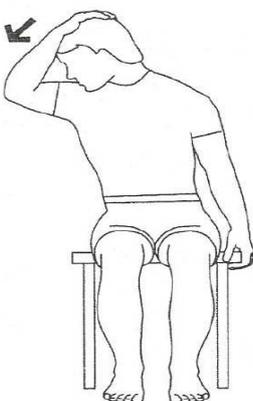
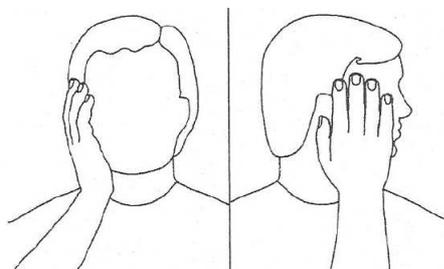
- Sit in chair with good back support.
 - Maintain proper posture.
 - Tuck chin in.
 - Bend neck back, keeping the chin tuck.
 - Return to start position and repeat.
- Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.

Stretch cerv rotn

- Place right palm against right jaw.
 - Gently rotate head to left as shown.
 - Repeat with left hand in left direction.
- Perform 1 set of 4 Repetition, twice a day.

Hold exercise for 20 Seconds.



Stretch Levator scapulae arm down

- Sit on chair
- Grasp seat with the hand on the side of the tightness.
- Place your other hand on head and gently pull down and diagonally to other side.
- You should feel a light stretch but it should not be painful

Special Instructions:

Look in the direction you are pulling.
Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.

Stretch thoracic rotn sit

- Sit tall in chair with arms crossed over chest.
- Turn and twist trunk to the right.
- Return and twist to the left.
- Repeat.

Special Instructions:

Keep trunk upright during the twisting motion.
Perform 1 set of 4 Repetition, twice a day.

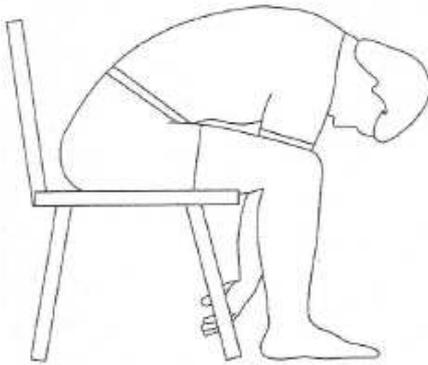
Hold exercise for 20 Seconds.



Stretch lumbar flx sit

- Sit in chair with knees apart.
 - Slowly bend forward and reach between legs.
 - Hold stretch and return to sitting position and repeat.
- Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.

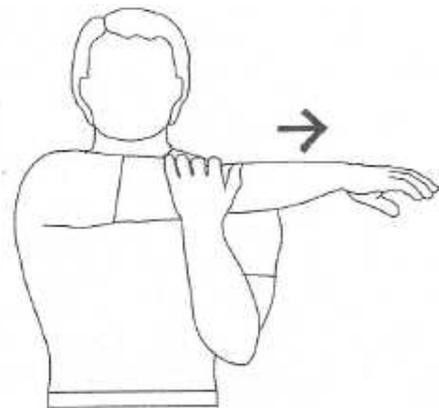


Stretch shld capsule posterior w/arm

- Bring involved arm across in front of body as shown.
- Hold elbow with other arm.
- Gently pull across chest until a stretch is felt in the back of shoulder.

Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.



Stretch shld capsule inferior

- Raise involved arm over and behind head, elbow bent.
- Grasp elbow or wrist of involved arm with uninvolved arm.
- Pull gently until a stretch is felt.

Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.



Stretch knee ext uni sit w/stool

- Sit in chair.
- Place right ankle on a chair or stool as shown.
- Relax leg and let gravity straighten knee.

Special Instructions:

Push down on knee if possible.

Perform 1 set of 4 Repetition, twice a day.

Hold exercise for 20 Seconds.



Stretch knee flx sitting

- Sit in chair.
- Bend involved knee to 90 degrees and place foot flat as shown.
- Gently move chair forward.
- Do not let foot move.
- Relax and repeat.

Perform 1 set of 4 Repetitions, twice a day.

Hold exercise for 20 Seconds.

Stretch toe flexors w/towel

- Sit with foot on floor.
- Loop towel under toes and gently pull up into stretch.
- Keep ball of foot on floor.

Perform 1 set of 4 Repetitions, twice a day.

Use: Towel.

Hold exercise for 20 Seconds.



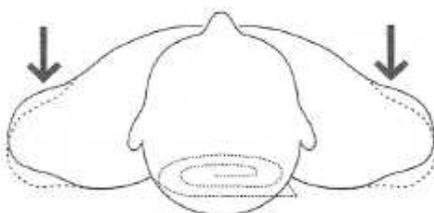
Stretch Pectoral supine static arms at side

- Lie on back with towel roll placed vertically between shoulder blades.
- With arms at side, gently allow shoulders to move toward floor.

Perform 1 set of 4 Repetitions, twice a day.

Use: Towel.

Hold exercise for 20 Seconds.



Making Beaches Accessible to All



People with a disability can take in the beach delights at Port Stephens

Getting onto Port Stephens' many beaches is now a whole lot easier for people with a disability thanks to two new Sandcruiser beach wheelchairs introduced by Port Stephens Beachside Holiday Parks.

The all-terrain wheelchairs are available for visitors and locals, and not just guests at the group's four Port Stephens holiday parks.

The state-of-the art wheelchairs feature pneumatic tyres which make navigating grass and sand easy.

The special wheelchairs are available for loan from Halifax and Fingal Bay Holiday Parks at no cost.

Port Stephens Beachside Holiday Parks is an enterprise of Port Stephens Council.

Contact: Halifax Holiday Park 02 4981 1522 or Fingal Bay 02 4981 1473 <www.beachsideholidays.com.au>

Keeping Our Minds Active by Using Special Games on the Internet

by Anne O'Halloran

Permission was given to include the information and name of the program with their suggested credit:- "From Active Memory – online brain training - www.activememory.com".

I have been "playing" games on the internet for 10 months.

You might have seen last year an ABC program where the main player was put through several tests which challenged the mind. Out of that grew an online program called "Active Memory". Scientific experts at the University of Melbourne and Florey Institute of Neuroscience and Mental Health work with the ABC to develop the games.

Active Memory offers a two week free trial of the games. If one decides to go further there is a monthly fee of \$12.50 which works out at around \$3.10 a week which I find very reasonable for such a challenging way of exercising my brain. Different games are added over time.

As one reaches certain goals set by Active Memory, further challenges are added. The games focus on memory, attention and flexibility. Progress scores are shown in the form of a graph.

At the risk of sounding pleased with myself I will admit to improving since my first game. The scores are Overall (memory, attention and flexibility); on 26 October 2013 I scored **298**, my latest score on 2 September 2014 shows an Overall figure of **839**. I am hoping to improve on the latter.

To play online one needs fine hand movement such as the ability to use a mouse and keyboard. If access to these tools is a problem maybe Technical Aid to the Disabled (TAD) could be contacted to invent an adaptation to assist.

The games are worth a go!



We love to hear from our members to get feedback and comments of any number of topics. Following are this edition's contributions, both sent to Support Group and Member Liaison Coordinators, Gary and Barbara Fuller, from members who appreciate his personal contact.

Last October I returned from a trip to France. I was surprised at the lack of disability-friendly facilities overseas for both visitors and residents alike. When one uses the metro in Paris one is met by many stairs, no lifts or escalators. It is exhausting for those suffering from Post-Polio Syndrome and/or in wheelchairs.

When I visited the art galleries and museums, for example the Musée Marmottan and the Musée D'Orsay, again there are not enough lifts, ramps and too many stairs. It is exhausting visiting these places when one has a disability. To enter the Musée d'Orsay, which houses the Impressionist artists that the Louvre does not house, I had to stand in line for more than half an hour. Anyone who has Post-Polio Syndrome knows it is hard to stand for any length of time and inside the gallery are dozens of stairs (downstairs when one needs to use 'les toilettes').

It is tiring getting around although both the sculptures and paintings are breathtakingly beautiful. Why should those of us who have a disability be seen as less important than able-bodied people? How do we improve the facilities for those of us with a disability who love art galleries and museums, both overseas and here in Australia.

Regards, Madeline Coelho



To Gary and Barbara

Good morning to you both, I write primarily to thank you and the Committee of Polio NSW Inc for the wonderful work you do. Only those of us who are a long way from the centre of activity can fully appreciate the value of your efforts. The receipt of your "support group letter" triggered many thoughts and memories for me which I will try and explain.

With your activities you have made me feel as though I am part of a network, which is comforting even though I'm a long way from the centre of activity. I am of course not the only one, as I'm sure there are many others. An example would be Mary Keast who was rung and welcomed. I do not know this lady but I know her location like the back of my hand.

I was holidaying with my grandparents on their grazing property in the Urbenville district when I got out of bed one morning and collapsed on the floor. Polio had struck. It was Sunday the 26th of January 1951, Australia Day. Unfortunately I had been in two other relatives' homes for a few days also on my school holidays and left a trail of polio behind me. A cousin and an uncle fortunately made good recoveries. Some years later, after becoming a tradesman and putting together enough money for a deposit on a property, I bought my first land quite close to the village of Urbenville. I spent 7 years on the Hospital Board at Urbenville before resigning to become a Councillor on Kyogle Shire. It was during this time that I became acutely aware of the need to express one's gratitude to people who work for others which is what you are all doing. I trust that you understand what I'm trying to say here. Thank you sincerely.

As an elected member of Council I had pleasure of meeting many people, not the least of whom was the Premier of Queensland at that time, Joh Bjelke-Petersen. I mention this because Joh was one of us, Barbara, he had polio in New Zealand before coming to Australia. He was much better on his feet than me as I struggled to keep up to him as we walked the street in Kyogle. He was a very down-to-earth man to discuss cross-border issues with (Kyogle Shire runs up to the Queensland border). In reading a book about his life many years ago, I was surprised to learn that one of the treatments tried on him in New Zealand involved him being strapped to bed and given electric shocks.

We now live hundreds of kilometres to the west of that area and I haven't been to Urbenville for some time, the move west prompted by pursuit of excellence in cattle breeding.

That's enough of my waffling, thank you again for the help you give. Best wishes, Neville Bryant



2014 Polio NSW Seminar Program

Saturday 18 October	Gungahlin Lakes Cnr Gundaroo and Gungahlin Drives Nicholls ACT	Country Conference – Canberra <i>See Page 2 for the Speakers and Topics</i> Return Registration Form by 10 October
Saturday 29 November	Burwood RSL 96 Shaftesbury Road Burwood	Annual General Meeting 25th Anniversary Lunch Guest Speaker to be advised

Management Committee – Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9487 3094
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Barbara Fuller, Gary Fuller, Alice Smart and John Tierney			

PPN Office and Other Contact Details

Office staff: George, Fatma. John		office@polionsw.org.au	02 9890 0946
Volunteers: Nola Buck			02 9890 0953
Anne O'Halloran	Seminar Co-ordinator	seminar@polionsw.org.au	02 8084 8855
Alan Cameron	Website Webmaster	webmaster@polionsw.org.au	0407 404 641
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.