

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

Welcome to this bumper issue of *Network News*. It has been a long time coming, and for that I must apologise. Several members of our small team were unfortunately out of action for different reasons over the last few months. For example, Susan Ellis, our co-Editor, moved house earlier in the year and has been without computer access as well as being kept busy packing and unpacking after moving from her home of 38 years.

Others were heavily involved as "lived-experience polio experts" in the Polio Australia/Rotary *Late Effects of Polio Clinical Practice Workshops* series, and were also busy with preparations for the *Australasia-Pacific Post-Polio Conference: "Polio – Life Stage Matters"*.

Following Polio NSW's 28th Annual General Meeting on 10 December (see full details on page 2), we are delighted that Mary-ann Liethof, National Program Manager, Polio Australia will be joining us to present on both the Conference and the Workshops. If you were unable to get to the Conference, and if you have been wondering how the Clinical Practice Workshops as previously advertised in *Network News* went, you won't want to miss this Seminar. Full details are on page 3.

To book your place, please complete the enclosed Registration Form and return it with your payment to the Polio NSW Office by Wednesday, 7th December 2016. We look forward to seeing you at both the AGM and the Seminar.

With the publication schedule of *Network News* now back on track you will be pleased to see that Sue Ellis has included part 1 of her eagerly-awaited report on our May Seminar (see pages 5-11), as well as other articles of interest.

Your Committee took advantage of the presence in Sydney of the Conference international keynote speaker Dr Bill DeMayo from Pennsylvania, USA, and so we put on an extra Seminar for members this year. Dr DeMayo conducted a Question and Answer session across a range of topics. Sue's report on Dr DeMayo's presentation will be in the next issue of *Network News*.

Finally, by the time you receive this newsletter the annual "Walk With Me" trip to Canberra will be over. Together with Polio Australia, Polio NSW (with the support of the ACT Support Group) participates in this fun event to jointly keep our post-polio issues in front of Federal parliamentarians, and raise some vital funds for both organisations. This year the *Parliamentary Friends of Polio Survivors* group will be launching the new and improved *Australian Polio Register* website, and an *Interdisciplinary Post-Polio Health Professionals Register* which enables health professionals and polio survivors alike to have ready access to polio-knowledgeable health professionals across a range of disciplines and locations. For more information on these initiatives, see:

[<www.polioaustralia.org.au/walk-with-me-2016>](http://www.polioaustralia.org.au/walk-with-me-2016)

[<www.australianpolioregister.org.au>](http://www.australianpolioregister.org.au)

[<www.poliohealth.org.au/post-polio-health-professionals>](http://www.poliohealth.org.au/post-polio-health-professionals)

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.

On Saturday, 10 December 2016, Polio NSW will hold our 28th Annual General Meeting, followed by our year-end Seminar (see page 3 for full Seminar details).

The AGM is your opportunity to have a say in the direction and programs of Polio NSW, and to help your fellow polio survivors by standing for election to the Management Committee (*there are vacancies to fill*).

We look forward to your participation in the AGM and Seminar.

Polio NSW 28th Annual General Meeting

Date: Saturday, 10th December 2016

Time: 11:00 am - 12:00 pm *Followed by Lunch and Seminar*

Venue: Burwood RSL Club
96 Shaftesbury Road, Burwood NSW
Parking is available on site but, as always, you are advised to be early

Annual General Meeting Agenda

1. Opening of Meeting
2. Present
3. Apologies
4. Confirmation of Minutes of 27th Annual General Meeting held 5th December, 2015
5. 2015/2016 Annual Report
6. 2015/2016 Financial Report
7. Auditor's Report
8. Election of Management Committee (*minimum 6, maximum 12*)
 - 8.1 President
 - 8.2 Vice-President
 - 8.3 Secretary
 - 8.4 Treasurer
 - 8.5 Committee Members (*minimum 2, maximum 8*)
9. Appointment of Auditor
10. Appointment of Patron(s)
11. General Business
12. Close of AGM

Included with this Network News is a proxy form so you can still have input to decisions made at the AGM even if you are unable to attend in person.

The 2015/2016 Annual Report and audited Financial Report will be sent to members separately.

**Don't forget to return the enclosed Registration Form
to the Polio NSW Office by Wednesday, 7th December 2016**

AGM Seminar presented by Mary-ann Liethof National Program Manager, Polio Australia

Australasia-Pacific Post-Polio Conference: Why, What and Who?



**2016 Australasia-Pacific
Post-Polio Conference**
Polio - Life Stage Matters



Polio Australia and Rotary District 9685 Partnership to Educate Health Professionals

Date: Saturday, 10th December, 2016

Lunch: 12:00 pm

Before the Seminar and following the AGM at 11:00 am

Time: 1:00 pm

There will be a tea break between Mary-ann's two presentations

Cost: \$15.00

For catering purposes, RSVP by Wednesday, 7th December 2016

Mary-ann Liethof worked as the Coordinator of Polio Network Victoria, from mid-2004 to December 2009. During that time, Mary-ann produced a DVD titled "*Post Polio Syndrome: The Australian Experience*" and was one of the Victorian representatives on Management Committee for Polio Australia. Following a small philanthropic grant and a private donation, Mary-ann was officially appointed as Polio Australia's National Program Manager in early January 2010 on a part-time basis, increasing her hours to full time in 2011 following a second grant.

In April/May 2008, Mary-ann visited 10 post-polio related services across North America on a Churchill Fellowship Study Tour, the purpose of which was "*To identify techniques to better manage the late effects of polio*". On her return, she produced a Report and series of videoed interviews titled "*Post Polio Syndrome: Shades of Grey*". Both were distributed widely to polio networks and support groups both nationally and internationally, and are available on-line on Polio Australia's website.

In April 2009, Mary-ann travelled to Roosevelt Warm Springs in Georgia, USA, for Post-Polio Health International's 10th International Conference "*Living with Polio in the 21st Century*" and 4-day Wellness Retreat to learn the benefits of this self-management model. With this knowledge, she facilitated Australia's first Chronic Condition Self-Management Residential Program (also known as the Polio Health & Wellness Retreat) for 60 polio survivors and their family/carers in April 2010 in New South Wales, and has continued to run them annually in the eastern states.

In 2011 and 2014, Mary-ann attended two European Post-Polio Conferences in Copenhagen and Amsterdam, as well as Post-Polio Health International's 11th International Conference in St Louis, USA, where she gave presentations on Polio Australia's Chronic Condition Self-Management Residential Program.

In 2016, Mary-ann realised a career ambition by staging Australia's first ever "*Australasia-Pacific Post-Polio Conference: Life Stage Matters*", in Sydney. This 3-day international conference for health professionals and polio survivors attracted 230 speakers and delegates from 11 countries, and received unanimously positive reviews. Her first AGM Seminar presentation will focus on the Conference and its outcomes.

At the Conference, Mary-ann presented on Rotary District 9685 and Polio Australia's joint project in 2015/2016 to run 8 Clinical Practice Workshops in Sydney's northern suburbs for 140 health professionals. Her second talk following the AGM will report on these Workshops.

The Mt Wilga LEOp Assessment Experience

by John Tierney – President, Polio Australia

In early July I undertook one of the three-hour assessment sessions at the Post-Polio Clinic at Mt Wilga Private Hospital in Hornsby. I highly recommend this experience to all polio survivors who are trying to understand where their LEOp condition is up to, what might lie ahead and what are the most appropriate therapies at this stage of their condition.

We have all been through the frustration of doctor shopping and trying to access the most appropriate treatment for our LEOp condition from medical professionals who have never had any pre-service or in-service training in the management of polio or the LEOp condition. With every new health practitioner I take along a lot of written material to educate them.

The Mt Wilga clinic and its highly professional team were a breath of fresh air. Not only were a multidisciplinary team involved, but they were highly knowledgeable about LEOp. Their assessments are now in high demand, which I discovered when I cancelled my May appointment because of a time clash and couldn't get back in until July!

The clinical assessment takes you through three one-hour sessions in turn, with a physiotherapist, an occupational therapist and a specialist medical practitioner. The experience starts with a number of physical tests that examine things like muscle strength and ends with discussion about the best way forward to better manage the LEOp condition.

Although some of the costs of the assessment are covered by Medicare, other costs have to be met by private health insurance or paid out of pocket. The cost of the physiotherapist and the occupational therapist are not covered by Medicare. All up this came to \$330, most of which will be reimbursed by a private health fund if you are a member.

Because not everyone can afford the cost, Polio NSW is currently in the process of taking a proposal to the NSW Minister for Health to have an LEOp clinic established in a public hospital in a different part of Sydney so that more polio survivors can receive this wonderful new LEOp assessment service.



Seminar - Managing Pain - 18th May 2016

by Anne O'Halloran, Seminar Co-ordinator

Our seminar in May, "Managing Pain" provided information on options for dealing with pain including strategies for self-management. Also extremely helpful were hints on shoulder care.

At the seminar one of the speakers, Dr Toby Newton-John, asked if members would be interested in taking part in a research project investigating the pain experiences of people with Post-Polio Syndrome (**see pages 16-24 for Dr Toby's presentation**).

If you would like to take part in the research, please send your details and contact address by email to: <toby.newton-john@uts.edu.au> or send the details by mail to:

Dr Toby Newton-John, Senior Lecturer, Graduate School of Health, PO Box 123 Broadway, NSW 2007.

The details requested are: Name Address Telephone Email Age

A research assistant will contact you. Thank you very much for your assistance.

Research Project

Anne O'Halloran has received the following email regarding Dr Toby's research project:

"My name is Kristine and I am a Master student under the supervision of Dr Toby. I will be conducting the research that explores Post-Polio Syndrome and pain coping strategies.

I am following up on the email you had sent Toby last week about the research project. I am currently writing up the research proposal for approval, and will be submitting the ethics application by December.

We hope to be able to launch the research survey by February/March 2017, and will keep you updated on the research progress. Warm regards, Kristine Koh"

Seminar Report - Managing Pain

by Susan Ellis

Wednesday, 18th May 2016

Amal Helou: Amal has over 30 years' experience in pain management, she is employed as a nurse practitioner in the Pain Management Centre at Royal Prince Alfred Hospital. She has particular interest in patient and family education and has actively worked and advocated for pain management in the older person in hospital and community settings. Amal is also interested in exploring patient narrative as a therapeutic intervention and the impact persistent pain has on the whole individual. She is on the ACI (Agency of Clinical Innovation) pain network steering committee which helps to support new pain services and develop pain research in NSW.

Pain Management

As a declaration I am not an expert in Polio or post-polio syndrome – I have learnt from:

- My experience
 - a few patients
 - my mother who contacted the disease when she was 18, she is now 90, a fighter
- Anne O'Halloran - Polio NSW
- Google scholar

How can pain be measured? Can pain be measured on a thermometer, on a computer or by a brain scan? The best way to measure pain is to talk to the individual experiencing it. If they can't talk about their pain, then observe them, look at their face – as you watch the person, you look at the way they relate to their environment, how they are moving, if they have gone off their food. It is very individual and personal.

What is pain?

The International Association for the Study of Pain says "*Pain is unpleasant and it causes suffering*". It can affect our emotions. Pain is our alarm system that our mind associates with there being a potential threat to our body. In acute pain when the medical problem is treated the pain will typically subside and go away. As an example, a burn on the finger from a touch of a hot frypan quickly cooled in ice water, the pain resolves. Pain usually begins as an acute or short-lived symptom that is due to a medical problem or an accident.

Pain has the following components:

Sensory - where the pain is and how it feels

Emotional - the meaning of the pain and my response to it

Cognitive - identifies the place where you experienced it and in what part of your body

How you look at pain in order to define it – Visible signs of Pain:

- Nociception – obnoxious stimuli or the unpleasant event that the nerves detect
- Pain is what happens in the brain when that event or trauma causes signals that go up to the brain to recognise pain
- Suffering is an emotional response to that pain
- Pain behavior is what the patients says or does that tell us they are in pain (Loeser)

Pain can be broadly divided into three classes:

(a) **Nociceptive pain** represents the sensations associated with the detection of potentially tissue-damaging noxious/unpleasant stimuli and it is protective. It stops the body from continuing further in that activity if there is pain which acts as a warning.

(b) **Inflammatory pain** is associated with tissue damage and the infiltration of immune cells and can promote repair by causing pain hypersensitivity until healing occurs. Inflammatory pain is often involved with arthritis, things that you feel or touch; if you touch the joint that is inflamed it will feel hot and sore. Icepacks help with inflammatory pain, but most would prefer something warm and when muscles are involved and there is pain due to muscular activity or overuse then heat is appropriate.

(c) **Pathological pain** is a disease state caused by damage to the nervous system (neuropathic pain) or by its abnormal function (dysfunctional).

Summary of pain:

Nociceptive stimulus ⇒ physiological transmission of nociceptive stimuli to the brain ⇒ pain perceived ⇒ processes that impact on the impulses are; descending inhibition (tell the body to calm down), effects emotions, effects behavioral responses, beliefs and attitudes, meaning of the pain.

If we know what the cause of the pain is, e.g. a burn or a cut, then we are not going to fear it as much compared to an unknown pain caused from say a disease process like cancer or heart attack. So if you know and understand what is creating the pain and what the components are you are not going to fear as much and then your response to it is lessened. So with education people can cope with their pain better.

Chronic Pain:

Unfortunately, for a proportion of the population their pain does not subside but rather persists long-term, even when the healing of the medical illness or the injury appears to have finished. And often it is not visible, you look normal, no one can see it, you look perfect.

Chronic Pain is pain which has lasted longer than the expected healing time and has persisted beyond >3 months. It can develop into a disease process with complex factors which can impact physically/psychologically on the patient and their coping style increases suffering.

Amal listed the following from her research that related to post-polio patients.

Conclusion: "Complaints of pain or fatigue in patients with PPS who are older or elderly should not be attributed "merely" to the process of ageing." *Pain and Fatigue in Persons With Postpolio Syndrome: Independent Effects on Functioning: Mark P Jensen, PhD, Kevin N Alschuler, PhD, Amanda E Smith, BS, Aimee M Verrall, MPH, Mark C Goetz, PhD, Ivan R Molton, PhD Arch Phys Med Rehabil* 2011;92:1796-801.

Results: that pain is a common and persistent problem in PPS, with more than 90% of our participants reporting problems with pain. *Pain in Persons With Post-polio Syndrome: Frequency, Intensity, and Impact: Brenda L Stoelb, PhD, Gregory T Carter, MD, Richard T. Abresch, MS, Sophia Purekal, BA, Craig M McDonald, MD, and Mark P Jensen, PhD*

(Also see article below: “Pain in Post Polio Syndrome” by Anne C Gawne, MD, Roosevelt Warm Springs Institute for Rehabilitation, Post-Polio Clinic, Warm Springs, Georgia)

Chronic Pain and Post-polio Syndrome: (by Mayo Clinic Staff)

Common signs and symptoms include:

- Progressive muscle and joint weakness and pain
- General fatigue and exhaustion with minimal activity
- Muscle atrophy
- Breathing or swallowing problems
- Sleep-related breathing disorders, e.g. sleep apnea
- Decreased tolerance of cold temperatures

In most people, post-polio syndrome tends to progress slowly, with new signs and symptoms followed by periods of stability.

Chronic pain and post-polio syndrome?

Main problems arising may include:

- Fatigue
- Muscle weakness faster than in normal ageing
- Muscle pain (deep aching pain)
- Gait disturbance
- Respiratory problems
- Swallowing problems
- Sleep apnoea
- Restless leg syndrome

Impact of pain?

It can have an impact on our daily life making it harder to do the things we enjoy, like work, exercise, playing sports or being involved in family activities. All the symptoms are made worse at the end of the day when the person is tired and struggling with staying functional.

What next?

We start asking our friends and family how to solve this problem, we may start seeing doctors or going to a chemist to buy medications and taking remedies that do not work or are short lived. Many go onto websites, read and become more enlightened and go to their GPs who are only too happy to listen but most don't know about post-polio pain.

Amal showed a video called “**Understanding pain and what to do about it in less than 5 minutes**” – it can be viewed on YouTube.

Video summary:

Pain comes from the brain and it can be retrained and when looked at from a whole personal broad prospective gives you a lot of opportunities to begin. So, get a helping hand if you need it, set a goal and begin.

Retrain the brain:

As you can see from this video there is hope, the brain can be retrained but it requires active management. Our approach is to explore the physical, mental/emotional and social/spiritual contributions impacting on pain; helping people to take control by teaching them how to manage their pain using cognitive behavioral therapy.

Team Approach

Therefore, the solution to managing chronic pain requires a team approach targeting the pain from various aspects.

Basic Principles of Management

- improve abnormal body mechanics;
- correct and minimize postural and gait deviations mechanically;
- relieve or support weakened muscles and joints;
- promote lifestyle modifications;
- decrease the abnormally high workload of muscles relative to their limited capacity

Management

Rehabilitation should take a multidisciplinary approach, with an emphasis on physiotherapy, including enhanced or individually modified physical activity, and muscle training. *The LANCET Neurology Volume 9, Issue 6, June 2010, Pages 634–642 Henrik Gonzalez, Tomas Olsen, Kristian Borg Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institute, Danderyd Hospital, S-182 88 Stockholm, Sweden.*

Patients with post-polio syndrome should be advised

- Avoid both inactivity and overuse of weak muscles.
- Evaluation of the need for orthoses and assistive devices is often required.

Classification of Pain (to aid in management of post-polio)

- post-polio muscle pain
- overuse pain
- biomechanical pain

Pain Management Clinics - Managing Chronic Pain

- Whole-person approach
- Multidisciplinary team
- Targeting pain from different angles
- Self-management

Ultimate goals are to Improve Functioning and Improve Quality of Life

Considering the Bio-psycho-social approach ... is a general **model** or approach stating that biological, psychological (which entails thoughts, emotions, and behaviors), and social (socio-economical, socio-environmental, and cultural) factors, all play a significant role in human functioning in the context of pain or disease. *The biopsychosocial approach was developed at Rochester decades ago by Drs. George Engel and John Romano.*

Strategies to try to turn down the alarm – RPAH Pain Management Clinic

Treat underlying disease process;

- Medications
- Injections, nerve blocks
- TENS machines
- Non-pharmacological strategies e.g. hydrotherapy exercises, gentle stretch.
- Nerve stimulators

Strategies to deal with the alarm that keeps ringing

- Individual sessions or Groups
- Education programs on chronic pain, how to modify your lives, how to speak to your GP, physio

- Exercise
- 'Pacing'
- Mindfulness
- Relaxation
- Cognitive Behavioural Therapy, Advanced Counselling Therapies

Meditation - What is it?

Awareness of our thoughts or mindfulness meditation – It takes time to learn

- calming the mind, who I am/where I am, what's happening with my thoughts, noticing rather than getting caught up in it, learning to be focused and in the moment – being mindful. Your brain needs to be engaged in the process of the activity of what you are doing. Meditation is not emptying the brain; it is being 'mindful'.
- changing the way we relate to the thought, looking outside as an observer at the thoughts, having the distance gives you a perspective to help you make choices, asking questions about my feelings and reactions - is this helpful?

Benefits of meditation

- side effect can be calming and relaxing
- noticing what is going on in the moment
- aligning behaviour with helpful thoughts, being aware of the thoughts, feelings and sensations we experience
- choosing to behave in a way that is helpful

Psychologists and psychiatrists

Part of the assessment may include being sent to a psychologist or a psychiatrist; this does not mean we think

- It is all in your head
- You have imaginary pain
- You are going crazy

Medications

Medications for Chronic pain (or pain that is neuropathic or nerve related):

- Simple analgesics such as paracetamol (suitable if your liver is healthy)
- NSAID's – non steroidal anti-inflammatories i.e. Nurofen, Mobic, Voltaren, Celebrex (suitable if your kidneys are healthy) useful in the short term in acute flare up 3-5 days.
- Antidepressant for both nerve related pain and depression caused by long term pain
- Anticonvulsant (usually used for epilepsy), dose should be the lowest dose e.g. 25mg at night for a week before increasing, this is a safer approach.
- Stronger analgesics e.g. opioids (these have limited efficacy for long term treatment)

Non-prescription medications – adjuvants

Some studies have shown

- Vitamin B1, B12, Folic acid, Multivitamin
- The B vitamins, especially B1, B12, folic acid, all help with nerve growth and nerve healing
- Calcium. Vit D and Magnesium or tonic water (contains quinine) for muscle spasms

General principles for taking medications

Before you start any medications ask your doctor...

- Are there any long term side effects?
- Will the side effects outweigh the benefits?

- How will this affect my mental health and clarity for thinking and doing activities of my daily life?
- People with post-polio syndrome should avoid muscle relaxants e.g. Valium.

Remember: Always ask the Doctor these questions

- What are the side effects of these medications?
- When will I stop taking them?
- Will they have a reaction/interaction with the other medications I am taking such as medical herbs, vitamins, alcohol etc.?
- If you were in my place would you take this?

Where to find help ...

- Local Doctor – GP
- Community Physiotherapists, Psychologists, Pain Specialists, etc.
- Community Centres - Polio support groups
- Pain Clinics at major hospitals

The Pain Management Centre

Doctors, Nurses, Physical therapists, Psychologists and Occupational therapists (help modify home environment)

Take home message

- Limit activities that cause pain/ fatigue
- Stretching
- Conserve energy by pacing i.e. take an activity and break it down into smaller bits, alternate with different activities i.e. some sitting, others moving around. Occupational therapists and physios are invaluable in this area. Pacing is something we have to learn and which needs patience. Some would rather just do the activity and then suffer for it later! You can manage better and achieve more if you change the nature of your activity, if your shoulders are hurting, give them a rest, change the type of activity and the duration.
- Stay warm - cold increase muscle fatigue and pain
- Avoid falls - falls prevention - good shoes, assistive devices
- Maintain a healthy lifestyle
- Protect your lungs

Golden Rule of Stretch

Do not overstretch

Be gentle on your body

Not everyone can do all the stretches

- Sit and twist
- Arm pit sniff
- Rock in chair – flex
- Stand and reach for the sky
- Slide one arm down reach over with the other



Questions:

Nola Buck: Four Corners recommended taking 600 units of Vit D. I take 1000.

Amal: 100 people were in a study who had pain and all had lower levels of Vit D, Vit B complex, Iron, Magnesium. These levels are determined by a blood test. Also note that Vit D is needed for calcium absorption.

Anne O'Halloran: Do you need a referral to a pain clinic?

Amal: Yes, ask your GP or specialist for a referral. Explain to them that you'd like to be assessed. You need your GP to be on side, your GP needs to be involved in your ongoing care. You will be required to complete a questionnaire beforehand, there will be a treatment plan, and you will see a doctor, physio, perhaps an OT. A minimum consultation time is 2 hrs, 1 hr is with the doctor, 1-1,5 with psychologist, then on another day, a physio and then perhaps a nurse practitioner like myself to explain medications etc., and to talk about how to look at things in a different way. At RPA they have a neurologist who works in a rehab setting, expert in the brain, headaches, neuromuscular disease, and pain. Investigations are sometimes needed to find the source of the pain.

Sue Ellis: How long does it take to get an appointment, how booked up are you?

Amal: Perhaps a 3-month wait list. There are pain clinics in most public hospitals, I am at Camperdown at RPA, there are clinics at Westmead, Royal North Shore. POW, Liverpool

Frank Featherstone: Do you have any success stories?

Amal: Success stories that I have are of patients who have moved from complete misery and who are stuck, to being able to say I really think there is hope, I have seen patients who have reduced their pain killers right down, their brains become clear and they are then able to do a lot more than they used to do. This is achieved by giving them information, education, explaining and giving individual care; there is no one formula for everybody.

John Tierney: How do I stop a medication? I have been on Celebrex long term for inflammation. How do I get off it?

Amal: NSAIDs should not be taken long term. My personal recommendation is to take Celebrex once a day along with Panadol 3 or 4 times a day for 3 or 4 days then stop Celebrex for a week. You have to weigh up the benefits against the harm. Celebrex is however easier on the gut, mildest form of NSAIDs.

Merle Thompson: I think I have acute pain flare-ups not chronic pain. It comes from perhaps an activity, bad posture, happens regularly.

Amal: Is it from inactivity, repeat action, how often? Labels don't particular matter, what matters is your experience and what works for you, drugs, psychological techniques, whatever works. You have long term persisting pain that comes and goes. Acute pain flair ups. What's important is how to manage your pain, with pacing/stretching activities or with physical/cognitive stuff. Labels don't particular matter, what matters is your experience and what works for you, drugs, physiological techniques whatever works. LEOp, ageing or arthritis - does it help to label the disease? Mentally we like to know what is wrong with us. Regardless, how do we manage, stretching, pacing. Referred or deferred pain, pinched nerve or facet joint in back. It's important to get a correct diagnosis.

Doug Sutherland: I have spinal canal stenosis and lower limb weaknesses. I have Cortisone injections 6 monthly ordered by a Sport Medicine Physician. How long should you be on it?

Amal: If this treatment lasts for almost 6 months and manages your pain then it sounds pretty good. However, long term oral cortisone (steroids) can have harmful side effects; causes bone problems, fat distribution problems. IV injection 6 monthly sounds pretty good.





Does chronic pain affect someone you know?

www.aci.health.nsw.gov.au/chronic-pain

Ask your Doctor

Ask your Health Professional

Ask your Pharmacist

Ask your Librarian

Information & Downloads for...

People in Pain:

- ▶ Pain Management Strategies & Videos
- ▶ Information, Handy Hints & Useful Links
- ▶ Pain Series for Young People
- ▶ Spinal Cord Injury Resources

Health Professionals:

- ▶ Clinician Support & Management Tools
- ▶ Statewide Pain Referral Information





Chronic Pain Services in NSW Partners in Pain Management

For people with pain or healthcare professionals considering a referral to a pain management service



Who should attend Chronic Pain Services?

Chronic pain is pain that persists for more than 3 months or beyond the usual time for tissue healing.

If you have been living with pain that refuses to go away and it is affecting your daily life, you could ask your GP if a referral to a pain service would be worthwhile.

What to expect?

After your GP refers you to a pain service, you will be contacted and usually requested to complete a questionnaire.



painaustralia

All working together



Pain in Post-Polio Syndrome

by Anne C Gawne, MD, Roosevelt Warm Springs Institute for Rehabilitation,
Post-Polio Clinic, Warm Springs, Georgia

Anne Carrington Gawne, MD received her medical training at the Uniformed Services University in Bethesda, Maryland, and did her residency at the National Rehabilitation Hospital in Washington, DC.

Before moving to Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia, Dr Gawne treated polio survivors at National Rehabilitation Hospital for nine years. She co-authored Post-Polio Syndrome: Pathophysiology and Clinical Management with Lauro S Halstead, MD, National Rehabilitation Hospital, which was published in Critical Reviews in Physical Medicine and Rehabilitation, Vol. 7, Issue 2, pages 147-188.

Symptoms of post-polio syndrome include fatigue, new weakness and pain in muscle and joints. Chronic pain is the second most prevalent symptom reported and frequently is the most difficult to treat. Improvement in the evaluation and treatment of pain can significantly improve comfort and restore function. The differential diagnosis is extensive, but many of the problems appear to be related to overuse of weak muscles along with abnormal joint and limb biomechanics.

To facilitate the diagnosis and treatment of pain, a classification that divides the pain syndromes into three classes has been developed:

1. post-polio muscle pain
2. overuse pain
3. biomechanical pain

POST-POLIO MUSCLE PAIN occurs only in muscles affected by polio. It is described as either a deep or superficial aching pain, which many survivors say is similar to the muscle pain they experienced during their acute illness. Characterized by muscle cramps, fasciculations or a crawling sensation, it typically occurs at night or the end of the day when one tries to relax. It is exacerbated by physical activity and stress, and cold temperatures.

OVERUSE PAIN includes injuries to soft tissue, muscle, tendons, bursa and ligaments. Common examples are rotator cuff tendinitis, deltoid bursitis and myofascial pain. Myofascial pain in post-polio is similar to that in others. It occurs most frequently in the muscle of the upper back and shoulders and is characterized by bands of taut muscles and discrete trigger points that elicit a jump response when palpated. These occur due to poor posture or improper body biomechanics.

Fibromyalgia with its associated symptoms is another cause of muscle pain that has been recognized by other investigators and has similar symptoms, but is distinctly different from post-polio muscle pain. The classic tender points are uncommon with post-polio muscle pain.

BIOMECHANICAL PAIN presents as a degenerative joint disease (DJD), low back pain or pain from nerve compression syndromes. Weakness induced by polio-affected muscles, as well as poor body mechanics, makes the joints more susceptible to the development of DJD.

Survivors who walk develop degenerative joint disease in the lower extremities because years of ambulating on unstable joints and supporting tissue increase the chance of developing further pain and deformity. Those who use wheelchairs or assistive devices such as canes, crutches or walkers are prone to DJD, or overuse syndromes, in their upper extremities, especially the wrist and shoulders. The joint pains are only rarely accompanied by swelling and/or inflammation, but do demonstrate tenderness and abnormal range of motion. X-rays of painful, weight-bearing joints may show degenerative changes proportional with the amount of stress the joints have sustained.

Nerve compression syndromes, including carpal tunnel syndrome (CTS), ulnar mononeuropathy at the wrist or elbow, brachial plexopathy and cervical or lumbosacral radiculopathy, are syndromes that can cause pain as well as neurological deficits in the post-polio individual. Risk factors for the development of focal neuropathies of the median and ulnar nerves include use of an assistive device such as a cane, crutch or wheelchair. These neuropathies can be detected on electrodiagnostic tests (EMG/NCS) before the individual has the characteristic symptoms of CTS.

The evaluation of post-polio individuals with pain requires careful investigation of all aspects of their pain. Among the questions asked are typical ones such as “*What makes the pain better?*” and “*What makes it worse?*”. The way pain interferes with the survivors’ ability to sleep and work is noted. Which treatments are helpful and by whom they are given is also documented.

Pain management in post-polio is based on a few basic principles, supplemented by class-specific recommendations. These basic principles include efforts to:

1. improve abnormal body mechanics
2. correct and minimize postural and gait deviations mechanically
3. relieve or support weakened muscles and joints
4. promote lifestyle modifications
5. decrease the abnormally high work load of muscles relative to their limited capacity

TREATMENT FOR POST-POLIO MUSCLE PAIN includes decreasing activity throughout the day, applying heat, and stretching. Stretching has a role in maintaining the extensibility of muscle and connective tissue; however, it must be performed judiciously because there are situations in which a polio survivor may derive greater functional benefit and be safer with tighter tendons and reduced joint range of motion.

A variety of medications are used to treat post-polio muscle pain, but the most common ones - such as nonsteroidal anti-inflammatories (NSAIDs), Tylenol, benzodiazepams, and narcotics - are of little use. The use of tricyclic antidepressants (TCAs), especially amitriptyline, can help with pain and also with fatigue.

TREATMENT FOR OVERUSE PAIN includes modification of extremity use, followed by modalities such as ice, heat or ultrasound, transcutaneous electrical nerve stimulation (TENS), and occasionally NSAID medications. Treatment for myofascial pain consists of myofascial release techniques, including spray and stretch and trigger-point injections. Often rest is not possible since many rely on upper extremities for both locomotion and self-care. In rare cases, steroid injections or surgery may be needed.

TREATMENT FOR BIOMECHANICAL PAIN includes posture and back-care education and decreased weight bearing through use of assistive devices such as braces, crutches, wheelchairs, and scooters. Abnormal biomechanics can often be modified with fairly simple and practical interventions such as cervical pillows, lumbar rolls, glottal pads, dorsal-lumbar corsets, and heel lifts. These pains are usually improved by conservative measures aimed at reducing mechanical stress - pacing activities, supporting weakened muscles, stabilizing abnormal joint movements, and improving biomechanics of the body during common daily activities. Anti-inflammatory agents are used sparingly, and then only in low doses to supplement conservative measures. In particular, efforts should be directed at improving routine daily activities such as sitting, standing, walking, and sleeping, as well as any repetitious activities at work. Weight bearing with the wrist hyperextended and radically deviated should be avoided.

For those with carpal tunnel syndrome who must use a cane or crutch, an Ortho-ease or pistol grip is prescribed to place the wrist in a more neutral position and spread out the weight-bearing surface on the palm. Providing adequate support for weakened muscles and unstable joints can often be a difficult challenge; however, the basic orthotic principles are similar to those used in the management of other neuromuscular diseases. For individuals with low-back pain, lumbosacral corsets, a shoe lift, or pelvic lift can help improve biomechanics. For genu recurvatum (back knee) or genu valgus (knock knee) due to quadriceps weakness or ligament instability, a long-leg brace (KAFO - knee, ankle, foot, orthosis) with a free ankle and an extension stop at the knee is used. Polio survivors with dorsiflexor weakness or ankle instability can benefit from an athletic ankle splint, high-top shoes, or a short leg brace (AFO - ankle, foot, orthosis).

Many individuals need an orthosis that combines strength and lightness. The new plastics and lightweight metals can often be used alone or in combination. Frequently, survivors prefer to repair and use their old braces rather than start over with new ones. Others may resist using any kind of brace for cosmetic and psychological reasons. Orthotics are recommended for the following indications:

- to improve safety by reducing the risk of falls;
- to reduce pain;
- to decrease fatigue by improving gait speed and symmetry.

Pain can be reduced by altering biomechanics and by changing to a lifestyle that reduces physical activity. These strategies may be difficult to accomplish, however, because they often require developing behaviours unlike the old, familiar ones. Altering the pace and intensity of discretionary activities and learning new ways to gain more control over when and how activities are performed is essential. Restoration of function as well as relief of pain can be accomplished by an interdisciplinary team that includes the polio survivor, physical therapist, occupational therapist, psychologist, rehabilitation engineer, and physician.

This article originally appeared in *Post-Polio Health* (Vol. 13, No. 1, Winter 1997) and is being distributed courtesy of Post-Polio Health International (www.post-polio.org), St. Louis, Missouri, USA. (Any reprint requests must be sent to Post-Polio Health International)



Dr Toby Newton-John: Dr Newton-John is a Clinical Psychologist and Senior Lecturer in the Graduate School of Health at UTS (University of Technology Sydney). He completed undergraduate psychology and postgraduate clinical psychology training at the University of Sydney before moving to the UK to undertake a PhD in pain psychology at the University of London. He has worked in a range of clinical health settings in Australia and the UK. He established a large multidisciplinary pain management program in Newcastle NSW and moved into an academic position in 2013. He continues to practice as a clinical psychologist in a part time basis at Northern Private Pain Centre, North Shore Private Hospital. Toby's clinical as well as research interest has been in the social aspects of chronic illness, particularly the reciprocal influences of the primary relationship on illness adjustment. He has ongoing research collaborations with Relationships Australia and overseas universities.

Self-Management of Chronic Pain – 5 Strategies to Consider

Today I want to share with you some practical things to consider when going about your daily management of pain. I suspect some of these things you will do already, that you have worked out for yourself.

This is what I would like to cover today:

- What is self-management of pain and why is it important?
- What has psychology got to do with it?
- What are 5 ways that you might improve your pain management using self-management methods?

You live with pain, it is impacting on your quality of life to some degree, how do you go about treating that, what are the approaches. Broadly speaking we can divide these into a biomedical approach and self-management approach. The biomedical approach, which focuses on the biological mechanism of pain, applying medical treatments for that, focuses on the physical disease, so a biomedical approach narrows down to joint or muscle or the underlying biochemical change, so it is very specific on the disease. Whereas a self-management approach looks at that disease process within the whole person, not just the knee or the nerve or the lumbar spine but what that disease looks like in the context of the rest of the person, it is a broader approach.

The biomedical approach requires the doctor, the physician, the health practitioner to make an appropriate diagnosis, to provide the appropriate treatment and then the patient gets better. The biomedical approach is really down to the doctor to make the right decision, the right kind of investigations leading to the right decisions to get the patient well. Self-management approach is much more in the hands of the patient who is managing themselves. So in the self-manage approach your health it is not really up to the doctor, it's actually up to the patient to do what he or she can do and needs to do in order to get themselves well, so the responsibility lies with them.

Associated with that, in a biomedical approach to the management of health generally and pain particularly, as a patient you are fairly passive in the process; you take yourself to somebody who does something to you. Whereas in self-management again you are the one doing the work, i.e. it could be doing the exercise, a much more active role in the self-management protocol. Critically, in the biomedical approach the goals are about symptoms relief whereas in the self-management approach to pain, the treatment goal is usually pain relief and as such it is broader, it is quality of life. These are the significant differences between the two approaches.

Biomedical Management

Focus on physical disease

Doctor primarily responsible for improvement

Patient has passive role

Treatment goal is pain relief

Self-Management

Focus on whole person

Patient primarily responsible for improvement

Patient has active role

Treatment goal is improved quality of life

In situations that are short term e.g. a cut hand, then a biomedical approach is the most effective way forward. If your symptoms are short term, i.e. less than 3 months in duration, then a biomedical approach is the most acceptable way forward. If, however, your symptoms are more than 3 months in duration then you have chronic pain, pain that doesn't go away, it persists and in many cases in post-polio syndrome it can persist for decades not just months but years. Chronic pain as an intractable form of pain is a very different kettle of fish to a sprain, cut or burn.

- Short term symptoms (acute); biomedical approach is most valuable e.g. cut hand
- Chronic pain is long term "intractable" pain
- Patients who self-manage chronic pain are significantly better off (Blyth et al. 2005)
- Long term symptoms (chronic); biomedical approach can lead to chronic pain

Patients who self-manage chronic pain do significantly better and one of the important distinctions I believe when we think about how to approach managing pain that doesn't go away is seeing the role that biomedical approaches to pain and the value they have versus what they can do long term which can be problematic.

Biomedical Management

Focus on physical disease

Physician primarily responsible for improvement

Patient has passive role

Treatment goal is pain relief

Long term consequences*Patient's overall welfare ignored**Patient keeps searching for a doctor who can fix them!**Patient becomes despondent and helpless**Frustration, anger, disappointment*

If we look on the biomedical approach which focuses on the physical disease, if somebody's pain doesn't go away, the long term consequence can be that the overall welfare can be ignored. They only focus on the knee pain (for example), not how it is affecting the patient's life, i.e. being able to continue to work, having to take increasing amounts of medication, ignoring all the other factors in this person's life. If the biomedical approach is allowed to go along long term so the physician is primarily responsible for any improvement, the patient keeps searching for someone else who can fix them, find the right treatment, an endless search where the patient becomes less confident that they will find the right help, the patient becomes despondent and helpless which does help the pain either. The focus is only on getting rid of the pain which leads to disappointment, frustration and anger.

Self Management

Focus on whole person

Patient primarily responsible for improvement

Long term consequences*Address all concerns and difficulties, not just symptoms**Patient gains sense of control and confidence*

Patient has active role

Adherence improves

Treatment goal is improved
quality of life

Improved quality of life despite pain

The goal that everyone with pain wants is to have no pain but unfortunately it isn't always possible. If we just keep focusing on that as the one outcome and it is not happening then you tend to see things like frustration, disappointment and anger, real disappointment that your life is not improving.

So the point I am making here is that it is all about timing, so if you have a short term problem e.g. cut hand, then a biomedical approach is absolutely right. But long term if you only keep that narrow focus on pain you can see a whole lot of detrimental changes which don't make the person's quality of life any better at all.

If we turn that around and we look at the long term consequences of a self-management approach we start to see something different, you see a focus on the whole person, which means not just their pain issues but all their associated issues such as how are they coping generally, what's life looking like for them overall, family, work. If we look at the patient's need primarily to improve then it is our job as health professionals to equip the patient with the tools that they need to be responsible, the strategies, the methods, the knowledge, the techniques so that they can self-manage the best they can, and the fact that they then know what to do they can feel better, their confidence boosts.

We also know that if you are given an active role you tend to follow the strategy better. Ultimately, the treatment goal of a self-management approach is if we can reduce pain, that is great, but it is more than that, and if we can't reduce pain then look at the other things that make your quality of life better and let's try and work on those things as well. That way we do get an overall gain in terms of what your life is like day to day without necessarily just focusing on one part which is the amount of pain you have on an average day.

What has all of this got to do with psychology?

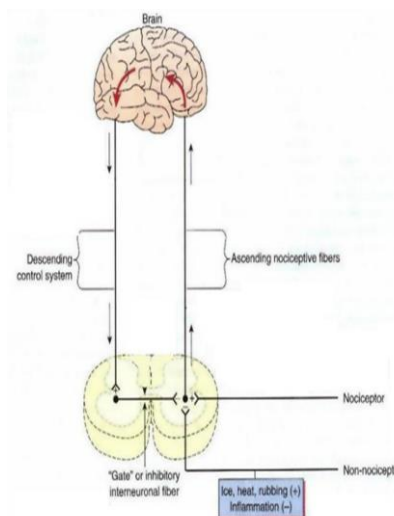
Have you ever:

- noticed a bruise or scratch on your skin and have no idea how you did it?
- wondered how ballerinas can leap around on the points of their toes - and smile at the same time?

So we have extremes, you might have tissue damage and no pain or there are examples of very minimal tissue damage and apparently a great deal of pain i.e. when having an injection at the dentist. What's going on?

Gate Theory of Pain (*Melzack & Wall, 1965*)

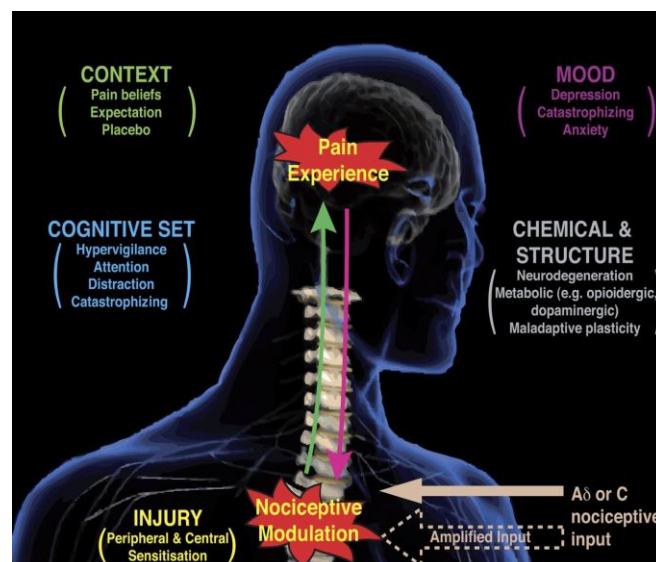
- At each level of the spinal cord, there is a chemical "gating" system that acts to inhibit or facilitate pain transmission
- The brain drives this system ("opens or closes the gate") through descending modulation
- Whether we experience pain, and how much we experience it, is the result of the "gate"



The Gate theory is now the leader in research and clinical practice and it basically says that all of us have two systems, we have a mechanism that tells our brains what is happening in

our body, so our nerves converge on our spinal cord and our spinal cord conveys a message to our brain to say that we have just trodden on a bindii but we also have a message that comes down from our brain which can amplify or inhibit or block that information coming up and where those two mechanisms meet, they are chemically driven mechanisms in our spinal cord and is known as the spinal gate. It is like a gate that opens and closes all through the day depending upon what information is coming into the system and also what our brains are sending back down and for all of us at any one point how much pain we feel is to do with where that gating system is, if it is fully closed we have no feeling even though there might be information coming up. If it is fully open it acts like an amplifier and we feel everything even perhaps more than is first coming into the system.

So the Gate Theory explains why you can have some people e.g. a soldier injured on the battle field or an athlete and they don't feel a thing, the gates are closed because the brain has decided that it is not important, that it's more important to survive, it is more important to win this game. Then at other times the gates are open and we are at the dentist and we feel everything and magnify the pain. So the Gate Theory was a way of explaining why people vary so much in their pain experiences



Information goes into the spinal cord, it gets transmitted up to the brain, the brain is also sending information back down the spinal cord which modulates the spinal cord, it turns it up or turns it down. There are a whole lot of factors that influence that and of course we have spoken about pain medications already. The job of a pain medication is to turn down that input (we don't take pain medication in the hope of curing it but to turn down the pain) and close the gate and our brains have a role to play into where that gate sits.

We usually associate pain with being a really bad thing but pain has a function and they are really important.

The Function of Pain:

Demands and dominates attention

Prioritises escape (hence "pain gates")

Promotes recovery and healing through energy conservation, vigilance, defence

Teaches avoidance in future - requiring attention and learning associated cues

Chronic pain is when the spinal gates remain open and the pain continues to be experienced although there is no survival advantage to the organism. If you have pain long term then the brain and spinal cord appear to 'adapt' over time and become more pain-sensitive (called neuroplasticity), meaning pain relief is more and more difficult to achieve.

What is it like to have chronic pain?

"Pain cannot easily be divided from the emotions surrounding it. Apprehension sharpens it, hopelessness intensifies it, loneliness protracts it by making hours seem like days. The worst pain is unexplained pain."

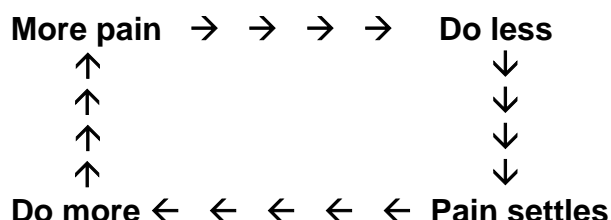
"Above all, a sufferer needs a way of talking about the pain – permission to talk about it – without feeling judged, without the implication that you lack moral fibre, or are exaggerating".

Hilary Mantel, two-time Booker Prize winning author, *"Wolf Hall"* about Henry VIII.

Fatigue and Pain

- Both unpleasant!
- Both can be the result of physical factors, or emotional ones
- Both common in PPS
- The following self-management strategies apply to both

Strategy 1 – Activity Pacing



People usually have good days and bad days, when pain is not so bad they like to get out and get stuck in and make the most of it and get things done. As a result, for many people with chronic pain they then have a flair up, an increase in chronic pain because they have been standing up for too long in the shops or sat too long in the movies with their friends, or walked too far; they have over done things in an activity which has caused more pain because they have stirred their symptoms up and are now worse, so they then drop the activity and do less. Eventually, that pain settles, it might take a day, a few days or a week, they are in real strife, really suffering. So eventually that pain does settle so what do we do when it settles? Off we go again because while we were out of action things have piled up and we have more things that we need to do and want to do.

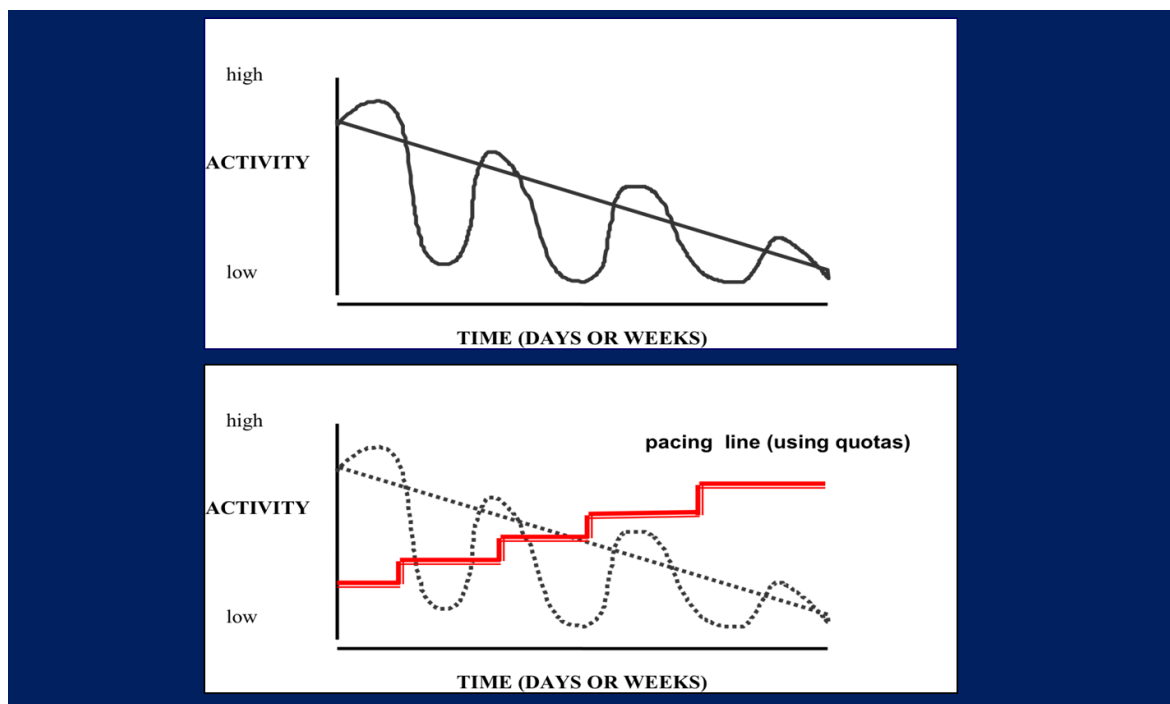
Breaking the overdoing-underdoing cycle

Your activity level is rising and falling over time because you are overdoing, then underdoing; your poor body actually doesn't know what it's doing from one day to the next. This can also affect your brain's concentration when you are in a flair up phase and you won't think as clearly. Pain has a terrible effect on concentration.

We need to learn how to change the way we go about doing things by **activity pacing**. On your good day when you feel good don't go over the top, on a good day hold yourself back because on a bad day you don't want to drop down too far either, you need to keep a much closer level of activity from one time to the next. So not out for the whole day and then in bed for two days, but out for a period of time and back home before you feel that you have stirred things up, before you feel that you have gone over the top, you still feel that you have some energy in the tank or you haven't reached a high level of pain yet. You stop the activity and take a break before you go again, not at a high level of activity OR a low level of activity just a moderate amount so that over time you regulate yourself so that you don't get into that cycle of provoking the pain and then suffering greatly. Look at moderate

amounts of activity. What can help you with that is to use a timer, on your phone perhaps, oven timer, any device that will prompt you to, say, walk for only 15 minutes at a time at the shops or I'm going to be out for just one hour. It is a very effective way to make you note your level of pain and that you need to take a break, go home, change your position. Activity pacing is a very effective way of preventing yourself from flaring up from overdoing and it is very effective in preventing you from deconditioning through doing an insufficient amount of activity.

Talking about it and doing it are two very different things and if you are a person who likes to get things done, can't bear to leave things half finished, likes to stay until the party is finished, then pacing is difficult. It's a very tricky thing to rein yourself back on a good day in order to not suffer the next day or that evening. If you CAN get to grips with it and you can spread your activities out over the day, couple days or a week then instead of cramming it all into the morning or all into one day, generally people find that this helps them manage better. You get just as much done but it is just spread out better. Changing habits of a life time are not easy to do.



If you continue overdoing-underdoing, fitness and ability to perform activities in good times reduces over time. Paced activity, or pacing up, allows this cycle to be broken.

Strategy 2 – Calming

- Pain can lead to stress
- Stress can lead to pain
- Once activated, our 'stress response system' is not easy to turn off
- Aim here is to be calm, rather than relaxed, despite pain
- Evidence supports effort (Williams & Eccleston, 2012)

One of the techniques that works is learning how to calm yourself, you can call it meditation, mindfulness or relaxation. This is an example of a calming method, it's free and it's portable!

1. Close your eyes (or keep them fixed on one spot)
2. Relax forehead, jaw and shoulders

3. Take two deep breaths, then breathe normally
4. Try to concentrate on one of three things:
 - Your breath
 - Keeping your thoughts in the present
 - What happens in your body – without judgement
5. Practice as much as you can – in bed is good

This can cause a reduction in your level of arousal, produce a calmness, some sense of quiet that no drug in the world can do, within a few minutes reduces arousal, has no side effects, no cost, no prescription required, totally portable and actually gets better with practice. Not so easy to do when your pain is bad but it is a useful strategy to have to keep yourself calm, also helps you to get to sleep.

Strategy 3 – Use Your Thoughts

- Every minute you are awake, you are thinking!
- Thoughts are automatic, often unconscious, usually unchallenged (we accept the way we think)
- Interpretations, judgements, reflections, assumptions, all play a critical role in how we feel
- The way we see ourselves, the world and our future effects the way we feel i.e. happiness, sadness, fear or joy which comes from the way we think and this is not always helpful....

Some Pain Thoughts

When I'm in Pain....

1. I worry all the time about whether the pain will end
2. I feel I can't go on
3. It's terrible and I think it's never going to get any better
4. It's awful and I feel that it overwhelms me
5. I feel I can't stand it anymore
6. I become afraid that the pain will get worse
7. I keep thinking of other painful events
8. I anxiously want the pain to go away

How would someone be feeling if this is how they were thinking? Anxious, depressed, pretty unhappy. Pain is a trigger, your thoughts come automatically but the content of your thinking can very much effect how you feel. So one of the strategies that we use to help manage pain is to help people use their thoughts as helpfully as they can.

Cognitive therapy looks at how to make the best use of the way you interpret what is happening to you physically, not just accepting your automatic thoughts that come but recognising that they are not particularly helpful and to use some alternatives.

- Cognitive therapy is the deliberate, effortful practice of identifying and “challenging” one’s unhelpful thinking, in order to reduce one’s negative emotional reactions
- It is not just “positive thinking”- what is positive about pain??
- Writing down your thoughts can help (Pennebaker, 2012)

So strategy 3 is using your thinking to make sure it helps.

Strategy 4 – Set goals

- We all need to feel a sense of achievement
- We all need to have things to look forward to
- Living with pain can greatly diminish both of these, they get stuck, living in the moment
- If you stop planning ahead, you are at risk for overdoing-underdoing pattern which is not helpful, and long term low mood; if you are not planning at all then you are not looking forward to things.

So setting goals is another very useful strategy when it comes to pain management.

- Spread your activity load over the week
- Don't forget to include some nice activities on your planner (not just chores and jobs!)
- No beating yourself up if you don't manage to achieve what you set out to achieve – it's only a guide

Strategy 5 – Talk

- Part of good self-management is talking about your pain to those 'nearest and dearest to you', those that do this manage their pain better (Newton-John & Williams, 2006)
- Talking does not mean whingeing, moaning, complaining etc.
- You need to get around the problem of not assuming that people around you know what you are experiencing; your partner, family, friends and doctors care about you, but they are not mind readers e.g. thinking that because you've been married for 55 years or you've been seeing your doctor for 10 years they know how you feel. They can't read your mind; you need to tell them.
- Having a conversation without blame or finger pointing but a very objective conversation about how you are managing, what perhaps they are doing well to assist you (positive feedback that we may forget to give often) but also an opportunity to say what you would like to be different, "I would like you to do more of or less of...", and have a discussion about that so that you don't have to feel that pain in something you have to manage in isolation on your own – is an important part of self-management. You can let people close to you in a little bit in terms of what you are going through by giving them some clues on how to help you best.

To Summarise

- Try to pace your activities, spread your activities across the day, use a timer to help avoid overdoing or underdoing
- Try to keep yourself calm, especially when the pain is bad, keeping your tension levels down as best you can be useful
- Try to keep your thinking helpful rather than allow it to undermine you
- Try to set some goals each day/each week so you have something to look forward to and have some sense of achievement
- Try to let people close to you know how you are feeling, the good and the not so good, start a conversation; it's all part of building intimacy and closeness.
- Self-management is hard work, not easy, time consuming so give yourself a reward for doing the hard yards!

Dr Toby then expressed an interest in ‘picking’ our brains about how **we** cope with long term pain and hopes that we might participate in a research program. It will include filling in some questionnaires or perhaps a telephone interview by a research assistant. (see page 2 and 3 above)

Questions:

How long should we do the breathing technique to calm ourselves?

Dr Toby: This varies for everyone how long they can concentrate to do this or in fact how long they are physically comfortable to do this. Ideally 20 minutes is good but even if you do it for a few minutes at a time throughout the day is beneficial e.g. while at the kitchen sink, in the car at traffic lights, at the shops, when the ads come on the TV, remember this technique is portable and free.

In regard to talking about pain to friends or family ... they don't really want to hear about it and don't understand, they don't have pain. Sometime it causes the end of some friendships. How do we go about it?

Dr Toby: It can become a pain competition. YOU need to tell them that you are suffering but they don't think they can do anything about it which makes them feel uncomfortable so they just want to get away. It's uncomfortable for them. To get around this you need to open up a conversation by saying “I don't expect you to do anything about this (you don't want them to fix it, or be responsible for it or even to feel sorry for you) but it would really help me if I could just let you know what is happening to me and for you to listen”.

After Anne Buchanan pointed out that many polio survivors are very determined and stubborn

Dr Toby then made a diagnosis that polio people have ‘*stubborn bugger syndrome*’, they don't want to let people know they are in pain because it makes them look weak which leads to them refusing to take a break, refuse to get some help.



The third speaker at our May seminar was Melissa McConaghy who spoke on “*Managing Pain*”. Melissa is a Specialist Neurological Physiotherapist and Fellow of the Australian College of Physiotherapists. She holds a Master of Health Sciences in Neurological Physiotherapy and Bachelors and Physiotherapy. Melissa is the Managing Director and co-founder of the Polio Clinic at Advance Rehab Centre. Her presentation, “*Care of the Shoulder*” will appear in our next newsletter along with Dr Bill DeMayo's presentation, “Q & A Seminar with Dr Bill DeMayo”, from our seminar on 15th September.

Dr DeMayo MD has been practicing in the field of Physical Medicine and Rehabilitation for 25 years. He is the Medical Director of the Specialty Clinics of the John P. Murtha Neuroscience and Pain Institute including the Post-Polio Clinic. He has a private practice in Johnstown (USA) where he sees a wide variety of patients with disabilities. Dr DeMayo presented at the “Polio – Life Stage Matters” Conference held in Sydney in September.

Dr DeMayo's Q & A Seminar presentation included an introduction and review of his experiences treating polio survivors in the United States as well as his current transition into a proposed “Virtual Clinic” providing education and consultation via telemedicine links. He also discussed his approach to lifestyle modification and self-empowerment.

So look out for Network Newsletter #99 to read about these two informative sessions.

Susan Ellis



WheelEasy Access Information Website

WheelEasy's aim is to create **better access to leisure activities for wheelchair users and their family & friends.**

As a wheelchair user I know that if I can't get somewhere, then everyone with me has the same problem! So WheelEasy is not just for wheelchair users, but also for everyone who wants to enjoy life to the full with them.

One of the biggest problems has always been **finding the right information.** So, we're launching this month with our first project - the **WheelEasy Access Information website** at www.wheeleasy.org.au.

www.wheeleasy.org.au is a **geolocation-based one-stop-shop for everything about access.**

There is access information to all sorts of things - from flat beach and bushwalk access, beach wheelchairs and picnic areas to theatres or train stations, and much more.

WheelEasy.org.au has specifically been **built with mobiles in mind** so that people can use it when out and about, without having to plan ahead.

Our ultimate aim is

- to make every wheelchair user in Australia aware of our site, and
- ask them to share their local knowledge and experience as a wheelchair user,
- so we all know what's great to see and do, as well as what's not.

We'd love it to become a permanent feature on every wheelchair user's mobile.

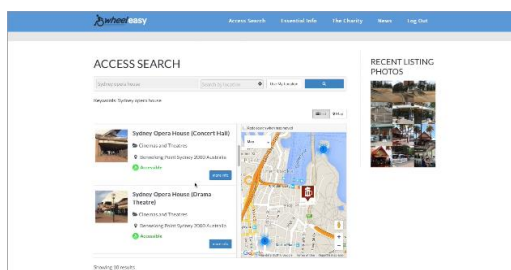
As a first step towards making our database more comprehensive and useful, **please** start adding your own information.

Please like us on Facebook and Twitter, share us with all your friends and pass our website details to everyone you think might find this useful to know about.

Many, many thanks in advance.



Max Burt Trustee





Understanding the NDIS

What is the NDIS?

The National Disability Insurance Agency (NDIA) is an independent statutory agency whose role is to implement the National Disability Insurance Scheme (NDIS). The NDIS is a new way for people with disability to access supports they need to live the life they choose. At the moment, it only operates in a few locations around Australia, but it is starting in other parts of the country soon. It will be across the whole of NSW and the ACT by June 2018, and across the rest of Australia by June 2019.

What is new about it?

The NDIA works with each person to develop an individual plan that addresses all of the supports that they need in their life.

The NDIA gives each person the funds that they need to choose the supports that will work for them, based on what is in their Plan.

The NDIS funds all people who are eligible for support, rather than people having to take what they can get or miss out on supports they need.

The NDIS encourages you to think big and to work towards life goals you may not have had an opportunity to think about in the past.

Is it for me?

- ✓ Under 65
- ✓ An Australian citizen, permanent resident or Protected Special Category Visa holder
- ✓ Have a permanent condition that makes it hard to do some things without help or special equipment
- ✓ Child under six with developmental delay
- ✓ Likely to require support for the rest of your life OR can show that getting support now will mean that you will need less support later
- ✓ NDIS is available in your region and for your age. Check the NDIS website at <http://ndis.gov.au/people-disability/access-requirements>

How do you get it?

If you are eligible and want to get support through the NDIS, you can follow these five simple steps:

1. Complete an NDIA Access Request Form

This will inform the people at the NDIA that you are trying to get support. You will need to be able to give them proof of your disability and the impact it has on your life. You can obtain this form by visiting an NDIA office or calling 1800 800 110.

2. Make an appointment with the NDIA

Start thinking about your goals. What do you want to achieve in life? What support do you think you will need to achieve your goals?

3. Attend your planning meeting with the NDIA

At this meeting, discuss your support needs and goals. You and your NDIS Planner will work together to develop your individual NDIS Plan. This includes giving you access to funds that you can use to purchase the services that you want.

4. Choose how to manage your funds

Decide whether you want to manage your own funds, or whether you want the NDIA or another fund manager to look after them for you. Whether you manage your funds or not, you can still make all the choices and decisions about the supports you receive.

5. Find supports and services to meet your goals

After your NDIS Plan is finalised, use your Plan and your funds to get the supports and services that you need to meet your goals. You can choose as many or as few providers as you want to get the mix of supports that works for you.

What do you have to know?

To get the most out of your supports, it helps if you know how to:

1. Tell people what you want and need, and what works for you
2. Make choices about the services you want based on things like quality, location and experience
3. Make plans for your life and follow steps to achieve them

Need more help?

Northcott's NDIS experts are here to help you get the most out of your NDIS Plan. We also stage events and other services that can help you prepare for the NDIS.

If you have any questions about the NDIS, contact us now:

Phone: 1800 818 286 **Email:** ndis@northcott.com.au **Website:** www.northcott.com.au



Proud to be the only not-for-profit
on the 2015 BRW Most Innovative
Companies list

The following article was reprinted from the Eastern News, Eastern Polio Support Group, May 2016

Our Guest Speaker was Dave Nicholson, a volunteer with the Melbourne Fire Brigade. His presentation relating to senior fire safety was extremely informative and very entertaining, despite the seriousness of the topic.

He advised that each year more people die and are injured in house fires than bushfires. In 2015 there were 1,565 preventable house fires in Melbourne resulting in the loss of five lives and causing almost \$30 million in property damage. 45% of those fires started in the kitchen, 9% in the bedroom, 5% in the lounge room and 4% in the laundry.

A few suggestions for you to follow:

- Keep emergency numbers near the phone.
- Practice your home fire escape plan regularly.
- Stop, drop, cover and roll (well, this might be difficult for most of us!)
- Get down low and go go go! (again, difficult) but this is what the Fire Brigade tells all the Prep classes each year to do. Important if there is smoke in the house as it is safer for breathing near the floor where the air is cooler and cleaner.
- Keep an approved fire blanket near the stove, ensuring you cover the flames from front to back. They are about \$10.00 at Bunnings.

Electric blankets: Put on during the day and check for hot spots – throw them out if any appear. Turn off your blanket when going to bed.

Power boards: Do not overload and don't use double adaptors.

Smoke Alarms: Did you know all smoke alarms need to be replaced after 10 years? When replacing an existing nine-volt battery smoke alarm consider installing a photoelectric smoke alarm with an inbuilt ten-year lithium battery. This will eliminate the need to change the battery every year. **Testing:** test by pressing with a broom handle monthly and vacuum around your smoke alarm vents yearly. Replace your 9-volt battery each year at the end of daylight saving. If you use Council services check to see if they will assist.

Heat Bags: Only purchase these with instructions and use according to the manufacturer's instructions. Throw out after 12 months!!

Mobility Allowance

<https://www.humanservices.gov.au/corporate/budget/budget-2016-17/disability-and-carers/mobility-allowance>

Information update: this Budget measure is subject to the passage of legislation.

Description of the measure:

The Government is providing \$46.5 million in extra support through the National Disability Insurance Scheme (NDIS) to help Australians receiving Mobility Allowance.

This means that Mobility Allowance recipients who are assessed to be eligible will receive NDIS support rather than the Mobility Allowance, once NDIS is available in their own locality.

The disability rules for Mobility Allowance will be aligned with the NDIS disability criteria which means new claimants must have a significant or permanent disability which prevents them from using public transport without substantial assistance.

From 1 January 2017, the Mobility Allowance will only be available to new customers who are:

- under 65 years of age with a significant or permanent disability

- engaged in work or vocational training, and
- not able to use public transport without substantial assistance

Existing Mobility Allowance customers will be grandfathered and remain on the payment based on the current eligibility criteria. If they cancel their payment, they will lose their grandfathered status and be subject to the new eligibility criteria.

The grace period during which a customer can receive Mobility Allowance while not engaging in a qualifying activity will also reduce from 12 to 4 weeks.

Where a NDIS customer exits the scheme, they will not be able to return to Mobility Allowance at a later date.

The changes to eligibility and entitlement rules are designed to support the transition of Mobility Allowance funding to the NDIS, as recipients move from the payment to NDIS or Continuity of Support arrangements.

Questions and Answers

Who is eligible for this measure

New and existing Mobility Allowance customers.

The date this measure will start and finish

This measure will start on 1 January 2017 and is ongoing until the Mobility Allowance ceases on 1 July 2020.

Taxi Transport Subsidy Scheme (TTSS)

www.transport.nsw.gov.au/customers/taxis/ttss

- Who is eligible
- Terms and conditions
- How to apply
- Reordering TSS travel dockets
- Travelling interstate
- Change of personal details
- Wheelchair Accessible Taxis (WAT)
- Feedback
- Forms and documents – visit the above website to download the documents described in this article

More support for taxi customers with disability

From 1 July 2016, the Taxi Transport Subsidy Scheme (TTSS) maximum subsidy has increased from \$30 per trip to \$60 per trip.

New \$60 docket books have been mailed to current TTSS customers.

From 1 July 2016, the Wheelchair Accessible Taxi (WAT) driver incentive payment has also increased from \$7.70 (ex GST) to \$15 (ex GST) per ride. This payment will help improve WAT services for wheelchair users.

If you have any questions about how the TTSS \$60 maximum subsidy works, please call the TTSS information helpline on 1800 200 592 or email <ttss@transport.nsw.gov.au>.

Who is eligible

Each application is reviewed by Transport for NSW's independent medical assessor. It is important that your medical practitioner or treating specialist provides enough detail and supporting documents to allow the severity of your disability or medical condition to be assessed. Receipt of an aged, invalid, blind or any other pension will not automatically qualify you for participation in the TTSS. Participation is not means tested.

For more details, read the eligibility criteria on the website.

Terms and conditions

Applicants for participation in TTSS are required to read and agree to the TTSS Terms and Conditions (pdf 205KB). Please read these specific requirements before completing the application. For more details, read the General Information booklet (pdf 145KB) to help answer further questions about TTSS.

How to apply

To apply for TTSS, enter your details in the Application Form (pdf 531KB), and provide the application to your medical practitioner or treating specialist for completion. Once complete, sign and date the form and then mail it to TTSS at the address provided. To request an application form be sent to you by mail, call TTSS on 1800 623 724 (toll free).

Reordering TTSS travel dockets

To order a new book of travel dockets use the green re-order form provided in the middle of the travel docket book, or download Reorder TTSS Travel Dockets (pdf 470KB) and send the completed reorder form to the address provided. **Important:** It is **not necessary** for existing participants to complete another TTSS application to reorder travel dockets.

Travelling interstate

TTSS participants who will be travelling interstate may order interstate travel dockets. Interstate travel dockets allow TTSS participants the benefits of the half fare taxi subsidy while visiting other states or territories (up to a maximum subsidy of \$60 per trip). Complete the Order Interstate Travel Dockets form (pdf 474KB), and send the completed order form to the address provided. **Important:** Generally, **a minimum of 2 weeks' notice** is required when ordering interstate travel dockets so please plan ahead. Regular TTSS travel dockets cannot be used for travel outside NSW.

Change of personal details

For your protection, and to ensure all requests can be authorised as genuine, all changes to personal identifying details (such as name, date of birth or gender) must be sent to TTSS either by fax or mail, with supporting evidence in the form of one of the following documents from the Office of Births, Deaths & Marriages as appropriate:

- Deed Poll
- Certificate of Marriage

Other official documents may be considered by the TTSS Manager.

Changes to contact details (such as address, phone number and alternate contact names) must also be submitted in writing.

Change Personal Details (pdf 243KB)

Important: Please be sure to notify the TTSS team of any changes to personal details as soon as possible to ensure that your continued access to TTSS is not unintentionally interrupted or terminated.

Important: In most cases it is not necessary to submit a new application to change your personal details.

Wheelchair Accessible Taxis (WAT)

The NSW Government has implemented an incentive payment for drivers of wheelchair accessible taxis to improve the accessibility, reliability and response times for TTSS participants who require a wheelchair at all times for travel.

Qualified wheelchair accessible taxi drivers can claim \$15 (ex GST) for each TTSS passenger approved for WAT travel they carry. TTSS participants who do require a wheelchair at all times to travel, but are not currently approved to travel in a wheelchair accessible taxi, should submit a supporting letter from their GP or specialist.

To determine if you are approved for travel in a wheelchair accessible taxi, refer to the account number on the bottom middle of each travel docket (example highlighted below in red). Docket numbers starting with '01' through '07' are not approved for WAT travel (referred to as M40), and docket numbers starting with '08' and '09' are approved for WAT travel (referred to as M50).

The image shows a pink Taxi Transport Subsidy Scheme (TTSS) M40 Travel Docket. The form is divided into several sections: Driver's Name, Date, Authority Number, Initialled by Driver, Account Name, Trip Details (Start, From, To, End, AM/PM), Fare (Meter, Extras, Total Fare), Amount of Total Fare in Words, Passenger's Signature, Amount Paid by Passenger, and Subsidy Amount. A red box highlights the account number '010000000' at the bottom left. The form also includes a warning about fraudulent use and a note about the subsidy amount not exceeding 50% of the total fare.

Example of Taxi Transport Subsidy Scheme M40 Travel Docket

Important: TTSS participants approved for travel in a wheelchair accessible taxi are not to be charged any extra money as the incentive is paid directly by Transport for NSW and is not to be added to the fare. Drivers are not permitted to ask you for extra money to cover this incentive payment.

Feedback

Suggestions, compliments or complaints about a taxi driver or a trip can be provided by either calling the Taxi Customer Feedback Management System on 1800 648 478 (toll free), or completing the online feedback form.

You must provide the taxi's number plate, the driver's number, the taxi network name, and the time and date of the journey.

All suggestions, comments and complaints are welcome and will be kept strictly confidential.

Last updated 01 July 2016

Chava Willig Levy Battles Against Stigma

by Mary Markos, Jewish Journal



Chava Willig Levy speaks to shatter stigmas against the disabled. *"I'm among the last in America to contract polio,"* said Chava Willig Levy, an award winning author, editor, advocate and internationally known motivational speaker regarding the virus that confined her at times to a motorized wheelchair at age three. In a cruel fluke of history that Levy, remarkably, does not bemoan, she was diagnosed with polio in August of 1955, four months after the release of the polio vaccine. Because distribution of the vaccine took some time, Levy was left vulnerable to the disease even as protection was making its way toward her. *"The fact that it happened that way, as a religious person, I feel that clearly God had something to do with it. It has to mean that God was a part of it,"* said Levy, explaining the philosophy that seems to guide her outlook toward the disease.

The first thing most people discover about Chava Willig Levy isn't that she is a New York-based writer, editor, advocate, and lecturer. And it isn't her love of children, French literature, the French language, psychology, music, words, and cooking.

The first thing most people notice about Levy is that she is in a wheelchair. However, if you ask her what has most negatively impacted her quality of life, she won't describe to you the physical limitations that accompany life with a disability. In her view, *"Disability doesn't destroy or damage one's quality of life. It really doesn't. It's the prejudices and the stigma of society that one must fight against."*

Chava Willig Levy and her husband met after she fell one day in her Manhattan apartment, and was unable to get up. Levy believes that all things happen for the good, even though at first the reasons may not be clear.

When Levy was in her late 20's a matchmaker suggested that she meet a gentleman who was 20 years her senior. He also had a disability. *"He really was a very nice person,"* although he was technically old enough to be a father to her. However, Levy explained to the matchmaker that she had met him in the past, and while she found him to be very agreeable there was simply no romantic chemistry between the two. She casually mentioned that she wouldn't object to meeting a man without a disability, the matchmaker, without missing a beat, replied, *"Chava, if a person without a disability agreed to go out with you, I'd wonder what was the matter with him you know, psychologically."*

According to Levy, a person with a disability can become convinced that he or she falls short in the eyes of the larger society. The challenge, believes Levy, *"isn't me or my disability. The problem is the stigma that is out there in our society."* Although Levy was often stigmatized, it motivated her to use her words to shatter those stereotypes about disabled people by writing her memoir, **"A Life Not With Standing"**. The title of the memoir is a play on words. *"If you say the name of the book quickly as three words – a life notwithstanding – that would convey the opposite of what I'm saying. I'm trying to say one can have a truly full and rich life and not be standing."*

Her interactive workshop, *"Mommy, What's Wrong with That Lady?"* has influenced hundreds of young people, ranging in age from 4 to 18. Levy has always had a special love for children, and when she speaks at events such as these, she asks the youngest kids to name the three most important things she should now about them. After calling on a few children, someone will ask Levy the three most important things about herself. *"None of the three things I mention is my disability."*

Famous for her humour, passion and compassion, Levy has captivated her audiences in the United States and abroad. In her mind, Levy has embraced life by being enthusiastic about the three most important things we should know about her, that she is passionate about music, children, and words.

TRAVEL - Accessible Cruising

by Millie Friend

Cruising is a fantastic holiday option for people with a disability, with many companies specialising in the organisation of specialised cruises or rental equipment, making the holiday relaxing and easy! Organisations such as Clubmates Australia and Special Needs at Sea help to organise and facilitate accessible cruising holidays, supplying disabled people with the necessary support and equipment. Different cruise liners also offer different levels of support for disabled passengers, including mobility support and Braille in public areas. More information on specific companies is detailed below.

CLUBMATES

<www.clubmatestravel.com> Ph: 1300 158 003 Email: <info@clubmatestravel.com>

Clubmates are a global leader in fully supported holidays for people with a disability. They are able to organise a variety of holidays, including cruises, for disabled people and their families and friends; keeping in mind the necessary features and equipment required for an enjoyable and easy holiday. Clubmates also ensure that passengers receive the best care and support throughout their cruise. Crew members are there to provide support to passengers whether that is one on one support or group support, and are also available to administer medication and assist with any other needs. This ensures all passengers are comfortable and supported and can make the most of their holiday.

SPECIAL NEEDS AT SEA

<www.specialneedsatsea.com> Phone: 1800 513 4515

Special Needs at Sea is an organisation that provides special needs equipment including wheelchairs, oxygen units and audio and visual aid rentals along with a range of other rentable items. Special Needs at Sea arranges all necessary equipment, tools and medical supplies, allowing for a person with disability or special needs to travel and cruise hassle-free. All rented goods are delivered directly to the passenger whether it is in their room on board, at a port or at a hotel. They are also the main service provider to all major cruise liners, demonstrating their expertise and outstanding service.

CRUISE SHIPS

P & O:

<www.pocruises.com.au/plan/know-before-you-buy/limited-mobility>

Phone: 1300 159 454

P & O Cruises is a well-known cruise company who provide options for accessible cruising. Subject to availability, there are wheelchair accessible rooms as well as other features such as specialised kits for hearing impaired guests. It is recommended that passengers alert the company to any special needs at the time of the booking. It is also important to note that access to some ports for the physically disabled may be limited. More information can be found on their website or obtained by phoning their office.

Royal Caribbean

<www.royalcaribbean.com.au/allaboutcruising/accessibleseas/home.do?wuc=AUS>

Phone: 1800 754 500 Email: <cruiseadmin.au@rcclapac.com>

Royal Caribbean is another major cruise company that provides accessible cruising options. The cruise caters for a range of disabilities with special provisions such as early boarding and boarding and departure assistance being made for those with mobility

disabilities. Facilities throughout the ship also accommodate the disabled, for example accessible blackjack tables in the casino and a lift into the pool. Braille is also used in all public areas and lifts and equipment and services for hearing disabilities can be obtained upon request. Other equipment such as shower stools, a transfer bench or a medical refrigerator can also be organised, however thirty days' notice must be given. Sixty days' notice must be given if you require sign language interpreting services. Passengers are encouraged to fill out a Guest Special Needs Form when booking to alert staff to any requirements.

SUPPLIER UPDATE

Equipment: Wondersheet

For many sufferers of short and long term illness or physical disability, turning over in bed can be a difficult and painful process. 'Neeki' have created the WonderSheet, a unique fitted sheet that makes getting into bed and turning over a much easier process!

Made from a combination of poly cotton and satin, the WonderSheet allows the user to easily turn on the specially placed strips of satin. This also benefits carers as it is easier to transfer someone into a bed and help turn them over.

The sheet can be custom made to fit any size bed and can be washed in a normal cycle. Ranging between \$79 and \$98, the WonderSheet is useful and practical and can be ordered online or purchased from one of the many stockists in Australia.

For more information on stockists please visit their website [<www.neeki.com.au>](http://www.neeki.com.au).

Email: [<info@neeki.com.au>](mailto:info@neeki.com.au) or Telephone: 07 5591 1629

The following articles are reprinted from the Newsletter of IDEAS, May/June, 2016

Private Accessible Transport

New resource helps people with disability 'Get Into Gear'

A new resource will help people with disability get into the driver's seat and enjoy the independence that driving provides.

Minister for Disability Services John Ajaka launched the Get into Gear program on the 11th April to help people with disabilities get their driving licence and where necessary, access modified vehicles. The resource also includes guidance for car dealers who provide online information about modified vehicles.

"Driving is a rite of passage and the NSW Government wants to make that journey easier for people with disability who want to drive, as part of our commitment to making communities accessible", Mr Ajaka said.

Get into Gear also lists car dealers selling modified vehicles, service centres that specialise in licence testing for people with disability, and relevant funding sources and schemes.

Mr Ajaka was joined at the launch by Professor Simon Darcy from the University of Technology Sydney, Andrew Meddings from the Blue Mountains who drives a modified truck as part of his business, and IDEAS NSW Executive Officer Diana Palmer.

"Being able to drive has meant that I can run my business, but more importantly, it has given me the freedom to get around and do the things I enjoy," Mr Meddings said.

"Navigating information that promotes great choices for people with disability is the bread and butter of what we do at IDEAS and the Get into Gear project puts individuals in the driver's seat literally and figuratively," said IDEAS Executive Officer Diana Palmer. "Best of all, it is Australian and has

verified data so that people can trust the accuracy and relevance of the information on the website. In addition to the creation of a 'one stop shop' for information, a key aim of the Get into Gear program is to influence on-line car sellers and re-sellers to include search fields into their websites, so that people with disability can search for a vehicle choice that best matches their needs. Which is why we are delighted to have the support of the NSW Government and the Dubbo community to help drive this important change."

The IDEAS website gathered information about the many separate processes a person with disability needs to gain or re-gain their independent driving ability.

It includes:

- Specialist driving instructors
- Specialist occupational therapists
- Driver assessors
- Detailed equipment and modifier suppliers

IDEAS would love to hear your story about the value of independent driving, or your need to get behind the wheel. Give them a call on 1800 029 904 and ask any questions you have.

For more information, go to **<www.ideas.org.au>**

We all love driving, right?

As Part of the 'Get into Gear' project, the IDEAS team produced a video which targeted car sales sites to help them understand the importance of driving to someone with a disability. The aim of the video is to change the mindset of online car sales sites by getting them to add extra fields and key words in their search functions. That way someone with a disability can search via specific key words which will highlight for them all the different accessible vehicles – rather than having to spend hours searching through all the different cars.

In the video they have a chat with Andrew Meddings and Diana Qian about how important being able to drive is in their lives. Below are snapshots from the video with a few quotes from both Andrew and Diana.



Andrew: *"When I go to the classifieds, internet and car sales, we have a look for vehicles and I've got to source through all the different vehicles. It would be so much easier if at my fingertips, like I have on the accommodation websites, if there was some sort of a field where it had 'the vehicle has already been modified', I could click on that and it would give me a list of the modifications. That way when I go to purchase a vehicle, I could see what is already equipped and I could buy a vehicle that I could drive home that same day."*



Diana: *"Being able to drive is the most liberating thing for me. It allows me to travel independently. I've been in really demanding jobs like managing organisations, going to lots of meetings and my car is the tool that is most important to me. It allows me to have a career and use my passion, my intelligence, my skill, and what I did at university and use it in a way to actually build a profession. I think I make a contribution to society through what I do."*

To watch the **"We all love driving, right?"** video make sure you head to the **IDEAS Disability Info YouTube Channel:** **<www.youtube.com/user/ideasnsw1>**

For more useful information: **<www.ideas.org.au/category/front/accessible-private-transport>**



2016 Polio NSW Seminar Program

Saturday 10 December	Burwood RSL Club Shaftesbury Road Burwood	AGM Seminar – Mary-ann Liethof “Australasia-Pacific Post-Polio Conference: Why, What and Who?” <i>and</i> “Polio Australia and Rotary District 9685’s Partnership to Educate Health Professionals”
---------------------------------	---	---

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 9894 9530
Merle Thompson	Secretary	secretary@polionsw.org.au	02 6352 3805
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Anne Buchanan, Nola Buck, Ella Gaffney, Anne O'Halloran, Alice Smart and John Tierney			

PPN Office and Other Contact Details

Office staff: George, John and Fatma		office@polionsw.org.au	02 9890 0946
Office volunteers: Nola Buck, Dianna O'Reilly			02 9890 0953
Anne O'Halloran	Seminar Co-ordinator	seminar@polionsw.org.au	02 8084 8855
Ella Gaffney	Webmaster/Support Group Co-ordinator	webmaster@polionsw.org.au	0407 407 564
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors <i>Network News</i>	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 around 3,000 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 a dedicated, secure, website at <www.australianpolioregister.org.au>. The Australian Polio Register is now assembling a rich data set of survivor numbers and related information.

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.



Volume 6, Issue



Polio Oz News

June 2016 – Winter Edition

A Taste Of Things To Come

The following [abstract](#) is one of the presentations which make up the Program for the Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters from 20-22 September in Sydney. Check the website for all details: www.postpolioconference.org.au.

Management of Spinal Issues in Polio Patients

By Carol Vandenakker-Albanese, MD

University of California, Davis, Health System

The spine provides structural support of the trunk and stabilizes the limbs. The polio virus attacks the motor nerves in the spinal cord, resulting in varying degrees of paralysis of muscles. This causes asymmetry of skeletal support and bone, altering posture and function.

These changes result in: loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments and increased stress on supporting soft tissues. Related spinal problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and nerve impingement secondary to spine degeneration that can mimic post-polio syndrome.

The risk of scoliosis in a polio survivor is 30%. Progression of the curve is correlated to degree of weakness and age at onset. Bracing is often unsuccessful in preventing progression and surgical fusion is often recommended. Progression of scoliosis can continue after skeletal maturity due to degenerative changes. Progression can cause an unbalanced spine, bony pressure points, and/or reduced lung function.

Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility. Spine (vertebral) fractures may occur with trauma or spontaneously.

Spine degeneration is common in polio patients. Stress on the spine is increased by asymmetry of muscle support, postural changes and altered mechanics of movement. Degeneration can



include slippage of vertebrae, enlargement of joints and ligaments and bulging discs. Degenerative changes may result in compression of nerves. Single level nerve compression can cause pain, weakness and/or loss of sensation in a limb.

Spinal stenosis refers to narrowing of the spinal canal, often as a result of degenerative changes. Symptoms can include: loss of balance and aching in the legs that increases with standing or walking. Pain is usually relieved with sitting or walking with shopping cart or walker and may be confused with symptoms of post-polio syndrome.

Medical evaluation is important to diagnose and focus treatment. Treatment options for spine conditions include: postural adjustments, activity modification, physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention. Spine bracing is safe but not always tolerated. Braces reduce motion and provide support. Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. Surgery may be considered when pain or nerve compression results in loss of function. Spine surgery is often major surgery with significant risks.

The preferred management of spinal conditions in a polio patient is conservative. Treatment should focus on changes in lifestyle, activity modification and a therapy program that includes postural correction, strengthening, stretching and cardiovascular conditioning. ●



2016 Australasia-Pacific
Post-Polio Conference
Polio - Life Stage Matters

20-22
SEPT
2016

FOUR
SEASONS
HOTEL
SYDNEY

SAVE
THE
DATE

Register Now

National Patron: Dr John Tierney, Ph.D., DAm

Polio Australia

Representing polio survivors
throughout Australia

Suite 119C, 89 High Street
Kew Victoria 3101
PO Box 500
Kew East Victoria 3102
Phone: +61 3 9016 7678
E-mail: office@polioaustralia.org.au
Websites: www.polioaustralia.org.au
www.poliohealth.org.au
www.australianpolioregister.org.au

Contacts

President—John Tierney OAM
john@polioaustralia.org.au

Vice President—Gillian Thomas
gillian@polioaustralia.org.au

Secretary—Jenny Jones
jenny@polioaustralia.org.au

Treasurer—Brett Howard
brett@polioaustralia.org.au

National Program Manager
Mary-ann Liethof
mary-ann@polioaustralia.org.au

Inside this issue:

Spinal Issues Abstract	1
Anaesthesia & Surgery Guide	3
Clinical Practice Workshops	4
Supporting Polio Australia	5
Rio Carnivale Party, Qld	6
Core Costs	7
Conference Update	8
Post-Polio In New Zealand	9
Why PPS Matters	10
Refining The Portrait of LEOp	11
Sister Kenny in Newcastle	12
NDIS Campaign	13
7 Secrets For Meditation	14
World Continence Week	17
Vit B12 Slows Brain Ageing	17
New Tack On Polio Vaccine	18
Immunity For Community	19
The 'Miracle' Glioblastoma Drug	22
Polio This Week	24

From the President



Dr John Tierney OAM
President

A few weeks ago Polio Australia Board member Sue Mackenzie, who is our (pro bono) fundraiser extraordinaire, put on in Brisbane her second successful event, a *Rio Carnivale Party*.

This event raised just under \$8,000 dollars in urgently needed funds to support the work of Polio Australia. On page six there is a full report of this highly entertaining event, which my wife Pam and I, and two other family members attended. They didn't realize that polio survivors could have such fun!

A funding cloud on the Polio Australia horizon is the difficulties created for our major fund-raiser, *Walk with Me*, after the organising body, *Ability First Australia*, lost its anchor sponsor *Dick Smith* when the business collapsed a few months ago. Gillian Thomas is leading negotiations on Polio Australia's behalf to re-establish this event under a new arrangement on the Polio Australia calendar.

Usually this event is held in September, but because of the Australasia-Pacific Post-Polio Conference in Sydney in September, at this stage we are thinking that the walks might be held as close as possible to *World Polio Day* on the 24th October. After a few years of raising a lot of money from this fundraiser, last year our efforts tailed off because fewer people took part.

I would really encourage you all to think about joining *Walk with Me* in October and approaching your family, friends, work colleagues and / or people in community groups that you know well to sponsor your participation. Again Sue Mackenzie has stepped

up to assist us with our efforts to reboot this event to once again become our major fundraiser. And having personally experienced Sue's creative flair, I'm sure there will be a distinctive festive feel to whatever she does.

I was recently invited by our friends across the ditch at Polio New Zealand to take part in their annual retreat which this year will be held in Rotorua in August. Since the appointment of Gordon Jackman to work full time on Polio New Zealand programs, Polio NZ has developed a range of initiatives to further the objectives of their organisation. When I am at the Polio NZ retreat, I look forward to catching up on their plans for the future. I will also be encouraging their members to join with us at our Australasia-Pacific Post-Polio Conference.

The conference registrations are going well, so please don't miss this opportunity to take part and learn about how to better manage your post-polio condition from the outstanding panel of Australian and international experts who have agreed to take part pro bono. Our conference received a terrific boost recently from a sponsorship of \$24,000 from the NSW Department of Health. To register for the conference please click this [Register Now](#) link.

Polio Australia is highly dependent on private donations to fund its work with the post-polio community. In the Autumn edition of *Polio Oz News*, I outlined initial progress on our work in developing a more robust *bequest* program. I wish to acknowledge the terrific work that Mary-ann has put into the development of this program and her and Jill Pickering's generosity in funding a dedicated part-time position at Polio Australia to advance this fund raising initiative. When you are updating your Will, we would like you to consider supporting the work of Polio Australia with a bequest. 🍌

John

From the Editor



Mary-ann Liethof
Editor

As we hurtle through the year at break-neck speed, excitement is mounting in the lead up to the Australasia-Pacific Post-Polio Conference taking place in Sydney from September 20-22 (P8). I am in absolute awe of all the presenters who are funding themselves to be there to share their experience, skills and knowledge with the delegates. Whilst there is much

discussion about the lack of information amongst health service providers in relation to working with the post-polio body, this Conference demonstrates a clear generosity of spirit from those who *do* have the knowledge. The combination of European, American, Australian, and wider world experts coming together to present on "*Polio: Life Stage Matters*" is unprecedented and unlikely to occur again. Do not miss this major event!

The LEO Clinical Practice Workshop series has been heralded as a great success (P4), and we now have 130 Sydney-based health practitioners who know about the condition. We can only hope to generate the interest and funding to facilitate these Workshops further afield.

And we are delighted to see that things are coming together for our cousins 'across the ditch' in New Zealand (P9), with funding from the Duncan Trust to provide training opportunities for health professionals wanting to learn more about the late effects of polio. What a wonderful

boon! We are very envious of this generous funding source here in Australia!

I was quite moved by poem penned by Peter Willcocks on his battle to get going in the morning (P12). It certainly put my grumbles into perspective.

And did you know that a Sister Kenny Clinic operated in Newcastle (NSW) between 1936-1943 (P12)? Although many would regard Sister Kenny as a rather controversial figure, her methods were certainly known and practised far and wide.

Also in this edition are contributions from the 'other' NDIS (Not Damn Interested In Seniors) campaigner, Lori Grovenor (P13); and Kristy Rackham, RN, guides us through the secrets of meditating and insists you can't 'do it wrong', so why not give it a try?

June 20-26 is World Continence Week, and you will find some helpful advice on how to manage this often unspoken-about condition (P17).

As always, there are a variety of news items based on the polio vaccine, with a couple of interesting reports on the incredibly ambitious 'Switch', whereby 155 countries changed their polio vaccine regime over a 2 week period during April. (P18 and P20).

For those of you who have read previous articles on the polio virus being used to fight brain cancer, a review of a related '60 Minutes' program will provide a few salient points to consider (P22).

Please enjoy! 🌈

Mary-ann

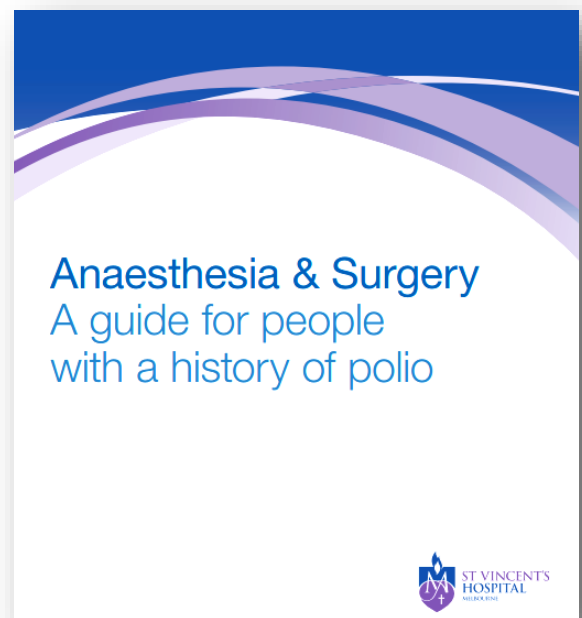
Anaesthesia & Surgery Guide

Anaesthesia & Surgery A guide for people with a history of polio

Polio Services Victoria, a service of St Vincent's Hospital, Melbourne (Australia) has developed a comprehensive new guide which can be viewed and/or downloaded from their website [here](#).

People with a history of polio have special needs when it comes to anaesthesia and surgery. This guide is for anyone who has had polio and will be having surgery. It has information to help you and your healthcare team plan your surgery. Take it with you to any appointments before you have surgery, and when you go into hospital.

Polio Services Victoria is a multidisciplinary team comprising a rehabilitation medicine physician, a physiotherapist, an occupational therapist, an orthotist and a social worker. They provide a specialist assessment and referral service, with limited capacity for direct treatment/therapy. 🌈



LEoP Clinical Practice Workshop Series Update

By Mary-ann Liethof
National Program Manager

Polio Australia partnered with [Rotary International District 9685](#) to stage seven **free** Post-Polio Clinical Practice Workshops throughout the Blue Mountains and North Western Sydney between November, 2015 and April, 2016. These Workshops were facilitated by [Melissa McConaghy](#), neurophysiotherapist and Principal of [ARC Health](#), based in St Leonards, NSW. Melissa is a member of Polio Australia's Clinical Advisory Group, and will be presenting at the [Australasia-Pacific Post-Polio Conference](#) in September. We also engaged Jennifer McConaghy, administration assistant at ARC Health, to provide admin support.

Rotary District 9685 secured funding through their Clubs to pay for Melissa and Jennifer's time, and project costs. Polio Australia supplied brochures, hard copies of "The Late Effects of Polio: Introduction to Clinical Practice" book, a PDF of "The Late Effects of Polio: Managing Muscles and Mobility", and a Certificate of Participation for 2.5 hours of Professional Development points.

The participating Rotary Clubs secured the venues, organised refreshments, and liaised with Jennifer regarding logistics, including dropping flyers into local health service providers.

The program was developed following preliminary discussions with John Tierney at a 2015 District Conference in Cessnock, NSW. Polio Australia had conducted a successful trial clinical practice workshop in Melbourne in 2014, and was seeking support to organise a further series of workshops to share resources and training for health professionals.

At the beginning of the 2015/16 Rotary year, the incoming District 9685 Governor, Gina Growden, was briefed on the discussions with Polio Australia and immediately supported the proposed series of Workshops. The Governor shared the concept with her Clubs and District leaders and agreed that the project had great potential to be further developed by Rotary International and play a role in the culmination of the Polio Plus campaign. It was emphasised that the proposed program had a strong 'fit' with Rotary's vocational base.

Over a six month period, seven workshops were run in: Ryde, St Leonards, Katoomba, North Rocks, Penrith, Hornsby, and Gosford.

Another has since been rescheduled for Windsor on the 28th of June. Polio Australia has secured the services of Catriona Morehouse,



Physiotherapist, [Post-Polio Clinic at Mt Wilga Private Hospital](#) to facilitate this Workshop, using the same presentation used by Melissa. More details and bookings [here](#).

The 130 health professionals who attended included: general practitioners, community health workers, exercise physiologists, massage therapists, nurses, occupational therapists, orthotists, physiotherapists, social workers, and a speech therapist. Participants came from a variety of work areas: public and private sectors, students, private practice, and even several retired practitioners.

Very positive written feedback was received from the majority of health professionals who took part in the workshops and these comments are being collated for future use, and will be presented by Mary-ann Liethof at the Australasia-Pacific Post-Polio Conference in September. It is hoped that a number of the Workshop participants will also attend the Conference.

Discussions are now under way for a similar program of Workshops to be facilitated in New Zealand by Julie Rope, a neurophysiotherapist who runs her own rehabilitation clinic in Auckland. Julie is working together with Polio NZ, and is being funded by the Duncan Trust to educate health professionals in the late effects of polio.

In her handover dinner, District 9685 Governor, Gina Growden, recorded the appreciation of her Rotary District and Rotarians in general for the outstanding support and commitment from all associated with Polio Australia and ARC Health, including the dedicated band of polio survivors who provided invaluable insight at every workshop: Gillian Thomas, Sue Ellis, Rosemary Cantwell, Merle Thompson, Anne O'Halloran, Di O'Reilly, Ben Tipton, Wayne Woolley, and John Tierney. 🌟

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 March to 30 April 2016.

Hall of Fame

Name	Donation
Jill Pickering	\$4,000
Rio Carnivale Party*	\$1,450.00
*More to come in May	
Total—\$1,850.00	

General Donations

Names				
Anthony Brain	Jill Burn	Katherine Guthrie	Hume Polio Self Help Group	
David Miller	Rotary Club of Albany Creek	Royal Overseas League	Liz Telford	
Total—\$768.20				

Facts You Need To Know About The Charity Sector

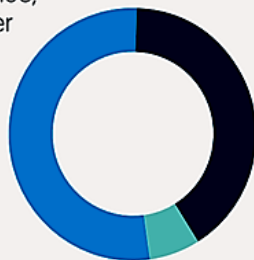
- ♦ Australia has around **54,000 Charities**, employing over **1M staff** and an annual income of **\$104B!**
- ♦ The largest **5% of Charities**, receive **80% of the sector's income**
- ♦ **64% of Australian Charities** receive **no Government Grants**
- ♦ Charities received **\$6.8B in donations and bequests** in 2014
- ♦ **31.5%** of Charities have **less than \$50,000 income** and **44%** operate with **no paid staff**
- ♦ The average age of a charity is **33 years** and **6%** are **over 100 years**
- ♦ **80%** of Charities **use volunteers**
- ♦ **64%** of Charities are **classified small**, **17% medium** and **19% large**

- Culture and recreation (6%)
- Development and housing (8%)
- Education and research (18%)
- Environment (3%)
- Health (9%)
- International (1%)
- Law, advocacy and politics (1%)
- Other/Unknown (11%)
- Philanthropy (6%)
- Religion (30%)
- Social services (7%)

- **\$54.5 billion** is from other income and revenue, including sales, member fees and user pays

- **\$42 billion** is from government grants

- **\$6.8 billion** is from other donations and bequests*



64% had no income from government grants

* Donations contribute to: **13%** of total income for large charities, **23%** for medium charities and **32%** for small charities

Statistics from Centre for Social Impact & Social Policy Research

Polio Australia is a typical 'small charity', receiving no Government Grants, with only one full time paid staff member, and many volunteers.

We thought it was interesting that 64% is the same statistic used for both the number of Australian Charities receiving no Government Grants, and those classified as 'small'.

Unlike larger charities, Polio Australia relies on your donations and bequests to do its work. Please consider supporting our 'small charity'—tax receipts provided for donations over \$2.00. 🌟

DONATE

**Request
Information**

Rio Carnivale Fundraising Party!



Rio came to Brisbane on Sunday the 15th of May thanks to Sue Mackenzie's Rio Carnivale Fundraising Party! Around 70 people attended the Brunswick Hotel to enjoy tapas, entertainment by the [SAMBALISCIOUS Dancers](#) direct from Rio, and a fashion parade by [SFH Designs](#). Sue and her team of volunteers organised the day, with generous sponsorship from [Gold Coast Benji](#), SFH Designs, [Red Works](#), and [Elliotts Accounting](#). Sue was kept busy announcing competitions and drawing over 30 raffle prizes. The total nett amount raised for Polio Australia was an amazing **\$7,821.67**—and a very good time was had by all! A big **THANK YOU** to Sue, and everyone who contributed to making the day such a wonderful success. Riba! Riba!! 🌟

- Ed

A note from Sponsor SFH Designs By Sarah Hutson (Owner)

Wow what an afternoon of colourful fun, dancing and, most importantly, fundraising! Our Rio Carnivale Party Fundraiser was a fabulous hit with everyone! Starting with the amazingly talented Sambaliscious dancers direct from the Rio Carnival 2016, in their feathers and sequins, dancing up a show-stopping storm. Our SFH Designs Fashion Parade showcased our colourful and exquisite designs from around the world. While our wonderful host Sue kept the fundraising happening with loads of raffles, lucky door prizes, silent auctions and donation request competitions. There was of course, a lot of hard work behind the scenes, with all the table floral arrangements including cut-out parrots and flamingos, table menus, a supply of pineapple lollies and table numbers, all personally made and sponsored by SFH Designs. We also had a SFH Designs Pop-Up Shop on the day, from which we donated an extra 20% of our sales (\$300).

Overall we were very pleased to have been able to help Sue achieve her fundraising target. Oh, and Sue is also my mum - what an amazing mum I have!

www.sfhdesigns.com.au
Instagram: SFH_DESIGNS
Facebook: SFH Designs
Twitter: @SFHDesigns



**Sambaliscious Dancers with Sue Mackenzie (back)
Mary-ann Liethof, and John Tierney**

More photos can be viewed on [Facebook](#). 🌟



Why Are Core Costs Important?

By Gillian Thomas, Polio Australia's Vice President and Business Manager

Polio Australia's [2015-2018 Strategic Plan](#) details its priorities over that period. The priorities have been developed in line with the Objects of the Polio Australia Constitution.

In order to achieve the objectives of the Strategic Plan in support of polio survivors, Polio Australia must develop its financial and human resources to ensure that both its core costs and its program costs can be met, and to ensure that planned programs, projects and activities are successfully undertaken.

Core costs are the expenditure items that are not connected with the levels of activity undertaken by an organisation. They are the awkward costs that are difficult to associate with any specific outputs, as they will exist *before* and *after* a project has been running. Core costs include governance, management and staffing, together with support costs such as office rent, admin and bookkeeping, communications and websites, and publications and promotion. Why are core costs important? These costs will always need to be funded, whether an organisation is running 30 projects or just three. They're fundamental to Polio Australia's survival, but can't be directly associated with any specific outcome. As such, it is very difficult to attract government or corporate funding towards these costs.

Polio Australia and the services it is able to deliver to benefit polio survivors are currently necessarily limited in scope and severely hampered by a lack of financial and, it follows, human resources. The lack of government or other recurrent funding means ongoing efforts must be put into raising funds to enhance and expand the organisation and its services through avenues such as one-off project grants, Rotary relationships, bequests, and donations.

In essence, tax-deductible donations are the life blood of Polio Australia's existence – and they need not be large. Donations can be viewed as blood transfusions – every precious drop is needed. As well as appreciating an end-of-financial-year donation, regular smaller donations are just as gratefully received.

Did you know that you can set up a recurring withdrawal from most internet bank accounts to make your donations automatically at the times you choose (for example, monthly or quarterly)? Just be sure to [let us know](#) the deposit details and we will email you our official receipt each time, then at the end of the financial year we will also send you a statement of your donations throughout the year, to help in preparing your tax return. 🍎

Rome wasn't seen in a day



Fold, Pack, Travel

1300 622 633

www.scootersAus.com.au

**scooters
australia**

Australasia-Pacific Post-Polio Conference Update

Have you Registered for the Australasia-Pacific Post-Polio Conference yet?

After 18 months of planning, the Conference is now only a little over 3 months away, so make sure you secure your booking for this unique international event soon.

Polio Australia is privileged to have access to the skills, experience, and knowledge of so many post-polio experts at this Conference. There are an unprecedented 54 separate speakers, and 6 poster presentations, with many of the presenters delivering more than one paper.

Apart from 35 Australian physicians and 'lived experience experts', presenters will be arriving from Denmark, India, Italy, Japan, the Netherlands, New Zealand, Spain, Sweden, the UK, and the USA. Several delegates are also attending from these countries, with the addition of Belgium, Georgia, Malawi, and Pakistan, providing a truly global overview.

Confirmed major sponsors to date include: NSW Health, GSK, and ResMed, with several more under negotiation. Sponsorship packages can be viewed [here](#).

REGISTER NOW

Polio: Life Stage Matters

Polio Australia is tackling the challenge of enhancing the knowledge base of health professionals in relation to the post-polio body by running the first ever [Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters](#). The Conference is being held at The Four Seasons Hotel in Sydney from 20-22 September, 2016.

In the past 6 months, 130 multi-disciplined health professionals have attended a series of Post-Polio Clinical Practice Workshops across Sydney.

Here are 5 outcomes the participants reported in their feedback:

1. I work with aged care facilities and we often have polio survivors. My follow-up action is for more self-education and awareness of my patients.
2. I will be including post-polio in my PT assessments, and I am very interested in educating our surgeons on the dangers/detriments of anaesthetics.
3. I have post-polio clients who I considered during the presentation. Amazing to hear the personal accounts – very powerful!
4. Working in physio private practice I see the occasional patient with the late effects of polio. I now have much more information to think about and am more aware of appropriate management and referral.
5. I knew so little about this topic and now feel inspired to learn more!

The late effects of polio affects thousands of Australians, with many unable to find health practitioners with sufficient knowledge to treat them. Make sure you are informed in the provision of gold standard, appropriate care required by your post-polio clients.

This Conference promises to facilitate better care and build international connections by bringing together health care providers, researchers, polio survivors, their caregivers and patient organisation representatives from the Australasia-Pacific region, and worldwide. The current [Program](#) and [Abstract Summaries](#) are now online and will be published in a special edition of the [Journal of Rehabilitation Medicine](#). 🌐

- Ed

Did you know?

- Registration options are available for 1, 2, and the full 3 days of the Conference.
- Health professionals are currently being offered a **group discount** when they book for 3 delegates, with the 4th one free.
- Day 3 of the Conference [Program](#) comprises 8 x 2 hour Master Classes for health professionals on a variety of post-polio conditions.
- Full registration includes free entry to the Welcome Cocktail Party and networking function on Day 1 at the [Museum of Contemporary Art](#).



Contact melanie@intermedia.com.au / 1300 789 845 (Australia) / +61 2 8586 6103 (international) to find out more.

Establishing Post-Polio Clinics in New Zealand

By Julie Rope, PT

Until recently polio survivors in New Zealand have had little support to either be assessed for the Late Effects of Polio (LEoP) or develop clinically robust rehabilitation plans. In 2015 Polio NZ developed a strategic plan with the development of polio clinics in NZ as a major goal. Gordon Jackman was hired by Polio NZ in November 2015 to implement the strategic plan.

At the same time the Sir Thomas and Lady Duncan Trust, founders of the Duncan Polio Hospital in 1945, had initiated a process with Julie Rope of [Rope Neuro Rehabilitation](#), Newmarket, Auckland, with similar aims. Polio NZ, the Duncan Trust and Julie Rope got together and developed a plan to create a clinical support network in New Zealand for polio survivors, wherever they were, to enable them to access expert assessment and supported rehabilitation plans, as well as ongoing support for them and their families.

It is considered that there is a mix of quality and experience of clinicians who have worked with polio survivors and a potential dilution of support across geographically wide areas. This limited ability to access expert assessment reinforces the lack of clinical practitioners who understand the management of polio and who understand the issues associated with the ongoing support for polio survivors and their families. There are currently no training programmes within New Zealand either at an undergraduate level or in care related employment and professional body education programmes.

The vision for the future would involve polio clinics in Auckland and at QE Health in Rotorua, with further clinics planned for Wellington, Christchurch and possibly Dunedin. Connecting all these clinics will be a virtual centre of excellence which will share resources, co-ordinate the training of clinicians and health professionals, and resource support in the home.

Conducting clinics in remote areas is also an aim, as many polio survivors have great difficulty in travelling to main centres.

Measures taken so far include initiating an epidemiological study of polio survivors in New Zealand with Auckland University of Technology to inform realistic discussions with District Health Boards (DHBs) on the provision of services. We have met with Ministry of Health (MoH) officials in Wellington about our proposals, receiving a very understanding hearing and ongoing support.

Polio Australia hosted Julie Rope at an "Understanding the Late Effects of Polio Clinical Practice Workshop" at Mt Wilga private hospital and have supported her with resource material so that she can deliver the workshops in New Zealand and in the future develop educational resources and webinars. Catriona Morehouse from Mt Wilga has been very generous in sharing her experiences with us. Other steps have included meeting with DHB directors to establish current DHB's level of provision for polio survivors with the LEoP and opportunities for collaboration in the future.

Julie Rope plans to open "The Clinic for Neuro Muscular Conditions" at her Balmoral, Auckland, neuro physiotherapy establishment which will initially focus on the assessment of the late effects of polio and the provision of rehabilitation plans for polio survivors. Julie plans to eventually expand the clinic to cater for a wider range of chronic Neuro Muscular Conditions.

She is interested in compiling a network of educated therapists with an interest in the management of people with the Late Effects of Polio and clinical expertise/resources to provide consistent assessment and relevant management/treatment.

If you would like to register your interest in the development of this polio clinic network project [in NZ] please contact Julie Rope via admin@ropeneurorehab.co.nz.

Former Duncan Hospital polios gather to celebrate

Over 600 people gathered on a Rangitikei farm near Hunterville to launch a new book "Otiwhiti Station", the story of the Duncan family.

Many Polio survivors owe their recovery to the Duncan Hospital, which was started by Mr & Mrs T.A. Duncan and funded from the proceeds from the Otiwhiti Station farm in the 1940s and 1950s.

Source: [Polio NZ 2011 News](#)



Post Polio Syndrome



What is it, and why does it matter?

By Ted Hill, CEO of The British Polio Fellowship

Source: www.hippocraticpost.com
—13 May 2016

Poliomyelitis, or Polio, as it is more commonly known, is one of the world's best known diseases. Having famously been contracted by Frida Kahlo, Neil Young and even Franklin Roosevelt, Polio was endemic throughout much of the 20th Century. However, one of the most successful vaccination campaigns in history has all but seen off Polio, with just 74 cases recorded last year, and just Afghanistan and Pakistan left as Polio endemic countries.

While the vaccination campaign is undoubtedly a huge triumph for medicine, the battle against Polio is not yet won. Members of the public and medical professionals alike are now unfamiliar with the symptoms of Polio and when it comes to Post Polio Syndrome (PPS) even less so.

Post Polio Syndrome is a badly misunderstood condition. Just seven per cent of the UK public have heard of PPS. That's despite 120,000 living with PPS in the UK today – a similar number to Parkinson's, which 86 per cent of the public are familiar with. Even more alarmingly, this lack of awareness also translates to the medical profession, where just 55 per cent of GPs feel able to diagnose the condition, and 18 per cent of GPs did not know how to manage the fever, fatigue, pain and breathing difficulties which characterise the condition when it is diagnosed.

A large part of my job as CEO of The British Polio Fellowship is to try and spread awareness of Polio and PPS – both among the medical profession and the public at large. Given that 80 per cent of people who have had Polio are likely to contract PPS, it is an important job both now and for the future, both here in Britain and abroad.

PPS symptoms include cold intolerance, increasing weakness, muscle and joint pain, stamina problems, sleep disturbance, breathing problems, swallowing problems, fatigue and pain. As you may notice, many of these symptoms cross over with other conditions, causing real problems with misdiagnosis, something which is only compounded by the similarity of the symptoms to common signs of ageing. Matters are made even more confusing by the similarities between PPS and Chronic Fatigue Syndrome, a condition which it shares much in common with.

Diagnosing PPS can therefore be extremely difficult, with symptoms often hard to separate from complications arising from the original

infection. There is no laboratory test for PPS, nor are there any specific diagnostic criteria. Instead, three key criteria are required to diagnose PPS: previous diagnosis of Polio, long interval after recovery and the gradual onset of weakness.

When PPS is finally diagnosed, there is no silver bullet or magic treatment. Instead, PPS can only be managed. While this outcome is not perfect for those living with the condition, much can be done to alleviate the pain it causes, as properly managed, PPS may stabilise or only progress slowly. Much can be done to retain independence, including appropriate treatment for symptoms, self-management strategies such as pacing and energy management, appropriate use of adaptive equipment, looking after your general health, and social and emotional support.

Currently, there are no UK specific guidelines to managing PPS, which means that access to appropriate services for people with PPS can vary greatly. To help combat this problem, The British Polio Fellowship produced a new document entitled [Post Polio Syndrome: A Guide to Management for Healthcare Professionals](#). This ground-breaking document is the first of its kind, and was produced with assistance from leading experts in the field. I hope it signals the start of a better understanding of PPS, and if just one person receives better care as a result of that document, then it will have done its job.

With the aforementioned document, and campaigns such as PPS Day, which we also run, The British Polio Fellowship take a two-pronged approach to PPS, providing both practical advice to members and helping to spread awareness of the condition. As time goes on, we are likely to see more and more people living with PPS, particularly in the developing world. I hope that by then, we will have made some serious headway into making the world aware of what has become the forgotten footnote of Polio. While Polio is one of the world's most recognised diseases, PPS sits in the shadows – and yet the reality is now, that PPS causes much more pain and suffering. The battle against Polio may be all but over, but the war is not won. It is now time for us all to focus our efforts on tackling, managing and understanding PPS.

Ted Hill, MBE joined The British Polio Fellowship in 2012 from a strong Third Sector background. Having worked in the voluntary sector for over 35 years, Ted was awarded an MBE for his services to the Voluntary & Community sector in the 2011 Queen's New Year's Honours. Prior to joining The British Polio Fellowship in 2012, he worked for Hillingdon Association of Voluntary Services.

Refining The Portrait of Late Effects of Polio

By Phil Stevens, MEd, CPO, FAAOP

Content provided by [The O&P EDGE](#)
—February 2016



I treat fewer patients with post-polio syndrome (PPS) than I used to. I suspect this is true for most clinicians who have a decade or two of clinical experience. As practitioners see progressively fewer cases of PPS, we are less able to evaluate a given case within a broader perspective of how this patient population generally presents and the extent of the disease's effects on things like muscle strength, gait performance, balance

and fall history, and activity levels. Clinicians, particularly newer clinicians, may never see enough cases to independently develop an accurate, comprehensive portrait of what the late effects of polio look like.

Fortunately, there are centers that still manage large numbers of patients with PPS. One of these, a rehabilitation clinic based in a university hospital in southern Sweden, maintains a database of over 300 cases. Researchers from this center have published a series of studies to describe a more complete portrait of patients who have mild to moderate PPS. This cohort is defined as individuals between 50 and 80 years of age who are able to walk at least 300 meters with or without assistive devices or lower-limb orthoses, but do not require a wheelchair as their primary means of mobility. This article summarizes some of those findings and refines the portrait of post-polio effects.

LOWER-LIMB ORTHOTIC USE

Early in my career, a mentor described a conversation he overheard in a hospital when a surgeon's rationale for performing a surgery was questioned. "Because", the surgeon tersely responded, "when you're a hammer, everything looks like a nail". I've always retained this conversation as a reminder that we are products of our collective experiences, and that these experiences may or may not accurately represent the bigger picture. Just as an experienced cranial orthotist might inaccurately assert that conservative repositioning will never adequately address deformational plagiocephaly because such corrected cases simply don't present in the

clinic (and why would they?), it would be easy for the orthotic community to conclude that because we ultimately brace almost every case that is referred to us for treatment, most patients with PPS utilize lower-limb orthoses. However, this does not appear to be the case.

For example, in a random selection from the Swedish database of 102 cases with a response rate of 79 percent, only 21 of 81 cases used lower-limb orthoses—with AFOs outnumbering KAFOs roughly 4 to 1. Similar numbers were observed in a separate cohort of 122 individuals extracted from the same database. Interestingly, this lower-than-anticipated use of lower-limb orthoses may not be entirely due to a lack of need. In a third trial, examining the relationship between muscle strength and gait performance, the strength of the more affected knee extensors were, on average, 35 percent weaker than the less affected extensors. More strikingly, the more affected dorsiflexors were, on average, 62 percent weaker than the less affected dorsiflexors. In fact, more than half of the 90 subjects included in the study had no measurable strength in the dorsiflexors of at least one limb, yet only 21 subjects walked with an AFO. Given the diligence with which these subjects have been managed within the rehabilitation clinic, this discrepancy would appear to be one of choice rather than a lack of access. Many patients in this population who might reasonably benefit from lower-limb orthoses choose not to use them.

Read more [here](#).

SUMMARY

When the Swedish data is viewed collectively, a composite portrait of PPS begins to emerge. It is a tremendously variable patient group frequently presenting with muscle pain, weakness, and fatigue. Despite the obvious potential benefit of lower-limb orthoses, many individuals choose not to pursue these interventions. Mysteriously, muscle weakness is only moderately correlated to gait performance measures, with greater correlations associated with walking endurance and elevated walking speeds. Impairments, limitations, and concerns about falling are frequently reported, yet this patient population generally remains fairly active compared to other populations of older adults. Of this activity, nearly three-quarters is done in and around the home.

This portrait allows practitioners to better assess how individual patients with PPS fit within the broader post-polio population and may guide clinicians to better predict and address areas of concern and limitations. 🟡

A Polio's Day Starts Hard

By Peter Willcocks
—May 2016

*Sleep deprived
we sit for a bit.
Tic Toc,
getting up
bit by bit.*

*Arms and legs are toxic,
chest heavy to breath,
rasping throat to swallow...*

*Groan to shower, stretch to dry,
drag clothes on and sigh.
Braces time...*

*Shoes, socks, pickup sticks,
shoe horns, steps and braces
all aligned,
just as pets
ready to play.*

*struggle...struggle...struggle...
sock it to me... sock it to me...
Exhausted, we start each day.*

*Gobbling experts'
antidepressant pain relief
just makes me.... urrh
Drugs can't dress me.*

*Daily we build
the pain, the frustration
and too often we despair.*

*Please DHHS¹ and PSV²
don't SWEP³ us away.
New braces. Now please.
Not in two years' time.*

*and please don't tell us
we need backup aids
when we're already
waiting on a list.*

*and please don't tell us
what can't be done.
Spend time in our homes,
start where the pain begins.*

*Burning out,
ageing too soon,
many things become
just out of reach.*

*Bring cups and fillers
to hand.
Change taps and knobs
to push 'n pull.*

*Health check our chairs and
things
Guide us to the manageable.
Reassure our carers, partners
and friends.
That there's lots of living
yet to do.*

*and please don't make us feel
a burden,
polio wasn't a choice of ours.*

*Work with us for dignity,
Work with us as a whole.
Work with us to share
your world
our world
for all of those who need.*

¹ Department of Health and Human Services
(Victoria)

² Polio Services Victoria

³ State Wide Equipment Program (Victoria)

Sister Kenny Clinic in Newcastle

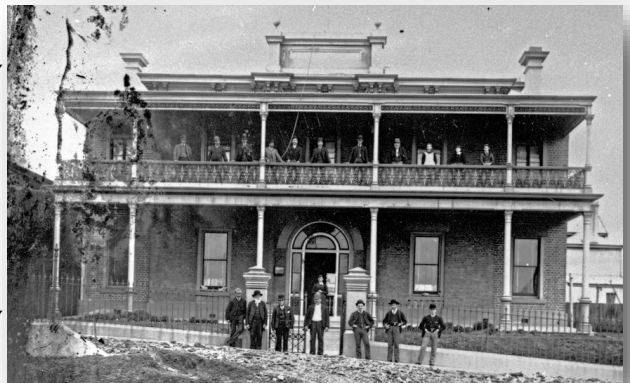
After 70 years of neglect, Alastair and Diane Kinlock decided to buy and restore an old historic building in Newcastle East (NSW), known as the *Cotts Sailors' Home*. Through the Heritage Impact Statement, they discovered the home was formerly used as a Sister Kenny out-patients clinic, which they knew would be of great interest to their friend, Dr John Tierney (President of Polio Australia). Excerpt follows:

Sister Kenny Clinic: 1936-1943

Following the decision not to go ahead with the accommodation of chronic invalids at the Coutts' Memorial Home, the Board of the Newcastle Hospital considered a proposal to establish the Home as a trial clinic for the treatment of infantile paralysis based on the methods adopted by Sister Elizabeth Kenny.

By June, 1938 an average of 75 patients were treated daily at the Sister Kenny Clinic. The clinic continued to function to capacity the following year by which time sufferers of infantile paralysis were also being treated at the Infectious Diseases' Hospital at Waratah. In 1940 the sister Kenny Clinic came directly under the control of the Newcastle Hospital and was subject to the same authority and discipline as other units of the Hospital. A decision was made in 1941 to move the treatment of all infantile paralysis cases to the Infectious Diseases' Hospital, Waratah.

Follow the restoration progress on the *Cotts Sailors' Home* blog [here](#).



NSW Wheelchair Users Get Increase In Taxi Subsidies

By Kimberley Martin

It's good news for wheelchairs users travelling in NSW taxis with support payments increasing from July 1. The increase is part of a \$15.5 million boost to deliver more accessible services and applies to both eligible Taxi Transport Subsidy Scheme (TTSS) customers and drivers of Wheelchair Accessible Taxis (WATs). The NSW Government has been reviewing all transport options for people with disability and part of the

reform package includes a reduction in a lot of red tape around taxi travel, namely an increase in the taxi subsidy paid to passengers with disability that has now doubled to \$60. WAT incentive payments will be doubled too, up from \$7.70 to \$15 for each pickup. License fees, which were previously an expensive annual cost, have been abolished along with the booking service fee.

Read full **Freedom2Live** article [here](#).

New Disability Discrimination Commissioner

Source: [Disability Australia Media Release](#)
—6 May 2016

Disability Australia Embraces the Appointment of the New Disability Discrimination Commissioner, Alastair McEwin

National people with disability organisations have embraced the appointment of the new Disability Discrimination Commissioner, Alastair McEwin.

Disability Australia congratulates the Attorney General, Senator the Hon George Brandis QC, for the appointment of a dedicated Disability Discrimination Commissioner.

"We welcome the new Disability Discrimination Commissioner, Alastair McEwin", said Matthew Wright, CEO of AFDO and spokesperson for Disability Australia.

"Alastair is one of us, he is a person with a lived experience of a disability (deaf) who is well regarded and from our communities".

"We know that he has a strong and extensive advocacy background, appreciates the diverse challenges we face and will continue to act in the interests of all people with a disability." said Mr Wright.

Alastair served on the Board of Deaf Australia; is the President of the Deaf Society of NSW; Chairman of the Disability Council of NSW; is the current Executive Director of Community Legal Centres (NSW); is the former CEO of People with Disability Australia and was the former Manager of the Australian Centre for Disability Law.

We still have a long way to go in realising the human rights of all people with disabilities and it is great that the government have appointed a full time Disability Discrimination Commissioner with a lived experience to realise equity for all people with disability.

"This is a good appointment by the government, a good appointment for people with disability and our organisations look forward to supporting Alastair in his new role in any way we can". ●

NDIS (Not Damn Interested In Seniors)



Lori Grovenor writes that she first became engaged in this issue through her own interactions with the aged care system as a person with disability. Her experience has been frustrating, undignified and complex and it concerns her to think how many people are likely to fall through the cracks in the future should these issues remain unresolved. To this end, Lori has assisted in the development of a grass roots advocacy campaign entitled **NDIS (not damn interested in seniors) = My Aged scare**. View a copy of the campaign briefing paper [here](#), which provides further details about proposed solutions to the following problems, as well as information about Australia's human rights obligations to older people with disability

The background:

In 2013, the government commenced rollout of the National Disability Insurance Scheme (NDIS) – a lifetime scheme of care and support for people with disability. But people who acquire a disability after the age of 65, or are over 65 when the scheme rolls out in their area are not eligible for the NDIS. These people are instead expected to access the support they need through the aged care system, through a gateway called My Aged Care.

The problems:

Lack of information: Many people with disability have had no interaction with the aged care system and are largely unaware of how it operates. Federal and state governments continue to inject significant amounts of money into projects that are designed to inform people with disability about their rights under the NDIS, but there has been no information provided to people with disability who are over the age of 65 to inform them about My Aged Care as it relates to the specialist support needs of people with disability. As a result, many people are falling through the cracks.

Hefty co-payments: Under My Aged Care, older people with disability are asked to make co-payments towards any services or supports they require. This requirement is unique to My Aged Care and does not apply to people accessing supports under the NDIS. Although co-payments were originally intended to be dependent on an individual's income and assets, it appears that

NDIS (Not Damn Interested In Seniors) (cont'd from P13)

this policy is not being honoured. The services and supports that are required by people with disability can also be far more cost-prohibitive than those of the average older person, making their cost of living significantly higher.

Lack of understanding of the specialist needs of people with disability: The aged care system was set up to accommodate the needs of people experiencing deteriorating health due to aging—not people with permanent and profound disability. As disability is the core business of the NDIS, staff at the National Disability Insurance Agency typically have a high level of empathy and disability awareness. The same cannot be said for the staff at My Aged Care who are largely unfamiliar with the broad spectrum of needs with

which people with disability may present.

In order for Australia to be considered to be meeting its international human rights obligations under the *Convention on the Rights of Persons with Disabilities*, there must be equality of support for all people with disability, regardless of factors associated with age.

Source: Email from Lori Grovenor—16 May 2016. View more on [Facebook](#) and [My Aged Scare](#) website.

Additional information on NDIS and Aged Care inequality can be seen on the *My Disability Matters* website [here](#).🌈

7 Secrets No One Told Me When I Learned To Meditate

By Kristy Rackham, RN

Meditation doesn't have to be hard if you understand a little about what it is, and what to expect! I started meditating and teaching meditation at age 20 when experiencing a spontaneous spiritual awakening and opening of my third eye. My spiritual teachers were 'not of this world' and so they were not able to help me with the nuances of a meditating human body and mind in the 3rd dimension! For me, opening to the enormous psycho-emotional and physical benefits of meditation was easy and immediate. However, establishing a regular practice was a little more difficult as it came with a whole host of belief systems and doctrines that no one could explain for me. I trust that these 7 secrets that no one told me when I learned to meditate will help you hone and enhance your practice and help you cut to the chase and help you get the most out of your meditations.

1. Your body will play up. It will wear you down like a small child on sugar and will not want to stay still for more than a few seconds before a random collection of aches, pains, itches and scratches kick in to grab for your attention. This is all OK and perfectly normal! It is not a sign that you're doing it wrong or are "no good at meditation". In this very fast paced world of ours, we have forgotten that being relaxed and peaceful is actually our natural state. A guided meditation can help you to focus and also teach you how to work with the body instead of against it.

2. You don't have to meditate like a Zen monk. Sitting with an Indian Guru and 'Ohm-ing' for hours on end really also isn't the most efficient way to make a difference to your wellbeing. Scientific studies now show that as

little as 10 minutes of meditation each day will have a beneficial effect on your entire being. It doesn't even have to be a sequential 10 minutes. In fact, the harder you try, the more resistance you create in your body and mind. This then contributes to greater stress levels and dis-ease! Just relax - Meditation can be very straight forward if you let it.

3 Meditation is not a team sport. It is an intensely personal, precious, quiet moment within your day that you get to be still and take the pressure off. The content of your meditation doesn't need to be shared, it isn't a competition, and it doesn't matter what someone else thinks of it. This is because it comes from YOU and your unique divine expression of the Universal energy - you're one of a kind, so please don't judge your 'brand' of meditation by other people's standards.

4. Meditation is not spiritual Hoo Har. It's also not about making yourself permanently blissful and walking around in a state of eternal ecstasy (although glimpses of that is definitely possible!). If anyone tells you they don't have any issues now that they're meditating, they're probably in denial. Meditation is a practical, perfectly natural method of enhancing body, brain and spiritual function getting in touch with your creative potential. From there you can take actions that bring you greater peace, strength, resourcefulness and wellbeing than you've ever experienced before.

5. Meditation gives you access to the 'real you'. The benefit of this is that you can begin or expand your ability to live consciously, purposefully and from a truly authentic place. For this reason, it can sometimes be very confronting and a not a little bit scary at times! We can

7 Secrets No One Told Me (cont'd from P14)

discover elements of ourselves that have previously been denied or hidden. This is a BLESSING when embraced for the gift that it is! Once seen, limitations can be cleared or transformed opening the way for a happier and more joyful life than you can possibly imagine.

6. You can't 'do it wrong'. I REALLY wish someone had told me this when I began. I might have better spent the energy I wasted on guilt and self-punishment! But hey, that was also part of my journey! Although Meditation is not something that you can make a mistake with, it becomes easier and the body and mind relaxation response becomes faster with practice, like everything! It is also worth noting that no two meditation experiences will be exactly alike – therefore, it is impossible to judge a meditation as good or bad without limiting your experience. Accept every meditation as it comes to you and trust that everything is exactly how it is meant to be right now for your highest evolution.

7. There is no single BEST way or better style of meditation than another – they all have merit and purpose. Although it can be said that certain meditation styles work particularly well for certain people, or certain circumstances. For example, guided Mindfulness and Creative Visualisation meditation are great for first timers. Mindfulness can help to manage out-of-control thoughts and switch off the fear centre of the brain to bring about an instance physiological relaxation response. Creative visualisation is great for beginners as it utilises our imagination – something that is usually pretty active in most people – to imagine positive outcomes and future experiences that we wish to bring about in our life.

Sometimes, taking the first step to start meditating is the most difficult. If you always wanted to try it, but perhaps you didn't think you'd be able to do it, or maybe it's not easy for you to attend a group class, you may find a private guided meditation lesson is a great place to start.

In a private session you will learn how to break through any beliefs that are stopping you from getting the most out of your meditation. You'll be able to hone in on any specific life challenges that are bothering you or weighing you down and get immediate relief, and I'll be there to guide you the whole way, which will help you to anchor your mind, reign in a restless body and really tap into your true personal power. We also record your live guided meditation for you to keep! A personalised meditation that is exactly customised to your needs can be used to practice your meditation skill as often as you like at home. Better still, you can come to the clinic and meditate with me in person, or via Skype if you're somewhere else in the world!

Do you want to learn to meditate but can't get to a group class?

Do you want to focus on a specific personal issue in a meditation but have trouble guiding yourself through it?

Are you interested in how meditation can help you manage chronic illnesses like pain and fatigue?

Find out more at www.myholisticnurse.org or call 0487 769 629. 🌐

Panadol Osteo To Remain Delisted

Source: [Pain Australia Newsletter](#) – May 2016

The Pharmaceutical Benefit Advisory Committee (PBAC) has restated its decision to delist Panadol Osteo from the PBS. The PBAC says it assessed the issues raised by stakeholders including the Pharmacy Guild and Painaustralia, but did not consider there was any basis to revisit earlier recommendations.

"The decision will be disappointing for many people who regularly rely on Panadol Osteo as the first line treatment for osteoarthritis", says Painaustralia CEO Lesley Brydon. "It is generally regarded as the least harmful option, and it is quite likely that patients, especially those on a concession, will ask their doctor for alternative PBS subsidised medication to help manage their pain, including low dose opioids".

An analysis by the Guild last year reported that on the PBS, two packs of Panadol Osteo for a patient with a concession card was \$7.52 a month, which equated to \$90.24 a year and less if the patient reached their Safety Net during the year.

Following the delisting the price increased to \$14 a month, or \$168 a year, and it no longer contributes to Safety Net eligibility.

The PBS says the active ingredient in Panadol Osteo can also be found in the immediate release form of paracetamol, which can be purchased more cheaply. However, it is the more convenient, sustained release formulation that made Panadol Osteo a drug of choice for many people with osteoarthritis. 🌐



Effectiveness of NSAIDs

Bruno R da Costa, PhD[†], Stephan Reichenbach, MD[†], Noah Keller, MMed, Linda Nartey, MD, Simon Wandel, PhD, Prof Peter Jüni, MD, Dr Sven Trelle, MD

Source: [The Lancet](#) – 17 March 2016

Effectiveness of non-steroidal anti-inflammatory drugs for the treatment of pain in knee and hip osteoarthritis: a network meta-analysis

Summary Background

Non-steroidal anti-inflammatory drugs (NSAIDs) are the backbone of osteoarthritis pain management. We aimed to assess the effectiveness of different preparations and doses of NSAIDs on osteoarthritis pain in a network meta-analysis.

Methods

For this network meta-analysis, we considered randomised trials comparing any of the following interventions: NSAIDs, paracetamol, or placebo, for the treatment of osteoarthritis pain. We searched the Cochrane Central Register of Controlled Trials (CENTRAL) and the reference lists of relevant articles for trials published between Jan 1, 1980, and Feb 24, 2015, with at least 100 patients per group. The prespecified primary and secondary outcomes were pain and physical function, and were extracted in duplicate for up to seven timepoints after the start of treatment. We used an extension of multivariable Bayesian random effects models for mixed multiple treatment comparisons with a random effect at the level of trials. For the primary analysis, a random walk of first order was used to account for multiple follow-up outcome data within a trial. Preparations that used different total daily dose were considered separately in the analysis. To assess a potential dose-response relation, we used preparation-specific covariates assuming linearity on log relative dose.

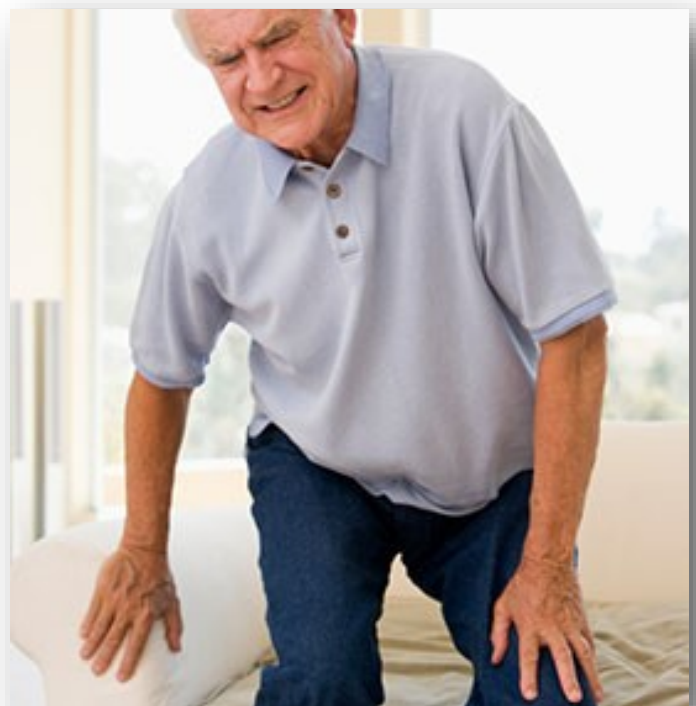
Findings

We identified 8973 manuscripts from our search, of which 74 randomised trials with a total of 58 556 patients were included in this analysis. 23 nodes concerning seven different NSAIDs or paracetamol with specific daily dose of administration or placebo were considered. All preparations, irrespective of dose, improved point estimates of pain symptoms when compared with placebo. For six interventions (diclofenac 150 mg/day, etoricoxib 30 mg/day, 60 mg/day, and 90 mg/day, and rofecoxib 25 mg/day and 50 mg/day), the probability that the difference to placebo is at or below a

prespecified minimum clinically important effect for pain reduction (effect size [ES] -0.37) was at least 95%. Among maximally approved daily doses, diclofenac 150 mg/day (ES -0.57 , 95% credibility interval [CrI] -0.69 to -0.46) and etoricoxib 60 mg/day (ES -0.58 , -0.73 to -0.43) had the highest probability to be the best intervention, both with 100% probability to reach the minimum clinically important difference. Treatment effects increased as drug dose increased, but corresponding tests for a linear dose effect were significant only for celecoxib ($p=0.030$), diclofenac ($p=0.031$), and naproxen ($p=0.026$). We found no evidence that treatment effects varied over the duration of treatment. Model fit was good, and between-trial heterogeneity and inconsistency were low in all analyses. All trials were deemed to have a low risk of bias for blinding of patients. Effect estimates did not change in sensitivity analyses with two additional statistical models and accounting for methodological quality criteria in meta-regression analysis.

Interpretation

On the basis of the available data, we see no role for single-agent paracetamol for the treatment of patients with osteoarthritis irrespective of dose. We provide sound evidence that diclofenac 150 mg/day is the most effective NSAID available at present, in terms of improving both pain and function. Nevertheless, in view of the safety profile of these drugs, physicians need to consider our results together with all known safety information when selecting the preparation and dose for individual patients.



World Continence Week

World Continence Week (June 20 – 26) is a timely reminder that incontinence is a significant, yet very treatable condition that can be prevented, cured or better managed in most cases, often through simple lifestyle changes.

This year, in addition to asking Australians to "improve their bottom line" by adopting healthy bladder and bowel habits, the Continence Foundation of Australia aims capture a significant portion of the population that has, until now, had limited access to information and resources.

This is the one in five Australians who live with disabilities; be they physical, intellectual, social, emotional or psychological. This group is the focus of the Continence Foundation's major project for 2016: *Finding the answers; improving access to continence information.*

At the launch of World Continence Week the Continence Foundation will deliver a number of initiatives aimed at making their resources more accessible to people with disabilities. These include Easy English fact sheets, assistive technology for accessing the Foundation's website, and website modifications to assist people using adaptive technologies.

Continence Foundation of Australia chief executive Rowan Cockerell said the project recognised the significant barriers people with disabilities faced every day when accessing health information. *"This is something we are doing to ensure all people, regardless of their*

personal limitations, have access to our information and resources", Ms Cockerell said.

"This project is an extension of the work we have done previously to improve accessibility for non-English-speaking people, with our fact sheets translated into 30 languages. Being as inclusive as possible extends our reach and ability to educate and inform. And our message is the same for everyone; incontinence is, in most cases, preventable and treatable", she said.

Ms Cockerell said the key steps to maintaining good bladder and bowel health were to eat well, drink well, be as active as possible, daily pelvic floor muscle exercises and practise good toilet habits.

She said people shouldn't be embarrassed about seeking help. *"There is a lot of help out there. The Continence Foundation has many resources and information on the website, as well as a free, confidential helpline staffed by continence nurses. They can provide callers with advice, information about their nearest continence service, and information about government subsidies"*, she said.

For more information about the prevention and management of incontinence go www.continence.org.au, and for free, confidential advice about incontinence, speak to one of the continence nurse advisors on the National Continence Helpline **(1800 33 00 66)** 8am to 8pm weekdays AEST. 🌐

Vitamin B12 May Slow Brain Ageing

By Liam Davenport

Source: Medscape - 11 May 2016



Individuals with increased levels of circulating homocysteine have faster rates of brain changes associated with aging than other people, whereas higher levels of vitamin B12 are associated with slower rates of brain aging, new research suggests.

Babak Hooshmand, MD, PhD, Center for Alzheimer Research –Aging Research Center, Karolinska Institutet, Stockholm, Sweden, and colleagues found that total brain volume losses were lower in individuals with higher baseline vitamin B12 levels, whereas the opposite was true of those with increased homocysteine levels.

"Vitamin B12 and tHcy [total homocysteine] might be independent predictors of markers of brain aging in elderly individuals without dementia", the investigators write.

They add, *"[I]f the association is causal, supplementation with B vitamins may be effective for prevention of brain damage due to increased levels of total homocysteine. Adequately timed and powered randomized clinical trials are needed to determine efficient treatment guidelines"*.

The research was [published online](#) April 27 in *JAMA Psychiatry*. 🌐

New Tack On Polio Vaccine

New tack on polio vaccine on the path to eradication

Words by [Julie Milland](#)

Source: www.thecitizen.org.au
—16 April 2016

Vaccination has led to a worldwide plunge in polio infections, but cases are still occurring in poorer countries.

Global health authorities are set to take a major step in the push to eradicate polio when 145 countries start switching to a new vaccine from Sunday.

The move is designed to eliminate the possibility of infection caused by one of the types of poliovirus found in the oral polio vaccine.

Australia has not used the oral vaccine since 2005, but it is still used in developing countries because it is cheaper and easier to distribute.

Bruce Thorley, head of the WHO Polio Regional Reference Laboratory at the Doherty Institute in Melbourne, said that although the oral vaccine could cause cases of polio in rare circumstances, it was important for global eradication because it was cheaper, enabled wide coverage and did not require trained medical staff to inject the vaccine.

Polio can cause paralysis or other effects lasting decades after infection, and can be fatal. Infection occurs with one of three types of naturally occurring – or wild – poliovirus (types 1, 2 and 3) or after exposure to special weakened forms of the three types of virus in the oral vaccine.

In 2015, the World Health Organization declared wild type 2 poliovirus eradicated, but a small number of infections are still caused by the weakened type 2 virus in the oral polio vaccine or OPV, according to Dr Thorley.

"The [oral polio vaccine], in rare circumstances, can cause polio, and it's considered this occurs in about one in every 2.7 million first doses of the oral vaccine, and that's because it contains a live virus".

He said the 12 cases of vaccine-derived type 2 polio in 2015 were in countries with low vaccination rates – Guinea, Myanmar, Nigeria and Pakistan.

Although Australia no longer used the oral vaccine, Dr Thorley said people should continue to maintain scheduled vaccinations with the injectable inactivated poliomyelitis vaccine (IPV), which protects against all three types of poliovirus.

Polio in Australia

- 400,000 cases
- 40,000 cases with paralysis
- 2000 deaths
- 1950s – Polio vaccine introduced
- Early 1970s – Last case of infection in Australia
- 2000 – Australia certified polio-free
- 2005 – Oral vaccine replaced by injected inactivated polio vaccine
- 2007 – Last case of imported polio
- 2009 – June Middleton dies after 60 years in an iron lung

Source: WHO, Polio Australia, Dr Thorley

Dr Thorley said WHO declared Australia polio-free in 2000, but Australians were still at risk from people infected overseas.

"Since the 1970s, we've had single cases [of polio brought from another country] and the most recent reported imported case was in 2007".

The WHO-coordinated global "switch" in vaccine use will take place over the two weeks to May 1.

Dr Thorley said countries would switch from using oral vaccines containing types 1, 2 and 3 poliovirus (known as trivalent OPV) to an oral vaccine containing only types 1 and 3 (bivalent OPV). Countries currently using OPV would destroy any remaining stocks of trivalent OPV.

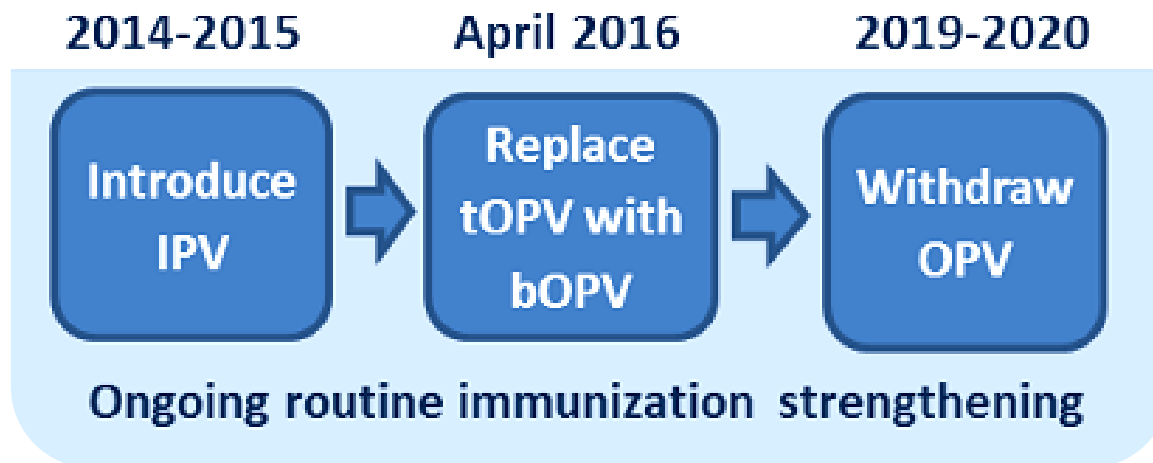
"This is a significant step because the WHO has had to negotiate with vaccine manufacturers so they can start producing enough bivalent OPV and also produce enough IPV . . . All countries will administer one dose of IPV by the time we have the switch so people will be protected against type 2".

The WHO polio vaccination program has led to a dramatic fall in polio cases from 350,000 in 1988 to just 74 in 2015, all caused by wild type 1 poliovirus in Pakistan and Afghanistan.

Wild poliovirus attacks the nerves and causes paralysis within hours in one-in-100 people infected. There is no cure for the disease, known as poliomyelitis, and only immunisation against all three types of poliovirus offers full protection.

Gillian Thomas, vice-president of Polio Australia, said poliovirus circulating in Australia (endemic) is thought to have infected approximately 400,000 people between the 1920s and the early 1970s, with about 40,000 people paralysed.

New Tack On Polio Vaccine (cont'd from P18)



She said people with few early symptoms could nevertheless suffer "late effects of polio" decades later. Symptoms can include fatigue, muscle weakness and pain, joint pain, breathing difficulties and nerve problems.

She said Australia introduced vaccines in the 1950s and so most of the people suffering the late effects of polio tended to be older Australians.

Ms Thomas, 66, contracted paralytic polio in 1950 at 10 months of age. Although she was eventually able to walk using two full-length calipers, the late effects of polio had severely restricted her movement.

"Polio affects both my legs and one arm," she

said. "I thought my right arm got away without damage but with the late effects, it's obvious that it has been affected. So, basically, it's attacked all my limbs; so I use a wheelchair now".

Ms Thomas said the 400,000 people infected would suffer late effects of polio, making this the largest group of people with a disability in Australia. Polio Australia had set up the Australian Polio Register and is holding a conference in September to help raise awareness.

People more than 65 years of age did not have support through the National Disability Insurance Scheme and needed to rely on lesser levels of financial assistance through aged care programs. 🌐

Immunisation-Immunity For Community

Source: Department of Health & Human Services, Victoria, Australia

Immunisation prevents many illnesses in children and adults. Immunising yourself or your children is important for not only your health, but also for the health of your community because when enough people are immunised diseases no longer spread. If you want to know more about immunisation – how it works, what vaccinations you need and what the possible side effects are – speak with your GP.

Click on the image (right) to view Dr Margaret Cooper's polio story.

You can also find out more about immunisation on this website.

www.betterhealth.vic.gov.au/immunisation 🌐

Dr Margaret's Story (video)

Immunisation



Polio Vaccine 'Switch' Not Without Risks

By Helen Branswell

Source: [The Boston Globe](#) – 19th April 2016

The world is in the process of trying something it has never attempted. Over the next two weeks, 155 countries must stop using a vaccine that has been protecting children from paralyzing polioviruses for more than a half-century.

Designed in the 1950s, the vaccine has helped take the world to the edge of polio eradication. In the 1980s, polioviruses crippled 350,000 children annually; this year they have maimed 10 in the only two countries where polioviruses still spread, Pakistan and Afghanistan.

It has been a monumental achievement in public health.

But for a while now, a component of the vaccine has caused more problems than it has solved, and has resulted in a relatively small number of cases of paralysis. So between this past Sunday and May 1, all countries that use the oral polio vaccine developed more than 60 years ago must stop administering the formula and replace it with a new version.

The unprecedented synchronized campaign, more than 18 months in the planning, is appropriately known as "the switch".

Hundreds of thousands of health workers around the globe have been involved. Countries have had to develop implementation plans, train volunteers, and manage vast inventories of vaccines, including by ensuring that stocks of the old one are discarded.

"I've been working in immunization since 1974 and nothing like this has ever happened before", said Dr Walter Orenstein, a polio expert at Emory University in Georgia.

If the planners' assumptions are correct and the switch is executed as intended, the world's children will be safer.

The switch does not come without risks. There are three strains of polioviruses. The new vaccine will not have a component that protects against Type 2. For the most part, that is not a problem — Type 2 polioviruses haven't been seen since 1999 and have been declared eradicated.

But after the switch, infants in some parts of the world won't have any protection against Type 2 polio. The old vaccine includes live-but-weakened polioviruses; if there are any Type 2 vaccine viruses left in the environment — or unleashed by the unauthorized or unwitting use of stocks of the old vaccine — those children could become infected and crippled.

Mathematical modeling suggests there probably will be at least one outbreak caused by Type 2 vaccine viruses after the switch, Dr Stephen Cochi, a polio expert at the Centers for Disease Control and Prevention, told reporters last week. The Global Polio Eradication Initiative, a public-private partnership that includes the CDC and the World Health Organization, has prepared for that possibility, stockpiling vaccines that could be used to control an outbreak if the need arises.

A little background on polio and the vaccines that protect against it is useful to understand what is at work here.

Back in 1988, the WHO, CDC, UNICEF, and the service club Rotary International embarked on an ambitious plan to get rid of polio. (The Bill and Melinda Gates Foundation joined the polio eradication partnership in the last decade.) At the time, there were three strains of the virus circulating.

Since then, Type 2 polioviruses have been declared eradicated. Type 3 viruses haven't been spotted in more than three years and are also thought to be gone.

The eradication toolbox contained — then and now — only two tools: an injectable vaccine, which is made with killed viruses, and the oral vaccine, developed by Albert Sabin.

Each has strengths and weaknesses. The injectable vaccine, which is used in the United States and most affluent countries, is safer; it does not paralyze. But it is more expensive and because it is injected, it must be administered by a health professional. The oral vaccine costs pennies a dose, and anyone with a few minutes of training can squeeze the drops into a child's open mouth.

Children who get the oral vaccine excrete those live-but-weakened vaccine viruses for a time when they have bowel movements. In places where sanitation is rudimentary, that initially was beneficial. Vaccinate some kids in a community and others will eventually also be protected as the vaccine viruses spread.

But as vaccine viruses move from one child's gut to the next, they evolve and can regain the ability to paralyze. When polio was crippling hundreds of thousands of children a year, the oral vaccine's advantages far exceeded its negatives. But as the polio math has shifted, so too have the scales on which the vaccine's risks and benefits are weighed.

Last year there were 74 children in the world paralyzed by polio. But 37 children were paralyzed by vaccine-derived polioviruses.

Polio Vaccine 'Switch' (cont'd from P20)

Over 90 percent of those cases in recent years have been caused by the Type 2 component of the oral vaccine. But given that there is no longer any risk from Type 2 polioviruses, that vaccine component is now more of a detriment than a benefit.

Polio eradication campaigners decided that in order to stop Type 2 vaccine virus cases from cropping up, that part of the vaccine had to go.

When the idea for the switch was proposed, experts who advise the WHO recommended a prerequisite for making the change. Before countries that use oral vaccine move to the version without Type 2, they should give all their children at least one dose of the injectable vaccine, to try to minimize the dangers inherent in the process.

That hasn't happened, admitted Michel Zaffran, director of the WHO's polio eradication team. Vaccine manufacturers weren't able to scale up production sufficiently to make enough of the injectable vaccine. At this point, about 30 countries haven't given children doses of the injectable vaccine; 20 won't get the needed supplies until some time in 2017. *"This is one piece that has not worked as effectively as we would have hoped", Zaffran said. "Nonetheless the progress has been quite remarkable".*

Orenstein said it would have been "desirable" if all countries had managed to give a round of injectable vaccine. But it was still felt the switch should go ahead.

But an expert committee, which met last week, expressed concern about the potential impact of the vaccine shortfall.

The available injectable vaccine supplies have been directed to countries felt to be at the highest risk of having vaccine virus outbreaks. Those that have been told they'll have to wait are countries where vaccination rates are known to be high — meaning many children are already protected against the Type 2 vaccine viruses. When vaccine coverage is high, vaccine derived viruses are less likely to circulate.

Over the two weeks of the switch, thousands of program monitors will be checking hospitals, clinics, and other venues where oral polio vaccine is given to ensure any remaining supplies of the old vaccine are removed from the supply chain and rounded up for safe disposal.

In addition to fixing the Type 2 vaccine virus problem, the switch will serve as a dry run for farther down the road, when all oral vaccine use must stop.

"We are very close to eradicating polio. We have never been this close", said Zaffran. "And we believe that we will be interrupting transmission in 2016".

That would open the door to a declaration of eradication in 2019, after a three-year monitoring period needed to ensure the virus is actually history.

Full article [here](#).

Click the following link to watch "The Switch" on YouTube: www.youtube.com/watch?v=dZbp-q2SJA4

The Switch (English version)

UNICEFpolio

Subscribe 81

276 views

358 views

The Switch (English version)

Up next

Autoplay

The Switch (Spanish version)

UNICEFpolio

353 views

4:28

The Switch (French version)

UNICEFpolio

238 views

4:28

The Switch (Mandarin version)

UNICEFpolio

42 views

4:28

The Switch (Urdu version)

UNICEFpolio

41 views

4:27

The Switch (Arabic version)

UNICEFpolio

71 views

4:28

App Finder Toolbox: setting a time

Takeda To Produce Cheap Polio Vaccine

With a polio-free world within reach, the Bill & Melinda Gates Foundation is funding a Japanese company to produce a low-cost vaccine.

Source: www.sbs.com.au / AAP – 9 May 2016

Japan's Takeda Pharmaceuticals is to get \$US38 million (\$A51.65 million) from the Bill & Melinda Gates Foundation to develop a crucial, low-cost polio vaccine for use in developing countries.

As part of a global plan to eradicate the crippling disease, with experts saying the world could see the last case this year, countries will need to switch from using oral polio vaccine (OPV) to using so-called inactivated polio vaccine (IPV) to ensure the disease does not reappear.

Experts fear a substantial worldwide shortage of IPV once every country in the world is ready to make the switch, and polio eradication strategists have been looking at how to avert that shortfall by encouraging new manufacturers into the sector.

Chris Elias, the Gates Foundation's head of global development, said the partnership would help "ensure that the world has enough vaccine to get the job done and maintain a polio-free world".

Takeda said in a statement it would use the Gates funding to develop, licence and supply at least 50 million doses per year of so-called Sabin-strain inactivated poliovirus vaccine (sIPV) to

more than 70 developing countries.

The shot will be made available at an affordable price for countries supported by the GAVI vaccines alliance, which is backed by the Gates Foundation, the World Health Organisation, UNICEF and others to fund immunisation programs in poor countries.

Polio invades the nervous system and can cause irreversible paralysis within hours - and WHO's repeated warning is that as long as any polio virus is circulating, people are at risk.

But the world is now on the brink of wiping out polio forever, with only 12 cases of the contagious viral disease recorded worldwide so far this year - in Pakistan and Afghanistan.

Global health experts say stopping all polio transmission is possible by the end of this year. The full official, global eradication of polio could be declared by the end of this decade.

Rajeev Venkayya, head of vaccines for Takeda, said the Gates funding would enable his firm to de-risk the investment needed to take the sIPV through final stage clinical trials, licensure, and then onto the market.

The vaccine, which was originally licensed from the Japan Polio Research Institute, has already completed mid-stage Phase II trials, Venkayya said. Once it has been fully developed, tested and licensed, it will be manufactured at Takeda's facility in Hikari, Japan. 🌐

The 'Miracle' Glioblastoma Drug

What '60 Minutes' Still Isn't Saying About The 'Miracle' Glioblastoma Drug

By [Arlene Weintraub](#), Contributor
I cover the science and business behind drug development and health.

Source: Forbes.com – 16 May 2016
Opinions expressed by Forbes Contributors are their own.

Last night, the hit CBS news program *60 Minutes* revisited a trial at Duke University that it had devoted two segments to early last year. Scientists at Duke are testing a modified form of the polio virus to treat glioblastoma, and the reason for the *60 Minutes* update was that the research has recently been granted "breakthrough" status by the FDA—which may shave some time off the development pathway. The development of engineered viruses, or "oncolytic viruses", to treat cancer is one type of immunotherapy that's generating excitement in oncology circles.

The breakthrough status for Duke is good news, to be sure. Median survival for patients with glioblastoma who are treated with traditional chemotherapy is only about 14 months and two-year survival is 30%, according to the American Brain Tumor Association. The disease claims 12,000 people per year in the U.S. and was to blame for the death of Vice President Joe Biden's son. Biden is now leading the government's cancer "moonshot" initiative, and as part of that he visited Duke, where he met the first patient treated with the virus, Stephanie Lipscomb, who entered the trial in 2012 and is still cancer-free.

But winning breakthrough status from the FDA doesn't guarantee that any treatment is actually a breakthrough. The Duke team has plenty of hurdles to overcome before the modified virus can become an approved treatment. In fact, the *60 Minutes* segment revealed that one of the patients hailed as a miracle in last year's broadcast, Nancy Justice, suffered a recurrence of her brain tumor and died on April 6 at age 60.

The 'Miracle' Glioblastoma Drug (cont'd from P22)

And it's important to remember that Justice, Lipscomb and the other 19 patients treated so far were in a Phase I trial in which 8 patients have died, three have achieved long-term remissions and the rest are still being monitored. That means it's too early to judge how the virus will perform in a larger patient population.

Here are some other key points to keep in mind about Duke's cancer-fighting polio virus.

Polio is not the only virus that's been shown to work against cancer. Several companies and academic groups are testing a variety of engineered viruses to fight cancer, including herpes, vaccinia (cowpox) and adenovirus. And in October, the first virus-based drug was approved by the FDA, Amgen AMGN +0.56%'s Imlygic (talimogene laherparepvec, or T-VEC) for the treatment of melanoma. It's an engineered form of the herpes virus that's injected straight into melanoma tumors, where it kills cancer cells directly and also recruits immune-boosting cells to the tumors to boost its potency. It's far from a miracle—studies show that it works best in a small subset of patients who are in Stage III of the disease, but overall it improves survival by only a few months—which is likely why the FDA declined to fast-track the drug to market last year.

But Amgen is still investigating Imlygic in different settings, which brings us to our next point...

Engineered viruses may work better in combo treatments than they do alone. The *60 Minutes* update introduced viewers to Brendan Steele, another participant in the Duke trials who went into remission after being treated with the modified polio virus. Seven months later, his cancer returned, so his doctors gave him a dose of chemotherapy. Oddly, his brain tumor melted away after that, even though he had not

responded well to chemotherapy prior to receiving the virus.

Steele's reaction led Duke's researchers to surmise that the immune response prompted by the virus may actually boost the effectiveness of chemotherapy. This idea is gaining steam among researchers and there are now trials underway combining oncolytic viruses with other treatments.

In the case of Imlygic, it is currently in a late-stage clinical trial in melanoma in combination with another type of immunotherapy, Merck's Keytruda (pembrolizumab), which inhibits the immune "checkpoint" PD-1. In an early trial, 56% of patients responded well to the treatment and two went into complete remissions—better results than had previously been seen with either drug alone.

Just because polio kills tumor cells in the test tube doesn't mean it works in people.

Towards the end of the two-segment *60 Minutes* feature, correspondent Scott Pelley told viewers that "in the laboratory" the engineered polio virus killed cancers of the skin, lung, stomach and more. He then had one of the researchers show how it caused a breast tumor from a mouse to shrink. Seeing as the polio virus has not even moved into late-stage testing in people with glioblastoma, it seems premature to start declaring the treatment to be a cure-all for so many cancers based on some experiments in test tubes and mice.

Even one of Duke's scientists urged caution. Darell Bigner, director of the Preston Robert Tisch Brain Tumor Center at Duke, told Pelley he's optimistic that years of science may finally be coming together for glioblastoma patients, a sentiment he called "enormous". But, he added, "I have to be very careful. I never want to give anyone false hope".

[Click to watch](#)



Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 1 June 2016

From 17 April to 1 May, 155 countries and territories participated in the historic trivalent to bivalent oral polio vaccine switch, withdrawing the type two component of the vaccine to protect future generations against circulating vaccine-derived polioviruses. Track the switch live.

Wild Poliovirus Type 1 and Circulating Vaccine-Derived Poliovirus Cases

Total cases	Year-to-date 2016		Year-to-date 2015		Total in 2015	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	16	3	26	2	74	32
- in endemic countries	16	0	26	2	74	3
- in non-endemic countries	0	3	0	0	0	29

Case Breakdown by Country

Countries	Year-to-date 2016		Year-to-date 2015		Total in 2015		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	5	0	2	0	20	0	04-Apr-16	NA
Pakistan	11	0	24	2	54	2	26-Apr-16	09-Feb-15
Guinea	0	0	0	0	0	7	NA	14-Dec-15
Lao PDR	0	3	0	0	0	8	NA	11-Jan-16
Madagascar	0	0	0	0	0	10	NA	22-Aug-15
Myanmar	0	0	0	0	0	2	NA	05-Oct-15
Nigeria	0	0	0	0	0	1	NA	16-May-15
Ukraine	0	0	0	0	0	2	NA	07-Jul-15

NA: onset of paralysis in most recent case is prior to 2015. Figures exclude non-AFP sources. Madagascar, Ukraine and Lao PDR cVDPV1, all others cVDPV2. cVDPV definition: see document "Reporting and classification of vaccine-derived polioviruses" at www.polioeradication.org/Portals/0/Document/Resources/VDPV_ReportingClassification.pdf. Implementation as of 15 August 2015. ●

**GLOBAL
POLIO ERADICATION
INITIATIVE**



every last child