



POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

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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>

<www.australianpolioregister.org.au>

<www.poliohealth.org.au/post-polio-health-professionals>

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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.





Pain Management Network

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.



International Association for the Study of Pain

IASP

Working together for pain relief

painaustralia

All working together



THE AUSTRALIAN PAIN SOCIETY

www.apsoc.org.au

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.

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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?

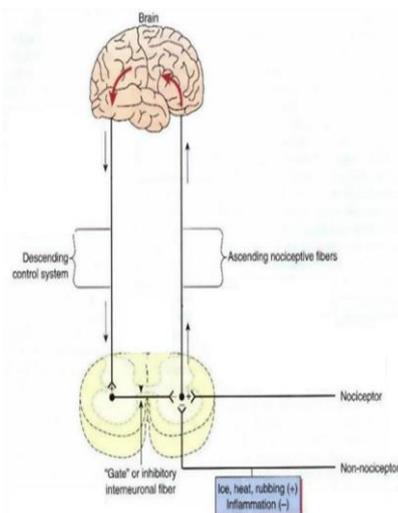
Have you ever:

- 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*)

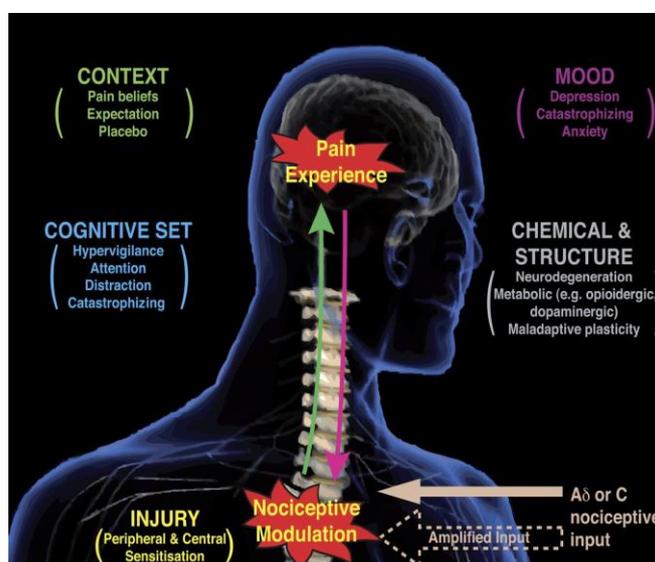
- At each level of the spinal cord, there is a chemical "gating" system that acts to inhibit or facilitate pain transmission
- The brain drives this system ("opens or closes the gate") through descending modulation
- Whether we experience pain, and how much we experience it, is the result of the "gate"



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.”

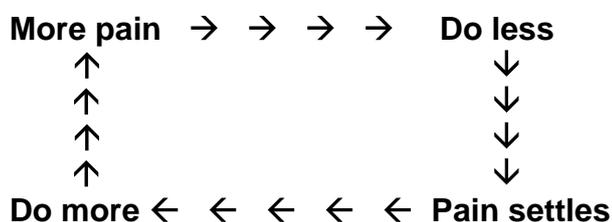
“Above all, a sufferer needs a way of talking about the pain – permission to talk about it – without feeling judged, without the implication that you lack moral fibre, or are exaggerating”.

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.

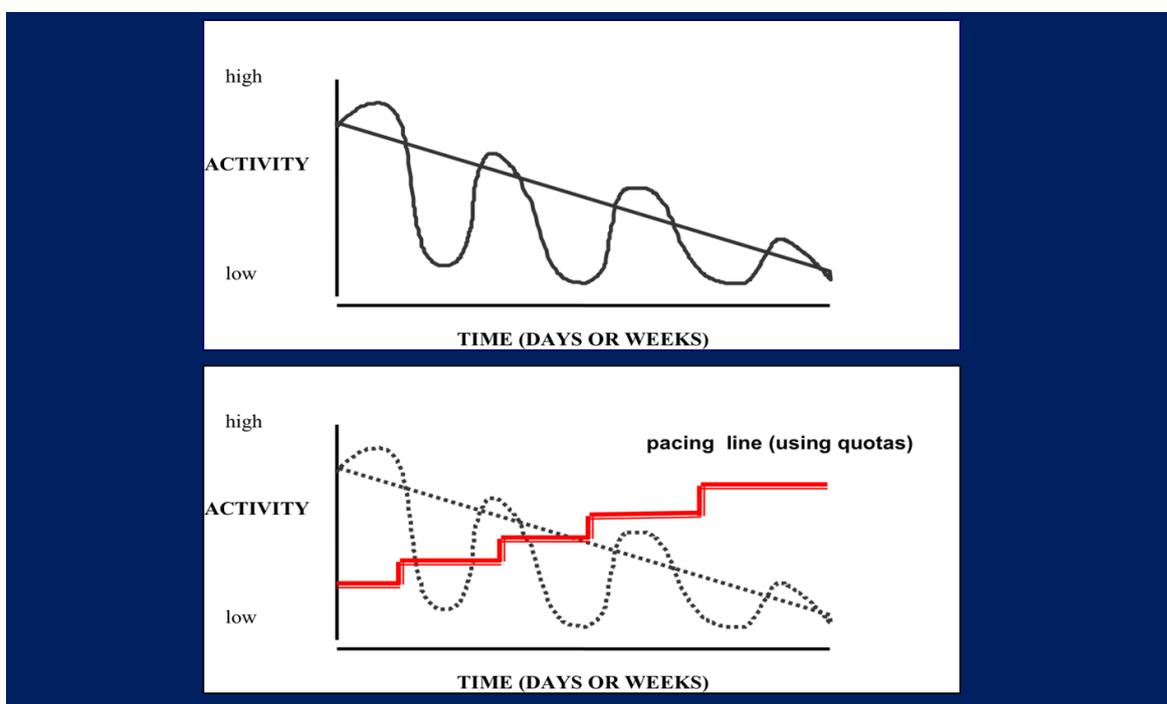
Breaking the overdoing-underdoing cycle

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.wheeasy.org.au.

www.wheeasy.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.

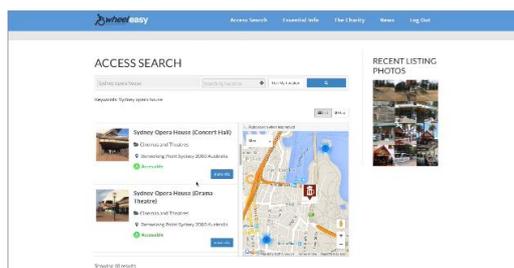
As a first step towards making our database more comprehensive and useful, **please** start adding your own information.

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 NDIS 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 docket
- 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 docketts

To order a new book of travel docketts use the green re-order form provided in the middle of the travel docket book, or download Reorder TTSS Travel Docketts (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 docketts.

Travelling interstate

TTSS participants who will be travelling interstate may order interstate travel docketts. Interstate travel docketts 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 Docketts 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 docketts so please plan ahead. Regular TTSS travel docketts 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 form includes the following sections:

- Header:** NSW Transport for NSW logo, 'For use only in taxis within NSW', 'TAXI TRANSPORT SUBSIDY SCHEME', and 'WAT Incentive Claim (mark X)'.
- Driver Information:** DRIVER'S NAME (please print), AUTHORITY NUMBER, INITIALLED BY DRIVER, DATE (day/month/year) with '20' in the year field, TAXI PLATE NUMBER.
- Account Information:** ACCOUNT NAME.
- TRIP DETAILS:** START (AM/PM), FROM, TO, END (AM/PM).
- FARE:** METER, EXTRAS, TOTAL FARE, AMOUNT PAID BY PASSENGER, SUBSIDY AMOUNT.
- AMOUNT OF TOTAL FARE IN WORDS:** Dollars, Cents.
- WARNING:** Fraudulent use of travel dockets or obtaining a benefit by deception is a criminal offence & will result in prosecution. This docket is to be used only as a licensed taxi. Payment may be refused if docket is not fully & legibly completed & submitted for payment within 28 days of the date of the journey.
- NOT TRANSFERABLE**
- PASSENGER'S SIGNATURE:** (with a line for signature)
- DO NOT MARK OR WRITE BELOW THIS LINE**
- Account Number:** A red box highlights the account number '04000000'.

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.pocruses.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>.

Email: <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”
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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

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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.