



**POLIO NSW INC**

formerly Post-Polio Network (NSW) Inc

# NETWORK NEWS

Incorporating – **Polio Oz News**

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## President's Corner

Gillian Thomas

The year is rapidly drawing to a close but it isn't yet time to wind down our activities. Our 27<sup>th</sup> Annual General Meeting will be held on 5 December and you are encouraged to come if at all possible. 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. The 2014/2015 reports are included in this mail out.

### Walk With Me – September/October 2015

This year Polio NSW members participated with Polio Australia in two fund-raising Walks – Parramatta and Canberra. In Parramatta, Gillian Thomas and Merle Thompson raised almost \$2,000; while in Canberra, John Tierney raised over \$6,000 (*these amounts being shared between the two organisations*). These wonderful efforts not only brought in vital funds, but once again raised our profile by reminding Australia that “We’re Still Here!”. Pictured below in Parliament House are some members of John Tierney’s team – John has asked me to record his thanks to Convener, Brian Wilson, and members of the ACT Support Group, who walked with us. Member Lyn Lillecrapp even travelled from Adelaide to join in!



### AGM and Seminar – 11 am to 3 pm, Saturday 5 December 2015 – Burwood RSL Club

This is a final reminder to come along to our Annual General Meeting and Seminar, *The New Assessment Clinic for Polio Survivors at Mt Wilga*. Dr Helen Mackie (Consultant in Rehabilitation Medicine and Director of the Clinic) and Nadege van Drempt (Occupational Therapist) will tell us about the Clinic and the services provided. Don't miss the opportunity to learn about how you can get your post-polio problems assessed and a management plan put in place. Ring the Polio NSW office to register (cost \$10 includes a light lunch) and also ask about your eligibility for a fuel card to assist with transport costs. We look forward to seeing you there.

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# Bushfire planning leaves behind people with disabilities

by **Sarina Kilham**, Research Fellow, Centre for Disability Research and Policy, University of Sydney  
*Sarina Kilham is a research fellow on a project funded by Australian Aid on "Promoting the Inclusion of People with Disability in Disaster Management in Indonesia"*

*Reprinted with permission from "Post Polio Views", Post Polio Victoria, January 2014*

When bushfires start, no one should be more worried than people with disabilities. Recent research shows people with disabilities are twice as likely to die or be injured than the general population during a disaster. They are also less likely to receive aid and less likely to recover in the long-term.

Jo Ragen, a senior research associate at the University of Sydney, describes her experience of a bushfire evacuation in the 1994 fires along Australia's eastern seaboard:

*We had over 100 young people with physical disabilities at a recreational camp, and I told the [State Emergency Service] we can't be leaving on trucks. Even though they thought we had enough time to get out, in the end, that's what happened: young people were loaded onto the back of trucks and utes and we left behind what was really essential equipment for those being evacuated – wheelchairs, ventilators.*

*It taught me that people with disabilities need to be involved right from the planning stage. Thinking that someone is going to turn up and 'rescue' a person with a disability means someone is going to be forgotten and a catastrophic outcome is real.*

As Australian authorities urge the general community to prepare and plan for bushfires, the early warning systems and public awareness campaigns are often failing to consider the needs of persons with disabilities.

Advice on the ground specifically for people with disabilities is pretty slim, and for bushfires is centred on the message of "leave early". But recent research by the Bushfire Collaborative Research Centre finds many people instead choose the "wait and see" option. In fact, less than 1% would leave their house on days of extreme or catastrophic fire danger.

This may be compounded for a person with a disability, as leaving early can be difficult as it means leaving behind essential equipment at home that is needed for daily living.

## **How we could be better prepared**

For people with disabilities, significant gaps exist in current approaches to bushfire risk reduction.

Communications about bushfire preparedness are often not in accessible formats. There are assumptions that people with disabilities are living in households dependent on others, when many are either living independently or are heads of households.

As Jo Ragen says:

*Plans that lump all people with disabilities together are like plans that say 'all people with blond hair must do this in a bushfire'. In my experience, when you wait for others to plan, or think someone else will evacuate you, you'll either get evacuated in a way that is not safe or appropriate, or you'll get left behind.*

There are various measures being done to improve this situation in Australia.

For example, a recent report on "*Increasing the Resilience of the Deaf Community in NSW to natural hazards*" found that while none of the natural hazard preparedness programs or tools cater specifically to deaf people, there were communication tools that could be considered "deaf-friendly" or required only small alterations.

A recent United Nations survey consulted nearly 6,000 people with disabilities in 126 countries, and found a high proportion of people with disabilities die or suffer injuries during disasters because they are rarely consulted about their needs, and governments lack adequate measures to address them.

In cases where they need to evacuate – such as during floods or earthquakes – only 20% of respondents said they could evacuate immediately without difficulty, 6% said they would not be able to evacuate at all, and the remainder said they would be able to evacuate with a degree of difficulty.

So where does that leave Australians during what is proving to be another dangerous bushfire season?

The only way we will ensure that no one is left behind is if people with disabilities are actively included in the consultation, planning and preparedness stages of thinking about disasters. Specific input and ideas from people with disabilities is essential for identifying risks and increasing the chance of survival if disaster does strike.



## Seminar Report - Retirement Living Choices for People with a Disability

by Sue Ellis

Wednesday, 3<sup>rd</sup> June 2015

**Marcus Brown** works for NSW Fair Trading and stood in for Alyson Dyer who was unable to be with us. Marcus is experienced with the legislation relevant to retirement village living and provides education about retirement village living across NSW. He addressed issues related to the rights and obligations of prospective residents of retirement villages. The information he provided encouraged people to make the right choice by seeking expert advice at the outset.

### Moving into a Retirement Village

NSW Fair Trading provides advice when considering moving into a retirement village. There is a brochure on this subject which covers all the key issues and which can be downloaded from their website <[www.fairtrading.nsw.gov.au](http://www.fairtrading.nsw.gov.au)>, or phone 13 32 20.

Marcus wanted to relay two key messages: firstly, that with retirement village living you are entering into a contract; and secondly, you are entering into a lifestyle change not just somewhere to live – it is not an investment choice, it is a lifestyle choice. To enter into a retirement village, you must be fully retired or over 55.

The contract covers the commencement of your journey into a retirement village, whilst you are there, and when you leave. Legislation contains the rights and obligations of residents and operators of retirement villages. Retirement villages must initially provide a General Inquiry Document and then a Disclosure Statement at least 14 days prior to signing a contract. When considering entering into a retirement village you can ask for these documents from the operator. It is advisable to get a number of these from different villages to compare the various facilities on offer e.g. bowling green, pool, bus service. A Disclosure Statement has more details than the General Inquiry Document and includes financial arrangements such as entry costs, live-in costs (monthly fee), and exit costs.

Contracts are required to include a cooling-off period, ingoing contribution, ongoing charges (monthly fee which changes yearly), list of service and facilities available, list of fixture and fittings provided, dispute resolution, contract termination, and departure fees.

Once you have decided what facilities are right for you, it is essential that you get legal advice to assist you to understand what your rights and obligations are. After signing a contract there is a 7-day cooling-off period. You can terminate the contract up to a 90-day settling period.

Any alterations or modifications to a property must be requested in writing, and a response received in writing, in order to get permission. These changes may have to be removed at your expense before reselling. Check before signing a contract that the premises meet your specific needs now and in the future (e.g. ramps, rails) and, if not, will they allow these alterations, or is it a problem?

It is the operator's obligation to set the monthly fees in consultation with the Residents' Committee. An audited budget needs to be presented 60 days prior to the end of the financial year.

## Prospective Resident's Checklist

Marcus emphasised most importantly – **DO NOT RUSH**. Discuss your decision with family, friends and advisers. Inspect a number of villages in the area you wish to live in. Ask a lot of questions. Make sure you fully understand the contract and seek professional legal and financial advice before signing anything.

*A few questions to ask yourself:*

- Have I fully discussed my decision to move with my family, friends, or advisers?
- Have I thought about whether community living in a village is right for me?
- Have I looked at a sufficient number of villages to be able to compare the services, facilities and financial arrangements?
- Have I received a General Inquiry Document and Disclosure Statement?
- How much will it cost me to move to, and live in, a retirement village?
- Can I afford to live there comfortably, even when the recurrent charges rise? (At what rate do the recurrent charges go up, is it tied to the CPI, what do the charges cover?)
- Is it more appropriate that I live in self-contained (independent living) or serviced premises?
- What type of arrangement does the village offer? Is it a loan/licence, leasehold, strata, rental, or company title? Does it have assisted care and/or nursing home facilities?
- Do I fully understand the contract and all the costs involved?
- What if I decide to leave the village? Will I be able to re-sell the unit? What are the termination fees (exit fees) and charges i.e. what percentage does the operator take of the sale price and who receives any capital gain?
- How many vacant units are there in the village? (This could indicate fewer facilities and a difficulty to sell.)
- What is the average time for the re-sale or re-letting of the type of property I am interested in?
- Are the services and facilities at the village what I need? Will this still be the case as I get older or if I get sick?
- Is there adequate parking for visitors?
- Are there local facilities such as doctors, shops, hospitals, libraries, churches, clubs and public transport near the village?
- Are there village rules that may affect my lifestyle? Are pets allowed?
- Will I be able to make changes to the inside of the premises, or to have someone visit or live with me?
- Am I able to do my own gardening?
- Is the village well maintained?
- Is the village reasonably secure? Is there adequate external lighting?
- Is there an emergency call system and/or staff on call?
- Are the paths designed for easy access?
- Will my premises still be suitable if my needs and abilities change in the future, e.g. are there any stairs I will need to manage?
- Have internal modifications related to frailty, such as bath rails, been made to the premises?
- Is there a Residents' Committee to liaise between residents and the operator?
- Have I obtained adequate legal and financial advice?

Pat and Frank Featherstone have lived in their retirement village for 10 years and Pat stated that it is so important to consider your needs in, say, 10 years' time – it may be that the 'frills and fancies' of a particular retirement village (resembling resort living) becomes less important to, say, public transport, being close to shops, or if the facilities are scooter friendly.

Elizabeth and Gary Hancock have recently moved to a retirement village which is a leasehold arrangement and required no payment of stamp duty, a considerable saving. Gary commented that they took one look at their new villa and were so excited that they left a deposit that day.

Marcus stated that the operators of retirement villages are not responsible for your safety. It is important to ask what part of your medical care they can provide. What services do they provide e.g. Vital Call, 24-hour nursing? A retirement village provides independent living, assisted living is provided by hostel care, and high care is provided by a nursing home.

Marcus ended by saying that Fair Trading services are free. They provide advice, but no recommendations. They are available to give talks on various subjects to groups on request.



**Robyn Helm** is the Care Development Manager, Home Services, BaptistCare, Baulkham Hills. She has worked in the aged and community service area for 20 years and is committed to the provision of quality home care services that meet client expectations and needs. Robyn is a Registered Nurse with a Diploma of Management. In her presentation, Robyn covered Home Care Packages (a coordinated package of services tailored to meet consumers' care needs), referred to as Consumer Directed Care, and the changes in effect from 1<sup>st</sup> July 2015.

## The Changing Face of Aged Care

### Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP)

There is a need for changes due to the ever increasing percentage of the population over 65. In 1901, 3% of the population was over 65; by 2010 it was 12%, and by 2040 it is predicted to be 22%. Added to this we are having fewer children resulting in fewer workers per retired persons and hence less tax money in the coffers. In 1970 Australia had 7.5 workers for every retired person, in 2010 it was 5 and by 2050 it is projected to be only 2.7 workers. A massive review of all services needed to be undertaken not only for monetary reasons but to also make it a simpler exercise to actually access these services.

In 2012 *Living Longer Living Better* was released by the Productivity Commissioner and promised:

- The establishment of a new Commonwealth Home Support Program to consolidate the existing National Respite for Carers Programme (NRCP), Day Therapy Centres (DTC), Assistance in Care and Housing for the Aged (ACHA) and Home and Community Care (HACC) programs.
- To undertake work to benchmark services, review service types and trial new approaches to reablement (working with, not for).
- The establishment of the *My Aged Care* website and telephone service (a one-stop shop) in conjunction with the initial development of a future new aged care gateway.
- Initiatives to support care for people with dementia (Dementia Supplement) and linking care with housing.
- A nationally standardised basic and comprehensive assessment process (National Assessment Screening Form). (You'll only need to provide your information once.)
- Full implementation of Consumer Directed Care.
- New Home Care package funding levels introduced including a low and intermediate care package. (There are now four levels of funding.)
- Initiatives released to support diversity, strengthen the health interface and improve care for dementia.

### So, how do individuals pay for this?

From July 2014 the government introduced new means-testing measures for Residential and Home Care called Income Tested Fees (ITF). If you are a self-funded retiree or part-pensioner, you may be liable for an income tested fee. These fees are currently capped at \$60,000 per lifetime.

From 1 July 2015 there are two aged care programmes for people (over 65 years) who want to remain in their home receiving support:

- **Home Care Packages Programme** – to be delivered as *Consumer Directed Care* (CDC).
- **Commonwealth Home Support Programme** – comprising *National Respite Care Package* (NRCP), *Home and Community Care* (HACC), *Day Therapy Centres* (DTC), and *Assistance in Care and Housing for the Aged* (ACHA).

### **Home Care Packages (HCP) Programme**

This programme provides a package of care that can be managed by the individual (*the money goes to the care provider but you can choose to self-manage it*) or in partnership with a care facilitator/coordinator. The funding is given to the service provider who will deduct funds for administration and care facilitation if required.

The programme is to be delivered under the Consumer Directed Care (CDC) principles of:

- Consumer choice and control
- Rights
- Respectful and balanced partnerships
- Participation
- Wellness and reablement
- Transparency

The Home Care Packages Programme (HCP) is divided into 4 levels of support:

- Level 1 gives access to \$7,821.95 per year for service provision
- Level 2 gives access to \$14,231.35 per year for service provision
- Level 3 gives access to \$31,291.45 per year for service provision
- Level 4 gives access to \$47,566.80 per year for service provision  
(*Level 4 is for someone with complex needs and is equivalent to nursing home level*)

Packages are allocated to providers such as BaptistCare. Individuals are able to choose which provider they prefer, the only restriction being whether the organisation chosen has the level of package still available (only a certain number of each package is allocated to providers).

Consumers have managed their own lives for a long time. They should be empowered to continue to manage their own lives by having control over the aged care services and support they receive. This requires the provision of, and assistance to access, information about service options that enable a consumer to build a package that supports them to live the life they want.

Consumer Directed Care should acknowledge an older person's right (based on their assessed needs and goals) to individualised aged care services and support.

*Care and services must be within the scope of the Home Care Packages Programme.* Items out of scope and not included are:

- Using funding as general income, e.g. paying bills
- Purchase of food, except as part of an enteral feeding program
- Payment of fees
- Payment for items covered under Medicare
- Entertainment activities, e.g. club memberships and sporting events
- Illegal activities

The development of respectful and balanced partnerships between consumers and Home Care providers, which reflect the consumer and provider rights and responsibilities, is crucial to consumer control and empowerment. Part of creating such a partnership is to determine the level of control a consumer wants to exercise.

Consumers should have the opportunity to work with the Home Care provider in the design, implementation and monitoring of a Consumer Directed Care approach.

Consumer Directed Care packages should be offered within a restorative or reablement framework to enable the consumer to be as independent as practical, potentially reducing the need for ongoing and/or higher levels of service delivery. There must be the assumption that the older person can regain their previous level of function and independence with reablement services being offered at a time that suits/supports the individual circumstances.

Community and civic participation are important aspects of wellbeing. Consumer Directed Care in aged care should support the removal of barriers to community and civic participation for older people if they want to be involved.

Under a Consumer Directed Care package, older people have the right to use their budgets to purchase the aged care services they choose.

To make informed decisions about their care, older people need to have access to budgeting information, including the cost of services, the contents of their individualised budgets and how their package funding is spent.

Clients in receipt of a Home Care Package are expected to make a daily contribution of \$9.77 per day. If clients are self-funded retirees, there may be an Income Tested Fee (ITF) applicable (see <[www.humanservices.gov.au/customer/forms/sa456](http://www.humanservices.gov.au/customer/forms/sa456)>). Any ITF fees are added to the amount of money a client spends on services. ITF is capped at approx. \$10,000 / year and \$60,000 / lifetime.

### **Commonwealth Home Support Programme (CHSP)**

This new programme enables older people living in the community to maximise their independence. It has brought together four previous programmes to make it easier to find the help that is needed:

- Commonwealth Home and Community Care (HACC) Programme
- National Respite for Carers Programme (NRCP)
- Day Therapy Centre (DTC) Programme
- Assistance with Care and Housing for the Aged (ACHA) Programme

The CHSP delivers timely, high quality, entry level support services taking into account each person's individual goals, preferences and choice, and underpinned by a strong emphasis on wellness and reablement.

CHSP also supports care relationships through providing respite care services for frail, older people which allows carers to take a break from their usual caring responsibilities.

Types of services available through CHSP:

- *Community and Home Support* – domestic assistance, personal care, transport etc.
- *Care relationships and carer support* – flexible respite, centre-based respite, overnight cottage respite.
- *Assistance with Care and Housing for the Aged* – people at risk of homelessness.
- *Service System Development* – still to be defined

### **How do I access support?**

All new referrals go through MyAgedCare (gateway) from 1 July 2015  
Phone number **1800 200 422** or website <[www.myagedcare.gov.au](http://www.myagedcare.gov.au)>

- Centralised electronic client record maintained by the gateway – this enables the client's details to be recorded once only, eliminating the need to tell 'your story' multiple times.
- Assessments will be completed by the Regional Assessment Services (RAS) for Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP).
- Aged Care Assessment Teams (ACAT) will be rolled into the gateway by December 2015.
- New National Assessment Screening Form (NASF) for all clients which will follow the client over their care journey.
- Three new portals to enable easy access to information (service provider portal, consumer portal, and regional assessment portal).

Robyn noted that Enable NSW will not provide equipment for individuals who are on a Home Care Package. The Home Care Package is supposed to supply all your needs. Gillian Thomas commented that if you needed an electric wheelchair then all of a Level 1 or Level 2 package would be taken up by that purchase.

### **In a nutshell – from the 1<sup>st</sup> July 2015**

1. My Aged Care will start the assessment process (or getting to know your needs) with general questions.
2. My Aged Care will email your referral to a Regional Assessment Service (RAS).
3. The RAS will ring you and make an appointment time for a visit where your goals and a support plan will be discussed.
4. If you require assistance and you are over 65 years, you go to the My Aged Care website or phone 1800 200 422.
5. RAS will ask if you have a preferred provider of services.
6. You might say – “Yes, I want BaptistCare”, or you may not know a provider and so your support plan will be broadcast through the portal to all providers in your area.
7. BaptistCare (or other provider in your area if you didn't express a preference) will pick up the referral from the portal and contact you.

*Frank Featherstone asked how long does all this take? Robyn stated that once you have contacted the Regional Assessment Service they have to make contact with you within 48 hours, then once the assessment is done, the provider has eight days to provide low care services and two days for high care services.*

### **Important to know**

- My Aged Care will ask for your consent at all stages of the journey.
- Only the service provider who accepts your referral sees your information – it is not seen by other service providers.
- COTA (Council on the Ageing) are supporting all the changes and have released information specifically for clients and service providers through their website: “Home Care Today”. Robyn encourages us to take a look, it is very informative and explanatory.

**[www.homecareservice.org.au](http://www.homecareservice.org.au)**

### **Members Questions**

*If you are under 65 are you eligible for Home Care Packages?*

People who are under 65 can get Home Care Packages if there is a need. If you are under 65 then you may be better off going through the National Disability Insurance Scheme (NDIS). However, NDIS is not available in all areas of NSW at this point and is specifically for people under 65 who have a permanent disability. Sadly, most polio survivors are over 65 and not eligible. Robyn feels that the Aged Care sector should be able to meet our needs.

For those who are carers themselves the government provides carers support centres and respite services. Carers are also eligible for packages of care and support in their own right.

***For more information: ring 1800 200 422 or visit <[www.myagedcare.gov.au](http://www.myagedcare.gov.au)>***



#### **Members' Panel: Nola Buck, David Carter, Anne O'Halloran, Merle Thompson**

*All now reside in retirement villages. They discuss what prompted them to consider other living arrangements, how they researched the available options, and what factors they took into account when selecting their current accommodation in a retirement village.*

**John Tierney** lead this session and emphasised the importance of making the right decision. John outlined how his parents and in-laws all left their decision-making to move too late which caused great difficulty. He himself has made poor decisions in that they built a two-storey house on a half-acre block with large trees and lots of land that needs mowing. Then they bought an apartment off a plan and it was also probably a mistake in that it only has one lift which could be a problem if it breaks down! His point being – you can make a lot of mistakes in this area.

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**Nola Buck** spoke about the emotional aspects of moving from the family home that they loved and lived in for over 40 years, and the sentimental issues of sorting through accumulated belongings. There were many memories – from having spent the first night of their marriage there, to bringing up four children in the house, as well as plants that had come from parent's and grandparent's gardens, it was a home filled with family history. Nola pointed out that it is a wrench to move from somewhere you are so familiar with to somewhere that would not have much character by comparison.

The reason for the move had become apparent as their home had stairs at the front and back and a sloping backyard. It was no longer suitable as ageing and the late effects of polio made it difficult for Nola to cope with the access to it – it was time to find a more accessible place to live. Nola's husband John never questioned the decision.

They then had to consider what they would like. They wanted to stay in the area, find something affordable, have an area for gardening, and a feeling of space. *"I am ashamed to say that disability requirements were not a top priority, but they were there. After all, that is why we were moving."* Nola and John looked at villas in complexes, but found nothing suitable. They were crammed together and had very little green area. Then came the thought, *"why not look at retirement villages – they usually have plenty of ground around them and as we would probably eventually move into one, we might as well make the move now"*. It was the ambience of the place that was important to Nola rather than accessibility. Originally Nola didn't think it was fair to expect John to have to go to a retirement village.

Nola and John looked at quite a few retirement villages until they found 'the one' at Pendle Hill, a small complex of 44 stand-alone, independent living, leasehold villas (1 or 2 bedrooms), built in 1983. It didn't have all the glamour of the more modern villages, but it was what they liked. It is a not-for-profit retirement village run by Uniting Care with affordable monthly fees. They were very excited once they found what they wanted and sent their deposit straight away. It was in the same area, near to an accessible railway station, shopping complexes, close to a major hospital, allowed them to attend the same church and was within scooting distance of Parramatta where there is Lake Parramatta, the Parramatta River, the ferry to Circular Quay, and the Riverside Theatre, as well as the Polio NSW office where Nola volunteers. Nola pointed out how important it is to look at the facilities that are available around, not just within, the complex itself.

They took the contract to their family solicitor who clarified different clauses with the village before signing. (Nola noted that after hearing the speaker from NSW Fair Trading they perhaps should have found a solicitor experienced in retirement village contracts.)

The move was a huge undertaking and required the assistance of her four children, one who lacked sentimentality, and Nola and John had to intervene several times to save some of their treasured 'stuff'! This was both a heart-wrenching and physical exercise, but it had to be undertaken and support is needed to achieve it. It is a really difficult job!

Nola and John are reasonably happy at Pendle Hill but it will never be the same as their own family home. Nola was concerned for John adapting to his new home. They each have their separate activities as well as shared outings i.e. concerts. John has his all-important garage to tinker in. They don't have everything they would like, the garage is not close to the villa, nor are the rubbish bins, but the villa is easily negotiated in that it is fairly spacious and easily managed. The grounds are not huge but adequate, with a gardening plot in front of each villa and a swimming pool (with some visiting ducks). Without John, Nola is not sure how long she could manage, but she would hope to be eligible for services such as domestic cleaning.

The village has a Residents' Committee to which Nola belongs; she thinks it's important to be involved in the decision-making, especially regarding the budget and maintenance fees. The committee also organises social events throughout the year.

As the village is small it does not have facilities for medium or high care, however, when residents require these services there doesn't appear to be a problem. The lack of facilities doesn't overly concern Nola. Like most people, she would hope that she will not need them!

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**David Carter** is 75 years old, has post-polio, is single, a retired barrister, has worked in Parramatta for the last 25 years, and lived in Wahroonga. About 7 years ago David decided that with his post-polio issues, the time had come to look for a retirement village. He looked at places in Waitara, Morisset .... He looked at many.

His concerns were to find somewhere close to Parramatta or Wahroonga. He didn't want to go too far, he wanted to be close to medical services, Westmead Hospital. He was interested in the problems of resale of units. He bought a unit at the Anglican Retirement Village at Castle Hill (previously known as Mowll Village). He absolutely loves it there and can't imagine why he looked at anywhere else and that he couldn't live in a better place. He stated that he is very optimistic, enthusiastic and biased!

This village is a big place; it is not-for-profit, 1,200 independent living residences, 900 residents, a 200-acre site in Old Northern Road, Castle Hill. It has independent retirement units and villas, residential care hostels (4), and nursing homes on the site. It provides a range of services including cafes, library, dentist, medical centres, doctors, nurses, physios and more. Also many clubs e.g. bridge, music, bowling, legacy, church, Probus, discussion clubs. Twenty-five percent of the residents are men and 75% women.

It is a very large site; it has a commercial bus service that drives through the village daily. The way the ARV organise their financial arrangements is simple and, he believes, very good. David paid \$360,000 for his 2-bedroom unit; a fixed contract. When it is time to sell, ARV keeps 30% of the original purchase price and the remainder goes to his beneficiaries. ARV keeps any capital gain. ARV pays the 70% to the estate straight away and then they refurbish and resell the unit. Maintenance fees are \$260 per fortnight for the unit and garage.

David pointed out that every retirement village is different. ARVs are all over Sydney and have different price levels, some allow pets etc. A pitfall of going into a retirement village is that you have no idea what your needs will be in the next 10 or 20 years, what you will need then.

*David's Mantra:* The early you go the better, don't wait until you are 90, go as early as you can and enjoy the place.

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The driving force for **Anne O'Halloran** was that she wanted to make the choice of where she lived. She didn't want to leave it too late. In 2008, she started looking. She wanted to move into a retirement village that had independent living, assisted living, and high level care.

She first started to look on the internet to find places nearby. She contacted them to send her information before she started visiting them. She quickly ruled out ones that she didn't like, until she narrowed it down to three retirement villages. She then put her name down on their waiting lists – two required a \$100 holding fee (which was refundable), while the third did not.

Anne had a pet and was managing okay in her home so wasn't in a hurry to move. Over a period of time she was called to look at 6 units and eventually narrowed it down to 2 that she liked, but ended up missing out on the one she preferred.

Anne moved to Southern Cross Care at Marsfield. There are 72 units with 72 women and 12 men, some couples. There are three levels of care.

Most of the units she visited didn't really cater for residents with long-term disability. At the time she was coping and didn't think she would deteriorate any further and would be okay. Then Anne had a fall and fractured her leg which set her back and took away some of her confidence.

Anne's advice is to ask for modifications if needed i.e. her clothes line was too high; the door to the shower was removed after her rehab. Positioning of the recycling bins are a problem.

In hindsight, Anne would do some things differently. She would pay the removalist to pack for her (an extra \$700). Family members and friends did help pack but it meant that Anne also had to help them which was exhausting. It would have been better to have them help her to unpack because there is less pressure then, you can take your time.

Anne noted that there is a group that advertises in the Seniors' magazine who can do it all for you, pack, move, get rid of stuff for you: *Downsizing with Ease*, Lorraine Cox 1300 795 526  
Email: <Lorraine@downsizingwithease.com.au>. Website: <www.downsizingwithease>  
You can download their "10 Tips to Making Downsizing Easier" booklet.

Anne also advises that you should accept any offers of help and not try to be so independent (it all helps), take more rest breaks and accept a longer settlement so you don't have to be rushed into a short time frame of selling house, paying deposit and moving. Also, don't look at everything when you go through things, it can waste so much time.

Anne still wonders if she should have stayed put, after all she did have helpful neighbours. Did she do the right thing at the right time? However, home maintenance was becoming an issue and the house was too big. Other considerations when making her decision were that she wanted to be near relatives and friends and shopping centre that provided scooters.

Anne also commented that even though there are three levels of care at her retirement village there is no guarantee that you will be able to move into the other levels of care if there isn't an available bed.

An audience member noted that local papers often advertise Open Days at retirement villages so you can see them and speak to residents to get a feel for the place. Anne stated that some units in her retirement village were rented and others purchased.

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**Merle Thompson** presented a slideshow which provided a summary of things to consider when making a final decision. The retirement village where Merle lives is in Lithgow and is owned by a private operator. It doesn't have any later-care facilities. The financial arrangement differs with her village in that, when you sell, the capital gain goes to the owner; the exit fee, which goes to the retirement village owner, is 30% of the purchase price (entry fee). The maintenance fee per month is \$260.

Why did she move into a retirement village? Merle had lived for 30+ years in a house with her older sister, Lyn. They had planned to move, but unfortunately Lyn passed away after a short illness. Merle's big sister/carer was determined, before she died, to find a place for Merle to live. They decided the retirement village would give Merle independence, physical help and companionship.

The retirement village would hold a deposit for 6 months until their house was sold. It was 5 months later that Merle moved in on her own.

It has a community-village feeling and is pet friendly which allowed Merle to take her cat.

*Things to consider:* What is the village community like, what shops and services are available and what social and cultural activities are there? How isolated or integrated is the retirement village in the wider community? If you don't drive, how accessible is the broader community?

Merle is happier in a smaller shopping centre, she doesn't like big complexes, she feels that it is friendlier and has a sense of community.

*Management:* Her retirement village is privately owned, had 35 villas at first and will have 148 eventually; at present there are 60 villas. Merle feels that the privately owned village has a more personal feel. It doesn't have as many facilities as perhaps David's and therefore the maintenance fees are less. There are no nursing services. The village grounds have no steps, and low gradients.

Merle's villa also has no steps; her garage is attached with an internal door into the hallway. Her clothes line is in her courtyard. There are visitors' parking spaces available.

*Medical and transport:* There is a bus stop, post box, and medical centre just outside her village, and a local hospital close by providing most services. The railway station is 4 kms away, it has a lift and a ramp and no gap between the train and platform.

*Things to check out:* needs to be wheelchair accessible – look at bench heights, bathrooms, kitchen arrangements, storage space, are hallways wide enough for a wheelchair, is the bedroom big enough for wheelchair moveability? What is the outlook like outside your windows? Look at heating and cooling issues – fans. How much freedom is there to make changes/additions inside and outside your villa? e.g. add awnings, rails, choice to do own garden or get help.

*Community Facilities:* There is a Lifestyle Centre which has good wheelchair access, has a meeting and activity room, lounge, library and a pool table. There is a transport bus for outings, e.g. shopping. Activities – carpet bowls, pool, darts, scrabble, mahjong, music appreciation etc.

*Drawbacks:* Distance from Sydney, 3 hrs in the train or 120 km by car. The village is a community: some people are pleasant, some less so, and then a few are problematic, and some things can disrupt your harmony – all are issues to consider when living in a community environment.



*Reprinted from The DAISI Link – Spring 2015, newsletter for the Disability and Aged Information Service Inc*

For more information:  
phone **1300 650 835**  
or visit <[www.returnmed.com.au](http://www.returnmed.com.au)>

Return your unwanted medicines to your pharmacy for safe disposal. Old medicines lying around the home 'just in case' are dangerous .....

Most of the medicines in our medicine cabinet we need, but what about the yellow pills in a jar that's lost its label, and the eye drops we have had for a long time. And what was that Quivinox B-Sulphamate for?



**If taken when they're out-of-date**

**If taken when not prescribed for you**

**If in reach of little prying fingers**

The RUM Project provides the safest and easiest way to dispose of unwanted and out-of-date medicines. It makes possible the return of all household medicines to any pharmacy at any time – for free and safe collection and disposal.

**Don't flush medicines down the toilet**

**Don't pour medicines down the sink**

**Don't throw medicines into the garbage bin**

RUM provides the best alternative – by returning out-of-date and unwanted medicines to our local pharmacy, we can make our home a safer place, help safeguard our community, and protect our environment.

**Step 1** – Sort through your medicine cabinet and drawers, putting to one side the out-of-date and unwanted medicines;

**Step 2** – Take them to your local pharmacy;

**Step 3** – Give them to your pharmacist for proper disposal; and

**Step 4** – Tell your friends and relatives about the RUM Project.

# Vale Ken Dodd

by **Nola Buck**

It was with sadness that Polio NSW learnt that member Ken Dodd had died in June. Ken was a larger-than-life person and he will be greatly missed, especially by people in the Coffs Harbour/Bellingen area. Polio NSW would like to express our sincere sympathy to his wife, Claire (also a member of Polio NSW for many years), and his daughters on their loss.

Ken contracted polio at age 2 in 1930 in Harden, NSW. He spent about 2 years in the Coast Hospital (Prince Henry Hospital) and Camperdown Children's Hospital. He experienced the usual treatment following the initial polio attack, mostly conventional but some Sister Kenny. He attended Canterbury Boys' High School and decided in 5<sup>th</sup> Year that he would like to become a teacher.

This was in 1947 when people with any kind of physical disability could not enter the Public Service. When Ken's first appointment as a teacher arrived it was only as a temporary staff member. This meant pay restrictions, no superannuation and no promotions. Ken did not accept this situation. He immediately went to the Education Department in Bridge Street, Sydney, and followed the doctor who had conducted the medical to his rooms where he and Ken carefully went through Ken's sporting activities at Teachers' College, some quite correct, some not so. After a short time, the doctor tore off the margin of his Sydney Morning Herald and wrote, "*K.R. Dodd, medically fit, N.J.*" Clutching this magnificent document in his hand, Ken proceeded to the Accounts Department and left with his superannuation papers.

Ken was very active in his community and the following are just some of those activities:

- Librarian at Bellingen RSL;
- started soccer locally, both Junior and Senior;
- zone-qualified basketball referee;
- Board member of Bellinger River District Hospital;
- active member (and Life Member) of NSW Primary Schools Sports Association;
- Teacher's Federation Representative (and Life Member), Bellingen;
- Life Member of the NSW Teacher's Federation;
- President (and Life Member) of Urunga Golf Club;
- engraving of trophies for local schools and sporting groups (and for Polio NSW);
- Probus Club Secretary for approximately 18 years, and also President;
- Life Member of the Fernmount Bushfire Brigade; and
- a volunteer in the Disadvantaged Schools Programme.

The following are some of Anne O'Halloran's memories of Ken. Anne started the Coffs Harbour Support Group, of which Ken was a keen member and later Convener.

*Ken became an active member of the Coffs Harbour Support Group in 1991. We met monthly at a Community Centre in Coffs. I remember Claire accompanying Ken to meetings. Some of our Support Group members travelled from Nambucca Heads by wheelchair bus/taxi and Ken was always a willing helper for the members when they arrived in Coffs. Mike and I returned to Sydney in 1998 and one particular memory I have of Ken is the help he provided to one of our Sydney members who was leaving hostel accommodation in Sydney to be closer to her son on the North Coast. I contacted Ken who found a suitable leisure type of unit in a village near Coffs where people with a disability were catered for and he sent her information. The lady moved up there. Ken visited her in hospital when she had an accident at the new abode, providing our member with valuable support.*

*When I ran across Ken and Claire in Urunga they would tell me they spent many happy hours canoeing together on one or other of the rivers in the area.*

*I take this opportunity to express my condolences to Claire and their family. Ken will be missed, not only by his family, but in the communities of Fernmount, Bellingen and Urunga.*

# Promoting Positive Solutions

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**Question:** *I worked so hard to walk again after acute polio. I have extreme pain in my hip in my weaker leg and since I had a knee replaced my back pain when standing is also extreme. I use a cane sometimes and I know I should use a scooter or a wheelchair, but I just can't overcome that horrible feeling of being a failure if I do. Besides that, I have gained weight and if I don't move some I will gain even more. Help!*

## Response from Dr Rhoda Olkin, PhD

*Dr Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and a single mum of two grown children.*

Ohhh, been there! I have pain in my knee area, my back hurts, I can't stand for more than a minute, and I spent my formative years doing everything possible to remain ambulatory. Now I use a wheelchair or scooter 90% of the time, crutches the remaining 10%, starting about 10 years ago. My weight gain has been alarming, and I no longer see in the mirror the person I think I am from the inside (who seems to be much younger, cuter, thinner and with great hair!). But I do not see a failure, only flaws that I can address. The flaws do not include the fact that I use a wheelchair, because doing so got me my life back. Pain and limited ambulation were forcing a reduction in activities that narrowed my world.

We get so many messages from everywhere about how walking is good and how the need for any sort of assistive devices is bad. Consider the language often used: "Wheelchair bound" (with emphasis on the inability to get out of the wheelchair), "non-ambulatory" (not able to walk), "suffers from polio" (as if that's all you are). What if we said "uses a wheelchair" and "fully mobile" (by whatever means!) instead? A wheelchair is not a failure, but a window into a wider world of options. Imagine you lived in a poor country with no access to wheelchairs. In such circumstances people devise their own sets of wheels, and getting a real wheelchair would not represent failure, but wings to fly.

Try to experiment. Go to a big store that has a scooter for customers to use. Do not use it. Go up and down each aisle. Note your level of fatigue and pain. Now go on another day and use the scooter, again going up and down each aisle, and again noting your level of fatigue and pain. What do the results tell you?

Okay, I'm not going to gloss over the significance of using a wheelchair. First, using a wheelchair often means less overall body movement, which can lead to secondary conditions (weight gain, decubitus ulcers, lassitude of some muscles). You have to be careful to avoid these. Since you can walk, do so a bit, or get on the floor and move/exercise, or do chair exercises. (Once a day I walk with crutches from my office to the bathroom and back, a total of 100 steps. I notice I feel better when I do this.) Second, it's a change in body image. People everywhere start reacting to you differently, and that feedback forces some recalibration of the self. Third, it can be harder to maintain or lose weight. Make sure you don't have another condition (hypothyroid, sleep apnea) and then find a balance in intake and output that you can live with. And when you do, write me, so I can use it as well!

Do not let anyone – family, friends, doctors, rehabilitation specialists, physical therapists – lead you to believe using a wheelchair represents failure. It is an alternate means of mobility and does not change the fundamental you.



**Question:** *Sixty years later I still live daily with anxiety stemming from hospital treatment, not abusive but certainly traumatic for a child. Do you have suggestions on how I can reduce the stress of this anxiety?*

## **Response from Stephanie T Machell, PsyD**

*Dr Stephanie T Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.*

So many of my clients struggle with this! The hospital experience was indeed traumatic. You had a serious life-threatening disease that in its acute phase included severe pain, a high fever and the inability to move and/or breathe on your own. Your family was absent and often unable to visit even briefly. And the treatments themselves could be painful and at times humiliating.

And no one was explaining why any of this was happening or letting you express your fears. If you tried, you were told to be brave, that big girls and boys don't cry, or something similar. At that time pediatric professionals believed that children didn't experience depression or anxiety and that only a disturbed child would suffer long-term emotional effects from polio.

Of course that wasn't true. And because what isn't addressed cannot heal, you like so many others still suffer the after-effects.

Anxiety can manifest as panic, worry, ruminations, obsessions, compulsions, frightening intrusive memories or nightmares, phobias, fears, a sense that something terrible might happen, avoidance of places or experiences (for example, medical care or wearing heavy clothing). Most likely you have more than one of these symptoms.

There are many self-help techniques for reducing anxiety. Mind-body techniques such as meditation, relaxation, guided imagery, gentle yoga, or tai chi "reset" an overactive autonomic nervous system.

Grounding techniques interrupt panic or flashbacks. For example: Open your eyes. Feel your feet on the floor and/or your butt in the chair. Breathe steadily. Look at something that reminds you you're safe.

Worriers can set a worry time of 15 minutes at the same time every day. For the other 23 hours and 45 minutes, when you catch yourself worrying, stop and say, "*I need to save this for worry time*". When worry time comes you MUST worry for 15 minutes. When the time is up, you MUST stop worrying until the next worry time.

Writing can be helpful. Part of what makes trauma traumatic is that it is unspoken and unshared. Putting your experience into words, even if just for yourself in a journal, helps you process and make meaning of your experiences. Others have used art in this way.

Reading about the trauma of polio helps some and overwhelms others, so use your judgement. Along with many memoirs there are some useful articles about trauma and the polio survivor. The best one, "*Bridges to Wellness*" by Linda Bieniek, is on the Post-Polio Health International website. The Lincolnshire Post-Polio Library contains some excellent articles. Though not specific to polio, there are also workbooks and self-help books for reducing anxiety and other after-effects of trauma.

Have you seen a psychotherapist? If no one in your area works specifically with polio survivors, look for someone who deals with trauma and/or disability. Many of my clients have found that once they dealt with their trauma, they had a reduction in their PPS symptoms, especially fatigue and cognitive difficulties. Finding a therapist and going through therapy isn't easy. But healing is worth it.



**Dr Stephanie Machell will be a Keynote Presenter**

*Resilience and resistance:  
a consultation with the polio patient*

at Polio Australia's  
**2016 Australasia-Pacific Post-Polio Conference**  
**Polio – Life Stage Matters**



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

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SYDNEY  
**SAVE THE DATE**

# Summary of Poliovirus Genome in Patients with Post-Polio Syndrome

## Mid-Study Report to Post-Polio Health International (PHI)

by Joan L Headley, Executive Director, PHI

*Reprinted from Post-Polio Health, Vol. 31, No. 3, Summer 2015, with permission of Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org)). Any further reproduction must have permission from copyright holder.*

In late 2013, Post-Polio Health International awarded \$100,000 to the team of Antonio Toniolo, MD; Andreina Baj, MD; and Martina Colombo, PhD – Laboratory of Medical Microbiology and Virology, Department of Biotechnology and Life Sciences, University of Insubria Medical Center, Varese, Italy, to expand its search for poliovirus genome in various populations. The team's work is enhanced by the expertise of Konstantine Chumakov, PhD, Associate Director of Research, Office of Vaccines Research and Review, FDA Center for Biologics Evaluation and Research, Silver Spring, Maryland.

The goals are: 1) to complete the systematic search of poliovirus genomes in the Italian cohort of post-polio syndrome cases, and 2) to verify if poliovirus genomes are also present in aging polio survivors with "stable polio" (i.e., those aged > 60 years that have not developed post-polio syndrome).

The team will compare virus prevalence of point 1 versus point 2 with the aim of establishing whether the presence of persisting polioviruses may have a pathogenic role in post-polio syndrome and of defining the peculiarities of genomic sequences of polioviruses detected in cases with post-polio syndrome as opposed to the genomic sequences of wild-type polioviruses.

### Why look for poliovirus genome?

For many, the origin of post-polio syndrome is still poorly understood. Some do not question its origin, but attribute its consequences to living active lives with bodies that have fewer nerves and fewer muscles. Time and age takes its toll. But, looking for an additional explanation makes sense.

Persistent poliovirus (PV) infection has been reported in individuals with B lymphocyte deficiency (and low or absent serum immunoglobulins; Li et al, 2014). Some evidence suggests that persistent PV infection could be associated with post-polio syndrome (Leon-Monzon et al, 1995; Baj et al, 2015).

Inflammatory changes in meninges, spinal cord and muscles have been reported (Ikemoto et al, 1996; Semino-Mora & Dalakas, 1998) and may suggest: persistent PV infection, autoimmune attack to central nervous system (CNS) targets, increased vulnerability of CNS to further infections.

### What has been accomplished?

Polio patients have been seen by neurologists and appropriately diagnosed with post-polio syndrome (PPS) (or other forms of polio) using current diagnostic criteria (Farbu et al, 2011). Participants in the study have included PPS cases, stable polio cases, polio-free family members of PPS patients, non-polio neurologic controls and healthy blood donors.

### What are some preliminary results?

Low-level genomes and infectivity *related to any one of the three PV types* have been detected at high frequency in PPS patients decades after the acute attack.

An additional conclusion of relevance to the field of public health (and also important for family members and co-workers of PPS cases) is that PV infection if not being transmitted from PPS patients to their family members.

Since effective treatments for PPS are still missing (Koopman et al, 2011), identification of chronic PV carriers might indicate the need of treatment with human IgG or antiviral drugs/antibodies that are under development (McKinlay et al, 2015). Some treatments (human immunoglobulins) are currently under clinical trial in a multicentre international study (<[post-polio.org/edu/pphnews/PPH31-3sum15p3.pdf](http://post-polio.org/edu/pphnews/PPH31-3sum15p3.pdf)>).

### What are the team's next steps?

Select viruses isolated from PPS cases are being examined at the FDA in order to define the peculiarities of genomic sequences of polioviruses present in PPS cases versus those of wild-type polioviruses.

The recruitment of polio survivors with "stable polio" is continuing, to extend the observations from the current to at least 30-40 cases.

The team will evaluate if anti-poliovirus antibodies may be effective in blocking the infectivity of poliovirus strains derived from PPS patients.

If positive, the results of the above tests will allow the team to propose “specific serotherapy” for treating PPS. In the meantime, they want to understand the possible role of poliovirus antibodies in the current therapy that is mainly based on the infusion of human immunoglobulins.



**Dr Antonio Toniolo will be a Keynote Presenter**

*Post-Polio Syndrome as a viral disease:  
research results*

at Polio Australia's  
**2016 Australasia-Pacific Post-Polio Conference**  
**Polio – Life Stage Matters**



The NDIS will be rolled out across NSW between 1 July 2016 and 30 June 2018.

From 1 July 2016, people living in Hunter New England, Southern NSW, Central Coast, Northern Sydney, South Western Sydney, Western Sydney and Nepean Blue Mountains will be able to access the NDIS.

From 1 July 2017, the NDIS will be in place across the rest of NSW, and people living in Northern NSW, Mid North Coast, Sydney, South Eastern Sydney, Illawarra, Shoalhaven, Murrumbidgee, Western NSW and Far West NSW will be able to access the NDIS.

Information is now available on the National Disability Insurance Scheme website re the roll out of the scheme across NSW and Victoria. For more information on the rollout of the NDIS in NSW visit:

**<[www.ndis.gov.au/about-us/our-sites/nsw](http://www.ndis.gov.au/about-us/our-sites/nsw)>**

## Companions in the Air - A Helping Hand When You Travel

*From The Senior Traveller EXTRA Tuesday, 6<sup>th</sup> October, 2015 Section:  
Travel, International travel, Travel Tips*



Singapore Airlines has partnered with *Medical Travel Companions* to offer a premium service for independent travellers who need assistance when they travel.

*Medical Travel Companions* can help with things like checking in luggage, clearing immigration, supervising medication while in transit and providing wheelchair assistance.

Companions are fully qualified nurses or paramedics and are matched to the passenger's needs. At present the service is limited to outbound flights from Australia and fees apply.

Ring **1800-070-051** or visit **<[www.singaporeair.com/mtc](http://www.singaporeair.com/mtc)>**

## Driving

Reprinted from the newsletter of IDEAS, Sept/Oct 2015

Driving is often a goal for everyone and that includes people with a disability or someone who is recovering from an injury or illness. It is an activity that is important in everyday life and it enables individuals to become involved with their community. It gives a person a sense of freedom and independence.

Having support by your side when you are learning how to drive for the first time or after an injury is vital. There are many of these supports around to help you get back behind the wheel.

For information about driving rehabilitation in your area please contact IDEAS on their toll free number: 1800 029 904. They will be happy to help you find a service to suit your needs.



## Sydney Festival Unveils 40th Anniversary Celebrations

Reprinted from the newsletter of Spinal Cord Injuries Australia (SCIA), Accord, Spring 2015

International as well as home-grown talent will light up performance stages to celebrate the Sydney Festival's 40<sup>th</sup> anniversary in January 2016.

*"The New South Wales Government is proud to support Australia's biggest and best summer festival. Over four decades, it has grown to become a wonderful showcase of home-grown and international talent"*, says NSW Deputy Premier and Minister for the Arts, Troy Grant.

During the three-week Festival from 7-26 January, events will be held in various indoor and outdoor locations and performance spaces. With a vast array of music, film, dance, opera, theatre and exhibitions on offer, there is definitely something for everybody.

The 2016 program is now available. *"Sydney Festival is proud to present international work by some of the world's most extraordinary artists including Peter Sellars, Toni Morrison, Rokia Traore, Robert Wilson, Tom Waits and Jette Steckel ..."*, says Festival Director Lieven Bertels.

One of this year's theatre highlights is the play *Woyzeck*. *"The piece is wild and lurid and exciting and it inspires your imagination. It makes you fear for the characters and reflect on your own life"*, writes musician and actor Tom Waits.

Spinal Cord Injuries Australia (SCIA) encourages all people with disability, their family and friends to attend the Festival. There are a large number of free as well as paid events around the city and Darling Harbour, and outdoor concerts in the Domain as well as around the city on Australia Day.

The Festival has a ticket pricing policy that offers people with disability the lowest priced ticket category for each event. Plus, it accepts the Companion Card. Discounts are also available when purchasing tickets for multiple events.

Although Festival venues, services and facilities should provide equitable access in compliance with the Sydney Festival Disability Action Plan, access barriers have occasionally occurred in the past. However, Festival organisers respond when issues are raised. If people have any adverse experiences, SCIA recommends raising these issues directly with the Festival organisers.

**For more Sydney Festival 2016 details, visit <[www.sydneyfestival.org.au](http://www.sydneyfestival.org.au)>, phone (02) 8248 6500, or email <[mail@sydneyfestival.org.au](mailto:mail@sydneyfestival.org.au)>.**

**Companion Card information is available by phoning 1800 893 044, emailing <[companioncard@nds.gov.au](mailto:companioncard@nds.gov.au)>, or visiting <[www.nswcompanioncard.org.au](http://www.nswcompanioncard.org.au)>.**



*Following are two emails received recently from members. Can you help Ann-Mason Furmage who is contemplating a shoulder replacement? There is also some mobility equipment for sale with first offer to polio members.*

I have been advised that I need to have my right shoulder replaced, due to wear-and-tear during the 65 years since I had polio (my left hand-arm-shoulder is paralysed, so my right shoulder has done double work for a long time).

I am not particularly excited about the prospect of this operation, but even less enthusiastic about the fact that my shoulder would be immobilised for 6 weeks after the operation.

In addition, I am concerned about the effect of the rehabilitation exercise regime which would follow the operation.

I wonder if anyone else in Polio Land has had a shoulder replacement operation and what their experience may have been? I would be very grateful if you could share this with me.

**Ann-Mason Furmage Email: <arose@exemail.com.au>**



Hello Gillian

As you know, Ken Lambert passed away recently. His wife, Marion, and their son, Ian, are offering Ken's mobility equipment for sale, with first offer to polio members. If anyone is interested in anything, please contact Ian directly. His details are below.

Brian Wilson, ACT Support Group Convener

Dear Brian

I take this opportunity to thank you for your support for Dad over these recent years. With Dad's death we are now trying to sell his various items of mobility equipment. I would be pleased if you could pass around your network that the following items are available:

**Mobility scooter** Shoprider Deluxe 889. Complete with accessories like sun canopy, carry basket, charger etc. Good condition. It is about 5 years old and was used by Dad every other day up until the last three months. Still holds a charge and runs well – I took it for a spin myself last week. I don't know when the batteries were last changed. Price around \$1,000.

**Cougar Power chair** \$1,500 ono, with recent new battery pack valued at \$660. Good condition.

Dad's car is also available. The vehicle is a silver **Ford Escape 2002 BA XLT 3LT AUTO**, 140,000 km, **complete with hydraulic mini-crane and 3-wheel mobility scooter**. As a package we would be asking around \$6,200, ono. We will get a RWC for it before sale. Rego runs out mid Dec.

**All prices negotiable.**

I am happy to answer any questions by email or phone.

Thank you for your assistance.

**Ian Lambert Email: <ianlambert@gmail.com> Mobile: 0447 965 900**





# 2016 Polio NSW Seminar Program

<b>Wednesday</b> <b>18<sup>th</sup> May</b> <b>2016</b>	Northcott 1 Fennell Street North Parramatta	<b>Mid-Year Seminar</b> <i>Look for details in upcoming Network News</i>
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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 9487 3094
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
<b>Committee Members</b> (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Ella Gaffney, Anne O'Halloran, Alice Smart and John Tierney			

## PPN Office and Other Contact Details

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	Support Group Co-ordinator	support@polionsw.org.au	
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	---
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

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

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



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

**20-22  
SEPT  
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Visit <[www.postpolioconference.org.au](http://www.postpolioconference.org.au)> for more information

# About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

Polio survivors, their family members and friends are all welcome to join Polio NSW, as are health professionals and anyone else who supports our aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors and their families.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

## Resources for Members

On joining Polio NSW, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet.

Polio NSW also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for members and postage is included. To order, just write to us – please make cheques / money orders payable to Polio NSW Inc.

<b>Books etc (* indicates Post-Polio Network publication)</b>	<b>Size</b>	<b>Cost</b>
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> <b>Second Edition</b> Edited by Lauro S Halstead MD ( <i>see description below</i> 📄)	288 pages	\$40.00 <i>incl 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
Polio NSW has for sale a four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

### 📄 ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

*The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:*

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Office.