No 269 October 2018

Mornington Peninsula Post-Polio Support Group

Next meeting: Saturday, October 13, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. The next social outing is lunch on October 23 at the Westernport Hotel, Hastings. For the record: meetings are held on the second Saturday of each month, with outingson the third Tuesday unless the meeting date is mid-month. Please contact the secretary for confirmation, venue and details, or if you need a lift.

World Polio month edition

Wear Orange for World Polio Day.

Polio Day each year falls on or near the birthdate of Jonas Salk (October 28). World Polio Day aims to increase awareness about polio virus and to encourage further actions to reduce it from spreading. The commemoration of the day also highlights the success of global strategies in reducing the spread of the disease. However, it is also a time for us to reflect on those people who contracted polio during the epidemics and are now living with the late effects of polio. For many tens of thousands of Australians, polio's reprise is a cruel twist of fate that impacts on all aspects of their daily lives.

Above: September meeting with guest speaker Kylie Knoble from Southern Cross Care on the complex subject of Aged Care packages. Pictured are Barbara Worme, Bill Crosbie, Kylie Knoble listening to a point made by Martin Fisher.

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A bumper crop for Polio Day - October 20 at Hawthorn Arts Centre, still time to book - $35! Telephone 1300 704 456 state you are calling about Polio Day.

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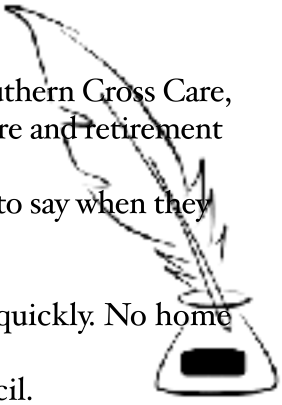

September meeting notes

WE welcomed Kylie Knoble, care manger and dementia consultant for Southern Cross Care, which provides in-home care and access to a network of residential aged care and retirement living options to support people to live the lives they want.

To give Kylie an idea of our conditions, we went round the table for each to say when they had polio and if they had a home care package.

- Bruce: 1953, during national service. No package. Barb does lawns.
- Bill: 1950, mistreated initially for meningitis, back playing footy very quickly. No home care package.
- Martin: 1950s, has domestic assistance at home from Frankston council.
- Leonie: 1949, was also mistreated for meningitis, paralysed down left side, treated at Fairfield.
- Graeme: 1950, affected for 12 months, immediately treated by Dame Jean Macnamara, five others in the street had polio. He was walking again and playing sport quickly. PPS evident with fatigue playing bowls. Has a home care package and domestic assistance.
- Ian: 1949, three at his school got it badly, recovered and forgot about it until eight years ago when couldn't play tennis. Had tests and was asked if he'd had polio. His home care support is Wendy, who also does the lawns.
- Fran: polio 1946, isolated case, cared for at home. Has Southern Cross home care package and counts herself very fortunate.

Leonie and Graeme receiving Kylie's 'show bags'.

Kylie explained that Southern Cross Care is a provider of Commonwealth Government home care packages designed to keep people out of nursing homes, living independently in their own homes. Kylie has worked at SCC over the past seven years as a care manager, also running the Dementia Advisory Service.

There are two levels of support for people over 65 years of age. Basic level and higher level. Everyone has to go through My Aged Care – this can be done either by telephone or online. You will be screened over the phone, lots of questions asked to ascertain basic level need or if a more comprehensive assessment is required. Most people get low level (basic help) but for a home care package more comprehensive assessment needs to be completed for approval.

When your needs change and the higher level package is needed, an assessor comes out to your home [see footnote]. There are four levels – one and two are a low level of support and you can generally access a maximum of 3.5 hours a week of services Level four is higher, equals up to 11 hours of service a week.

Assessor asks lots of questions. While waiting for a Home Care Package to be approved and allocated you may need entry level support. There are 104,000 people on the national queue waiting for a Home Care Package. There is also a few months wait for an assessment, but you won't be left without services. Likely to start with Commonwealth Home Support Level services such as cleaning and shopping etc.

When a package is allocated you are given 56 days to find a provider. When people have been waiting for more than a year to be approved, this can be confusing. A code is given to you in a letter stating that you can use this code to find a provider and activate a Home Care Package.

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The system has been in place since 2015 when major reforms were brought in. Southern Cross care previously had over packages in the Southern Region. When someone left we could go out and offer that package to someone else on the waitlist. Now the individual has to shop for a provider once they get a letter to say their HCP has been allocated to them. A case manager comes out and tells you how much service you can get and develops a care plan with you based on what you need and want.

Kylie was asked about the contribution required. She said Government likes a contribution and each organisation has the right to collect a basic fee. She explained administration costs and charges taken out monthly. A monthly statement is provided so people can see how much they have accrued and how much each service costs.

Southern Cross does not ask for a basic fee, the government's contribution goes into the package budget so a contribution is usually only needed if you have to top up your budget. There are income tested fees for some people based on income and assets test.

If on a full aged pension you do not have to pay an income tested fee. With so many people on the waiting list, the government wants self-funded retirees to pay an income tested fee and contribute more to their care. Some people work out that a daily fee wasn't worth having a package and hire their own help. This could be a way the government is reducing the waiting list.

The packages are delivered under consumer directed care – this means you decide what help you need. It is our job to help clients understand what is available. Everyone has a different care plan. You can be creative and decide to purchase aids and equipment, technology, remedial massage, hydrotherapy, chiropractic, physiotherapy, podiatry, gardening. It is very flexible, no one size fits all.

Transport is a big issue – a worker can take clients to appointments by taxi with an escort, for example. We have affiliations with volunteer transport organisations to help. We pay mileage for the volunteer.

If someone has a budget of $200 per week after costs are taken out, if only using $180 then the $20 accrues. This money cannot go to another individual. A lot of clients have thousands accrued in case they need additional services.

The amounts appear in the monthly statement. When the first statement comes the care manger will come and work through it to explain. We do have government guidelines, clients cannot just go out and purchase anything. We have to show why the purchase will help the client – for example, we can even purchase a computer if that will help a client stay in touch with family if that will help their wellbeing.

Kylie was asked if a stairlift could be purchased from the allocation. She said one client had a number of falls. The OT assessed her home and garden and found she had a steep driveway. She was at risk when going to the letter box daily. So the garden was redesigned with steps and railing. A stool was provided for meal preparation, plus a shower seat, device for putting on shoes and socks. The client had money in her budget to cover these things for when she really needed it. Three quotes were obtained for the steps and railings from three companies.

Bruce asked about value of blocks of land reducing pension. Kylie said they stayed at arm's length from client's finances and the income tested fee is determined by the Department of Health but an appeal could be made to the Department of Health. The government provides funding to the

Kylie kindly handed out 'show bags'. Fran has a couple spare.

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organisation each month for a client's services minus what the client needs to fund through their income tested fee. Veterans Affairs provides home care services. The white card would cover items like equipment. You cannot double up on a Home Care Package and Veteran's services at the same time. Statements give clients a chance to see the real cost of everything you purchase – that can be quite a shock. It is important to understand those costs so you don't miss out on services you need and can choose your priorities.

A care manager will help clients decide on services. For example: if you are hospitalised we will work out a discharge plan and ensure you are back on your feet.

Southern Cross Care offers a complimentary service of sending out a care manager to help someone apply for My Aged Care. We do that knowing the person may not choose us, but we can see a lot of people are falling through the cracks. Many people choose not to go through it because it seems so complicated.

We had time for questions on this complex subject:

Q: Given it is a Federal Government program does this mean we will lose our council cleaners?

A: No, if you like your current cleaner you can keep them. Council sends the bill for full cost to your package provider. You can also continue to use familiar service providers if they have gone through the contract process with SCCV and have a service agreement.

Q: are there expensive exit fees?

A: yes, while packages are portable, we have 70 days to transfer unspent funds to another provider. This means the client can only access money coming in, not their excess. We charge a $500 exit fee to cover the significant administrative work to get in all invoices from various service providers. Sometimes we waive the fee if the client does not have any money left. We don't want to chase it from the client.

Q: what if there is nothing in the bank?

A: we wouldn't collect an exit fee if a client has no money in their package budget. Some organisations are for profit, others are not for profit.

There are rumours that government is looking at the amounts people are accruing and finding too much. If you have $15,000 for instance and are not seen to be needing or using it, government might reduce it in the future so we are continually encouraging clients to spend their funding on services they need and not to try to save it all up for a later day.

This is not real money. When someone passes away, any excess goes back to the government. It cannot be used by relatives for a funeral for example. If a client goes into a nursing home, the package ceases. The aim of these packages is to help people stay at home.

The type of person who accrues a lot of money is someone who says they have lived through the depression and cannot just spend that money. However, the government could drop it down. On the other hand, it is hard for us to say to someone that they are over budget and knock back requests.

We were most grateful to Kylie for this clear presentation and she was kind enough to check these notes for accuracy.

NB: A reminder from Polio Australia's Steph Cantrill on this subject: when being assessed for a package, do not downplay how you are managing. Respond as if it is your worst day.

General business:

Bruce suggested a $200 budget for taxis to bring members to meetings. But there were several offers of lifts from Sorrento, Rosebud, Mt Martha, Hastings. Pls contact if you'd like to come and need a lift. Questions about balance arose so have sourced some answers.

Polio Services Victoria is running a Medical and Allied Health Clinic on Thursday October 18 and a fatigue management seminar on Friday October 19. You need to have registered interest before September 26. Many people have received by mail notices of the

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clinics but new members may not be on their list. And while this newsletter will be received after Sept 26, it may be possible to still apply for a cancellation.

Once interest is expressed, a PSV team member will discuss polio-related concerns before an appointment is made. These will be prioritised on concerns given limited availability. There is no cost for the clinic or the workshop. You do not need to attend both.

The Fatigue Management Seminar covers understanding of polio, polio fatigue and strategies on how to manage it. Will be conducted by the PSV Occupational Therapist and Social Worker. At the completion of the seminar the aim is to understand: polio related fatigue; importance of receiving a medical diagnosis of polio related fatigue; principles of energy conservation and work simplification, how to apply these to your daily lifestyle; how allied health staff can assist you manage fatigue; where and how to access allied health staff if you need further assistance. Contact details are: ph: 9231 3900 or 1800 303 324 or at www.psv.svhm.org.au.

How to join in Walk With Me 2018

Walk With Me is Polio Australia's annual fundraising event. This year it is being held in conjunction with the PA Retreat being held at Glenelg in South Australia. Participants are invited join in a relaxed 1km walk or wheel in the sunshine, along the Glenelg beach esplanade. Walkers/wheelers assemble at 3pm on Thursday, October 11, between Moseley Square and Glenelg Pier. Polio Australia encourages everyone to ask friends to donate or to hold their own walks. For further information and how to donate: *www.polioaustralia.org.au/walk-with-me-2018/*

A new history of physiotherapy including polio

Professor Joan McMeeken's ‘*Science in our hands - Physiotherapy at the University of Melbourne 1895-2010*’ has been published by the Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne ($29.99 Readings).

There is a big chapter on Poliomyelitis and Physiotherapy, with familiar names: Marjorie Farnbach, Betty Fussell, Phyllis Frost with another look at Sister Kenny.

The book was launched by Professor Janet McCalman AC (polio survivor).

Prof McMeeken's next task is a book on Poliomyelitis and Physiotherapy for which she has already undertaken many interviews.

Illustration from Orthopaedia, the art of correcting and preventing deformities in children. Illustration by Nicolas Andry de Bois-Regard 'L'orthopedie ou l'art de prevent et decorriger dans les infants les deformities du corps - Paris 1741. Wellcome Images.

Triggers of Restless Leg Syndrome

NOTE from Dr Richard Bruno: this article mistakenly lists "twitching" as an RLS symptom. The article does mention neuropathy (see definition below) but other neurological damage could cause RLS for polio survivors with late effects and twitching could ring a bell despite Dr B's comment.

However, maybe some information here of use.

Newswise — People with restless legs syndrome (RLS) experience twitching and discomfort in the legs, usually during the evening and night time hours. "The feeling is usually accompanied by a strong urge to move your legs, to keep them active and lessen the uncomfortable sensation," says Jacqueline Chang, MD, a pulmonologist in BIDMC's Sleep Disorders Clinic.

"The feeling differs between patients, but most describe RLS as an aching, burning, itching, crawling or tingling sensation," she says. "This feeling only gets better when you move your legs, which can lead to other sleep-related issues."

Exactly what causes RLS is unknown, but it is often linked to common triggers or another disease or condition.

Common triggers for RLS include:

- Changes in sleeping patterns
- Too much caffeine or sugar
- Certain antihistamines and other over-the-counter medications
- Certain prescriptions such as antidepressants and anti-psychotic medications

"If someone is suffering from a mild case of RLS, we can usually address it by making a few behavioural changes," Chang says.

Common behavioural changes include:

- Adequate sleep hours and healthy sleep habits, including going to bed at the same time every night and reducing the amount of light (natural or electronic) before bed
- Avoiding caffeine and foods high in sugar
- Exercising and meditating
- Changing medications

"I often recommend some sort of physical or mental stimulation for RLS, like placing a hot pack to the area, massage, or even mental stimulation, like doing a crossword puzzle," Chang says.

RLS can be linked to another disease or condition. These include:

- A family history of RLS
- Iron deficiency
- Neuropathy (nerve damage)
- Kidney disease
- Pregnancy

There are a variety of medications that your doctor could prescribe to help ease the discomfort of RLS. Other treatment options may include lifestyle changes and relaxation techniques. "A sleep medicine specialist can work with you to find the best plan of care," Chang says.

The multidisciplinary team at the Sleep Disorders Clinic at BIDMC includes neurologists, pulmonologists and psychologists who treat patients with a full range of sleep disorders, from restless legs syndrome, to sleep apnea, insomnia, narcolepsy and more.

What is neuropathy?

Neuropathy refers to damage of the nerves. The damage may be caused by disease, infection, injury, medications, long term alcohol abuse or another reason. Different types

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of neuropathy are named according to the body part affected, the cause of nerve damage or the number of nerves affected.

Autonomic neuropathy occurs when there is damage to the nerves that control the body's automatic functions, such as digestion, blood pressure and bladder function.

Diabetic neuropathy is caused by diabetes most commonly affects the nerves of the hands and the feet. It can also affect nerves controlling automatic functions of the body, such as digestion, or nerves in the hips and thighs.

Peripheral neuropathy affects nerves in outer (peripheral) parts of the body such as the feet, legs, hands and arms.

Proximal neuropathy affects the muscles of the hips and the shoulders.

Focal or mononeuropathy affects only one nerve. An example is carpal tunnel syndrome.

Polyneuropathy affects several nerves. Most people with neuropathy have polyneuropathy.

There are many known causes of neuropathy, including:

- diseases like diabetes, Guillain-Barre syndrome and AIDS
- long term alcohol abuse
- chemotherapy and radiation
- vitamin deficiencies
- some medications
- spinal tumours
- pressure on a nerve.

A question of balance

At our September meeting problems involving further loss of balance were mentioned. For polio survivors with funny legs, hips and shoulders this is not surprising. So rather than just reach for the falls prevention information, here are outlined other causes from the Mayo Clinic and falls study from Post-Polio Health International.

A balance disorder may be caused by viral or bacterial infections in the ear, a head injury, or blood circulation disorders that affect the inner ear or brain.

Many people experience problems with their sense of balance as they get older. Balance problems and dizziness also can result from taking certain medications.

Inner ear infection or inflammation can make you feel dizzy and unsteady. The flu or an upper respiratory infection can cause this condition. Meniere's disease changes the volume of fluid in your ear, causing balance problems, hearing loss, and ringing in your ears. This can cause balance problems.

Gait and balance disorders are common in older adults and are a major cause of falls in this population. Common causes include arthritis and orthostatic hypotension; however, most gait and balance disorders involve multiple contributing factors.

Determining that a gait is abnormal can be challenging, because there are no clearly accepted standards to define a normal gait in an older adult. Studies comparing healthy persons in their 70s with healthy persons in their 20s demonstrate a 10 to 20 percent reduction in gait velocity and stride length in the older population.

Other characteristics of gait that commonly change with ageing include an increased stance width, increased time spent in the double support phase (i.e. with both feet on the ground) bent posture, and less vigorous force development at the moment of push off. These changes may represent adaptations to alterations in sensory or motor systems to produce a safer and more stable gait pattern.

The term “senile gait disorder” has been used to describe disturbances in gait in older persons when an underlying disease cannot be identified. It is characterised by a slow, broad-based, shuffling, and cautious walking pattern.

However, current understandings of gait disorders challenge this term because most major changes in gait and balance are attributable to one or more underlying conditions. Up to 20 percent of older adults maintain normal gait patterns into very old age, reinforcing that ageing is not inevitably accompanied by disordered gait.

Senile gait patterns may actually represent an early manifestation of subclinical disease, because their occurrence correlates with increased risk of cardiovascular disease, dementia, institutionalisation, and death.

Causes:

Medical conditions associated with gait and balance disorders may be for a variety of reasons, such as causing pain, dyspnea (shortness of breath) imbalance, diminished strength, limited range of motion, poor posture, decreased sensory perception, fatigue, deformity, and decreased awareness of and ability to adapt to and traverse through possibly hazardous surroundings. In addition, recent surgery or hospitalisation and other acute medical illnesses may lead to gait and balance disorders. The use of multiple medications (four or more), as well as specific classes of medications, can lead to gait disorders and an increased rate of falls.

Polio survivors have a variety of symptoms that are known risk factors for falls in older adults and people with neuromuscular diseases such as muscle weakness, joint pain and fatigue. One study showed that the rate of polio survivors who fell at least once in the past year was four times that of other adults over 55. This study also found polio survivors report falling more often in the afternoon and inside the home. Three important predictors of falling were identified for polio survivors – a) Problems maintaining balance, b) Weakness in knee extension in the weakest leg, “knee buckling” and c) Fear of falling.[6]

Polio Survivor Data from our Survey

Many Post-Polio Health International readers participated in our survey that asked some questions about falling. Here are the responses of people with post polio syndrome:

- 242 (54%) reported a fall within the last 6 months.
- 385 (86%) are concerned about falling.
- 366 (82%) reported not doing things because of fear of falling.

What can you do to prevent falls?

Knowledge is half the battle. Falls inside the home have been linked to stairs with four or more steps, slippery floors, sliding rugs, low lighting levels, missing handrails, uneven flooring and obstructive walkways. Falls outdoors are often linked to walking on uneven or cracked sidewalks, curbs or streets.

Other fall prevention tips include:

- Have your vision and hearing checked regularly.
- Talk to your doctor about side effects of medication that could affect coordination and balance or increase weakness.
- Wear rubber-soled and low- heeled shoes that fit well and fully support your feet, and replace worn cane and crutch tips.
- Avoid wearing socks when walking inside on hardwood or linoleum flooring. Socks with the grippers on the bottom or wearing Crocs while inside help prevent indoor falls.

- Be careful when walking outdoors on slippery paths. Carry your mobile phone on walks. Try to anticipate fatigue and bring what you might need for more support (stick, walker, etc.) or even a friend or family member.
- Ask your doctor what exercises you can do regularly to maintain strong bones, strength and flexibility. Exercise that improves balance and coordination (Tai Chi or Yoga) are most helpful.
- Keep your home safe – remove things you can trip over (shoes, papers, books, clothes) from stairs and high traffic areas. Keep clutter down!
- Install handrails or grab bars in your bathroom or other frequently used areas where you may need extra support (stairs and hallways).
- Improve the lighting in your home. As you age, you need brighter lights to see well.

The importance of colour in our lives

By Lee J. Kahrs

BRANDON ARTIST TECARI Shuman, left, fist bumps his good friend Robert Black.. Photo by Lee J. Kahrs

"Colors are important to me." So begins the artist statement of Tecari Shuman of Vermont, USA in his catalogue of paintings.

"I don't know exactly why, but they are. It goes back to my landscaping days. I noticed that certain colours just go well together — just feel right. Working in the landscape, I became connected to nature. Through this intimate relationship, I discovered that I am nature ... that we're all nature."

Nature has been both friend and foe to Shuman, 73. He contracted polio as a child growing up in Flushing, Queens, N.Y., and recovered, but the disease left him with spinal issues. In the early 1990s his left leg began to atrophy. Still, he spent years as a gifted and successful landscape architect, only to have the shadow of post-polio syndrome rear in 2008. The motor neurons that were affected by the disease began to fail. Shuman was diagnosed following a foot and leg reconstructive surgery. What he and his wife Ann Marie Roth didn't know was that anaesthesia-like paralytics, which render the patient immobile, can also affect those post-polio motor neurons. "They never wake up again," Roth explained. "After that surgery, he lost 30 pounds of muscle and started failing."

Shuman started walking with a cane, then crutches. But he kept doing physical therapy and started to gain back strength. But in 2012, Shuman suffered another blow. He was diagnosed with hydrocephalus, a condition where the cerebral fluid does not drain properly and pressure builds, affecting brain function. There is no cure, and the fluid can only be removed surgically.

In 2005, the couple on the advice of a doctor, moved to New Mexico, a warmer and drier climate that was supposed to be better for Shuman's chronic pain. "I was ready to come back after the first year," Shuman said. "The sun is so intense, I'd go out and I'd wilt." "It was so debilitating," Roth added. "It was worse than the winters here."

With the hydrocephalus diagnosis in 2012, they decided to return to Vermont, and fate chose Brandon for them. Not long after they moved, Shuman discovered his afternoon "coffee guys." The group of 10 local older men meets for coffee, discussion and good-natured ribbing every afternoon at 2:30 p.m. at Gourmet Provence in downtown Brandon. "George Wetmore and Charlie Jakiela would pass by walking in the morning and invite him to come along. The group has done so much. They make it possible for him to go to coffee," said Shuman's wife.

But Shuman's medical troubles were not over. In 2016, he was diagnosed with Parkinson's Disease, a progressive disease of the nervous system marked by tremors, loss of muscle control and balance. Now using a motorised scooter to get around, his motor skills have declined, he has memory issues and speaks very little, but he counts on those coffee meetings. Wayne Rausenberger from the coffee group built a ramp for Shuman on the front of his house. Jack Fillioe built a platform for Shuman's scooter behind the house. On the days Shuman isn't up to making the trip to coffee, Blaine Cliver comes up and visits.

Still, ongoing medical issues and chronic pain were taking their toll on Shuman's mental health. He became more and more withdrawn. Robert Black, a local architect, is also part of the coffee group. A great believer in the power of art, Black came to Shuman's house armed with painting supplies. "He said, 'We are going to paint today,'" Shuman recalled. "And he sat down with me and we painted. He's a very positive person, it was contagious."

Black began by talking to Shuman about art and life and what it meant to him. "So we took our paper and a pen and just started doodling," Black said. "After that we just put on aprons and put down some plastic and started painting." There was much more to the act of painting than something to do. "Especially important here is that Tecari was discouraged and wasn't feeling particularly hopeful," Roth said. "I was depressed," Shuman said matter-of-factly.

Black began coming to the house once a week and the two men would paint together. Now, over a year later, Shuman has created 112 paintings. Black helped him pick out 40 for an exhibit at the Arts Center in Brandon.

Grove by Tecari Shuman

For Shuman, painting has become a lifeline, a tool he uses to feel better. "When I was in a lot of pain, sometimes I would make myself paint, and it would come out ugly," he said. "I was very depressed and I found art really drew me out of that. I started to see life differently. I started to be more positive.

"I really love it. It always helped to shift my mood. I always want to step into the painting and be uplifted by it."

"I think it's improved his fine motor skills, as well as his emotional health," his wife said. "While he's not able to do fine detail work, I think painting has helped his brain and his body to communicate better."

The aims and objects of our group are to gather and disseminate information on Post-Polio Syndrome and Late Effects of Polio, to support each other in anyway we can. Opinions expressed in this newsletter may be those of the writers only. We do not purport to be medically qualified. Consult your doctor before trying any medication or new form of exercise. Give relevant information to your doctor and help them to help us. We do not endorse any product or services mentioned.