



polio
network
victoria

Polio Perspectives

The newsletter for Victoria's polio survivors, families & friends

Chair report from Bev Watson

FOLLOWING an extraordinarily difficult beginning to the year, I hope everyone has stayed safe and unaffected by the dreadful fires and floods that devastated so many areas of Victoria and interstate.

Thanks to those who have advised about the method you want to *receive Polio Perspectives* and to those who have paid a subscription to receive a hard copy. These contributions mean we will be able to continue to provide the valuable connection and information to Polio survivors however you receive it. We now have the database and will work through it in an effort to have the correct method and addresses for you to receive *Polio Perspectives*. Please bear with us if we don't get it right first time.

I can advise that soon Polio Network Victoria will have its own phone. The number will be circulated via our website once available. Our website polionetworkvic.org has a wealth of information, I urge you to check it out.

With the incorporation process complete, we have our own bank account, so if you can donate to assist with the expensive exercise of printing and posting *Polio Perspectives*, this can be done directly via our Bendigo Bank account name – Polio Victoria Inc. – BSB 633 000 Account no. 169 887 320 – be sure to include a name in the reference field.

We have been able to secure a small meeting room at a reasonable rental at Kensington Town Hall for our bi-monthly committee meetings. Believe it or not, we are already starting to plan for Polio Day, 2020. As we alternate between metropolitan and regional venues, this



year we will look for a location in the metropolitan area.

This day provides an opportunity to enjoy each other's company, learn something new or practice something old. We need to secure funding to present this special annual event. Please let us know if you hear of any grants/funding opportunities.

As we move into Autumn, I wish you all the best for cooler days and nights and thank you for supporting the Network.

Finally, I thank committee members, Joan and Graham Tie, Elaine Smythe, Lyn Bates, Maxine Keystone, Anne Clapham, Dawn Baudinette, Jude Drake and Fran Henke – Editor of *Polio Perspectives*. These wonderful people travel great distances to attend Committee meetings and I am truly thankful for such amazing support.

All the best.

Bev Watson

Chair – Polio Network Victoria

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How to manage Brain Fog caused by chronic pain

BY PETER ABACI, MD, anaesthesiologist
and pain specialist

DO you find that you're more forgetful or fuzzy-headed when in pain? Is it harder to concentrate? Like many with chronic pain, you may be experiencing signs of brain fog, also known as cognitive dysfunction. If this is happening to you, rest assured you are not alone.

When we say "cognitive function" we're talking about a variety of mental activities including memory, learning, problem solving, decision making, and attention. Over the past decade, we have come to learn that the experience of pain can play a big role in how well we perform these mental activities, and the more intense the pain and the more body parts that are affected, the more disruptive it seems to get.

Perhaps the best-known example of this is "fibro fog," which is a term commonly used by those with fibromyalgia to describe the cognitive difficulties they experience on a daily basis. Common complaints of fibro fog include forgetfulness, poor concentration, difficulty finding words, and trouble carrying on a conversation. But this feeling of mental cloudiness can occur with other chronic pain syndromes as well, including migraines, back pain, and painful nerve disorders like diabetic neuropathy and complex regional pain syndrome (CRPS).

Research has shown that chronic pain can interfere with a variety of cognitive functions, with the most recognisable being memory. Chronic pain is associated with greater recall problems for words and information, as well as for objects and places, also known as spatial memory. The more widespread the pain is in the body, the bigger the memory deficits. Pain has also been shown to interfere with how well we concentrate and stay on task, as well as our ability to organise our thoughts (known as executive function). For example, pain seems to interfere with the brain's ability to adapt to change when performing tasks.

Other factors related to pain can also contribute to brain fog, including depression and anxiety. Insomnia, also highly associated with chronic pain, can reduce mental sharpness and cognitive performance.

We're still trying to better understand the causes of this brain fog, but one possible explanation may be found in research suggesting that a brain in pain is over-activated and over-stressed. Parts of the brain that would normally get time to rest don't get a break with chronic pain, resulting in changes to how well the brain can store information and perform executive functions. It is much harder to have a conversation with someone when there are a bunch of other people in the room talking to you at the same time. Experiencing pain may create a lot of extra brain noise, making it that much harder to focus.

So, if experiencing pain seems to leave you with brain fog, what can you do?



Polio survivors experience brain fog when severely fatigued but this explanation may also help

One way you may be able to decrease brain fog is by clearing out some of this extra unwanted background noise. One proven way to do this is through meditation. Mindfulness meditation training boosts focus while calming the nervous system, which can lead to improved cognitive performance and less brain fog. Distraction can also help dampen some of this background interference. Simple distraction tricks can include listening to music, journaling, drawing, or colouring. And a lot has been published on the powerful effects that exercise can have on brain performance, even in old-age. Research has found that exercise stimulates the production of a protein called brain derived neurotrophic factor which has been shown to boost mental function and improve both depression and anxiety.

Along with trying out some of these tools, consider taking notes and making lists to help be prepared for moments of cloudiness or forgetfulness. Carrying a notepad with critical information (like your medication list) to places like doctor appointments or when running errands can help remind you of what is most important. Improving brain function is still an active area of research, so hopefully we'll see more helpful treatments on the horizon soon.

Peter Abaci, MD, is one of the world's leading experts on pain and integrative medicine and serves as the co-founder and Medical Director for the Bay Area Pain & Wellness Center. He is a dedicated healer, author, and radio celebrity.

Continence for Polio Survivors

by Zsuzsanna Snarey

IT is hard to talk about continence seen as an embarrassing subject. Many people do not seek advice from their GP because they believe it is a normal part of ageing or because they are too embarrassed. Many people are not aware that there are successful treatments available and don't like to bother their GP. But given that the polio virus affected the whole body it is probable that bladders and bowels were also affected. It is a very common problem of polio survivors.

Even in the general population, approximately 10% of all adult women suffer from urinary incontinence. It affects 11% men and 20% women over the age of 60. That means one in every five older women and one in every 10 older men have problems with continence. Older women experience more incontinence than breast cancer, heart disease or diabetes. The number of affected men also increases with age. Men aged over 75 are likely to experience bladder problems because of an enlarged prostate. This can be treated with drugs from the GP.

If you decide to consult your GP he (or she) will probably ask you about your symptoms and medical history, whether urinary incontinence occurs when you cough or laugh. This is called stress incontinence. If you need to go to the toilet frequently during the day or night, you might have an oversensitive bladder. The GP will ask if you have any difficulty passing urine when you go to the toilet and if you are currently taking any medication, also how much fluid, alcohol or coffee and tea you drink.

Caffeine has an irritating effect on the bladder. You might try and see if giving up tea and coffee has any beneficial effect. You may also have some tests and examinations to rule out things that may be causing incontinence.

Cont P4

We also need to think about the 'almost' leaks and the people who get to the toilet 'just in time', because providing advice and treatment at this stage may prevent incontinence from developing later. Lower urinary tract symptoms and incontinence is never normal and should always be investigated and treated. A significant, painless urinary infection can cause a general sense of being unwell, fatigue, weakness and confusion. A painless urinary infection can cause incontinence and frequency of urination during the day and the night. If undetected and untreated, it is responsible for a great deal of problems.

The normal bladder functions as a reservoir to store between 350–500ml of urine. The bladder has two phases – filling and emptying. The kidneys constantly filter urine into the bladder, gradually filling it. During filling, the bladder, which is made of muscle, should remain relaxed and slowly expand to a point where you become aware of a sensation of fullness. It is normal to be able to put off urinating until a convenient time and place is found. When ready to pass urine, the bladder should squeeze to empty itself completely. Then the filling begins all over again.

In females there is only one actual bladder neck sphincter, the external sphincter, comprising striated/skeletal muscle under the voluntary control of the somatic nervous system. This muscle can be exercised and will strengthen with pelvic floor exercises. Compared to males, females are more at risk of problems with their urinary continence, as they have a short urethra and only one bladder neck sphincter. They are also more at risk of infections because the anus is fairly close to the urethra.

Males have two sphincters:

1. Bladder internal/neck sphincter, smooth muscle is continuous with the detrusor muscle and is under involuntary control or autonomic control; the function of this sphincter is to keep the bladder closed at the time of ejaculation.
2. External bladder neck sphincter, striated/skeletal muscle at the base of the prostate and is under voluntary control of the somatic nervous system. This muscle can be exercised and will strengthen with pelvic floor exercises.

The pelvic floor muscles are made up of slow and fast twitch fibres. It requires the combination of both slow and fast twitch fibres for the pelvic floor to work. It is also important to also understand the interrelationship between pelvic floor and abdominal muscles. When abdominal muscles are contracted strongly the entire pelvic floor contracts in response. This is known as co-contraction. It may be advisable to be instructed by a qualified nurse about the correct way of doing pelvic floor strengthening exercises.

Urgency and accompanying urinary leakage may be due to an over reactive or irritable bladder which may want to empty even when not very full. You may feel as though you are busting but when you get to the toilet there may not be much urine to pass. There are many reasons why a bladder may become irritable such as infection, poor bladder habits, poor fluid intake, constipation. Sometimes we just don't know the reason why. Bladder training involves learning techniques to help you to calm the bladder down.

The aim is that your bladder will, eventually, squeeze to empty only when you are quite ready for it to happen and will hold larger volumes of urine. This may take time, patience and determination. You should expect good and bad days for a while. Learning pelvic floor muscle control is essential to success.

Other ways to help yourself are

- Drinking 2 litres of water a day and cutting down on tea and coffee
- Not drinking 2–3 hours before going out where there is no toilet access
- Not drinking 3–4 hours before going to bed
- Not suppressing a desire to void
- Visiting the toilet so that voiding volume generally is 200–300 cc
- Taking time for toilet visits
- Going to the toilet before going out where there is no toilet access
- Going to the toilet just before going to bed.
- Make access to the toilet as easy as possible
- If having trouble getting pants off quickly, consider elasticated waistlines.
- Increase ability to fully empty the bladder by leaning forward slightly when sitting on the toilet – rest elbows on knees to give urine a “straighter” path.

Swollen legs which cause more voiding at night may be relieved by elevating legs as much as possible when sitting, exercising such as walking to stimulate the venous pump in the legs, and using compression stockings. Swollen legs can be caused by diseases other than weak muscles. If you have swollen legs you should discuss it with your doctor. Contact your GP if these symptoms have arisen within 1–2 years or if the above advice is of no help.

Many health conditions are a result of being overweight or obese. Weight gain is a result of eating too much fatty, sweet or high-calorie foods, coupled with too little exercise. Many of today’s common health conditions are called “lifestyle diseases” as they’re caused by our poor choices of (more) food and (less) activity over time. If you’re overweight, you’re in a high-risk group for poor bladder or bowel control.

Further reading ‘Slow Guts & Polio Survivors’ <http://postpolioinfo.com/library/SlowGuts.pdf>



Had enough of inaccessible public transport?

OVER the next few weeks, Disability Resources Centre is hosting a series of free, one-day campaigning workshops focused on improving access to public transport for people with disabilities. Participants will learn how to use their experiences with inaccessible public transport to make changes in the system, working with writing mentors, public speaking trainers, the Public Transport Ombudsman and others passionate about improving how we get around Victoria. DRC will be partnering with regional advocacy groups and local councils to hold workshops in:

SALE TRARALGON GEELONG WARRNAMBOOL BALLARAT SHEPPARTON
WODONGA and MELBOURNE

Melbourne event is on Wednesday, April 8, 10:00 am – 4:30 pm
Ross House Association, 247-251 Flinders Lane, Melbourne.

Polio Services Victoria regional clinics for 2020

PSV Co-ordinator Denise Currie, is in the process of finalising details for regional clinics for this year. In some instances, she says it is challenging to arrange room bookings as regional services are experiencing increasing demands on their service. "I am currently working on the following dates, however there may be changes depending on availability of rooms at regional sites and level of interest expressed by people registering to attend. "We would encourage anyone who considers they may benefit from seeing us to please contact the service. We have access to Telehealth so can arrange a Telehealth appointment with clients (sometimes this may include their GP), if appropriate.

Dates are:

Bendigo	Thursday 20/02/2020 (last week) Friday 20/03/2020	Medical and Allied Health Fatigue Management Seminar
Geelong	Wednesday 29/04/2020 Thursday 30/04/2020 Friday 15/05/2020	Allied Health Medical and Allied Health Fatigue Management Seminar
Horsham	Thursday 25/06/2020 Friday 10/07/2020	Medical and Allied Health Fatigue Management Seminar
Shepparton	Wednesday 19/08/2020 Thursday 20/08/2020 Friday 04/09/2020	Allied Health Medical and Allied Health Fatigue Management Seminar
Rosebud	Wednesday 30/09/2020 Thursday 01/10/2020 Friday 16/10/2020	Allied Health Medical and Allied Health Fatigue Management Seminar
Traralgon	Wednesday 25/11/2020 Thursday 26/11/2020 Friday 11/12/2020	Allied Health Medical and Allied Health Fatigue Management Seminar

3rd European Conference of Post Polio Syndrome – June 10-12, 2020; Vitoria-Gasteiz, Spain

The PSV team has submitted two abstracts. Two staff are planning to attend. The abstract topics:

1. Long term exercise engagement following a physiotherapy prescribed gym program
2. The changing face of polio services:
Understanding current trends

Breaking news: PNV committee member and SE region convenor Lyn Bates, with Bayside convenor Peter Willcocks featured in an ABCTV News report on Saturday, Feb 29, on access to assistive technology for those too old for the NDIS. Story was sparked by a COTA campaign (Council on the Ageing). Link to report: [ABCTV News, Disability advocates escalate fight to end NDIS funding Age Discrimination.](#)

Disability advocates escalate fight to end NDIS funding age discrimination

By James Hancock
Updated Sat at 11:05am



PHOTO: Ms Bates said the NDIS discrimination was a bureaucratic mess that needed to be sorted out. (ABC News: James Hancock)

Polio survivors fight for proper treatment of post-polio syndrome

'We were just cut loose': Polio survivors struggle as PPS often dismissed, misdiagnosed
 Donna Carreiro · CBC News · Manitoba, Canada

Joan Patenaude describes her husband Albert's struggle with post polio syndrome The last remaining survivors of North America's worst polio epidemic say they are living out its grim legacy — post-polio syndrome — with a medical community that doesn't know enough about the syndrome or the epidemic that caused it.

"I tell a doctor I had polio as a child, he'll just look at me with a blank stare, like 'so what?'" Altona resident Al Giesbrecht said. "You might as well call it X-Y-Z disease because it has no meaning." Giesbrecht, who contracted polio in 1952, is one of an estimated 16,000 remaining survivors across Canada living with post-polio syndrome, a neurological disorder that targets up to 60 per cent of polio survivors decades after their original bout with the virus.

Some symptoms are inconvenient, like the midday fatigue dubbed the "polio wall." Others are life threatening, like the inability to swallow which leads to choking, even on one's own saliva.

"I have this constant fear that one day I am going to be alone at my table and I'll choke to death," Giesbrecht said. "I've almost strangled myself on a crust of bread," says Albert Giesbrecht, who now fights the debilitating effects of post-polio syndrome.

But those living with post-polio syndrome describe a medical community unwilling to acknowledge the syndrome or its severity. Albert Patenaude's post-polio syndrome robbed him of his ability to walk or climb stairs. His family doctor didn't buy the post-polio explanation. Instead, he advised getting a new doctor.

"The doctor said to him ... 'If you can't make it up these stairs and into the waiting room, then I can't see you,'" said Joan Patenaude, Albert's widow. "We were just cut loose."

Carol Rankmore knew something was strangely wrong when she began to fall — repeatedly, and for no apparent reason. The falls were so bad she sustained fractured bones, skull injuries and strained tendons. She later learned the falls were a common symptom of post-polio syndrome. Her doctor, however, thought she was just clumsy. "He didn't even suggest I get a walker," Rankmore recalled.

Their concerns are ironic, they say, given Manitoba's notorious history with the virus. While polio ravaged communities throughout Canada in the early 20th century, Manitoba's outbreaks were among the most virulent.

Polio survivor Carol Rankmore, was aged four when her polio diagnosis was confirmed. Her right leg became shrunken as a result of the polio. Today, she lives with post polio



Joan Patenaude - "what other disease comes back 20 years later? It's a cruel disease", she said.



Albert Giesbrecht, constant fear of choking

Cont P8

syndrome. Six epidemics gripped the province between 1928 and 1953. The last one made headlines around the world. Winnipeg, specifically was deemed as having the worst outbreak, per capita, of any North American city. More than 3,100 Manitobans caught the virus, and 190 ended up in iron lungs. Eighty-nine people died.

Despite this fact, experts concur with the survivors — polio is off the medical radar, even in Manitoba, with its infamous connection to the disease. "That is a fair description of it as it exists," said Dr. Ming Chan, the executive director of Canada's only dedicated post-polio clinic, offered through Edmonton's Glenrose Rehabilitation Hospital.

"The last group of people were infected so many years ago, polio is not an ongoing disease. People see symptoms of post-polio today, but don't think to make the link." As a result, Chan said, it's easy for the medical community to misdiagnose the post-polio symptoms. Instead, those living with it rely on each other to learn the research and spread the word.

"The next doctor I saw, I said 'I'm going to make it easy on you,'" Carol Rankmore recalled. "I said, 'I have post-polio syndrome. Here's an information pack* about it.'"

***So what information do we have to 'make it easy for doctors'?**

THANKS to Polio Australia, Post Polio Victoria, Polio Services Victoria and PNV, Australian polio survivors experiencing the late effects of polio or Post Polio Syndrome, have access to a wide range of information – if practitioners take the time to read it.

On **Polio Australia's** website are: Anaesthesia and Surgery; LEOP do you know the signs; Insomnia and Polio Patients; 20 Exercise Tips; Energy Conservation; and Exercise Guidelines for Physiotherapists; Falls Prevention; Fatigue; Footwear; Orthoses; Save our Shoulders; How to manage Pain. These can be found on www.poliohealth.org.au

Post Polio Victoria also has surgery related articles, as well as a valuable collection on respiratory issues; financial assistance and mobility aides www.postpoliovictoria.org.au

Polio Services Victoria appears to be providing direct referral information for practitioners rather than updating the fact sheets on which we used to rely before the days of the world wide web. svhm.org.au/polio

Polio Network Victoria's role is providing information to the state's survivors through support groups and to health professionals. Our website www.polionetworkvic.org has a comprehensive list of information sources from around the world. And, we publish this quarterly newsletter.

WE NEED YOU!



To continue to publish and post *Polio Perspectives*, we are still developing a data base of postal and email addresses. We have received a grant to print the newsletter in order to reach those who do not use computers. If you have not provided permission for us to access your postal address previously held by Independence Australia, please do so. However, a donation of \$10 annually will help cover postage. If you have an email address and are content to receive *Polio Perspectives*, email PNV on polionetworkvic@gmail.com

NB: this list will not be used for anything but communications from PNV.

Useful info

Polio Services Victoria (PSV) 9231 3900

St Vincent's Hospital, ground floor, Bolte Wing, Fitzroy, 3065. Team of allied health professionals offers: access to a rehabilitation consultant (referral required); specialist assessment; referral to & collaboration with mainstream health providers to develop client service plans; information & education service to health providers, clients who had polio, & the wider community.

PSV online:

www.psv.svhm.org.au

Independence Australia 1300 704 456

Not-for-profit organisation supporting people with a disability or other physical needs, providing services and products to regain and extend independence including attendant care, psychology, respite and accommodation services. This includes personal care, domestic assistance and overnight care.

Mobility Aids Australia

offers electric scooters, lift chairs, wheelchairs, walkers, electric beds, bathroom and toilet aids and much more. 1/820 Princes Hwy, Springvale Ph: 9546 7700

Home & Community My Aged Care

Australian Government website and phone line on what aged care services may be available. Telephone 1800 200 422.

NDIS

If aged under 65 with a disability, to participate in the NDIS, first be assessed against access requirements.

Contact 1800 800 110

Equipment funding

State Wide Equipment Funding – SWEP

Ph: 1300 747 937. Aids and equipment to enhance independence at home can be arranged through SWEP's physio or OT.

Leef Independent Living Centre 652

Glenhuntly Rd, Caulfield South, Ph: 1300 005 333. Stocks scooters, walkers, assistive technology, shoes and clothing.

Disabled Motorists Australia, 2A Station St, Coburg, Vic.

Ph: 9386 0413 Assists motorists with disabilities to gain independence through motoring. Referrals & support.

Orthotics Neuromuscular

Orthotics Phone: 1300 411 666. 1846 Dandenong Rd, Clayton. Darren Pereira - Principal Orthotist. Website: www.neuromuscular-orthotics.com.au

Garth Talbot Orthotics,

20 Clarendon Street, Frankston. Ph: 9781 0400 www.gtorthotics.com.au

Travellers Aid

Buggy service at Southern Cross and Seymour stations; equipment hire, luggage storage, and companion services for medical appointments

Phone: (03) 9068 8187 for assistance from Flinders St, and 03 9670 2072 – Spencer St station.

Regional clinics for Polio Services Victoria 2019

- Bairnsdale November 27-29
 - Contact PSV on (03) 9231 3900 or 1800 030 324
-

Make it a date

PNV meetings 2020:

April 17, 11am Training room, Kensington Town Hall.

Contact Bev: 0438 542 728 kyrama@westnet.com.au with any questions and for venues of meetings.

For any queries or ideas for content within PP contact editor Fran Henke polionetworkvic@gmail.com

Post Polio Victoria

Ph: 0431 702 137. www.postpoliovictoria.org.au PPV was established to advocate for people with Polio so access information and services needed to live actively and independently. info@postpoliovictoria.org.au

Polio Support Groups

While some groups are in recess, local contact emails are provided

Bairnsdale in recess

contact: d-mgriffiths@bigpond.com

Ballarat meets first Wednesday

aliceshirreff@gmail.com

Bayside first Tuesday

howshirl6@gmail.com

Bendigo third Saturday bi-

monthly. Bev: 0438 542 728

Echuca in recess

dilauder@gmail.com

Eastern Region in recess

gordonjanice@hotmail.com

Geelong first Monday

sharynmatthews56@gmail.com

Hume second Saturday

joan.tie@bigpond.com

Knox Yarra Ranges meets

socially: joansgra@bigpond.com

Lilydale - socially at Gracious

Grace Café, 2nd Thursday

monthly; Jan Green ph:5797 2429

Mornington Peninsula: second

Saturday, lunches third Tuesday

Contact Fran: 5979 7274

Northern region in recess.

rosslyn.pickhaver@bigpond.com

Shepparton quarterly first

Tuesday.

rhonda.white@gvhealth.org.au

South Eastern Region second

Saturday lyn.bates@bigpond.com

Traralgon in recess

Contact Elaine Smythe

bastian@dcsi.net.au

Warrnambool fourth Tuesday.

anne.clapham@yahoo.com

The PP bookshelf



Life Skills for Polios – a light-hearted handbook

Everything you wanted to know about post-polio but were too afraid to ask? This is the ideal book for those wanting to know how to manage not only post-polio symptoms, but life in general.

Published by MPPPSG to benefit PNV and Polio Day

Cost \$15 plus \$7 postage and packaging.

As an e-book \$US5: www.postpolioinfo.com/lifeskills.php

Iron Wills – Victorian Polio Survivors' Stories

Iron Wills includes a history of polio; how Polio Network Victoria was founded, plus survivors' own stories. Cost \$20 plus \$7 postage and packaging.

The Polio Day Cookbook – fine food for the fatigued - inc. recipes, nutritional advice.

Cost: \$15 plus \$5 postage/packaging

Travel/takeaway mug –\$12.

Polio Network Bags - \$15

Strong with strap for shoulder or scooter/wheelchair back. Also drawstring bags \$15

to purchase Polio books and merchandise email Fran Henke

polionetworkvic@gmail.com or ph:03 5979 7274

Opinions expressed in this newsletter may be those of the writers only. 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.

A post-polio story from New Zealand

Thousands of people who overcame the disease as kids are feeling the late effects of polio, or post-polio syndrome.

It took Anne Fitzpatrick a while to make the connection between her worsening fatigue and the fact she'd had polio as a baby during one of New Zealand's last epidemics of the disease in 1953. Polio had a big effect on Fitzpatrick's childhood, temporarily paralysing her right leg below the knee. She wore a calliper until she was 10, and although she regained her mobility – and was very active as a teenager, taking part in competitive swimming, diving, netball and tennis – she walks with a limp. That eventually caused arthritis in her right ankle, which has been operated on three times. She'd always experienced some tiredness but it wasn't until she joined Polio New Zealand that she realised the deep fatigue she was feeling was a symptom of what's known as the late effects of polio (LEoP) or post-polio syndrome.

"Fatigue is the standout symptom – for me, it went well beyond just having a tired leg." Her other symptoms include respiratory problems and an intolerance for some drugs, particularly anaesthetics. "I get really knocked around with anaesthetics."

Before a vaccine came along in the mid-1950s, polio killed thousands of children worldwide every year and left many thousands more with permanent muscle weakness. Up to 6000 New Zealanders in their sixties and older are now dealing with the long-term effects of the virus. Their symptoms include fatigue, muscle pain and weakness, joint pain and sleeping and breathing difficulties. Some, like Fitzpatrick, have an unusual sensitivity to anaesthetics. "It's really important for anaesthetists to know if someone had polio."

The symptoms of LEoP are caused by damage to the nerves that control muscle movement. Although the body can compensate for this damage for many years, it eventually starts to take its toll. According to neurologist Gareth Parry, LEoP affects not only people who had paralytic polio but also those who had a milder form of the disease. Parry spoke at a recent seminar in Wellington organised by Fitzpatrick to raise awareness about LEoP among doctors and physiotherapists, many of whom either don't know about it or don't make the connection between their patients' symptoms and the fact they had polio as a child. "Doctors don't ask, but patients don't necessarily see it as significant either," Parry says. "They think it was something that affected them as a child and don't realise it could be causing their problems now."

Parry, who trained in New Zealand and recently returned after a long medical career in the US, also had polio as a child, though not the paralytic type. However, like others who had a milder form of the disease, he started experiencing premature fatigue and aches and pains in his fifties.

"If I compare myself to my wife – we're roughly the same age – she rushes around the mountains of New Zealand and goes hiking, but I can't keep up with her." He says the more severe the original disease, the more likely people are to experience problems later, with up to half of those who had paralytic polio likely to be affected as they get older. A few will develop what he calls post-polio muscular atrophy, a more serious condition that causes progressive weakness in the muscles originally affected by the virus. If the original disease affected the muscles that control swallowing or breathing, the consequences of this more serious condition can be catastrophic. If it affected their legs, they might experience increasing disability and eventually need to use orthotics (leg braces) or a wheelchair.

LEoP can't be cured, but it is possible to treat the symptoms and stop them from progressing through a graded exercise program developed by a physiotherapist familiar with the needs of people with neuromuscular diseases. Parry says there's no place for a gung-ho "use it or lose it" approach when it comes to treating people with LEoP.

"You have to do enough exercise to prevent getting deconditioned, but not tire yourself out. If you overdo it, you will pay a price; your aches and pains will get worse, your fatigue will get worse and your life will be a misery."

By Ruth Nichol, first published December 14, 2019 issue of the New Zealand Listener.

The newsletter for Victoria's polio survivors, families & friends

Polio Perspectives
Newsletter of Polio Network Victoria
PO Box 205 Woodend Victoria 3442

PRINT
POST
100028553

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