

InTouch Newsletter

April #2, 2021

Parkinson's Community Heroes off to a good start

Parkinson's NSW this year launched the Parkinson's Community Heroes program to both commemorate Parkinson's Awareness Month and provide opportunities for Support Groups to recognise their local supporters – while also raising their Groups' profiles within their communities.

The Heroes program was not designed to recognise Support Group participants, but local community heroes who had assisted them.

The 18 Support Groups which took advantage of this opportunity to generate publicity in their communities were:

- Chinatown Bilingual
- Coffs Harbour
- Dubbo
- Eurobodalla
- Illawarra North
- Inner West
- Kiama
- Lismore
- Maitland
- Nambucca Valley
- Narrabri
- Nepean/Blue Mountains
- Newcastle
- Orange
- Port Macquarie
- South Coast Young Onset and Nowra
- Snowy Monaro
- Tweed

“Nominations varied widely – including Members of Parliament, Allied Health practitioners, supportive community organisations, and active fundraisers,” said Support Group Coordinator Felicity Jones.

“It was heartening to see Groups taking advantage of this new opportunity to acknowledge their local supporters while driving publicity and hopefully also attracting new participants.

“We are looking forward to seeing more Groups take advantage of the Parkinson’s Community Heroes program in April next year,” she said.

Meet our Staff Member

Denee Baker, NDIS Support Coordinator

Denee Baker was already familiar with the Parkinson’s NSW offices when she joined the team as an NDIS Support Coordinator in late March 2021.

Denee, who is completing the final year of her Bachelor of Social Work, did a university placement with Parkinson’s NSW in 2020.

“I already knew about the organisation because of a family member living with Parkinson’s but it was great to see how things operated during my placement,” said Denee. “Now coming here to work is great because I can see the theory I’ve studied actually in practice.”

Before Denee began her degree course, she had completed a Diploma of Community Services and a Certificate III in Children’s Services. She also worked in early childhood education for nine years.

“I didn’t have a career ambition from childhood,” says Denee. “I just knew that I wanted to do something to help people and my work has developed from that.

“Now I am happy to be able to use my interpersonal skills to support people through their choices in life. This new position will also expand my skills range, too.”

While Denee has been very busy with university and work in the last few months she remains passionate about sports, gym, and the beach.

“I grew up in Wollongong and being able to splash around in the water makes me happy,” she says. “I was heavily involved in sports as a child, but I haven’t had the time for much of it for a while now.”

Denee also enjoys reading and spending time with friends and family and often drives back to Wollongong to catch up.

“Something else which has taken up a lot of time in the last year is planning my wedding,” says Denee. “We were meant to be getting married in Bali this year with friends and family there. Of course, that hasn’t happened but I’m hoping that it will all be fine for the end of next year.”

Parkinson’s Specialist Nurses in action

Parkinson’s Specialist Nurses are highly trained and experienced nurses based in communities of need. They are dedicated to supporting local people living with Parkinson’s.

These Nurses are funded 50/50 by Parkinson's NSW and the Local Health District in which they are based. This series of articles invites clients to talk about the value of Nurses to their local Parkinson's community.

Brian Harrower – Supported by Rachael Mackinnon

Brian Harrower, now 70, was diagnosed with Parkinson's when he was just 58.

"I think I'd had a couple of years with it before that," said Brian, who lives near Port Macquarie. "I retired once I got the diagnosis."

As the years passed, Brian found his treatments were becoming less effective and a few months ago he had a Duodopa pump fitted.

He met up with Parkinson's Specialist Nurse Rachael Mackinnon as a result of having the procedure.

"I had it done over in Port Macquarie," Brian says. "I think Rachael contacted me from that. She is just brilliant, she is so helpful, always there on the phone or not far away if you need her for anything. If I say to her that I'd rather talk to her in person about something, she will come and see me.

"She also goes to the Support Group meetings we have. She will pick you up and take you to the meeting. She has no problem with any sort of meeting."

Rachael is also on hand if Brian needs to have a telehealth appointment with his doctor or specialist.

"Rachael and my doctor are a great pair," he says. "It's very handy. My specialist has given me his home number. There's not many specialists that will do that."

Brian says that having the Duodopa pump meant he could get back to playing golf again.

"I still struggle a bit with things, but I try to play every Thursday," he says. "I used to play at a pretty high standard, and I loved it and missed it when my Parkinson's meant I just could not do it anymore.

"Things had got pretty bad. But I just said to myself when I got this pump I'm going to try again. I'm not going to let it get me down. The more you can do, the better it is for you."

Eye Exam Could Lead to Early Parkinson's Disease Diagnosis

A simple eye exam combined with powerful artificial intelligence (AI) machine learning technology could provide early detection of Parkinson's disease, according to research conducted at the University of Florida in the U.S.

The progression of Parkinson's is characterised by nerve cell decay that thins the walls of the retina – the layer of tissue that lines the back of the eyeball. The disease also affects the microscopic blood vessels of the retina.

These characteristics present an opportunity to leverage the power of Artificial Intelligence (AI) to examine images of the eyes for signs of Parkinson's disease.

The multidisciplinary team of researchers deployed a type of AI called Support Vector Machine (SVM) learning that has been around since 1989. Using pictures of the back of the eye from both patients with Parkinson's disease and control participants, they trained the SVM to detect signs on the images suggestive of disease.

The results indicated that the machine learning networks can classify Parkinson's disease based on retina vasculature, with the key features being smaller blood vessels. The proposed methods further support the idea that changes in brain physiology can be observed in the eye.

Traditional imaging approaches with MRI, CT and nuclear medicine techniques can be very costly. In contrast, this new approach uses basic photography with equipment commonly available in eye clinics to get an image. The images can even be captured by a smartphone with a special lens.

The approach may also have applications in identifying other diseases that affect the structure of the brain, such as Alzheimer's disease and multiple sclerosis.

Sources:

University of Florida in Gainesville, Florida
Radiological Society of North America

[Parkinson's Life](#)

Sleep and Parkinson's Disease

By Dr. Mark Ryan

Consultant Psychiatrist and Clinical Director, neuroCare Clinics Australia

Sleep problems long predate the emergence of symptoms of Parkinson's. They are apparent after the diagnosis has been made in a large majority of people with clinically apparent Parkinson's.

There is a possibility that sleep disorders play a role in the process of neurodegeneration leading to Parkinson's and may have a role in the course of the illness once it becomes clinically apparent.

It also has a role in many of the symptoms considered comorbid with Parkinson's – such as memory, cognitive and mood problems – appears to aggravate the motor

symptoms of Parkinson's and has a role in many other of the common diseases of our population such as obesity, Type 2 diabetes, heart disease, etc.

Inadequate sleep undermines wellbeing and quality of life independent of the above issues.

Circadian rhythm and sleep

All our body processes have approximately a 24-hour cycle. Sleep and wake are manifestations of this rhythm.

All cells and body systems have clock genes which are entrained largely by light-dark signalling via the retina. Sleep and wake are very different states – physiologically, biochemically, immunologically, and behaviourally.

Sleep represents a vital and essential state for health span and life span. Melatonin release is triggered by 'dark' signalling and entrains the body-wide physiology into 'sleep mode'.

Both dopamine and melatonin are under circadian control with retinal photoreceptor cells playing a key role in this diurnal regulation. Dopamine inhibits melatonin release and vice versa and this synchronisation also points towards dopamine having a role in sleep-wake regulation.

Circadian dysregulation of dopamine is related to impulsivity – including substance abuse and sexual impulsivities and compulsions.

The hypocretin/orexin system has a role in modulating and orchestrating the many signals for arousal and sleep. This system projects throughout the brain enabling situation/task appropriate vigilance arousal, apparent in rapid eye movement (REM) and non-REM sleep and sleep-to-wake transitions as well as appropriate arousal in the awake state.

This system is also degenerated in Parkinson's.

Rapid eye movement (REM) sleep is under circadian control. REM Behaviour Disorder is a well-known marker of a sleep disturbance related to the subsequent development of Parkinson's.

More commonly – but less often detected and treated – are a range of sleep and circadian rhythm disturbances and clock gene dysfunctions that may well play a role in the development of Parkinson's and contribute to and aggravate its range of symptoms.

Clonazepam is commonly used to treat REM Behaviour Disorder but it has negative impacts on the power and quality of the overall circadian sleep processes and cycle.

Sleep plays a major role in memory consolidation. In slow wave sleep, glymphatic drainage clears misfolded proteins, beta amyloid, tau protein and alpha-synuclein from the brain.

Accumulation of these proteins is found in dementia, Parkinson's, and other neurodegenerative diseases – and is associated with neuronal loss. Long term sleep problems – especially with impaired, inadequate slow wave sleep – are now thought to play a role in the development of these neurodegenerative diseases.

Sleep disturbances are related to an increased risk of cardiovascular disease – hypertension, cerebro- and cardio-vascular diseases, which also have an elevated prevalence in those with Parkinson's.

Autonomic dysfunction is a common feature of significant long term sleep disturbances including obstructive sleep apnoea as well as circadian rhythm sleep disorders.

Similarly, cognitive, memory and mood problems are also common both pre- and post- diagnosis with Parkinson's. Sleep problems are increasingly seen as causally relevant to mood disorders, cognitive decline, and dementia.

Likewise, psychomotor impairments such as prolonged reaction times, impaired fine motor movements and impulsivity and other impairments occur with sleep disturbance and in all likelihood will aggravate/load onto the Parkinson's symptoms.

It is likely that problems with impulsivity, compulsiveness and related issues that can occur in Parkinson's and that are usually attributed to the disease may at least in part be due to dysregulations arising from executive impairments related to cognitive decline and self-regulation due to sleep disorders.

Excessive daytime sleepiness is a common complaint both before and after starting Parkinson's medications, indicating that dopamine therapy impacts on sleep and circadian rhythm (with some studies reporting a dose relationship between dopaminergic medications and sleepiness). It also reflects the pre-existing sleep and circadian problems.

Clock genes have a role in modulating response to dopamine and the rhythmic diurnal dopamine-melatonin synchronisation is important in the proper regulation of the circadian sleep-wake cycle.

The range of other drugs commonly part of the polypharmacy in Parkinson's is also likely to contribute to this somnolence. Also relevant is the loss of relevant neurons involved in the wake promoting system – the orexin and noradrenaline neurones of the hypothalamus and locus coeruleus, respectively.

Insomnia also is related to L-Dopa dose but also long predates the emergence of Parkinson's symptoms. The implied role of circadian and sleep disturbances

suggests that there might be a best time in the 24-hour circadian cycle to take Parkinson's medications for 'best' effect.

Any sleep disorder can also occur in Parkinson's including obstructive sleep apnoea.

Recommendations

Using a personalised or precision medicine methodology and looking beyond the label and symptoms to identifying underlying causal processes can reveal several relevant causal processes.

If all are addressed, across the board improvement can occur in symptoms, wellbeing, and functioning.

This means that not all symptoms and severity of symptoms should be exclusively attributed to the Parkinson's diagnosis. This approach is called personalised or precision medicine and represents the immediate future in best practice.

Check your sleep!

Are you watching our *Wellness Wednesday's* videos?

Wellness Wednesday's videos are hosted by Parkinson's NSW Exercise Physiologist Alyson Blanks.

Topics include short and easy exercises you can do anywhere, nutritional advice, tips on mindfulness and other health matters.

You can join in on Facebook every Wednesday at 1pm by clicking this link:

<https://www.facebook.com/parkinsonsnsw>

Or you can view the growing collection of short videos at your leisure on YouTube here:

https://youtube.com/playlist?list=PLNNFUfiPBotL3pJw0XD3zgL3EtKc_juZIG

Topics covered so far include:

- Balance exercises
- Daily stretching exercises
- Neuroplasticity
- Getting started and maintaining an exercise routine
- Movement for Motor Symptoms and posture checking
- Stretches to target stiffness
- The importance of Speech Therapy

For all online meeting (Zoom) details please go to:
<https://www.parkinsonsnsw.org.au/online-meetings-for-support-groups>