

# In Touch Newsletter

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# Exercise and mental health

We know that regular exercise has measurable benefits for our body's health, but an often-overlooked benefit is the impact exercise has on our mental health.

Recently the prevalence of anxiety, depression and other mental health conditions has exploded.

People living with Parkinson's often experience mental health concerns as part of their symptoms. Mental health and Parkinson's are a complex issue. Parkinson's doesn't directly cause mental health issues, but it increases the likelihood of depression, anxiety, and psychosis.

There are both mental and emotional tolls of being diagnosed and living with the complexity of Parkinson's – added to the physical drop in dopamine production in Parkinson's. Dopamine not only effects the transmission signals to the muscles but it's also one of the happy hormones that help hold depression etc at bay.

Anxiety and depression are common mental health symptoms of Parkinson's. Signs to look out for include:

- 1. Changes in appetite either eating too much or too little
- 2. Excessive tiredness
- 3. Stress or irritability
- 4. Lack of interest in hobbies and activities
- 5. Feeling hopeless or 'down' most days
- 6. Feeling fearful or constantly worried

If you're struggling with the mental or emotional effects of Parkinson's disease, you should talk to your doctor. He or she may suggest changing or adjusting your medication.

However, one of the most researched benefits of exercise is the positive effect it has on mental health and mood. Exercise may seem a simple solution but there is a complex chemical process occurring inside the body each time you exercise.

This chemical process has several positive effects on your brain.

As you begin to exercise, important chemical messengers called neurotransmitters are released through your nervous system. Endorphins and lesser-known endocannabinoids play an important role in your brain during exercise.

Exercise increases these neurotransmitters which can help block pain and increase the sensation of pleasure.



Dopamine reduction is one of the main causes of Parkinson's and exercise is one of the most stimulating activities for increasing dopamine production.

Dopamine plays an important role in how you feel pleasure. It's also responsible for other processes, such as regulating heart rate, sleep cycles, mood, attention, motivation, working memory, learning, and pain processing.

This sounds an awful lot like some common Parkinson's symptoms, doesn't it?

Exercise also increases production of serotonin which helps improve your mood and can help reduce any feelings of loneliness and isolation, while improving the drive to become more social, and help put you in touch with other people.

Neuroplasticity is also promoted by exercise. Neuroplasticity is the ability of your brain and nervous system to change their actions in response to internal or external stimuli. This also helps in learning new skills, activities, and languages, which assist in improving your mood.

Another mood-improving factor of exercise is as your heart beats faster whilst exercising, which increases the oxygen supply to your brain. This results in changes to the blood vessels in your brain promoting potential improvements in executive function, including working memory, flexible thinking, and self-control – making you feel more in control.

Exercise also stimulates the connections between the nerve cells in the brain. This improves your memory and also helps protect your brain against injury and disease.

How much exercise do you need? Australian guidelines recommend adults do at least 30 minutes of moderate to intensive physical activity on most or all days of the week. You can make up 30 minutes over the day by combining shorter 10-to-15-minute sessions.

Practising mindfulness while doing exercise also reduces your stress and improves your mental health.

While exercise benefits mental health it is important that if you're struggling with the mental or emotional effects of Parkinson's disease, you should contact your health professional.

#### **References:**

- https://www.healthdirect.gov.au/exercise-and-mental-health#:
- <u>https://www.healthline.com/health/depression/exercise#How-does-exercise-impact-the-brain</u>?
- <u>Australian Government Department of Health</u> (Australia's Physical Activity & Sedentary Behaviour Guidelines)
- <u>British Journal of Pharmacology</u> (Exercise acts as a drug)
- <u>Black Dog Institute</u> (Exercise & depression)
- Jean Hailes for Women's Health (Physical activity & exercise)
- Physical Activity Australia (Exercise and mental health)



# How not to lose sleep over Parkinson's disease

Did you know that 90 percent of people with Parkinson's suffer sleep disturbance? Here is advice from an advanced nurse practitioner, a physiotherapist and a person living with Parkinson's about why good sleep hygiene matters.

"Have you ever been fishing and caught a fish – and it's landed, flipping around, on the bank?" asks Matt Eagles.

He is describing his typical night in bed with Parkinson's.

"I can be very, very still, then start flapping. My wife leans over and puts her hand on my leg or my tummy and, usually, it stops. During that time I'm semi-conscious, but it's not a good quality of sleep."

Throughout his 46 years of having Parkinson's, Matt has tried many ways of getting to sleep. Like 90 percent of people living with the condition, he suffers from sleep disturbance brought on mainly by troubles with movement when lying in bed – although he admits things are not as bad as they once were. His limbs can go from being highly active, to completely rigid.

"Trying to move your legs in the middle of the night can be like you've got somebody else's legs, or you're stuck in treacle, frozen in your bed," he says.

Years of trial and error have taught him what makes a difference. He is now a firm advocate of good sleep hygiene which, these days, involves going to bed between 22:30 to 23:00 every night, and waking up at 7:30. He aims to get at least seven hours of sleep a night.

#### What is sleep hygiene?

To ensure we get a good night's sleep, the human body has an internal alarm clock that regulates our sleep-wake cycle. Keeping to a regular night-time routine, creating an ideal sleeping environment, and getting into healthy habits during the day can all help you develop good sleep hygiene.

Brian Magennis, an advanced nurse practitioner in Parkinson's disease and movement disorders, thinks sleep hygiene is vital to improving your sleep.

"It's one of the most important things I consider when assessing the sleep problems of a person who has Parkinson's. There are other things like insomnia, urinary issues, movement problems and mind disturbances – but sleep hygiene is an obvious first step," he says.



"If you get this right, you'll be on your way to improving the quality and quantity of your sleep. If you still have problems, you need to talk to your doctor or neurologist, who can help adjust your medication as getting the timing and dosage of this right is essential too."

# How to get a good night's sleep

General habits like having regular mealtimes and going to bed at the same time every night, keeping alcohol and caffeine to a minimum and ensuring your bedroom is cooler during the night have all been shown to improve the quality and quantity of your sleep.

Sleeping in total darkness and making sure you have the right bedding can also be important as Matt testifies. "We have black-out curtains in the bedroom which really help," he says. "And a good mattress is essential. I have a memory foam mattress which is very comfy. The only issue for me is that it mimics my body shape and sometimes it means when I want to turn over, I have to climb out of the dip I've just created for myself!"

One thing that's not a healthy habit is exposure to blue spectrum light before bedtime. Computer monitors, smartphones, tablet screens and televisions all produce light in the blue spectrum, which tricks the brain into believing it's daytime, thereby reducing the production of melatonin — a hormone that helps you sleep.

Getting your nutrition right is also key to a good night's sleep. It's important not to eat too late and to ensure you don't have too many high-protein foods, or carbohydrates, which can sometimes interfere with the absorption of Parkinson's medications or be associated with poor sleep quality.

A good dose of exercise can also aid sleep quality. Physiotherapist Josefa Domingos helps people with Parkinson's to improve their functional wellbeing.

She says: "During the day, it's important to get proper aerobic exercise when you have Parkinson's – not only because it potentially helps delay progression of the disease, but also because it's been shown to improve sleep and relieve a variety of motor and non-motor symptoms."

Stretching and slow mobility exercises before bed can also help in reducing rigidity and some discomfort during the night too, according to people with Parkinson's.

For Matt, improving his sleep hygiene has helped to boost his energy and cope better with the condition. "Parkinson's is exhausting," he says. "If you wake up and you're tired, apathy can kick in and you really don't feel like doing anything. I think sleep is so important to Parkinson's."



#### 7 ways to improve your sleep

1. *Keep to a regular routine*, including a regular pattern of meals, exercise and going to bed and getting up – it will help your body clock get into the habit of sleeping.

2. *Get your nutrition right* – regular mealtimes and a well-balanced Mediterraneantype diet has been shown to have therapeutic effects on sleep.

3. *Stay hydrated during the day*, depending on your body type and needs, and avoid caffeine and alcohol which are stimulants.

4. *Exercise on a regular basis* – how much you should do depends on your personal fitness and circumstance.

5. *Sleep in a cool, dark room* – but take care to have some kind of lighting should you need to get up in the night.

6. *Upgrade your sleeping accessories* – pillows, mattresses and sheets can all make the difference between a comfortable and uncomfortable night.

7. *Avoid electronics* at least one hour before bed. Computer monitors, smartphones, tablet screens and televisions all produce blue spectrum light, which mimics daylight.

#### Source:

European Parkinson's Disease Association

# Improving medication safety for Parkinson's patients

Michael Ortiz has Parkinson's. Like many with this disease, he's been hospitalised on many occasions for conditions other than Parkinson's.

On too many of those occasions, according to Michael, the medication <u>levodopa</u> – vital to help him with his Parkinson's symptoms – wasn't administered on time and his stay in hospital and levels of comfort were impacted.

As a trained pharmacist Michael was keen to improve outcomes for himself and others. He reached out to the Clinical Excellence Commission's Medication Safety team. He also sought out the best clinical practice in caring for patients with Parkinson's.

The clinician doing a wonderful job according to Michael Ortiz, is Vince Carroll, Parkinson's Clinical Nurse Consultant at Coffs Harbour Hospital. Vince's position is co-funded by Parkinson's NSW and the Mid North Coast Local Health District.

Vince and two other clinicians – Jess Andrews, a pharmacist and Kirsten Deutschmann, an occupational therapist – led a multidisciplinary team in an award-



winning clinical practice improvement project to improve safety for this vulnerable patient group by addressing medication management.

# In their project, conducted at Coffs Harbour Hospital, the team found in patients with Parkinson's who were admitted to hospital each year only 44 percent were receiving medications on time.

Delaying medications for greater than 15 minutes can worsen tremors, rigidity, confusion, agitation, and anxiety.

The Coffs Harbour team's interventions focused on bridging departmental and professional barriers with exact medication routines, identifying and avoiding certain medications harmful to patients with Parkinson's and identifying alternatives for when a person cannot take medication orally.

# Results showed improvements in patients having medications on time, a reduction in average length of hospital stay for Parkinson's as a secondary diagnosis from 9 to 6.2 days, more rapid access to correct medications, and both improved teamwork and consumer satisfaction.

In addition to the contribution to the project of the CEC's safety notice, it also was influential in development of the Parkinson's education module on *My Health Learning* – the NSW Government Health Education and Training (HETI) online training platform.

It was also foundational to a research collaboration between Parkinson's NSW, the Mid North Coast Local Health District and Charles Sturt University on the benefits of a Parkinson's specialist nurse.

Changes to clinical practice made by the team included simply moving medications to make them easier to access.

The very simple thing was the Emergency Department (ED) staff saying 'well let's put the first line medications in the ED and trial and see how it works'. That was a simple fix but it took cultural change to make it happen.

Michael Ortiz and Vince Carroll have both published articles on improvements to Parkinson's medication management in hospitals.

#### Sources

Michael's paper is <u>'On time – every time'</u> and Vince Carroll has documented results of the project in Coffs Harbour in <u>'Purposeful collaboration: Enriching lives for people with</u> <u>Parkinson's disease'</u>.

Article courtesy of the NSW Government Clinical Excellence Commission (CEC) and the Mid North Coast Local Health District.



# Mindfulness meditation may lessen depression

Mindfulness meditation – mental training of being focused on the present moment without interpretation or judgment – was better than physical exercise at lessening depression symptoms and maintaining emotional stability in people with mild-to-moderate <u>Parkinson's disease</u>.

That's according to data from a small clinical trial conducted in Hong Kong that also showed both practices resulted in an immediate, positive effect on cognitive function.

Overall, "...mindfulness meditation appeared to be a feasible strategy for managing depressive symptoms and maintaining emotional stability, with comparable benefits in cognitive performance, among patients with mild-to-moderate Parkinson's disease," the researchers wrote.

The study, '<u>A randomized clinical trial of mindfulness meditation versus exercise in</u> <u>Parkinson's disease during social unrest</u>', was published in the journal *npj Parkinson's Disease.* 

Parkinson's disease is known for its hallmark motor symptoms, such as tremors and slow movement. However, patients often experience non-motor symptoms like depression, emotional instability, sleeping problems, fatigue, and cognitive decline.

Besides pharmacological approaches, "...non-pharmacological, lifestyle approaches including physical activity, stress management, and social support are recommended by clinical guidelines to provide additional symptomatic relief in the illness trajectory," the researchers wrote.

Evidence suggests that physical activities, such as yoga, can lessen both motor and non-motor symptoms. However, the impact of mindfulness mediation in Parkinson's patients remains largely unclear.

Now, a team of researchers in Hong Kong conducted a clinical trial (<u>HKUCTR-2681</u>) from August 2019 to February 2020 to assess the potential of mindfulness meditation to lessen anxiety and depression in people with mild-to-moderate Parkinson's compared with stretching and resistance training exercise (SRTE).

# Study design

In total, 68 patients (mean age 64.5 years, 57.4% women) were assigned randomly to undergo either the mindfulness program (33 patients) or the SRTE program (35 patients) for eight weeks.

The mindfulness meditation training program consisted of a 1.5-hour session per week, and 20 minutes of home-based practice, twice a week. The weekly session included: body scan, guided meditation with focus on the breath, guided meditation focusing one's awareness to bodily sensations and non-judgmental awareness, and practicing awareness during daily life activities by using the breath as an anchor for the attention.



The SRTE program involved 90-minute weekly sessions of full-body physical exercise, in addition to 20 minutes of home-based practice, twice a week. The exercise protocol included warm-up, stretching, resistance training exercises with moderate intensity, and cool-down exercises.

At the trial's start, most patients (60.3%) had moderate Parkinson's. Also, 21 patients (30.9%) presented clinically significant anxiety symptoms and 20 (23.5%) had significant depression symptoms, as assessed with the Hospital Anxiety and Depression Scale.

Two patients in the mindfulness group did not attend any sessions, while those in the SRTE group attended at least two sessions. Most patients in both groups attended at least six sessions: 72.8% in the mindfulness group and 88.6% in the SRTE group.

#### **Mixed results**

Results showed that depressive symptoms were lessened significantly immediately after the mindfulness program, while they remained stable in the SRTE group. This meant that mindfulness meditation was associated with a significant reduction in depression, when compared with SRTE. This reduction reached marginal clinical significance.

However, no significant differences were seen between both groups at three months after the intervention.

Also, no significant differences in anxiety were seen within groups or between groups at any time point.

The mindfulness meditation program also was associated with significant improvements in overall mindfulness and overall cognitive performance immediately after the program, and in non-judging aspect of mindfulness at three months after the program.

The SRTE group showed a significant reduction in motor symptoms, as assessed with the Movement Disorder Society's Unified Parkinson's Disease Rating Scale – Part 3, immediately after completing the program. Also, delayed recall and overall cognitive function were improved significantly.

However, a significant worsening in non-reacting aspect of mindfulness – which allow experiences to come and go without reacting in an effort to change them – was observed at three months after the intervention.

Overall, compared with patients in the SRTE group, those undergoing the mindfulness program showed a slight improvement in quality of life immediately after the intervention, and significant improvements in the non-reacting aspect of mindfulness at the final evaluation.



Adverse events were reported in one patient in each group: temporary back pain in the mindfulness group and temporary mild knee pain during and after squatting exercises in the SRTE group.

All participants were satisfied with the study. More than half of patients in the mindfulness group (67.7%) and SRTE group (51.6%) reported less constipation and improvements in their sleep, which were not objectively quantified in the study.

"These findings suggest that mindfulness meditation might be a promising complementary lifestyle practice for cultivating non-reactivity and managing depressive mood among patients with PD, which exerts similar benefits on cognition as compared to conventional physical exercise," the researchers wrote.

"The observed improvements were confirmative because interventions and assessments were conducted during the strikes of social unrest and/or the COVID-19 pandemic," they added.

"Further investigation is warranted to establish the mechanistic effect and compliance of various forms of mindfulness practices," the team concluded.

# Sources

Summary article by Patricia Inácio, PhD

Parkinson's News Today

Study published in npj Parkinson's Disease.

# My [Parkinson's] Life

Having Parkinson's is just one aspect of a person's life story. We want to share more stories of the varied lives of people currently living with Parkinson's.

# **Keeping it Simple**

# By Marty Cobcroft, 61

It just didn't look right. As I watched the replay of a short promotional music video I was shooting, my left leg was shaking and it wasn't in time with what I was playing.

It was a little confronting. Just like the chronic, acute lumbar pain that no one could really see a justifiable cause for. And the unexpected and numerous bouts of fatigue? The fact that I hadn't been able to smell anything for years?

These instances were happening throughout 2016. I was very busy, teaching, writing and recording – music had been my profession for almost all of my



working life. But behind it all, from 55 years of age, these nagging, painful and uncomfortable symptoms became more insistent.

A chiropractor I was seeing for my back pain noticed a resting tremor in my left leg. She advised me to see a neurologist.

However, as the saying goes, life gets in the way and I plodded on. And then things changed. Everything had slowly become worse and the painful cramping in my lower back and my left foot were more insistent.

Some mornings, I felt I just couldn't get up. The tremor, mainly in my left leg, was a daily occurrence around the clock and I found that my sleep pattern had changed to only three to four hours a night maximum, almost every night.

Some nights I wouldn't't sleep at all and I'd sit in the dark, wondering what the hell was wrong. I was in a constant state of chronic pain, discomfort, and fatigue.

In January 2018, a colleague insisted I go see my doctor. I was beginning to worry now. And I was worrying my wife and other people, which I couldn't tolerate.

I obtained a referral from my GP to a neurologist . He was a very kind, patient and approachable specialist; we discussed my symptoms. He was very cautious, very thorough. In August 2018, the diagnosis was Parkinson's Disease. I was 57.

I was understandably shocked. Now, the three main symptoms for me – pain, dystonia and that nagging tremor – had reached a point where I could no longer work as I had.

I was having regular sleep attacks throughout the day. I tried to see the humour in some of these. One afternoon my wife and I were at a pre-school end-of-year concert for the children of close friends.

There were at least 50 or more adults and children, talking, laughing and making more noise than some rehearsals I'd had. I was sitting quietly right up the front, in the thick of it all, asleep. Oblivious.

Still makes me laugh. But there were more serious overtones to these episodes. They began to happen when I was driving. Or when I was in a restaurant. Sometimes when visiting friends.



Static positions became mine fields of discomfort. I could no longer feel confident in being able to play gigs. I could still do session work but that's erratic and not a constant.

Mornings were especially bad. Turning over in bed had become a process instead of an easy transition. I had ceased to move as much during sleep and would wake every morning feeling like I was walking through thick mud. My posture and gait started to reflect the symptoms and my arms no longer swung as they should when I walked. I had begun to stoop.

I began to research Parkinson's. The only way I was going to be able to deal with this was to stay informed and active. To keep moving. I knew very little about Parkinson's before I was diagnosed so I set about changing that. My new job was to learn, move and concentrate on the blessings in my life. And I have more than my fair share of those.

I contacted Parkinson's NSW and was supported wonderfully. Then, I engaged a terrific occupational therapist, physiotherapist, and several exercise physiologists.

They continue to look after me, three mornings a week with excellent programs that keep me active. I reduced my caffeine intake – no coffee after midday as it was exacerbating my tremor and just adding to my sleep issues.

I found a local boxing gym that trains for Parkinson's with the Knock Out Parkinson's Program and started training three times a week. It became evident that the quality of my life was acutely proportionate to the effort I put into exercise, diet and maintaining my mental health each day. It's not good enough for me to simply take the drugs I'm prescribed and spend my days watching Netflix.

But as a musician, I was worried about how I might be affected. Primarily, I'm a session singer and I'd learned that one of the more common symptoms is softness of speech. Fortunately, to date, this hasn't affected me.

To be unable to do it is not something I like to think about. But we are only given a day at a time to live and at present, thankfully, I'm still able to write, record and produce music. Since 2018 when I was diagnosed, I've had a number of releases and I'm continuing to work on albums.

While I don't play live music anymore, I'm still able to do session work. Life still has its rewards. The real wealth in my life is the quality of the people in it – personally and professionally. I'm privileged to have them, especially my wife,



Amanda, who is easily the best person I know. It's no picnic for the partners and carers of those with Parkinson's and they deserve the very best in life.

Parkinson's is a complex thing, so I keep it simple. Things could be so much worse.

Learn more about Marty Cobcroft's music and photography at:

www.martycobcroft.com

Marty Cobcroft on Instagram

Marty Cobcroft YouTube Channel

# Sexual intimacy and Parkinson's

Concerns around sexual intimacy not only affect the Parkinson's community but are common in the general population as well.

There can be many 'risk factors' that impact sexual function including age, smoking and chronic illnesses.

Maintaining sexual intimacy is a topic many people with Parkinson's are interested in but may be embarrassed to discuss. It's an important topic, as maintaining physical intimacy with your partner is something that can become challenging as the disease progresses.

A lack of intimacy can be related to sexual desire or sexual function, and everyone experiences these things differently. Here are some tips for maintaining a healthy sex life with Parkinson's.

#### Be open with your partner

It's natural to feel vulnerable and anxious if your sex life has changed. We're often afraid to discuss issues surrounding sexuality because we fear judgement or shame. Likely, opening a dialogue with your partner will lead to greater understanding and mutual satisfaction.

The first thing you should do if you're concerned about your sex drive is to be open with your partner. Discuss how you think it's affecting you and how it makes you feel. Don't be shy, communication is key for helping your partner to understand your concerns.

If you're struggling with specific activities, discuss and suggest alternatives to match your comfort level. If you're having issues with libido, a dialogue will help avoid misunderstandings and stress, and find something that is satisfying for both partners.

# Talk to your healthcare providers



Challenges in the bedroom aren't uncommon with Parkinson's and your doctor might be able to help! Medications related to managing Parkinson's can both increase or decrease libido, so you may want to talk to your doctor to learn more about the effects of your specific medications. Likewise, they may have suggestions or resources depending on the specific issues you're facing. Before meeting, be sure to document your specific questions or concerns to help get your doctor on the right track.

Therapy is another option that might be useful for you. Sex therapists may be able to evaluate your concerns and suggest techniques and methods to help get you in the right place both physically and mentally.

#### Be patient

Sexuality is a complex part of the human experience with many variables, both physical and mental. Stress, diet, sleep, and overall mental health are all factors that may be affecting your sex life, and it's important to focus on wellness and balance.

As a person living with Parkinson's, you may notice changes, but that doesn't mean you can't adapt. If you're a partner of someone with Parkinson's, patience and good communication can help you to maintain a satisfying sex life together.

#### Source

Parkinson's Canada