

## InTouch Newsletter

September 2021

### 7 WAYS TO IMPROVE YOUR SLEEP

Up to 90 percent of people living with Parkinson's find it difficult to sleep.

Identifying the root causes of sleep issues is the first step. Disrupted sleep can be due to a number of things such as poor sleep hygiene, the symptoms of Parkinson's, or medicines for controlling it.

Here are some quick tips on improving your sleep hygiene.

1. Keep to a regular routine – including a regular pattern of meals, exercise, and times of going to bed and getting up. It will help your body clock to get into the habit of sleeping.
2. Get your nutrition right. Regular mealtimes and a well-balanced Mediterranean-type diet have been shown to have therapeutic effects on sleep.
3. Stay hydrated during the day, depending on your body type and needs. Avoid caffeine and alcohol which are stimulants.
4. Exercise on a regular basis – depending on your personal fitness and circumstances.
5. Sleep in a cool, dark room – but have some kind of lighting should you need to get up during the night.
6. Upgrade your sleeping accessories. Good pillows, mattresses and sheets can make the difference between a comfortable and uncomfortable night.
7. Avoid electronics for at least one hour before bed. Computer monitors, smart phones, tablet screens and televisions all produce light on the blue spectrum which mimics daylight.

**Source:** [Parkinson's Life](#)

## CARER DE-STRESSING EXERCISES

Whether caring begins gradually or happens suddenly, most carers will need to develop new knowledge and skills. One of the most experienced effects of caring is stress.

Learning to manage your stress is an important and possibly new skill you will need to learn. If you don't care for yourself, you won't be able to care for someone else.

These five simple tips can help you manage your stress.

1. **Stay positive.** Laughter lowers stress hormones levels, reduces inflammation in the arteries, and increases 'good' HDL cholesterol levels.
2. **Meditate.** Practice focused thought and deep breathing. They have been shown to reduce heart disease risk factors such as high blood pressure. Meditation's close relatives – yoga and mindfulness – can also relax the mind and body.
3. **Exercise.** When we exercise our body releases endorphins. Exercising not only helps you to de-stress, it also protects against heart disease.
4. **Disconnect.** It is difficult to de-stress when it follows you everywhere. Unplug yourself. Avoid emails and TV news. Take some quiet time for yourself each day.
5. **Things you enjoy.** Simple things like a warm bath, listening to music, or spending time on a favourite hobby, and being creative can all help to lower the stress in your life.

Make time to exercise. Many of us find it difficult to carve out time to exercise – but 30 minutes of moderate activity daily will assist you to manage the emotional and physical challenges of being a carer.

Regular exercise improves resilience, promotes better sleep, reduces stress and depression, increases strength and flexibility, and increases your energy and alertness. It also helps maintain a healthy weight and build immunity, and protects against common health problems.

Here are some easy de-stressing exercises you can do at home.

### Belly Breathing or Abdominal Breathing

When we are stressed, we generally breath shallowly in the chest. Taking deeper breaths and filling the lungs completely triggers many physiological changes. Your heart rate slows, blood pressure decreases, and muscle tension eases.

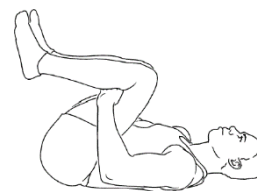


Lie down and put one hand below your belly button. Breathe in through your nose to completely fill your lungs (your stomach should rise). Slowly release, breathing out through your mouth. Continue for a few minutes.

### **Knee Hug**

This exercise will help relieve a tired back and release stress.

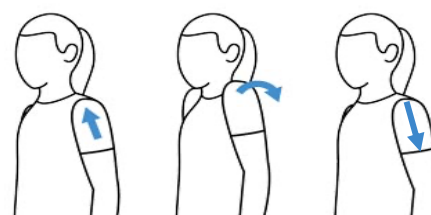
Lie down and hug 1 or both knees to your chest. If you can hug both knees at the same time, rock from side to side to massage your spine.



### **Shoulder Shrug**

Holding tension in your neck and shoulders is common. Shoulder shrugs can help release the tension.

Sitting comfortably with good posture. Breathe in and bring your shoulders up towards your ears. Tighten your arm and shoulder muscles. Breathe out and relax your neck and shoulders pulling your shoulder blades down. Repeat a few times.



### **Corpse Pose**

In this exercise you're trying not to do anything. Sounds a bit contradictory but it's more difficult than you think. It's about noticing and acknowledging your thoughts and feelings but not dwelling on them.



Lie down with your arms, palms up, relaxed at your sides. Close your eyes and focus on the rise and fall of your breath. If you have invasive thoughts, acknowledge them, and visualise them floating away. Return to focusing on your breathing and relaxing any tight muscles.

If one method doesn't work for you, try another. Learning to de-stress takes practice. Be patient with yourself and you will reap the benefits.

Getting help from a professional is always a good idea, especially if you feel that nothing seems to help. Talking to your primary care doctor is a great place to start.

Contact Carers NSW on 02 9280 4744 or Carer Gateway on 1800 422 737 or visit [www.carergateway.gov.au](http://www.carergateway.gov.au)

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## **FAECAL TRANSPLANT TRIAL MAY REDUCE DISCOMFORT FELT BY PEOPLE LIVING WITH PARKINSON'S**

After a career in the health sector, Cassandra Hewett has become accustomed to bodily functions and fluids. So, when she was first presented with the option of being part of a trial that involved receiving a poo transplant, she jumped at the opportunity.

"There's no fear in terms of what might need to be involved having worked in areas of research ... in fact, I'd find it very interesting and very keen to have the outcomes," Ms Hewett said.

"I'm not afraid of anything to do with body parts, we're all a very complex organism."

Ms Hewett was diagnosed with young onset Parkinson's disease three years ago.

Young onset Parkinson's disease presents visible symptoms such as tremors of limbs and the face as well as postural instability. People living with the disease also suffer from symptoms not seen, like depression, sleep disturbances and constipation.

"There can be a fair bit of time spent in the toilet, which can be really inconvenient, plus through the discomfort of having to deal with that issue," Ms Hewett said.

"My husband gets very concerned about me being in the bathroom a long time... so I think it's not only the person that has the condition, it also affects the family around you."

In a collaboration between The Queen Elizabeth Hospital, the Royal Adelaide Hospital and biotechnology company BiomeBank, faecal transplants are the latest treatment option being trialled in people living with Parkinson's to help manage their debilitating symptoms by replenishing their healthy gut bacteria.

With constipation affecting 90 per cent of people with Parkinson's, research has indicated the microbiome within the gut may influence the response to existing therapies for the disease.

Robert Bryant, a gastroenterologist at The Queen Elizabeth Hospital and co-founder of Translational Medicine at BiomeBank, said the study of faecal microbiota transplantation (FMT) is an important step in microbial drug development.

"Constipation is a common problem for many people with Parkinson's and has a wider impact on the person's health and wellbeing," Dr Bryant said.

"The aim of this trial is to meet an unmet medical need, exploring whether our microbial therapy is safe and tolerable in people with Parkinson's disease. The study

will also provide some preliminary information on whether FMT might improve motor and non-motor symptoms of Parkinson's including constipation."

The trial has been financially backed by Adelaide businessman Kevin Weeks, who lives with Parkinson's disease.

"Gut health has been linked to so many conditions and it is exciting that a South Australian company might improve our understanding of this connection," Mr Weeks said.

"I'm funding this trial because I want to back research that produces immediate improvements for people living with Parkinson's."

A start date for the trial has not yet been determined.

**Source:**

Original article by Charles Brice, [ABC News Online](#)

## HOW HALLUCINATIONS AFFECT PEOPLE LIVING WITH PARKINSON'S

*Around 50% of people with Parkinson's disease will experience hallucinations. But what are they and what causes them? Professor Per Odin – a neurologist and head of the Neurology Department at Lund University, Sweden – shares what you need to know about the symptom.*

### What are hallucinations?

[Hallucinations](#) are sensory experiences that appear real but are created by our brains. They can affect all five of our senses.

You might hear voices that no one else hears or see things that no one else sees. They are normally separate from illusions, which are distorted or misinterpreted real perceptions – for example, you could see a person where there is actually a tree.

### What causes hallucinations in people living with Parkinson's disease?

Hallucinations are very common in Parkinson's disease. More than half of patients experience them at some stage.

They are normally thought to be an effect both of the condition itself and of Parkinson's medication. The risk of hallucinations increases with [cognitive impairment](#), longer disease duration, age, and other diseases.

Visual (seeing) and auditory (hearing) hallucinations may occur as a side effect of drugs which are used to treat Parkinson's. They are often dose-dependent – and in principle reversible.

### **What types of hallucinations can people living with Parkinson's experience?**

Visual hallucinations are the most common in Parkinson's disease. Auditory hallucinations occur mainly in depression. Tactile (touch) or olfactory (smell) sensations are unusual.

Often the symptom starts with lively dreams, then illusions, then hallucinations at night-time. After that hallucinations can also appear in the day.

Initially the patient understands that the experience is a hallucination, but if things progress it becomes difficult to say what is real and not.

Further progression could mean that the hallucinations become scary, and patients can develop confusion or delusions (for example, believing that a partner is unfaithful). Auditory hallucinations are seldom linked to Parkinson's.

Mild hallucinations do not need to impact life very much and can even be experienced as entertaining in some cases. But when the hallucinations become more pronounced and it is difficult to differentiate them from reality, they can have a big effect.

### **Can hallucinations be treated?**

The treatment for hallucinations consists primarily of removing any existing medical cause, especially reducing, or stopping any triggering pharmacological cause – for example by reducing a dose or discontinuing treatment with a certain drug.

If the increase in [motor symptoms](#) then becomes troublesome, a return to the earlier anti-Parkinson's drug may be considered – but with the addition of an atypical [neuroleptic drug](#) (a type of drug acting against hallucinations and psychosis).

Most neuroleptics can worsen Parkinson's (sometimes dramatically) and are forbidden when treating people with the condition.

Medications for dementia can also reduce the incidence of illusions and hallucinations when there is underlying cognitive impairment.

Parkinson's treatments are developing fast, and it is likely that we will see even more effective ways of avoiding and treating hallucinations in the coming years.

The most important thing is to report hallucinations to your doctor or nurse, and to discuss if they should be treated in some way.

## **Do you have any advice for the family, friends, and caregivers of people with Parkinson's experiencing hallucinations?**

Tell the patient that what they are experiencing is not real and do not pretend that you also experience the same thing. Be calm and friendly with the patient – experiencing hallucinations can be quite stressful.

*Per Odin is a neurologist, professor, and head of the neurology department at Lund University, Sweden. He also works at an outpatient clinic in Bremen, Germany. He has focused on Parkinson's disease, both clinically and in research, since 1987.*

Author: Saskia Mair

First published in [Parkinson's Life](#)

## **JOHN WATKINS AM JOINS BOARD OF PARKINSON'S NSW**

Former Deputy Premier of NSW John Watkins, AM – who is living with Parkinson's – has been appointed to the Board of Parkinson's NSW.

“John is highly respected in both the political and not-for-profit spheres,” said Margaret Scott, President of Parkinson's NSW.

“His career in the NSW State Government spanned six Ministerial portfolios and culminated in his appointment as Deputy Premier in 2005. Following his retirement from politics, he became CEO of Alzheimer's Australia NSW for nine years and subsequently held an extensive range of non-executive director roles on the Boards of not-for-profit healthcare and international aid organisations.

“John's expertise will be invaluable to the Board in advocacy, as well as health and aged care policy and planning,” said Margaret.

In 2015, John was announced as a Member of the Order of Australia (AM) in the Queen's Birthday Honours List for his significant service to the community through leadership in health, education, and the Parliament of NSW.

John also was an Australia Day Ambassador from 2011 to 2017 and was awarded an Honorary Doctorate by Macquarie University for his services to the community.

His previous not-for-profit Board experience includes:

- Chair of the Board of the Little Company of Mary Health Care Ltd (Calvary Health) which is one of Australia's largest not-for-profit healthcare providers, responsible of over 20 public and private hospitals, aged care institutions and extensive community care services.
- Chair of the Catholic Health Australia Board, which represents all Catholic hospitals and aged care providers in Australia
- Member of the Council of the Australian Healthcare and Hospitals Association



- Governing Council of Neurological Research Australia (NeuRA)

## NEW DEVICES MAY RELIEVE HARD-TO-TREAT SYMPTOMS

There are some novel research projects going on in the U.S. and Netherlands aimed at developing technologies to ease two Parkinson's symptoms that are difficult to treat with medication.

These symptoms include freezing of gait and difficulties swallowing.

[Vibrating socks](#) have been developed as a novel cueing device that gives tactile stimuli to reduce freezing of gait without being visible for bystanders.

A soft, wearable, and wireless device called a [therapeutic swallow sensor](#) is being developed to assist the 80 percent of Parkinson's patients who experience difficulty with swallowing.

The sensor is being designed to be worn on the upper chest. It will gently vibrate to remind people to swallow more and with greater force – strengthening the associated muscles of swallowing.

It is hoped this will improve swallowing function long term and reduce the risk of choking events.

## MY TELEHEALTH EXPERIENCE

### Louise – With Professor Dominic Rowe, Macquarie Hospital

Louise – who prefers that her surname not be used – has been living with Parkinson's for a decade but has only been living in the Port Macquarie area for the past two years.

She discovered the local Parkinson's Specialist Nurse Rachael Mackinnon two years ago, while reading about the service in her local newspaper.

“When I saw the piece in the newspaper, I rang and got in touch with Rachael,” recalled Louise who is in her senior years (but generally feels much younger).

“Rachael knew Professor Rowe in Sydney who is my neurologist.”

Louise was concerned that the long drive down to Sydney to see Professor Rowe had become too tiring for her. So instead, Rachael offered to arrange a Telehealth conference for Louise, with Rachael assisting in the link-up.

Louise said the Telehealth meeting was just as helpful as actually being in Professor Rowe's surgery.

“This allows me to get the same service from Professor Rowe and it saves the travel,” said Louise. “I have a ventriculoperitoneal (VP)\* shunt inserted in my brain to



help manage the effects of Parkinson's and I can also get an update on this with him in these Telehealth appointments.

"It's so helpful to be able to get an appointment without leaving here."

Louise has also phone Rachael for assistance on other matters relating to her Parkinson's.

"She's very helpful. Rachael is very, very good," said Louise. "I've also got a good GP here, so I feel like I am getting assistance from a team of good people."

*\* A VP shunt works by taking the fluid out of your brain and moving it into your abdomen (belly), where it's absorbed by your body. This lowers the pressure and swelling in your brain.*