

## *InTouch*

### Supporter Group Newsletter

December 2021

#### Healthy sleep and Parkinson's

The dictionary definition of sleep is *a naturally recurring condition of rest, in which there is unconsciousness with the nervous system inactive and muscles relaxed.*

A good night's sleep is vital for physical, mental, and emotional wellbeing. It is the time when the body repairs and rebuilds itself.

Normal sleep patterns are characterised by a regular bedtime and a similar amount of sleep each night.

Your sleep pattern is set by your body clock. This follows the 24-hour clock and is called the circadian rhythm. Circadian rhythms are cycles that are part of the body's internal clock running in the background to carry out essential functions and processes.

During the sleep/wake cycle, different systems of the body follow circadian rhythms that are synchronized with a master clock in the brain. This master clock is directly influenced by environmental cues, especially light – which is why circadian rhythms are tied to the cycle of day and night.

When properly aligned, our circadian rhythm can promote consistent and restorative sleep. But when this rhythm is thrown off, it can create significant sleeping problems.

Research is also revealing that circadian rhythms play an integral role in diverse aspects of physical and mental health.

Light exposure causes our master clock to send signals that promote alertness and help keep us awake and active. As night falls, the master clock initiates the production of melatonin, which is a hormone to promote sleep. It then keeps transmitting that signal to help us keep stay asleep through the night

This cycle then gives the body opportunity to have a restorative rest period ready for increased daytime activity.

#### **Sleep disturbance in Parkinson's**

Sleep disorders are some of the most disabling of the non-motor Parkinson's symptoms.

When you are living with Parkinson's, sleep can become disturbed – and this disturbance can even predate the diagnosis.

Sleep disturbance can be challenging for both the person living with Parkinson's and their partner. It can lead to fatigue and impacts on cognition and can result in injury, all of which reduce the quality of life.

Sleep plays a major role in memory consolidation and thus impacts on cognition. Long term sleep problems are thought to play a role in the development of neurodegenerative conditions.

Sleep problems increase mood disorders, cognitive decline, and dementia.

Sleep disturbance can decrease reaction time, reduce fine motor skills, and increase impulsivity which makes the Parkinson's symptoms worse.

Sleep disturbance can be divided into three stages.

1. Early sleep stage, which can be caused by discomfort and or anxiety.
2. Mid-sleep stage insomnia can be caused by nighttime urination and sleep apnea.
3. The third stage is early awakening and can be due to depression or mood disorder.

### **Impact of symptoms on sleep**

The symptoms of Parkinson's really impact on sleep. These symptoms include tremor, rigidity, dyskinesia, depression, nighttime urination, pain, dystonia, breathing issues, REM sleep disorder, and restless leg syndrome.

There may also be other underlying causes of sleep problems which may be unrelated to Parkinson's and these need to be investigated.

Common complaints about sleep from people with Parkinson's are:

- Medications are not lasting the full time – a that is 'wearing off'.
- A difficulty getting in and out of bed.
- Difficulty turning over in bed.
- Need to get up to the bathroom overnight – sometimes several times.
- Dystonia or prolonged muscle cramping.
- Anxiety and depression.
- Fluctuating blood pressure.
- Increased daytime sleepiness.
- Restless legs.
- Pain.
- Sleep apnea.
- REM sleep disorder.
- Vivid dreams.

Sleep issues should always be discussed with your neurologist. A medication review may be able to improve the symptoms and manage things better to improve sleep, which then impacts positively on the rest of your day.

## **REM Sleep Disorder**

REM Sleep Disorder or Dream Enhancement Disorder is common in people with Parkinson's and can also be an early sign of Parkinson's before other symptoms develop.

It occurs in the dreaming phase of sleep. Normally when people dream, their muscles are paralyzed; only the eyes and the tiny hammer, anvil and stirrup bones in your ear canal are able to move during sleep.

Due to the changes in the brain that Parkinson's causes, the muscles are not paralyzed during the REM sleep phase – allowing vigorous movement of arms and legs, possibly injuring their partner.

People can act out a violent dream and may or may not be able to remember this later.

People experiencing REM sleep disorder need to consider safety measures for both themselves and their partner – and put in place some interventions to reduce the risk of injury to themselves or their partners.

These measures may include:

- Clearing the area around the bed
- Making sure there are no nearby sharp edges, glass, or anything that can be broken or knocked
- Using a large pillow barrier between them and their partner.
- Continuing to sleep in the same room but in single beds.
- Lowering the bed to reduce the risk of injury if you fall out – which sometimes people do.

People living with Parkinson's should also be checked for issues with sleep apnea. Alcohol should also be avoided before bed.

Another way to manage this could be also to be making sure that you're giving good information to your neurologist and your GP so they can make some informed decisions about whether melatonin – which is very safe medication – could be used to try and reduce that dream disorder.

Also, clonazepam is also used to manage the REM sleep disorder by trying to reduce that dream problem. However, it has side effects which can impact your balance and increase daytime sleepiness.

## **Restless Leg Syndrome**

Restless Leg Syndrome is the overwhelming need to move your legs and is usually worse at night, having a major impact on your sleep pattern.

Restless Leg Syndrome can occur when nerve cells are damaged, reducing the amount of dopamine produced. This then causes those muscles to spasm and involuntary leg movements result.

Prior to any treatment being commenced, a check should be made on the lower leg circulation. There may be peripheral neuropathy and also iron deficiency can have an impact on your legs as well.

Treatment for Restless Leg Syndrome includes treating those underlying causes or ruling them out – and then sometimes medications such as dopamine agonists, codeine and gabapentin can be used under medical supervision.

These medications can also have the side effect of excessive daytime sleepiness, so sometimes it's a tradeoff.

## **Sleep Apnea**

Sleep apnea is a condition where a person momentarily stops breathing whilst asleep. This causes them to wake, take a few breaths and then go back to sleep again.

They don't usually have the memory of this happening because it's brief, but it disturbs their sleep.

The symptoms of sleep apnea include loud snoring, choking noises while asleep, and that prolonged intake of breath. This also ends up being causing excessive daytime sleepiness.

Treatments for sleep apnea include weight loss, use of a Continuous Positive Airway Pressure (CPAP) machine, and a review of the medication regime.

## **Sleep hygiene for Parkinson's**

Sleep hygiene – things that can help to improve your sleep – is important when living with Parkinson's. Make the things in this list part of your routine:

- Exercise regularly.
- Manage pain issues with medication and hot packs, repositioning, and making sure you're comfortable.
- Avoid large meals in the evening.
- Get enough sunlight to promote a healthy circadian rhythm.
- Make a plan for tomorrow so you don't lie awake thinking or worrying about the next day.
- In the early evening, give yourself time to relax so you don't have things rolling around in your mind when you're getting into bed.
- Relax before you go to bed – try reading, music or whatever chills you out before you get into bed.
- Avoid heavy exercise before bed.
- Ensure that your bedroom is a calm and comfortable place. It should be used for sleeping and intimacy only.
- Your room needs to be a comfortable temperature because people living with Parkinson's have major issues controlling their temperature – hot or cold.

- Go to bed when feeling sleepy and reduce daytime napping. It's very easy to feel fatigued when you are not getting a good night's sleep and then fall asleep in a chair. It's a better idea to have a short afternoon nap and then get back up.
  - Reduce noise and light in the bedroom – including digital clocks, cell phones and computers.
  - Avoiding using your computer or cell phone immediately before bed.
  - Avoid caffeine before bed.
  - Avoid alcohol before bed, as well as smoking and consuming illicit drugs.
  - Reduce the time when in bed when you're not actually asleep. If you wake up, consider getting up, taking a break, doing some of the things that relax you and then going back to bed and trying to get to sleep again.
  - Set an alarm clock – not the digital type – so you can relax because you know you will wake up at whatever time you need the next morning.
  - Avoid sleeping with pets. They can be very disturbing to people overnight.
- 

## Sex, intimacy, and Parkinson's

*Parkinson's Life recently shared a series of four articles dealing with sex, intimacy, and Parkinson's.*

*The articles were jointly written by Nurse Consultant Norna Moore from Tel Aviv Medical Center and sex therapist Gila Bronner from the Institute of Movement Disorders at Sheba Medical Center, also in Tel Aviv, Israel.*

### 1. Intimacy, sexuality, and Parkinson's

In the first part of the series, Gila and Orna discuss the importance of intimacy, and give a four-step, practical guide on ways to improve closeness in a relationship.

Intimacy, they explain, is an area that “frequently goes unnoticed and un-discussed”.

The two experts recommend spending quality time with your partner, ensuring you both have moments alone to relax, committing to intimate time without the pressure to move on to sex, and sexual time.

“Couples need these four elements, even if some time passes without realising all four of them. It is important to invest in intimacy in a relationship.”

[Read the full article here.](#)

### 2. Getting help

Part two of the series focuses on the significance of communicating with healthcare professionals about difficulties with intimacy, as many symptoms are common and have several solutions or forms of treatment.

Gila and Orna emphasise that people with Parkinson's may not realise that their condition is the cause of their sexual dysfunction, which is why it is important to talk about any issues with medical professionals – and for healthcare professionals to encourage this discussion.

“A loving relationship includes encouragement of intimacy, sensuality, companionship, and friendship, as well as continued knowledge and understanding about the effects that one's health conditions, medications, and treatment have on sexuality and functioning.”

[Read the full article here.](#)

### **3. The needs of caregivers**

In part three, the experts summarise some of the issues that those caring for a partner with Parkinson's face in relationships, including a lack of time for their own needs.

Gila and Orna share ways to ensure the wellbeing of both partners, such as respecting each other's needs, having personal time away from one another, sleeping in separate beds if sleep is being disrupted, maintaining intimacy even if it's not sexual, having strong communication and making small, thoughtful gestures that the other will appreciate.

“Spouses and care-partners frequently face contradictory roles,” they explain. “On one hand, as intimate partners, they may have their own needs for intimacy and sexual activity. On the other hand, they are required to function as caregivers who cope with the implications of a chronic progressive illness.”

[Read the full article here.](#)

### **4. Sex and young onset Parkinson's**

In the final part of the series, Gila and Orna discuss coping with disturbed sexual function – one of the most common non-motor symptoms in people with young onset Parkinson's – and share the difficulties many face of sustaining a sex life due to lack of time and other priorities.

“Young people with Parkinson's experience the disease differently. They are coping with its various symptoms while also being in the middle of life challenges.”

They say openness is crucial to sustaining a healthy sexual relationship. To tackle any issues, they advise seeking professional help when necessary, being honest with one another, and being open with children about the effects of Parkinson's.

[Read the full article here.](#)

**Orna Moore** is a nurse consultant, working with families with neurodegenerative diseases. She works at the Department of Neurology, Tel Aviv Medical Center, Israel.

**Gila Bronner** is a sex therapist specialising in sexual rehabilitation. She is director of the Sex Therapy Service at the Sexual Medicine Center, Tel Aviv, and a sex therapist at the Institute of Movement Disorders, Sheba Medical Center, Israel.

Story first published in [Parkinson's Life](#)

---

## Tips on coping with Parkinson's during the Festive Season

### Have a plan

Planning is the key to an enjoyable, less stressful Christmas and holiday time.

Everyone is keen to catch up and celebrate with family and friends again after the long lockdown periods. It is essential to be organised during this time as there will be less opportunities to obtain prescriptions, fill scripts, make appointments, organise shopping, and the list goes on....

It can be very helpful to keep a diary to remind you of your appointments and a list of things that need to be done.

### Manage stress and anxiety

It is important to recognise that the festive season is an emotional time for everyone. While the festive season is an enjoyable time, it can also be incredibly stressful – particularly with family issues and this year with Covid vaccination choices.

It may be that you haven't physically seen some family or friends for a lengthy period, and they may comment on changes that they are noticing. This can be upsetting for all concerned.

Stress and anxiety make the Parkinson's symptoms worse so please seek assistance to reduce your stress levels. If your anxiety escalates it can develop into panic attacks.

If you are feeling depressed and needing to talk to someone then please call Lifeline 131 114.

If you are feeling anxious in any situation STOP and take a deep breath – then use all of your senses to check things around you to reset. For example, look for five things you can see and four things you can touch.

### Prepare your medication

Medication is essential and therefore ensure that you have a sufficient supply of your regular medication – including aperients and pain medication. It is also important to have backup scripts and a list of your medication in case of any issues when away from your regular pharmacy.



Ensure that you have a pill box and alarm to prompt you to stay on time every time with your medication routine when you are going on outings.

Have a supply of medication in your hand luggage if you are traveling. Have a list of medications and letter provided by your doctor if you are traveling overseas.

You need to adapt to the time zone where you are so don't stay on your Australian timetable for medication. Once you are into your international flight then adapt to the new time zone. The same goes for returning to Australia – change back to the time zone that you are arriving in.

When going through airport screening, always tell the security officers if you have a DBS, Apomine or Duodopa device.

### **Stay hydrated**

Water is an important part of your daily routine. It assists in managing many Parkinson's symptoms including constipation and orthostatic hypotension

Alcohol is dehydrating so limit the intake and remember to drink water in between alcoholic drinks.

### **Don't overdo it**

Fatigue is a common symptom of Parkinson's. It is especially important to prioritise your energy levels – don't overdo it and take frequent breaks.

Remember that it is OK to say no. You can only do so many things well, so it is important to choose what are the most important things for you to achieve. Consider what gives you the most joy and plan to undertake those things.

Time out is important as you need time to refocus, rest and then reset. Be kind to yourself. It is great to spend time with family and friends, but you will need a quiet space to de-stress and relax – especially if you have family staying in your home.

Also consider communication. It may be worth planning to meet in smaller groups face-to-face for improved communication. It is hard to communicate well in larger groups with more distractions and many conversations going on at the same time.

### **Concentrate while eating**

Sharing meals is a wonderful way to celebrate, however it is very important to remember that you need to concentrate while eating to ensure safe swallowing.

That means no talking or watching TV and eating at the same time.

Be aware of protein and your medication timing. Also consider the size of the meals you are eating as this can also have an impact on your medication absorption and gastric issues.



## Don't neglect exercise

Remember to take the time during the holidays to exercise. Exercise is the second most important way to manage your symptoms so keep up your exercise in whatever modified way you can during the festive season.

---

## Exercise on the go – Planes, trains & automobiles

We're into the summer months and restrictions are lifting, so many of us are planning our holidays and will be travelling – for one day trips or longer journeys to visit family or go sightseeing.

Long car, plane or train rides can be uncomfortable, causing stiffness, aches, and pains. The following tips can help you stay comfortable and active during long trips whether driving, flying, or catching a train.

Firstly, it's important to get yourself as comfortable as possible. In a car, make sure you have your seat in a supportive position.

For planes and trains remember to bring a cushion or foot stool to help make your journey more comfortable. However, the best way to reduce your stress and fatigue is to give yourself regular pit stops or breaks and do some stretches and exercises.

In the car you can do **Triceps Pushes** to exercise your triceps. Hold the steering wheel, a ledge or railing tightly while keeping your elbows bent. Straighten your elbows and push your back into the seat and hold for a few seconds. Try doing around eight repetitions and repeat as often as you need.

Another exercise is **Seat Pushes**. Sitting straight with your feet flat on the floor. Place your hands flat on the seat beside your hips, keeping your elbows bent. Straighten your elbows to lift your butt up off the seat. Do around eight repetitions and repeat as often as you need.

If you're driving only do these exercises when the car is stationary!

**Seated Side Bends** are another good exercise for your back, shoulders and neck. Sit tall, with your hands behind your head and your fingers clasped. Keep your spine straight and slowly bend to one side. Hold for a few seconds then return to upright and slow bend to the other side. Repeat a few times on each side.

Then try **Calf Raises & Toe Points**. Place your feet flat on the floor. Lift your heels high, putting pressure into the balls of your feet and toes. Then rock back on your heels and lift the toes as high as possible. Do around 10 repetitions.

If you have a short stop in your journey, make sure you always get out of your seat and move. Sitting still for extended periods can cause lots of health problems such as blood clots, varicose veins, and back issues. Here are some exercises you can do outside of the vehicle in which you're travelling.

**Lunges.** Stand tall with feet hip-width apart, engage your core, and step forward with one leg and place your heel flat on the floor. Lower your body straight down until both knees are at 90 degrees. Keep your body and weight above the back leg. Return to the starting position and change to the opposite leg. Do as many as you can without extreme discomfort.

**Push-Ups** Place your hands shoulder distance apart on a sturdy surface, like a car's bumper or boot. A picnic table or bench, or a flat fence will also do. Step your feet back keeping your body straight. Bend your elbows 90 degrees as you lower your chest. Exhale as you push up. Do as many as you can without extreme discomfort.

**Toe Taps** Standing tall with your core engaged, lift your knees high to tap your toe to the car bumper, bench, or ledge. Alternate each leg. Repeat for a desired number of sets. Start with five repetitions for each leg but build up as it becomes easier.

There are many more exercises you can do while travelling. If you are having trouble finding an appropriate exercise, just call the 1800 644 189 Infoline for advice on an exercise that suits you.

---

## Food, mood, and stress

Stress is a demand made on your body. A stressor can be people, places, or events that you see as a threat. Stress is a normal chemical reaction in your body which can be either good or harmful.

Parkinson's is a chronic condition that can lead to many different kinds of stress. People with Parkinson's are often under great stress which can lead to health problems. If stress does not stop then your body never gets a chance to heal itself.

It is important to try to identify the stressors in your life. These could include:

- Change of personal circumstances
- Moving house
- Changing your job
- Concerns about family or friends
- Medications new or changed

Learn to recognise the signs of stress:

- Dry mouth
- Headache
- Confusion
- Nightmares
- Clammy hands
- Tearfulness

- Depression
- Feeling faint
- Fingernail biting
- Decreased talking
- Speaking too much or too quickly
- Chain smoking
- Over or under eating
- Heart palpitations
- Fatigue/weariness
- Anger, resentment, or irritability
- Gut issues including constipation, nausea, diarrhoea, or indigestion

These signs and symptoms occur because the body and mind become exhausted from trying to deal with the constant state of stress. Identifying stressors can lead to taking action to manage and reduce stress.

The best ways to manage stress are:

- 1. Nutrition** – Eating a well-balanced diet of smaller, more frequent meals results in smaller serves of protein reducing the interference with levodopa. It will also maintain blood sugar levels instead of fluctuations and this produces a calming effect.

Foods that assist the body to form serotonin (a chemical that signals the body to relax) are bananas, pineapple, papaya, dates, plums, figs, pecans, walnuts, tomatoes, and kiwi fruit.

Eat six serves of complex carbohydrates per day as well as two or three moderate portions of protein and less fatty foods. Drink plenty of water as it decreases fluid retention and aids in the management of constipation.

- 2. Exercise** – A natural stress buster that can help to work off anxiety and muscle tension. Regular exercise aids in giving a better outlook on life generally.

It can also strengthen your immune system, maintain bone strength, and manage cholesterol. Examples of exercise are walking, gardening, cycling, swimming, dancing, stretching, yoga, boxing, and tai chi.

- 3. Relaxation** – Reduces stress and improves quality of life. Examples of stress reducers are meditation, yoga, going to bed on time, and delegating tasks to others.

In general it is good to ask for help, have a back-up plan, and find some time for yourself. Remember how important you are, join a support group, and think of what you are grateful for every day.

## Can equine-assisted therapy benefit people with Parkinson's?

Researchers from Texas Woman's University, USA, are investigating how equine-assisted therapy – which involves working with horses to promote wellbeing – can benefit people living with Parkinson's

As part of the five-month study – funded by the non-profit Human Animal Bond Research Institute – 30 men living with Parkinson's disease are being randomly assigned to participate in equine-assisted therapy or simulated horseback riding.

The participants' motor performance, balance, gait, and symptoms related to Parkinson's will be assessed before, during and after the therapy.

Rhett Rigby, principal investigator of the study, said: "There is currently no known study that utilises equine-assisted therapy as an intervention treatment for those with Parkinson's disease.

"Our research could have a significant impact on an understudied population and help contribute to the existing literature on human-animal interaction."

**Author:** Simge Eva Dogan

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

---

## Q&A: Looking forward to 2022

*A quick chat with Support Group Coordinator Cassie Morgan about what the coming year holds for Parkinson's NSW Support Groups.*

### **What are your priorities for 2022?**

Doing whatever we can to enable a return to effective and rewarding face-to-face Support Group meetings.

Many Support Groups have resumed face-to-face meetings already or will do so in early 2022. We are here to support you in adjusting to the new COVID normal when resuming face-to-face meetings.

The danger from the pandemic has lessened, but it has not completely gone away. Already we are seeing a new variant of the COVID virus appear in the NSW community – it is called Omicron. Therefore COVID safety remains a priority.

### **What COVID-safe measures are required?**

It is important to have a COVID-safe plan in place to understand what you can do to keep your Support Group participants safe at meetings and reduce the risk of infection.

Stick to the basics including remaining 1.5 metres apart, providing hand sanitiser, keeping an accurate record of who attends each meeting, and not sharing pens, microphones, or plates of food.

It will be incredibly beneficial to reconnect with your Support Group participants and rebuild social connections with one another – but let's do it safely.

### **How can Groups rebuild their participant numbers when meetings resume?**

We understand that many Support Groups are experiencing a drop in participant numbers and a lack of engagement after repeated lockdowns.

I am working with colleagues in the Marketing Department on a project to boost the presence of Support Groups in the wider community, promote the benefits of being involved in a Support Group, and attract new and old participants to your groups.

We will also work one-on-one with Groups which need assistance getting their participant numbers back up after being shaken up by lockdown. We can do this by helping you reach out to local media, community newsletters, bulletin boards, social media etc.

If this is something that your Group could benefit from, please email me at [supportgroups@parkinsonsnsw.org.au](mailto:supportgroups@parkinsonsnsw.org.au)

---