

In Touch Newsletter **February 2024**

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](#)

How to plan nutritious easy-to-chew meals for people living with Parkinson's

Parkinson's disease can slow the normal swallowing movement of the throat (peristalsis). This condition is called dysphagia and can lead to choking, or the inhaling of food into the lungs.

Together with chewing problems – another common symptom – this means mealtimes can become difficult for patients. In the long run, chewing difficulty and/or poor oral health can also lead to malnutrition.

This article does not apply to the condition of dysphagia, only to chewing difficulty. If swallowing is a problem, or if you have choked, it's very important to ask your doctor for a referral to a speech therapist.

They can determine whether you are at risk and can demonstrate safe swallowing techniques. If needed, they may order a special diet of puréed foods and thickened liquids.

Digestion difficulty

Let's think about what happens to a piece of boiled potato just after we place it in the mouth. The teeth chew the potato, grinding it up into smaller pieces.

If not for the teeth, the potato might be too large to swallow, and we would choke. Besides that, the stomach would have a hard time with a single, large piece of food – it can digest small pieces much better than large ones.

The teeth and tongue also move the potato around the mouth, and that movement stimulates the taste buds, which helps us enjoy our food. After the food is chewed, the tongue pushes it to the back of the mouth in position for swallowing.

But for some people with Parkinson's chewing can be difficult. Nerves that guide the muscles of the jaw and tongue become weaker. It may take an unusually long time just to chew a bite of food. Then the tongue has a difficult time moving food to the back of the mouth in position for swallowing.

I've known people who have needed three to four hours to finish just one meal, which means there is hardly enough time in the day to eat the amount of food necessary to maintain a healthy weight and get all the necessary nutrients.

Besides the nerve damage that Parkinson's can cause, there are other concerns. Dry mouth, which is common in patients; poor oral hygiene, due to difficulty managing a toothbrush; and sugary foods, can all cause tooth decay and/or tooth loss.

Soft solutions

If your ability to chew food properly is affected, you'll need to focus on eating soft foods that can be easily swallowed, but also a variety of foods for good health. Nutrition is just as important, perhaps even more so, when it's hard to eat.

Protein

When looking for softer proteins, ground or puréed meat and flaky, canned fish are good choices, as they don't require much chewing.

Cottage cheese contains high-quality protein and adds texture and flavour to casseroles and other dishes. Grated cheese mixed with mayonnaise is a good option.

Eggs can be scrambled, fried, or soft-/hard-boiled and diced for egg salad.

Cooked dried beans are not only high in protein but are also rich in fibre. They can be mashed and thinned or thickened as required.

Peanut butter can be blended into smoothies as it can get stuck in the mouth or throat when eaten on its own.

Note: for those who use levodopa and are especially sensitive to protein, plant proteins such as beans may not block levodopa absorption as severely as animal proteins.

Vegetables and fruits

These are important sources of vitamins, minerals, antioxidants, and fibre but can be hard to chew. Cooking and puréeing solves the problem – for example, making apple or pear sauce.

Bananas can be difficult to move to the back of the mouth for swallowing, but they are very easy to swallow when blended with liquids into a smoothie.

Vegetables such as potatoes, sweet potatoes, squashes, turnips, carrots, and peas can be cooked and mashed. You can make a hearty soup of green beans, zucchini, squashes, tomatoes and sweet peppers. Make sure that they are finely chopped and cooked with broth and ground meats.

Grains

These have complex carbohydrates and fibre as well as trace minerals and vitamins.

Cooked cereals such as oatmeal, bread pudding made with whole-wheat bread, and rice pudding made with brown rice are all good choices. Sandwiches may not work well, but sauces, gravies, and cream soups can be poured over whole-grain bread to moisten it and make it easier to chew.

Dairy products

Milk, yogurt, custard, and puddings are all easy to chew and are rich in protein, calcium and B vitamins. You can add fresh or dried milk to casseroles, cooked cereals and soups.

Note: Some people who use levodopa find that milk protein blocks levodopa absorption to a greater extent than other proteins. Others are allergic to dairy. If so, consider one of the milk alternatives – almond, soy, or coconut milks and vegan cheeses.

Source

Kathrynne Holden, former National Parkinson Foundation dietician (UK)

Visit her website, nutritionucanlivewith.com, for more Parkinson's-related nutrition information

Best exercise for Parkinson's

All exercise is beneficial and different styles, variety and intensity offer different benefits. However, multiple studies have shown that intense exercise can delay the progress of Parkinson's.

Intensity creates a lot more opportunities for the brain to change and create new neural pathways. by being challenged above its comfort zone.

One study (see reference section at the end of this article) involved participants walking for 30 minutes, four times per week.

Those in the study who did moderate exercise (60 to 65 percent of maximum heart rate) showed no slowing of their Parkinson's and only a small decline of 1 or 2 points on the Parkinson's disease scale.

The Unified Parkinson's Disease Rating Scale (UPDRS) is the most widely applied rating instrument for Parkinson disease. The Total UPDRS score includes 31 items across three subscales: (I) Mental Activity, Behaviour, and Mood; (II) Activities of Daily Living; and (III) Motor Examination.

Those who did mild or no exercise, (under 60 percent of maximum heart rate) showed some worsening of their Parkinson's, with an average decline on the Parkinson's disease scale of more than 3 points.

However, those doing intense exercise (80 to 85 percent of maximum heart rate) significantly slowed the progression of Parkinson's. And importantly, it was well managed by all participants.

This study demonstrated that intense exercise can both be both safe and significantly slow the progression of Parkinson's.

The challenge is, it's hard to keep up high intensity exercise. As Parkinson's causes slow unsteady movement and a false perception of intensity, it's not recommended that you do the bulk of your intense exercise alone.

It works best when you have someone to watch and encourage you or join a class for that extra push. Feedback from a heart rate device is great for keeping you at the correct 80 to 85 percent intensity.

Be sure to speak to your health professional for guidance and how to work around these issues.

So make sure whatever exercise you do you do it with intensity. Ensure you are safely pushing yourself by adding speed, i.e. doing your exercise faster or by adding some extra weight or increasing the duration of your exercise. These will all increase the intensity of your exercise.

Also know that different types of exercise focus on different Parkinson's symptoms.

Cardio exercise does improve symptoms overall but if balance is bothering you, also do some balance exercises. If your memory is a concern, add in some cognitive exercises.

But the overall best exercise for Parkinson's is to increase the intensity of every workout.

References

<https://jamanetwork.com/journals/jamaneurology/article-abstract/2664948>

<https://rebelfitclub.com/high-intensity-exercise-beneficial-parkinsons-disease-high-intensity/>

<https://pubmed.ncbi.nlm.nih.gov/30531382/>

<https://parkinsonsdisease.net/diagnosis/rating-scales-staging>

New Choir for People with Parkinson's

You are cordially invited to join a new choir for people living with Parkinson's.

Come along with your carers and friends to have fun singing out loud together, and enjoying the benefits singing can offer to all. You'll sing all sorts of songs, strengthen your voice, meet new people, and above all, have fun.

"You don't have to have a good voice. If you can make a noise you belong!"

Peter K. Bushlarks Choir, ACT



"Oh, but I can't sing!!!" Have you been told "just mime the words" or "keep it to the shower"? In this group, everyone is encouraged to give it a go, no-one will judge, so join in, have fun and set your voice free! There's safety in numbers, and you could be surprised how much you'll gain from lifting your spirits and letting your voice grow strong, in good company.

Chrissie Shaw is a musician/educator with many years of experience working with individuals and community choirs. Chrissie was Musical Director of the Bushlarks Parkinson's Choir in the ACT for 5 years. Back in Sydney, she is looking forward to establishing the new choir.

WHEN AND WHERE?

DAY: Tuesday mornings, starting 6th February 2024

TIME: 10am – 12 (Includes 20 mins. coffee/tea and chat!)

VENUE: Meeting Room, Annandale Community Centre, 79 Johnson Street

COST: \$10 per session. Carers and partners free.

CONTACT: If you would like to give it a go, contact Chrissie Shaw:

Mobile phone: 0407 079 748 Email: chrissieshaw44@gmail.com

Please leave your name, phone number and email address, and Chrissie will reply!

This choir is an opportunity for people to get together in a warm and friendly environment, and sing in a group!

In Australia and overseas, choirs for people living with Parkinson's are having great success in helping people deal with voice, breathing and swallowing problems, as well as providing a relaxing and enjoyable activity.

Singing out loud is not only fun, it is also beneficial for people with Parkinson's as it exercises the lungs and abdominal muscles. Singing gives us a heightened feeling of wellbeing and can provide a range of health and holistic benefits, including:

- regulating breathing
- strengthening the voice – volume and projection
- building-up the vocal chords
- improving mood
- enhancing confidence
- aiding concentration,
- and helping swallowing

The focus of this choir is not necessarily on performance, but this is an option if people decide they'd like to perform for family and friends down the track!

Research Participation Opportunities

Survey of cannabis and related substance use in the Parkinson's population and its impact on Parkinson's symptoms.

University of Sydney

What it is:

An anonymous research study on the use of cannabis or cannabis related substances for managing symptoms of people living with Parkinson's – both motor and non-motor symptoms.

Who can participate:

Australian residents over the age of 18 with a formal Parkinson's diagnosis, and who have tried cannabis or cannabis related substances for symptom management.

What participation involves:

Completing a 10-minute online survey. The survey will check eligibility, seek consent for participation, and ask questions about the impact of cannabis on Parkinson's symptoms. It will also include questions on your Parkinson's history, medication taken and your motor and non-motor symptoms. No identifying data such as name or email address will be gathered.

How to participate:

Visit: <https://redcap.sydney.edu.au/surveys/?s=47YMFR4E98XNL38J>

For more information:

Email Sarah Cleophas at scle0647@sydney.edu.au

Australian Parkinson's Pain Study (APPS)

University of South Australia

What it is:

An investigation of the characteristics of pain in Parkinson's. This will enable the researchers to develop a comprehensive profile of Parkinson's-related pain, a deeper understanding of the needs of people living with pain due to Parkinson's, and patient-centred recommendations on the provision of pain care services.

Who can participate:

People who have been diagnosed with Parkinson's and have experienced pain symptoms in the past month.

What participation involves:

Completing an online survey.

How to participate:

Visit: www.australianparkinsonspainstudy.com.au

For more information:

Email Anthony Mezzini at anthony.mezzini@mymail.unisa.edu.au

Neuropsychological Assessment in Parkinson's Disease

University of Queensland

What it is:

Researchers are working to improve neuropsychological assessments for early and more effective diagnosis of dementia in people living with Parkinson's.

Who can participate:

People living with Parkinson's, or their family care partners, who have undergone a neuropsychological or cognitive assessment – regardless of what the outcome was.

What participation involves:

Three options – participating in focus groups over Zoom teleconferencing, questionnaires completed online, or surveys over Zoom.

How to participate:

Visit: <https://clinical-research.centre.uq.edu.au/pdcognicare>

For more information:

Email Dr. Daniel Bailey at daniel.bailey@uq.edu.au

Useful advocacy organisations

Australian Government Aged Care Quality and Safety Commission

The role of the Aged Care Quality and Safety Commission (Commission) is to protect and enhance the safety, health, well-being, and quality of life of people receiving aged care, according to its web site.

If you have a loved one in an Aged Care Facility and have concerns about their care, you can lodge a complaint with ACQSC by calling 1800 951 822. Or visit its web site: www.agedcarequality.gov.au

Also, on the web site you can view a register of providers who have not complied with their responsibilities under the Aged Care Act.

Older Persons Advocacy Network (OPAN)

The Older Persons Advocacy Network (OPAN) is a national network of nine organisations which deliver advocacy, information and education services.

The state organisation with which OPAN is connected in NSW is the Seniors Rights Service: Telephone 1800 424 079 or web site <https://seniorsrightsservice.org.au>

It provides advocacy services to assist older people who receive aged care services (either at home or in a facility) as well as their caregivers and family members, to ensure their rights are observed.

It also delivers education sessions in aged care facilities to raise awareness about people's rights. OPAN and the Seniors Rights Service have some informative

videos on their resources web page that are very helpful – all related to your rights in financial matters, aged care, help at home, carers, elder abuse and more.

Insight into Parkinson's Online Conference 11-13 April 2024

Discover the future of Parkinson's at the 7th Annual INSIGHT 2024 Online Conference – 11th to 13th April 2024.

Join global Parkinson's leaders during World Parkinson's Awareness Month at INSIGHT to PD, brought to you by PD Warrior, the pioneer behind the world's most comprehensive Parkinson's rehabilitation program.

You will hear from Parkinson's specialists on topics across the latest medical advancements, research breakthroughs, mindset, nutrition, movement and caregiving. Whether you're living with Parkinson's, a caregiver, or a Health Professional, this event is tailored for you.

INSIGHT to PD is proud to partner with Parkinson's charities and since inception has raised over \$200,000 to support people living with Parkinson's. Parkinson's NSW is a proud partner of the 2024 conference.

As a charity partner, for the month of February, you can receive a 15% discount off the premium ticket price. When registering use this link [Insight Premium - PD Warrior](#) and enter this code **FEBPARTNER15OFF**
