

In Touch Newsletter **March 2024**

Healthy brain region works overtime to control Parkinson's symptoms

In people with Parkinson's disease, the cerebral cortex of the brain can compensate for disease-related dysfunction in the basal ganglia, the main part of the brain affected by Parkinson's.

Researchers found that patients with milder Parkinson's symptoms have more compensatory activity in the cerebral cortex, while patients with more severe symptoms tend to have less activity. This finding implies that boosting the cerebral cortex's activity may be useful in easing such symptoms.

Their study, 'Clinical severity in Parkinson's disease is determined by decline in cortical compensation', was published in *Brain*.

"In Parkinson's we solve the dopamine deficiency with drugs. But with these new findings we are now going to look much more at how we can strengthen that compensation by the cerebral cortex," said Rick Helmich, MD, PhD, a study co-author and neurologist at Radboud University Medical Center in the Netherlands.

"We saw in a previous study that exercising three times a week helps against symptoms and prevents shrinkage of the cerebral cortex. Thanks to the current study, we know why that cerebral cortex is so important," he added.

Parkinson's is caused by the death and dysfunction of nerve cells responsible for making the signalling molecule dopamine – possibly as a consequence of the accumulation of toxic forms of the protein alpha-synuclein. These cells are mostly located in the basal ganglia, a part of the brain that helps control movement and cognition

Basal ganglia dysfunction causes problems

It's established that basal ganglia dysfunction causes problems with neurological signalling that ultimately leads to disease symptoms. But from patient to patient, the amount of dysfunction doesn't show a clear connection with symptom severity, and most patients continue to experience symptom progression even after the basal ganglia is completely destroyed.

Other parts of the brain might be compensating for the damaged basal ganglia, with symptoms worsening only when those other regions are no longer able to handle the extra tasks

"The presence of dysfunction in one brain region would in turn call for compensation elsewhere in the nervous system," the scientists wrote.

Prior work specifically has suggested that parts of the cerebral cortex – the outer layer of the brain that is known to play important roles in higher cognitive processes – may have compensatory activity in Parkinson's.

Researchers at Radboud University tested this idea through an experimental setup where MRI scans were used to track brain activity while participants underwent a task requiring motor control and cognitive effort. Basically, participants played a computer game where they had to hit different buttons as quickly as possible in response to cues.

“We used an action selection paradigm to investigate cerebral mechanisms underlying abnormal motor control in Parkinson's disease, which implicates both motor symptoms (e.g. bradykinesia) and cognitive deficits (e.g. decision-making), and which was designed to elicit cortical compensatory mechanisms,” the scientists wrote.

Using this setup, they assessed brain activity in 353 people with Parkinson's disease and 60 people with no known neurological problems. Patients were divided into three groups – diffuse-malignant, intermediate, and mild-motor predominant – based on the severity of their Parkinson's motor symptoms. These sub-types are thought to reflect distinct routes of alpha-synuclein propagation.

Parkinson's patients had reduced basal ganglia activity

As expected, Parkinson's patients had markedly reduced basal ganglia activity compared to people without disease. However, no clear differences in basal ganglia activity were seen based on disease severity.

Patients with less severe symptoms, however, tended to have more activity in certain parts of the cerebral cortex, specifically the superior parietal and premotor cortex.

Researchers noted that this compensatory cerebral cortex activity was especially apparent during parts of the task where participants had to be actively making decisions about what to do.

“We showed that lower symptom severity was consistently associated with higher activation in superior parietal and premotor cortex, particularly during high demands on action selection,” the researchers wrote. These findings, they added, may explain why patients tend to experience worse symptoms during voluntary movements that require choosing between different actions, as this may overburden the cortex.

Parkinson's patients with milder symptoms actually tended to have more cortex activity compared to what was seen in people with no disease – implying that, in these patients, the cortex is working overtime to compensate for the dysfunctional basal ganglia.

“People with mild symptoms showed much more activity in the cerebral cortex, especially in areas that are involved in controlling movement. These areas were even more active than in healthy volunteers, which demonstrates their compensatory role,” said Martin Johansson, a PhD candidate at Radboud and study co-author.

“In patients with severe symptoms, on the contrary, the cerebral cortex was much less active than in healthy volunteers,” Johansson added.

In further analyses, the researchers showed that Parkinson’s patients with more cortex activity also generally had less severe bradykinesia (slowed movement, a classic disease motor symptom) as well as better cognitive scores.

Overall, these findings “...support the hypothesis that person-to-person variability in symptom severity in Parkinson’s disease may be determined by compensatory cortical processes rather than basal ganglia dysfunction,” the scientists wrote.

“Accordingly,” the team added, “we predict that the worsening of motor symptoms is primarily driven by decline in parieto-premotor compensation.

The researchers currently are working on a study to further test this idea by tracking changes in patients’ cortex activity and motor symptoms over time.

Sources

[Parkinson’s News Today](#)

[Brain](#) journal

Diets proven to boost the body against Parkinson’s

So, how do you pick the best diet for Parkinson’s disease? Start with two basic ideas:

1. Eat whole foods. There is a strong association between pesticide and herbicide use and risk for Parkinson’s disease. Whether you choose animal or plant foods, select those that are raised as naturally as possible: meat and dairy from grass-fed cows; meat and eggs from pastured poultry; organically-grown whole grains, fresh vegetables, and fruits.

These nourish and maintain the body’s brain, bones, and organs. They may be more expensive, but consider the cost of disease, which is much greater.

2. Avoid foods that have been made from refined or highly-processed ingredients, such as refined flour and sugar, canned meats and soups, frozen ready-to-eat meals. Over time, these rob the body of health, strength, and thinking ability, and lead to cancer, diabetes, heart disease, stroke, and other diseases.

Who are the healthiest people and what do they eat?

Next, consider the diets of the longest-lived populations in the world. According to *National Geographic* Fellow Dan Buettner, who wrote influential diet and nutrition book *The Blue Zones: Lessons for Living Longer from the People Who’ve Lived the Longest*¹, the places where people live the longest, and the foods that make up their diet, are:

Ikaria, Greece

Staple foods: potatoes, wild greens, goat's milk, honey, garbanzo beans, black-eyed peas, lentils, fruit, wine, and small amounts of fish.

Okinawa, Japan

Staple foods: tofu, sweet potatoes, seaweed, turmeric, sake, bitter melons, garlic, brown rice, green tea, shitake mushrooms, and small amounts of fish.

Sardinia, Italy

Staple foods: goat's and sheep's milk and cheese, durum wheat, barley, fennel, fava beans, chickpeas, tomatoes, olive oil, almonds, milk thistle tea, and red wine.

Nicoya Peninsula, Costa Rica

Staple foods: beans, rice, corn, squash, yams, green vegetables, papayas, bananas and other fruits, cheese, eggs, and small amounts of meat.

Loma Linda, California

Staple foods: avocados, nuts, beans, oatmeal, whole wheat bread, soy milk, grains, fruits, nuts, and vegetables. They drink only water; some choose to eat small amounts of meat and fish.

But what about you?

Choose a plan that appeals to you and try it for a few months. Keep a daily journal and write down what you ate, at what time, how you felt afterwards – whether your Parkinson's symptoms are affected, and in what way.

This will tell you whether the diet choice is a good one for you personally and meets your individual needs as a person with Parkinson's disease.

If you have gastroparesis – a digestive problem that's a non-motor system of Parkinson's – you may find that a diet lower in fat helps your medications take effect more quickly.

If you suffer from constipation, a diet that includes plenty of prebiotic foods and fibre is ideal. Yet, you might have both gastroparesis and constipation and still find that a paleo diet improves your Parkinson's symptoms and that you can cut back on your medications.

You are the best judge

Your doctor only sees you for a few minutes every few months. Diet gurus will probably never meet you at all. You, on the other hand, live in your body 24 hours a day, seven days a week.

No one knows you better than you, yourself. That makes you best person to discover and take control of the optimal eating plan for you.

Source

Kathrynne Holden, former National Parkinson Foundation dietician (UK)
Visit her website, nutritionucanlivewith.com, for more Parkinson's-related nutrition information

References

Buettner, Dan, The Blue Zone: Lessons for Living Longer from the People Who've Lived the Longest, National Geographic Books, 2008

Getting started with Parkinson's-appropriate exercise

Regular exercise is second only to medication in improving your quality of life with Parkinson's. It is that important! When you do regular exercise, you'll quickly begin to see and feel the advantages it can have on your body and well-being. In just three to six weeks you should start to feel the beneficial changes.

Why should you exercise if you have Parkinson's? Because the benefits will be even greater to you than someone without Parkinson's. You will get the regular benefits we all know about such as improved heart and lung health, stronger muscles, and reduced risk of other health issues. Exercise will also lift your mood, improve your mental health, and help you sleep better.

On top of these benefits people with Parkinson's will also enjoy better symptom management and a greatly improved quality of life. For example those who do cardio-vascular exercise will commonly report a reduction of their tremor after exercise, along with improved balance, reduced fatigue, and increased energy levels. Parkinson's-specific exercise can also benefit neurological symptoms. In short, exercise is powerful and can help improve your life.

However, working it into your daily routine and sticking with it takes determination and discipline. Here are some strategies that can help you keep your exercise on track.

What to consider before you begin

1. Check your health. It's important to consult your healthcare provider and get a physical examination before starting an exercise routine.

This is particularly important for those new to strenuous and vigorous physical activities which, when safely done, are great for people with Parkinson's.

2. Choose a trainer who is a Parkinson's specific physiotherapist or exercise physiologist.

They can optimise your workout and make it manageable for you. Working with a Parkinson's specific trainer will help you understand your limitations and create an exercise plan tailored to your particular needs.

3. Make a plan with realistic goals. Use steps you know are achievable and build on those. For example you may want to be able to walk to the shops. Start by doing shorter walks around the house, then to the corner, building to the next corner... until you can make the whole walk to the shops.

Starting with small achievable goals will increase your chances of success and keep you motivated every step of the way.

4. Make exercise a habit. Making a schedule to exercising at the same time every day is a good way to sustain your routine and make it last. Even on days you don't feel well, do some form of milder exercise such as stretching or meditation in your normal exercise time.

For example, you can make exercise a habit by planning to work out every day, first thing in the morning. It's important to choose a time that works best for you and when your medication is working at it's optimum level.

Men and Parkinson's Disease

Men are twice as likely as women to have Parkinson's disease.

Ongoing research shows that probable reasons for this difference include toxicant exposure, head trauma, mitochondrial dysfunction, or genetic risk factors.

In fact, the sexes even experience Parkinson's symptoms differently.

Male Parkinson's patients show greater deficits in attention and working memory than female patients. They are also more prone to severe drooling and impulse control disorders such as pathological gambling and hypersexuality.

Biological sex also differently impacts emotion processing. For example, men show worse recognition of the emotion anger accompanied by reduced neural response.

Physically, men are also more prone to the severe forward bending of the trunk that occurs while standing or walking.

That's a diverse list of symptoms which illustrates that Parkinson's is a highly complex disease. It has more than 50 non-motor symptoms which manifest in different combinations and at different times in each individual.

Parkinson's is a life-long disease that is difficult to diagnose and there is as yet no cure. However we do know a lot about useful treatments which will help to maintain quality of life for as long as possible.

Medication for Parkinson's

Most people with Parkinson's disease eventually need a medication called levodopa. Levodopa is absorbed by the nerve cells in your brain and turned into the chemical dopamine, which is used to transmit messages between the parts of the brain and nerves that control movement.

Parkinson's is a movement disorder so topping up dopamine in your brain will help to treat stiffness and tremor as Parkinson's progresses.

Value of exercise

Vigorous exercise is second only to medication in effectiveness for slowing the progression of Parkinson's.

Research has shown that exercise can improve gait, balance, tremor, flexibility, grip strength and motor coordination.

Non-contact boxing and dancing are particularly helpful because they combine multiple rhythmic movements which require coordination as well as building muscular strength.

Other popular exercises include yoga, Tai Chi, treadmill training, Nordic walking (using poles to engage arms as well as legs), high intensity interval training and biking.

Parkinson's also affects the vocal cords, causing degeneration in speech quality and projection. Therefore, singing is a useful exercise as well – and there is a side benefit of social engagement if you join a choir.

What services will I require?

- Your neurologist will diagnose Parkinson's then put you on a course of medication. They will then monitor your progress and recommend changes in treatment as medicines wear off and other options become available.
- Your GP will also monitor your medication regime and offer ongoing advice on managing side effects and other symptoms such as difficulty sleeping, constipation, etc. They can also refer you to Allied Health providers who will assist you to proactively manage your condition.
- Allied Health services useful for people living with Parkinson's include physiotherapists, exercise physiologists, speech therapists, occupational therapists, and psychological counsellors (who will help you manage issues such as apathy, depression, and grief)

Where do I start? How do I make sense of my diagnosis?

Call 1800 644 189. This is the Parkinson's NSW InfoLine.

This is a specialist service (not a generic call centre) staffed by an experienced Parkinson's Registered Nurse and a pharmacist.

The InfoLine can:

- Talk you through the initial shock of diagnosis and advise on first steps to take
- Listen to your concerns and recommend practical changes you can make and/or services which can help – including Specialist Movement Disorder Neurologists.
- Connect you with Allied Health and Parkinson's NSW services including:
 - Community-based Parkinson's Specialist Nurses – many in regional and rural areas
 - Parkinson's Support Groups for social opportunities and non-judgemental peer support
 - Counselling
 - Verified providers of Allied Health Services
 - Parkinson's Clinics
 - National Disability Insurance Scheme Advocacy

1800 644 189
Parkinson's NSW InfoLine

Making a harp for Judy

By Geoff Grundy

Geoff Grundy, 72, lives with his wife Sue in a retirement village on the Central Coast. He was diagnosed with Parkinson's when he was 63. This is his story of how he put his musical and wood-working skills together to make his sister-in-law a harp.

Judy, my wife's sister, came to visit. I was playing a few tunes on my guitar. She said she would have liked to learn to play a musical instrument.

This was difficult now as Judy had a stroke which had left her paralysed on her left side.

I thought, what could she play? A harp! I had previously attempted to make a harp, but this was a failure. I underestimated the tension placed on the soundboard by the strings.

So I proceeded to design and make a harp, limiting myself to two octaves. I looked up a chart for string lengths, tensions, and sizes. Looked at a few different designs.

This time it worked – or at least didn't pull itself apart. It sounded terrible (twang twang). I tried a string change which made a difference. Tried a different harmonic arc. Finally sounds and looks ok.

I hope she enjoys learning to play it. I have put her in touch with fellow 'Parky' musical mate Martin Prior to assist her.

I have found making small instruments is good for my Parkinson's, the concentration, calculations, and planning keep me going.

There are days I am unable to do anything. Tools are very sharp, and one slip can cause a lot of damage – best not to touch when having shaky days. Frustrations when my mind is not quite connecting to the body.

The village where I live has a workshop where I can get assistance to break down the pieces of timber that I need. I try to recycle as much as I can: timber from old pianos, furniture and building materials.

After I get the timber roughly to size, everything is done by hand, There is not a lot needed – a good Japanese pull saw, a few sharp chisels of assorted sizes, a plane, scraper, measuring tapes, rulers, and lots of clamps. Oh... and patience – do a bit, wait for the glue to dry; do a bit more, wait for the glue to dry.

What once would take me one hour now takes two or more. There is confusion when doing calculations. Some days I can do nothing at all. Others I can manage.

I have built guitars, having made my first locally at the Australian Guitar Making School. So I was able to use the woodworking skills learned from this to make the harp.

Through Parkinson's I met Martin, who also has Parkinson's. We both have music interests. Martin has made several recordings. Hopefully, we will be able to get together and make a CD of our music using homemade instruments. (I will have to learn to play a harp first!)

It has now been seven years since my diagnosis. There have been some difficult times. I have learned to live within my limitations and have a good life with my wife, Sue, who puts up with the dust from sanding wood and hearing the same songs over and over until I get it how I want it (not necessarily as written).

I am 72 years young. Now my days start with meditation and tai chi. I walk when and where I can, One helps the brain, the other the body. I hope to have many good years ahead, Never give up.

Support Group Round-up

By Stacey Foster, Support Group Coordinator

Anytime I can visit with a Support Group or SGL either online or in person, I am happy! Thank you for having me, I enjoy meeting you all.

Starting off the year, I visited Albury-Wodonga Support Group online and share information of who Parkinson's NSW is and how we support people living with Parkinson's and their families. There were some great questions around nurses and

current research opportunities. Thank you for having me! The Support Group is very well led by Leanne Torpy, a Nurse Continence Specialist with Albury Wodonga Health. Leanne has a good team of health professionals around her too. Thank you for the work you all do running this Support Group!

Also in February, I visited Goulburn and Illawarra North Support Groups.

In Goulburn, I joined Parkinson's Nurse, Lauren Hogan. I gave a brief overview of Parkinson's NSW and Lauren spoke on the importance of exercise. It was great to see many people at the meeting and asking Lauren further questions about exercise and even her role as a nurse in the community. After a year of communicating with leaders Mick and Gill and assistant leader, Warwick either over email or online, it was wonderful to meet them in person. They are doing an excellent job whilst juggling many other pursuits and challenges. I extend my thanks to their new Treasurer, Rob Edwards for coming on board and supporting the leadership team.

Rounding out the month was my visit to Illawarra North. The purpose of my visit was to support outgoing SG leader, Sue Sarlos and the SG in transitioning to new leadership. It was wonderful to meet Sue and Jill (SG treasurer) in person, as well as the rest of the group. It was a very hot and humid day but we managed (I think!). A big thank you to Jill, Sue B, Trish and Lynda who all volunteered and are dividing the tasks amongst themselves to create a strong leadership team.

Before I go, I wanted to bring your attention to National Volunteer Week 20 – 26 May. It's *the* celebration of volunteers in Australia and provides an opportunity to highlight the important role of volunteers in our community. This year's theme is 'Something for Everyone'.

I look forward to celebrating with our volunteers that make up the Support Group Leaders and Teams in May

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.

Reserve your spot <https://pdwarrior.com/insight/>

April is Parkinson's Awareness Month

Share information about Parkinson's on your social media platforms, in your community, and among your friends, family and colleagues. Educating others about the symptoms, challenges, and available support for Parkinson's can help reduce stigma and increase understanding.

More information and resources [World Parkinson's Day is 11 April](#)

1800 644 189
Parkinson's NSW InfoLine