In Touch Newsletter
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30% of People use Coffee and Cannabis for Parkinson's, Study Finds

A new study in the Journal of Parkinson's Disease *reports that over a third of people use natural health aids like coffee and cannabis for Parkinson's – but less than half had discussed this with their doctor.*

A study published in the *Journal of Parkinson's Disease* has discovered that more than one third of people with Parkinson's are using natural health products to help treat their condition's symptoms.

The results of this study also revealed, however, that a worrying percentage of these people are not revealing to their healthcare professionals that they're using products like coffee, turmeric and cannabis for Parkinson's.

The study – by authors including Sandra Diadhiou from Université Laval in Canada, and Professor Bas Bloem from Radboud University Medical Center in the Netherlands – surveyed 367 people with Parkinson's from across the Netherlands, all of whom are part of the PRIME-NL (Proactive and Integrated Management and Empowerment of Parkinson's Disease – Netherlands) database.

The goal of the study was not only to find out about the prevalence of using natural health products to alleviate Parkinson's symptoms, but also to discover if respondents were aware of potential interactions between natural health products and their Parkinson's medication, and whether they'd discussed using natural health products with their doctor.

The results showed that:

- **36%** of respondents confirmed they were using natural health aids like coffee and cannabis for Parkinson's
- Of these, **coffee** was the most popular product in use (16% of respondents), followed by **cannabis** (13%) and **turmeric** (10%).
- Other supplements used included **velvet bean** and **chamomile**.

- **39%** of natural health product users were aware of possible interactions with prescribed Parkinson's medication.
- **Only 39%** of users had discussed these supplements with their healthcare provider.

The results of the survey led the study to make two recommendations: firstly, that there is "…the need for additional research efforts into the health benefits and safety of these products", and secondly, that "…open discussions with their healthcare providers are encouraged to ensure efficacy and safety."

A previous survey by the Michael J Fox Foundation in the USA during 2022 showed that, of almost 2,000 people surveyed, 70% were using medical cannabis for Parkinson's, but a third hadn't yet told their doctor.

Cannabis for Parkinson's: the facts so far

Parkinson's Europe and the Michael J Fox Foundation are among several prominent Parkinson's organisations – including The Parkinson's Foundation in the US, Fight Parkinson's in Australia, and Parkinson's UK – which have urged people to exercise caution around using cannabis for Parkinson's, citing a lack of current evidence into its efficacy and safety.

Parkinson's Europe Research Manager, Amelia Hursey, said:

"With homoeopathic and natural product treatments it's rare to be able to purchase products over the counter that have a high enough concentration level of the active compound to have a therapeutic effect. For instance, using Cannabinoids or CBD (an active ingredient in cannabis that is derived from the hemp plant) as a relaxant can work, however knowing what the concentration is within the item you consume and how much you would need to have a therapeutic effect is very hard to evaluate."

Parkinson's UK is currently running a research trial to see if Cannabidiol (CBD) can be used by people with Parkinson's to treat hallucinations and delusions.

Coffee for Parkinson's: the facts so far

There is a mixed consensus around how effective coffee is as a treatment for Parkinson's symptoms.

While some studies suggested that caffeine might help slow the development of symptoms, other research found that certain symptoms improved when treated with caffeine, but others got slightly worse.

A more recent study, which appeared in the *Annals of Neurology* journal in May 2024, concluded that caffeine does not improve symptoms.

Turmeric for Parkinson's: the facts so far

Turmeric is a spice made from the ground rootstalk of the curcuma plant, and an active ingredient of turmeric is curcumin, which has long been believed to have medicinal properties.

Turmeric is thought to help certain Parkinson's symptoms due to its antioxidant, anti-inflammatory and neuroprotective properties. A Japanese study has also found that turmeric oil could be beneficial in treating Parkinson's.

Sources:

Original article by Laura Vickers-Green
Parkinson's Europe
Journal of Parkinson's Disease
Annals of Neurology

Communication Tips for Family and Friends if Your Loved One has Parkinson's

If your loved one experiences speech and communication problems as part of their Parkinson's, there are ways you can support conversations. Here are some useful strategies to reduce frustrations and help make your conversations more successful.

1. Make sure you and the person with Parkinson's can see and hear each other. Facing someone with Parkinson's can be particularly important to help them communicate clearly and understand you. You don't need to shout.

2. Be patient. Give the person affected the opportunity to get involved in a conversation but don't pressure them to speak if they don't want to. They may need extra time to respond, so try not to interrupt or walk away.

3. Try to avoid speaking above noise, such as a TV or radio. Try not to be too far away – for example, in another room – when talking.

4. Be reassuring and help them to relax if you can see they're stressed.

5. If you don't understand what they say, ask them to repeat it more loudly and slowly. If it's just a key word you've missed ask them to repeat that word.

6. Try not to pretend you've understood if you haven't.

7. Try not to talk for the person, unless it's absolutely necessary.

8. Avoid finishing their sentences.

9. Don't accidentally ignore the person affected by asking someone to speak for them.

A speech therapist will be able to give you more advice on what you can do to make communication easier. Call the Parkinson's NSW InfoLine for more information on 1800 644 189.

Source:
Parkinson's UK

Bone Health and Parkinson's

People with Parkinson's have a higher risk of fracturing a bone than the general population, so it's especially important to look after your bone health.

Key points

- Bone health is important for everyone, but especially if you have Parkinson's.
- You are at more risk of getting osteoporosis when you have Parkinson's, which can weaken bones and make them more likely to break.

- Your healthcare team can assess you and may prescribe medication to help improve your bone health.
- Strength exercises and maintaining a good diet can also help.

What is bone health?

Bone health really means having ‘healthy bones’. Healthy bones are strong enough to prevent fractures, for example when we have a fall. Our bones are more healthy when we have enough calcium in our diet (from milk, and dairy products like cheese) and when we use our arms and legs (such as with exercise).

Both women and men need to make sure that they do the right things to keep their bones healthy.

Why is bone health so important if you have Parkinson’s?

Bone health is important for everyone, but especially if you have Parkinson's. This is for lots of reasons.

Osteoporosis is a condition that affects the bones, causing them to become weak and fragile and more likely to break. It’s often diagnosed in people with Parkinson’s.

The absorption of important nutrients like calcium is reduced if you have Parkinson’s. This can result in thinner bones that increases the risk of a fracture.

Loss of balance and falling affects many people with Parkinson’s. If your bone health is poor, a fall could lead to a broken bone.

Women are generally more likely to have ‘thinner’ bones than men, and bones become thinner as we get older. But men who have Parkinson’s may also develop thinning bones. So both women and men need to make sure that they do the right things to keep their bones healthy.

How does someone know how good their bone health is?

A number of different factors can help to work out what your risk of poor bone health is. These are combined in a ‘risk calculator’ that works out your future chance of having a bone fracture (usually over the next 10 years).

Your specialist, Parkinson’s nurse or GP can calculate your risk score. The Royal Osteoporosis Society also has a risk checker you can use.

When the risk is high, there are treatments that help to thicken bones and prevent fractures.

When you're at medium risk, you may be sent for a bone scan, also called a DEXA scan. This takes a scan of your bone density and can help decide if any treatment is needed.

When the risk is low, medication is not needed, but you should try to protect your bone health. See below for ways you can do this.

What can someone do to look after their bone health?

If we become inactive our bones get thinner, which increases the risks of having a fracture. Physical activity and exercise is good for bone health, as well as helping you manage your Parkinson's symptoms.

Diet is also very important, particularly calcium. Sources of calcium include milk and dairy products like cheese. Try to aim for 3 servings of milk or dairy foods every day to get the calcium you need.

Vitamin D helps to keep your bones healthy and helps your body absorb calcium. Most of the vitamin D you need comes from the effect of sunlight on your skin but what you eat can also help, especially during the winter. Good sources of vitamin D include oily fish (such as salmon and mackerel), red meat and eggs.

Is medication an option if you have poor bone health?

Medication can improve bone health when the risk of bone fracture is high, or if there is evidence of osteoporosis on a bone density scan.

Supplements like Vitamin D and calcium can help to strengthen bones. If someone is at higher risk, your doctor may also prescribe medication, which can make more calcium enter bones and help make them stronger.

In some people, a mixture of these treatments is helpful. In other people, a supplement is enough to improve bone health.

Like any medication, there are benefits and risks to taking a drug to improve bone health. Speak to your health professional to discuss whether they might be helpful for you to take to prevent or lower the risk of poor bone health.

Sources:
Professor Donald Grosset, Consultant Neurologist
Parkinson's UK

Choosing the Right Equipment to Help You Get Around

If your Parkinson's symptoms affect your ability to move around, there is a range of equipment available that you may find helpful. Here are some of the things you should consider to get the right aid for you.

Choosing a walking stick

1. ***What shoes do you usually wear?***

Wear your usual footwear when you choose or adjust your walking stick. If you stand with good upright posture the handle should line up with the bump at the bottom of your wrist bone, with your arm hanging naturally at your side. This will mean that your elbow bends slightly when you hold the handle.

2. ***How much upper body strength do you have?***

If your upper body isn't very strong, choose a stick that is light and easy to move forward in time with your stride. You may find the heavier three- or four-footed sticks are more difficult to move forward and may trip you up.

3. ***How is your dexterity?***

Choose a handle that is a shape and size that lets you grip it as strongly as you can.

4. ***How much do you weigh?***

Walking sticks are tested to a maximum weight, so check that yours is appropriate before buying.

Choosing a walking frame

1. ***Where will you use your walking frame?***

There are different sizes of walking frames. For example, will it fit through doorways when you're at home?

2. ***How tall are you?***

Four-wheeled walking frames tend to offer more support than three-wheeled ones because they are wider and are usually made of heavier materials. This makes them

good for taller or heavier people. But heavier frames may be more difficult to use, and to lift in and out of cars.

3. ***Do you fall often?***

A four-wheeled walking frame, which is heavier, may be more steady if you fall over more often, experience involuntary movements (dyskinesia) or tremor.

4. ***Do you experience rigidity or weakness in your hands?***

Sometimes a walking frame may 'get away' from the person using it and cause them to fall. There are different types of brakes available, but make sure they're easy for you to use as some can be difficult if you experience rigidity or weakness in your hands.

Choosing a wheelchair

1. ***Will you or someone else be regularly putting a wheelchair in a car?***

Look for one that is not heavy to lift, collapses easily and fits into your car or boot space.

2. ***How tall is the person who may be pushing you?***

Make sure handles are at a height that means the person pushing the wheelchair doesn't have to stoop down to reach them.

3. ***Where will you be using your wheelchair?***

Choose a wheelchair to suit the types of areas you will be out and about in. For example, if you'll be on pavements a lot, choose large enough wheels to go over kerbs easily and has anti-tipping features. A lap strap can be helpful, especially when going over kerbs or single steps.

4. ***How is your posture?***

A chest harness may be helpful if you slide out of a chair, or a one-way glide sheet that is designed to limit how easy it is to slide forward.

5. ***Do you experience dyskinesia?***

If so, look for a wheelchair which has sturdy footplates. Plastic footplates can break more easily, or can interfere with the freedom of the front wheels, especially for turns and reversing if they are pushed down.

Source:
Parkinson's UK

DBS-Plus Trial Shows Potential

At 69, Hoyt “Corky” Ball knew something was wrong when his right hand began to tremble uncontrollably. His primary doctor ruled out Parkinson’s, but the prescribed medication failed to alleviate his symptoms.

It wasn’t until Ball met Zain Guduru, M.D., a neurologist with the Kentucky Neuroscience Institute and Associate Professor in the University of Kentucky College of Medicine, that he received a definitive diagnosis.

“In about 10 minutes, he knew I had Parkinson’s,” Ball said.

Guduru suggested a treatment called deep brain stimulation (DBS). DBS is described as a ‘pacemaker for the brain’. By placing electrodes within malfunctioning brain pathways, DBS disrupts abnormal signals that causes tremors and other symptoms.

As Ball began researching his diagnosis and suggested treatment, he came across Craig van Horne, M.D., Ph.D., and his work on a procedure known as DBS-Plus.

First-of-its-kind clinical study

Van Horne, who is a neurosurgeon, is Co-Director of the University of Kentucky HealthCare Neuro-restoration Centre (NRC) and a team of physician-scientists and researchers leading a first-of-its-kind clinical study aimed at stopping or reversing the degenerative effects of Parkinson’s.

The study combines DBS with an experimental nerve-grafting procedure. The nerve cells are transplanted during DBS surgery, meaning patients do not have to undergo additional procedures.

In this combined approach, now known as DBS-Plus, the surgeon transplants peripheral nerve tissue into an area of the brain where neurons are dying. The grafted cells are being tested for their ability to release chemicals believed to rejuvenate the brain’s weary dopamine-producing neurons.

Van Horne and his team take a small piece of nerve tissue from the patient’s ankle and implant it in their brain. Because the tissue is from the patient’s own body, there are no concerns about rejection. DBS-Plus is considered relatively safe with only minimal additional risk.

To test the effect of the graft, researchers can simply turn off the DBS pulse generator and evaluate patient's symptoms at a baseline level. The team's vision is to alter the course of Parkinson's.

"Our concept for DBS-Plus, the 'plus' part being the nerve grafting, is disease modification," van Horne said. "Previously, all of the other transplant models were looking at symptoms and not disease progression and from that standpoint, that's where we can say the DBS-Plus has its big advantage."

Intrigued by the potential of DBS-Plus to not only help him but also advance medical understanding, Ball decided to participate. "I really didn't want to have DBS without doing DBS-Plus. It might not help me, but it may help somebody later," he said.

Remarkable improvements

Ball's journey with DBS-Plus began in February 2023, and he has since experienced remarkable improvements. Before DBS-Plus, his tremor made daily tasks nearly impossible.

"Talking to somebody, my hand just went crazy. I couldn't do anything with my right hand," he remembers. It was a tough reality for someone who was often on ladders and rooftops working in construction.

Today, Ball reports being 90% better.

"I don't think I will ever be 100%, but my life has improved greatly. My overall health is better. You can't tell I ever had Parkinson's," he said with a smile. Ball says his medication has reduced from 12 pills a day to just three.

"I've been able to continue my work as a school bus driver – a job I have done and love for eight years now. I also can play the guitar again which is also something I love to do."

How Often Should You Change Your Exercise Routine with Parkinson's?

Neuro physiotherapist Josefa Domingos gives expert advice on when and how often you should change your Parkinson's exercise routine.

Parkinson's can be an unpredictable and ever-changing condition, so getting your physical activity at a level that works for you can be an ongoing challenge, and leave you asking: "When and how often should you change your exercise routine?"

As an experienced neuro physiotherapist specialising in Parkinson's and other movement disorders, our Josefa Domingos has spent the last two decades helping people with Parkinson's to answer that very question, so we asked her for her expert tips:

What reasons are there to change your exercise routine?
"Here are some criteria I suggest people use to assess whether their current exercise routine remains beneficial and if changes are needed:

- **When it is no longer effective for their current health needs or goals.**
  This means that either a) the patient and/or family don't perceive any benefits, b) the person feels bad after exercise, or c) it doesn't help to achieve the person's goal.
- **When it is no longer safe**
  For instance, if a person feels unease during the activities and feels worse afterwards.
- **When they believe they can't do it**
  For instance, because of their skill level or health status.
- **When they stop enjoying it**
- **When it's no longer accessible**
  For reasons like time, location, costs, and how sustainable your routine is.
- **When scientific evidence identifies safety issues with your current choice of exercise**"

7 questions to ask yourself before changing your exercise routine
"The question of how often to change your exercise routine depends on many factors, so I recommend regularly asking yourself the following questions to help ensure that your current activities align with your needs and safety:

1. **Am I enjoying this?**
   Does the activity bring you joy, or is it causing stress or discomfort? Exercise should be something you look forward to.

2. **Is it safe for me?**
   Consider the safety of the environment, the intensity of the exercise, and whether you're using proper techniques. Is there a risk of falling or injury?
3. **Am I noticing positive changes?**
   For instance, are you experiencing improved mood, energy levels, balance, or overall quality of life?
4. **Do I have the right support?**
   Support is crucial to maintaining an exercise routine successfully. Do you have a workout buddy, trainer, or group that provides encouragement and assistance when needed?
5. **Is my routine flexible enough to adapt to my needs?**
   Can you adjust your exercise schedule or modify activities if your symptoms change or medication timing varies?
6. **Does it align with my health goals?**
   Are the activities you're doing helping you reach your fitness or mobility goals, or do you need to adjust your routine?
7. **Am I taking adequate rest and recovery time?**
   This is so important. Are you allowing yourself enough time to rest and recover between sessions to avoid overexertion and burnout?

What are the criteria for changing from high to low intensity exercise?
I would use the same questions as I suggested for the need for a change in general (see above).

Should people with Parkinson's who want to take up a new sport seek medical advice first?
Yes, it's highly recommended. All exercise guidelines suggest undergoing a full medical assessment before beginning any new sport or exercise program. This is especially crucial for people with Parkinson's due to the potential impact of symptoms on physical activity.

If you can't get an assessment immediately, make it a priority to schedule one as soon as possible to ensure that you're taking up the new sport safely and with the right precautions in place.

Sources:
Original article by Laura Vickers-Green

Parkinson's Europe

Take 5 - *April, 2025*

A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team (call 1800 644 189).

1. Managing Tremors with High-Intensity Movement

Regular high-intensity exercise can help manage tremors by improving motor control and brain health. Activities like boxing, cycling, and resistance training may reduce symptom severity. Programs like PD Warrior focus on neuroactive exercises specifically for Parkinson's. For tailored advice, contact our InfoLine for a referral to an experienced physiotherapist.

2. The Impact on Carers – Support Available

Caring for someone with Parkinson's can be physically and emotionally demanding. Parkinson's NSW offers carer support groups, counselling, and the InfoLine to provide guidance, emotional support, and practical advice. Additionally, Carer Gateway provides access to government-funded support services, including respite care, financial assistance, and coaching for carers. Seeking support can make a significant difference in maintaining well-being.

3. Early Onset Parkinson's

Parkinson's isn't just a condition affecting older adults—some people are diagnosed under the age of 50. Early onset Parkinson's can come with unique challenges, including work, family, and financial concerns. Connecting with tailored support through our InfoLine and specialist Movement Disorder Neurologists can help individuals navigate these challenges and access the right resources.

4. Deep Brain Stimulation (DBS) – When to Consider It

DBS is an option for some people with Parkinson's when medication alone no longer provides adequate symptom control. It's usually considered for those experiencing significant motor fluctuations or medication side effects. Consultation with a Movement Disorder Neurologist is essential to assess suitability. Parkinson's NSW also runs a DBS & Advanced Therapies Online Support Group, providing a space for those considering

or undergoing treatment to connect and share experiences. Contact our InfoLine for more details.

5. Low Mood and Anxiety – Supporting Mental Well-being
Many people with Parkinson's experience low mood or anxiety, which can be as challenging as physical symptoms. Exercise, social connection, and diet play a role, along with medical or psychological support when needed. Read about the 'four happy hormones' and how to boost them on the Parkinson's NSW website.

For personalised support or more resources on these topics, contact the InfoLine on 1800 644 189. We're here to help!

For evidence-based information and advice call the Parkinson's NSW InfoLine

(02) 8051 1900

Parkinson's NSW InfoLine

Email: **pnsw@parkinsonsnsw.org.au**

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