



Avoiding Toxins, Head Injury Key To Parkinson's Prevention, Study Says

(Parkinson's News January 2024)



Factors such as exposure to environmental toxins and repeated blows to the head – all of which can be reduced with prevention efforts – may account for nearly 1 in 3 cases of Parkinson's disease among men, and 1 in 4 among women.

That's according to a study of the neurodegenerative disease by researchers at the University of Alabama at Birmingham (UAB), who noted that "intrinsic risk factors (age, sex, and genetics) are inescapable, but environmental factors are not." These scientists are looking at risk prevention as a means of reducing Parkinson's prevalence.

"Parkinson's disease is rising fast globally, and there is an unspoken assumption that there is no prevention – but there is," Haydeh Payami,

PhD, a professor at UAB's Department of Neurology and in the Center for Neurodegeneration and

Experimental Therapeutics, said in a University news story.

Payami, the study's first author, added that this work "puts a number on how many cases of [Parkinson's] could potentially be prevented if toxic chemicals were eliminated and if we made contact sports like football safer."

The study, "Population fraction of Parkinson's disease attributable to preventable risk factors," was published as a brief communication in *npj Parkinson's Disease*.

Thank you to all who have recently raised funds to support Parkinson's Tasmania



Wynyard Ladies Golf Club



Bike Ride to End Parkinson's

From the President

– Mike Whitehouse

Members of the Parkinson's Tasmania Committee always have the interests of all our Tasmanian families affected by Parkinson's forefront in our minds. We aim to improve the wellbeing of all directly impacted by Parkinson's, their families and their carers. We undertake the commitment to pursue that in several ways. Here are some recent development highlights for you.

In Tasmania, Glenda Halliday Lecture

I am hopeful that many members of Parkinson's Tasmania were able to attend a free symposium with Professor Glenda Halliday, as keynote speaker, that was held on 19th February 2024. Glenda is an Australian leading neuroscientist specialising in neurodegeneration. She presented new information on Parkinson's, how it's caused, what happens to a person, new ways for diagnosis and concepts for treatments and cures. Parkinson's Tasmania was a major sponsor of the symposium.

Parkinson's Tasmania New Management Committee member.

The Management Committee of Parkinson's Tasmania is delighted to welcome Claire Myers as a new member. Clair is a lawyer; her skill set is that she is strategically minded, commercially

focused with nearly 20 years' experience in legal and corporate governance. Both her father, and grandmother lived with Parkinson's so appreciates firsthand the importance of support and information for those living with Parkinson's as well as their families and carers.

Nationally

National Parkinson's Action Plan

The National Parkinson's Alliance taskforce, as detailed in our November 2023 Journal, formally met with Senators Katrina Bilyk and Wendy Askew in Canberra during November 2023. They are the co-chairs of the Parliamentary Friends of Parkinson's, a group of 30 plus members from all political parties with a shared interest in Parkinson's. The concept of developing and delivery of a National Parkinson's Action Plan was set out by several speakers including a powerful presentation from Associate Professor Michele Calasaya, a Parkinson's Tasmania Committee member.

Since that meeting, the taskforce has prepared a Federal budget submission for funding to develop a National Parkinson's Action Plan. This strategy to address the unmet needs of the Parkinson's community will inform Federal and State government policy, strategies and initiatives in health, disability, aged care and research to ensure people living with Parkinson's and their families receive fair and equitable access and benefit from strategic investment in research. This will support improved integration of the needs of the Parkinson's community into current and future systems of support and care.

A National Summit to End Parkinson's will present the budget submission to members of the Parliamentary Friends of Parkinson's to seek their support in late March 2024. This Summit will provide an update on global progress to end Parkinson's and the key areas and initiatives required to support a new agenda for the Australian Parkinson's community through the development of a National Parkinson's Action Plan.

Types of Parkinson's

(Extract from Parkinson's UK)

Parkinsonism is a term that covers several conditions. This includes Parkinson's and other conditions with similar symptoms, such as slow movement, rigidity (stiffness) and problems with walking.

What is 'Parkinson's disease'?

Parkinsonism is an umbrella term used to cover a range of conditions that share similar symptoms to Parkinson's.

Some, including healthcare professionals and people living with the condition, will say Parkinson's disease, or PD for short. We call it Parkinson's. We don't use the word 'disease' because some people with Parkinson's have told us it sounds negative, or like an infectious illness. But unlike the flu or measles, you can't catch Parkinson's from someone.

We don't yet know exactly why people get Parkinson's. Researchers think it's a combination of age, genetic, and environmental factors that cause the dopamine-producing nerve cells to die. But they agree Parkinson's is not infectious, so we avoid the term 'disease'.

What are the main types of parkinsonism?

There are 3 main forms of parkinsonism, as well as other related conditions.

Idiopathic Parkinson's

Most people with parkinsonism have idiopathic Parkinson's, also known as Parkinson's. Idiopathic means the cause is unknown.

The most common symptoms of idiopathic Parkinson's are tremor, rigidity and slowness of movement.

Vascular parkinsonism

Vascular parkinsonism (also known as arteriosclerotic parkinsonism) affects people with restricted blood supply to the brain. Sometimes people who have had a mild stroke may develop this form of parkinsonism.

Common symptoms include problems with memory, sleep, mood and movement.

Drug-induced parkinsonism

Some drugs can cause parkinsonism.

Neuroleptic drugs (used to treat schizophrenia and other psychotic disorders), which block the action of the chemical dopamine in the brain, are thought to be the biggest cause of drug-induced parkinsonism.

The symptoms of drug-induced parkinsonism tend to stay the same – only in rare cases do they progress in the way that Parkinson's symptoms do.

Drug-induced parkinsonism only affects a small number of people, and most will recover within months – and often within days or weeks – of stopping the drug that's causing it.

Other types of parkinsonism

Multiple Systems Atrophy (MSA)

Like Parkinson's, MSA can cause stiffness and slowness of movement in the early stages. However, people with MSA can also develop symptoms that are unusual in early Parkinson's, such as unsteadiness, falls, bladder problems and dizziness.

Progressive Supranuclear Palsy (PSP)

PSP affects eye movement, balance, mobility, speech and swallowing. It's sometimes called Steele-Richardson-Olszewski syndrome.

There are several other, much rarer, possible causes of parkinsonism.

How is parkinsonism diagnosed?

You should be referred to a Parkinson's specialist for the diagnosis of any parkinsonism. They may wish to explore different things before giving you a diagnosis.

Your specialist will look at your medical history, ask you about your symptoms and do a medical examination.

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Telling the difference between types of parkinsonism isn't always easy, for the following reasons:

- The first symptoms of the different forms of parkinsonism are so similar.
- In many cases, parkinsonism develops gradually. Symptoms that allow your doctor to make a specific diagnosis may only appear as your condition progresses.
- Everyone with parkinsonism is different and has different symptoms.

One of the most useful tests to find out what sort of parkinsonism you may have is to see how you respond to treatment.

If your specialist thinks you have idiopathic Parkinson's, they'll expect you to have a good response to Parkinson's drugs such as levodopa (co-careldopa or co-beneldopa). A good response means that your symptoms will improve.

Sometimes, it will only be clear that you've responded to medication when the drug is reduced or stopped, and your symptoms become more obvious again.

If you don't have any response to Parkinson's medication, your specialist will have to look again at your diagnosis.

If you have both unusual symptoms and no response to Parkinson's drugs, this doesn't automatically mean you have another form of parkinsonism. But it will make your specialist want to reconsider your diagnosis.

In this case, your specialist may use the terms 'atypical parkinsonism' or 'Parkinson's plus'. These terms are not a diagnosis, they simply mean that you probably have something other than Parkinson's, perhaps one of the conditions mentioned in this information. Your specialist will be able to tell you more.

Getting the most out of your healthcare

(Extract from Parkinson's UK)

Good management of Parkinson's – including physical, emotional and social needs - lies in getting the right treatment for the right person at the right time – there is no 'one size fits all'

When you visit your GP, Specialist, Parkinson's Nurse or other Health Professional, you often don't have a lot of time to talk in detail about how you are. You may also see them when you're having a good day but the reality is that most of the time you are finding things difficult and need more help.

Monitoring your Parkinson's

Many people with Parkinson's find that keeping a diary is a helpful way of monitoring their condition.

A weekly or monthly Parkinson's diary can be very helpful in understanding how you are affected over a period of time. It can help with monitoring how the symptoms of Parkinson's affect you, how you respond to your medications and difficulties you encounter with everyday activities. A written record can be an accurate reflection of your life with Parkinson's over a period of weeks, months or years and can help in highlighting:

- the pattern of symptoms you experience
- the effectiveness of the medications you take and how long they last
- any side effects of medications
- any changes in your emotions or behaviour that may be related to medications.

Writing down your own individual experiences on a day-to-day basis can also help you effectively communicate any changes to your symptoms or your feelings with your Doctor and Nurse. This can be very useful, particularly as appointments are often too short for Doctors to ask lots of questions, and your visit may be on a day when your symptoms do not follow their general pattern. Being able to review how you have been over a period of time can help your Doctor and Nurse:

- understand how effective medications are for you personally
- pinpoint any particular difficulties you have with daily activities
- pinpoint patterns of symptoms
- decide on any necessary adjustments in medication dosage and timings.

Maintaining a diary can also help track your response to medications if adjustments have been made, to see how effective these changes have been and to decide if further alterations are necessary.

Of course, carers can play an important part in keeping a diary, helping to prompt you to note useful information on a regular basis. Your carer may wish to make contributions. They may also want to keep a carer's diary.

What type of Parkinson's diary should I use?

You may hear the terms 'Wearing off' and 'Motor' diary – both are ways of recording your symptoms in relation to medications you take. It can be helpful if you write details about medications in red and notes regarding symptoms and problems you experience in blue. You and your Doctor will then be able to see at a glance if there is a link between symptoms and your drugs, and if your medication needs adjusting because it is no longer providing adequate symptom control.

It may also be helpful to keep a medication record in which you record the name of each medication, the dosage, timings and also any special instructions for taking them, such as at mealtimes etc. This will provide your Doctor and Nurse with a snapshot so that you don't waste precious appointment time explaining to him or her what you take. Also, let him or her know of any difficulties you have with your medication regime, for example if you struggle with safety caps on bottles or if you have any difficulties swallowing tablets.

Keeping a communication record can also be helpful as this allows you to record specific things

you would like to discuss with your Doctor or Nurse at your next appointment.

What information should I record?

Providing the information is accurately recorded, the structure your diary takes is entirely up to you – you may prefer to write information on a blank sheet of paper or on a printed template for each day, or you may wish to use a computer. The most important thing is to record information that will be helpful to your Doctor or Nurse, such as:

- the times of day you take your medications
- the times of day you have good symptom control
- which symptoms re-emerge during the day and when
- which symptoms you experience at night
- any complications you may experience, such as dyskinesia, and when they occur – particularly in relation to medication times
- what meals and snacks you eat and at what time. Make a note of whether eating certain foods affects your symptom control – protein, for example, can interfere with the absorption of some medications wearing off symptoms – it may be helpful to rate each of these on a scale of one to five, according to how much they impact on your daily life. This can help evaluate the effectiveness of any change to your medication or dosage.



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Combat constipation with a diet rich in fiber from sources such as fresh fruits and vegetables, whole grains, vegetables, legumes, and whole-grain breads and cereals. Drinking plenty of fluids and exercising can also help you avoid constipation.

Dehydration: Medications that treat Parkinson's disease can dry you out. Not only can dehydration leave you more tired, over time, it can also lead to confusion, balance issues, weakness and kidney problems. Be sure to drink plenty of water and other fluids throughout the day.

Medication interaction: The drug most commonly used to treat Parkinson's disease, carbidopa-levodopa, is absorbed in your small intestine. That absorption can be disrupted if you take your medication shortly after eating a high-protein meal, since it involves the same process. To help maximize the medication's effects, eat high-protein foods at other times of the day. If you take your medicine in the morning, have oatmeal rather than high-protein eggs for breakfast, and save your protein intake for later in the day.

The Role of Exercise

Exercise can make the greatest impact on the course of your disease, says Denise Padilla-Davidson, a Johns Hopkins physical therapist who works with patients who have Parkinson's disease. "Movement, especially exercises that encourage balance and reciprocal patterns [movements that require coordination of both sides of your body], can actually slow progression of the disease," she says. Here's what you need to know:

Get your heart pumping: Many symptoms of Parkinson's disease that limit physical ability, such as impaired gait, problems with balance and strength, grip strength, and motor coordination, show improvement with regular cardiovascular exercise. For example, a review of studies on treadmill training found that regular walking workouts helped increase normal walking speed and lengthen stride length, which tends to shorten with Parkinson's disease.

Move it or lose it: As Parkinson's disease motor symptoms, like a slowed gait or tremor, become apparent, patients may become afraid of losing their balance and falling or dropping things, which leads to excessive caution and fear, which in turn

leads to an even more sedentary lifestyle. Experts know that formal exercise helps keep patients active and healthy, and research also shows that normal physical activity may be just as or more important than trips to the gym. Keeping up with routine daily activities, like washing dishes, folding laundry, yardwork, shopping — anything that gets and keeps you on your feet — helps delay the degeneration of motor symptoms.

Work out your brain: Exercise — again, anything that gets your heart pumping — may help the brain maintain neuroplasticity, which is the ability to maintain old connections and form new ones between the neurons in your brain. "The neuroplasticity created from exercise in patients with Parkinson's disease may actually outweigh the effects of neurodegeneration," says Padilla-Davidson.

Study finds pain to be common in early-onset Parkinson's

(Parkinson's News January 2024)

More than three-quarters of people with early-onset Parkinson's disease (EOPD) experience pain, according to a recent study conducted in Vietnam, with more severe pain reported by older patients and those with nonmotor symptoms such as depression, sexual dysfunction, and hallucinations.

Additional studies with well-validated tools are needed to further understand pain in this patient population and its interplay with other Parkinson's symptoms, according to scientists.

"Pain may be more common and severe in EOPD patients than previously appreciated," researchers wrote. "We hope this study will raise the astute clinician's suspicion when a patient with EOPD presents with uncontrolled pain."

The study, "Pain is common in early onset Parkinson's disease and pain severity is associated with age and worsening of motor and non-motor symptoms," was published in the *Journal of the Neurological Sciences*.



IN THIS TOGETHER
parkinson's
TASMANIA

Dates to Remember



SUPPORT GROUP MEETINGS

SOUTH

2.00pm Senior Citizens Club Rooms
Lambert Ave., Sandy Bay
28th February, 27th March, 24th April,
29th May 2024

NORTH

2.00pm Launceston Conference Centre,
Door of Hope Church, 50 Glen Dhu St., Launceston
12th March, 9th April, 14th May, 11th June 2024

NORTH WEST

2.00pm Gnomon Pavilion,
3 Wharf Road, Ulverstone
13th March, 10th April, 8th May, 12th June 2024

CARERS GET-TOGETHER

SOUTH

10.00am 12 Adelie Place, Kingston
21st March, 23rd May 2024

NORTH

2.00pm Launceston Conference Centre,
Door of Hope Church,
50 Glen Dhu St., Launceston
15th March, 14th June 2024

NORTH WEST

2.00pm Willaway Apartments,
2 Tucker Street, Ulverstone
14th March, 13th June 2024

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Contact Details

Mike Whitehouse President
42 Auburn Road, Kingston, TAS 7050
Mobile: 0448 710 882
Email: mike.whitehouse@bigpond.com

Pauline Domeney Secretary/Treasurer
12 Adelie Place, Kingston, TAS 7050
Phone: (03) 6229 2509 Mobile: 0407 314 933
Email: pdomeney@netspace.net.au

Business Address
PO BOX 608, Kingston, Tasmania 7051