

## In Touch Newsletter

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### Detecting Parkinson's by smell

By Elizabeth Quigley  
BBC Scotland news

A Scottish woman who found she could detect Parkinson's through smell has inspired scientists to develop a swab test that could be used to diagnose it.

Researchers in Manchester UK have created a new method which they say can detect the disease in three minutes.

Further study will be required to validate the findings before they can develop a diagnostic test that could be used in clinics or by GPs. Their work was inspired by Joy Milne, a retired nurse from Perth.

Joy, 72, knew her husband Les had Parkinson's more than 12 years before he was diagnosed when she identified a change in the way he smelled.

"He had this musty rather unpleasant smell especially round his shoulders and the back of his neck and his skin had definitely changed," she said.

She only linked the odour to the disease after Les was diagnosed and they met people at a Parkinson's UK support group who had the same distinctive smell. Les died in June 2015.

Now a team in the University of Manchester, working with Joy, has developed a simple skin-swab test which they claim is 95 percent accurate under laboratory conditions when it comes to telling whether people have Parkinson's.

The researchers analysed sebum – the oily substance on skin – which was collected by using a cotton swab on patients' backs, an area where it is less often washed away. Using mass spectrometry, they compared 79 people with Parkinson's with a healthy control group of 71 people.

The research found more than 4,000 unique compounds in the samples, of which 500 were different between people with Parkinson's and the control group.

The study is published in the *Journal of the American Chemical Society*.

Prof Perdita Barran, who led the research, said there was not currently a chemical test for Parkinson's disease and many thousands of people were on waiting lists for a neurological consultation. She said developing a confirmatory test that could be used by a GP would be "transformative".

“At the moment we have developed it in a research lab and we are now working with colleagues in hospital analytical labs to transfer our test to them so that it can work within a National Health Service environment,” she said.

“We are hoping within two years to be able to start to test people in the Manchester area.”

The scientists now need to validate their findings in a clinical lab before it can be used for patients.

James Jopling, the Scotland director of Parkinson’s UK, said the discovery could make a real difference to people living with the disease.

“Currently with no definitive test people have to wait months or years to be diagnosed so the fact that you could get the treatment and support you need and that researchers could begin new treatments is incredibly important,” he said.

Joy knows what an earlier diagnosis would have meant for her and her family.

“We would have spent more time with family,” she said. “We would have travelled more. If we had known earlier it might have explained the mood swings and depression.”

The night before her husband died, he made her promise to investigate her sense of smell.

According to Joy, he said: “You must do this because it will make a difference.”

She hopes her accidental discovery will do exactly that.

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## **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](http://nutritionucanlivewith.com), for more Parkinson's-related nutrition information

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## **Moving Around Safely at Home**

At home there are many things you can do to ensure safety if you experience postural instability.

### **Entry**

- Make sure the path or entrance to your front door is clear of trip hazards and well lit.
- Have handrails on both sides of all entry steps.
- Install a grab-bar or ramp if the front doorstep is difficult to negotiate

### **Kitchen**

Loss of balance can easily happen due to the stretching, bending, lifting and carrying that happens in the kitchen.

- Don't have things hanging. Put pans on the bench or leave them on the stove instead of hanging them or putting them into a cupboard.
- Store plates, bowls, cups and other regular items in a single, easily accessible drawer or shelf – not spread around the kitchen.
- Invest in a Reacher\*. This inexpensive tool can help in picking things up from the floor and getting things of high shelves or wiping spills while seated or standing.
- Have a sturdy chair close by in the kitchen so you can sit to do a variety of tasks.
- Use slide-out shelving, a Lazy Susan or tea cart to help make things easier to reach and move around the kitchen.
- Keep the floor dry and clean. Ensure you have paper towels and a Reacher close by to clean up spills immediately.

### **Living/Lounge Room**

Here are some minor adjustments can make your living room easier to navigate:

- Arrange the furniture around making moving around easier. Move anything that makes it difficult to get around. If you use a wheelchair or walker, you'll need extra room around the furniture.
- Make it easier to get into or out of chairs or sofas by adding a pillow to help raise the height or buy some chair-risers to use under the chair legs to raise the height of the seat.
- Remove all mats and rugs to prevent tripping. If this isn't possible, make sure there is a non-slip mat underneath and that the rug lies flat with no edges or corners sticking up. Tape them down if necessary.
- De-clutter and get rid of any trip hazards like electric cords and phone wires.

### **Bedroom**

- If your bedroom is upstairs, ensure you hold onto the railing when going both up and down – or if possible, convert a downstairs room into your bedroom.
- Have a rail by the bed so you have something to hold onto when getting out of bed in case you become dizzy.
- Make sure what you want at night is close by (like water, pills and phone). Also ensure there is a clear path to the bathroom. Use a torch if turning on a light will wake others.
- Use a sturdy armchair to dress and undress to save hopping around and possibly losing your balance. A long-handled shoehorn can help with putting shoes on, saving you bending and losing balance on the way up. Keep your clothes within easy reach so you're not reaching or bending to get them.

### **Bathroom**

- Don't rush to the bathroom. Go before you get desperate.
- Use low-pile, non-skid bathmats on wet and slippery floors. Non-slip rubber mats can be applied in the tub or shower to prevent slipping.
- Put a waterproof non-slip chair in the bathroom so you can sit whilst grooming yourself. These chairs can also be used in the shower.
- Keep shampoo, soap, etc within easy reach, on a shelf or ledge. Use a long-handled brush to clean feet, which save bending over and getting dizzy.

- A toilet seat riser and or safety rails are helpful when going to the toilet.

Bigger home modifications are expensive but sometimes necessary. Here are some ideas that may help.

- For a high curb or guttering, look into having it cut down.
- If the garage door sticks or is too heavy to lift, consider an automatic door.
- If outside stairs are a problem, cover them with a ramp or have a separate ramp installed.



*\* Reachers can be purchased at Kmart, Bunnings, mobility suppliers, and chemists.*

#### **References:**

<http://www.cec.health.nsw.gov.au/patient-safety-programs/adult-patient-safety/falls-prevention>

<https://www.medicalnewstoday.com/articles/balance-problems#when-to-see-a-doctor>

<https://www.webmd.com/women/features/avoid-falls>

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## **My [Parkinson's] Life Update**

### **Graham Saxby and his assistance dog Archer**

Just over three years ago Graham Saxby shared his life story with the Parkinson's NSW team.

His story included his career in hospitality and his volunteer work as a swimming instructor in the summer months, with about half the students having learning or physical limitations. He was also busy raising his two daughters after his marriage broke down.

Graham had been diagnosed with Parkinson's six years before, but he had continued employment until the COVID-19 lockdown put paid to many jobs.

When we first talked with Graham, he explained he'd decided to apply for a special assistance dog to prepare for the time when he would be living alone with his condition deteriorating. Now he explains why it took so long to be approved for a special assistance dog – along with changes to his house to help with his disabilities.

“Back then I had attended a Parkinson's support group meeting where an assistance dog trainer attended with their dog, to give a talk on how dogs can assist people with particular issues,” recalls Graham. “I was trying to plan for when my children leave home, and I knew that pets are good for a number of reasons.

“An assistance dog would also be able to help me in certain ways as my condition deteriorated and would keep me motivated-to get out and get exercise and talk to people each day, as well as providing company.”

### **Beginning the application process**

Graham duly put in an application through the NDIS process, filing the appropriate forms and lengthy reports from his occupational therapist, his clinical neuropsychologist, his neurologist, and other healthcare supports – as well as gaining acceptance of an application to the dog trainer.

“COVID interrupted the process but once it was put in, it was declined,” says Graham. “There were no formal reasons why and a new NDIS plan was just sent in the mail.”

Graham was shocked but followed up with an updated round of reports from all of those involved with his healthcare, and it was again declined.

“This time I was informed it was for duplication of supports, risk of harm (self or others), and the reasonable and necessary clauses,” says Graham. “There were a number of things which I didn't agree with.

“This time I decided, with help from Disability Advocacy, to appeal through the Administrative Appeals Tribunal (AAT) which again included all of the updated information on why an assistance dog would be to appropriate for me.

### **Missing documentation**

“This become even messier, as I discovered that 75 pages of medical and allied health reports had not been included in the original application appraisal and internal NDIS appeal. I had to resubmit the missing documentation to the AAT and to the NDIA. The home modifications were added at this time to the appeal.

“At the next AAT conference, I was asked to see an 'independent' neurologist by the NDIA. This was altered at the last minute to a review of only my medical records provided by the NDIA. So without full and up to date records, physically seeing me, a video conference or a phone call, the short report supplied by this professional questioned my diagnosis. Which meant it also questioned eight years of treatment, the competency of my treating health professionals, the value of support groups and finally the benefits that an assistance animal would provide me.

“That did my head in for a significant amount of time. I went from seeing my psychologist every few months to seeing them once a fortnight. I had to get more information to refute it with a specialist, physiotherapist, a dog trainer, and other things progressing on from there. It took quite a while, and it was still being refused by the NDIA. I ended up with a couple of thousand pages of documentation in this application and appeal process.”

In February this year Graham applied to have a review by an Independent Expert Review (IER) panel which had become available through the new Labor Federal Government.

“By April I had an acceptance and acknowledgement of all recommendations by the NDIA of the IER report,” says Graham. “After all the work, time, and delays before which took years, this review only took six weeks. During those three years I’d had my name down for three different dogs, two of which had finished their training and been placed with other people while I was still awaiting approval.”

### **Graham and Archer together at last**



The third dog, a labradoodle named Archer, has recently finished general training, and Graham and Archer are now getting settled in his newly modified house.

“He’s 20 months old,” says Graham. “We are working on him being able to do particular things like put certain items on a bench, pick up things, pull my socks off for me. They are specific tasks to help with my symptoms.

“An important one is that he does tactile prompting to get me out of reactive freezing – when I can’t move without tactile stimulus. We have bonded so well together, and he is giving me confidence to go out again to places with him, that I had found too difficult on my own.

“We are training together so I can be confident he can do things with me which will help me, aside from encouraging me to go out. It also means I can be independent and go out when and where I want to, without needing anyone else to come with me.”

Graham’s house modifications included new slip-resistant floorings, a wet-room bathroom, widened doorways, changed tap

fittings, new electric locks, improved lighting and replacement of worn manual roller shutters to help regulate heat retention and cooling.

His older daughter and her companion cavoodle moved back with her mother during the renovations and they hope to find her independent accommodation to assist her to independence as she lives with autism.

His younger daughter is doing her HSC this year.

“She is studying animal care as part of her HSC studies,” says Graham. “She loves dogs, so Archer fits right in.”

Planning for the future is something Graham continues to do proactively.

“I’ve also followed through with looking at medications and trialled Duodopa,” he says. “It’s the new in-clinic model instead of having to go into hospital, which is easier. That’s another known pathway going forward now.

“I want to do as much preparation for my future as I can while I have the capabilities. Having my house modified and having Archer able to keep me independent is so important for me. Getting things in place is vital before you’re unsafe.”

Meanwhile Graham plans to continue to work on fundraising for Parkinson’s NSW and looks forward to taking Archer to his support group, and explaining to others how an assistance dog could help them.

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## **Addressing Thinking Changes in Parkinson’s**

Parkinson’s disease changes the brain, which can impact the whole body. While slowed movement and stiffness are among the more familiar PD symptoms, Parkinson’s can also affect cognition – the way someone thinks, how they learn, make decisions, approach, and solve problems.

Though some people notice thinking changes (also called cognitive changes) decades after living with PD, others can begin noticing challenges even prior to a diagnosis.

Cognitive changes can be difficult to discuss. People sometimes fear that others will see or treat them differently if they open up about their thinking issues. Additionally, they may worry about losing their place in the family, livelihood, or independence.

Though challenging, recognising and talking about cognitive changes can help you and your care team identify the best therapies and coping strategies to promote your mental well-being.

## **Recognising Parkinson’s-related thinking changes**

Have you ever said, “don’t talk to me while I’m cooking,” or doing a specific task? While everyone struggles to some degree with multitasking, it is particularly difficult for people with Parkinson’s.

Other tasks that rely on executive function, such as participating in group conversations, reading a book, or balancing a bank account, can also be challenging.

Executive function is an umbrella term used to cover many cognitive skills that impact daily living. These skills include attention, focus and multitasking, as well as those involved in problem solving, planning, and following multi-step instructions.

These abilities help us accomplish everyday tasks and make important life decisions. Parkinson’s can also impact other cognitive areas, such as thinking speed, word-finding, language and speech, vision, depth perception and more.

### **Addressing cognitive symptoms**

Since Parkinson’s disease affects cognition, it can be hard to know whether memory and thinking changes are Parkinson’s-related or due to normal aging, medication, stress, sleep issues, depression, anxiety, or other health conditions.

If you or a loved one suspect memory or thinking changes, talk to your neurologist. Sometimes, adjusting Parkinson’s medications can help. Other times, effectively treating other symptoms and conditions can improve thinking issues.

Exercise is a powerful tool to improve not only PD movement symptoms, but some non-movement symptoms such as changes in memory and thinking.

Research shows that exercising regularly can improve concentration, information processing and overall cognition. Participating in a Parkinson’s-specific exercise class, going for a walk, taking a yoga or Tai Chi class, or stretching can help to improve your cognitive function.

Your neurologist might also refer you to other specialists, such as neuropsychologist or speech-language pathologist. These healthcare professionals offer specialised assessments and teach strategies to cope with thinking changes and improve daily living.

Self-care and support are important to a care partner's well-being at every stage of Parkinson’s. When a loved one is experiencing significant cognitive changes there is an increased risk of caregiver burnout.

### **Prioritizing mental wellness throughout cognitive change**

Self-care, creative strategies and staying social can help you maintain your mental well-being while coping with thinking changes. These tips can help:

Give yourself permission to feel grief. Our thoughts, memories, and the way we think form part of our identities. Experiencing cognitive change can cause feelings of loss. Recognise and honour your feelings around these changes.

Lighten your load. Accept help – whether with medication management, making your home safer, or transportation. Even though it can be difficult, accepting help allows you to focus on other important tasks and activities.

Lessen your stress. Research suggests stress can worsen movement and non-movement Parkinson's symptoms, including executive function and cognition. Exercise and mindfulness, the practice of being fully in the present moment, decrease stress and are linked to symptom improvement.

Use strategies to compensate. Sticking to a daily routine and limiting distractions can make it easier to remember the essentials. Reminders on your smartphone or on a piece of paper in the right location can also provide useful cues to keep you on track. Other strategies include gathering all items needed for a task – preparing a recipe, for example – and putting them away as you go.

Stay engaged. Building healthy social connections can help keep cognition strong. Foster relationships with friends, family, and members of your community. Consider finding a new support group to share your experience and connect with others.

### **Advanced Thinking Changes**

As Parkinson's advances, thinking changes can evolve from subtle changes to mild cognitive impairment (MCI) or even dementia – more severe thinking changes that can impact independence. Talk to your doctor about how to best manage advanced thinking changes.

Research shows some medications used in Alzheimer's disease may have benefits in Parkinson's disease dementia (PDD), including donepezil, galantamine and rivastigmine.

**Source:** [Parkinson's Foundation](#)

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## **“Finding information about being a woman with Parkinson's was challenging”**

*By Kathleen Reardon*

I was diagnosed with Parkinson's in 2002. I'd noticed something not quite right at the age of 49 but it took over two years of disagreements about what was wrong with me – doctors disagreed, mainly because I had mostly non-motor symptoms at first.

I felt adrift. Then a doctor was visiting at the place where I had an appointment. The visiting doctor quietly walked up to me after I was told it wasn't Parkinson's and privately said, "Come see me. It looks like Parkinson's to me".

### **Women are heard differently in medical settings**

I'm sure men experience a sense of feeling less attractive, but most cultures place a lot of emphasis on female beauty. Parkinson's is largely a disease of older people and so it's easy to feel older before you really are.

Facial masking can steal some of your sparkle and expressions can be misinterpreted. I found that a challenge at times even though my masking has been relatively minimal.

From earliest childhood, women are taught that it's important to smile. Girls and women, more than boys and men, are expected to be and appear amicable, sensitive and empathic.

When our facial expressions don't meet those societal expectations, people may take offense or withdraw as friends without ever even realising that they are reacting to something entirely out of our control. When it comes to doctors, they can assume that a woman with Parkinson's disease is depressed because expectations of amicable expression are greater for women.

### **'Complain' has significant implications for women**

I think it's important for women to insist that their medical practitioners remove the word 'complained' from their records. Doctors are often taught to write, 'The patient complained of x, y or z'. I explain to my doctors that the word 'complain' has more significant implications for women.

Research indicates that women are heard differently in medical settings. Doctors may inadvertently tune out if they consider what a female patient is saying as a complaint. While my doctors have smiled when I've mentioned this, they've changed their approach and in two cases taught their students to do the same.

They now write, 'The patient explained, described, discussed or emphasised'. If nothing else, it raises their awareness to an unconscious bias.

As women with Parkinson's, we need to listen to ourselves, and observe whether those around us, including our doctors, are hearing and heeding what we're saying.

We must work on maintaining and strengthening the volume of our voices – work with a speech pathologist or seek out one of the many videos or other tools designed for this. It is important, too, to prioritise what we have to say, and emphasise issues and items that are high on our list.

### **You're not alone**

I was a preventive medicine researcher, so finding sources about Parkinson's disease was not difficult. However, finding information about being a woman with Parkinson's was challenging.

For those issues that are not clinical, including those regarding gender, other female Parkinson's disease patients tend to be the best sources. Sharing provides understanding and empathy. It often leads to a sense that you're not alone.

Finding resources focusing on women and Parkinson's is still a challenge. Social media outlets have provided more opportunities to hear from and learn from women. If we had more opportunities for interactive discussions about issues particularly relevant to women, that would be useful.

## Sources

First published by [Parkinson's Life](#)

*Kathleen Reardon was a professor at the University of Southern California, and a visiting professor at Stanford University, US, Trinity College Dublin and University College Dublin, Ireland, and a distinguished research scholar at the Irish Management Institute, Ireland. She moved to Ireland shortly after her diagnosis with Parkinson's.*

## Being heard by doctors

Kathleen Reardon shares emphatic phrases to use when communicating with healthcare professionals.

- "This is key" – This is a good way to introduce a symptom that has become problematic.
- "That was important for me to tell you, but this is also critical" – This will cue a doctor to listen more carefully.
- "This is what I really want you to hear" – If you've already asked a question or delivered a message but the doctor is not providing the information you need in response, use this phrase before repeating or rephrasing as concisely and accurately as you can.
- "I'd like to repeat what you told me earlier because we skimmed over it" – Doctors may be pressed for time, but a patient should never agree to finish a visit without a thorough understanding of what has been discussed.