

PROGRESS

The research magazine of Parkinson's UK | Summer 2024

No one size fits all

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Research update

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PARKINSON'S^{UK}
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WELCOME

Hello and welcome to Progress magazine. My name is Nicky and I am a member of this wonderful community of people living with Parkinson's, and of the Progress editorial board.

My journey with Parkinson's began four years ago, just before the first Covid-19 lockdown. Despite being surrounded by a hugely supportive family, at the beginning it was incredibly lonely. Almost a year after my diagnosis, I was still trying to come to terms with the situation. Until one day, I stumbled across a quote which said, once you accept something you can work with it rather than battling it.

Acceptance was the turning point for me. My Parkinson's diagnosis was not a choice, but making the most of it was.

From that day I changed my approach. For the first time, I typed "Parkinson's" into Google, and that's when I found Parkinson's UK. I had so many questions, as did my family, and there is so much information to navigate. We've included answers to questions like I had on **page 4**.

Determined to make the most of my diagnosis, I became a Research Champion and a member of the editorial team for Progress. I'm now proud to take part in research, improving the lives of everyone with Parkinson's. If you'd like to know more about how you can take part too, head to **page 22**.

Life with Parkinson's is not without challenges, which is why my personal experience of Parkinson's is so valuable as a member of the Progress editorial team. I can help shape the magazine to focus on research that matters to me and others. I was particularly interested in reading more about the gut on **page 10**.

I have met some incredible people through the Parkinson's community who have supported me. I now know that it's there and I'm part of it, which has helped me to feel more confident looking to the future. Whether you are newly diagnosed or you have been navigating this journey for some time, I hope this latest edition of Progress brings some hope about the future of Parkinson's research.

Nicky Parsons



This magazine is produced by Parkinson's UK alongside our volunteer editorial board.

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GETTING ANSWERS



Nicky shared what it felt like when she was starting to come to terms with her diagnosis of Parkinson's, she had so many questions. We hope some of these answers might help those that may feel overwhelmed with questions.

What's Parkinson's?

Parkinson's is a condition where cells in the brain that produce a chemical called dopamine start to die over time and can't be replaced. Dopamine controls many things in the body, from mood to movement. So this lack of dopamine can lead to over 40 symptoms, which can be different for everyone.

What treatments are currently available?

There are currently no drug treatments that can slow or stop Parkinson's. But medication can help replace the lost dopamine, and improve symptoms. Deep brain stimulation (DBS) is a type of surgery that people may be offered if drug treatments become less effective at easing movement symptoms. And other non-drug treatments like keeping active, physiotherapy and speech and language therapy can go a long way to help manage symptoms.

What are the main research themes?

There's a lot going on in Parkinson's research. Researchers are working to better understand what causes the condition, as well as finding new ways to manage symptoms, and investigating treatments that could slow or stop Parkinson's.

Is there any research to improve diagnosis?

We know it can be difficult to get a diagnosis of Parkinson's. There is currently no simple test for the condition. But research is looking to change this and see if a blood test, or even a simple skin swab could help improve diagnosis. Better ways to help diagnose and track progression of the condition could help improve all aspects of research including finding new and better treatments for Parkinson's by improving how we measure whether a new drug is working.

How can I find more information and support?

Being diagnosed with Parkinson's can be a lonely experience. But Parkinson's UK is here to help you through your Parkinson's journey. Find support and advice on our website, request printed resources to read or call our helpline. We can help you find your nearest local group, emotional and practical support, health and wellbeing services or social activities.

Get the latest research news and opportunities sent to your inbox by signing up to the **Research Support Network** by scanning the QR code or visit parkinsons.org.uk/rsn



You can also email the Research team at research@parkinsons.org.uk or call them on **020 7963 3606**.

PARKINSON'S: NO ONE SIZE FITS ALL

There are over 40 symptoms associated with Parkinson's. And one person's experience can look very different to another. But why is that? And why could understanding this help in the search for better treatments?



Is Parkinson's more than one condition?

This is the million pound question, and the short answer is that at the moment we don't know. But what we do know is that Parkinson's can look very different from person to person.

We know that Parkinson's is a condition that affects the brain. Historically the main symptoms people have associated with the condition are movement symptoms such as tremor. But Parkinson's is more than this. The brain and nervous system are complex and span the whole body and therefore Parkinson's can cause a wide range of symptoms. There are over 40 symptoms that we know of so far, and there's no straight line path through a Parkinson's journey.

The variation in symptoms, experiences and progression of an individual's Parkinson's impacts on treatments too. What might work really well for one person, might not have the same effect for someone else. This also needs to be considered when designing research studies to measure the potential of new treatments.

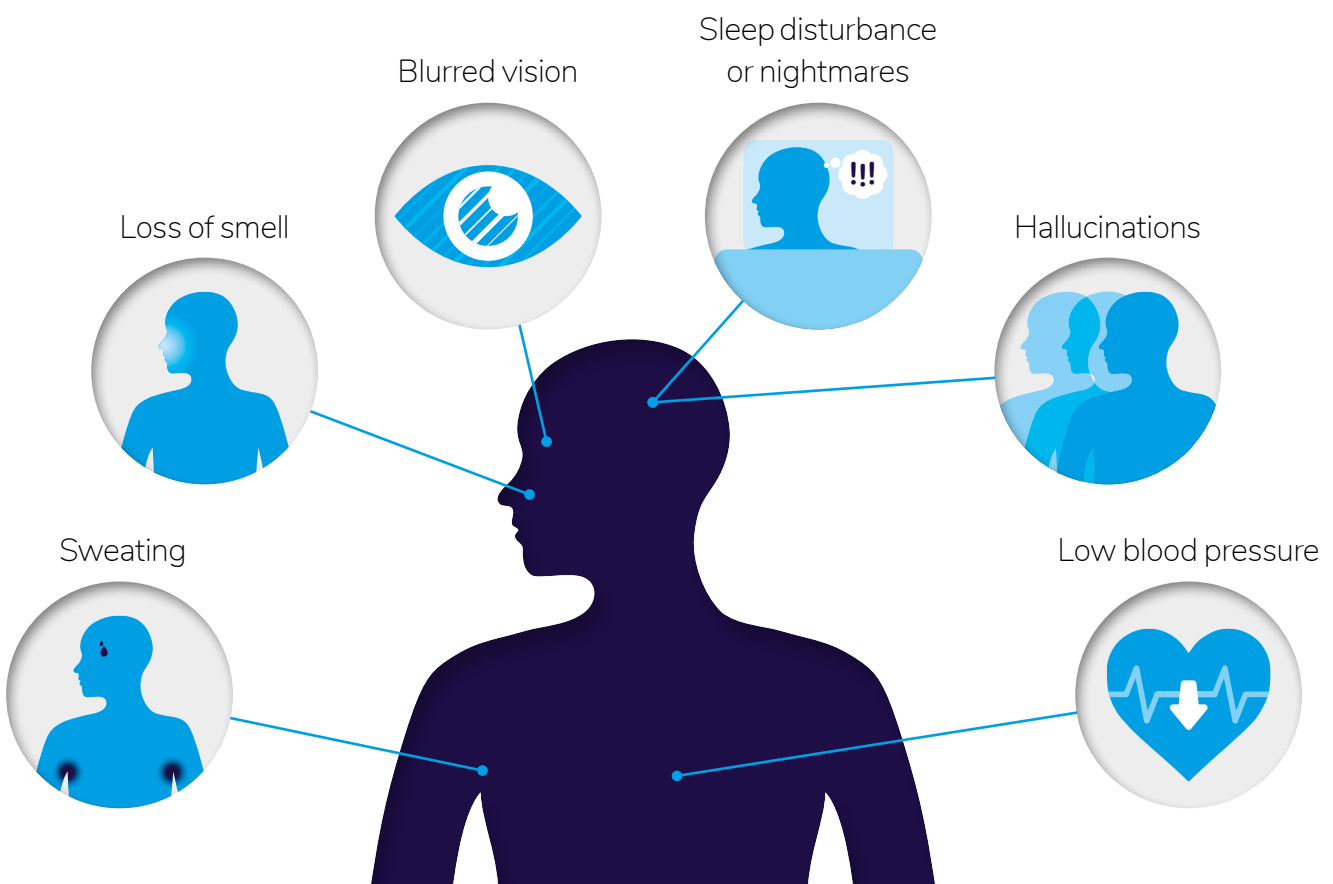


Margaret, a member of the Progress editorial board, said:

“As a carer for someone with Parkinson's, I found it helpful to be able to talk to others

at groups or meetings about the different symptoms they had, or their experiences on various medications. It becomes evident quickly that everyone is different. We found comfort in knowing that this was 'normal'.”

When you first think of Parkinson's, you might think about a tremor. But did you know these symptoms can all be associated with Parkinson's?



Why does Parkinson's look different?

A major need is for better ways of tracking the onset and progression of Parkinson's. To start characterising different types of Parkinson's, and group people who experience similar symptoms together. Understanding this could lead to a better and more personalised way to test new treatments, accelerating research.

Researchers are starting to build a picture.

Genes could predict risk of Parkinson's symptoms

Every person is different, and part of this is down to our DNA. DNA is packaged in groups of information, called genes, which hold the instructions that determine things like eye colour, hair colour and height. But they also hold the instructions for a huge range of proteins that carry out important functions that keep our bodies healthy. A mistake in a specific set of instructions might lead to someone being at a higher risk of developing particular health conditions.

While there isn't one gene that determines whether or not someone will develop Parkinson's, there are some genes that have been linked to an increased risk of the condition. One of the most common of these is a change in a gene called GBA1. It is thought anywhere between 3% and 20% of people with Parkinson's might have this.

It is also thought that in some cases changes in certain genes may also be linked to the likelihood of developing specific symptoms. For example, a study in 2022 showed that people who have changes in the GBA1 gene and Parkinson's might be more likely to experience memory and thinking problems.

Women could be more likely to experience some side effects to medication

But other factors outside of our genes could be important too. As research studies start to include more women living with Parkinson's, it has become evident that some symptoms are more common in women, such as depression or fatigue. And when evaluating treatments, women reported more side effects like uncontrolled movements, known as dyskinesia, than men taking the same drug.

Cramping could be more common in people diagnosed younger

Cramping or slowness of movement might be more common in people diagnosed with young onset Parkinson's. However, people with young onset Parkinson's tend to find their symptoms progress more slowly than someone diagnosed at an older age.



Early signs of Parkinson's may differ between people of different ethnic backgrounds

We know that people of Black, Asian or mixed heritage have not always been represented in Parkinson's research. This means we could be missing clues about Parkinson's in people with these backgrounds. More research is starting to focus on improving diversity of participants to ensure experiences are representative of the whole Parkinson's community.

A Parkinson's UK funded study Predict PD is leading the way to understand more about the early signs of Parkinson's in a group of over 10,000 people that are representative of the UK population in terms of background, race and social factors.

Knowing more about these different experiences can help researchers and healthcare professionals understand how a person is progressing with the condition, or what their 'normal' might be.



Ellen, a person with Parkinson's and a research volunteer at Parkinson's UK, said:

“Parkinson's is frustrating. With such a wide range of symptoms, it's hard to know what is due to Parkinson's and what

isn't. It feels like almost anything can be ascribed to Parkinson's, and you are losing your identity in Parkinson's land.”

“Wouldn't it be great if we could have more clearly-defined types of Parkinson's, where an individual understood the reasons for a symptom, and had a better idea of what the future might hold for them in terms of progression and specific treatments.”

Why is this happening?

Some people would argue all of these different experiences suggest Parkinson's might actually be an umbrella term and that people have a specific type and stage of Parkinson's.

For most people, Parkinson's is associated with a buildup of clumps of a protein called alpha-synuclein. The clumps of alpha-synuclein can start to contribute to the damage of cells in the brain.

Clumps of alpha-synuclein can be found in an area of the brain that produces a chemical called dopamine, which controls movement. But by studying brain tissue samples donated by people with Parkinson's to places like the Parkinson's UK Brain Bank, researchers have found other areas of the brain can also be affected. For example, researchers have seen clumps of alpha-synuclein in areas of the brain that control sleep, or sense of smell, or memory and thinking.

Clumps of alpha-synuclein have been found in other parts of the body too, particularly in the gut.

The brain-first vs body-first theory of Parkinson's

Some researchers suggest that the difference between individuals' experience of Parkinson's might be down to where these clumps of alpha-synuclein first start to form. This is known as the 'brain-first vs body-first' hypothesis.

The brain vs body hypothesis suggests that for some people with Parkinson's, clumps of alpha-synuclein are first found in the gut. And for many, early symptoms of Parkinson's do include problems with digestion and constipation. This could be evidence for body-first Parkinson's.



Professor Per Borghammer of Aarhus University is a Consultant Neurologist and researcher. He shared with Progress magazine:

“An improved understanding of fundamental mechanisms of Parkinson’s is crucial and may lead to breakthroughs in treating and preventing the disorder. The brain vs body model represents a new framework for conducting research and testing hypotheses.”

For others, alpha-synuclein clumps might first start to form in the area of the brain that controls smell, the olfactory bulb. A loss of smell might be their first symptom - this is evidence for brain-first Parkinson’s.

Over time, alpha-synuclein could then spread to other areas in the brain or body. So someone might start by noticing a loss of smell, but then start to experience other symptoms as the clumps spread to other places, like changes in mood, or a disturbance to their sleep.

It might be many years before they experience problems with movement, such as a tremor, as the clumps of alpha-synuclein haven’t reached that area of the brain yet. But often it’s only when these symptoms occur that the person receives a diagnosis of Parkinson’s.

Why is this important?

If we can understand more about different types of a condition, we can go a long way to help treat it. Take breast cancer as an example. Researchers discovered that breast cancer tumours had different properties, so while some had more of one protein, others had less. Using this knowledge, they were able to develop treatments that were specifically targeted to one type of cancer cell over another. Not only does this increase the chance a treatment might be successful, it could also help reduce potential side effects.

It would be great to have a similar approach for treating Parkinson’s. If we could pinpoint the exact origins of someone’s Parkinson’s, we might be able to develop personalised treatments that could slow or stop its progression.

Having a better understanding of different types of Parkinson’s could help improve research studies too. We might be struggling to show the benefit of new treatments because the groups we are currently testing them in are too broad.

Not one size fits all

The jury is still out on whether or not Parkinson’s really is more than one condition. But there’s plenty of reason to look into this area of research in more detail.

What we do know for certain is that everyone’s experience is unique. Which is why it’s all the more important that everyone is represented in Parkinson’s research. Unless we can capture the full picture, we risk developing treatments that aren’t suitable for everyone, or building research studies that suit some experiences of Parkinson’s more than others. Head to **page 20** to find out more about why Parkinson’s research needs you.



LOOKING AFTER YOUR GUT

What's the research evidence for why gut health is important in Parkinson's?

What are we talking about when we say the gut?

“The gut” is often used when people are referring to the gastrointestinal system, which includes the stomach and intestines.

The gut is responsible for breaking down the foods that we eat to provide energy and nutrients to support the health, protection, repair and function of our bodies. Tiny microbes in our guts have a role to play in this.

What is the gut microbiome?

Everyone has trillions of microbes (microscopic organisms) living in their gut, especially in the large intestine. These make up our gut microbiome, which can help send signals to control important processes within the body.

A lot of these microbes are what people refer to as “good” or “helpful” bacteria, aiding digestion and general health. As well as this, they keep the potentially harmful microbes at a level where they don't cause trouble. This is what happens in a healthy gut.

But this careful balance can be disturbed. This is known as dysbiosis. Diet is one factor in maintaining a healthy gut but researchers are also trying to understand how dysbiosis is involved in health conditions such as Parkinson's.

Does Parkinson's start in the gut?

The gut-brain axis is a two-way communication system where our gut and our brain can send messages to each other.

It is the vagus nerve that connects the brain to all of our organs, including the gut. The simplified illustration to the right might help you visualise this.

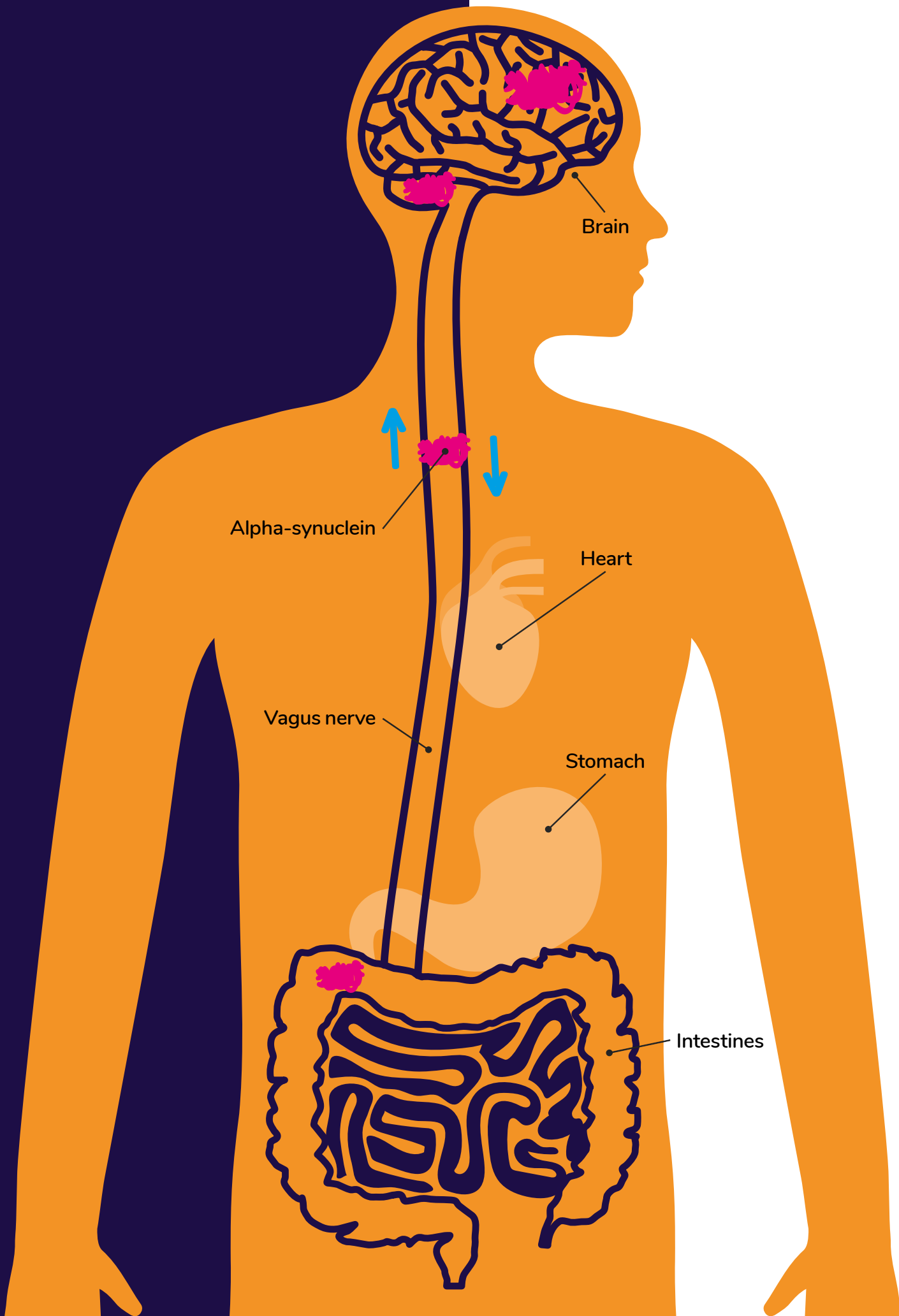
As introduced in the previous article, there is research that is looking to uncover the origins of Parkinson's and this may be outside of the brain.

A protein called alpha-synuclein, which is known to stick together and form troublesome clumps in brain cells of people with Parkinson's, might actually originate in the gut. The vagus nerve is thought to offer the route for alpha-synuclein to travel around the body and ultimately cause problems in the brain.

There are a few key pieces of evidence to support the spread of alpha-synuclein from the gut to the brain:

- Toxic clumps of alpha-synuclein have been observed in the gut of some people up to 20 years before a Parkinson's diagnosis.
- Alpha-synuclein has been found in the vagus nerve that links the gut and the brain.
- A procedure from the 1970s and 1980s to treat ulcers, where they cut the vagus nerve, was linked to a reduced risk of Parkinson's.

It is thought particular bacteria in the gut microbiome may play a role in speeding up the spread of alpha-synuclein from the gut to the brain.








The gut microbiome and Parkinson's




There have been a number of studies looking at stool (poo) samples from people with and without Parkinson's to understand how the gut microbiome differs. In January 2023, the most comprehensive of such studies was published. The researchers looked at samples from 490 people with Parkinson's and 234 people without Parkinson's. They found that 55 gut bacterial species were increased and 29 were decreased in people with Parkinson's compared to those without the condition.

The researchers looked at the properties of these pinpointed bacteria to start building a picture of what impact these changes might be having for people with Parkinson's.

Contributing to the progression of the condition

-  Increased levels of gut bacteria linked to higher levels of inflammation. While inflammation is the body's natural response to injury, high levels of inflammation can cause damage.
-  Increased levels of gut bacteria that might lead to accelerated clumping of alpha-synuclein.
-  Reduced levels of bacteria that are usually involved in protecting the brain against toxins.

Contributing to symptoms

-  Increased levels of bacteria that might actually break down Parkinson's medication, such as levodopa, in the gut before the medication can be absorbed.
-  Increased levels of bacteria that may actually inhibit the production of dopamine, which is already in short supply in Parkinson's.
-  Reduced levels of bacteria that help with regular bowel movements. This might help explain why constipation is a common symptom of Parkinson's.

This research offers a snapshot into how changes in the gut microbiome might be contributing to Parkinson's. More research is needed to explore some of these bacterial species in more detail.

Restoring the balance in the gut

It is not clear when and what is causing changes in the gut microbiome in Parkinson's. More research is needed to understand this. But the good news is there is work underway to find ways that could help to restore the balance.

There are a few different areas of research that are underway, including the investigation of transplantation of gut microbiomes from people without Parkinson's into people with the condition, looking at the role of diet and supplements, and finding ways to replicate the protective effects of certain bacterial species for Parkinson's.

Let's spotlight some of the progress in this area.

From worms to humans: Update on Dr Maria Doitsidou's research

Some of you might remember in previous editions of Progress, we mentioned work funded by Parkinson's UK being carried out by a research team in Edinburgh, led by Dr Maria Doitsidou. Her team were looking at worms to pinpoint gut bacteria that might have a protective role in slowing the accumulation of the troublesome protein, alpha-synuclein. In 2020, they published their findings that *Bacillus subtilis* looked like it might play this role in worms. This research is now gathering momentum to try and uncover how this particular group of bacteria might be providing protection with the hope this could lead to drug development in this area.

As well as this, they are carrying out a study that uses a probiotic *Bacillus subtilis* made by ADM-Protexin to see if it has any benefits in people with Parkinson's. This is currently underway and researchers expect for the results to be shared late next year.



“Thanks to a grant from Parkinson's UK, made possible through the generosity of their supporters, we were able to make key discoveries that have now progressed from observations in worms to a clinical study for people with Parkinson's.”

Clinical trial results showing potential for Symprove

The SymPD clinical trial was awarded funding by Parkinson's UK to Professor K Ray Chaudhuri and his team, at King's College Hospital NHS Foundation Trust. The team investigated whether Symprove, a patented water-based solution of live and active bacteria for gut support, could help with motor and non-motor symptoms of Parkinson's.

The researchers carried out a study in 74 people with Parkinson's who experience constipation, where half received Symprove daily for 12 weeks and the other half received a placebo (dummy solution). The researchers set out to see if the probiotic was changing the participants' gut bacteria, as well as looking at motor and non-motor symptoms.

Covid-19 hugely delayed this research but the initial results have now been shared.

The results suggest that Symprove alters gut bacteria, changing levels of certain bacteria that might have an overall beneficial effect. Symprove also seems to be helping Parkinson's drugs to work more quickly (achieving quicker 'time-to-ON') and therefore helping with movement symptoms. There is also evidence to suggest an improvement in non-motor symptoms, especially in anxiety, fatigue, constipation and sleep.

We are waiting on the publication of the full results and will be working to understand what's next. The results from this study offer more evidence for probiotic use in Parkinson's.

Is Symprove available now?

- We've partnered with Symprove for a number of years to offer Parkinson's UK members the supplement to try at a discounted price. To find out more or to order and claim your discount, call Symprove on **01252 413 600** to speak to one of their experts.
- Not a member? Find out more and join us at parkinsons.org.uk/join or call our Supporter Care Team on **0800 138 6593**.
- This information is not provided as health advice and we would encourage people to consult their healthcare professionals before making dietary changes or taking new supplements and probiotics.
- Symprove is not the only supplement supporting gut health available to buy.





What can people do now to encourage good gut health?

Probiotics

Probiotics have live bacteria in them with the aim to boost “good” bacteria in the gut and help manage gut symptoms as well as having the possibility to help with others. It is important to note that not all probiotics on the market will have been tested to check the bacteria actually reach the gut. Symprove and bio-kult are two probiotics that have been shown to reach the gut and are being used in Parkinson’s research.

Balanced diet

It has been shown a balanced diet can help encourage a healthy gut microbiome.

Professor K Ray Chaudhuri, Consultant Neurologist and leading Parkinson’s researcher, shares some of the advice he uses when consulting with his Parkinson’s patients:

“There is evidence to suggest that a Mediterranean style diet might be beneficial in Parkinson’s. This means lots of leafy greens and pulses, or swapping butter and ghee for olive oil. Adding fibre rich foods like brown or ofada rice may also help.”

Helping Parkinson’s medication to work

A lot of Parkinson’s medication is taken orally which means it needs to be absorbed from the gut into the bloodstream, to then travel to the brain. This is essential if medication is to work properly.

Professor K Ray Chaudhuri also shares how he has helped his patients to optimise their medication regime and shows how small changes might have a huge impact on how someone manages their condition:

“We advise that people take medication on an empty stomach to help absorption (30-40 mins before a meal or wait 30-40 mins after a meal). This is because protein in diets can directly compete with medication, slowing down how the medication is working. A lot of people will avoid eating but some will forget that drinking a milky coffee or tea after taking medication is going to hinder medication absorption. We call this the Café latte effect.

“We understand that it can be a challenge to space out eating around medication but I encourage people to chat to their healthcare professionals if they are concerned about the efficiency of their medication.”

There are other ways of delivering medication which we explore in the Q and A section on **page 25**.

WHAT'S NEW IN RESEARCH AT PARKINSON'S UK



I am Professor David Dexter, Director of Research, and I want to share some updates and things to look out for.

Back in 2023 I became the Director of Research. I work with a fantastic team of 19, along with five colleagues working in the Parkinson's Virtual Biotech. Together we fund, communicate and involve people with Parkinson's and their loved ones in research.

Flurry of activity towards better tests for Parkinson's

There is an increasing number of stories in the news about new tests for Parkinson's, from the potential of blood tests to eye scans. The hope is to explore how these tests might help detect Parkinson's earlier and be used in clinical trials to select the right people for research and to better measure the success of possible new treatments.

We are part of an international collaboration to strengthen this area of research. Earlier this year, the collaboration published a framework to show that two new tests could and should be used in clinical research.

- A new test that can identify misfolded alpha-synuclein.
- A brain scan called a DaTSCAN that can tell if there is a lack of dopamine inside the brain.

These two tests are a great start and we hope to see more sensitive and patient friendly tests added into the framework in the near future.

Tests have made a huge difference in other conditions like cancer and HIV and now it's time for the same revolution in Parkinson's.

We're currently funding **over £15m** towards our research grants programme across **45 projects**. **16 new research projects** joined our portfolio in the last year, including:



4 new projects to develop pioneering non-drug approaches to manage Parkinson's



3 drug accelerator awards to help researchers take discoveries from the lab into drug development



7 project grants exploring important new research ideas



2 fellowships to help foster the next generation of leading Parkinson's researchers.

Things to keep an eye on

We've been working on a new way to help people with Parkinson's make confident choices about devices and apps that might improve their quality of life. This Parkinson's UK Tech Guide will be built around comprehensive product reviews, as well as other information you might need. It will be available on our website, in print and by email. We're extremely excited about this project and hope it will make a real difference for our community.

We continue to collaborate and stay up to date with what other organisations and charities are up to. I am particularly excited about the results of the phase 3 trial of a drug called exenatide, funded by Cure Parkinson's. Exenatide is a type two diabetes

drug that is being investigated for people with Parkinson's to see if it can slow the progression of the condition and results are expected later this year.

We are part of an exciting collaborative effort to explore and set up a multi-arm, multi-stage clinical trial for Parkinson's, called ACT-PD. This means testing multiple drugs or therapies in groups of people with Parkinson's at the same time, with a more continual flow of progress. If something is shown to be successful it won't need to be paused for long periods of time to seek further funding or set up new separate trials. The planning is taking shape and it will hopefully be something you will be hearing more about.

Ellen, one of our lay grant reviewers, shares what new research she is most excited about.

“I saw this particular project all the way through the process from the initial proposed idea for the grant application, to the grant application, to it being awarded. It is a research project led by Dr Julie Jones, in Scotland, to use portable augmented reality glasses that enable the wearer to interact with physical activities and exercises that aim to help improve mobility. 60 people with Parkinson's will trial the glasses over a period of six weeks.”

“I like that this research is practical, will use immediate feedback of whether the glasses and physical activity are useful and follows the individual's progress and gets harder accordingly. It gives the control to the person with Parkinson's. I look forward to following the progress of this study.”

Thank you

None of our research would be possible without your interest and support.

To discover more about our research projects, like Dr Julie Jones' (pictured below), you can scan the QR code or go to parkinsons.org.uk/projects



AN UPDATE FROM THE PARKINSON'S VIRTUAL BIOTECH

What is the Parkinson's Virtual Biotech?

- We believe new and better treatments for Parkinson's are possible, but there is simply not enough focus or investment in turning exciting discoveries into new treatments.
- That's where the Parkinson's Virtual Biotech comes in, to bridge this gap and invest in drug development, to help move new drugs towards clinical trials and even help invest in the trials themselves.



We have invested in **18 projects** so far through the **Virtual Biotech**.



5 new projects announced this year!

Results

Hope for a new treatment for dyskinesia

The Parkinson's Virtual Biotech partnered with a company called Neurolix and the Michael J. Fox Foundation for Parkinson's Research to carry out a clinical trial to assess the safety and benefit of a drug called NLX-112.

Encouraging results were shared in July 2023 to show the drug's promise for managing dyskinesia, involuntary movements, and also movement symptoms more widely.

22 people with Parkinson's took part in the trial. 15 participants had the drug and seven participants had a dummy drug, also known as a placebo. The participants took the drug for eight weeks.

A larger study is now needed. Neurolix are keeping us updated and we will share more information when we have it.

Active projects to keep an eye on

- We're getting closer to the start of a phase 3 trial for Ambroxol (ASPro-PD), the final hurdle for investigating a potential treatment before it can be approved.
- The TOP HAT trial looking at ondansetron for Parkinson's hallucinations has closed to recruitment but data is being analysed to understand the potential for people with Parkinson's who experience hallucinations.
- A trial of cannabidiol (CBD) continues to recruit people with Parkinson's who experience hallucinations or delusions. See **page 22** for more information.

New projects

Reducing harmful inflammation in Parkinson's

Total investment approved to date: **£2.1m**

Working with a company called Neumora Therapeutics to test the safety of a new drug, that has the potential to slow or stop Parkinson's by targeting neuroinflammation, in animal models to progress it towards clinical trials.

UK based clinical trial of potential drug to protect brain cells

Total investment approved to date: **£1.25m**

Investing in Mission Therapeutics, alongside the Michael J. Fox Foundation for Parkinson's Research, to see whether a potential new treatment, MTX325, is safe, gets into the brain and improves energy production in brain cells of people with Parkinson's. The clinical trial is in the planning stages and we hope there will be an opportunity for a small number of people in the UK to take part.

Clinical trial to explore benefits of a pioneering treatment

Total investment approved to date: **£1.55m**

Investing in Herantis Pharma, alongside The Michael J. Fox Foundation for Parkinson's Research, to carry out the first clinical trial of a pioneering new treatment, HER-096, in people with Parkinson's. It is a potential treatment that might be able to protect brain cells. This new study will see if it is safe and start to explore its potential benefits.

Past projects

Our Virtual Biotech portfolio is in constant flux, new projects are added, projects get completed or investment stops to be refocused on something else. Here are some updates:

Future GDNF trial: decision made

The project looked at finding a way forward for a clinical trial of device delivered GDNF (glial cell-derived neurotrophic factor) that has potential to help slow, stop or reverse the progression of Parkinson's. The decision has been made not to continue investing in device delivered GDNF as there may be other opportunities for alternative, less invasive ways to investigate the potential of GDNF.

Trial to look at drug for Parkinson's dementia: update

Last year we shared in Progress magazine that we approved investment to encourage a phase 2 clinical trial of ENT-01 to see if it helped people with Parkinson's dementia. Unfortunately, despite their best efforts, the company has not been able to raise sufficient investment to take the study forwards at this time. However, Enterin remains fully committed to delivering life-changing new treatments for Parkinson's and continues to focus on constipation in Parkinson's.

Find out more

Read the full list of our active research projects on our website: parkinsons.org.uk/projects



RESEARCH NEEDS YOU

It's thanks to the huge effort of the Parkinson's community getting involved or taking part in research that we are continually moving towards new and better treatments.



Work alongside researchers to shape their projects

Patient and public involvement (PPI) is when researchers and people with conditions, such as Parkinson's, or those who love and care for them, work together from the very beginning by identifying the research question, to designing the study, to sharing results.

By working in partnership with people affected by health conditions, research is able to be of a higher-quality, more efficient, and it focuses on what matters most to those living with the condition. People with Parkinson's and those who love and care for them are experts in understanding what living with the condition is really like. Everyone's experiences and perspectives matter, regardless of whether they have a scientific background or not. All contributions are important and bring a unique voice that helps shape Parkinson's research.

At Parkinson's UK, people with Parkinson's and those who love and care for them work together with researchers to shape research all the way from the lab through to clinical trials. Involvement can happen in lots of ways, for example, reviewing documents, attending focus groups, sitting on project advisory groups, and answering surveys to make sure that Parkinson's research will benefit the community that it is intending to serve.

Want to get involved? We'd love to hear from you.

If you would like to learn more about how you can help shape Parkinson's research, or you're interested in finding out more about the PPI contributor role, please get in touch with our Research Involvement team at Parkinson's UK.

Call **Anne Gill**, Research Involvement Officer, on **020 7963 3603** or email us at **researchinvolvement@parkinsons.org.uk**



Uniting to develop a device for monitoring symptoms



Dr Tina Smith
Senior Lecturer
in Biomechanics
University of
Wolverhampton

Dr Tina Smith from the University of Wolverhampton started looking into developing a device to better monitor Parkinson's symptoms.

Tina has been working alongside a group of people living with Parkinson's to help guide and shape the research. They are spread out across the UK and meet once a month.

"We discuss the project and I let the group know what I'm doing. They then share their feedback. The group is really engaged with the whole project and they feel like part of the team. They have strengthened grant applications and made the research more accessible.

“For example, a trial was originally going to be 12 months, but the group let me know that it was too long. We shortened the length to six months so it would be more manageable for participants.”



Chris Jones
PPI contributor for
Dr Tina Smith's project

Chris has Parkinson's and is part of the group that is shaping Tina's research into the device, from reviewing documents to asking questions in the regular meetings.

Chris shares what it is like to be involved in this project:

“At meetings, everyone has a voice and is respected. All comments and questions are given attention. Tina's so enthusiastic and has great drive and energy.”

“I'm pretty sure that being part of one of the meetings gave me a similar dopamine shot as doing an hour's high intensity training!”

“It's also humbling to think that I may be in some small way helping people with Parkinson's to lead a better life.”

TAKE PART IN RESEARCH

Participating in research has a huge impact on advancing the understanding of Parkinson's, helping to find better treatments, faster. Parkinson's research needs everyone.

Taking part in Parkinson's research might involve trialling a new drug treatment or trying out a new device to monitor your symptoms. It can also include sharing your experiences in a survey or interview. Whatever you're ready for, you can make a difference.

Studies looking for participants

CAN-PDP: Trial of cannabidiol (CBD) for people with Parkinson's who experience hallucinations or delusions

Some people with Parkinson's will experience hallucinations and delusions at some point. This means seeing, hearing or feeling things that aren't actually there, or having fixed beliefs that are not true.

The aim of this study is to understand whether cannabidiol (CBD) may be useful for treating these symptoms in people with Parkinson's.

Who can take part?

120 people with Parkinson's who are over 40, have experienced any symptoms of hallucination or delusions for at least one month, are not taking clozapine, and have someone who can attend study visits with them.

What is involved?

You will take part in an initial assessment to see whether you are eligible to participate in the trial. If eligible, you will trial the CBD or a placebo for 12 weeks. You will be asked to attend six visits, which may take place over the telephone, online, at your local research centre or at home.

One of the lead researchers, Dr Sagnik Bhattacharyya, Professor of Translational Neuroscience and Psychiatry at King's College London, says:

“Your participation is vital to help us answer this question and is necessary to take the next step towards making a better treatment accessible for people with Parkinson's psychosis”.

Barry was involved in the first part of the CAN-PDP study. His wife Brenda said:

“The trial gave us hope. With it being double-blind we're not sure if he's been taking the study drug or the placebo. But we know it's important to gather all the data to come to a conclusion. Drug development cannot happen without people like Barry putting themselves out there and getting involved.”

Interested?

For more information, visit our Take Part Hub to find your nearest research centre parkinsons.org.uk/cbd-trial

You can also contact the CAN-PDP research team at:

Email: canpdp.trialoffice@kcl.ac.uk

Phone: 07936545178 or 07936545250



Understanding more about exercise for people with Parkinson's

Regular exercise can help with balance, strength and mental health in people with Parkinson's. However, not everyone has access to exercise classes or physical therapy. Researchers at the University of Birmingham are aiming to further understand the impact of exercise on people with Parkinson's and learn more about what may prevent some people from staying active.

Who can take part?

900 people with Parkinson's.

What is involved?

You can take part in the study by filling out a questionnaire that will take 1 hour to complete. This can be completed online or over the phone.

Interested?

For more information, visit our Take Part Hub at parkinsons.org.uk/access-and-benefit-exercise

You can also contact Dr Anisa Choudhary if you have any further questions:

Email: a.choudhary.1@bham.ac.uk

Phone: 0121 4146 845.

Dr Anisa Choudhary, Assistant Professor in Clinical Pharmacy and Pharmacology at the University of Birmingham:

“I am an experienced researcher dedicated to improving outcomes and reducing health inequalities in Parkinson's. Your support in this study will assist in identifying and reducing current health inequalities affecting those with Parkinson's. Thank you for your support, this would not be possible without you!”



Find other opportunities

You can browse our Take Part Hub to find the latest studies looking for participants parkinsons.org.uk/take-part-hub

If you have any questions, get in touch at participation@parkinsons.org.uk.

Not online?

Ring the Parkinson's UK Research team on **020 7963 3606** to get in touch about any of the opportunities featured. We can also help you find out what research is happening near you.

New to research? Not sure where to start?

Sign up to receive 3-4 emails a month with the latest news, events and opportunities related to research. Join our

Research Support Network by scanning the QR code or visit parkinsons.org.uk/rsn.



QUESTION TIME



Answering some of the common questions from you, our readers.



Can supplements be beneficial for people with Parkinson's?

Emma Rodgers,
Research Communications
Officer at Parkinson's UK, said:



Eating a well-balanced diet is usually the best way to get all of the vitamins, minerals and nutrients that we need to keep our bodies healthy and functioning properly. Whilst there is no clear scientific evidence to suggest that taking supplements is beneficial for people with Parkinson's, it is an active area of research. We would always recommend speaking to a healthcare professional before introducing a new supplement into your diet.

Although more research is needed, a few supplements have shown potential. In 2023, researchers added to existing evidence that vitamin B3 may help to slow down the progression of Parkinson's, although a larger study is needed to investigate this further.

Similarly, vitamin B1, also known as thiamine, has shown potential benefits in small trials. Whilst promising improvements in symptoms were reported, the researchers and participants knew who was receiving thiamine, so the results could have been impacted by the placebo effect.

For many supplements, the research is conflicting. Glutathione, an antioxidant, has not shown clear cut benefits for people with Parkinson's, similarly with omega-3 fatty acids. Other supplements under investigation include curcumin which is found in turmeric and caffeine. Some studies suggest benefits for Parkinson's, but results are inconclusive and further research is needed.

Got a question about research?

Email research@parkinsons.org.uk with the word "Progress" in the subject line or ring us on 020 7963 3606 (leave a message with your name and number and we will get back to you).



What research is being done into the way Parkinson's medication is delivered?

More than 50 years since its discovery, levodopa remains the leading treatment for Parkinson's. Traditionally, levodopa is taken orally, in pill or capsule forms, and must be taken at specific times throughout the day. For some people with Parkinson's, taking oral medication for a long time can cause involuntary movements, called dyskinesia, and 'off' periods, when the effect of the drug wears off before the next dose is taken. New delivery methods could help to reduce some of these problems. This is especially important for people who have had Parkinson's for many years.

Skin patches can help to reduce 'off' periods. When applied to the skin, medication is released slowly over a 24 hour period. Rotigotine skin patch (Neupro), for example, is a skin patch that releases a type of dopamine agonist medication when applied to the skin.

Phil Hockey, who's lived with Parkinson's for six years and took part in the research trial of Produodopa, said:

“I was surprised at how effective Produodopa was at controlling my symptoms. Having the pump working 24 hours a day is a key benefit and it gave me back a degree of control in the management of my symptoms when I was on the trial. It even meant a return to my favourite sport, cycling!”

The benefits also could have a huge impact on caregivers for people with Parkinson's. Phil shared:

“As there was no wearing off as there had been with my regular medication, I could get in and out of bed independently, and turn over without my partner, Kate's, help. And it improved my gait, so I was less worried about falling.”

Dr Katherine Fletcher, Research Communications Lead at Parkinson's UK, said:



Other methods involve medication being delivered directly into the body. Duodopa is a gel form of levodopa. It is delivered directly into the gut using a pump and a tube that is inserted into the intestine.

In 2023, a new Parkinson's treatment, called Produodopa, was approved for people with severe movement symptoms in England, Scotland, Northern Ireland and Wales and is now being rolled out on the NHS in these countries. Produodopa is delivered 24 hours a day by a small pump that delivers a continuous dose of the medication from a syringe. The fine needle is inserted just under the skin. If you are interested in this delivery method, we recommend speaking to your Parkinson's nurse, neurologist or GP. You can also ring our helpline on **0808 800 0303** for more information.



JOIN US FOR

2024 PAR-CON

Our free, 2-day event for the Parkinson's community to hear from expert speakers, connect with others and learn more about living well with Parkinson's.

When? 11-12 October 2024

Where? Online, or at the Royal Armouries Museum, Leeds (limited number of in person places available)

Planned in collaboration with a team of people living with the condition, Par-Con gives you the chance to hear directly from experts – including researchers, health professionals and people with Parkinson's.

We'll have sessions on the latest research, cutting-edge technology and living well with Parkinson's. There'll be opportunities to try physical activity tasters and meet and connect with others.

Register to attend

To find out more and reserve your place, visit parkinsons.org.uk/par-con-2024

If you have any questions, get in touch:

Email: researchevents@parkinsons.org.uk

Phone: 020 7963 9253

Par-Con 2024 will also include the Annual General Meeting, and a celebration of everyday heroes through our Community Awards.

Par-Con 2024 is a hybrid event, with all talks and panel sessions available for audiences online and in person. You can choose to attend a single day, or register for both days.



WE WANT TO KNOW WHAT YOU THINK

For information on how we use your personal information, please visit parkinsons.org.uk/privacy-policy

Our magazine is produced in partnership with our volunteer editorial board. But we'd also really appreciate your feedback. You can complete this short survey:

Online at <http://parkinsons.org.uk/summer-progress-2024>

Or

Return this page by post to:

Research team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 15J

The responses will remain anonymous, please do not include your name.

1. On a scale of 1 to 5, how interesting do you find Progress magazine? (please mark one option)

(Not interesting)

(Extremely interesting)

- 1
 2
 3
 4
 5

2. How do you feel after reading Progress? (please tick all that apply)

- Hopeful
 Inspired
 Frustrated
 Confused
 Informed
 Disheartened

Other (please specify):

3. How could we improve Progress magazine and what would you like to read about in the future?

4. What is your connection to Parkinson's?

- I have Parkinson's
 I am a Parkinson's UK volunteer
 I am a partner, family member, friend and/or carer of a person with Parkinson's
 I am a health or social care professional (doctor, nurse, therapist, social worker, etc)
 I am a bereaved partner, carer, family member or friend of a person with Parkinson's
 I am a researcher and/or a student with an interest in Parkinson's

5. After reading our magazine, how likely are you to get involved in research?

For example, take part in a study, join an event or volunteer. (please mark one option)

(Not interesting)

(Extremely interesting)

- 1
 2
 3
 4
 5

6. Are you signed up to receive our regular research emails through our Research Support Network?

- Yes
 No
 I am going to sign up now at parkinsons.org.uk/rsn
 I don't know





We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

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Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

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