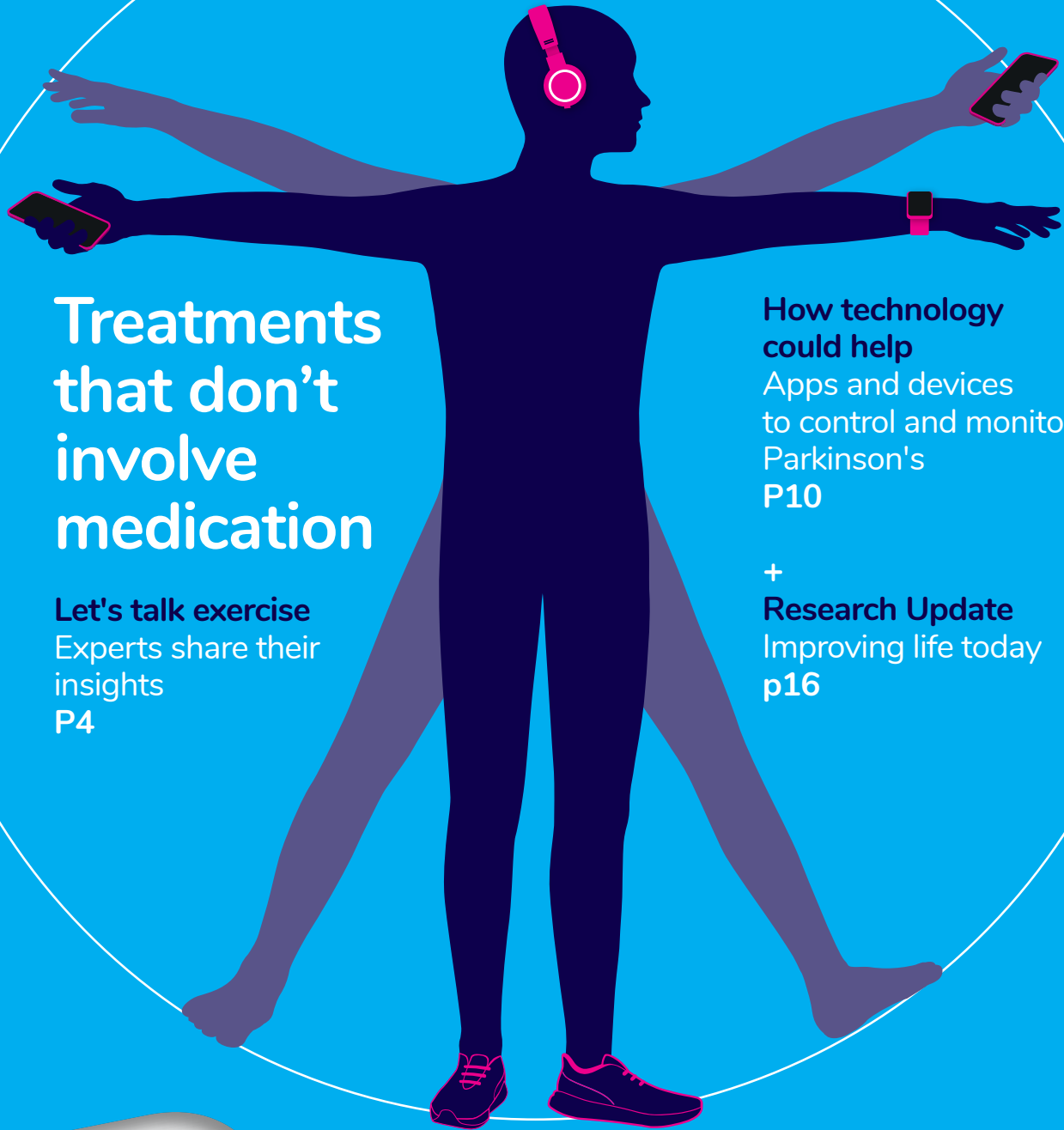


PROGRESS

The research magazine of Parkinson's UK | Winter 2021



Treatments that don't involve medication

Let's talk exercise
Experts share their insights
P4

How technology could help

Apps and devices to control and monitor Parkinson's
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PARKINSON'S^{UK}
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We answer your questions on Parkinson's research.

Read *Progress* online and find further reading at parkinsons.org.uk/progress. For more information or to help shape future magazines, contact us at research@parkinsons.org.uk or on 020 7963 3964



WELCOME

Hello and welcome to *Progress* magazine. I'm Kathy, and as a member of the *Progress* Editorial Board and volunteer at Parkinson's UK, I am delighted to introduce this issue of the magazine. The focus is on research into various aspects of symptom management.

You might remember in the last edition we focused on research looking at ways to get closer to a cure. While research continues to look for ways to slow and stop the condition, there are also important studies looking to find better ways to manage the many symptoms of Parkinson's.

This area of research is something I'm passionate about as I have had Parkinson's now for three years, and I know how important it is to stay on top of what's going on to help me live better with the condition.

For me, diet, exercise, rest and general wellbeing care are important for my Parkinson's. I'm always amazed at just how different the condition is for each individual and I hope this edition shows the breadth of research underway.

I am particularly interested in research looking into physical activity and exercise with Parkinson's, and try to stay active where I can. For example, I do yoga and pilates several times a week which helps my balance.

So, I was pleased to shape an article about this, where we hear from others who are living with Parkinson's and researchers to answer some of the burning questions about research in this area. Go to **page 4** to read the article.

Also make sure you read to the end, as the Q and A section on **page 24** has some great questions submitted by you, our readers.

As I'm sure you'll agree, it's been a tough year with coronavirus (COVID-19) still impacting our lives. But the fact that research is continuing towards better treatments and a cure for Parkinson's gives me hope, and on behalf of myself and the rest of the editorial board I really hope you enjoy this edition of the magazine.

Kathy French

PS The magazine is shaped by people like myself, people with Parkinson's and the people who love and care for them. We're always keen to hear what the wider Parkinson's community think and want to read about in the future.

So, fill in our super quick survey (see page 27) or drop us an email at research@parkinsons.org.uk

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

Many thanks to:

- Richard Hill
- Clive Bartram
- Margaret Emsley
- Kathy French
- Emily Kerr
- Iona Lister
- David Wilson

LET'S TALK PHYSICAL ACTIVITY AND EXERCISE

We gathered some experts from across the globe to discuss what's happening with research into physical activity and exercise for Parkinson's.

We came together over Zoom and Laurel and Andrew, who have Parkinson's, led the discussion and asked the researchers some important questions.

This article captures the highlights of this discussion.



Laurel Miller

Diagnosed with Parkinson's 7 years ago

Laurel feels strongly that research findings about the benefits of physical activity and exercise should be made clear at diagnosis. Before lockdown she attended regular face-to-face PD Power, yoga, pilates and dance classes. She's found it harder to stay motivated to keep active and exercise at home, and welcomes the gradual return to group activities.



Andrew Cassy

Diagnosed with Parkinson's 11 years ago

Andrew is an enthusiastic table tennis player who also finds dog walking, regular stretching and physiotherapy sessions helpful. He's a firm believer that physical activity and exercise is vital in the management of Parkinson's and tries to do one hour of exercise a day.

Over the past few years, people with Parkinson's have heard a lot about the benefits of physical activity and exercise but the recommendations are often unclear. We explore this a little further with our panel.



Professor Erika Franzén

Physiotherapist and Professor at the Karolinska Institute in Sweden

Erika's research focuses on Parkinson's. She's currently involved in running a clinical trial to understand how an exercise programme that improves balance might help people with Parkinson's, including motor and non-motor symptoms. She is also interested in looking at what happens in the brain after a period of exercise to understand why exercise is beneficial.



Dr Serene Paul

Physiotherapist and researcher at The University of Sydney

Serene is particularly interested in finding sustainable ways to keep people with Parkinson's active and understanding what activities people enjoy. She's also working with Dr Natalie Allen to find ways to incorporate physical activity and exercise at any stage of the condition.



Julie Jones

Physiotherapist and researcher at the Robert Gordon University in Scotland and Co-Chair of the National Exercise Hub

Julie is currently researching a collaborative exercise intervention called PDConnect, which combines one to one specialist physiotherapy, group based exercise and supported self-management. This approach is being tested to see if it is a feasible and effective way to support people with Parkinson's to engage in physical activity and exercise. This work is being part funded by Parkinson's UK.

Q Are there specific symptoms of Parkinson's that being active and exercising can help with?

Erika: "We have seen a lot of evidence that being active and exercising can help with a range of symptoms and behaviour, for instance helping to increase balance, faster walking and improving various motor symptoms of Parkinson's."

"There is also some evidence that physical activity and exercise is helpful for non-motor symptoms of the condition, such as mood, cognition and helping with anxiety."

Serene: "There is also emerging evidence that physical activities that involve an element of mindfulness can be beneficial, for example yoga and tai chi can really help improve mood."

Q Does research show certain types of physical activity and exercise to be better than others?

Erika: "We know keeping active and exercising is beneficial but we don't have that much evidence on which activities are better than others. Generally keeping active in any way is good."

Laurel and Andrew's tips on using physical activity and exercise to help manage symptoms

- Stretching and physiotherapy sessions help with stiffness.
- Walking is a great way to incorporate physical activity, whether that's a short stroll, Nordic walking or a brisker walk to get your heart pumping.
- Hand exercises and table tennis help with fine motor skills.
- The social aspect of being active helps boost your mood.
- Physical activity and exercising can help with fatigue and finding motivation for other tasks.

Q What's happening in the brain when we exercise?

Erika: "There's not a lot of research on this topic, but the feeling is that periods of high intensity exercise might be altering the way the brain works, to improve symptoms and even potentially slow the progression of the condition. This is on top of the general benefits for anyone staying physically active. We are looking to better understand exactly what intensity and type of exercise programme might have this effect."

"When we exercise we know this is helping with what is called neuroplasticity – improving brain connections and function. But now we need to understand exactly what is happening when

someone with Parkinson's exercises.

"Our research is hoping to understand how the balance based exercise programme is changing the way the brain functions in people with Parkinson's through the use of brain scans and looking at levels of a protective factor called brain-derived neurotrophic factor (BDNF)."

Read more about BDNF in the green box.

Q So, does exercise boost dopamine levels in the brain?

Erika: "I don't think exercise is leading to the replacement of the dopamine producing cells

that are lost in Parkinson's, but it might be strengthening the connections that are still in place. So for instance, helping the brain cells that haven't been lost to work more efficiently or even boosting alternative pathways that aren't affected by Parkinson's."

Q Could there be an exercise pill in the future?

Erika: "I doubt it would be that easy. I think there is a possibility that various medications could boost and enhance the benefits people with Parkinson's get from exercise."

"For instance, a medication or therapy that could help the release of protective factors that we believe are being produced during exercise could increase the therapeutic impact for people with Parkinson's."

"Also, medication to improve motivation and reduce symptoms of depression may also help people to stay active."

Q When should physical activity and exercise be looked at as a management strategy?

Erika: "As early as possible! It is too late to wait for someone to fall or have trouble walking. It should be encouraged at diagnosis. Just as medication is prescribed and

reviewed, physical activity and exercise should also be part of this."

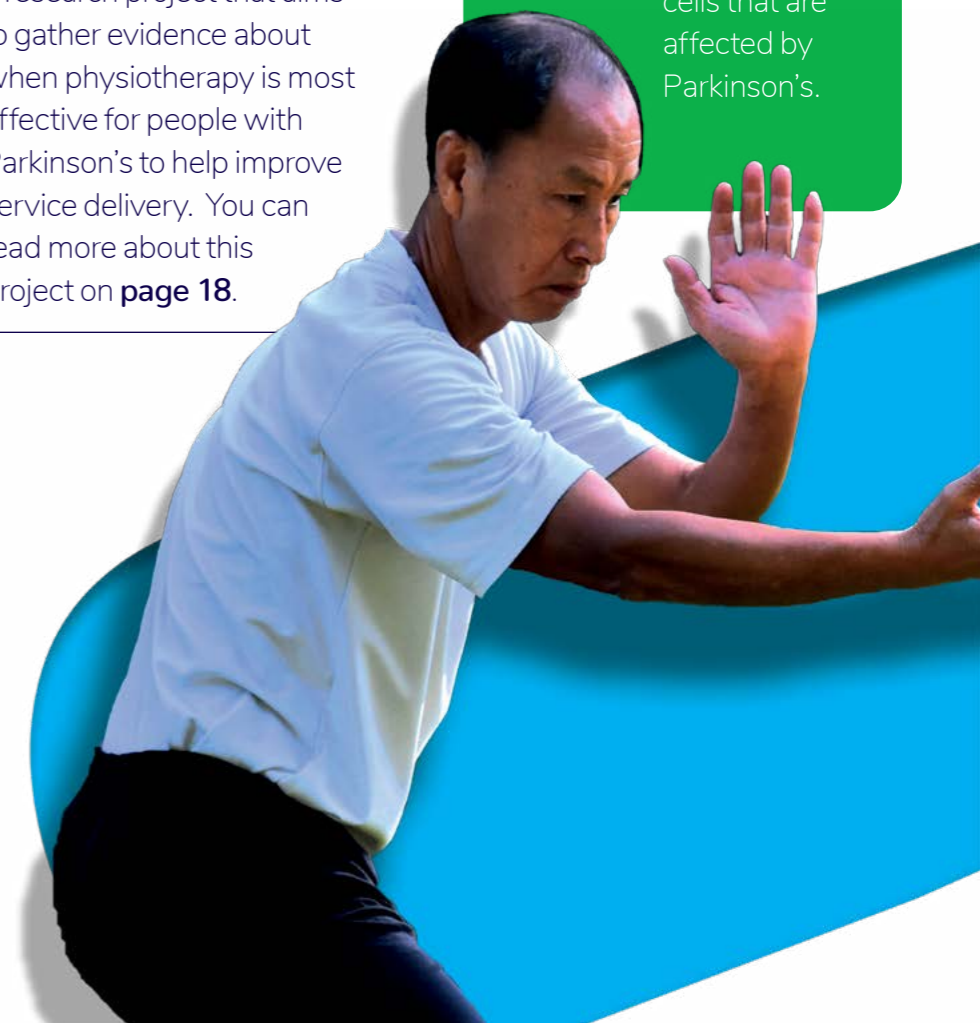
Julie: "Sometimes when people are diagnosed they go through that phase of bewilderment, shock, denial and actually they're not really in the headspace to be able to go away and find their own management strategies."

"That's why a team and network needs to support individuals from diagnosis, and physical activity and exercise should be integral to this early management."

Parkinson's UK is funding a research project that aims to gather evidence about when physiotherapy is most effective for people with Parkinson's to help improve service delivery. You can read more about this project on [page 18](#).

Exercise boosts a helpful factor in the brain

One way exercise is thought to be helping in Parkinson's is by boosting the levels of brain-derived neurotrophic factor (BDNF). Some studies have shown that exercise can boost levels of BDNF, and regular exercise helps sustain these levels over time. BDNF is what is known as a growth factor – an important set of molecules that play a role in the growth, development and survival of the brain cells that are affected by Parkinson's.



Q Is there any research looking at the best way to deliver exercise programmes?

Julie: “Perhaps not surprisingly there isn't going to be a one size fits all approach. Physical activity needs to be tailored to the individual.

“We also realise that just telling people that they need to be physically active

or participate in exercise is not enough for people with or without Parkinson's to stick to a consistent management plan.

“We need to give people the tools to develop sustainable physical activity habits and achievable goals. We need a flexible service that can change with people's circumstances and Parkinson's to support them to adopt physically active lifestyles.”

Q How can technology be used to encourage physical and exercise activity at home?

Serene: “Our research has shown that if digital tools are going to be used for providing professional support to encourage physical activity, for instance video calls, then people much prefer to have a face-to-face visit before using these remote methods.

“We also know that not everyone likes to use these types of digital tools and sometimes keeping it simple with people is best.

“Another aspect that was highlighted in the discussion was gaming. People have told us how useful gaming platforms such as the Wii Fit are in helping to motivate them to keep active and have an element of competition.

“Andrew also shared a specific type of gaming that he finds useful involving virtual reality (VR), where you can put on a VR headset and play sports such as table tennis or bowling.”

Q Are there any recommended devices to encourage people to stay active?

Serene: “Wearable devices can be incredibly useful for an individual to motivate and challenge themselves. A simple step counter, known as a pedometer, is a readily available option. Some of the old style pedometers that are worn on the hip as opposed to the wrist are usually better for people who walk slowly and find themselves shuffling.

“It's very much about getting the individual to pick something that works for them.”



What should the future priorities for physical activity and exercise research be?

The discussion highlighted that more research is needed to understand the evidence for specific physical activity and exercise recommendations for people with Parkinson's. Specifically focusing on personalised approaches to support and encourage people to stay active.

The panel put together their list of what they would like to see addressed in Parkinson's research:

- Clear evidence of what physical activities and exercise is best for people with Parkinson's and specific symptoms.
- Larger and longer-term studies, across multiple sites and countries to understand the long-term benefits of physical activity and exercise.
- Tried and tested, multidisciplinary, personalised exercise programmes to support people with Parkinson's to set goals and monitor progress.
- More funding to invest in supporting people to keep active.

Feeling inspired?

Parkinson's UK has some great resources to encourage you to stay active.

And Laurel and Andrew recommend some great programmes too:

- [Browse our exercise hub parkinsons.org.uk/exercise](https://parkinsons.org.uk/exercise)
- [Find support and exercise classes near you parkinsons.org.uk/information-and-support/support-you](https://parkinsons.org.uk/information-and-support/support-you)
- [Power for Parkinson's](https://powerforparkinsons.org) Free online exercise classes for people with Parkinson's
- [PD Warrior](https://pdwarrior.com) Created by two physiotherapists in Australia, this offers support and coaching for people to stay active with Parkinson's

These are not the only resources and classes available, there are lots to choose from – it's important people find what works for them in coordination with their healthcare professionals.

COULD TECHNOLOGY HELP WITH PARKINSON'S SYMPTOMS?



What if new treatments didn't involve more medication?

How could technology help better manage, monitor and even treat Parkinson's?

In this article we explore a variety of apps available today and research into potential devices that could help people with Parkinson's.

Devices

Devices are often an electronic piece of equipment made for a particular purpose.



Apps

Apps refer to a piece of software that can be loaded onto a smartphone or computer tablet to carry out a specific function.

Apps to aid everyday living

There are a variety of apps available (for smartphone or tablet) to help people connect, play games and manage their health. Parkinson's UK set up its own apps library to help showcase some tried and tested examples that are designed to help manage specific symptoms of Parkinson's.

Everything included in the library has been carefully reviewed and approved by an expert panel of people with Parkinson's. You can browse the devices and apps library by visiting our webpage: parkinsons.org.uk/devicesandapps. Here are three examples:



An app to help with sleep problems through the use of sounds and music.

"This app is very easy to use. The narrative is very soothing and relaxing. It helps me get to sleep quicker and easier than usual, but not to stay asleep. But I've found that if I use it every time I wake, I still get a little more sleep than usual. The alarm feature is also very good – it allows me to wake more slowly and naturally, but still be awake when I need to be. I would recommend the app to anyone if they experience sleep issues." **Michelle**



Beats Medical

Tailored daily activities to help with mobility, speech and dexterity. To help individuals to monitor and manage symptoms.

"I found the speech exercises on the app had a fairly immediate effect on my voice. I'm aware of my weak voice, and try to do regular singing. After just a few days with the voice exercises, my singing voice was noticeably stronger." **David**



COVE

An app to capture and express mood. Through a personalised diary and encouraging the use of music.

"It is absorbing and helps me to put my anxieties aside. I would happily continue using Cove, especially in situations where distraction techniques would be helpful ie. when travelling. I would definitely recommend it." **Joe**

Wearable technology to monitor symptoms

Currently, symptoms are monitored infrequently and often involve taking a trip to see a healthcare professional. These appointments only give a snapshot of someone's condition and are often quite subjective.

There is work underway to understand how technology could address some of these limitations. This could ultimately lead to better informed management strategies for an individual.

Technology offers a way to monitor symptoms round the clock where the data could be sent straight to healthcare professionals. It could also be a powerful tool in clinical trials to capture how people with Parkinson's are responding to new medication.

It might sound simple, but these types of monitoring devices need to be rigorously tested to see whether they can be used as a tool in the clinic or in clinical trials. There needs to be consistency, reliability and data security. This might offer some of the reasons why there currently isn't a device that is being used across the board in Parkinson's, but here are a couple that are under investigation:

MM4PD

One wrist worn device under investigation is a smartwatch based system called MM4PD, also known as Motor fluctuations Monitor for Parkinson's Disease.

It aims to use sensors, for example in the Apple Watch, to continuously track fluctuations in resting tremors and other involuntary movements, as well as identifying changes due to alterations in medication.

This has been tested in over 300 people with Parkinson's. It was able to determine when a participant regularly stuck to their prescribed treatment plan, highlight days where symptoms were worse, as well as identify unexpected responses to treatments that may not have been caught by traditional clinical assessment.

The evidence now needs to be assessed to see if this software and associated device is good enough to be recommended for use in a clinical setting. If not, further development and research may be needed.

Dr Camille Carroll says: "People with Parkinson's are really keen to understand their symptoms and be partners in their care. Devices can help with understanding, self-awareness and self-management. This can help a healthcare professional develop a partnership with people with Parkinson's and provide the best care possible."

KinetiGraph Watch

Similarly, the KinetiGraph is a wrist worn device which provides a continuous measure of movement.

The device was created to tackle an increase in demand on the NHS and to help patients keep track of symptoms if there was a delay between appointments.

The KinetiGraph is programmed with personalised medication regimes and reminders, so the person wearing the device can be notified and can acknowledge once they've taken their medication.

Dr Camille Carroll at the University of Plymouth uses the KinetiGraph in her clinical service and has seen first hand how useful devices like this can be for people with Parkinson's.

These examples and others show the move to incorporate technology into care and better symptom management, which could have a huge impact for people living with Parkinson's.

Non-surgical medical devices under investigation for symptom management

Devices aren't just being used as a means to monitor Parkinson's. There are clinical trials underway exploring devices as a non-invasive way to treat specific symptoms.

A lot of the devices under investigation involve various methods of nerve stimulation to improve the way brain cells

communicate. This idea is not new and is changing the way people treat a number of conditions, including pain.

For instance, sticky electrode patches attached to a battery pack can be used to send electrical impulses through the body. These impulses can help relax muscles or boost brain chemicals that act as natural pain relief.

This is not a new idea in Parkinson's treatment, as deep brain stimulation (DBS)

involves very fine wires being carefully inserted into the brain to electrically stimulate particular groups of brain cells involved in controlling movement, to adjust their activity.

This continues to be an effective and important treatment option for many.

Now researchers are hoping to harness the power of nerve stimulation through the use of non-surgical options to improve a number of different symptoms.



Trials investigating nerve stimulation devices for Parkinson's

So, what is nerve stimulation? Our nervous system spans the whole body and is made up of an intricate network of nerves, connecting different parts of our body to the brain. Nerve stimulation involves brain cells either directly or indirectly being energised using electrical currents to help boost their activity. This has potential in Parkinson's as electrical circuits within the brain are disrupted, affecting how the brain communicates to control things such as movement.

Investigating an earpiece device for motor and non-motor symptoms

Research being led by Professor David Wilkinson is investigating a headset with earpieces attached to stimulate a nerve in the inner ear – called vestibular nerve stimulation. They want to see if it can improve a variety of motor and non-motor symptoms.

Where's the research at?

A trial of the device in 33 people with Parkinson's showed that it was safe and improved symptoms including mobility, decision-making, mood and quality of life ratings in those receiving the active treatment. A larger clinical trial is in the pipeline with the aim of recruiting 150-200 people across the United States and England. The new research is focusing on non-motor symptoms.

Activating nerves in the leg to potentially improve balance and walking

Professor Paul Taylor recently carried out a study looking at peroneal nerve stimulation in Parkinson's. This nerve controls the muscles in the leg that lift the ankle and toes upward. The researchers investigated using electrical stimulation to activate the nerve whilst people with Parkinson's were walking.

Where's the research at?

The research took place over 18 weeks in 64 people with Parkinson's to gather initial evidence for the benefits of this device for things like walking speed and balance. The results were published earlier this year and showed promise. A larger clinical trial in 250 people across seven centres in the UK will hopefully be taking place next year.

Exploring a handheld device to stimulate nerves in the neck to improve mobility

Dr Alison Yarnall is a researcher funded by Parkinson's UK and is investigating a small stimulation device to see if it can improve coordination in people with Parkinson's and help improve walking. The device is held to the neck to stimulate the vagus nerve, which connects the brain to the rest of the body.

Where's the research at?

40 people with Parkinson's in the Newcastle area are being recruited to the study to test the device over 12 weeks. If this research is shown to be beneficial, it will hopefully lead to larger studies.

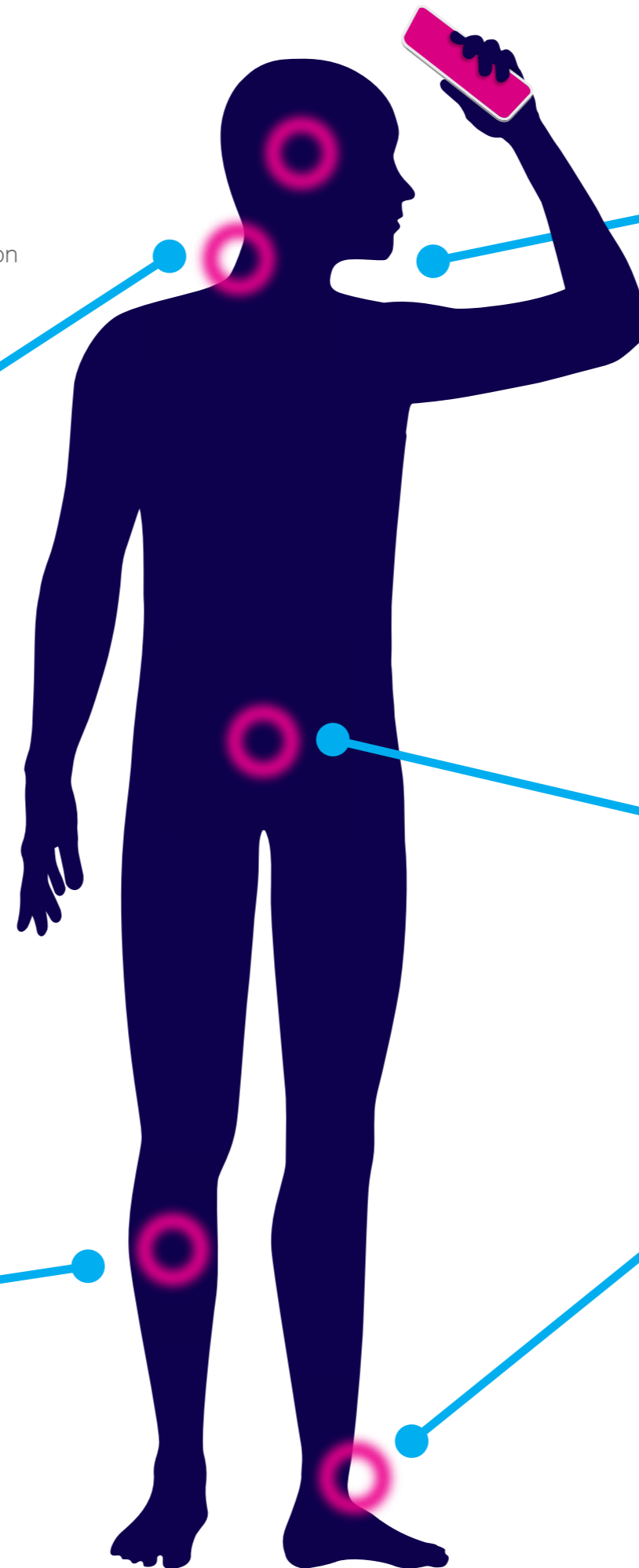
Understanding the potential of a device to help with bladder control

Professor Doreen McClurg is investigating a device that uses small patches that are attached to the surface of the skin near the ankle to deliver small electrical impulses. The research which is funded by Parkinson's UK, aims to understand how this stimulation might help improve bladder control.

Where's the research at?

200 people with Parkinson's who experience bladder symptoms have been recruited and have been supported to use an active or placebo stimulation device. Researchers are currently gathering and analysing the data.

Whether technologically minded or not, apps and devices have the potential to be accessible to everyone and offer hope for better ways to manage Parkinson's.





OUR RESEARCH PROGRAMME: IMPROVING LIFE TODAY

Claire Bale, Head of Research Communications and Engagement at Parkinson's UK, highlights how we are working with people living with the condition to drive forward treatments to tackle symptoms and transform lives.

joined Parkinson's UK back in 2008 and over the past 13 years we've helped drive forward a revolution to learn from, and involve, people living with the condition in every part of the research process.

Our research programme looks the way it does because you've told us what you want from research – faster drug development, better clinical trials and more opportunities to take part in and shape research.

Now, we work with over 300 volunteers across every aspect of our research. Volunteers contribute in so many ways, helping us to plan our strategy, make funding decisions, and work in partnership with researchers and companies.

While our overall goal is to find a cure for Parkinson's, we also know that people with Parkinson's need better treatments, therapies and services right now.

Research starts with you

We know that to deliver the treatments people with Parkinson's want and need, we must start with the community. In 2013-2014, we worked with people with Parkinson's, their families and professionals to come up with a list of key priorities for improving everyday life for those living with the condition today. Over 1,000 people took part. The results were published in the British Medical Journal and revealed 10 priority areas the community wanted to see progress in.

Top 10 research priorities

1. Balance and falls
2. Stress and anxiety
3. Uncontrollable movements
4. Personalised treatments
5. Dementia
6. Mild thinking and memory problems
7. Monitoring symptoms
8. Sleep
9. Dexterity
10. Urinary problems



CLAIRE BALE

These priorities have helped researchers internationally to target their efforts on the things that matter most to people living with Parkinson's, and continue to do so. We're currently investing over £6m in projects that address these priorities.

And we're now starting to see important new treatments being tested in clinical trials, including a drug that's in late stage trials to see if it can help reduce falls. This important study is recruiting now across the UK. Find out more on [page 23](#).

Listening to people living with Parkinson's is something we need to do on a regular basis and in different ways to ensure our research is focused on what matters most. We surveyed our community again in 2019 to understand what symptoms people find most troublesome. The findings from this survey of almost 800 people were published in 2021. The results echo many of the findings from our 2013 and 2014 work but also highlight some new concerns and the fact that peoples' priorities change as the condition progresses.

Key learnings from the 2021 results include:

- Tremor was the most reported issue in this survey.
- Non-motor symptoms, including problems with psychological health, fatigue, cognitive function and pain, were highly reported from the very early stages of Parkinson's.
- People who'd lived with the condition for 10 years or longer reported problems with walking, balance and falls, speech problems, freezing and dyskinesia.

We hope that the results of this survey will drive more research into all of these areas and help accelerate the solutions that people with Parkinson's need.

A huge thanks to everyone who took part and shared their experiences to inform research.

Pioneering non-drug approaches

Alongside medication, other approaches, such as living aids, devices, exercise and therapies, can play a vital part in helping people to manage symptoms.

And we know that many people with Parkinson's are keen to see more research into these practical approaches.

That's why we launched a dedicated new grant scheme to encourage more research in this area in 2020 and beyond.

Let's take a look at some of the research we're funding through this new grant scheme and wider:

Investigating the benefits of physiotherapy



Physiotherapists play a role in advising on suitable exercise and helping people to stay active. This project aims to explore the impact of early physiotherapy before movement problems have been identified, versus physiotherapy deferred to the time of need. The findings will provide important evidence to improve physiotherapy services for Parkinson's.

Weight-shift training to overcome freezing



Freezing – feeling like your feet are stuck to the ground – is a common symptom in Parkinson's. Researchers are investigating whether a weight-shifting strategy can help overcome freezing. The team will test whether people can learn this strategy from an instructional video and use it safely in daily life.

A new telehealth approach to speech therapy



Many people with Parkinson's experience difficulties with speech and communication. Speech and language therapy can be helpful but is not always easy to access.

This project will develop and test whether speech therapy can be effectively delivered remotely using a computer.

A device to prompt swallowing



In Parkinson's, people may swallow less often and drooling can become an issue. This research will test if a simple wrist-worn device, which gently reminds people to swallow by vibrating, could offer a way to help manage this problem.

The project aims to recruit 3,000 people with Parkinson's to trial and give feedback on the device.

We're working closely with the researchers and hope this opportunity will be open soon.



Our Virtual Biotech: developing drugs to improve lives

The Parkinson's Virtual Biotech was launched in 2017 to accelerate new and better treatments for the condition.

We now have 10 projects, which include those that aim to develop new drugs that can slow, stop or reverse the condition. And three clinical trials of drugs which aim to rapidly deliver new treatments to improve life for people with Parkinson's.

A new drug for dyskinesia

We're partnering with US charity The Michael J. Fox Foundation (MJFF), and company Neurolix, to test whether a drug called NLX-112 can help people with Parkinson's who experience dyskinesia.

Dyskinesia is a common side effect experienced by people with Parkinson's who take levodopa. It can be disabling and distressing.

This trial will take place in Sweden and is aiming to start in the coming months.

CBD for Parkinson's psychosis

Evidence indicates that up to 60% of people with Parkinson's go on to develop symptoms of Parkinson's psychosis such as hallucinations and delusions as their condition progresses.

We're partnering with researchers at King's College London to carry out a clinical trial to see whether CBD, a chemical found in cannabis, also known as cannabidiol, is safe and effective for treating symptoms of Parkinson's psychosis. The first phase of this groundbreaking study is now underway in London, and if all goes well, should be expanded to include other locations around the UK in 2022.

Ondansetron for hallucinations

Hallucinations, seeing, hearing or feeling things that aren't really there, can be a frightening symptom of Parkinson's. Current treatment options are limited. That's why we're funding this important trial to test whether ondansetron, a drug currently used to treat nausea in chemotherapy patients, may be effective in reducing hallucinations for people with Parkinson's and dementia with Lewy bodies. This UK-wide trial is recruiting now.

[> Find out more about taking part on page 22.](#)



TAKE PART IN RESEARCH

Here we highlight three studies looking for people to take part today.



FINDING A TREATMENT TO HELP WITH LOW MOOD AND MOTOR SYMPTOMS



The study is called ADepT-PD. It will look at two existing drugs to see if they can help with symptoms of low mood in Parkinson's, as well as improving movement.

The trial will investigate escitalopram and nortriptyline, currently used as antidepressants.

The study is being coordinated at University College London (UCL), led by Professor Anette Schrag. Researchers aim to recruit 408 people with Parkinson's at over 20 sites across the UK.

The team have adapted the study to run remotely, which minimises the need to go to the research site in person. The trial will take place over 12 months.

Colin, who has Parkinson's, shares his experience of low mood, some management tips and why he is considering taking part in this study:

"I have Parkinson's and I lost my wife Jeanie a number of years ago. The grief and my Parkinson's sometimes stops me from seeing the blue skies and the pandemic hasn't helped.

"I go through periods where my mood drops very low and I find it hard to bounce back. I want to build resilience and a toolkit to be able to do this.

I am trying out counselling and I find the following things helpful to boost my mood: playing music, making other people happy and researching a topic of interest to focus my brain. I am also interested in finding out more about the ADEPT-PD trial once the site closest to me is open for recruitment."

Interested?

Visit parkinsons.org.uk/ADepT-PD to find out more or email the researchers at neuro.adept@ucl.ac.uk



LOOKING AT A STICKY MEDICATION PATCH THAT COULD HELP REDUCE FALLS

This research is at the phase 3 stage, the final hurdle before a medication is approved and made available. The trial is looking at whether a treatment applied as a skin patch can improve balance, walking and help prevent falls.

The treatment being investigated is called rivastigmine and the trial is called Cholinesterase Inhibitors to prevent falls in Parkinson's Disease (CHIEF-PD). The phase 3 trial builds on previous research funded by Parkinson's UK, where results showed those receiving the drug compared to the placebo were 45% less likely to fall and much steadier on their feet.

The researchers are now looking for 600 people with Parkinson's, who have fallen in the past year and can walk at least 10 metres without a walking aid or assistance. The study is happening at over 20 sites across England, Scotland and Wales. People will be asked to attend 2 visits, one at the beginning of the research and one at the end. The visits can be at the hospital, or in some areas may be done over video call or as a home visit. Participants will take the medication for 12 months and record any falls that they experience in diaries. There will be regular check-ins with the researchers by phone.

INVESTIGATING A TREATMENT FOR HALLUCINATIONS IN PARKINSON'S

The study is called **Trial of Ondansetron as a Parkinson's Hallucination Treatment (TOPHAT)**, and was mentioned on page 19.

Ondansetron is an existing drug used as an anti-sickness medication but it has potential to be repurposed to reduce hallucinations in Parkinson's or dementia with Lewy bodies.

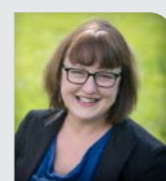
The study is looking to recruit 216 people with Parkinson's who experience hallucinations. The trial will take place at multiple sites over 12 weeks.



Lead Researcher, Suzanne Reeves, Professor of Old Age Psychiatry and Psychopharmacology, UCL says:

"Finding treatments for hallucinations that are both effective and safe is an area of great unmet need. This trial will enable us to find out if ondansetron is effective and safe as a treatment and if it is, we could see clinicians prescribing an inexpensive drug with fewer side effects to people with Parkinson's throughout the UK."

Interested?
Visit parkinsons.org.uk/TOPHAT to find out more information and where the research is taking place.



Dr Emily Henderson, lead researcher at the University of Bristol says:

"If successful, this treatment will improve the lives of people living with Parkinson's now. We are working hard to tackle one of the most disabling complications of Parkinson's."

Interested?
Visit parkinsons.org.uk/preventfalls or email the researchers at chief-pd@bristol.ac.uk to find out more.

Find other opportunities
Browse our Take Part Hub with over 30 studies looking for participants – parkinsons.org.uk/takepartresearch.

Not online?
Ring the Parkinson's UK Research Team on 020 7963 3964 to get in touch about any of the opportunities featured or help find out what research is happening near you.

QUESTION TIME

Keeping to the theme of symptom management and lifestyle, here are some of your questions answered.

Q I have been reading about various diets and would like to know if there is any research evidence for the benefits of ketogenic diets for Parkinson's?

A It's still unclear what the best diet for Parkinson's is beyond the recommendations of a healthy balanced diet.

The ketogenic diet, which is high in fats and low in carbohydrates in theory forces the body to shift its usual energy source from glucose (sugar) to fats.

Studies conducted in cells and animal models suggest that a ketogenic diet may have

protective effects on the brain. And results from early stage clinical trials show it may help improve non-motor symptoms such as thinking and memory or even boost exercise performance.

Larger, long-term studies in people with Parkinson's are now needed to assess whether this diet is practical, safe or effective in the long-term. Please note this is not medical advice and we encourage people to talk to their healthcare professionals before making changes to their diet.

If you're online and want more information please visit parkinsons.org.uk/diet.

Got a question about research?
Email research@parkinsons.org.uk with the word "Progress" in the subject line.

Q Is there any research out there that looks into pain and Parkinson's?

A Pain can be a hidden symptom of Parkinson's. There are a few different types of pain that are common, from muscle related pain to rigidity to shooting pain that can be due to a trapped nerve. But why some people experience pain and not others is yet to be determined.

People with Parkinson's who experience pain often feel misunderstood. That's why vital research is underway to develop understanding and management tools for pain in Parkinson's.

For instance, we're currently funding Dr Kirsty Bannister's research at King's College London to investigate causes of pain in Parkinson's. The researchers will do various tests to build up pain sensitivity profiles in people with Parkinson's. This will help the researchers understand why some people experience this symptom to help shape future treatment strategies.

If you're experiencing pain we recommend that you seek medical advice as there are medications and painkillers that can help. There are also exercises and some complementary therapies that some people find useful. If you're online and want more information and advice please visit parkinsons.org.uk/pain.

You might be interested to help fund this research that could have a life-changing impact for people who experience pain.
parkinsons.org.uk/treatpain.

Q I just want a good night's sleep! What's happening to address sleep problems in Parkinson's?

A We know that addressing sleep problems is a high priority for research and we heard about an app that might be useful on page 11. Building on this, earlier in the year, Parkinson's UK worked with the biotech company Clexio Biosciences Ltd to gather input from the Parkinson's community to better understand sleep problems associated with the condition.

This was done through a survey shared with our Research Support Network. The 400 responses are now helping to shape and plan Clexio's upcoming clinical trial to investigate a potential treatment to help with sleep problems and early morning off in Parkinson's.

And if you'd like more information or advice visit parkinsons.org.uk/sleep.





Interested in getting more involved in research?

Then join our growing online Research Support Network. You'll be part of a community of almost 6,000 other people affected by Parkinson's who are connecting with, supporting and driving research.

As part of the Research Support Network you can:

- Stay up to date with our regular research emails, featuring all the latest research news and opportunities.
- Hear from the experts with our online and local events. You can ask questions and discover what's really happening inside the lab.
- Find opportunities to take part in research and help make tomorrow's treatments

a reality. From surveys to research trials, there's something for everyone, whether or not you have Parkinson's.

- Share your expertise on what Parkinson's is really like by getting involved in research partnerships and helping shape the future of Parkinson's research.
- Connect with like-minded people through our local research interest groups, or get help setting up a new group in your area.

Join today at parkinsons.org.uk/RSN

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

TELL US WHAT YOU THINK OF PROGRESS MAGAZINE?

Our research magazine is produced in partnership with our readers and our editorial board, which is made up of people in the Parkinson's community. We want to know what you think.

1. On a scale of 1 to 10, how interesting do you find *Progress* magazine? (please mark one)

(Not interesting)

(Extremely interesting)

PLEASE MARK

1
 2
 3
 4
 5
 6
 7
 8
 9
 10

2. How does reading *Progress* magazine make you feel? (please tick all that apply)

Inspired
 Hopeful
 Informed
 Confused
 Frustrated
 Disheartened

Other (please specify):

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

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

(You can find out more about how to get involved on the back of this page)

(Not likely)

(Extremely likely)

PLEASE MARK

1
 2
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 6
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 9
 10

5. Are you already a member of the Research Support Network (RSN)? (If you are, you'll receive regular Research Roundup emails from the Parkinson's UK Research team). (please tick one)

Yes
 No
 I don't know

Send us your answers

BY POST: Tear out this page and send it to:

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

ONLINE: Fill out our quick questionnaire online at parkinsons.org.uk/winterprogress-2021.

If you'd like to help shape future magazines, please email research@parkinsons.org.uk or call 020 7963 3964.



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

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