THE PARKINSON
Summer 2018

Christian's story

Why I chose to have deep brain stimulation in my 30s

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

Welcome to your summer issue of *The Parkinson.*

You've probably already noticed that we've had a lick of paint! Many thanks to our brilliant design team who have given our pages a fresh look for the summer. We hope you like what you see. It's all part of our commitment to make your magazine the best it can be.

Of course, we're bringing you the same great read with all your regular news, views and features.

ALSO IN THIS ISSUE...

Inside, we look back on an amazing World Parkinson's Day, find out about some of the steps you can take to look after your feet, meet Christian and others who share their different experiences of deep brain stimulation surgery, and hear how a former MP coped with his Parkinson's diagnosis.

We always love hearing from our readers, so please let us know what you think of this issue. Is there anything you'd like to see more of, or less of? Or would you like to share your story of living with Parkinson's?

And watch this space for news about our exciting plans to make your magazine, with even more great features, available on the Parkinson's UK website.

In the meantime, have a great summer!

Your magazine team
Amy, Sion, Jennifer and Matthew
(pictured left to right)

What is a Parkinson's movement?

As a member of Parkinson's UK, you're part of a community of more than 35,000 people, helping bring forward the day when no one fears Parkinson's.

We've always been led by our members, and together we've been working hard to transform the lives of people across the UK.

But as the world changes around us, and the number of people diagnosed and living with Parkinson's increases, our community must unite and grow. And we need your help!

Over to you

Before the end of the year, we'll be launching a new Parkinson's UK membership offer and inviting more people to join us.

There's a role for you, and your friends, family and colleagues in this Parkinson's movement.

We're creating new opportunities for you to show your support, take action and make a difference.

We don't have all the answers yet, so we want to hear from you.

How can we encourage more people to join us?

Please share your thoughts about how we can welcome more people like you, and your friends and family into the Parkinson's movement as members of Parkinson's UK.

It's really easy to share your ideas:

- Visit **parkinsons.org.uk/ourmovement**
- Email **involvement@parkinsons.org.uk**
- Write to Gemma Instrall at
  Membership Programme,
  Parkinson's UK, 215 Vauxhall
  Bridge Road, London SW1V 1EJ

Gemma Instrall, who joined Parkinson's UK in March, is our new Membership Programme Lead. She's working with members, staff, volunteers and supporters to achieve our vision of a strong membership made up of lots of different people.

"I'm really excited about what we can accomplish together," says Gemma. "As we build our membership package and grow the movement, your ideas will be vital every step of the way."

What is a movement for change?

When we talk about a Parkinson's movement, we mean getting lots of different people working together, focused on achieving a shared goal.

For the Parkinson's community, it's about bringing forward the day when no one fears Parkinson's.

The more people who join this movement as members of Parkinson's UK, the stronger we'll be! ■

Changes to data protection laws

In May, the law changed, meaning that we had to ask you if you still wanted to receive emails about the work we're doing to lead the fight against Parkinson's.

You may have received many similar emails from other organisations, asking you about staying in touch. This is because of GDPR, which stands for General Data Protection Regulation.

This new piece of data protection legislation gives you greater protection and rights as an individual. Our promise is that:

- we will do our very best to only send you emails that you're interested in, something which we're continually striving to get better at
- we will only ever get in touch in the ways that you tell us are ok – and you can opt out of hearing from us at any time
- we will stick to our full privacy policy – and we'll never sell or rent your information to anyone else

We will soon be writing to all members explaining this in more detail, and providing a copy of our updated privacy notice. In the meantime, if you're not currently receiving emails from us about useful Parkinson's information and support services, involvement in research, campaigning opportunities and more, all you need to do is sign up at **parkinsons.org.uk/enews**

This won't affect you receiving *The Parkinson* magazine. ■

Moving towards our new strategy

A huge thank you to those of you who have taken the time to help shape the future strategy for Parkinson's.

Many of you returned the postcards that went out with the last issue of the magazine, or commented online. Your feedback is being analysed but some big themes are already emerging.

These include the importance of a strong focus on exercise, a wish for greater awareness about Parkinson's, the need for improvements in social care and better support when life with Parkinson's gets more difficult, and of course the urgency of finding a cure.

There'll be more chances to have your say later in the year.

These include the Annual General Meeting in October, when we'll build on the insights already shared and start to think about how, together, we can deliver the change people living with Parkinson's want to see.

Look out for more updates in future issues. ■

In praise of our campaigners

Volunteer John Hinson (left) and Parkinson's UK's Benali Hamdache

In May people from across England who have campaigned for Parkinson's UK gathered in Birmingham for our first ever campaigner celebration. Volunteers and staff spent a lively day discussing campaign successes and sharing tips and ideas.

Benali Hamdache, Parkinson's UK Campaigns Engagement Manager, said, "It was a real privilege to spend the day celebrating the hard work of all our volunteers, and to plan our next steps to build a campaigning movement. It was great to share stories and ideas about a whole range of issues and campaigns, including Get It On Time, access to Parkinson's nurses and accessible transport."

John Hinson, who is one of Parkinson's UK's campaign volunteers in Humberside, said, "If there was just one thing I could share from this inspirational event, it would have to be the hard-hitting stories that people told.

"While I've still got a voice and some energy, I realise I can do as much or as little as I can manage to help campaign for Parkinson's UK. As a volunteer campaigner I can help make a difference by doing something as simple as filling out a petition."

It's been an exciting year for the Policy and Campaigns team. Our Local Campaign Officers have been spending their time recruiting and supporting volunteers up and down the country.

This year we've supported 15 different local campaigns, from South Tyneside to Kensington and Chelsea. If you'd like to find out more or get involved, please contact Benali using the contact details on the next page. ■

Concerns over Northern Ireland assessments for PIP

Personal Independence Payment (PIP) was introduced in Northern Ireland in 2016, with 300 people having to be reassessed to see if they qualify for the new benefit.

Capita are a private company who carry out PIP assessments on behalf of the Department for Communities (DfC). We've been working with these two organisations to discuss the issues people with Parkinson's are having with the assessment process.

We've provided both Capita and the DfC with guidance notes to help them understand Parkinson's better. They also received details of our workplace training, which they've pledged to undertake.

In conjunction with other organisations, such as Citizens Advice and the Northern Ireland Law Centre, we're campaigning to make sure people with Parkinson's who have been subjected to a reassessment are having the 'no review' box ticked on their claim form. Parkinson's is a progressive condition with no cure, so there should be no need for reassessment.

If you live in Northern Ireland and are having issues with your PIP claim, please contact Service Manager Patricia Jordan on **0344 225 3682** or **pjordan@parkinsons.org.uk** ■

Left to right: Dr Chris Thomas, Ana Palazon (Director, Parkinson's UK Cymru), Vikki Howells AM, and David Murray and Sharon Martin who live with Parkinson's

Get It On Time goes to the Welsh Assembly

People affected by Parkinson's from across Wales met with Assembly Members in April to talk about the importance of getting medication on time in hospital.

At the event Dr Chris Thomas, consultant geriatrician specialising in Parkinson's at Cardiff and Vale University Health Board, explained why timely Parkinson's medication is crucial in helping people manage their symptoms. Sharon Martin, who has Parkinson's, shared her personal experience of getting her medication on time during a recent hospital stay.

"When I was waiting to be admitted to hospital I explained to the ambulance crew that I had Parkinson's and my medication was soon due," said Sharon. "They were brilliant and made sure I got my pills when I needed them. The hospital staff let me self-medicate, as I was well enough to do so. It made a real difference to keeping my Parkinson's symptoms under control and I'm sure it helped me recover more quickly."

Parkinson's UK Campaigns and Policy Officer for Wales, Rachel Williams, will be spreading the Get It On Time campaign message in Wales.

She'll be working with Assembly Members to help put pressure on health boards to introduce policies allowing patients to administer their own medication. ■

Find out more

For more information on our campaigns, please visit **parkinsons.org.uk/campaigns** or contact our staff to find out how you can get involved:

England
Benali Hamdache,
Campaigns Engagement Manager
campaigns@parkinsons.org.uk
or **020 7963 9349**

Northern Ireland
Caroline McEvoy,
Campaigns, Policy and Communications Officer
cmcevoy@parkinsons.org.uk
or **0344 225 9868**

Scotland
Tanith Muller,
Policy and Campaigns Manager
tmuller@parkinsons.org.uk
or **0344 225 3726**

Wales
Rachel Williams,
Campaigns and Policy Officer
rwilliams@parkinsons.org.uk
or **0344 225 3715** ■

GETTING TO THE ROOT OF ANXIETY

As well as physical symptoms, people with Parkinson's can often experience mental health symptoms. We talked to a leading researcher about his work on finding a new way of treating anxiety.

Everyone feels anxious occasionally, and different situations – perhaps a trip to the dentist – will cause different people to feel anxious.

For most people these anxious moments are rare and are over quite quickly. For someone who struggles with anxiety, these feelings can happen more often, last longer and feel more intense.

While anyone can experience it, it's estimated that significant symptoms of anxiety affect around 30% of people with Parkinson's. Having more severe Parkinson's symptoms and being diagnosed at a younger age are both linked with an increased likelihood of anxiety.

What is anxiety?

Anxiety is a feeling of unease, worry, fear or dread. It can create a physical reaction in your body, such as sweating, dizziness or nausea.

Anxiety is a normal response when we find ourselves in a threatening situation. A surge of adrenaline makes our hearts beat faster, our breathing deeper and blood rush to our muscles – preparing us to fight an enemy or flee from danger. However, this response sometimes happens when it doesn't need to, which causes problems.

Richard Brown, Professor of Neuropsychology and Clinical Neuroscience at King's College London, is running a research project looking at anxiety in people with Parkinson's, funded by Parkinson's UK.

Q. What's the connection between Parkinson's and anxiety?

A. People with Parkinson's seem more prone to anxiety. Some of this will be down to brain chemicals. However, some of it will be down to how anxiety and Parkinson's interact. When someone is stressed and anxious, the symptoms of Parkinson's tend to get worse because of widespread effects on different systems in the brain. This in turn can make someone feel even more anxious, and create a vicious circle.

Q. Are existing treatments for anxiety helpful for people with Parkinson's?

A. Anxiety and depression are routinely treated with a type of antidepressant drug called Serotonin Reuptake Inhibitors (SSRIs).

Medication can certainly be useful to help manage anxiety and depression. Talking therapies, especially cognitive behavioural therapy (CBT), have been specifically developed to treat anxiety and can be highly effective. However, we don't have any formal scientific evidence to demonstrate exactly how well SSRIs or CBT work in Parkinson's.

Q. Why is there a need for a new approach to managing anxiety?

A. One disadvantage of CBT is that it can be hard to access for some people and it involves a considerable time commitment. We're looking for simpler treatments that people can do on their own via a tablet or smartphone, over a period of weeks rather than months.

Q. Your research is centred around something called 'interpretation bias' – what is that?

A. Previous research has shown that people who are anxious have a tendency to interpret situations as more dangerous or threatening than they actually are.

For example, imagine you see a friend across the street and they do not wave. An anxious person may worry that the friend is upset about something they did (a negative interpretation), rather than assuming the friend did not see them (a neutral interpretation).

This negative interpretation bias can trigger feelings of anxiety and, in this scenario, may cause the person to worry about the event or avoid the friend.

Q. How will you test whether people with Parkinson's have this tendency?

A. We'll use a range of approaches. For example, we'll present people with hypothetical scenarios that can be interpreted in more than one way. We expect that anxious people are more likely to draw a negative interpretation, which serves to strengthen and maintain anxiety.

Q. What are you hoping to achieve?

A. Previous studies have shown that people can be trained to make more positive or neutral interpretations and thereby feel less anxious. If we find that anxious people with Parkinson's have this interpretation bias, we will see if computer-based training is beneficial for them.

Having zero anxiety would not be good for us. Fear has evolved to keep us safe from real danger, so a person with no fear would not survive very long! We're just aiming to turn down the level of fear and anxiety, so that it stops being unpleasant and problematic.

Find out more

You can read the full version of this blog, which includes Richard's tips for coping with anxiety, at **www.medium.com/parkinsons-uk** ■

#UniteForParkinsons

What did you do for World Parkinson's Day this year? It was another busy one for us, with staff and supporters alike putting in enormous effort to spread the word.

Comedy writer Paul Mayhew-Archer, who has Parkinson's, at BBC Radio

Paul with Steve Ford, Parkinson's UK CEO, on Sky News

A dance flashmob and brass band in Stockton

The Kelpies monument in Falkirk, Scotland, was specially lit

Parkinson's UK's Professor David Dexter at BBC News

To mark World Parkinson's Day on 11 April, we teamed up again with the European Parkinson's Disease Association and other organisations in Africa, Australia, India and the US to work on #UniteForParkinsons.

This is a global campaign that aims to show what Parkinson's truly is, through the eyes of people living with the condition. Even though around 10 million people worldwide have Parkinson's, the public are still relatively unaware of many of the symptoms.

To try to change this, we launched a video of clips of real people with Parkinson's from around the world talking about their symptoms, challenges and achievements.

The video had an amazing impact. It was watched by more than 187,000 people on our Facebook page alone, and had almost 8,000 likes and shares.

On the day itself, we encouraged people affected by Parkinson's to share their own stories on social media and mention #UniteForParkinsons. We were overwhelmed by your support. More than 16,000 people from 99 countries used the hashtag.

You can read some of their messages and watch the full video at **uniteforparkinsons.org**

And it didn't stop there – our hard-working media team ran a 24-hour media marathon and secured more than 130 pieces of news coverage in the UK.

We had our first radio interview at quarter past midnight with LBC and finished with Emma Lawton and Matt Eagles, who both have Parkinson's, talking on BBC Radio 5 live in the final hour of the day.

All of this activity was underpinned by the constant support of our local groups and volunteers. We saw so many amazing events organised to celebrate this important day – thank you! ■

DBS and me

Some people affected by Parkinson's undergo deep brain stimulation surgery (DBS). Here, we share four people's different experiences of DBS in their own words, and speak to Dr Monty Silverdale about what to expect from the procedure.

Christian: having DBS in my 30s

"It got to the point where I just couldn't tolerate the medication." Christian Booth describes how he came to the decision to ask his doctor about having deep brain stimulation (DBS) surgery, at the age of just 36.

"I'd tried so many different drugs, from levodopa to apomorphine, but the side effects were ruining my life. The meds helped control my tremor, but at what cost? I had involuntary movements, I was feeling sick, hallucinating. I developed addictions. I'd always liked placing a football bet but it became ridiculous. I had to ban myself from online gambling. It didn't seem like real money when it was just a number on a screen – it wasn't like you were pulling a tenner out of your pocket."

For a while Christian, who lives in Stoke-on-Trent with his wife Samantha and three children, stopped taking medication altogether, feeling that the side effects outweighed the benefits.

"People would argue, saying that I needed to take it to make me better. I used to say to them, 'Well you take one. You take a tablet and tell me how well you function in work, all day, without feeling really dizzy or wanting to throw up.'"

With an uncontrollable tremor and becoming increasingly frustrated, Christian went to his consultant to discuss having the DBS surgery he'd read about. At the time Christian was working in a factory, after having to give up his job in the building trade where he had worked fitting offices, including working on the Olympic media park in 2012. Despite support from his colleagues, the manual labour required for the job had become too difficult, what with worsening symptoms and the debilitating side effects of medication.

His consultant referred him to the Salford Royal Hospital for a DBS assessment, with Christian expecting it to be a straightforward process.

"Firstly the doctor ignored my original notes and wanted to do his own report. And I was then told that I wasn't eligible for the surgery because I'd only had Parkinson's for three years. I just remember thinking it was ridiculous. It was tough to hear."

Christian ploughed on, taking a minimal amount of the medication Madopar, to counteract really bad days, but to avoid unwanted side effects.

"The doses I was on weren't really doing anything though, so it was pointless in a way," he adds.

As a last ditch attempt, Christian got in touch with the hospital again to plead his case. Eight months later they agreed to carry out the surgery.

"Once they told me that I could have it, that's when I started to panic! But actually the staff were brilliant and put me at ease. They talked me through the procedure and what the risks were, and I had

an MRI scan so that the surgeon could map out my brain. I was just keen to get it done at this stage as I wasn't functioning very well at all."

In October 2017 Christian underwent the DBS operation where small electrodes were implanted into his brain and connected to a pulse generator placed under his skin. This was carried out under general anaesthetic.

The procedure went smoothly, and after three days Christian was discharged from hospital. "Obviously I felt a bit battered and bruised and ragged around. There was a slight discomfort in my chest where the battery had been fitted. But overall I felt OK – I didn't experience any headaches and my head healed really well.

"A few days later a nurse came to my house to take the stitches out. All in all, considering what I'd just had done and the fact that I had wires running down from my brain into my chest, I thought they'd done a good job!"

And how did the surgery impact his symptoms? "I had to wait 10 weeks for the brain to 'settle' before they switched it on. I felt pins and needles down my body. But it was amazing. I went from 40% functionality to 90% with one flick of a switch.

"My tremor – which at times could have been violently strong, to the point where I couldn't text or write my name – instantly improved. My posture was better too. My friends and family noticed the difference straight away."

Since the operation, Christian has been able to go back to work at his friend's building company, in a more manageable role. He has to attend regular appointments to make sure his surgery hasn't affected his memory or psychological state, but is so far doing well.

He adds: "DBS hasn't been an instant cure. I still have a tremor, but it's much milder now. The next steps will be fine tuning it.

"My first thought when I was diagnosed with Parkinson's was, 'Is this going to kill me?' But I try to take things in my stride. I have my dark days, but there's no point getting down or hung up on life when there's still a long way to go."

Briony: my DBS operation

I was first on the waiting list on the morning of my surgery. Earlier that morning I had been visited by the anaesthetist, who explained carefully the sedation process. First, my forehead was to be injected with local anaesthetic so that a metal frame could be securely fitted on to my head. I would then be sedated before they drilled two holes into my skull, where electrodes would be attached to my brain.

The anaesthetic room had an astrological picture on the ceiling of children leaping happily over the stars. I was given the sedative. I began to feel relaxed, and no longer afraid of what was about to happen. My advanced practitioner nurse held my hand and another nurse held the other hand. I was wheeled to the operating theatre and the job began.

The process of injecting my forehead was uncomfortable, but I reasoned dozily that complaining was pointless – the procedure would go ahead.

It sounded more like a lesson in carpentry as the surgeon chatted to his assistant, but I was somewhat alarmed by his comment: “We seem to have a screw missing. Anyone seen it?” Lying flat on my back with the surgeon behind me, it was impossible to know whether this was a joke or not. Either way, it would have some mileage as operation tales go.

I kept checking with the surgeon how far along we were. The last thing I remember him saying was “about three-quarters of the way”. Suddenly it was over and I was being wheeled to the CT scan room to check that everything was in order. It had taken four hours.

The second operation was due to take place a week after the first. The two electrodes would be connected to the neurostimulator which would be embedded in my chest. The donning of the shapeless hospital gown was followed by the fight with anti-DVT (deep vein thrombosis) socks, the struggle to remove my wedding ring and the hours of waiting hungrily in bed for the porters to turn up.

The time finally came the next morning for me to ‘go down’. I was having a general anaesthetic this time. As I looked upwards, the kiddies in the astrological landscape on the ceiling started bobbing up and down crazily as I went under.

When Parkinson’s strikes it gives us no choice but to grin and bear it. The timing is never ideal and its relentless progress continues to test us. I was 61 when I had my DBS. For now, the treatment options are limited, but we have choices and this gives patients a sense of power and control over their condition.

DBS involves a degree of risk, but the encouraging outcome for me has been worthwhile.

Mark: having my DBS reprogrammed

In November 2011 I was assessed as being suitable for DBS, and five months later I was 'switched on' at Frenchay Hospital, Bristol. I was 48 at the time.

Once everything had settled down, my life improved hugely, and years of uncontrollable shaking finally ceased.

Since then I have made a number of visits back to hospital, all as an outpatient, to have the DBS unit reprogrammed.

Parkinson's gets worse over time, so it stands to reason that from time to time adjustments are necessary.
I can make minor adjustments to the DBS unit at home, but occasionally I need to visit the team in Bristol for help.

Personally I quite look forward to these visits. It affords me one-to-one time with my specialist nurse, which is really helpful in all aspects of managing my condition.

As far as the reprogramming is concerned, as a patient, this is really easy. Every time something in the programme is changed, it is recorded in great detail by the specialist nurse. This means that any changes can be made in line with the current programme.

Usually it takes about 20 minutes to adjust the settings to improve my movement, although this can vary. At first I was having adjustments every three months or so, but now it is only really about once a year.

I had a new battery fitted last year, again as an outpatient.

The biggest drawback is travelling from Devon to Bristol each time I need retuning, but it is a small price to pay for such a huge improvement to my life.

Fiona and Stephen: our problems with DBS

In 2014 my husband, Stephen, who was 64 at the time, had DBS surgery. It successfully helped to alleviate his severe tremor.

Before the procedure he'd read that dystonia was a risk of the surgery. But nowhere did it mention that blepharospasm – dystonia of the muscles around the eyes, which can cause uncontrollable blinking and eyelid closure – might be a long-term side effect. In extreme cases the person's eyes clamp shut so that, at times, you are effectively blind. This is what happened to Stephen.

Since then, despite the best efforts of his neurologists and movement disorder nurses, his eye problems have gradually worsened. Often the only way to open his eyes is if he manually forces them open.

The following are just a few of the things we've tried to improve the problem, with no success:

DR MONTY SILVERDALE, CONSULTANT NEUROLOG

DBS involves implanting very fine wires, with electrodes at the tips, into the brain. These are connected to a pulse generator (a device like a pacemaker). The surgery is often carried out in two stages under local or general anaesthetic, depending on your specific hospital.

When the device is switched on, the electrodes deliver high frequency stimulation to the targeted area. This stimulation changes some of the electrical signals in the brain that cause the symptoms of Parkinson's. It can be very effective for many people with the condition. But it's not suitable or effective for everyone.

Everyone who is being considered for DBS needs to go through an assessment phase. This usually involves checking cognitive functions (including memory), mobility and how well the person

- Reprogramming the deep brain stimulator – done by Stephen's neurological team and also an expert from the DBS manufacturer
- Botox injections in the muscles around his eyes
- Ptosis props – adapted glasses that lift the eyelids
- Tight-fitting hats, baseball caps and scarves (and goggles)
- Pressing his temples, tapping under his eyes and pressure on his cheeks
- Hypnotherapy
- Referral to a German neurological consultant whose prices for further exploration would have been unaffordable for us
- Trying to obtain CBD cannabis oil on the NHS (with the support of the neurological consultant and our GP) in the hope it would relax the muscles around Stephen's eyes. The applications were turned down because of insufficient medical evidence.

Because MRI scans are not possible with the type of DBS that Stephen has, it is not possible to undertake further investigations.

There are risks to further brain surgery and no guarantee it would be successful anyway.

The vast majority of people with Parkinson's who have DBS operations have their lives transformed for the better. In Stephen's case, it has had a major side effect that neither he nor the hospital staff could have predicted. The benefit is that his tremor continues to be significantly less than before he had DBS.

However, knowing what he now knows of the possible side effects, Stephen is not sure whether he preferred life with tremor before DBS, or the difficulties of living with sight loss he has now.

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responds to levodopa. Many centres also carry out mental health assessments too. The process usually takes a few months.

It's important to realise that the assessment process is not an 'exam', but simply a way to determine whether DBS may be helpful for them and to make sure there aren't any problems which might potentially be made worse by the surgery.

Current guidelines state that DBS should only be offered to people after they have been diagnosed with Parkinson's for more than five years. This is because sometimes people with what is thought to be Parkinson's actually have a different condition, with similar symptoms. These conditions respond very poorly to DBS, and will almost always become obvious five years after diagnosis. Sometimes DBS can be considered for people who have had their diagnosis for less than five years, but only after very careful assessments.

Sometimes after DBS people get side effects including tingling in the face or twitching of the muscles. Side effects such as dystonia of the eye muscles, as described in Stephen's case, can occur, but are rare.

Occasionally it can be difficult to improve the Parkinson's symptoms without causing some of these side effects, although normally they can be minimised by changing the DBS unit settings.

Find out more

You can find out more information about deep brain stimulation surgery at **parkinsons.org.uk/surgery** ■

STAYING HEALTHY AND CONNECTED

If you're busy caring for someone with Parkinson's, while perhaps working or raising a family, often you don't have time to think about yourself. But it's important that you get the information and practical support to care safely without harming your own health and without losing important relationships with others.

In the last issue of *The Parkinson*, we asked you how you stay healthy and connected to others. Thank you for getting in touch to share your own tips and personal, candid experiences of caring for a loved one, family member or friend. We print some of them here.

I can't call myself a carer in the sense of doing lots of 'hands on' care for my husband, but I am a carer nonetheless.

He has only been diagnosed for a year, and so far his symptoms are manageable. Superficially our lives haven't changed much, aside from the changes that come with ageing. But his diagnosis was a shock, and something I've found difficult to come to terms with. He'd always been the strong leader and his diagnosis threw me into mild depression. To get support, I decided to see a private counsellor. She has been very understanding and helpful, and herself has an elderly mother with more advanced Parkinson's.

Frances

At the beginning of the year I was motivated to do a couch to 5k programme [an NHS-led running programme] to raise money to help our Parkinson's UK local group. It was a nine-week programme finishing with a 5k race in March. I felt an enormous amount of satisfaction being able to do this and the health benefits were so good that I continued running.

I have made new friends at my local running club and I now have a training plan for my next challenge in September, which is the 5,000m race at the World Masters Athletic Championships in Malaga.

This training is designed to fit around my caring role. The psychological boost I get, as well as the obvious physical benefits, really helps me to help my husband.

Val

I have Parkinson's and my hubby, Peter, cares for me while also caring for his 91-year-old mum. We get three hours of respite weekly, when Peter enjoys a cycle ride. He also enjoys gardening in half-hour slots.

Brenda

I have to make sure that I stay fit and healthy as I am 76 and my wife is 71. She worries what would happen to her if I wasn't around, as she hasn't got anybody else to look after her. I make sure I eat healthily and when I am able to leave for a little while, I go walking and exercise as much as I can.

Ernest

My wife lives with Parkinson's dementia and incontinence. For me, the stress and worry I experience are considerable. I am unable to understand my wife's requests at times because of her speech difficulties and we can no longer have rewarding conversations. Yet she relies on me for care and attention for up to 18 hours a day.

Carers are given little guidance or training for what gradually becomes a full-time job, often at a time in life when they thought that they would be able to retire or embark upon fulfilling activities such as travel or creative pursuits which they had been unable to pursue earlier in life. My limited respite time is often devoted to shopping or household duties. I even have to write this message late after my wife has gone to bed. In the daytime I am nervous if I leave my wife alone for more than a few minutes.

I try to stay healthy and connected through occasional contact with friends or family, help from local health workers and a glass of wine every night. However I am not sure how long these will continue to prove effective.

Michael

Tips for staying healthy and connected

❶ Accept your feelings and talk about what you are doing and how you are feeling to the person you care for, family, friends or other people in a similar situation.

❷ Tell friends, your employer or colleagues (and your children's school if relevant) how caring fits in with the rest of your life and how they can help you.

❸ Encourage independence – it's important to let the person you care for be as independent as possible, even if tasks take much longer. Resist the temptation to take over, and offer support rather than inundating the person you're caring for with advice and practical help.

❹ Make changes to how you divide your roles and responsibilities – these can still be shared, so that neither person carries all the responsibility.

❺ Look after yourself and keep time aside for you. Make sure you don't neglect your own health and quality of life, and accept support from others. You may need to make arrangements for someone to look after the person you care for, but try to keep your social life as normal as possible and do things you enjoy.

❻ If you can, plan things together and try not to let Parkinson's dominate everything. Do things you enjoy doing together, even if this means doing them differently.

❼ Get support before problems reach crisis point. Your GP or Parkinson's local adviser can assist you – ask them what help they can give, so you're prepared, even if you don't think you need help right now. ■

Last year we told you about how we'd teamed up with the National Free Wills Network, who offer free Will-writing services to different charities.

Since then, more than 160 Parkinson's UK members have had their Wills written for free, with Parkinson's UK covering the cost. Although members are under no obligation to include a gift to us, three out of four members who have used the service have done so.

Who are the National Free Wills Network?

The National Free Wills Network offer free Will-writing services to different charities, including Parkinson's UK.

You can meet with a local solicitor to have a single Will or joint Will made (with your spouse or partner) or updated for free. Parkinson's UK will pay the cost of your Will.

The service is available all year round with 400 participating solicitors across the UK.

How do I join?

Visit **parkinsons.org.uk/willwritingpartners** and complete our online form, or call our Supporter services team on **0800 138 6593** (9am-5pm Monday to Friday).

We will then pass on your contact details to the National Free Wills Network, who will post you a pack containing details of participating solicitors in your local area. This is a limited offer.

Make a difference by including Parkinson's UK in your Will

The kind gifts we receive in Wills help fund almost half of what we do as a charity – meaning they are vital to us.

Indeed, the gifts we receive today are helping us towards our aim of doubling the amount we spend on our research.

We receive gifts both small and large, from £100 to a staggering £1million. All gifts make a difference.

It's easy to include a gift in your Will – you simply need to instruct a solicitor of our charity name and number and they will assist with the type of gift you want to leave. Our full details for this are:

Parkinson's UK, a charity registered in England and Wales no. 258197 and in Scotland no. SC037554. Registered office. 215 Vauxhall Bridge Road, London SW1V 1EJ. ■

Francis's story

Wills and Parkinson's

> “Getting my Will made through the network was really straightforward – I found the information pack useful and easy to use, and I set up a meeting with a solicitor local to me. The whole process went so smoothly. My main motivation for including a legacy gift to Parkinson's UK was to increase my support, and being able to update my Will for free was a bonus. I would certainly recommend the network to other members.”
>
> **Francis,**
> **Parkinson's UK member**

ASK THE HELPLINE

Our specialist advisers answer the questions you have about living with Parkinson's.

I am concerned that my pharmacist is sometimes unable to get hold of my medication, what can I do?

There are a number of reasons why a pharmacy may not have your drugs in stock. It can happen because they are waiting for a delivery from the wholesaler or there may be wider problems with the supply or manufacture of the drug.

It's always a good idea to plan your repeat prescription early. Organising this with your pharmacy will mean that if there are any problems with the supply or delivery of your medication, you will have enough to last until it's available again.

If delays are part of a wider supply issue, check if your pharmacist has contacted the distributor and manufacturer of your medication. They might be able to arrange for a special one-off supply to be delivered.

Your pharmacist may also suggest taking a generic (non-branded) version of your medication until your usual brand is available again. Most people don't have any problems when they take generic medication, but if you are concerned about this you can speak to your consultant or Parkinson's nurse. You can also ring the helpline to speak to one of our advisers or Parkinson's nurses.

What can I do if I go on holiday in the UK and I forget to take my Parkinson's medication with me?

A local pharmacy can usually give you an emergency supply of medication of up to 30 days' treatment if they have it in stock.

To get an emergency supply you must have been prescribed this medication before by a registered UK health professional. If you contact your GP or pharmacist they should be able to supply the local pharmacy with an electronic prescription.

In some areas of the UK you may also be able to go to a walk-in clinic or contact out-of-hours medical services if needed. Please remember that services will not be the same everywhere in the

UK and in some cases it may take more time to get a prescription than others.

Try putting supplies of your Parkinson's drugs in more than one place, such as in your coat, wallet and car, before you travel to help you remember it.

I experience tremor and a weakened grip, which makes using cutlery and cups more difficult. Is there anything that can help with these issues?

There are a number of options available. You could try using cutlery that is extra large or made with moulded rubber handles. This means you can grip it more easily. Curved foam sleeves can be helpful, too. You can place them onto your existing cutlery so you can hold it better.

Mugs also come in different shapes and sizes to make things easier. To help improve grip and reduce the chance of spills, try two-handled cups.

Alternatively you can use ones with wide, non-slip bases and tall necks, called 'tumble-not' mugs.

Using a sip or sports cup with a lid can stop liquids from spilling. If the sip cup is being used for hot drinks, it's important to make sure that the cup is made out of a material that won't soften or melt.

To buy any of these items you can visit our shop at **shop.parkinsons.org.uk**

Alternatively, search online for adapted cutlery or crockery – a number of different websites stock a range of helpful products.

Clarification

In the winter 2017/18 issue of *The Parkinson* we printed a helpline question advising that the drug rasagiline can safely be taken with antidepressants.

The answer should have made it clearer that clinical trials carried out into the combined use of rasagiline and antidepressants excluded two particular drugs – fluoxetine and fluvoxamine. Because of this lack of evidence, taking fluoxetine or fluvoxamine alongside rasagiline is not recommended. But, if you're not taking rasagiline, then taking fluoxetine or fluvoxamine is not harmful.

Our confidential helpline is staffed by specialist nurses and advisers who can answer your questions on any aspect of Parkinson's.

Call us free on **0808 800 0303** or on our NGT Relay **18001 0808 800 0303** (for textphone users). You can also email **hello@parkinsons.org.uk** The helpline is open Monday to Friday 9am–7pm and Saturday 10am–2pm. ■

Helplines Partnership
MEMBER

Peter with his wife, Julia, in Venice

PARKINSON'S IN THE PUBLIC EYE

Experiencing Parkinson's symptoms before you're diagnosed can be a bewildering and frustrating time. But imagine going through this when you have a high-profile, demanding job that means you could end up being headline news. Former MP Peter Luff shares his story.

As a Member of Parliament for 23 years, Peter Luff has experienced the cut-throat world of Westminster from the inside. In such a competitive environment, health conditions or problems are very rarely discussed.

"Any sign of weakness is hard to admit in politics," says Peter. "Levels of scrutiny on people in public life are so great. It's really good that the Prime Minister, Theresa May, is so open about her diabetes. We should be encouraging public figures to speak out about their health. However, I think it does take rather more courage for someone well-known, because your whole personal life is stripped bare.

"If you don't explain what's happening, it's very difficult for your family because you are on show and people notice you've changed. Before my diagnosis, and before I decided to go public, people would ask my wife and our children what was wrong with me. First, like me, they didn't know. Then, even when they did know, they couldn't say anything until I'd spoken about it publicly.

"I do know people in public life who are concealing their Parkinson's. Everyone knows they've got the condition. If you have tremor, it's very difficult to hide. I think they'd be stronger if they said, 'Yes, that's what I've got' and explained how they were managing it. Their lives would be easier in many ways. They would also help other people understand that Parkinson's is nothing to be ashamed of, because it isn't."

Having run the office of former Prime Minister Sir Edward Heath, Peter became an MP in 1992. He went on to serve as private secretary to Ann Widdecombe and chaired several parliamentary select committees. Peter first noticed a change in himself while he was a defence minister in 2011.

"The very first symptom I noticed, without knowing what it was, was that my voice would go hoarse," says Peter. "Then I noticed that my left arm got stiff and would freeze in position. I remember I had a cup of tea in my hand at the House of Commons and my arm froze so that I could hardly put the tea down. I had to take my left arm with my right hand and almost force it down."

Peter started off with what he describes as symptoms that aren't perceived as being classic signs of Parkinson's – a prickly sensation down his back, aching limbs, excessive saliva production and a hoarse voice, with faster speech. He described these to an occupational health consultant, a dentist and a physiotherapist, but none of them felt there was anything for him to worry about.

"All these various symptoms and no one put them all together," says Peter. "I started Googling a bit and eventually went to my GP and had to ask, firmly but politely, to be referred to a neurologist. That first appointment was months away, of course. From my first symptom to the diagnosis was four years."

Just before the general election in 2015, Peter was all set to retire from parliament – a decision he'd been planning for some time. As he was about to take up a new role as Chair of the Heritage Lottery Fund, he was diagnosed with Parkinson's, at the age of 60.

"I didn't want my new colleagues to worry that I wasn't able to perform the duties the job demanded," says Peter. "I wanted to earn people's respect first, before they knew I had the condition. For most people at the organisation I think it came as a surprise when I told them.

"If I'd been diagnosed after the election and was still in the House of Commons, I think I'd have talked publicly about my Parkinson's much sooner. After 23 years as an MP, I would hope that if I felt fit to do the job, that would have been enough for my colleagues and constituents."

One of the symptoms that Peter has found most difficult in his professional life has been losing his natural facial expressions – sometimes described as 'masking'.

"It can look as if you're not concerned or interested in something, or don't find something amusing when you do," says Peter. "In public life that can be quite a disadvantage because you're judged so much by how you look, rather than how you sound. You can't leave it to your reflexes – you have to remember to smile or show concern.

"I had a horrid incident at a restaurant a few months ago in London where I went in and a customer held the door open for me. I thought I was smiling gratefully, but obviously I wasn't. He got very cross, swearing at me, and it almost turned into a fight because I hadn't looked appreciative as he opened the door. That taught me a lesson, the hard way!"

Overcoming these challenges, including having to battle for his diagnosis, is something that Peter is keen to talk about. And his advice for anyone who might be in a similar situation to the one he was in several years ago is very clear.

"I do think there's a lack of awareness around Parkinson's in the medical profession and of what the condition entails," says Peter. "I'm surprised how little understanding there is among GPs of the avenues for referral for treatment.

"It's taken me three years to be referred to a neurophysiotherapist [a physiotherapist specialising in neurological disorders, such as Parkinson's]. It turned out I could have just self-referred at the very beginning. That's frustrating, and there's a real wake-up call to the health service here.

"My message for people who think they might have Parkinson's is to fight for your diagnosis, understand your rights, and talk about your condition as openly and positively as you can, because it makes life easier."


Peter during his time working as a defence minister 2010-12

Find out more

Through our telephone peer support service, you can chat to someone with a similar experience of Parkinson's to you. Find out more on the next page, or visit **parkinsons.org.uk/peersupport** ■

Talk to someone who understands

Our peer support service

The experience of having Parkinson's, or having a partner or relative with the condition, can be isolating and frightening at times. Whatever your concerns about living with Parkinson's, talking to someone who has been there can be a great comfort.

Our free peer support service puts you in touch with a trained volunteer who has a similar experience of Parkinson's to you – someone who understands.

> "We shared experiences and identified solutions in a very supportive and positive way. We also shared laughter and tears in a safe and secure environment."
> **Person with Parkinson's**

What is the telephone peer support service?
This is a free and confidential service provided by trained volunteers who are ready to listen, offer emotional support and share their experiences and understanding.

We will match you with a volunteer with a similar experience of Parkinson's. They will phone you at a time that's convenient for both of you. Our volunteers bring a wealth of knowledge about Parkinson's.

They are ready to provide general support and offer a 'listening ear' as well as share their personal experience of managing the condition.

The service offers short-term support and you can arrange to have up to six telephone sessions with a volunteer.

Who can use the service?
The service is open to anyone personally affected by Parkinson's, whether you're newly diagnosed or have been living with the condition for some time. It's also available to carers, partners and family members.

> "When I used the service, the volunteer gave me realistic advice on how Parkinson's and deep brain stimulation surgery felt – something my consultant couldn't do. This had a hugely positive impact on me. In return I wanted to do the same for others, so I became a volunteer myself. Knowing I'm making an impact on others is very satisfying."
> **Josie, who has volunteered for the service since 2015**

Find out more

If you would like to use the peer support service or if you would like more information, simply call our helpline on **0808 800 0303** or email **peersupport@parkinsons.org.uk** ■

Your views

Thank you for sending in your thoughts, opinions and experiences of life with Parkinson's. These are some of the things you've written to us about recently.

"My wife, Rachel, died in November 2016. Thankfully, her Parkinson's progressed slowly, but for the last six to eight months her quality of life was poor.

With the benefit of hindsight there are a number of things my family and I might have done differently to make life easier for both of us. I have put together a few suggestions, based on our experiences:

- If moving is not an option, consider getting a stairlift installed, sooner rather than later, to avoid future handling problems and preventing falls.
- Review the layout of the bathroom. It may not be possible to convert it to a wet room, but having a large shower cubicle with a seat and grab rails would make washing and bathing less stressful. And grab rails at the toilet are a must.
- Is your car user-friendly? Can you get a wheelchair into the boot? Consider changing to a wheelchair-accessible vehicle (WAV) instead – something I wish we'd done sooner.

I hope these might help others with the future care needs of their loved ones."

Stuart

"I came across an article in *The Times* a couple of weeks ago in which the journalist Deborah Ross used an expression 'like a drunk with Parkinson's'. I found this analogy offensive and insensitive. I wrote to the editor of the newspaper to express my concern.

The use of such an analogy shows quite clearly the lack of appreciation in how the condition can affect people.

In a separate email, I have asked *The Times* to ensure that their journalists make time to inform themselves about Parkinson's so that expressions like these are never repeated. I can only hope that future issues, and other media outlets, will devote more space to describing some of the invisible symptoms too.

In doing so, this would go some way to improving the readership and the wider public's understanding of the condition."

Stuart S

Ed. Thanks for getting in touch about this matter, Stuart – it's really important that we highlight these issues so that we can change attitudes for the better. It's great that you've been in touch with *The Times* to let them know the impact of this on you and others affected by Parkinson's. We have been in touch too, and hope not to see phrases like this appearing in the future.

“I always enjoy getting my copy of *The Parkinson* magazine, and I’m grateful for all the support the charity offers.

But, I feel a lot of the stories and information I read in the magazine are geared towards people relying on their family, friends or partners for support. Personally, I’ve never married, I have no children or significant others, and no family. Because of my Parkinson’s and other health problems, I wasn’t able to work and I find it difficult to socialise.

I don’t necessarily feel isolated or alone, and I do get out and about. But sometimes, it just feels like a slap in the face when I’m always reading about the support people have when I’m just not in that situation. I don’t begrudge these people from having other people to rely on – far from it, in fact I wish them all the best and perhaps I am slightly envious even. But I can’t be unique in feeling like this and I do find it difficult sometimes.”

Person with Parkinson’s

Ed. We are sorry to hear this. We appreciate all feedback and try to take as much of it on board as possible, to make the best magazine we can for people affected by Parkinson’s. In the meantime, you may find our *Living alone with Parkinson’s* information useful, which you can read at **parkinsons.org.uk/living-alone**

“In the last issue of *The Parkinson* there was an Ask the Helpline question about a supermarket worker who was afraid that she would lose her job because she is slow in the mornings.

I myself experienced similar problems with being slow in the morning. So, I asked my consultant and GP if they would trust me to work out the timings and strength of my daily medication (within agreed limits) over a trial period.

They agreed, the GP gave me a prescription for eight weeks of the consultant’s recommended dose, I varied the dose weekly and kept a diary of how I felt. At the end of the trial I was not only feeling better in the mornings, but I had also reduced the intake of one drug by nearly 10%.”

David

Write to: The Editor of *The Parkinson*,
215 Vauxhall Bridge Road, London SW1V 1EJ
Email: publications@parkinsons.org.uk
Phone: 020 7932 1316

Please note some editing may occur and entries express personal opinions – not necessarily the views of Parkinson’s UK.

THE UK PARKINSON’S EXCELLENCE NETWORK

In 2015 people affected by Parkinson’s told us that access to high quality healthcare was a key priority. In response to your feedback, Parkinson’s UK established the UK Parkinson’s Excellence Network. Here, we update you on what’s been happening with the Network over the past year.

What is the Excellence Network?

The UK Parkinson's Excellence Network brings together health and social care professionals to transform care for people affected by Parkinson's. It works to improve services by:

- strengthening the voice of people who use Parkinson’s services
- equipping professionals with evidence, tools and resources to improve their services
- enabling professionals to collaborate and share good practice
- building an expert Parkinson’s workforce through training and development

Since the Excellence Network was set up, professionals have been working together to improve standards of healthcare in 22 Excellence Network regions across the UK.

The Excellence Network supports health professionals to do this through service improvement tools (for example, the Parkinson’s exercise framework), training programmes and awarding money for specific service improvement projects.

Our UK Parkinson’s audit

Every two years Parkinson’s UK runs a UK-wide audit to measure the quality of Parkinson’s healthcare services. The 2017 UK audit results have been combined with responses from our Your Life Your Services survey providing the most complete picture of Parkinson’s services to date.

Results from over 477 services and 9,000 people affected by Parkinson’s showed:

- an impressive 16% improvement in the overall quality of Parkinson’s service across the UK
- an 11.4% narrowing of the gap between the best and least well performing services. This is a huge achievement at a time when health services have been under real pressure
- 79% of people think their service is good or improving

But while these results show some great progress, it’s still the case that fewer than half of those with Parkinson’s admitted to hospital get their medication on time.

And while access to key members of a Parkinson’s healthcare team is rising, we know that people with Parkinson’s aren’t being referred to speech and language therapists and physiotherapists as early as they should be.

The Excellence Network is using the results to address these and other priority areas. It will work with healthcare services to address gaps in care and to achieve high quality services for everyone affected by Parkinson’s.

> “Developing and improving our work is key to achieving great care for everyone affected by Parkinson’s.”
>
> **Donald Grosset, Clinical Director, UK Parkinson’s Excellence Network and Consultant Neurologist at the Institute of Neurological Sciences, Queen Elizabeth University Hospital, Glasgow**

Excellence Network Awards

Each year the Excellence Network Awards highlight outstanding Parkinson’s health and social care services.

One of last year’s winners was Leeds Teaching Hospital NHS Trust. They introduced a range of measures to improve people with Parkinson’s getting access to medication on time, significantly cutting down missed doses and reducing the length of hospital stays.

The Leeds approach is now being rolled out in other hospitals to improve inpatient care around the UK.

Look out for the chance to nominate your service for an award later in the year.

Transform care locally

Want to get involved in improving standards of care locally? Why not become a volunteer educator?

The role involves visiting care homes and other local care providers to present sessions about Parkinson’s.

The aim of the sessions is to make sure professionals have in-depth knowledge of the condition to provide the best possible quality of care. You will receive training about Parkinson’s to make sure you have the right information to improve care in your area.

Who can get involved?

Anyone affected by Parkinson’s or who wants to help health professionals provide excellent care.

What will you get out of it?

You will:

- increase your knowledge and understanding of Parkinson’s and the work of Parkinson’s UK and the Excellence Network
- share your knowledge and experience with interested professionals, improving their care for people with Parkinson’s
- develop your organisational and public speaking skills

Find out more

Contact the Excellence Network at **excellence@parkinsons.org.uk** to find out more information, or read Val’s story on page 38 about becoming a volunteer educator. ■

Fanatical about feet

Physiotherapists Bhanu Ramaswamy and Fiona Lindop join us to talk about feet and how to keep them in tip top condition.

Physiotherapist **Bhanu Ramaswamy** admits to being in awe of feet "in a way that only a physio, a podiatrist or Prince Charming can be!" In this article Bhanu explains why she thinks you should pay them more attention.

This is the time of year when feet are allowed to come out of hiding, after a long winter of shoes and thick socks. Next time your feet are bare, take a good, long look at them. Marvel that under your skin are 26 bones of the ankle and foot (that's nearly a quarter of the total number of bones in your body), 33 joints and more than 100 muscles, tendons and ligaments. These individual parts work together to keep your whole body balanced upright when you are stood on top of them.

As we age, natural changes occur in our feet, as well as alterations brought about by the shoes we wear, our activity habits, work patterns and any medical conditions we develop. Each of these stress the foot in different ways. Some can change the shape of our feet over time and also change the effectiveness of how we move, including our balance.

Many people with Parkinson's gradually develop a stooped posture, which affects the feet in two ways.

Firstly your body compensates for your weight being held more to the front of your feet, and causes your toes to 'claw' as they grip the ground or your footwear. Over time, your toes get stuck in this position and cannot flatten properly to help you keep your balance.

The second change is in the length of the muscles around your ankle to cope with the shift in your weight. The changes in position mean that some muscles get stretched, while others shorten. Both of these changes alter how efficiently you walk and mean you don't put your heel down first as much as you used to.

The heel striking the ground is the body's signal to the brain to generate the power to push forward. If you're not doing this it means that your steps will be shorter, you'll have less power to propel yourself and it will be harder to balance when standing on one leg to step the other forward.

People with Parkinson's can also experience balance problems if their brain isn't receiving the right messages from their body about movement and which areas are bearing weight. This means the brain can't work out how to move the body safely. Without signals from the rest of the body, the brain resorts to judging things visually. For example, looking at the ground while walking, rather than looking straight ahead.

Muscle strengthening and balance exercises can help with this issue, but it's important to get professional help to understand which areas of your body you need to work on.

If the condition of your feet affects how your body moves, and therefore affects your safety when walking, ask your GP if you can be referred to a physiotherapist who specialises in neurology.

Feet exercises to do at home

Exercise 1

1. Stand upright beside a chair or table, with your feet a few inches apart.
2. Gently move your weight forwards, making sure your toes do not curl and your heels remain on the floor.
3. Stay in this position for five seconds before moving back to upright. Again, keep your feet glued to the floor – don't allow your toes to lift.
4. Repeat this exercise a few times, forcing your feet to relax as your body is slowly moved over them in a controlled manner.

Exercise 2 (good for swollen feet)

1. Sit on a chair and bring one foot up to rest on the other knee.
2. Gently massage the soles of your feet in a long, steady stroke from the base of the heel to the end of each toe.
3. Do this five times on each foot to stretch and loosen the skin, muscles and joints.

If you have become stiff at the knees and hips, you may find getting into this position difficult. It's worth practising, but if it's not possible, see if you can find a willing friend or family member to massage your feet for you!

Turn over for more foot care and footwear advice

From poor balance and posture to dystonia and stiffness, there are many problems with foot care that people with Parkinson's can experience.

Here, physiotherapist **Fiona Lindop** answers seven key questions.

1 If people have a tremor or involuntary movements (dyskinesia) how can they look after their feet safely?

It may be helpful to avoid sharp tools, such as nail clippers or scissors.

You should file your toenails weekly with a nail file (emery board) instead.

You may also find a 'diamond deb' file useful because it is stronger and has a rougher surface.

2 What is swelling and what can people with Parkinson's do about it?

Swelling is a common problem for people with Parkinson's, particularly for those who have movement difficulties. If you don't exercise very much, fluid can build up in your feet, ankles and lower legs. This is known as 'oedema'. Ankle swelling is also a side effect of some Parkinson's medication.

Swelling can get worse during the day and go down overnight. Sometimes this is called 'postural oedema' because gravity causes the build-up of fluid around the ankles when you stand up.

While the swelling is usually mild, some people describe their legs as feeling heavy. They may also have difficulty putting on shoes because they feel tighter than usual.

Wearing footwear that can be loosened during the course of the day may help, but it is important to make sure your shoes still hold firmly on to your feet to avoid the risk of falling.

Being active can help reduce swelling. Try the following:

- When sitting, have your legs raised on a footstool and exercise your ankles regularly (for example, flex them up and down).
- Lie flat with your legs slightly raised on a pillow three to four times a day to help reduce excess fluid.

3 What is your advice on footwear for people with Parkinson's?

Make sure your shoes fit well, as shoes that don't fit correctly can damage your feet and increase the risk of tripping or falling.

Try to choose shoes that have a low, broad heel, and that fasten over the top of the foot close to the ankle. Shoes with laces, Velcro or a strap and buckle have a better hold on the foot.

Leather-soled shoes should be avoided as they can increase the risk of trips and falls.

4 How can foot dystonia affect people with Parkinson's?

Dystonia is a movement disorder that causes contractions in various muscles. This is when muscles become tighter and shorter than normal, making them difficult to stretch. This can happen in your feet.

One feature of foot dystonia is toe curling. This is where your toes cramp and curl under your foot. You may also experience your ankle turning inwards.

Dystonia in your feet can be linked to the 'off' period, where your medication is not as effective at controlling your symptoms. Talk to your specialist or Parkinson's nurse to see if adjusting your medication regime may help.

5 How can a chiropodist, podiatrist or physiotherapist help people with Parkinson's look after their feet?

If you have problems with your feet, you can visit a podiatrist or a chiropodist for advice – there is no difference between them.

Podiatrists look at all areas of foot care, including how the foot should work during 'normal' walking and the problems caused by not walking in a typical pattern.

Your podiatrist can train you to stretch and exercise your muscles to reduce the effects of stiffness or rigidity on your feet. They can also show you simple massage techniques to improve your movement and circulation.

Physiotherapists can also help you. They often work with podiatrists on foot-related mobility problems and to help prevent falls.

6 Exercise is especially good for people with Parkinson's. What are your top footwear tips for those who have problems with their feet but want to get moving?

When exercising, make sure that your footwear fits securely and has a supportive sole.

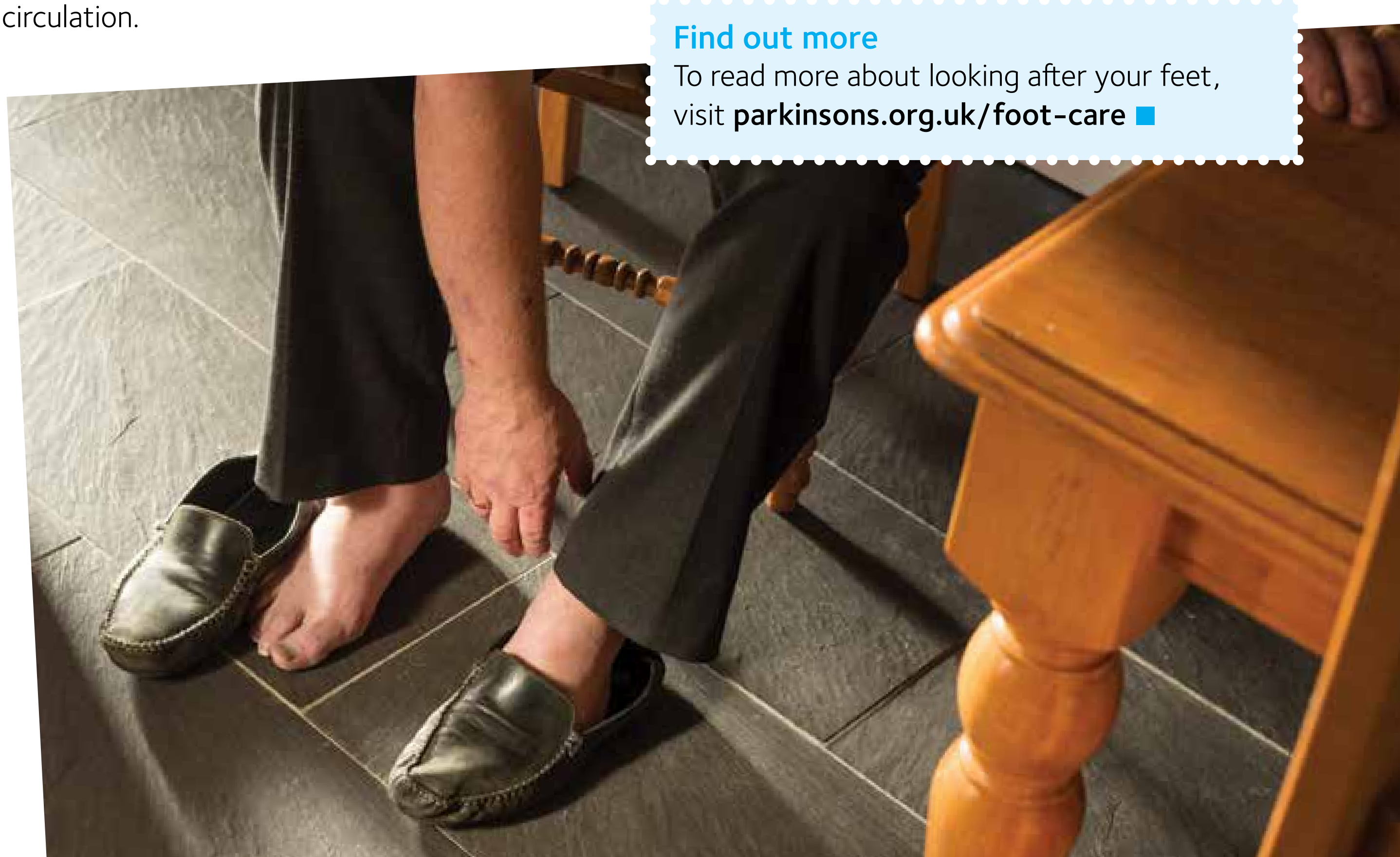
A trainer-style shoe will give support, but it's important to choose trainers that are right for the exercise you are going to do. Good sports shops can help with this so it's worth asking.

7 What exercise is best if someone has foot problems?

It's important to do exercise that is right for you and your Parkinson's. This could be as simple as chair-based exercises or muscle stretches. Find out more about the benefits of exercise and the different types to focus on at **parkinsons.org.uk/exercise**

Find out more

To read more about looking after your feet, visit **parkinsons.org.uk/foot-care** ■



PAR FOR PARKINSON'S

Par for Parkinson's offers golfers everywhere the opportunity to pitch in and drive off to raise vital funds for Parkinson's UK.

Whether you want to take part with friends and family, members of your golf club or work colleagues, Parkinson's UK has everything you need to help you organise the perfect Par for Parkinson's event. Our downloadable pack includes posters, quizzes, fundraising activity sheets, flag templates and a sponsorship form. Your regional fundraiser will also be on hand to help with additional fundraising advice and materials.

Many golfers have already supported the charity with their own events and activities, and during 2018 we are delighted to be partnering individuals and golf clubs throughout the UK.

Clark Contracts of Paisley chose to organise a golf themed day – in the office! Their day involved dressing up in their best golfing outfits and holding a Masters sweepstake fundraiser, prize raffle draw and 'Guess the Number of Tees in the Jar'. They raised a fantastic £1,000 as part of their Charity of the Year partnership with us in 2017.

Supporter Nichi Macer from Boston Spa, who has Parkinson's, organised a golf day at Rudding Park, Harrogate, last summer. The event encouraged golfers to take part and enjoy bacon sandwiches on arrival, 18 holes of golf, a BBQ on the terrace, prize giving and goodie bags. A raffle and auction helped Nichi raised an amazing total of £6,500.

Tee up with friends and family

Get friends and family together to organise the perfect Par for Parkinson's event. Test your stamina with our three-course golf challenge and fly the flag for Parkinson's UK.

Tee up with your golf club

Organise a golf day, a golf competition, a golf quiz and much more using our fundraising ideas, hints and tips. Or why not nominate Parkinson's UK as your club's Charity of the Year?

Tee up with colleagues

You don't have to hit the golf course to enjoy a golf-themed fundraising event – hold an event at your workplace. With a bit of imagination and support from us, you could include fun competitions, fancy dress, games and quizzes.

Find out more

If you, or a golfer you know, would like to get involved, you can download a fundraising pack at **parkinsons.org.uk/golf** or email **fundraising@parkinsons.org.uk** for further details. ■

A gift from the National Garden Scheme

Since 1927 the National Garden Scheme (NGS) has been inviting garden owners to open their gardens to the public.

Last year more than 3,600 of Britain's most beautiful and memorable gardens were opened to raise money for charity through entry fees, teas and cake. And this year Parkinson's UK was honoured to receive a gift of £185,000 – the largest of our six-year partnership.

An incredible £957,000 has now been raised over the course of the partnership to help provide holistic care and support to people with Parkinson's.

George Plumptre, CEO of the National Garden Scheme, says: "It's been another record-breaking year and we are extremely pleased to be able to fund even more vital work in the areas that we are passionate about – nursing, gardens and health."

Visit a garden this summer

There are thousands of gardens that will be open again this summer for you to discover. Remember each visit directly supports the work of Parkinson's UK and the other NGS beneficiary charities.

To find your nearest garden, go to **www.ngs.org.uk**

Enter to win prizes

If you visit any NGS gardens this summer, remember to take your camera or phone and snap your entry for their annual photography competition, held in association with *BBC Gardeners' World Magazine*.

Submit any photographs you take at a NGS garden opening before 28 August 2018 to be in with a chance of winning a selection of gardening prizes from WOLF-Garten.

The winning image of the *BBC Gardeners' World Magazine*: Fantastic Flowers category will also appear in the magazine's 2019 calendar.

Look out for monthly blogs from Parkinson's UK supporter and expert photographer David Plummer, which we will be sharing over the summer on our social media channels.

To find out more and to enter, visit **www.ngs.org.uk/photo** ■

Getting to know...

a Parkinson's UK volunteer

My husband was diagnosed with Parkinson's 30 years ago. In 2006 I took early retirement to look after him. I was determined to make the best of this so I became a Parkinson's UK volunteer.

I have three roles altogether. I am the treasurer of Tavistock Parkinson's Support Group. We started running exercise classes at the group in 2011 after my sons raised money to fund them.

Latest research shows that exercise can slow the progression of Parkinson's symptoms. So these classes are particularly important. They've been a fantastic success in helping people manage their condition. People look much happier at the end of a class!

My husband and I have learnt a lot about dealing with Parkinson's and we've also realised it can be misunderstood. I became a volunteer educator so that other people could learn from our experiences. In this role I visit care homes, nursing homes and care providers to educate them about Parkinson's and its challenges, and provide strategies for dealing with it day-to-day.

I am also a training co-ordinator for the Peninsula Parkinson's Excellence Network. The network brings together health and social care professionals to transform care for people affected by Parkinson's.

Val Evans, Parkinson's UK volunteer

Part of my role is to design courses for them. One course I designed aims to help professionals understand Parkinson's better. I designed it because I know some people have mixed healthcare experiences, but I realised that this never happens on purpose.

I work with dedicated people who only want the best for their patients. Some may just need help in understanding how someone's Parkinson's affects them. I think everyone should use the wealth of information on the Parkinson's UK website, too.

Volunteering for Parkinson's UK means I have met a lot of lovely people and made new friends. I get so much out of it. But best of all, something positive is coming out of my husband's condition.

Find out more

You can find lots of different volunteering roles at **parkinsons.org.uk/volunteer** ■

Parkinson's UK

215 Vauxhall Bridge Road, London SW1V 1EJ
020 7931 8080
hello@parkinsons.org.uk
parkinsons.org.uk

Helpline

0808 800 0303
NGT Relay **18001 0808 800 0303**
(for use with smart phones, tablets,
PCs and other devices).

hello@parkinsons.org.uk
The helpline is open Monday–Friday 9am–7pm,
Saturday 10am–2pm.

Local advisers

For details of your Parkinson's local adviser, visit **parkinsons.org.uk/localadvisers** or call our helpline.

Local groups

For details of your nearest group, visit **parkinsons.org.uk/localgroups** or call our helpline.

Information and publications

All of our most up-to-date information is available at **parkinsons.org.uk**. You can order printed copies by calling **0300 123 3689.**

To receive our magazines

Become a member for £4 a year for UK members and £15 a year for overseas members and get four issues of *The Parkinson* and two issues of *Progress*, our research magazine. To join, visit **parkinsons.org.uk/join** or call **0800 138 6593**.

- The magazine is published quarterly. If you would like to make a contribution, please contact the Editor on **020 7932 1316** or email **publications@parkinsons.org.uk**
- We work with the RNIB to produce an audio version of *The Parkinson*. If you would find it easier to listen to the magazine rather than read it, contact us to join our audio mailing list.
- Photos on the cover and pages 2, 12, 13 and 14 by Amit Lennon.
- All items aim to provide as much information as possible but, since some information involves personal judgement, their publication does not mean that we (Parkinson's UK) necessarily endorse them. While due care is taken to ensure the content of *The Parkinson* is accurate, the publisher and printer cannot accept liability for errors or omissions. While every care is taken of text and photographs submitted, we accept no responsibility for any loss or damage, whatever the cause. We do not endorse any products mentioned in this magazine.
- *The Parkinson* is printed using vegetable-based inks on FSC certified paper. The printer holds the environmental standard ISO 14001.

Work with us

We want people affected by Parkinson's to apply for jobs at Parkinson's UK. Each year we have around 100 job opportunities in a range of different professional roles throughout the UK. If you see a job that matches your skills and experience, get in touch to find out more about our flexible working options. For all our current vacancies, visit **parkinsons.org.uk/jobs**

Text PARKINSONS to 70500 to give £5

Help us support more people living with Parkinson's. Your text will be charged at £5 plus one standard network rate message (based on your network provider). Always get the bill payer's permission first. Parkinson's UK receives 100% of your donation.

*For terms and conditions visit **parkinsons.org.uk/texttodonate**

Choose 100 or 200 miles

BOXCAM 200

BRISTOL – OXFORD – CAMBRIDGE

22–23 September 2018

Last year's BOXCAM 200 raised £75,000 for Parkinson's research – this year we hope to raise even more. All to help us deliver new and better treatments in years, not decades, as well as help fund research that'll improve life for people with Parkinson's now.

parkinsons.org.uk/boxcam200

HSBC UK BRITISH CYCLING
REGISTERED SPORTIVE

BOXCAM

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CHANGE ATTITUDES.
FIND A CURE.
JOIN US.