THE PARKINSON

Autumn 2018

"I'm Alex's mum, not just his carer."

Sarah and Alex's story

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

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REGULARS

Welcome to your autumn issue of *The Parkinson* magazine.

I was diagnosed with Parkinson's in 2011. I used to work in a busy role at a global bank. I really enjoyed it there but I had to wind things down after my diagnosis, as my job involved quite a bit of travel. I still like to keep myself as active as possible and among other things I volunteer at a local theatre. I'm also a member of *The Parkinson* editorial board. Which means I helped put this issue together!

I got a lot of support from Parkinson's UK when I was diagnosed, and I really wanted to give something back to the charity. I applied to join the board in 2016, and it's something that I still really enjoy doing. It's a chance for someone with lived experience of the condition to give their views and comments on the magazine, to make sure it's relevant and helpful for other readers. The meetings are relaxed and informal, and everyone is respectful of the fact that people will be offering different opinions and experiences. It's also a nice way to meet staff and chat to other people with Parkinson's.

You'll notice on page 29 that we're recruiting more members to join the board. If you're affected by Parkinson's and think you might fit the bill, then please get in touch.

It's a great role and I'm proud to introduce this issue to you – I hope you enjoy reading it.

Dave Nichols
The Parkinson editorial board member ■

New cell transplant trial in Japan

In a world first, Japanese researchers announced in August that they were starting a cell transplant trial for Parkinson's.

News of the trial followed positive results from a team working at Japan's Kyoto University. Last year they carried out tests on monkeys to show that cell transplants were able to improve movement symptoms.

In the tests, a type of stem cell was used to make brain cells that produce dopamine, which researchers then transplanted into the brain. Brain scans carried out after the transplant showed that the new cells were functioning normally and continuing to produce dopamine. The team also published results showing that they had successfully used the principles of matching for organ donation to select the best brain cells for transplantation. This reduced the chances that the body's immune system would reject the transplanted cells.

"We firmly believe stem cell research has the potential to reverse the symptoms of Parkinson's," said Dr Beckie Port, Parkinson's UK Research Communications Manager.

"While there are still questions about whether these transplant therapies will improve non-motor symptoms of Parkinson's, such as problems with memory, pain and anxiety, this is an exciting study that will start to test the extent to which cell transplants can help.

"We are eagerly awaiting the outcome of the trial and hope that it will contribute to more research in this area and future opportunities for those in the UK to take part." ■

Shop online for information

You can now order our printed information resources through the Parkinson's UK online shop.

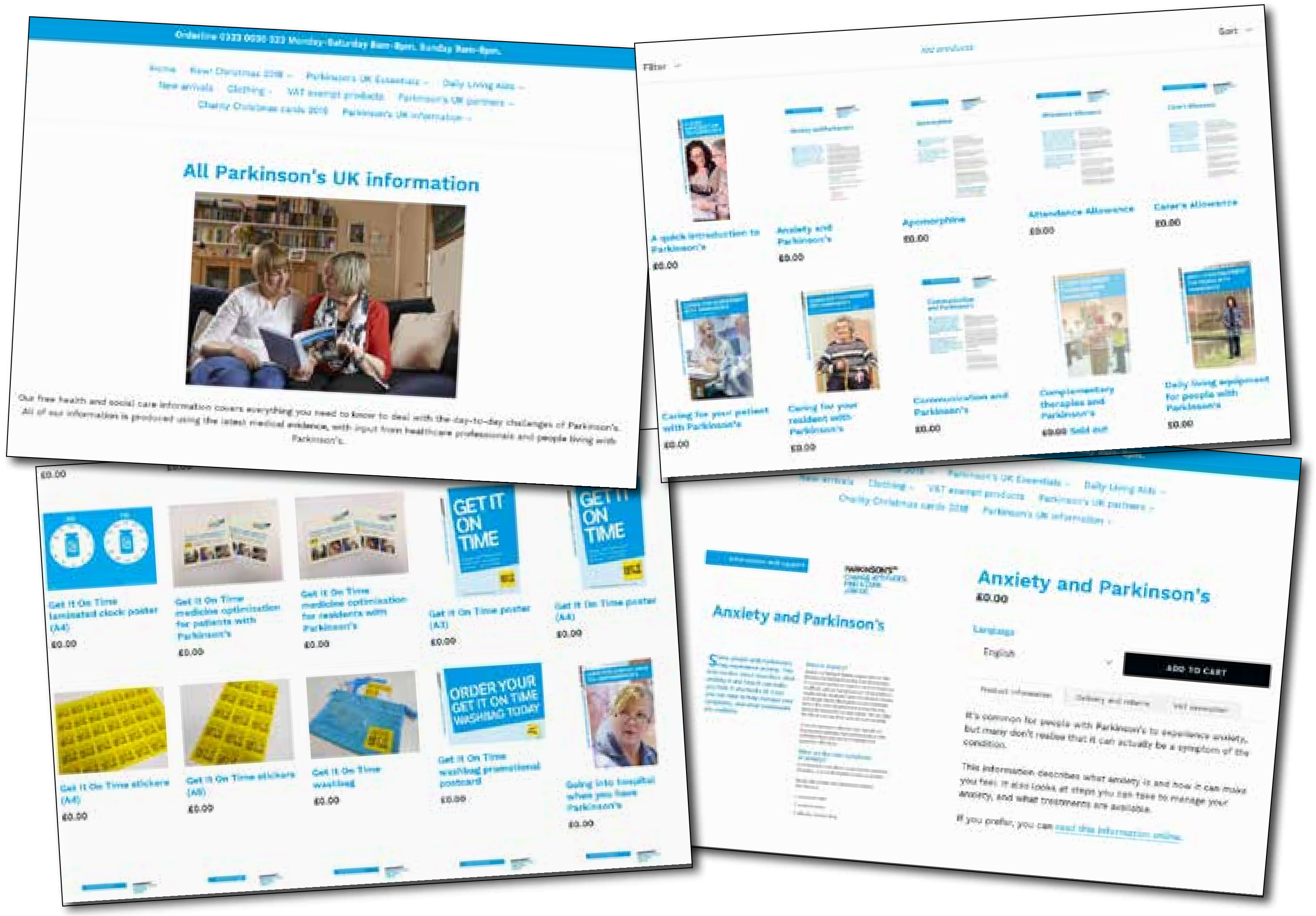
There are more than 100 different items – all completely free of charge. These include information sheets and booklets on all aspects of living with Parkinson's, from bladder and bowel problems and freezing, to driving and benefits. You can also order DVDs, audio CDs, translations of our information and practical items, such as our alert card. Each item has its own page in the shop where you can read more about it, see pictures of it and add it to your shopping cart.

You will also see a link to read the information online instead, if you prefer. The advantage of reading online is that you'll get access to your information immediately, rather than waiting up to two weeks for it to arrive in the post.

Information resources can be added to your shopping cart, in exactly the same way as shop items. There is no postage and packing charge for information if you live in the UK. If you live overseas, contact us to ask about postage costs.

If you're ordering shop items as well as information, then the standard shop postage charges will apply.

Have a look at our new 'Parkinson's UK information' section at **shop.parkinsons.org.uk** ■



Our free health and social care information covers everything you need to know to deal with the day-to-day challenges of Parkinson's. All of our information is produced using the latest medical evidence, with input from healthcare professionals and people living with Parkinson's.

It's common for people with Parkinson's to experience anxiety, but many don't realise that it can actually be a symptom of the condition.

This information describes what anxiety is and how it can make you feel. It also looks at steps you can take to manage your anxiety, and what treatments are available.

If you prefer, you can read this information online.

Parkinson's UK goes face to face with MPs

This year we met with MPs at Labour and Conservative party conferences to raise awareness of Parkinson's and get their support for our campaigns.

We engaged with MPs on issues like improving mental health services, scrapping prescription charges in England for people with long-term conditions and making Personal Independence Payment (PIP) work for people with Parkinson's.

Two volunteers with Parkinson's shared their experiences of PIP: Sajid Ahmed, who faced losing his motability car when he was reassessed, and John Hinson, who said the process of applying was emotionally and physically exhausting.

Sadly they are not alone. MPs listened and promised to write to the Work and Pensions Secretary to raise our concerns.

John, who attended the Labour party conference, said: "I've been invigorated. I feel our campaigns were really listened to and some MPs enthusiastically took on board what we had to say. I hope to see some of our ideas in their manifesto!"

Sajid, who attended the Conservative party conference, said: "It was great to speak to MPs, especially those with a personal connection to Parkinson's. They were very understanding and supportive of what we had to say. It was demanding, but I'd do it again! I'll be telling others in my local group to come next time." ■

Regular PIP reassessments scrapped for those on highest rates

In June the Department for Work and Pensions announced that people who get the highest rates of Personal Independence Payment (PIP), and whose needs are expected to stay the same or increase, won't have to attend regular reviews. Instead they will receive an ongoing award with a light-touch review every 10 years. The Department for Communities in Northern Ireland also confirmed they would apply this change.

We welcomed this announcement and worked with the Government on the guidance that PIP assessors were given. This will make a real difference for people of working age.

We're pleased that the Government listened to us after our 'get a grip on PIP' campaign last year. But we know that only half of people with Parkinson's will be covered by this change, as many don't qualify for the highest rates of PIP, so we'll keep campaigning to end unnecessary reassessments.

For help making a PIP claim, please contact the Parkinson's UK helpline on **0808 800 0303**. ■

Why Sharon campaigns for Parkinson's awareness

Sharon Martin, 48, from Tylorstown in Rhondda, Wales, was diagnosed with Parkinson's at 39.

Since diagnosis, Sharon has become a keen campaigner, sharing her story to help decision makers better understand what it's like to live with Parkinson's.

At the Get It On Time campaign launch at the Welsh Assembly earlier this year, Sharon told Assembly Members about her recent emergency admission to hospital and how being able to manage her own medication during her stay made a difference to her recovery. Sharon also bravely shared two videos that showed the difference in her symptoms when she is 'on' and 'off', as a powerful way of demonstrating the importance of people getting their medication on time.

"One evening I'd forgotten to take my medication so I asked my husband to film me to really show what it's like when you miss a dose. The next day when I had all of my usual medication he filmed me again.

"The contrast is clear and I thought it would be a great simple, visual way of showing people who may not understand, about being 'on' and 'off' so that it's easier to grasp."

Since the Assembly launch Sharon has followed up with her Assembly Member, Plaid Cymru Leader, Leanne Wood, in a one-to-one meeting.

"My AM is extremely busy and was unable to attend the launch event so I kept making contact until she agreed to meet! Persistence was key and when we did meet she agreed to support the campaign by writing to the local health board about self-administration of medication policies."

To find out more about getting involved in campaigning and the Get It On Time campaign in Wales, contact Rachel Williams. ■

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** ■

Starting medication

If you have Parkinson's it's likely you'll take medication on a daily basis to help manage your symptoms. So, lots of people understandably have concerns about starting Parkinson's drugs and the long-term benefits and risks. Our Research team look at the evidence to answer some of the most common questions.

WILL THE DRUGS HELP ME CONTROL MY SYMPTOMS?

For most people, yes. For a long time, evidence has shown that medication to boost dopamine levels in the brain is effective for improving movement symptoms including tremor, stiffness and slowness. More recently, research has suggested that Parkinson's medications may also improve some of the other symptoms including depression, anxiety and sleep difficulties.

WHAT'S THE BEST DRUG TO START WITH?

Although there are a range of Parkinson's medications, the best comparative study suggests there is not much to choose between the different classes of Parkinson's drugs in terms of symptom control and quality of life in the early stages. So, we still need better evidence on longer-term effectiveness of the different drugs to get a better idea of which drugs are best to start with.

WILL I EXPERIENCE SIDE EFFECTS?

Parkinson's drugs can have side effects which can be serious. But not everyone will experience severe problems. The two side effects people worry about most are dyskinesia and impulsive and compulsive disorders.

- Dyskinesias are involuntary muscle movements such as twitches, jerks, twisting or writhing movements. Research shows around half of people with Parkinson's will experience dyskinesias after taking levodopa for five years.
- Impulsive and compulsive disorders are harmful activities based on an instant reward, including gambling, hypersexuality, compulsive shopping or eating. They are more common with some medications than others. The largest study on impulsive and compulsive disorders found that they happen in 13.6% of people with Parkinson's. This is 2–3 times higher than the general population.

One of the most effective ways to minimise dyskinesias and impulsive and compulsive disorders is for people to have their medication reviewed and adjusted.

DON'T THE DRUGS JUST STOP WORKING AFTER A FEW YEARS?

No, Parkinson's medication does not suddenly stop working. Research has shown that dopamine-based drugs continue to be very important throughout the course of Parkinson's. But, over time, most people experience 'wearing off' where they go from having good control over their symptoms (being 'on') to having less control (being 'off') and it becomes more challenging to control symptoms and minimise the side effects.

Find out more

- **parkinsons.org.uk/drugtreatments**
- **parkinsons.org.uk/blog** (search for 'starting medication') ■

Sarah and Alex's story

Sarah Hill is mum to Alex, who has Parkinson's. Alex was diagnosed when he was just 11 years old, although experts think he may have shown symptoms from as early as three. In this story, Sarah shares her experience of being a mum and carer to her son.

When Alex was very little he enjoyed doing all the things that other kids did, like playing with friends at school and staying around at other people's houses. But when he was around seven, I noticed things change. He would panic a lot and often didn't want to leave my side. He would get tired easily, his handwriting suddenly deteriorated and over a period of six months he almost lost the ability to write altogether.

I asked for help from the GP, but they just said it wasn't anything out of the ordinary. I felt I was dismissed as being an overly anxious mother and left to deal with it.

He then started to have falls for no reason. The falls became so regular that we sought help from a paediatrician [a doctor who specialises in children's illnesses].

At first they thought he had epilepsy and gave him medication to treat it, but it made no difference. It got to the point that he was falling up to 28 times a day and couldn't sit down because he was so bruised.

Eventually, after a lot of persisting, we managed to get a referral to a top paediatrician in London at the Evelina Children's Hospital. After quite a few tests for coordination and cognition, they told us he had Parkinson's. It was, to say the least, a massive shock. Health professionals looked at some of our home videos and said they could spot signs of Parkinson's in Alex when he was just three years old, and were equally as surprised. I was petrified – I had no idea that this was something we'd ever have to consider at his age, and it felt like we were being thrown into a massive black hole, where nobody really knew any answers because of how unusual it was.

As a first-line treatment, he was put on levodopa. This, however, was like giving him rocket fuel. Within minutes of taking it, he would start running around the house, up and down stairs and all over the place. He would phone 999 constantly and talk to the police. It clearly had an impact on his mobility, but it was also making him manic. I had to hide phones and on numerous occasions apologise and give explanations to frustrated (yet sympathetic) police officers.

I was spending a lot of time in London at the Evelina Hospital with him at the time, so my mum helped look after his older sister, Becky. It was a tough time for everyone, but we all rallied around.

Eventually, Alex stopped responding to the levodopa. His dose was doubled, which I was very nervous about, but this made no difference. He was then put on rotigotine patches, which he still uses now.

Alex with his sister, Becky

Despite the drug treatment, his mobility declined and he was given a wheelchair aged 12. By the age of 14, his condition had worsened to the point that he was offered deep brain stimulation (DBS). This type of surgery is usually offered to people whose symptoms no longer respond to medication and who have had Parkinson's for a number of years. Obviously, the unusual thing in Alex's case was that he was in his early teens, and this was a huge decision for everyone to make. But, the professionals gave us lots of information on the benefits and risks and we felt very informed. Also, at this stage, we were told it was his best chance of regaining some quality of life, so we decided together it was the best way forwards.

Alex had high expectations about the surgery. He was as cool as a cucumber going into the eight-hour operation – as opposed to me, who was a bag of nerves. His bravery was indescribable. Thankfully it was a success and some of his symptoms, including his tremor and problems with involuntary movements, improved. It gave him his smile back, which we had all really missed.

As time went on, Alex ended up needing 24-hour care. He finds it difficult to speak, has sleep issues and his hands don't really work anymore, so he needs assistance with everything.

Being a young adult, he became isolated. I became his full-time carer as well as his mum. I didn't dare switch off and I wasn't sleeping at night, while during the day I tried my best to keep him entertained. Naturally, things became strained. Three years ago, when Alex was 21, we both made the decision that he would have better support in a nursing home. This was a difficult decision but one that improved our lives. He's just down the road from me now and it means I can be his mum again, not just his carer.

Despite all of this, it's not all doom and gloom. Alex has an amazing relationship with Becky, who idolises him. We often go on days out together to the beach and still enjoy family holidays. He has also kept his sense of humour. People often don't know how to interact with Alex – despite good intentions, they may just give him a pitying look and not know what to say. What they don't realise is that we may share a joke about them in secret. At the care home, he gets to mix with people his own age, who he has more in common with, and he is hugely popular there.

I wanted to share our story because the hardest thing can be feeling like you are fighting Parkinson's on your own. I asked about prognosis once and was just told to keep Alex as fit and healthy as I could. I'm past the point now of looking for answers, as I know that, with Parkinson's, sometimes the answers just aren't out there.

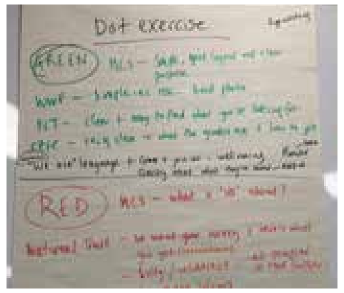
To anyone else going through this – trust your gut instinct as a parent. It's hard to know whether you're doing the right thing at the time but be persistent in getting help.

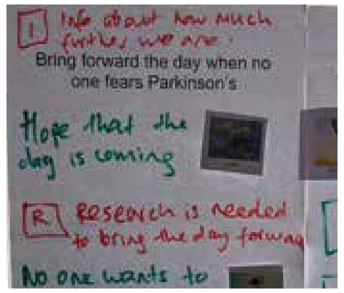
One thing I think I got wrong was that we didn't grieve. We were told the news and, even though it was devastating, we ploughed on and put on a brave face. But it's OK to wallow now and again. Get it out of your system and you'll feel stronger to carry on.

We're still surviving and living every day like it's our last. There is no way we're going to miss out on any opportunity together as mother and son. ■

BUILDING OUR MOVEMENT FOR PARKINSON'S **TOGETHER**

Membership at Parkinson's UK is having a revamp. From early next year, we'll be launching an exciting new membership offer and inviting more people to join the movement for Parkinson's.





We're doing this because the more people who join us, the stronger we'll be – and the quicker we'll find breakthroughs in Parkinson's. Over the last few months we've worked with lots of different people – including current members and potential new members – to shape what this new offer will look like.

A new membership pack

In September we ran workshops across the UK where people could share their thoughts about membership and give us feedback on our plans so far. Workshop participants created their own membership packs that aimed to inspire others to join Parkinson's UK and be part of the movement.

We gave people the option to design their own membership card and pin badge, and then write a welcome letter and membership manifesto (a short overview of the purpose of membership). There were some great ideas from this activity, and we're now developing and testing them to see what'll work best.

Here are some highlights:

- Membership cards can help members find useful services or opportunities – including the helpline or brain donation – as well as being functional.
- Some participants created pin badges with a purpose – for example "I'm donating my brain to Parkinson's UK" – while others thought badges should be witty and spark conversation.
- A key theme of the welcome letters was creating a connection to local groups and opportunities, often including specific information on local groups.

Alongside this, we've challenged the Parkinson's community to respond to one important question: how can we encourage more people to join us? We've had a strong response, including comments on the price, purpose and types of membership.

Do you have any ideas about how to make membership of Parkinson's UK better for everyone? It's really easy to share your ideas and we'd love to hear from you.

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

Muscle power and Parkinson's

The stronger you are – regardless of age – the better your ability to stay mobile and to live longer. In this article, physiotherapist Bhanu Ramaswamy discusses everything to do with muscle strength and power, including how to judge if you are strong enough and how you can build and maintain your muscle function.

Muscle strength describes the ability of our muscles to produce force against resistance. This might be the force it takes to push open a heavy door, or to lift the weight of a full pot of tea. Adding speed to strength gives you power, and maintaining that strength over a period of time requires muscle endurance (think walking 30 minutes or more in a park).

Strength, power and endurance are important for us to move around safely. The body monitors this by checking the tension and length of the muscles and feeding this back to the brain according to the activity we are carrying out. Age and having a condition that affects your nervous system, such as Parkinson's, can interfere with this, so your body needs to work at staying strong enough to cope with life's demands.

Checking your strength

The easiest ways to check your strength are through your grip and how strong your legs are. If you find any of the following impossible or hard, then you need to work on your strength:

- opening a jar lid or a bottle top
- playing tug of war with your grandchildren, children or dog
- easily and safely altering the speed you walk from slow to fast
- rising from a chair without the use of your arms (especially a low or soft one)
- getting down to and up from the floor (even if holding on to something)

How do you get stronger muscles?

Building strength, power or endurance means following an exercise programme at least twice per week. The weights you use or the time you spend on the programme must progressively, however gradually, build towards what is known as higher intensity resistance training. This type of training should involve the major muscle groups of the arms, legs and trunk (back and stomach).

Where and how can I do this?

Think about working out at home at a time that suits you. This way you can spend as much or as little as you want on equipment, depending on your finances and the space you have. For some, this means building a home gym, but this isn't necessary – weights (dumbbells), medicine balls, kettle bells and elastic resistance bands don't cost the earth and don't take up too much space. There are many online training programmes and DVDs that show you how to use this equipment.

Many gyms and leisure centres, and Parkinson's local groups, offer sessions suitable for people with health conditions. Some personal trainers may be able to supervise or suggest appropriate exercise if you want to follow your own programme.

If you don't have a lot of room or you don't want to spend money on equipment or gym memberships, you can improvise. Given that the main muscles affected in Parkinson's are the ones that keep you upright, you can use your body weight to strengthen your legs, and household objects, like a tin of beans, to strengthen your arms.

Not everyone finds it easy to exercise. For many, movement itself might be a challenge at times. But if the reason you should build your strength is important enough, you will find a way to do it, or someone to help.

The no-excuses daily home starter programme

Combine exercise with an activity, such as watching TV, waiting for the kettle to boil or brushing your teeth. Be inventive!

For example, when the TV ads come on, stand up from your chair (without using your hands to push up, if possible) and do either five squats or five lunges on each leg before sitting back down. Fitter people should do jumping jacks.

Now lift your weights (a tin of beans in each hand will do). This exercise is more effective if you do it while standing. Lift the weights 10 times out to each side and back down, then 10 times forwards and back to your chest, then 10 times behind you. Finally, 10 times straight up to the ceiling and back to your shoulders.

Repeat the sit to stand and lunges/squats. End by sitting back down and reaching over to give yourself a pat on the back. Remember to do each arm to stretch the muscles out!

Find out more

You can find out more about the types of exercise you should be doing at **parkinsons.org.uk/exercise** ■

LIVING ALONE WITH PARKINSON'S

Annette (pictured) was diagnosed with Parkinson's in 2011 when she was in her early 70s. She's found different ways of staying connected, supported and safe while living alone, and shares some of them here.

Diagnosis

I was on my own at the appointment when I found out I had Parkinson's. I came out of the hospital and took a taxi straight to some very dear friends. When I told them my news I became very upset. They comforted me and said that they'd come with me to my next appointment.

Talking to friends

Because I live alone, I immediately told my close friends about my Parkinson's. They were all shocked but very supportive. One friend who has Parkinson's herself was especially helpful and put me in touch with Parkinson's UK. Over the years I've found lots of information in *The Parkinson* magazine and the other resources available. I eventually told my wider circle of friends and acquaintances, so that people would understand if I had a problem with my balance or couldn't find the right word.

Remembering my medication

I always have my prescription in my handbag and the telephone number of a friend in case of emergency. As I don't have anyone to remind me to take my medication I set an alarm on my phone. I also have a note on my front door that says 'pills' to remind me when I leave the house.

Adaptations at home

I've done a few things to make life easier and safer at home. I have banisters each side of my stairs – fitted for free by my local authority. I've also had my bath removed and replaced with a shower. When I decided I wanted a small dishwasher a friend pointed out I could trip over the door when it was open, so I had one installed on top of the kitchen counter, which is great.

I have a gas fire but I was worried I might have a fall bending down to turn it on. I was delighted to find out you can have a gas fire controlled by remote, so I now turn the fire on and off while sitting on my sofa!

Social groups

I'm an active member of a local choir and I go to U3A (University of the Third Age) groups. I also regularly attend a Parkinson's exercise class and a Parkinson's dance group – these classes are very enjoyable for the exercise and the socialising.

Good days, bad days

Having Parkinson's can be very frustrating and everyone has good days and bad days.

I try to have some simple strategies to help me cope with the bad days. I avoid doing things that can affect my balance, so I won't start weeding in the garden if I don't feel up to it. I try not to lose my patience when I drop things, or can't open a can or find the milk. I just remove myself from the situation and come back later.

If I'm feeling low, I pick up the phone and arrange to visit a friend for a hug and a cup of tea, or to get a lunch date in the diary. Sometimes it helps just putting some music on or watching a favourite TV show.

Thinking ahead

If I felt like my situation was changing I'd think about joining an emergency alarm scheme so I could get help at the push of a button. I'd also talk to my GP, Parkinson's nurse and neurologist. And, of course, I'd talk to my friends. But I don't really live alone anyway – I have my lovely cat Jasper with me!

Find out more

To read more about living alone when you have Parkinson's, visit **parkinsons.org.uk/livingalone** ■

Peace of mind

Research has found that mindfulness reduces anxiety and depression in people with chronic physical illnesses. We're looking into how it could help people with Parkinson's and, in the meantime, we've developed a mindfulness toolkit that you can use.

What is mindfulness?

Sue Newsham is an independent health and wellness coach, and an Area Development Manager for Parkinson's UK. Sue presents our new mindfulness toolkit.

"We all have the ability to be mindful. Mindfulness is about paying attention in the present moment, without bringing our judgements to what's happening in that moment. So many times, if we're in pain, either mentally or physically, our judgements make things worse.

"As an example, some mornings I wake up and my back hurts. My instinctive reaction would be to start musing on this. 'My back hurts. It's going to get even worse as I get older. I wish I hadn't done that gardening yesterday.' So now not only am I feeling the pain of my back, I'm also feeling anxiety about the future and regret of the past.

"Mindfulness helps us acknowledge a situation for what it is, then gives us the space to choose how to respond."

More than a third of people with Parkinson's experience depression or anxiety. Treatments for these symptoms are usually either medication or talking therapies, which can be difficult for some people to access, for lots of different reasons.

In the summer 2015 issue of *The Parkinson*, we brought you news of a study that aimed to find out whether mindfulness could reduce anxiety and other symptoms of Parkinson's. Funded by Parkinson's UK, Dr Angeliki Bogosian and her team at City University London used Skype to test a mindfulness course on people with Parkinson's. The course was originally developed for people with multiple sclerosis and it had successfully reduced their feelings of distress and improved their symptoms of pain and fatigue.

Although the study only consulted a small group of people with Parkinson's, the participants said they were experiencing less anxiety and depression after taking part in the mindfulness sessions. And this was still true when they were asked again during a follow-up three months later.

Unfortunately the group didn't notice any difference in their other symptoms, such as pain, fatigue and insomnia. However, they enjoyed sharing the experience as a group and meeting others with Parkinson's, and they felt less fear about how their symptoms might progress in future.

Dr Bogosian's team are hoping to get further funding to assess mindfulness with a larger group of people with Parkinson's, and to compare it to another treatment, such as cognitive behavioural therapy (CBT).

Want to try mindfulness?

We've developed a brand new toolkit for you to use whenever you want. It contains short videos of mindfulness techniques that you can do at home, at work or on the go.

There's also a 15-minute mindfulness audio session, which is designed to help you manage anxiety and depression, and enhance your overall wellbeing. You can listen to the session on your own or with others, but you should be somewhere that you feel comfortable and can complete the session without being interrupted. Explore the toolkit at **parkinsons.org.uk/mindfulness**

If you're keen to try mindfulness, here are toolkit presenter Sue Newsham's top three tips.

1. Stop what you're doing

Take a moment to gather your thoughts. Stop what you're doing, focus first on your right foot and then on your left. Take a slow, deep breath and choose how to continue.

> "It was incredibly helpful. It settled me down and it actually slowed my tremor down ... It's something I'll be looking into and I shall take up."
> **Jim, who has Parkinson's, took part in a recent mindfulness session**

2. Focus on your breathing

Simply focusing on your breathing can help combat periods of anxiety. Try taking a minute or two to focus on your breath, either sitting or standing. This can be very helpful before going into a crowded room or before a hospital appointment.

3. Be aware

Fully focus your attention on everyday tasks, becoming aware of each of your senses in turn. For example, when you're washing your hands, notice how the water feels on your hands, how the soap smells and the trickle of the water. ■

Deciding to become a brain donor

Have you considered leaving your brain to Parkinson's research? We spoke to one family who are proud to be part of the search for a cure.

Eve with her mum, Jenny

The Parkinson's UK Brain Bank, based at Imperial College London, is the only brain research facility in the world that's solely dedicated to Parkinson's research. Around 120 brains arrive there each year, from people with and without the condition. These are critical to unlocking the mysteries of Parkinson's, as well as new treatments and, hopefully one day, a cure.

Thanks to these donations, we've already made major advances in our understanding of Parkinson's. Recently, information gathered at the Brain Bank helped a team of scientists to develop a new technique that means human brain tissue can be studied in 3D. This gives us a more detailed insight into connectivity within the brain and what is different in the brains of people affected by Parkinson's.

Our work at the Brain Bank simply wouldn't be possible without donors. But becoming a donor isn't always an easy decision. Sisters Eve Williams and Clair Chinnery supported their mum, who had Parkinson's, when she decided to donate her brain to Parkinson's research.

Clair explains: "Our mum, Jenny, was diagnosed with Parkinson's when she was 46 years old, after experiencing symptoms and having tests for some time. She passed away in December 2014, aged 67."

"Mum's approach to Parkinson's was to just get on as usual," says Eve. "She wasn't interested in new therapies and experimental techniques – she always said she didn't want to be a guinea pig. But when the option to become a brain donor came up, it was the easiest decision for Mum. She didn't need to think about how she might feel. In her mind, once she had passed away, she wouldn't feel anything anyway.

"Mum, Dad and I all signed up to be brain donors at the same time. I've been a registered organ donor since I was 13. It's always been clear to me that being a donor could help others. Registering was simple, and nominating a next of kin who could carry out our wishes was easy, as we'd discussed the decision as a family.

"When the time came, and we knew Mum was fading, Clair contacted the Brain Bank for instructions. We didn't want to miss the one chance we'd get to donate for Mum due to any delays or confusion.

"The donation process was very straightforward. We were prepared and we knew what Mum wanted. Having one person to lead the process, my sister, really helped.

"Knowing what would happen to Mum, where her brain would go and how she would be cared for after the donation was very important to us. The information provided was very reassuring.

"Signing up to be a donor is a personal choice. My wife doesn't like to talk about it. Not everyone finds those conversations easy, but she knows my wishes and respects them."

Clair agrees: "Some people aren't comfortable with the idea of their loved ones donating tissue. I only recently registered as a Brain Bank donor.

"Like Eve, I was already an organ donor, so it was not a difficult decision in that respect. But I initially felt resentful towards Parkinson's, so much so that I didn't want anything to do with the condition, and I think that held up my decision to donate.

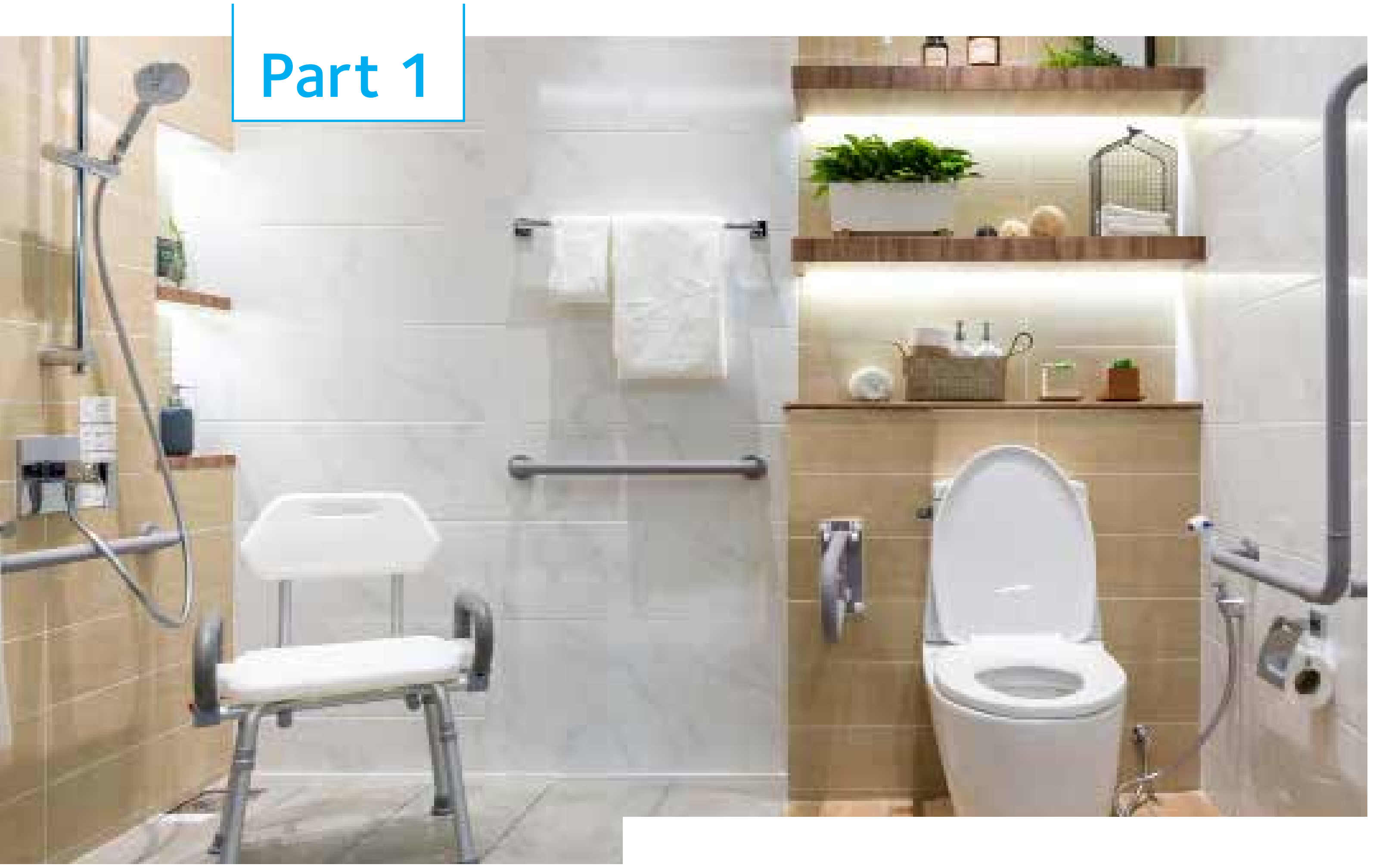
"However, fulfilling Mum's wishes gave me such a wonderful feeling. In the midst of our loss, something good was able to happen. Mum's donation means that she lives on through the research she is helping to further. I really like the thought that a part of Mum is doing an important job to help others."

Eve adds: "A few months after Mum passed, we received a letter from the Brain Bank. They had completed their research on her brain and confirmed the valuable contribution she'd made to further understanding Parkinson's and finding better treatments. Receiving the letter was emotional, but also a celebration."

How do I become a donor?

If you're interested in donating your brain to Parkinson's research, please discuss it with your next-of-kin and those close to you.

You can find more information and the registration forms at **parkinsons.org.uk/brainbank**, or you can call **020 7594 9732** or email **brainbank@imperial.ac.uk** ■



Part 1

Adapting your home

As Parkinson's symptoms progress and have more of an impact on everyday life, you may find your home no longer meets your needs.

In the first of a two-part feature we look at how to find out what changes to your home or equipment might be useful to you.

If you, or the person you care for, wants to stay at home there are adaptations that can make life safer and easier.

Advanced Parkinson's symptoms can make daily activities, such as getting out of bed or having a shower, a lot more difficult. If you're a carer, there may be occasions when you have to physically lift or help the person you care for.

Moving to a care home with trained staff on-hand is an option, but it's also worth considering whether you could adapt your own home.

There are many types of equipment and daily living aids that may mean you, or the person you care for, can be more comfortable and stay in familiar surroundings.

First steps

An occupational therapist can advise you on how to make your home easier and safer to live in and get around. They may suggest rearranging furniture or installing grab rails or other equipment.

Always get advice from an occupational therapist before you buy equipment. They will have a better understanding of your condition and the effect it has on your life than the company selling the items. Basic items to help you move about more easily at home can sometimes be provided on loan, either free of charge or in exchange for a small refundable deposit. For example, items that help you get in and out of chairs or bed. A local occupational therapist will be able to assess your needs. Together you can discuss all the options before you make any decisions or purchases.

You can request an appointment for an occupational therapist to visit you at home through your GP, social services or social work department, or your local health and social care trust. If you have a Parkinson's nurse they may be able to refer you to an occupational therapist with specific experience of working with people with Parkinson's. The advice of an occupational therapist is usually free of charge and provided as part of your health and social care service.

Try before you buy

If you decide to buy a piece of equipment, it's best to try it out first. There may be different models available that you want to compare, or useful features that you're not aware of.

The Disabled Living Foundation (DLF) have a list of equipment demonstration centres on their website at **www.livingmadeeasy.org.uk/contacts_edc.php**. At these centres all across the UK you can see and try a wide range of equipment. If you arrange an appointment it's often possible to try out an item with an occupational therapist present (phone before you visit to ask about booking this service, if available). The DLF also have an online tool, AskSARA, to help you identify suitable equipment and suppliers, and compare products. Visit their website at **www.dlf.org.uk/content/asksara**

Paying for equipment and adaptations

If you need major changes to your home, such as an extension to create a ground-floor bedroom or bathroom, or installing a stairlift, you may be eligible for a disabled facilities grant. Find out more at **www.gov.uk/disabled-facilities-grants** (in England, Wales or Northern Ireland) or contact your local authority.

Funding for home adaptations is often means tested. So the decision as to whether you get money from the government or local authority to help pay for something depends on how much money you have, including your savings.

> "If a specific adaptation to your home or a piece of equipment would improve your day-to-day life, but finding the money for it is a problem, ask your occupational therapist or Parkinson's UK local group if other funding options are available to help you."
> **Ana, Occupational Therapist**

If you're disabled or have a long-term condition, you shouldn't be charged VAT on products designed or adapted for your own personal or domestic use. This includes adjustable beds, wheelchairs, alarms and building work, such as installing ramps. You also shouldn't be charged VAT on repairs, maintenance or spare parts for equipment.

If your home is substantially adapted to meet your needs, you may be eligible for a reduction in Council Tax. Call your Council Tax department to find out if you meet the criteria.

Next issue: Part 2

In the second part of this feature, we'll share tips on specific pieces of equipment that may be useful in your home.

Find out more

Visit **parkinsons.org.uk/occupationaltherapy** to read about how to find a local occupational therapist and how they could help you. ■

ASK THE HELPLINE

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

I've read a lot about people with Parkinson's having insomnia, but I'm the opposite – I get really sleepy, especially during the day. Is this a symptom of my Parkinson's?

Parkinson's medications can cause excessive daytime sleepiness or sudden onset of sleep, also known as 'daytime hypersomnolence'.

This may be more likely to happen to people with advanced Parkinson's symptoms, who are on several types of medication. It can also occur when you're increasing your medication, particularly dopamine agonists.

On the other hand, you might just not be getting enough sleep at night. This can cause you to doze off during normal waking hours.

In some cases, it can even lead to the sudden onset of sleep, which can be dangerous if you work and your job involves driving or operating machinery.

Speak to your GP, specialist or Parkinson's nurse if you're concerned about excessive daytime sleepiness. They can advise you on how much sleep you should be getting and whether medication may help.

I have a wheelchair that I no longer use, but it's still in good condition. Is there anywhere I can donate or sell it?

Some equipment isn't re-useable because it has been designed for a specific individual, or because it must meet certain safety standards. However, a lot of second-hand disability equipment can be donated or sold.

Donating equipment

- Some local charities will accept donations of disability equipment. For example, Scope will accept items from within a 30-mile radius of their head office in Milton Keynes. Visit **www.scope.org.uk** for details.
- Some local Salvation Army branches will accept donations of second-hand wheelchairs. Find your nearest branch at **www.salvationarmy.org.uk**
- Disabled Equipment Sent Overseas (DESO) accepts donations including crutches, walking sticks and wheelchairs, and gives them to people in need overseas. Visit **www.desouk.org** for details.
- Sites like Freegle (**www.ilovefreegle.org**) and Freecycle (**www.freecycle.org**) connect people giving away an item with those trying to find something.

Selling equipment

- The Disability Equipment Service (DES) (**www.disabilityequipmentservice.co.uk**) is an online marketplace for new and used equipment.
- Disabled Gear (**www.disabledgear.com**) is a free-to-use site where you can advertise and search for second-hand equipment.
- The Mobility Market (**www.themobilitymarket.co.uk**) lists second-hand mobility equipment for sale.
- Some companies will buy back second-hand equipment, such as stairlifts, as they can be re-conditioned. Contact the supplier of your item to ask.
- Ebay (**www.ebay.co.uk**) has a section for selling mobility, disability and medical equipment.

I have bladder problems and often find it hard to unfasten my clothing quickly when I need the toilet. Do you have any tips?

There are lots of clothing adaptations that can help with this, so investigate what might work for you. If you have Parkinson's symptoms that affect your movement or coordination, don't put unnecessary pressure on yourself to be able to undo buttons or zips in a hurry.

One of the simplest ideas is adding a tab to a zip, so that you have something bigger to grip.

You can also add thumb loops to underwear and choose styles that aren't too tight, making it easier to pull them up and down.

Trousers with an elasticated waist may help. Skirts can be tucked into the waistband, so that you have both hands free to hold grab rails. This prevents your skirt from dangling into the toilet.

Speak to an occupational therapist to find out more about different types of specialised clothing.

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

A CATCH UP WITH A PARKINSON'S CAFÉ

Montserrat and John

Set up as an informal way for people to meet, socialise and chat, Parkinson's cafés are popping up all over the UK and are run by volunteers and Parkinson's UK staff. In this feature we meet John, who helps run two cafés in Lancashire.

John Birmingham, 57, lives in Haslingdon – a town nestled in the heart of Lancashire. He was diagnosed with Parkinson's in his early 40s and lives with his partner, Montserrat.

"I first noticed symptoms when I was using the phone – my hand would shake when I held it to my ear," says John. "It wasn't long before I was diagnosed with a condition I knew absolutely nothing about. It's awful, because you can feel quite alone and scared."

In 2009 John was made redundant from his job making parts for machinery. Feeling at a loss, he started working part-time at a local charity, Maundy Relief, who offer community services. "I felt like I was contributing so much more at the charity. We offered lots of local support, from counselling services and advocacy, to drug addiction and mental health outreach.

"However, over time my speech deteriorated and some afternoons I would end up slurring my words. Ironically people started confusing me for one of the patients of the drug addiction services. It became too difficult in the end and I felt it was time to step down."

In 2016 John joined a group of people affected by Parkinson's attending a small drop-in café in Blackburn called the Nelson – a park pavilion and café run by a social enterprise. "Parkinson's cafés were a relatively new thing – just somewhere informal for like-minded people affected by the condition to meet up now and then," he adds.

It was there that he met Rebecca Ward-Dooley, an Area Development Manager at Parkinson's UK. "I got talking to Rebecca and she suggested I volunteer at the café. I decided to give it a go and completely loved it. I would introduce new visitors and make sure they felt comfortable and relaxed. It was something I could do at my own pace too, knowing that I had support if I needed it."

The success of the Nelson café in Blackburn got John thinking about the lack of support in his own area.

"We knew there wasn't really anything for people closer to Rawtenstall, so Rebecca said, 'Why don't we start looking for venues to bridge the gap?' Montserrat and I did some scoping around on the internet to see if there was anywhere suitable. It was important that it was accessible and that it was financially viable. We treated the whole thing like a little project."

They stumbled across The Whitaker, a picturesque not-for-profit museum and art gallery, and got the thumbs up from Rebecca.

"We put the word out through Parkinson's nurses and flyers in GP surgeries, supermarkets and libraries, and suddenly we were getting 20-30 people turn up each month. People loved it."

John explains that he feels the café's success relies on it being friendly, informal and, most importantly, somewhere for people to meet who feel isolated because of their condition.

He adds: "We have people turn up on their own who haven't really seen anyone for months, other than their Parkinson's nurse. Some people say they feel judged when they go out, and this can really knock their confidence. We want to offer a casual space where people can be themselves, not have to worry about being stared at and drop by for just a coffee and a chat."

As well as offering a space to socialise, John says that Parkinson's cafés can be a valuable source of information too. "We may have a Parkinson's nurse come along to answer medical questions, or put people in touch with benefits advisers, or tell them about speech and language therapists. Partners and carers will often ask Montserrat questions about how she manages in a caring role, and she gives them tips."

At the moment, the Nelson café meets twice a month and Rawtenstall once a month, although John is keen to expand. He explains: "The bigger the group grows, the more regularly we'll need to meet. We're also looking at other areas, as some people can't drive and find it hard to travel. But I need to make sure I'm not overdoing it. If I'm not healthy myself, then I can't help as much as I'd like to."

John adds that his message for anyone thinking of attending is to give it a go. "It's all about human contact. At its heart, it's a place for people to drop by and have a cuppa. Nothing too serious."

The Nelson café currently meet fortnightly every Friday. The Whitaker at Rawtenstall café meet on the last Tuesday of every month. Both meet between 11am and 1pm.

To find out more about Parkinson's cafés in your area, talk to your Parkinson's local adviser or call our helpline on **0808 800 0303**.

Join *The Parkinson* editorial board

We're looking for enthusiastic new members to join *The Parkinson* editorial board and help decide what the magazine includes and what it looks like. Could you be one of them?

Who are the editorial board and what do they do?

The Parkinson editorial board are an important part of our editorial process. Made up of people affected by Parkinson's and Parkinson's UK staff, the board get together before each issue of the magazine is published to advise the editorial team on the content, tone and layout of the magazine. Members also have the opportunity to suggest ideas for future issues.

Where does the board meet?

We normally meet at the UK Office in London. We send each member a draft of the magazine before the meeting, so they can read it through and consider what they think. Each meeting lasts for about three hours, with a break for lunch which we provide.

We organise the meetings in the middle of the day so that attendees avoid the busiest travel times. We know that travel to London may not be possible for everyone and we do have some members who provide feedback via email or over the phone.

Our building is accessible and we also have the ability to use video link for people who can't travel long distances. We're happy to try to accommodate any specific needs you may have.

Who are we looking for?

We're looking for people with experience of Parkinson's – whether you're living with the condition or you're a family member, partner or carer – who can give measured, honest and constructive feedback on each issue. We're looking for a mix of ages, and it doesn't matter whether you're newly diagnosed or have been living with the condition for a number of years. We're not looking for people who have a background in writing, editing or journalism – our staff take care of that. This role is more about offering an opinion on content based on your personal experience of living with Parkinson's and what matters to you.

We try to make sure we have a variety of people on the editorial board. So while we welcome anyone to apply, we're particularly interested to hear from:

- people living in Northern Ireland, Scotland or Wales
- people from a minority ethnic background

Can you cover my travel expenses?

Yes. We cover travel expenses for editorial board members (excluding first class travel) to come to each meeting and we provide lunch on the day. We may also be able to cover the cost for a partner or carer to travel with you, if needed, and for the cost of an overnight stay in a hotel in some circumstances.

How do I apply?

If you're interested, please fill out the online form at **parkinsons.org.uk/editorialboard**. If you're not able to fill out the form then please write to us at *The Parkinson* magazine, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ, telling us about yourself and why you're interested. The closing date is Sunday 25 November 2018. ■

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.

“I have just come back from a minibreak at the Revitalise Centre in Netley near Southampton. Revitalise provide short respite holidays for people who need some care and support away from their normal environment.

Some guests go with their carers and others, like me, with a companion. Some go on their own. The centre is designed for people with mobility issues and well-staffed by a mixture of professionals and volunteers.

Before the holiday you get to plan the levels of nursing and social care you or the person you're going with will need. But, like everything else there, they can be flexible if your circumstances change or things come up. There are outings, entertainment and activities organised for those who want to participate but no pressure if you would rather sit and just read a book. There was always somebody on hand to give me a cup of coffee, push my wheelchair or just have a chat. I met some delightful volunteers from all over the world.

I believe they have three centres – one in Netley, near Southampton, one in Southport, Lancashire, and one in Chigwell, Essex. Their website is **www.revitalise.org.uk**.

I would highly recommend them!”
Caroline

“Since my tremor has worsened I've found it increasingly difficult to hold and enjoy books. A close friend recommended Listening Books, a charity who provide audiobooks, available as downloads, streams or MP3 CDs.

I was a little unsure at first but I found it extremely easy to use and managed to quickly download books I enjoy and start listening to them.

I have always enjoyed listening to the spoken word via the radio. The beauty of Listening Books is that you can relax completely. In the past I enjoyed reading in bed but now find the effort required to handle a book sometimes takes away from the enjoyment.

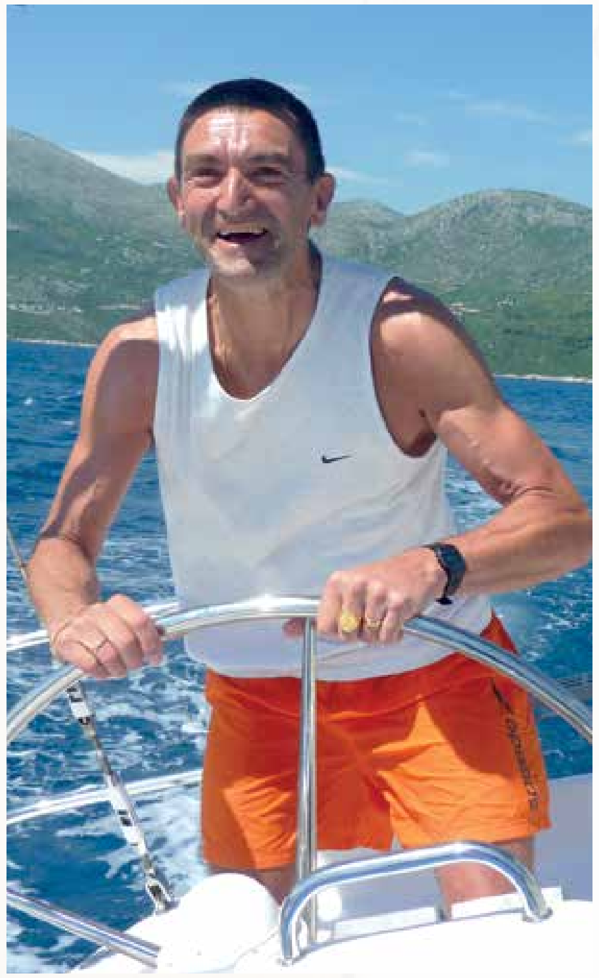
The best feature I have found so far is the sleep function, which I can set to a range of time lengths so if I fall asleep it will cut off. The other fantastic thing is that membership is only £20 for the whole year, no matter how many books I download, plus there are lots of up-to-date authors.”
Gill

Ed. This is great to hear Gill. For anyone wanting more information on Listening Books, you can call them on 020 7407 9417 or email info@listening-books.org.uk

“I was diagnosed with Parkinson's in 2009 at the age of 57. My first thought was that it was something only older people got.

It also concerned me, as for the past 40 years I had been a club athlete, competing in two London Marathons (finishing in just over three hours), and had been Essex county champion at 400 metres in the over-40s category.

My Parkinson's was controlled by a cocktail of rasagiline and ropinirole and I continued to stay fit and active. But one day I suddenly started to get a dull ache in my groin while out jogging.



One of my friends suggested I get checked for prostate cancer as he had had similar problems a couple of years before.

My doctor confirmed it was cancer. I was anxious about surgery so opted for radiotherapy.

During my recovery I went on a new adventure, sailing around the islands of Croatia with friends I had met at the gym. By the end of 2013 I had finished my radiotherapy treatment and my cancer had cleared.

Then recently, I was diagnosed with osteoarthritis. So I now face a new challenge!

The one common thing that helps keeps my body and mind well is exercise. I continue to take part in sprint triathlons, 5k park runs, sailing and cycling. All the doctors I've seen since 2009 have been impressed with the level of sport and exercise I do.

I don't know what the future holds for me but providing I can stay active I feel I'm in with a chance of staying well.”
Ray

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.

Fatigue

Fatigue is a symptom of Parkinson's that can affect your routine but there are lots of ways to manage it day to day. In this article we look at what fatigue is, how it can affect you and give some tips on how to manage it.

Fatigue has been described as an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. It is more than a one-off feeling of tiredness that will go away after sleeping well.

Anyone can feel fatigued when they are working too hard, or when pressures at work or at home cause stress. But fatigue can also be a specific symptom of a medical condition such as Parkinson's.

Are fatigue and tiredness the same thing?

Fatigue and tiredness are separate issues. You can feel tired after many things like exercise, a bad night's sleep or mental effort. Tiredness usually goes away with rest.

However, fatigue happens without the effort of any activity and does not improve with rest.

What causes fatigue in Parkinson's?

We don't yet fully understand what causes fatigue in Parkinson's but it may be because of chemical changes in the brain.

Other factors can also affect fatigue, including the following:

- It may be related to the timing and dosage of your medication.
- Tremor, stiffness or involuntary movements that some people with Parkinson's experience may put stress on your muscles. This means they can become fatigued.
- If you experience slowness of movement (bradykinesia), tasks will take you longer to complete than they used to, leading to fatigue.
- Parkinson's and its symptoms can cause stress at work or home and this can make fatigue worse. This is particularly true if stress builds up over time.

Your fatigue may be related to other treatable conditions. These include thyroid problems, vitamin deficiencies, anaemia and diabetes.

Talk to your health professional if you are unsure.

Mental fatigue

Mental fatigue can be just as difficult to manage. Some people may find it hard to concentrate for a long time without a break.

> "I asked if I could space my two [working] days over the week. That break in the middle is important so I can keep going. I don't want to wear myself out too soon."
> **Anna**

What can I do about fatigue?

There are a number of things you can do yourself to try to help avoid or minimise your fatigue.

◆ **Physical and mental exercise**
Physical exercise can help you manage your fatigue, boost your mood and help you sleep well. You can find out more about the benefits of exercise and the different types to focus on at **parkinsons.org.uk/exercise**

Mental exercise is also important. Try to stay involved with any hobbies and interests. If you have time during the day, try to do a variety of activities, as boredom can also lead to fatigue.

◆ **Diet**
Some people find that a small snack every couple of hours provides them with a constant supply of glucose, which is used for energy and can help reduce the feeling of tiredness in the short term.

It is also important to try not to become constipated (when stools are hard and difficult to pass), as this can make you feel sluggish. Ask your health professional if you need help managing constipation.

You may also find the following things helpful:

- Try non-drug treatments like cognitive behavioural therapy (CBT), a type of talking therapy. This can help you manage fatigue practically by focusing on what is causing it and its impact.
- Spread out or pace your physical and mental activity because fatigue can be made worse by doing too little or trying to do too much.
- Achieving a good balance between rest and activity will help you handle fatigue and improve your general quality of life.

> "You can do most things you want to do, it just takes a lot more time, effort and planning."
> **Karen**

Non-motor symptoms questionnaire

Non-motor symptoms include things like fatigue and mental health problems. They are not related to movement. We have a non-motor symptoms questionnaire to help you and your healthcare professional assess these issues. You can download it at **parkinsons.org.uk/nonmotorquestionnaire**

Find out more

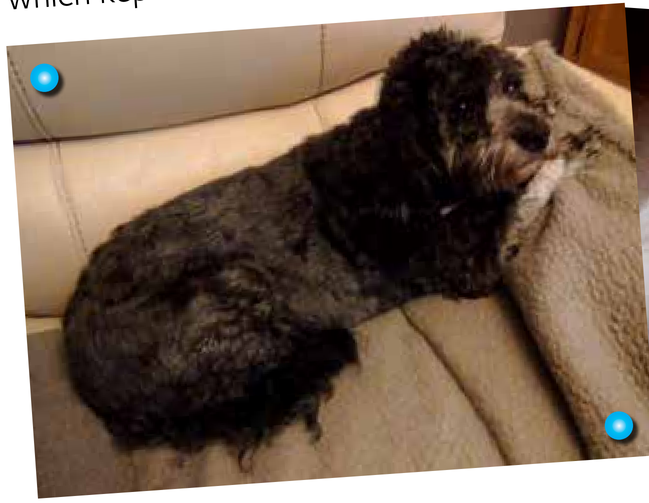
You can read our full information on fatigue at **parkinsons.org.uk/fatigue** ■

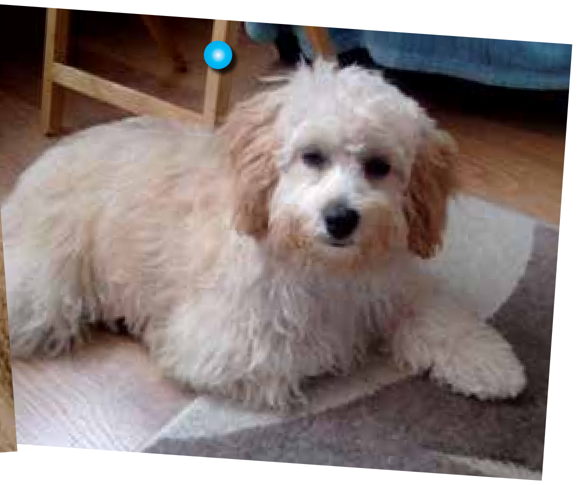
THE BARKINSON

Autumn 2018

We're always keen to hear about the joy and affection people get from their pets, and many of you tell us about your love of dogs. So we decided to share some photos of your pawsome four-legged friends.

"I have two lovely dogs, Bonnie and Bella. When I first got Bonnie I used to exercise her every day which kept me active. Bella is a recent addition to the family and is a bit of a handful but very loving. We wouldn't be without them – they are a joy to be around."
Libby





"This is our dog, Chase, pictured with me and my kids Mimi (left) and Teyi (right). We've had Chase since 2014, when he was an eight-week-old pup. My motor symptoms started in 2010, so he has always known me to have Parkinson's. To be honest, I sometimes think he knows and treats me with special care."
Omotola

"Walking Ruby gets me up and out in the morning and keeps me fit. People chat to you when you've got a dog. She's great for my social life and my mental health."
TV presenter Dave Clark

"Dogs are a great source of enjoyment and companionship for me. We are a family of spaniel lovers and this is Willow, my daughter's dog, with my grandson Jayce."
Dave

"This is me with my buddy Freyja. She helps keep me company and can be seen here showing off her Parkinson's UK 'walkies' bandana."
Radio presenter David 'Kid' Jensen

Find out more

Ruby and Freyja are sporting the Parkinson's UK walkies dog bandana, available to order from our shop at **shop.parkinsons.org.uk** or by calling **0333 0030 523**.

Going for a walk makes dogs very happy. Walk for Parkinson's provides the perfect opportunity for you to walk your pooch in some of the UK's most beautiful parks, countryside and cities while supporting Parkinson's UK. Join us in 2019 – **parkinsons.org.uk/walks**

“I’ve learnt an awful lot, and I want to do something to help”

Dennis, centre, with his family

Paydens Group run 128 pharmacies and three care homes across south-east England. They’re partnering with Parkinson’s UK to raise £100,000 to support people living with Parkinson’s and fund vital research. Chairman Dennis Pay – who’s had Parkinson’s for 11 years – tells us his story, and why his company is supporting the charity.

I set up my first pharmacy in 1969 – the year Parkinson’s UK was founded. Next year we’ll both celebrate our 50th anniversaries.

In 2004 I was diagnosed with Parkinson’s. I’m proud to see Paydens Group support Parkinson’s UK. It’s nice to be involved with something I understand.

I’ve learnt an awful lot about the condition as I’ve gone along, and I want to do something to help. We also want our pharmacists to have more understanding to pass on to their patients.

Life with Parkinson’s

When I was first diagnosed, my wife Rosemary and I just had a cry. We only told family at first. I didn’t want people asking how I was all the time.

We just carried on as if nothing had changed. Medication managed my symptoms, and I continued working full-time. I felt it was better that Parkinson’s had its place, rather than letting it take over my life.

That worked for about eight years, but then my symptoms became more obvious. But life still goes on – exercise has really helped, alongside a healthy diet.

I’m still chairman of Paydens, and work part-time. My four children run the company now.

There’s no real reason not to carry on a normal life.

About the partnership

Parkinson’s UK is Paydens Group’s first ever charity partner. Staff are aiming to raise £100,000 by April 2019.

Paydens pharmacists will also be trained to help people with Parkinson’s understand how their medicines should be used and why they’ve been prescribed, and to identify any problems.

“It’s fantastic that Paydens has now chosen us to be their charity partner,” says Steve Ford, Parkinson’s UK CEO. “We’ll be able to reach more people with Parkinson’s than ever, and test new ways to improve their quality of life.” ■

Walk for Parkinson’s: a brilliant year

2018 saw an amazing **5,817** supporters raise **£447,042**. Could you take part in 2019?

What an incredible year it’s been for Walk for Parkinson’s. With 37 walks to choose from, more than 5,817 walkers joined us to improve life for people affected by Parkinson’s. Together they raised £447,042 – with money still coming in.

What’s more, hundreds of amazing people volunteered to help us at every walk in 2018. From taking photographs, to cheering and handing out medals, we couldn’t have done it without them.

We’d like to thank everyone who took part for making the walks such a success. Now we’re working hard to make 2019 Walk for Parkinson’s even bigger and better!

Find out more

For more information about Walk for Parkinson’s 2019 and to register your interest, email **fundraising@parkinsons.org.uk** ■

Hold a quiz night for Parkinson’s UK

Quizzes are great fun. How about putting one on for Parkinson’s UK?

What’s better than a quiz to keep you entertained as the nights draw in – and why not raise money for Parkinson’s UK at the same time? Elaine Hockley organised a quiz in memory of her mum Maureen, who had Parkinson’s and passed away in 2016.

Elaine explains how much fun – and how satisfying – it was: “I wanted to raise money but I didn’t want to ask my friends and colleagues to sponsor me again. I also wanted to do something local, involving my mum’s friends, that appealed to all ages. When I saw that Parkinson’s UK had a ready-made quiz night pack available – well, bingo! Well no, not bingo – quiz night!

“I raised around £1,400, which was amazing. It was hard work but it was good fun too and incredibly satisfying knowing that I was able to contribute to Parkinson’s UK’s great work.”

Get a quiz night pack

We’ve recently updated our quiz night pack, which is full of tips on how to organise your event and raise money.
Visit **parkinsons.org.uk/quiznight**, email **fundraising@parkinsons.org.uk** or call **020 7963 3912** to request your pack! ■

Getting to know…

Beccy Rae, Events Co-ordinator, Parkinson's UK

I work in the Events team on running and challenge events, such as cycle rides and skydives. At the moment I'm looking after our supporters who are doing the London Marathon, the Edinburgh Marathon, Ride Across Britain and a cycle ride in Italy – all next year.

I help them get ready for their event, with fundraising and training advice. I send out monthly newsletters and run Facebook groups so that they can chat to others who are taking part. To be able to answer questions, I have to know a lot about each event, like how to get to the start line and where people's family and friends will be able to see them.

Sometimes I'm in contact with participants for up to a year before an event. I do get really close to them, and that's why it's so lovely going to events and meeting everyone. It makes me remember why I do what I do, especially when I hear people's stories.

There are 13 of us in the Events team and our time is split between four or five events a year each. It's a case of organising everything from the big stuff, like booking a marquee, to the detail of when people will get a hot shower or a cup of tea afterwards.

On the day of the event, I usually have an early start and a late finish. Everything has been building up to that one day, and I know that getting our support right makes such a massive difference for those taking part.

We have amazing staff and supporters who volunteer for us. At the London Marathon there are usually 40–50 volunteers, plus a team of student masseurs. The volunteers encourage our runners on at cheer points along the route and manage the post-race reception we hold at a nearby hotel.

If you can't take part in an event, we're always looking for volunteers to help us get a good atmosphere going. It's really exciting when you see your first runner or cyclist with a Parkinson's UK vest on! I've run half marathons before and when you're tired, the cheer points really do mean the world.

My most memorable moment in this job has to be seeing *Game of Thrones* actor Enzo Cilenti and his dad, Pietro – who has Parkinson's, cross the finish line of Ride Across Britain. They cycled 980 miles in 9 days on a tandem from Land's End to John O'Groats. I saw them at pitstops along the way. When they reached the finish they were both buzzing with energy, and I was the one feeling emotional!

Find out more

If you'd like to volunteer at one of our events, check the calendar at **parkinsons.org.uk/events** and then contact the team on **020 7963 3949** or **events@parkinsons.org.uk** ■

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

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, 10, 11 and 12 by Paul Meyler.
- 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.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (948776). Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ. A charity registered in England and Wales (258197) and in Scotland (SC037554).

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**

If you haven't seen our Christmas catalogue yet, don't worry, you aren't too late!

To order your copy, call **0330 124 3250**, email **shop@parkinsons.org.uk** or visit **parkinsons.org.uk/christmas**

We have everything you need from Christmas cards to hampers, Christmas crackers to gift wrap, and books to gifts.