

Summer 2021

THE PARKINSON

RISING
TO THE
CHALLENGE

Jackie
reminds herself
what she is
capable of

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

Hello, my name is Karen and I'm delighted to welcome you to the summer issue of *The Parkinson* magazine.

I've worked on the magazine for a number of years now and feel very privileged I've been given the opportunity to become editor. I'm really looking forward to building on the legacy *The Parkinson* has established – whether you have Parkinson's or know someone who does, we aim to bring you a read that is informative and enjoyable.

In this issue we meet Jackie, who shares how challenging herself after she was diagnosed with Parkinson's has reminded her what she is still capable of.

We introduce you to Chris, who is living with Parkinson's and dementia, Nathan who was diagnosed in his early 30s, and Laxmi who explains how her friends and family are a great support.

You'll find tips for handwriting and maintaining dexterity, the benefits of working with a personal trainer and many more great features.

No matter where you are in your Parkinson's journey, everyone's voice is just as important as the next. If you're interested in sharing your own story, please do get in touch using the contact details on page 31.

I hope you enjoy this issue,



Karen

Karen Spillett
Editor of *The Parkinson* 



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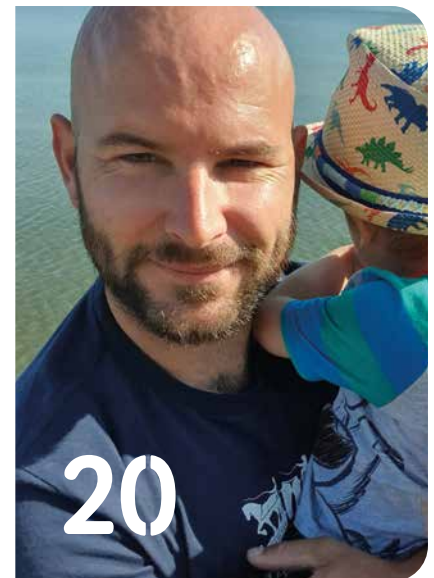
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QUESTIONS FOR A PERSONAL TRAINER

We meet Tom Burridge, a personal trainer based in Exeter, who works with people with Parkinson's.



Can you tell us a bit about your day-to-day work?

I currently work at Westbank, a charity that helps improve the health of communities across Devon. Westbank offers personal training and activity programmes, and works closely with local GPs and health professionals who can make exercise referrals to us.

I have been given the opportunity to work with a number of people living with Parkinson's, creating safe and effective fitness programmes, tailored to their needs. I've always been passionate about

helping people of all ages and abilities and I am a strong believer that everyone can benefit from some form of exercise.

What can someone expect from a personal training session?

Different things will influence what your personal training session will look like, including the stage of your condition. However, the main goal of each session should be to focus on compound movements (exercises that work multiple muscle groups at the same time), to help strengthen your upper and lower body.

One of the major advantages of working with a personal trainer is that they are able to adjust to and accommodate your needs. For example, you can choose the best time to have your session to fit it around your medication and any side effects.

They can also easily tweak your session from week to week depending on how you are feeling, to make sure you always get the most from each workout.

How do I find a personal trainer?

My recommendation for someone with Parkinson's looking for a personal trainer would be to do your research first.

Check what qualifications they have. If someone has a level 3 exercise referral and level 4 in a specific condition, this demonstrates that the trainer has a greater understanding of working with clients with more complex conditions. Level 4 is the highest qualification a personal trainer can achieve.

Most personal trainers will also offer a free consultation, and this is a great chance for you to find out more information about them and make sure they are the right trainer for you.

One-to-one sessions can be done in the comfort of your own home either in person or online.

How can someone with Parkinson's maintain their health and fitness levels?

If you're new to exercise or looking to get back into it, I would recommend starting small and gradually building it up. One of the biggest mistakes I see people make when starting physical activity and exercise is trying to make too many changes all at once.

Jumping into it too fast can make you fatigued and sore and you'll develop a bad relationship with exercise.

Keep it simple and do what you enjoy. This will help you to keep it up and the benefits will follow.

Sally, who has Parkinson's, started having sessions with Tom in 2018

Having a personal trainer has helped to make exercise a key part of how I manage life with Parkinson's.

It's helped with motivation because there is a greater incentive to go to the gym, knowing someone is waiting for you!

An individual exercise programme means that we can focus on particular problem areas, and there is flexibility to adapt things if my needs change or I'm not having a good day.

My symptoms and side effects from medication seem to respond well to the resistance of the equipment we use in the gym, and the repetition of the exercises. The sessions help with my memory, coordination and attention too.

I've developed confidence in relation to body image and I always leave feeling I have achieved something positive. **P**

Talk to your GP or Parkinson's nurse about what exercise referral schemes are available in your area. Find out more about exercise and Parkinson's at [parkinsons.org.uk/exercise](https://www.parkinsons.org.uk/exercise)

EXCESSIVE DAYTIME SLEEPINESS



Some Parkinson's medications can cause excessive daytime sleepiness or sudden onset of sleep. Parkinson's nurse Lee Kieft explains more.

What causes excessive daytime sleepiness?

Excessive daytime sleepiness is a non-motor symptom of Parkinson's, but researchers aren't sure whether it's part of how Parkinson's progresses or if it's caused by Parkinson's medication.

Evidence suggests that it's more common if you are taking Parkinson's drugs, especially dopamine agonists. It can also be common in people taking levodopa. Amantadine, another Parkinson's drug, can cause insomnia, which can cause tiredness the following day.

There are also other factors that can contribute to excessive daytime sleepiness. People with Parkinson's who experience night-time sleep disturbances are more likely to experience excessive daytime sleepiness. If you have fatigue, another common Parkinson's symptom, you may also have daytime sleepiness.

How can excessive daytime sleepiness be managed?

If you experience daytime sleepiness, it's important to speak to your specialist or Parkinson's nurse.

One way of managing it is to reduce the amount of medication you are taking that may be causing the symptom. But that may mean your Parkinson's symptoms aren't as well controlled.

For mild to moderate excessive daytime sleepiness, things that can help include:

- regular, daily exercise, such as walking
- taking a short daytime nap
- playing board games or electronic games when you begin to feel tired
- eating healthy food and avoiding alcohol

At night, good sleep hygiene can be helpful – having a good night's sleep can help reduce feeling tired during the day. Sleep hygiene 'rules' include keeping to a regular routine and reducing noise and light in your bedroom.

Can medication treat excessive daytime sleepiness?

In some people, drug treatments may be an option. The drug Modafinil is used to treat daytime sleepiness, but it remains controversial. There is little evidence that it works for the symptom and the medication does have significant side effects. More research is needed and other drugs are also being considered.

Drinking tea and coffee, which contain caffeine, during the day is often recommended, but again, there is little evidence that it works.

Andrew was diagnosed with Parkinson's in October 2019. He began experiencing excessive daytime sleepiness after he was prescribed ropinirole, a dopamine agonist.

I had been taking levodopa three times a day since I was diagnosed without too many side effects. After six months, my Parkinson's nurse prescribed ropinirole that I took in addition to my levodopa.

My goodness the side effects hit me hard. Within 30 minutes of taking the drug, I began to feel nauseous, then had an overwhelming desire to yawn and needed to sleep. If I didn't eat something before taking my medication, I would spiral into drowsiness and experience a tightening of my chest.

I spoke to my Parkinson's nurse about these side effects and she instead gave me Repinex XL,

a slow release dopamine agonist. My reactions to this medication were different, however I still had issues with fatigue. During a follow-up appointment, I was advised to take both doses before I went to bed, rather than one in the morning and one in the evening.

I still suffer from fatigue, especially in the morning after I take other medication, but now I feel more in control. I also try to maintain some daily exercise including Nordic walking. Now that lockdown has eased, my gym has re-opened, so I will be regularly visiting there. P





RISING TO THE CHALLENGE

Jackie shares how she began facing up to her Parkinson's diagnosis and in the process, has reminded herself what she is still capable of.

When my consultant told me I had Parkinson's, I truly believed my life was over," remembers Jackie, who was 56 at the time. "I was handed a prescription, advised to exercise and sent on my way. In reality, I had no idea what to do next, which way to turn or how or what exercise I was supposed to do.

"I was devastated, I was scared and I felt very lonely. I had never been ill before so it all felt very overwhelming," says Jackie.

"I remember at that first appointment, I sat under a whiteboard in the waiting room which said 'Parkinson's nurse clinic' and I just thought, 'This is me now, I'm a patient.'"

Getting help

When Jackie was diagnosed, a friend recommended Jackie might benefit from seeing a private neuro-physiotherapist, who could help to improve her balance, mobility, core strength and general fitness level.

"I'd been trying to cope with everything, but really, I was very broken," admits Jackie. "It felt like after my diagnosis nobody gave me anything positive to hang on to. But in my very first appointment with my physio, he told me I had a future – perhaps not the future I had planned, but I still had a life to lead.

"I'd been seeing him for about six months when he pointed out to me I was so focused on what I couldn't do, I was missing out on what I could – he even told me I could climb a mountain if I wanted to."

Ascending

This conversation proved to be a turning point for Jackie. A friend had always wanted to climb Snowdon in Wales, so Jackie agreed she would try and do it with her.

“To my surprise, I found I really enjoyed the training,” says Jackie. “And the fitter I got, it felt as though I was taking back some control over my physical limitations. This helped boost my confidence and improved my overall wellbeing.”

Almost a year to the day after being diagnosed with Parkinson’s and with the help of a guide, Jackie successfully climbed Snowdon. The sense of achievement was huge.

“When I was diagnosed, I told my consultant that I walked everyday in local woodlands. He was horrified and told me I had to avoid uneven ground as I was a ‘high falls risk’. And now here I was, having just climbed a mountain!

“I started to think that perhaps if I could set myself a monthly challenge it would serve as a positive focus, a reminder of living for today and what may be possible – and that’s how it began, this new life of mine.”



Facing the fear

“For me, I need to deal with the fear which can overwhelm me with Parkinson’s head on,” says Jackie. “So I like to take on activities that directly challenge the restrictions Parkinson’s tries to impose on me.”

Jackie’s stability can be affected, so she completed a high-ropes course. Her symptoms get worse when she is cold, so she went wild water swimming in a freezing Scottish loch, and to tackle her balance issues and problems with performing repetitive movements, Jackie tried stand-up paddle boarding. She loved being on the water so much it’s since turned into a hobby.

Jackie has also been paragliding, rode pillion on a motorcycle and tried horse riding. “The latter terrified me the entire trek, but I survived to tell the tale!” she laughs.

“Although most of the challenges are very physical, the psychological benefits are paramount. They help me feel that I’m not defined by my diagnosis – that I’m capable of fighting back and not giving in.”

But perhaps Jackie’s biggest hurdle is being able to tell people she has Parkinson’s.

Opening up

“After the diagnosis, I didn’t want to tell anyone,” says Jackie. “All that was going round in my head was, ‘How has this happened?’”

“Perhaps I was too wrapped up in myself, but I thought it was my story to tell. And I felt embarrassed, which I’m ashamed to admit now.”

The first time Jackie started talking more openly about her condition was just under a year after



I JUST DON'T WANT ANYONE LOOKING AT ME DIFFERENTLY. I'M THE SAME PERSON I'VE ALWAYS BEEN – JUST WITH A LITTLE EXTRA BURDEN.”

she was diagnosed, when she went on a local radio station to talk about her Snowdon climb as part of a fundraising effort. Three years on from her diagnosis, opening up is still difficult for Jackie.

“There have only been two occasions when it came out easily. When I did the high-ropes course, I was standing on a platform waiting for my instructor to get to where he needed to. I said to the man behind me that I had Parkinson’s and he just said, ‘Well good on you for doing this.’ Another time I was paddle-boarding and mentioned it to someone who was with me.

“I’m still selective about who I talk to and what information I share with people,” admits Jackie. “People can be intrusive, but I am learning that people are not shocked or horrified by the news.

“I just don’t want anyone looking at me differently. I’m the same person I’ve always been – just with a little extra burden.”

Looking forward

As Jackie continues to set targets for herself, she reflects on what these challenges have given her. “I have met so many wonderful people who have helped and supported me and I’ve had experiences I’d never have contemplated before Parkinson’s.

“If I think about the future too much, I can get into a spiral of negative thinking. But when things get bad I remember what I’ve achieved and those who have helped me get there, and I plan what to do next.”

Jackie adds: “I take each day as it comes, but I know I’m going to be OK. I have a future. Everything is not over and I can cope.” **P**

If you or someone you care for is struggling to come to terms with a diagnosis of Parkinson’s, you can contact our helpline for support on **0808 800 0303** or **hello@parkinsons.org.uk**

DEXTERITY AND PARKINSON'S

Parkinson's can make using your hands for small movements tricky. Specialist physiotherapist Bhanu Ramaswamy tells us more.



There are 27 bones in each hand and wrist that work together so your hand can move – that's a lot of coordinated muscle and joint activity. Like many parts of the body, we take them for granted until they start to work less efficiently.

What is dexterity?

Hand movements can be extremely precise and quick. A movement can be something small, like typing a text on your phone, to large movements like grabbing a rail to pull your body up the stairs, or pushing yourself up off a chair.

Our brain coordinates these movements, and this is called dexterity. Your hand, or hands, behave as a steadying force to allow the other part of the hand (or the other hand) to carry out the actual task.

When you button a coat, one hand holds the material and creates the buttonhole gape so the other can grasp the button and push it through.

When you reach into your purse or wallet, one hand holds it steady, so the other hand can use precision to pick out a coin or note while separating it from the others.

How does Parkinson's affect dexterity?

In the same way that the cold or arthritis can affect movement, stiffness (rigidity), slowness of movement (bradykinesia) or shaking from a tremor in Parkinson's can all make hand and wrist movements more difficult.

Parkinson's can also cause 'striatal' hand, where the hand is pulled into an uncomfortable position which makes it harder and sometimes painful to use.

3 HAND EXERCISES TO TRY

1. To keep your wrists, hands and palms flexible

- > Place your palms together (as if in prayer).
- > Take a steady breath in, and as you breathe out, lower your shoulders and slowly push your hands against one another. You should feel a slight stretch in your fingers and palms.
- > Hold for 30 seconds and try to maintain even pressure on each side. Make sure that your stronger hand doesn't push the other one sideways.
- > To make it more challenging, raise your elbows out towards the shoulders so the wrists are stretched further.

Repeat the same exercise above, but incorporate your arms

- > Link your fingers, then turn your hands so your palms are facing away from your body, and push your arms out.
- > Stretch your arms gently. Try not to raise your shoulders.
- > Try and hold for 30 seconds.

2. Before doing small movements such as doing up zips or buttons

- > Shake out your hands to loosen them up.
- > Create a tight fist then stretch your fingers and palms out.
- > On both hands, touch the tip of each finger to the tip of the thumb. Repeat this movement and slowly get faster.
- > Make sure both hands keep the same timing and size of movement.
- > Repeat.

3. If your grip is a problem, rather than movement

- > Hold a sheet of paper between your thumb and first two fingers.
- > Using your other hand, try and pull the paper from your grip. Hold the paper tight to prevent this from happening.
- > Try it with different objects, such as a mug or a ball.
- > Repeat with other hand. **P**

Having particular problems with handwriting? Turn over to read more.










TIPS FOR IMPROVING HANDWRITING

Having problems with your handwriting? We look at why this happens and what can help.

If you have Parkinson's, you may have found that your handwriting has become 'spidery' or difficult to read. Some people notice that their writing starts off normally, but becomes smaller over time. The medical term for this is micrographia.

Many things can cause problems with handwriting. These include tremor, lack of coordination, muscle stiffness, difficulty controlling small movements and difficulty putting enough power into your movements.

Not being able to write as well as you used to can be frustrating, but the following things can make it a bit easier.

-  Use pens and pencils with a thick or padded cover to help you get a better grip.
-  If you have a tremor, a weighted cuff may give you more control. This is a heavy padded strap that you wear around your wrist. The Disabled Living Foundation can advise you on where to get one (livingmadeeasy.org.uk).
-  Use a clipboard or a non-slip mat to stop your paper slipping.
-  Write on lined paper, to help keep your writing straight.
-  Take your time to write so it's not as tiring.
-  If your voice is loud and clear, you could record voice messages instead of writing things down, using your mobile phone or a dictation machine.
-  If you need to sign a cheque or document, you could ask someone else to fill in the details for you, so you just have to add your signature.

Alternatives to using a signature

1. Use a credit or debit card template

This is a plastic guide with a hole where the signature should be. They can help make it easier to sign in the right place. Your bank might provide these.

2. Change your signature

Speak to your bank about accepting a simpler signature. For example, you might find it easier to write your first initial and surname, instead of writing your name in full.

3. Use a photo identification card

Some banks offer credit cards that can show your photo instead of a signature. In some cases you

can also use a passport or driving licence as proof of identification.

4. Use a rubber stamp

You might find it useful to use a signature stamp. Some banks provide them and you can buy them in most stationery shops. (In Scotland rubber stamp signatures are not accepted in all banks, so check before using them).

5. Avoid using cheques for payments

Try using Direct Debit or standing orders to pay regular bills, subscriptions or donations. Many utility companies give a discount for payment by Direct Debit, so it's worth asking.

6. Use telephone or internet banking

This avoids the need for signatures.

Debbie, 55, realised she had Parkinson's when her handwriting began to shrink.

In my job as a solicitor, I need to be able to sign and date things. One of the biggest challenges has been my signature getting smaller and continuing to shrink. Initially, I thought this was because I don't write very much and type most of the time.

I first started noticing my handwriting was deteriorating up to three years before I was diagnosed with Parkinson's in 2020. My writing was getting illegible and kept on shrinking. I realised I might have Parkinson's after reading an article about the condition, which mentioned micrographia as a symptom.

Before my GP referred me to a neurologist, I had seen doctors about various issues, which I now know were Parkinson's symptoms, but at the time I didn't think they were related. These included anxiety and having difficulty with

playing the violin – my left hand (my playing hand) was seizing up and I couldn't hold the violin properly with my chin any more.

To help improve my writing, I enrolled on an online handwriting course aimed at people with Parkinson's. During the course, I learned hand exercises and techniques for making my handwriting bigger, such as writing big letters in the air, tracing over big letters and some finger exercises. Chunky pens have also helped to improve my grip.

My handwriting isn't back to where it was but it's definitely got a lot better. **P**





FUTURE PLANNING

Putting your affairs in order can ensure that your rights are protected and your wishes and preferences are carried out. It also helps you to feel more confident and reassured about what lies ahead. We find out more.

Making an advance decision

An advance decision can be made to specify which medical treatments you would accept or refuse under certain circumstances.

You can make an advance decision in writing, by telling a health professional, or by having a note made in your hospital or GP medical notes. If your advance decision includes refusing life-sustaining treatment, it must be in writing and signed and dated by you and a witness.

It's a good idea to review your advance decision and re-sign it and date it every few years, so that it still reflects your wishes.

In England and Wales, an advance decision is legally binding. In Scotland, you need to create an Advance Directive to make your wishes known. Although an Advance Directive is not legally binding, it's likely to be followed by your medical team. There is currently no legislation in force in Northern Ireland covering the use of advance decisions.



Richard has made an advance decision after he was diagnosed with Parkinson's in his 70s.

I discussed making an advance decision with my wife and she reacted calmly, but with some concern. Over several conversations though, she came to realise I was very serious about it and understood I had thought through the implications. Eventually she said she was willing to support

me and we shared my intentions with our two grown-up sons.

I wrote a draft and discussed it with my GP. She made some helpful comments and suggested I also talk to our local hospice. These conversations helped me refine my decisions.

In the final document, I outlined the circumstances under which the advance decision would come into effect and what treatment I would not accept. It also stated what basic care, such as pain relief, I would want to keep me comfortable. I signed and dated the decision and had it witnessed. Then I sent copies to my family members and to my GP practice.

I found the process very helpful. It relieved me of the worries I had about losing control of my life. It also allowed me to communicate my thoughts to my family, on a topic that might otherwise be hard to discuss.

Now having made my arrangements, I feel I can get on with my life.

Making a Power of Attorney

A Power of Attorney is a written legal document giving someone else authority to take actions and decisions on your behalf. It's always best to make a Lasting Power of Attorney before it may be needed.

In England and Wales, Finance and Property Lasting Power of Attorney allows someone to deal with financial matters such as paying bills or collecting pensions. Health and Welfare Lasting Power of Attorney allows your Attorney to make health and social care decisions on

your behalf when you can't do so because of mental incapacity.

If you live in Scotland, you can make a Continuing Power of Attorney for financial affairs or a Welfare Power of Attorney for social and health care needs. A Combined Power of Attorney gives both financial and welfare powers.

Currently in Northern Ireland, you need to make an Enduring Power of Attorney. It only formally covers property and affairs. The legislation enabling a Health and Welfare Attorney is not yet in force.



Natalie cares for her dad, Gareth, who has Parkinson's dementia. She and her sister, Emma, now have Power of Attorney for both Gareth's finances and health and welfare.

Dad can get very confused, or doesn't understand concepts, like how much he's spending. He'd often struggle speaking to his healthcare team on the phone, so pass them onto me or Emma – but they couldn't share anything with us because of patient confidentiality.

We suggested to Dad that he arrange a Power of Attorney while he was still deemed to have mental capacity. It was very important to us he understood we would always act in his best interests, and enable him to keep his independence as much as possible. But it was also something that would help all of us in the long term.

It felt like a massive weight was lifted once everything was finalised. I now have a bank card and a log-in to Dad's online accounts, so can keep an eye on things. Recently there was an issue with his medication, which I could sort out and then tell Dad later once it was resolved, which saved him any distress.

The system isn't perfect – different companies can decide how they want to administer the Power of Attorney, which I wish we'd been prepared for – but it has definitely given us all peace of mind.

Making a will

Anyone over the age of 18 (or age 12 in Scotland) can make a will. This means you can decide what happens to your property and possessions after your death.

Making a will is important because otherwise your assets – savings, investments or property – will be divided according to legal rules rather than your

wishes. This is particularly important in the case of step-children, who will be left out if there is no will.

Your will should be updated if your circumstances change in order to ensure your wishes are properly carried out.

It's also a good idea to sign a Power of Attorney at the same time as making a will.

Joyce's story

Joyce is 69 and was diagnosed with Parkinson's in 2009. She recently made a will through Parkinson's UK.

Making a will is quite a hard thing to face and it took me a while to get around to making one. You're thinking about when you're not around anymore, and the impact that will have on your partner and others. I talked it through with my husband, aunt and within the family first. It is something that we all need to consider doing.

Before I made my will, I thought carefully about who should act as my executor and administer my estate. I chose my husband and two of my cousins because I could trust them with this and they were happy to do it.

I then thought about the assets I have. This even included my caravan – if it's still about! And the things that I hold dear, such as my jewellery and a big collection of craft items. As well as including my friends and family in my will, I also decided to include




a gift to Parkinson's UK because I hope in a small way, this will help other people with Parkinson's.

Writing my will also gave me the opportunity to have a say about my funeral arrangements. I would like to be buried and for the people at my funeral to wear bright colours as I wouldn't want it to be a somber affair.

If I can give any advice, I would say, go ahead and do it. Once I'd thought about everything, it was easy to do. It didn't take long and gives me peace of mind. At the end of the day, I feel like I've done something worthwhile.

Parkinson's UK has partnered with Farewill, the largest will writer in the UK.

Write your will online (in England and Wales only) for free by visiting farewill.com/parkinsons-mag21. You can also make a will over the phone (including in Scotland and Northern Ireland), by calling Farewill on **020 8050 2686**. You must notify the Customer Service team at the start of the call that you are a Parkinson's UK supporter.

There is no obligation to include a gift to Parkinson's UK if you use this service, but we hope it is something you may consider, once loved ones are provided for. All gifts, large or small, make a difference. Together we will find a cure and improve life for everyone affected by Parkinson's. 

Read more about your rights and legal options at parkinsons.org.uk/rights-legal-options



I'M EMBARRASSED ABOUT MY PARKINSON'S

How do you cope when you feel self-conscious or embarrassed about your Parkinson's symptoms?

In my last job, I used to get called 'glider' and 'robot' because of how I walked. It was classed as banter and a laugh, but it used to bother me quite a bit."

Nathan lives in Staffordshire, and was diagnosed with Parkinson's in 2019 in his early 30s. He has dystonia, rigidity and joint pain and walks with a stiff gait. He describes how he often gets

comments about his Parkinson's when he's out and about, which he feels is made worse by the fact that he is younger.

"People don't realise that you can have Parkinson's when you are my age," Nathan says. "I get embarrassed when I walk down the street because I'm paranoid about what people are thinking about me. When lockdown happened I actually liked it because it meant I could stay in and not face people.

"I was once out with a group of people and one of them asked me why I was walking funny. When I told her it was because of my Parkinson's, she was shocked. I think people do end up feeling bad when they find out."

He adds: "I find I'm always having to justify myself. I've been in the supermarket trying to pay and I can hear people huffing in the queue behind me. I've learnt to explain to them that I'm slower because I have Parkinson's and I need a little more time."

Nathan explains how his wife Leona tries her best to support him. "My speech can sometimes be mumbled or I may have difficulty getting words out. She doesn't like seeing me feel embarrassed or awkward so will sometimes jump in and help me. It's tough for her to see me struggle."



Nathan is starting to get more support from his Parkinson's nurse and has also joined the Parkinson's UK Facebook Community Group. He has a three-year old boy called Charlie and likes to focus on having good days with him.

"I think it's important for others to know that you can't just go around judging people or making comments. You don't know how it might affect them."



PEOPLE DON'T REALISE THAT YOU CAN HAVE PARKINSON'S WHEN YOU ARE MY AGE."



Jennifer Foley, Clinical Neuropsychologist, tells us more.

Lots of people with Parkinson's feel self-conscious about their symptoms.

People might feel embarrassed about the visible signs of Parkinson's, such as a tremor. Others might feel embarrassed about the non-motor symptoms, such as problems with memory. It can be so overwhelming that it can stop some people from socialising at all.

These are some tips that might help:


Face your fears. Avoiding social situations might have a short-term benefit of reducing embarrassment, but long-term, it increases the problem. If you routinely avoid social situations, you don't give yourself the chance of developing coping strategies or reducing your anxiety, and this only serves to increase worry and negative feelings.

Silence your inner critic. If you notice a thought like, 'Everyone will think I am useless', recognise it as a negative thought. Importantly, negative thoughts are not facts,

but the sound of your inner critic. If you notice negative thoughts, try to question and challenge them. Is this fact or just my opinion? How would you respond if your friend voiced such negative thoughts about him or herself? If you can be compassionate to a friend, can you be more compassionate to yourself?

Focus on others. Take your focus off yourself by thinking about others. If you are going to a social event, is there someone there you are particularly looking forward to seeing? When with others, try to focus on what is being said, rather than on your own worrying thoughts.

Breathe. Learning to slow your breathing can reduce feelings of anxiety. Practising breathing exercises when at home alone can make you more prepared to use this skill when you feel embarrassed. You can also try to reduce general anxiety by using other relaxation techniques, such as mindfulness exercises.

Share how you feel. Talk to other people with Parkinson's – the likelihood is that they will have had similar feelings. It can be good to talk to someone who knows exactly how you feel and might have ideas on how to cope. 

Chris lives with vascular dementia, Parkinson's and dementia with Lewy bodies. Here she shares her story.

A year later, Chris was taken to hospital with another suspected stroke and was referred to the elderly care assessment service. There, at just 60, she was diagnosed with vascular dementia.

"I was so upset. I didn't want to speak to anyone. I didn't want to leave the house. It felt like a death sentence," Chris reflects. "At the time, I was living alone in Cardiff. Each morning I had

they decided Chris would move from Wales to the south coast.

But Chris's health continued to deteriorate. "I'd developed a tremor in my hand which got worse if I felt anxious. I had swallowing problems, so stopped eating and was feeling very tired and depressed." She was eventually diagnosed with Parkinson's.

Becky, the nurse Chris saw that day and continues to see, has had a huge impact. Chris explains: "She was, and is, absolutely amazing. As soon as she started me on medication, I became a different person. My tremor improved and I had so much more get-up-and-go."

Sadly, the improvement didn't last and after a series of scans, Chris was told she had dementia with Lewy bodies.

Seeking support

"When I was diagnosed with vascular dementia, I didn't know what was going on and thought I was going mad," Chris admits. "I wasn't given any information about the condition and had no idea where to get the support that I needed.

"I think I cried for about three months. But then I realised I had a choice – I could either stay at home and spend the rest of my days in front of the TV, or I could help myself.

LIVING WITH PARKINSON'S AND DEMENTIA

I'm a glass half full person and despite everything, I'm still optimistic," says Chris, who, at the start of last year, was told she has dementia with Lewy bodies.

In 2017, Chris had three small strokes. "I was told everything would go back to normal, but I knew something in my head was just not right."

three things to do – make a cup of tea, take my medication and feed my cat. But sometimes I'd do none of those things. I'd get confused and just end up wandering around my house."

Life changes

During this time, Chris's partner, Heather, was living over 200 miles away in East Sussex and the pair would travel between their two houses. Eventually



“So I called the Alzheimer’s Society and spoke to someone on their helpline. It was there I realised I’m not on my own.”

Chris experienced the same feelings of hopelessness when she received her dementia with Lewy bodies diagnosis. Through the Lewy Body Society she spoke to an Admiral nurse, and they shared strategies and tasks to help Chris manage.

“Eventually Heather and I had sessions together and we would talk about how we are both coping. It was really insightful and taught us a lot about what we were thinking.”

Living with dementia and Parkinson’s

“I have good days and bad days. On a bad day, I can’t do anything at all. My energy levels are low and I feel fatigued.

“But I do have lots of coping strategies. I may go for a stroll along the beach, or I’ll do something to distract myself. We also have a touring caravan, which we still like going away in. It means we can just go, and I don’t have to think about anything or anyone. It’s escapism really.

“I’m also honest with Heather – if she tells me something that

I’ve forgotten, I’ll just say, ‘If you told me, I don’t remember.’

“On a day-to-day basis, I don’t tend to look forward too much. If I make plans and then for whatever reason, I can’t do them, I can get disappointed.

“But I’m always reminded that I should be kinder to myself. I often beat myself up about the things I can’t do anymore.” But, as Chris adds: “Importantly, I also know there are lots of things I can still do.” **P**

There are many types of dementia. Find out more at parkinsons.org.uk/dementia

MEETING A PARKINSON'S NURSE

Nick Bryden is a Parkinson's nurse in Ayrshire, Scotland. We find out more about his day-to-day work.



Q What's your background and how did you get into your current role?

A. I trained as a general nurse in my early 30s. When I qualified I worked in a geriatric rehab ward, where I met lots of people living with Parkinson's.

I ended up shadowing a Parkinson's nurse in my spare time and went on home visits with her. Seeing a person in their home environment with their partner or family helped me develop a real sense of the condition and I learned a huge amount.

I was lucky enough to become a Parkinson's nurse for the Ayrshire region in 2010. I'm one

of two Parkinson's nurses covering our region, and we work closely with the consultant and the Parkinson's local adviser. At the moment we have around 700 patients.

Ayrshire is a beautiful place and a popular area for people to retire to, so we do find we have more and more patients using our service. I also have three relatives with Parkinson's – two of which use the same service.

Q What does a Parkinson's nurse do?

A. During an appointment we'll have a conversation with a patient about their symptoms and any other medical issues that

they might be having problems with. A large part of the role is helping people manage their medication, so they get the best results and fewer side effects. I'm a prescriber which means I'm qualified to make changes to someone's medication, but not every Parkinson's nurse is able to do this.

We'll often have patients who are newly diagnosed and coming to terms with their diagnosis. Talking to someone's partner, relative or friend really helps a nurse to get a more rounded picture of what is happening, and we can offer support and information to them too.

If there's something that we can't help with, we'll make a referral to someone who can, like a speech and language therapist or physiotherapist.

Parkinson's nurses also provide a lot of education – for example, training other healthcare professionals to make sure people with Parkinson's get their medication on time in hospital.



What health and care tips can you give to someone with Parkinson's?

A. My top tips would be:

- Invest in a medication timer, or use your mobile phone. Set two alarms each time your medication is due – this helps make sure you never miss a dose.
- Use a sealed cup for carrying drinks around the home – it ensures you don't spill anything and means you can concentrate more on walking.
- If it's safe, use a steak knife for cutting up any food. This helps if you find it hard to use pressure when using cutlery.

- Stay as active as you can – exercise helps in so many ways, both physically and mentally.



How can someone best prepare for an appointment with their Parkinson's nurse?

A. Our region was one of the early adopters of video calls as coronavirus first hit, and it's still something we're using. Whether you have a video, phone or face-to-face appointment, there are always things that will make an appointment run smoother.

It's always good to think about your top three issues relating to Parkinson's. What is bothering you at the moment? What is difficult?

It's helpful to have a list of drugs you're taking, or even bring your medication along if it's a face-to-face appointment.

Please bring someone close to you if you like – this is helpful for both parties.

And be honest with us! Please tell us everything so we can help you. Some people come to see us not wanting to bother us, but that's what we're here for. **P**

The process for accessing a nurse is different depending on where in the UK you live. In some areas you can self-refer, or you may have to be referred through your GP or specialist.

Try asking your GP surgery as a first point of call. If you have any problems or would like to find out more, please contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**

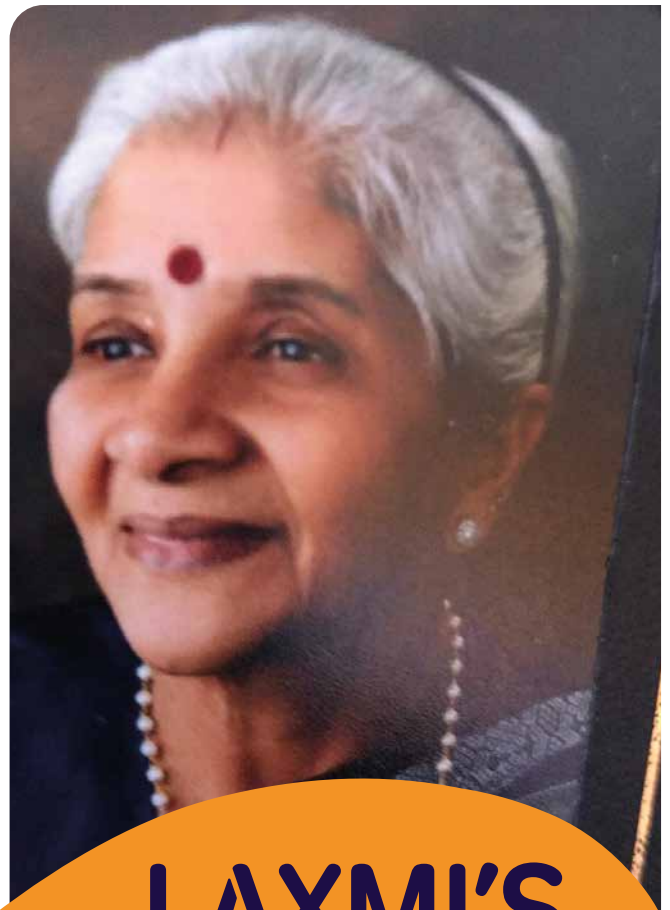
PARKINSON'S AND ME:

Laxmi is 71 and was diagnosed with Parkinson's in 2011. Here she talks about the challenges of living with Parkinson's and how despite these, her friends and family are always there to support her.

I first noticed my finger was shaking on my right hand. Over time, my whole hand would shake," explains Laxmi. "Then I began falling over, so I went to see my doctor.

"I didn't know anything about Parkinson's. So when the specialist told me I had the condition, it was very bad. I started crying. But he told me not to worry and that medication will help me."

After Laxmi was diagnosed, her husband Ramesh took early retirement. Laxmi says: "I struggled with cooking as I would spill things. Ramesh was very reassuring and told me he was going to look after me."



LAXMI'S STORY

Sharing news

Laxmi took her time telling other people about her diagnosis. "If I went to a wedding, I would hide my hand in my shawl in case someone saw it shaking and ask me about it.

"My daughter is a GP and she told me things happen to everyone and I shouldn't worry



I CAN STILL BE SHY ABOUT MY PARKINSON'S AND SOMETIMES I DO FEEL ASHAMED. BUT MY FAMILY ALWAYS TELLS ME, 'AUNTY, YOU DON'T HAVE TO FEEL SHY AROUND US.'"

about it. But I was still concerned in case people thought, 'What kind of condition is this?'

"I eventually told a friend and she said that if I ever needed someone she would always be there for me," remembers Laxmi. "Then slowly, slowly, my relatives began to find out."

Three years ago Laxmi's husband died suddenly when they were on a trip to India. "I miss him so much, but I am lucky to have a very good family." She has a son and two daughters and nieces and nephews who all look after her.

"I can still be shy about my Parkinson's and sometimes I do feel ashamed. I can't wear saris anymore because it is too hard to wrap them. So when I see ladies wearing their saris, I get sad and wonder why God is punishing me. But my family always tells me, 'Aunty, you don't have to feel shy around us.'"

Making friends

Laxmi also has a wide circle of friends in the community. She still goes to temple and she describes the congregation as her family. Her neighbours regularly check in on her and before the pandemic she had started going to the Leicester Parkinson's cafe, which was set up for the South Asian community in the area.

"I was listening to the radio one morning and heard an advert for it. As soon as I walked in, I was made to feel very welcome. It made such a difference to go and talk to other people who understand what I'm going through.

"Sometimes I wish I never got Parkinson's. It can get so bad and it can feel very lonely. But I have met good friends at the cafe and we chat often on the phone about our days and the challenges living with the condition can bring.

"I will often ring another friend at night if I can't sleep as I know she will be awake too. I do worry about the future, but talking definitely helps." **P**

You can read this article in Gujarati on our online magazine, parkinsons.org.uk/magazine

We also produce a range of resources in other languages, as well as accessible formats such as large print, audio CDs and easy-read. Find out more at parkinsons.org.uk/accessible-formats-and-other-languages

Could you help us tell your story that is reflective of people living with Parkinson's from all backgrounds? If you're interested, please do get in touch at magazine@parkinsons.org.uk

CARE PLANNING

Thinking about future care options is a common concern. Mary has Parkinson's and lives alone in retirement housing near Exeter since her husband died two years ago. At 87, she has recently been considering her future care arrangements.

I've always been very independent. If someone asks me if they can help with anything, I normally say no, unless I am desperate for something. But recently, I've been thinking more about having carers come into my home as opposed to moving into a care home. At the same time, I'm trying to judge how quickly my condition will progress.

Some days are better than others, but on the bad days it would be lovely to have some help, even if it was just to make me a cup of tea. I feel I might be in more need of help at night too, because I have to get up a number of times. I often wonder what it would be like not to be responsible for all the jobs involved with running a household alone, especially with restricted movement.

But if I was in a care home, perhaps the family who visit me now wouldn't be able to do so as easily.

Recently, my sister helped me find details of local homecare agencies. I left it for a month or so and then mentioned to her I might look into it. She told me I should treat myself!

I now have a regular carer for 30 minutes at 7am every morning, who I get on well with. She helps me get dressed, makes the bed, sorts out the commode and makes me my breakfast. I do appreciate this help – sometimes I think I should have done it sooner. It's expensive though, and I worry this will become costly if my needs increase.

There is a warden here, which gives me peace of mind, but I don't see her unless there's a problem. I also have a personal alarm, which can alert her in an emergency.

I'm not ready for residential care yet, but there are plenty of pros and cons about it to consider. It feels a pity to move when I'm happy here, so it's not an easy decision.



SOME DAYS...IT WOULD BE LOVELY TO HAVE SOME HELP, EVEN IF IT WAS JUST TO MAKE A CUP OF TEA."

The decision about care and where you live is a personal one. It is also important to recognise that the support available can vary depending on where you live. Here we share some things to think about before making care decisions and what options may be available to you.

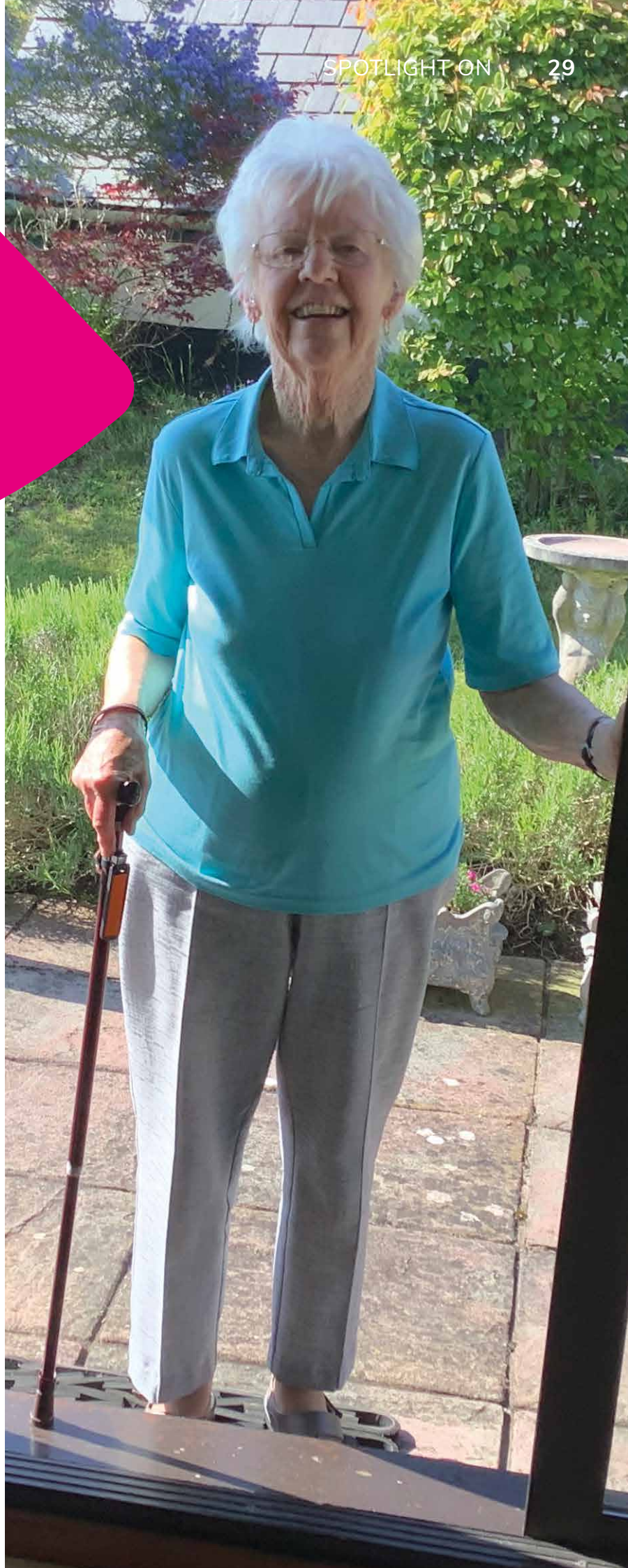
You may feel very attached to your home and its happy memories. Or you might be in a house that is increasingly difficult to live in comfortably, so a move to a more accessible property would be a relief.

Before making any major decisions, it's important to think about what your main concerns and fears are and whether these can be managed in other ways.

For example, if you are worried in case you have an accident or become ill, arranging a daily visitor or phone call can be helpful to check everything is OK. If you experience falls, carrying a personal alarm can offer reassurance.

If you're concerned about being isolated at home, you could explore community transport options or volunteer drivers. These schemes can enable you to attend your usual activities.

If local support still doesn't ease your worries, this may be a hint that a change of living arrangements may be the right choice for you. There's a range of options on the next page.





Home care

If you are happy at home, but need support with day-to-day tasks, your social services or social work department – or health and social care trust in Northern Ireland – has a responsibility to assess your needs and arrange services that can help you stay in your home. This includes help with housework or personal care.

Who pays for the care depends on your finances and whether you qualify to receive the services where you live.

Sheltered or retirement housing

If moving might be an option, but you value your independence, sheltered or retirement housing is specially designed for older people and you can live there with a partner, if you have one.

Sheltered housing can offer more support, in some cases including personal care. Residents have the independence of living in their own flat but may have meals prepared for them.

Care homes

A care home is staffed 24 hours a day, with personal care and meals provided. Some care homes provide nursing care too.

It's always good to explore care home options before you need it. For example, do you want to stay local? Or perhaps move closer to family?

The Care Quality Commission (cqc.org.uk) in England, the Regulation and Quality Improvement Authority (rqia.org.uk) in Northern Ireland, the Care Inspectorate (careinspectorate.com) in Scotland or the Care Forum Wales (careforumwales.co.uk) in Wales can help you research different homes. Homes also often have brochures to help you assess the facilities.

If you find a home you like the sound of, you could always request a trial stay. You will have to pay for this, but it can give you a better sense about the setting and whether you might enjoy living there. **P**

Do you have questions about future care options, including your choices and any financial issues that you may need to consider? Our helpline can provide information and advice. Call **0808 800 0303** or email hello@parkinsons.org.uk

Get in touch

If you're feeling isolated, worried or struggling to cope, our team of Parkinson's advisers are here for you.

You can chat to a member of our team or request that they give you a call back to talk about any issues you're facing, and to give you the information and support you need.

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.

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