

Spring 2022

THE PARKINSON

SPIRIT AND DETERMINATION

Why Ken will never
accept a problem
can't be solved

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

After another long winter, I'm delighted to welcome you to the spring issue of *The Parkinson*. And with World Parkinson's Day just around the corner, it feels there's plenty to look forward to.

Inside, I'm so pleased to share Ken's story with you. Ken admits he will never accept there's nothing he can do about a problem – and the way he has lived with Parkinson's for the past eight years is no different.

Sachdev speaks powerfully about what caring for his wife, Mito, means to him, and Neil shares how running has helped him manage his Parkinson's.

We shine a spotlight on complementary therapies and how helpful some people have found them. Clinical neuropsychologist Jennifer Foley also discusses how to manage your feelings and emotions after a Parkinson's diagnosis.

It's our readers who help shape the magazine, so please do let us know what you think of this issue. Is there anything you'd like to see more of, or less of? Or would you like to share your story of living with Parkinson's? You can get in touch using the contact details on page 31.

I look forward to hearing from you, but in the meantime, I hope you enjoy this issue.



Karen

Karen Spillett
Editor of *The Parkinson* 



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“ART SAVES MY LIFE EVERY DAY”

In early 2020, Alex Echo was diagnosed with Parkinson's. He had experienced symptoms for around seven years beforehand, but he was reassured he was just getting older. It wasn't until Alex woke up and wasn't even able to write his own name, that he knew he needed a second opinion.



I'm an American-born artist. My professional art career has spanned four decades, and I've worked on a huge range of projects and campaigns. Creating fabric designs for fashion designer Paul Smith, billboards for Absolut Vodka and a bespoke guitar for Eric Clapton. I recently digitally created 89 original art pieces at the NHS-UCLH Proton Beam Therapy Centre in London.

So when I was finally diagnosed with Parkinson's having experienced symptoms for several years, I was shocked. I was full of self-pity.

I was always so strong, athletic, powerful and confident. Now, there are good and bad days. Some days I feel like brittle parchment paper, like I could blow away. Other days I feel very strong and can laugh.

I find huge humour in things. I'm aware that I look like a drunk, but I'm so sober it's not even funny. I've been in recovery from alcohol



addiction for over 24 years now and I have to live one day at a time.

I know I'm not alone

The first person I told about my diagnosis was my friend Nick. He put his arm around me and told me it's going to be OK. And then I just started talking about it. I relished in the kindness and compassion people showed me. I want to give that back.

I've always had a strong fellowship around the world in recovery. With Parkinson's I have a whole new fellowship and I know I'm not alone. If they can laugh at themselves, then I can laugh at myself.

It's been really wonderful to be introduced to the huge community of people who are battling something really quite debilitating. But with humour. I'm proud to be part of it.

Making it familiar

For me, talking to my daughter and giving her support was like ripping off a Band-Aid. I said, "Your dad has Parkinson's. But don't worry. I'm going to be OK." We went step-by-step through knowledge and information and she said, "Yeah, you're going to be alright."

I introduced Parkinson's to my family by making it funny. We've softened the blow by making it familiar. It's not to be feared. My family knows I'm OK with it and laugh with me about it.

At the dinner table when my family are all together, they can see me struggling to get a fork full of food to my mouth. But they don't stare at me. I know they're aware of my struggle, but they offer me great dignity. That means the world to me.

There are no rules

My Parkinson's has slowed down my painting career. Five years ago I used to paint 40 paintings a month, now I'm down to 10. But truthfully, I think my paintings are better now because I take them more seriously.

It's been difficult, but my Parkinson's hasn't stopped me being creative. It's forced me to evolve and now I create digital art. Adapting to this realm has been a lifesaver. I have a predicament, but I don't have a death sentence.

I would really recommend art to anyone who's been diagnosed with Parkinson's. But let's be clear: there are no rules in art. You can't make bad art. Everyone's an amateur. It's a zen meditation.

When I'm doing art, time disappears. Parkinson's disappears. Worries disappear. Art saves my life every day and has done for 42 years. **P**



PARKINSON'S MOTOR SYMPTOMS



Motor symptoms affect your movement. Specialist physiotherapist Bhanu Ramaswamy explains more about three common motor symptoms and how you can manage them.

Tremor

A tremor (shaking) is an uncontrollable movement that affects a part of the body, for example the hand. It's one of the main symptoms of Parkinson's.

The most typical tremor in Parkinson's is called a 'pill-rolling' rest tremor, as it looks like you are trying to roll a pill between your thumb and index finger.

Commonly, a Parkinson's tremor starts in the hand before 'spreading' to the rest of the arm. The tremor can also affect the foot on the same side of the body, or in someone's jaw.

Things like stress, feeling very tired and caffeine can make your tremor worse.

How to manage a tremor

There is no cure for a tremor, although drug treatments for Parkinson's can often help to manage this symptom. Speak to your specialist or Parkinson's nurse about this.

You can also try these exercises that may help in the short-term:

- You can ease a tremor in your hand by pushing your palms firmly against each other before completing an action, like reaching into your purse.
- Chewing gum may help if you have a tremor in your jaw.
- If you have a tremor in your foot, try standing up and walking around.

As anxiety or stress can make a tremor worse, it's important to find ways to relax. Exercise that includes relaxation, such as yoga, may help. Some people learn to breathe deeply and to concentrate on the area of the tremor, which can reduce the shaking for a short time.

Dyskinesia (involuntary movements)

Dyskinesia are muscle movements that people with Parkinson's can't control. They can include twitches, jerks and twisting movements.

Dyskinesia can affect the arms, legs and torso.

A lot of people with Parkinson's experience dyskinesia after being on levodopa medication for many years.

Some people can have dyskinesia for most of the day. Others may only experience it after taking their medication or just before the next dose is due. Dyskinesia can often make people feel self-conscious.

How to manage dyskinesia

Dyskinesia can be difficult to treat. This is because if you take a lower dose of levodopa to reduce dyskinesia, your Parkinson's symptoms may not be as well controlled and you may experience more wearing off or 'on/off'.

If you develop dyskinesia, you should talk to your specialist or Parkinson's nurse. They will advise you on what changes you can make to your drug regime to balance treating the motor problems and control your Parkinson's symptoms.

Although there is no evidence to suggest a specific exercise can help reduce dyskinesia, regular exercise is especially good for you if you have Parkinson's and can have a positive effect on dyskinesia.

Dystonia

Dystonia happens when incorrect brain signals cause contractions in your muscles. They become tighter and shorter than normal, making them stiff. Dystonia can feel painful and uncomfortable, especially when it causes a twisting response in

the muscles that are affected. In Parkinson's, dystonia is often linked to levodopa.

Dystonia can often happen when you're doing activities that involve a set posture such as writing, or if you've walked or run for a long distance. It can also cause you to blink more than normal.

How to manage dystonia

The first step is to try to work out what is causing your dystonia. If your dystonia is connected to levodopa, your medication regime may need adapting.

Keeping active can help keep your muscles and joints flexible. A physiotherapist or exercise professional can give you advice on the best type of exercises to do.

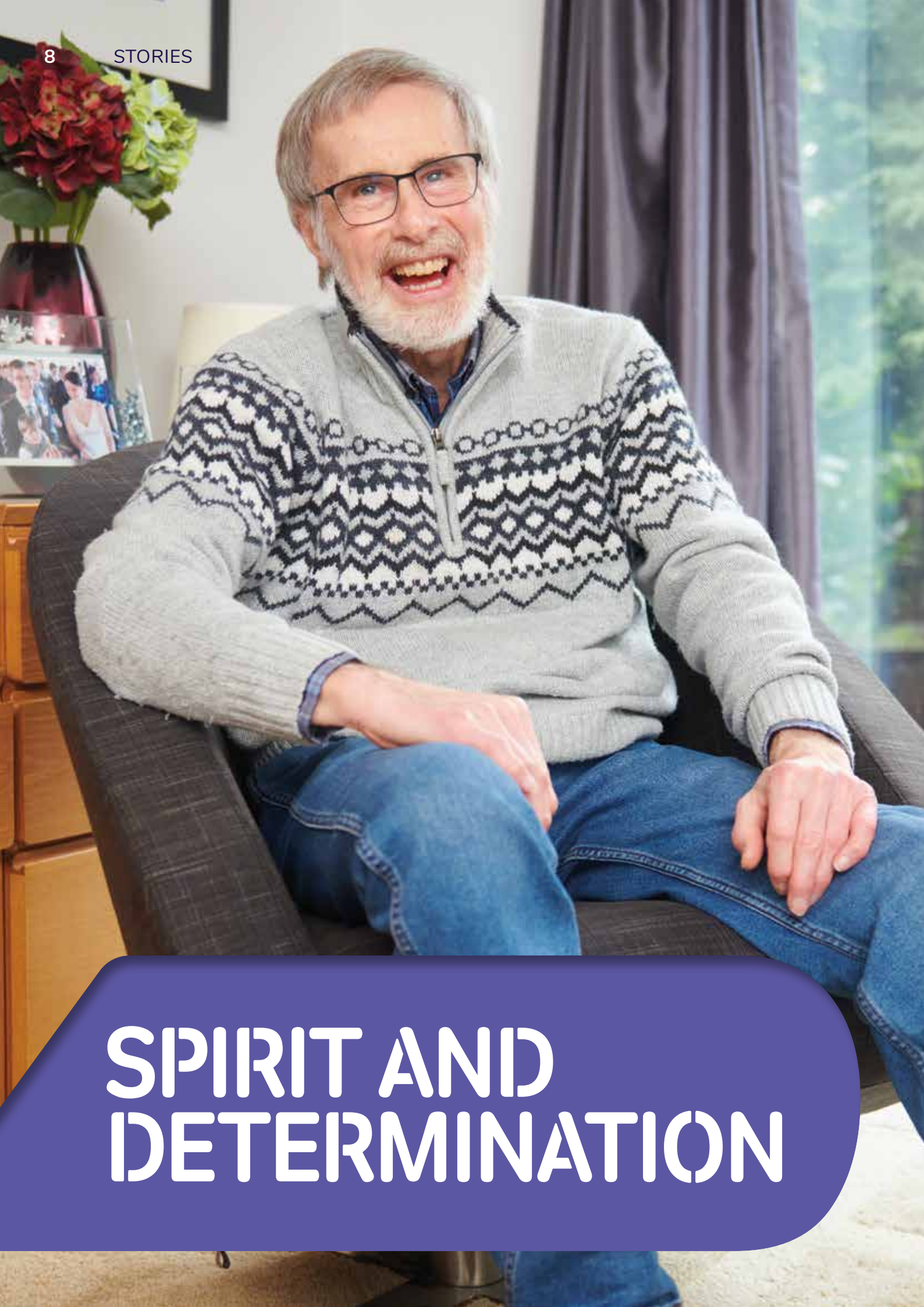
If you find dystonia affects your voice, speech and language therapy can be helpful.

These are some other things that may also help:

- Apply pressure above the eyelids if you experience excessive blinking.
- Stretch out toes and the soles of your feet before going for a run or long walk.
- Try botox injections. These block the signals in your brain causing your dystonia, and weaken your muscles for a short period.

You can speak to your specialist or Parkinson's nurse about whether this treatment may help you. **P**

Find out more about motor symptoms at parkinsons.org.uk/motor-symptoms



SPIRIT AND DETERMINATION

When Ken was told he had Parkinson's eight years ago, he refused to be beaten. He began trying to understand as much as he could about the condition and remains determined to use what he's learnt to keep fighting back.

Some people say that I'm a stubborn so and so!" Ken laughs as he recalls his initial reaction to receiving the news he had Parkinson's.

When Ken was 18, he attended a school, which had the motto, 'To serve, to strive and not to yield'. Since then, Ken has always tried to live his life by that principle and the challenge of Parkinson's has been no different.

"The consultant I saw was a blunt Yorkshire man and he told me, 'It's Parkinson's. Your best hope is to take the medications prescribed for you, and you might get two or three good years,'" Ken says. "Blow that, I thought!

"I will never accept there is nothing I can do about a problem facing me. I decided there and then that I'd prove him wrong," Ken says.

Helping himself

Ken set about educating himself about Parkinson's and discovered things he could do to help.

He read that protein can interfere with how well levodopa is absorbed, so he looked at his diet. Now he tries to avoid protein in dairy and

meat products during the day when his 'off' periods are worse.

"Apart from eggs, there are plenty of plant-based alternatives on the market which, to my taste, are just as good, if not better," says Ken. "This approach might not work for everyone. But for me, I now have a better balance of 'on/off' periods during the day."

Exercise has been another way Ken manages his symptoms. "I didn't know much about how exercise can help Parkinson's symptoms for around three years following my diagnosis," Ken admits. "Then a friend told me about an exercise programme for Parkinson's. The exercise was hard, but the benefits to both my physical and mental health have been tremendous.

"I've since done boxercise classes and, at the other extreme, I do a daily online 'wake up and stretch' class. It's very useful to a stiff, creaking 75-year-old like me!

"With Parkinson's, I think you need to find out as much about it as you can, accept the diagnosis – but don't accept the prognosis. You have the condition, but you need to fight back. There is always something you can do."

Facing the challenge

Ken has become really interested in social and communication problems in Parkinson's and understands the impact these issues can have.

"These problems can be embarrassing and people stop socialising," explains Ken. "So I was pleased to help organise and run the four drop-in cafes established by our local group, where people can get together in a friendly environment and share tips and ideas about managing their symptoms."

For those whose voices have been affected by the condition, Ken helped establish the first Live Loud! classes in Cardiff. At the moment, he's particularly enjoying preparing a 'Live Loud Haka', based on the traditional Māori challenge performed by the All Blacks before a rugby game, for the class to do.

Recently, Ken realised the subject matter was closer to home than he first thought. "I had noticed people saying 'Pardon?' to me more often when

I spoke, but I had a rude awakening during a research webinar," Ken admits.

"I saw a recording of my presentation at the online event, and I didn't recognise myself. It definitely made me think that we should see ourselves as others see us – and do something about it, if necessary!"

Ken's philosophical about the challenges the condition presents. "Another thing that Parkinson's has stolen from me is my smile," Ken says. "I'm a fairly cheerful chappy, always ready to have a laugh and a smile. But now, even though I'm smiling inside, I can have this grumpy fixed Parkinson's face.

"But if there's one lesson I've learned, it's that you only get one go at life, so don't waste this glorious opportunity by being negative and miserable. There's a funny side to every situation – sometimes it might just take a bit of imagination to find it!"



“There’s the saying ‘Where there’s life, there’s hope’. Well, I firmly believe that this can be turned around to, ‘Where there’s hope, there’s life!’ A cure is not likely in my lifetime, but let’s give future generations a chance.”

Unwavering support

Ken has been married to Kate for 43 years and together they have three daughters and three grandchildren. Their support has proved invaluable to Ken.

“I can’t find words good enough to describe how well Kate looks after me,” says Ken. “She’s the type of woman who never complains and she doesn’t let me mope, she gets me up and about.”

Ken is an active member of his local Parkinson’s UK group in Cardiff, but it was actually Kate who first found out about them. “When I was first diagnosed, I didn’t know anyone else with Parkinson’s,” Ken remembers. “By complete coincidence, Kate saw a local group meeting in the library and asked who they were.” Reluctant at the start, Ken now credits the group with giving him the drive to keep fighting.

Ken’s children are also on hand for moral support and are another source of inspiration. “My youngest daughter, Kiryn, ran the London

Marathon for Parkinson’s UK last year. She trained for a year, getting up at 5am and going for runs before work. Her unswerving dedication really inspired me.”

Hope

Ken is a passionate supporter of research, something driven out of his natural sense of curiosity.

“I’m a great believer in the saying, ‘If you want to win the battle, you’ve got to know your enemy,’” Ken explains. “I don’t like not knowing answers to questions I have – and the more I know, the more I can fight.”

Ken has volunteered for several questionnaire-based studies over the last few years. He is currently involved in two clinical trials. “I have definitely put my money where my mouth is!

“Getting involved in research doesn’t have to mean taking a new drug. It could simply mean reporting how you are managing day-to-day, or using wearable technology to assess your movements,” he explains.

“In my opinion, everybody who can, should get involved with research in some way. Who knows? Your input could be the catalyst that leads researchers to a breakthrough.

“There’s the saying ‘Where there’s life, there’s hope’. Well, I firmly believe that this can be turned around to, ‘Where there’s hope, there’s life!’ A cure is not likely in my lifetime, but let’s give future generations a chance.” **P**

You can find out more about getting involved with research at parkinsons.org.uk/get-involved-research

GETTING TO KNOW...A CARE HOME MANAGER



Sam Fraser has worked in the care sector for 27 years. She now manages a 28-bed residential care home in Aberdeenshire in Scotland.

Q What do you enjoy most about your job?

A. Making sure residents get the support they need to keep them as independent as possible. I want to give them a sense of self-worth and that they matter.

As a manager, I'm not as involved in the day-to-day care of residents as I used to be, but I do enjoy covering shifts.

Q And which parts are the most challenging?

A. The biggest challenge is when someone's mobility starts to deteriorate. That can be very difficult. We can't always meet their full care needs then and sometimes they may need to move to a nursing home. It's very hard to see a resident have to move on.

As a residential care home, we don't have nurses on site, but we do work closely with the local Parkinson's nurse, physiotherapists, occupational therapists and speech and language therapists. Together we make sure our residents can stay as independent as possible for as long as possible.

Q What support should someone expect when they go into a care home?

A. Before someone comes into the home, I will receive a care assessment from their social worker (or care manager in Scotland). After I have read that, I decide if we can meet the person's care needs.

Often I will have a chat with the person on the phone or I go and visit them. Although COVID has made this harder, I would usually invite them

to spend a day with us at the home. It's an opportunity for them to get to know us and for us to get to know them.

We understand that Parkinson's can fluctuate and that some days or times are better than others. So once someone has moved into the home, we are always assessing people to make sure they are able to carry out tasks they need to or want to do.

We keep a daily record of how someone has been and this helps give us a bigger picture over a period of time. If a carer has concerns, they will bring it to my attention and we can look at what might be happening.

For example, if a resident seems off their food or is struggling to eat certain types of food, we could look at a referral to the speech and language therapist. If a resident isn't getting on with their walker as well as they used to, we can talk to the physiotherapist.

Every six months, I do a care review with a resident and use the daily records to guide the chat. We talk about how things have been going and if they feel they need extra assistance with anything. If they've already received extra help from a therapy team, we'll see if the resident feels like it's helping and what the next steps might be.

What support should family members expect?

A. Before someone moves into the home, I like to meet family members. We have a chat so I can understand what their expectations are. It also gives me a chance to explain what we're about and what we can offer their loved one. The family is usually supported through the process by their loved one's care manager.


I'm very honest, so if I can see we might not be able to help someone, I will recommend another home that may be more suitable. It's so important that family members know their loved one will be safe and happy.

What advice would you give a person and their family considering a care home?

A. It's important to be selective when considering your care. There are lots of fantastic homes out there, but it needs to be right for you.

Think about your needs now and how they might change in the future. For example, if you have concerns around your mobility, can a home offer you a room downstairs? This might mean you can maintain your independence for longer as you won't need to rely on staff to help you to and from an upstairs room.

Our home is very relaxed. People can choose what they want to do across the day. We have three communal lounges and a large garden. In the dining room, mealtimes are huge social events! But everyone has an off day, so if someone would rather eat lunch in their room one day, that's absolutely fine. I think that option is important, so think if a home is able to accommodate this.

If you can, go and look at different homes. Ask yourself, "Do I feel comfortable here? Can I see this as my home?" It sounds very simple, but it's really important to get right. 

MANAGING BRAIN FOG AND CONFUSION

Mild memory and thinking problems, such as confusion, can be a normal part of getting older. But sometimes, these symptoms are caused by Parkinson's.

Brain fog and confusion are common in Parkinson's and can happen at any stage of the condition. If you do experience these symptoms, your doctor may describe it as 'mild cognitive impairment'.

What do the symptoms look like?

- Problems with activities such as planning, multi-tasking and moving quickly from one activity to another, or doing tasks in a particular order.
- Problems with attention and concentration can also make everyday activities more difficult.
- Slowed thinking, so it could take you longer to make decisions or respond to questions.

What causes these issues in Parkinson's?

It's thought these symptoms are caused by problems in the brain pathways that pass messages from one area of the brain to another.

There may also be other reasons, including:

- anxiety and depression
- sleep problems

- dehydration and lack of a balanced diet
- other health conditions – infections, vitamin deficiencies and thyroid problems can affect memory and thinking, and low blood pressure (hypotension) can cause confusion

Getting treatment and support

It's important to tell your specialist or Parkinson's nurse about any thinking or memory problems you're having. They can look at your medical history and how long these problems have been going on, then discuss treatment options with you.

They may also ask you to complete a series of cognitive tests. These are pen-and-paper tests that your Parkinson's nurse can perform to assess your memory and thinking. The results of these can reveal the exact nature of the problem.

Some types of Parkinson's drugs help with memory and thinking problems, but others can make these symptoms worse. Your specialist can adjust your Parkinson's medication if necessary.



Emma Bracher is an independent occupational therapist. She explains how occupational therapy can benefit people with Parkinson's who are having problems with thinking, memory or confusion.

An occupational therapist will discuss with you any issues you're having and will help to find the best strategies and techniques for managing your symptoms. They can also teach you and your family more about Parkinson's-related memory and thinking problems, what to expect and when to seek further advice or support.

They may help your specialist or Parkinson's nurse by giving them some simple memory and thinking tests to try with you. These can be useful for helping to pinpoint any specific issues you might be having. The tests will also allow them to measure and track any future changes in your symptoms.

What tips and strategies can help people with Parkinson's perform everyday tasks more effectively?

- Avoid too much change in your usual routine or environment. If changes are unavoidable, make them gradually and give yourself time to adjust.
- Make family, friends and colleagues aware of the difficulties you're having and what can help make things easier for you.

- Use a diary or calendar for appointments and important dates, and to keep track of what you've been doing.
- Use a smartphone, speaker or smart watch for medication and appointment reminders.
- Put important items, such as your keys, wallet and medication, in the same place every time. Keep all important documents and reminders filed and in one place for easy access.
- When you're having an important conversation, reading a document or focusing on a key task, find a quiet, well-lit light space and keep distractions to a minimum.

What advice do you have for family, friends and carers?

It can be difficult, but try not to get frustrated when your loved one forgets what you've told them, tells you the same things twice, or if they keep misplacing things. It's not their fault, and reacting can make the person's anxiety worse and affect their self-esteem.

Instead, tell them what you've said again, or ask them to repeat what they've said. If they've misplaced something, join in the search to find what they've lost. If appropriate, make light of the situation. Sometimes a little bit of humour can go a long way and will help someone to relax and think more clearly. **P**

For more information on mild memory problems and confusion in Parkinson's, visit parkinsons.org.uk/mild-memory-and-thinking-problems

IS DELAYING DRUG TREATMENT RIGHT FOR ME?

When you're diagnosed with Parkinson's, your specialist may recommend you start medication to manage your symptoms. But together, you might choose to wait until your symptoms cause you more problems.

We find out more from Linda Moss, a Parkinson's nurse.



Q Why might someone choose to delay taking medication?

A. If you have mild symptoms that are not impacting your day-to-day life, you may decide not to start treatment immediately.

Your specialist will consider the impact your symptoms are having on you – age is less of a factor. For example, if your symptoms are impacting your daily life, your specialist may recommend you start medication. If you have very mild symptoms, you and your specialist may agree to wait until symptoms become more difficult.

Some people may not want to start taking medication because of the potential side effects. If you take levodopa (the main drug used for Parkinson's) for a long time, you might start to develop side effects, such as dyskinesia (involuntary movements). But not everyone will experience severe problems and medication can usually be adjusted to minimise them.

Sometimes starting medication immediately can be helpful. If your specialist isn't sure whether you have Parkinson's, they may suggest medication to see how your symptoms respond. Drug treatments then can help determine a diagnosis.

Parkinson's symptoms can improve with medication. This is why it's important that delaying treatment should be a joint decision made between you and your specialist.

Q What does the research say?

A. Research has shown that levodopa does not slow the progression of Parkinson's, but it can have positive effects on symptoms. Current research is aiming to understand whether early drug treatment for Parkinson's is helpful.

So there is still more work to be done before researchers can say if Parkinson's drugs have any effect on how quickly Parkinson's can progress.

Q How else can someone manage their Parkinson's?

A. Drug treatments are the main way to manage Parkinson's symptoms, but other things can help.

Exercise is good for everyone and it is especially good for you if you have Parkinson's. It can be as important as medication in managing symptoms.

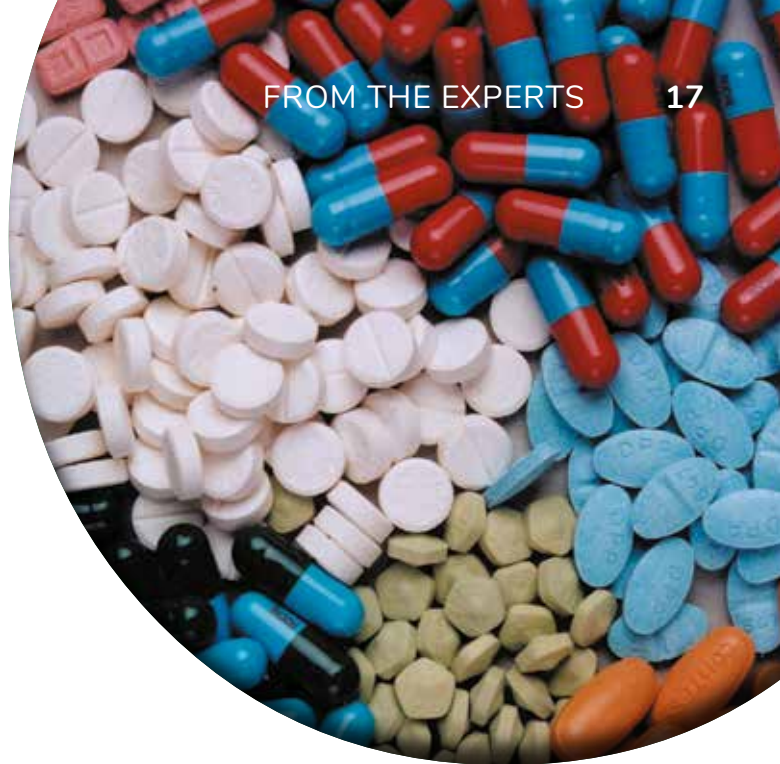
The type of exercise you choose depends on the way Parkinson's affects you. But there is something for everyone. Find out more at parkinsons.org.uk/exercise

Therapies can also help by focusing on a specific issue you may have. The three main types of therapy are physiotherapy, speech and language therapy and occupational therapy. You can read more about what might help at parkinsons.org.uk/therapies

Q When is the right time to start medication?

A. If your symptoms begin to have an effect on your day-to-day life, it might be time to start thinking about taking medication. This impact might be on how well you can move, or if you are able to get out and about socially.

If you become stiffer and are losing muscle, it can be difficult to turn back the clock. It may be easier if



you are younger. But the risk of delaying treatment is that your condition will progress and your symptoms will get worse. Starting on medication can mean keeping things better for longer.

Q If someone is worried they will develop side effects, what should they do?

A. It's natural to worry about side effects. It's good to be informed, but don't dwell on them. Your specialist or Parkinson's nurse will always talk to you about the main ones, such as dyskinesia and impulsive and compulsive behaviours at your appointments.

If you start medication and do start developing side effects, you should talk to your specialist or Parkinson's nurse. They can come up with a plan for you to come off the medication slowly and consider a different option. **P**

If you do choose to take medication for your condition, it's important that you don't stop taking it without first discussing it with your specialist or Parkinson's nurse.

You can read more about drug treatments at parkinsons.org.uk/parkinsons-drugs

“RUNNING GIVES ME BACK CONTROL”

Since Neil was diagnosed with Parkinson's four years ago, running has given him a sense of control over the condition. He shares his story.

For 12 months before Neil was diagnosed with Parkinson's, he experienced a tremor in his right hand. His GP said it was an essential tremor and Parkinson's was initially dismissed. But after seeing three different neurologists, the specialist Neil still sees today told him he had Parkinson's.

“By that point, I knew. I'd worked things out for myself. I wasn't massively shocked, but I was eager to know if I could keep running.”

Neil had started running at school and over the years, moved to competing in triathlons. After a bad bike accident, he sold his bikes and returned to running again.

“It was like a knee-jerk reaction and I just blurted it out. The neurologist said yes and that was like music to my ears,” remembers Neil. “At that point, the Parkinson's diagnosis almost became irrelevant.”



“I’ve got Parkinson’s...”

Coming to terms with the diagnosis though, proved to be a process over the coming weeks and months for Neil.

“Parkinson’s is like an annoying little puppy, not doing as it’s told. It’s over-excitable and doesn’t know better. Getting cross with it is not the answer then, but reality did begin to kick in,” admits Neil.

“‘I’ve got Parkinson’s’ became a little niggle that kept playing in the back of my mind. I don’t sleep well and if I woke up, I’d be thinking about Parkinson’s.

“So I made a conscious decision not to find out what happens in Parkinson’s. Otherwise, I’ll be lying in bed thinking ‘Oh God, is that a symptom?’ It will play on my mind.

“For my sins, I bury my head in the sand and just take each day as it comes. Today is today, tomorrow is tomorrow,” says Neil.

Facing challenges

Neil was prescribed medication, which began to manage his Parkinson’s symptoms. Managing his mental health, however, was more challenging.

“I was in a dark place. The only relief was my running,” admits Neil. As he began to cover longer distances, he started to miss not having a race to focus on. “It was while I was training for my first ultramarathon that the idea to run from John o’Groats to Land’s End started to form.

“I’ve always done things that challenge me, whether it is work or sport and the idea went in and out of my mind for sometime,” says Neil. “I talked it over with my partner Nicky who was very positive about it, but there was still an element of self-doubt.”

A few months previously, Neil had been to an event and seen Luke Tyburski, an endurance athlete, give a talk. Afterwards, he decided to email Luke about his idea. To Neil’s surprise, Luke replied and told him to go for it.

After Neil’s neurologist gave him his blessing, he trained for a year for the challenge. In July 2021, Neil completed 36 back-to-back marathons to successfully run the length of the country. While running he wore a t-shirt, which said ‘Because I can.’


Keep going

“What I did is extreme,” laughs Neil. “But for me, physical exertion is about looking after my mental health. When I’m not running, I’m moody. I can be difficult to be around. When I’m fitter, I feel better – I can deal with things just that little bit easier.

“There’s no way you need to do remotely close to what I did, that’s what worked for me. But just start by going for a walk to raise your heart rate a little – exercise doesn’t need to be purgatory!

“My Parkinson’s hasn’t deteriorated in a long time. Is that my stubbornness? Is it my running? I don’t know,” admits Neil. “But I will challenge anyone to say they feel worse after running.

“Sometimes you can feel you are at the mercy of Parkinson’s, but running gives me back control. I’m 64 now and am still planning on running when I’m 74.

“Of course, I do have my own internal battles with Parkinson’s, but I am not a quitter,” says Neil. “I just point blank refuse to let it beat me.” 

Read more about exercise and Parkinson’s at parkinsons.org.uk/exercise

COMPLEMENTARY THERAPY AND PARKINSON'S

Complementary therapy is treatment used alongside conventional medicine, such as drug treatments. We find out more.

While conventional medicine focuses on the treatment of symptoms, complementary therapies adopt a more holistic approach. This means considering all aspects of how a condition may affect someone, rather than just focusing on medical symptoms.

There is little evidence that complementary therapies can slow, stop or reverse the progression of Parkinson's, but many people living with the condition have found different therapies helpful.

What you get out of a complementary therapy may also depend on what you expect from it. You may feel a particular therapy is not having a positive effect on your Parkinson's symptoms, but you enjoy the experience. For you, this might be enough of a reason to continue.

Depending on where you live, some hospitals and GP practices offer complementary therapies like acupuncture, aromatherapy, massage, osteopathy and chiropractic treatments.

If your chosen therapy isn't available on the NHS or HSC, you may have to pay. Costs for

complementary therapies will vary, depending on the type of therapy you want, the length of the treatment and where you live.

Before choosing a therapist it's important to find out if they're reputable, insured and, where relevant, belong to a regulatory body. You may find it helpful to ask your GP, specialist or Parkinson's nurse, or someone else with Parkinson's, a friend or family member. Always check the therapist's credentials – an honest, reliable practitioner won't mind you asking about their qualifications.

We've spoken to three people who have shared their experiences of what therapies have worked for them.

Complementary therapies don't work as a replacement for Parkinson's medication. Stopping or making changes to your Parkinson's medication can be dangerous without the guidance of your specialist or Parkinson's nurse.

Acupuncture

Acupuncture is a form of ancient Chinese medicine. It involves thin needles being inserted at particular points on your body.

Traditional practitioners believe that energy flows round the body through channels which, when blocked, can cause illness. The role of acupuncture is to unblock the channels.

Some scientists believe the needles act to stimulate muscles and nerves, which is what causes the effects.



Steve was diagnosed with Parkinson's in 2015. He has daily acupuncture sessions.

I'm lucky that my wife, RongRong, is trained in acupuncture. She began giving me this treatment daily while I waited to be diagnosed with Parkinson's. Since then, I've not been brave enough to stop daily sessions – for me, I feel that the overall benefit builds up.

A session will normally last about 30 to 45 minutes and I usually have needles inserted on my head, forearm, lower legs and feet. Sometimes I have them on my back too. I usually have between 10 or 20 needles inserted, but it can vary if I'm having an 'on' day or 'off' day. When the needles are in, I can feel a tingling sensation, but nothing too unpleasant.

After an acupuncture session, I'm definitely not as rigid. I mostly have sessions in the evening before bed, so it helps me to relax and I find I sleep much better. A good night's sleep also really helps me with my energy levels the next day.

25 years ago, I had a bad back and RongRong gave me some acupuncture at the time, but my



general thoughts on the therapy were similar to my ideas on spiritualist meetings. That is, I had a healthy scepticism, combined with being open to – and receptive of - new, previously untried ideas which may be of great benefit.

For me, acupuncture is nothing ventured, nothing gained!

Reflexology

Reflexology is based on the theory that different points on the feet and hands correspond with different areas of the body. By massaging chosen areas of the feet and hands, the corresponding area of the body can be treated.

Reflexology is often used to promote relaxation, and to help with a wide range of problems, including digestive and hormonal issues, stiffness in the back and neck, and insomnia.

Jane has had Parkinson's for 18 years and enjoys reflexology sessions.

I was at a party in our village and started chatting with a reflexologist. I told her about my Parkinson's and she offered me a free session.

I'd had reflexology before in a beauty salon, so I knew it would be relaxing, but I was interested to hear what she found. That was four years ago and I now see Cat every two weeks. She has a real gift.

In the treatment room, I lie on a bed. The curtains are drawn, there is soft lighting and music playing quietly in the background. Sometimes we chat during a session, or I may fall asleep, it's completely up to me.

Each session lasts about an hour and Cat massages my feet in turn. She uses aromatherapy oils, which smell wonderful. It's very calming and feels lovely. Sometimes she might suddenly touch a point on my foot that will cause me slight discomfort, but it doesn't really hurt. There's been times when Cat has found things during a session I've not mentioned, such as a urine infection.

I always leave a session feeling very relaxed. Sometimes the next day I can feel a bit unwell and it might actually make my symptoms worse, but then I will feel better. It really does give me a general sense of wellbeing.



Osteopathy

Osteopaths stretch, move and massage muscles and joints to treat health problems. They'll use their hands to find areas of tenderness, restriction or strain in your body.

Osteopathy is commonly used for conditions caused by problems with the nerves, joints and muscles, such as back and neck problems, joint pain or injuries.



Gordon has had Parkinson's for 11 years and regularly sees an osteopath.

A few years before I was diagnosed with Parkinson's, I'd been in a bad car accident which left me with back problems. I used to have regular sports massage to help, but the practice was eventually closed.


It was my wife who encouraged me to see an osteopath. I hadn't seen anyone for two years before that. My back was still a problem, but I experience rigidity and muscle cramps with my Parkinson's, which can be painful.

I see my osteopath every six weeks now and treatment will depend on how I've been feeling in the week before. She might use massage, gentle manipulation or stretching. It doesn't hurt, but the noise of cracking bones can make me tense!

My osteopath has a special interest in Parkinson's. She understands it and talks to me about it when I'm there. We learn from each other and I do think you get more out of something if you connect with a person.

If my osteopath has worked me really hard, it might be a couple of days before I start feeling



the benefits. But often I feel better as soon as I walk out of the door. It's the best money I spend and helps me dramatically. 

As with all treatments for Parkinson's, different therapies work for different people. So we encourage anyone affected by the condition who is interested in complementary therapies to explore what works for you.

You can find out more at parkinsons.org.uk/complementary-therapies



THAT'S WHY I NEED TO CARE."

Sachdev and Mito have been married since 1973. 49 years, a move from India to England and four children later, Sachdev is now a full-time carer for Mito, who has multiple health problems, including Parkinson's.

Mito first noticed Parkinson's symptoms in 2007, while she was visiting India for a wedding. She was sitting on the floor in a temple and felt stiffness and pain, but put it down to a pulled muscle.

Two years later, a neurologist diagnosed her with Parkinson's. Her husband, Sachdev was terrified by the news.

"We didn't know much about Parkinson's at the time," admits Sachdev. "You don't see much information in the South Asian community about the condition.

"We were shocked. All our dreams, ambitions and plans to see the world came crashing down."

Turned upside down

Mito's Parkinson's diagnosis turned her world upside down.

She had to leave her job as a gift box maker, which she'd been in since 1974, because of the company's policy on safety.

Things have been further complicated when she was diagnosed with diabetes and high cholesterol in 2013 and lung cancer in 2020. Last year, Mito was admitted to hospital with coronavirus (COVID-19).

In hospital, it was tricky for Sachdev and their family to be able to care for Mito, because of the visiting restrictions in place.

"At the end of the day it was tragic for us," says Sachdev. "They said she can't come home. I was angry and fearful. I have to be everywhere with Mito to help her with eating, talking, sharing life with her. To make sure she's comfortable."

When Mito came home from hospital after recovering from

coronavirus, Sachdev and Mito's son Sanjeev moved back home to help care for her.

"My son made a welcome poster that said 'Get well soon' and I think that's the dream. It's coming true in a way against all the odds. Mito is fighting. The only way I see it is we cannot give up. We need to fight it bravely, as much as we can."

Knowledge is power

Sachdev has found power in knowledge. He's taken time to learn more about Parkinson's in order to give Mito the best possible care.

"I attended a conference in Birmingham to understand more about Parkinson's. I was told that it doesn't affect the lifespan but the lifestyle is impacted."

He's a passionate advocate for understanding Parkinson's, particularly in the South Asian community.

"We have to get Parkinson's understood in the South Asian community because there is a stigma around it," says Sachdev. "There's a misconception about Parkinson's and what causes it. It's not about fate, destiny and past lives. These beliefs have to be broken down.

"It's far more important to understand what Parkinson's

is, how complex it can be, how many symptoms there are and what is available to treat it."

What makes us human

Sachdev's day revolves around caring for Mito. He typically wakes at 2am to change her continence pad to keep her dry and protect her skin. At 6am he records Mito's medication and checks her temperature, blood sugar, oxygen levels and blood pressure.

He does it because he loves her, and because he believes caring for Mito is part of a bigger picture.

"Why do I care for Mito? It is not just one thing. She is my wife. She is my life partner. She is a mother. She is a grandmother. She is a sister. She is an auntie. She is a friend. She is a daughter and granddaughter. That makes her the centre of a small community. That's why I need to care.

"Caring, loving, living, understanding and valuing life is the first step to being human. If we don't believe in a healthy society we won't value life, we won't love life. We don't want that type of society." **P**



Read more about caring and Parkinson's at parkinsons.org.uk/caring

CHOOSING TO END WORK WHEN YOU HAVE PARKINSON'S

If you still work, there may come a time when you feel you need to leave a job or retire because of your Parkinson's. Here Karl, who is 59, shares his experiences.

I found out that I had Parkinson's six years ago. I started having problems putting my jacket on and was struggling to get my arm above my head. I'd also noticed other things like my handwriting getting smaller. When my GP referred me to a specialist, they started mentioning much worse conditions than Parkinson's. So when I got the diagnosis, I was actually relieved.

At the time I was working as a veterinary surgeon at a practice in Kent, where I'd spent 25 years of my career. I was already planning to retire, but the new owners of the practice had asked me to stay on. Getting the diagnosis of Parkinson's made me reassess things, and I decided to bring forward my retirement plans of travelling abroad. I simply told them I was leaving, went on holiday, and then never returned. I didn't even have a leaving do, as I didn't like the idea of lots of sympathy because of my diagnosis.

The decision itself was quite easy. I'd already been thinking about ending work, but I was

also lucky enough to have permanent health insurance, or 'income protection'. This covers me because of my Parkinson's and means I don't need to dip into my pension until I'm older. So I had planned ahead in some regard.

Since ending work I've thrown myself into being more active. I realised that exercise – specifically walking – helps my symptoms enormously, probably more so than the medication. I end up





quite stooped over, if I don't walk regularly. I recently walked the Pennine Way, which was a long-held ambition following a childhood conversation with my late father. It was beautiful, as it passed some of the remotest areas of the country. I also raised money for Parkinson's UK in the process.

I can no longer play golf, as I can't maintain the same swing with my tremor. Instead, I've taken up ten-pin bowling. The weight of the ball means my hand doesn't shake. I go quite regularly – it gives me a sense of achievement and there's a social aspect to it as well.

I think ending work affects people in different ways. I have many friends who haven't coped well with retirement – I think it might be something to do with losing a sense of status. Some went back to doing part-time work to fill their days, until quickly realising that they preferred not working at all! I enjoy the downtime and, COVID-permitting, means I can see more of the world.

When should I stop working?

If you're thinking about stopping work it may help to consider the following:

- Don't rush into a decision. If you're finding it difficult to manage your symptoms, you may need to make changes to your medication regime – and to take some time to adjust to this.
- Look carefully at your finances, including your pension, benefits and savings. Keep in mind that any benefits you get from work will end. It may be helpful to seek advice from an independent financial adviser. You can read more about what benefits you may be entitled to at [parkinsons.org.uk/money-grants-and-benefits](https://www.parkinsons.org.uk/money-grants-and-benefits)
- Speak to your employer or trade union to make sure you're leaving on the right terms, and at the best time. Some companies encourage their employees to attend training courses on preparing for retirement.
- Consider the alternatives, such as working part-time or volunteering.
- Think about how stopping work will affect you emotionally. If you do decide to retire, it may take time to adjust to life without work. Talking to someone about the decision may help. This may be a family member, trusted friend, others who have gone through retirement, or a trained counsellor. **P**

You can read more about work and Parkinson's, including options for the future, at [parkinsons.org.uk/work-and-parkinsons](https://www.parkinsons.org.uk/work-and-parkinsons)

COMING TO TERMS WITH A PARKINSON'S DIAGNOSIS



Have you or someone you know been recently diagnosed with Parkinson's?

Here clinical neuropsychologist Jennifer Foley talks about how to manage your feelings and emotions.

For many people, it can take time to adjust when you're diagnosed with Parkinson's.

Getting used to living with a condition you may know little about and needing to take new medication can be difficult at first.

You may also feel lots of different emotions, including:

- **shock.** You may not have expected the diagnosis or believe it's true
- **relief.** At getting the diagnosis after a period of not knowing what the symptoms were, or that it isn't something more serious
- **anger, sadness or worry.** You may have anxiety about what the diagnosis means for you or how symptoms might progress

You may find that you experience different emotions from one day to the next. It's also very common to try to ignore the diagnosis completely. All of these responses are completely normal.

What can help

It's important to get the right information and support, when it's the right time for you. Health professionals like a Parkinson's nurse can provide a lot of useful information and support at this stage. You can also read practical information on Parkinson's UK's website or printed resources, or contact the Parkinson's UK helpline (**0808 800 0303** or hello@parkinsons.org.uk).

Searching for answers

After getting a diagnosis you may question what causes Parkinson's and why you have it.

We don't yet know why people get Parkinson's – and this can be hard to hear. It can also be hard to live with the uncertainty of how your condition will progress.

What can help

Rather than ignoring or suppressing normal feelings, try to acknowledge and accept them.

Talking to others who understand what you're going through, and hearing how other people have coped and navigated their diagnosis, can help you make sense of your emotions. This could be through a local Parkinson's group or an online forum.

Some people find writing about their feelings and experiences useful, perhaps in a letter or a journal.

It's important to remember to look after yourself and make time for self-care. Some people find calming activities like mindfulness or deep breathing helpful, or relaxing exercises like yoga or tai chi. These can help reduce stress and improve your wellbeing.

Physical activity and exercise can also help, like going for walks, swimming or joining a fitness class. Regular exercise can boost your mood.

Adjusting to change

With time and support, people often feel more in control of their symptoms and find ways to manage their condition.

But adjustment can be an ongoing process. You may feel better or worse depending on how your symptoms are affecting you and what else is going on in your life. For example, if you develop new symptoms, you may feel shocked or angry. These feelings may then go away as you get more used to the symptom and get the right support to manage it.

What to do if you're struggling to come to terms with your diagnosis

For some people, the distress can be hard to shift. You may have lasting feelings of anxiety or low mood. At this stage, it's important to reach out for help.

Talk to your GP, specialist or Parkinson's nurse, who can look at ways to help you feel better. They may talk to you about different types of talking therapies, or medication that can help with how you feel.

You can learn how people with Parkinson's have coped with their own diagnosis on the next page.





We asked the Parkinson's community how they coped with their own diagnosis.

"I am now nine months into the diagnosis and still trying to come to terms with it. It sucks and the 'Why me?' always comes into my thoughts, but it's all normal. It's life changing but not life ending."

"My local Parkinson's UK group is amazing. It's been an absolute lifeline and I couldn't imagine managing without it."

"I do think about how I might be in a year, five years, 10 years, but there is no point worrying about it, it won't change anything. I try to focus on what I can do NOW."

"Accepting the diagnosis was difficult. But then I eventually realised I was still exactly the same person I was the day before the diagnosis – only now I knew what was wrong."

"Tell all of your friends and family – they will become a pillar of support."

"There's no right way to take the diagnosis. Let yourself grieve awhile. Then start looking into ways to help yourself."

Our booklet **Parkinson's and you** covers everything you need to know about being newly diagnosed with Parkinson's. An updated version of the booklet will be available this spring. [P](#)

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-6pm, Saturday 10am-2pm.

Information

All of our most up-to-date information is available at parkinsons.org.uk

You can order printed copies by calling **0330 124 3250**

- The magazine is published three times a year. If you would like to make a contribution, please contact the editor at magazine@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 page 8 by Paul Meyler.
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- *The Parkinson* is printed using vegetable-based inks on FSC certified paper. The printer holds the environmental standard ISO 14001.

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