

## **Airing Pain Programme 127: Pain Management & Taking the Sting Out the Tail of Neuropathic Pain**

*This edition of Airing Pain has been funded by a grant from The RS Macdonald Charitable Trust and The Stafford Trust.*

***Issues covered in this programme include: Insomnia and sleep clinics, burning and gnawing pain, pain signals, biomechanics, stress/psychological states and their impact on pain, analgesia, bradykinesia, gabapentin, pregabalin, managing chronic pain and Parkinson's disease.***

*Do you, someone you care for or perhaps your patients, suffer from persistent burning or gnawing pain? Many don't know that often, neuropathic pain presents as a burning sensation. Persistent pain can impact all areas of our lives. It can stop us from sleeping, working and pursuing the hobbies we enjoy. Unfortunately, sometimes the healthcare professionals we see about our pain are unaware of the multitude of pain management techniques we can adopt to try and minimise the impact pain has on our lives. Different types of pain are widely misunderstood and many of us don't know much about the conditions that can cause them.*

*What do you think of when you think of Parkinson's Disease? Many would say a tremor or shaking limbs, but persistent pain can be one of the most debilitating symptoms of Parkinson's Disease. The fastest growing neurological condition in the world is poorly understood and pain is a major unmet need in those who live with it.*

*Ground-breaking studies funded by the charity Parkinson's UK are shedding new light on the relationship between Parkinson's pain and neuropathic pain. In this programme, Paul Evans speaks to Kirsty Bannister, a doctor of neuroscience at Kings College London, who discusses the role that 'pain-blocking nerve pathways' and psychological status play for those who experience chronic pain. We also hear from former primary school teacher Janet Kerr, who shares with us her own experience of dealing with Parkinson's Pain and how she manages it with things like yoga and distraction techniques such as massage.*

**Paul Evans:** This is ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for those who care for us. I'm Paul Evans, and this edition of ***Airing Pain*** is funded by the RS MacDonald Charitable Trust and The Stafford Trust.

**Janet Kerr:** If I was to walk around with a grimace on my face of how I truly feel inside, I wouldn't want to be with me. But I'm sitting here and the leg is shaking, but it's also on fire.

**Dr Kirsty Bannister:** Constant pain is a poorly understood and a major unmet need in people with Parkinson's Disease.

**Evans:** The banner headline you read on the Parkinson's UK website at [parkinsons.org.uk](http://parkinsons.org.uk) is blunt. Parkinson's Disease is the fastest growing neurological condition in the world and currently there is no cure. But, and it's a big but, we're getting closer to major breakthroughs.

**Bannister:** This grant got awarded in November, so Ray and I celebrated as much as we could in lockdown because we really believe that this is going to be a project that is going to make a real difference.

**Evans:** Parkinson's disease is a condition in which parts of the brain become progressively damaged over many years and I think what most people would associate with Parkinson's disease is tremor, or uncontrolled shaking, of the limbs. Carol Vennard is Clinical Nurse Specialist in Parkinson's Disease at the Queen Elizabeth University Hospital in Glasgow.

**Carol Vennard:** That is a misconception because I do an educational talk and what I have named it is, 'All that tremors is not Parkinson's, and Parkinson's does not always tremor.' About a third, if not slightly more, of the patients do not have a tremor. It is one of the three signs but you often get patients who don't have tremor at all. So that can make it difficult because often patients will go the GP and the GP will say, 'Oh you've got a tremor, you might have Parkinson's.' But it could be something else, so you always have to keep that in mind.

**Evans:** What are the other two signs?

**Vennard:** So, rigidity. Stiffness in muscles, and what we call bradykinesia which is slowness. And often if you ask them about it, they're not really that aware. But I often use the analogy-, well, when we could go on holidays [laughs], people will often say to you, "Well, I noticed it two times of the year." At Christmas time, if it's a woman, because when she's gone to write the Christmas cards she's noticed that her writing is a bit smaller, because we don't write very much

now and that is one of the times of the year when it becomes more apparent. Or the other time is, 'We were on holiday', and often people go to the same place on holiday, 'and last year my husband/wife was able to keep up with me and this year they're not.'

It's sometimes something they've not done for a while that makes it obvious something's not right. It's often subtle things that change, and unless you're in that frame of mind and putting all the bits of a jigsaw puzzle together it can be very difficult. We often get patients referred to us who have been sent by their GP to see physios because they were told they've got a frozen shoulder or they've got tennis elbow and it turns out it's not, it's just an early sign of Parkinson's.

**Evans:** Clinical Nurse Specialist in Parkinson's Disease, Carol Vennard. Janet Kerr is an ex-primary school teacher and she has Parkinson's disease.

**Kerr:** I believe I started to develop subtle symptoms in my early 40s but I was officially diagnosed at 46, after going back and forward to the doctor for years. And the very first thing that I went to him about was pain. Now, if you go to a doctor and say you've got pain, the last thing they're going to think is, 'this person's got Parkinson's.' But for me it was my first symptom, and the symptom that is still with me and is the bane of my life. It's something that's there all the time, there's no respite from it. I score it on a scale of one to ten. Very rarely am I under a five. My husband will say, 'How are you scoring today?' and I'll say 'I'm an eight, nine.' Sometimes I'm a ten and it's at the forefront of my life.

At first, it felt like a trapped nerve which is stingy and nippy and cutting and biting. It's a nasty pain, it's not a dull, throbbing pain. It is a really stingy, nippy, hot, burning sensation. It started in my lower back and my hip and my groin and then it just seemed to progress on down my thigh. When I went to the doctor, I think he thought of sciatica, but that goes down the back of the leg. This was going down the front of my leg. Occasionally, it goes down the side of the calf and down to the foot.

**Evans:** Is there a problem with diagnosis in primary care?

**Vennard:** I think if you had asked me that question twenty years ago, I would have said possibly. I think now, because of the education that is done around Parkinson's by myself and all the other PD nurse specialists up and down the country, we teach in educational centers, so universities and colleges, and we speak to student doctors, student nurses, student physios, student OTs... And there are many more Parkinson's clinics now than there were before so doctors coming through are exposed to it more than they were, say, 25 years ago. So, if you look at it that way,

they're more likely to think about it because they've seen it, or they've attended a clinic when they've been doing their training, or someone's been and spoken to them about it.

I think the other thing that some areas struggle with is the waiting times between when patients are referred into a service and when they're actually seen. It's a bugbear of mine that often patients are referred to neurologists, who are great, but they're not the be all and end all of Parkinson's care. If you've got a 70-year-old who's got Parkinson's disease, they need to be seen by a multidisciplinary team and they're often within elderly care units. Lots of geriatricians do Parkinson's as a special interest, so it's them that are running the clinics. And I'm nowhere near a geriatric but if I was to have Parkinson's that's where I would want the center of my care to be. But I don't necessarily know that you would want that if you were 20 or 25 years of age.

**Kerr:** I wouldn't even take a paracetamol when I was ill. If I had a sore head, I had a sore head. I was not a pill-taker at all. So when I, almost literally, crawled into the doctor's surgery because I'd had the pain for a couple of years, it was one of those things where you think, 'Oh I'm a hill-walker, I do a wee bit of exercise. It's a trapped nerve and it'll go away.' I was training; I had a career change and I was training to become a teacher. My husband said, 'If you don't get up to the doctor's, I am going to throw you in the car myself and take you up there.' I think I just had it in my head that it was going to go away. Two years later it hadn't. So, he gave me gabapentin and I had to try it for a few weeks. I went back and said, 'Look, it's not touching it.' He would up the dose. We had a bit of toing and froing until I hit a dosage level that took the sting out of the tail, that's how I described it. I ended up going on to the top dose with a baseline of eight paracetamol [doses] a day. And it did work initially. Then I noticed that I was in so much pain. I was describing it as a level ten and that's whilst I was on the gabapentin. I thought, 'I'm crying myself to sleep here.' Because sometimes it just becomes overwhelming that you put on a brave face and you try your hardest to just carry on with life. But occasionally it just overpowers you and I'd end up crumpling into a heap and I'd just cry. I started to wean myself off it and after a few months I came off it altogether because it wasn't working for me.

**Vennard:** If I have a Parkinson's patient who's complaining of pain, 1. it might not be the Parkinson's that's causing it so you always have to rule out other things. 2. a really good history of type of pain. Is it stabbing? Is it there all the time? Is it gnawing? What time of the day is there? Or is it in the morning? Does it come and go? What helps it and what doesn't help it? Whatever analgesia they may happen to be on, are they taking the correct dose? Because one of the big things I get is, 'My GP gave me co-codamol and it's not helping.' And I'll say to them, 'How many are you taking?' 'Oh, I've just taken one twice a day.' Well, that's not the correct dose of co-

codamol. So, the first thing I'll say to them is, 'Well, if you go back to your GP all they're going to say to you is you're not taking the right amount. You need to get yourself up to the right amount and then if it's not working you can go back and say, 'I've had this and it's not helping.'

Sometimes it's not analgesia that they need. It might just be that they've got a bit of muscle cramp, or a bit of dystonia because their Parkinson's medication is wearing off. So that's why it's really important to get a good history from the patients. But the consultant I work with is very good. He'll take them so far and then think, 'Do you know what, this is not working. They really need a bit more help.' We also use the pain clinic. But sometimes the waiting list for the pain clinic can be long, so at least we can start to do things while they're waiting on that and then if the appointment comes in and they don't actually need it that's fine, they can cancel it. Rather than fiddling about, for want of a better word, and then six months down the line they're no better and *then* we put the referral in. We would rather do that ahead of time and try and manipulate therapy while we're waiting.

**Kerr:** I went to the pain clinic. I had an appointment there for six weeks and it's where you see all different specialists. And they don't just concentrate on pain; they look at sleep, different medications, and devices like a TENS machine. I ended up buying one of those to see if that would help. Little acupuncture things you can put in your ear... Nothing was working, but what the pain clinic did was; sleep is an issue. It can be a symptom, for people with Parkinson's, that they don't sleep very well. There's a lot of insomniacs in Parkinson's. We seem to survive on-, well, I survive on average on four hours' sleep. So, I used to fight against it and it used to stress me. Which possibly was not conducive to suppressing pain when you're in a state of stress as well. But it was because I was thinking, 'I've only had three hours' sleep and I've got to get up and teach a class of 30-odd children and cope with this condition.' The sleep clinic had said, they taught you about the sleep patterns. They asked, 'How much sleep do you need?' and we all sort of said, 'Seven or eight hours', and he said, 'Well, who said you need that?' They said if you have four hours then it's obviously quality four hours that you feel enough to function throughout the day. Four hours is all your body needs. And I thought, 'Do you know what, I'll just make peace with the fact I don't sleep.' That was like a lightbulb moment.

That did actually change my quality of life, just coming to terms with the fact that it's okay to have four hours' sleep. It's not an issue, don't make it an issue. If you're making it an issue, you're stressing yourself out. We had a chance to speak to a pharmacist as well. So, the pharmacist tried me on the sister drug of gabapentin which is called pregabalin. It didn't do anything at all, it didn't even take the sting out of the tail. But it was good to be able to have a one-to-one session

with these specialists. They really did want to help, and I had a session with a physio. But since then, I've been trying meditation, hypnotherapy and massage. They're not really helping to eliminate the pain or anything like that. They're a distraction, and they feel good at the time.

**Evans:** So the pain is still there, but it's helping you manage that pain?

**Kerr:** Yes. It's just given me a little bit of respite to think about something else.

**Evans:** We're recording this in the middle of the second lockdown crisis in February 2021. So, even though you're in Fife and I'm down in South Wales, a couple of hundred miles away, we can do this over a video link. Now I can see that you're smiling. You don't look like somebody in pain. Do you think that's a problem?

**Kerr:** If I was to walk around with a grimace on my face of how I truly feel inside, I wouldn't want to be with me [laughs]. But I'm sitting here, and the leg is shaking, but it's also on fire. And my hand-, I'm trying to think what I've done today. I'll be quite honest; it's called putting a brave face on it, and the only person that truly sees what happens is my husband. But if I was to sit and go, 'Oh God, oh ow, oh ow!' it doesn't make for good listening shall we say! [laughs]. But you're not the first person to say that. But normally what happens is, and I can assure you this'll happen because I've been sitting for a while, I am going to be in agony trying to get up and what I'm going to have to do is roll myself onto my side - well, I've got a chair next to me -, almost go on all fours [laughs] to be able to stand up. Because this is the longest, I've sat for a long time, but it's because we're sitting doing this interview [continues to laugh]. There's a social thing as well, Paul. If I'm in somebody's company, I try my hardest not to tremor and move about, because I feel embarrassed by doing that, but there's consequences for doing that as well. So, the consequences are I'll do my 'ouch' and my 'oh no', I'll do all that, when you don't see it.

**Evans:** The other thing about that is that, if you and millions of other people who have chronic pain, if we wear our chronic pain on our faces, in many ways it's the pain that defines us, not who we really are. That is our identity, pain is not our identity.

**Kerr:** That's exactly the case. The fact that I don't sit on the couch, the fact that I'm trying to be proactive, I'm trying to be a proactive host of my Parkinson's, I'm trying to be a proactive host of the pain rather than a passive host that gives up. I still feel that in order to have as best a quality of life as I can, I have to move. It's as simple as that. And if it means having an interview or speaking with people with a painted-on face that's not expressing the pain, or the stinging or nipping or burning that's going on, that's how I'm learning to cope with it. It's how I'm learning to

lead as normal a life as possible, a socially-acceptable life, because if I met people and just mumped and moaned about my pain, they would never want to see me again. But, every now and again, they do say to me, 'Oh Janet, are you alright?' because I do let my guard down occasionally when, you know, I've had no choice, I haven't meant it. They do show care and concern but I'm sure if they had that all the time, that's not the fun Janet I want to be!

**Evans:** Health professionals have traditionally tended to treat people with Parkinson's disease as if the pain is caused by muscle, joint or mobility issues. Now, neuropathic pain is pain resulting from when the nerves don't work properly and send the wrong signals to the brain, and this is different from pain caused by, for example: a pulled muscle, a sprain, or indeed Parkinson's-related mobility problems. You can find out more about neuropathic pain in [Airing Pain 116](#) on the Pain Concern website, which is [painconcern.org.uk](http://painconcern.org.uk). Here's Janet again:

**Kerr:** My first symptom was pain. So, I didn't know I had Parkinson's for a few years after having the pain. I started to develop a log-like leg and a heavy foot, and my leg stride was shortening, so the pain was making me limp. And because the leg stride had shortened and because it's only on one side, there is biomechanical issues that developed. So the biomechanical issues come with their own issues and own problems where there's pain. For example, my foot doesn't flex properly. So when I try it, it's quite painful, so I do avoid walking. I can't walk distance at the moment because it's just too painful. If I move the wrong way it's a sharp pain, but it's like a stiffness as well. When I try to stand up, it takes me a little bit longer at the moment, but I do make lots of old man noises! [Laughs]. And I don't mean that in a- [laughs], I suppose I should say old lady noises too, because things are not as naturally flowing. I'd said to the doctor, 'I know I've had x-rays. I know I've had scans. Can you please send me for an x-ray?' I was convinced there was something not right there. And the x-ray came back fine. And I was just like, 'How? What? I can't understand how I am in so much pain and for nothing to show up?' And my doctor said, 'Right, for neuropathic pain we can do *this*.' And that was five or six weeks ago and that's the first time somebody's ever called it neuropathic pain. I've always called it Parkinson's pain.

**Evans:** Well, groundbreaking studies funded by the charity Parkinson's UK are throwing new light on the relationship between Parkinson's pain and neuropathic pain. Dr Kirsty Bannister is a doctor of neuroscience at King's College, London. Her area of research and expertise is in the understanding of why pain becomes chronic or persistent. A study she's just embarking on comes under the catchy name of 'Investigating the Somatosensory Phenotype of People with Parkinson's Disease.'

**Bannister:** Your somatosensory phenotype is really... it's your sensory profile. If I place a feather on your hand, does that hurt, or not? If I was to bang your hand with, this isn't part of the test by the way, If I was to bang your hand with a certain kind of force, does that hurt or not? So, your sensory profile is how you, as an individual, respond to a non-painful, as well as a painful, stimulus. And what's really important to note there is that; you know, I'm very fortunate as a healthy individual who doesn't suffer from persistent pain. I experience pain differently according to my psychological status. If I'm tired, and if my children have been home and been fighting and I am to bang my elbow as I'm trying to get up the stairs to tell them to stop messing around, that's going to hurt me much more than in a situation when I'm out with my girlfriends and we're in a bar, and we're having some nice dinner and we've had some drinks and I bang my elbow and I don't even notice it. So, when you're thinking about an individual's sensory profile, it's not as simple as, 'You're sat in front of me. How do you perceive this non-painful sensation, or how do you perceive this painful stimulus?' It's much more complicated than that, and it's really important that we remember that the way we perceive pain is context-dependent and changes on a daily manner. It fluctuates.

So, my chief area of expertise is actually to understand activity in inhibitory pain-blocking nerve pathways. So healthy people don't have constant pain, because they have functional activity in these pain-blocking nerve pathways that travel from the brain to the spinal cord to depress the sensation of pain. What we've shown is that this pathway is dysfunctional in certain rodent models of chronic pain and in certain chronic pain patients. Therein a mechanism has been discovered as to why certain cohorts experience persistent pain, because if they don't have the functioning inhibitory pain-blocking nerve pathways then they are going to experience high levels of pain. So, if we bang our elbow, or if we stub our toe, or if we've had our Covid vaccine then the tissue aches, the toe aches or our elbow hurts. We rub it. After a while we shouldn't feel that pain anymore and that's precisely because of this functional activity in these inhibitory pain-blocking nerve pathways that we have. In an individual who has chronic pain the same pathways don't function properly, and so what this means is that their pain will persist, and they will experience the pain of a knocked elbow, or a Covid vaccination, or a stubbed toe much worse than someone who is healthy.

**Evans:** So do you mean with this inhibitory pain pathway, that when we have our vaccine or we stub our toe, it hurts once and then the brain says, 'Forget about it, it was fine, no problem,'?

**Bannister:** Yes absolutely, because we have to remember that the pain experience manifests not only from sensory discriminatory aspects, so, 'I've banged my toe, I know I've banged my toe,'



but also from effective motivational aspects. So, issues such as fear, hopelessness, or helplessness can escalate pain levels to an unbearable level. However, in the situation where an individual doesn't have a persistent pain state and they have a stub to the toe, because of the context of their effective motivational pain processing, linked with that sensory discriminative aspect, 'I've banged my toe,' [it] means that the brain can very quickly equilibrate, if you like, what those brain signals are. And we have this wonderful functional activity in our inhibitory pain-blocking pathways that immediately dampens down all activity in pain processing circuitry that could otherwise escalate the pain. So, we're very lucky if we're healthy and our body can very quickly dampen a pain signal. And exactly that, it's the brain saying to itself, 'We don't need to worry about this pain, it's not going to cause us any serious long-term damage. Let's inhibit that so we can get on with making our coffee or playing outside with our children.' So, if we consider the project that I'm doing with Parkinson's UK right now, let me outline to you the background to it to understand how we might translate what we see in the laboratory to what we might see in the clinic with patients.

Because I use animals to research the reasons why pain might be persistent in varied diseased states, I was able to show previously nerve-blocking inhibitory pathways that travel from the brain to the spinal cord to reduce pain. I was able to show previously that these inhibitory pathways don't work properly in a rodent model of Parkinson's disease. So, we can use a specific lesion in an area of the brain that induces a Parkinson's-like state in an animal. Again of course we can't say that it's *truly* representative, it's as representative as we can get in the laboratory. When I made these observations, I approached Professor Ray Chaudhuri, who's the director of the King's Parkinson's Centre clinic, and proposed to him that we should do a world first bridging study so that the observations made in these Parkinson's animals could be applied to consenting people with Parkinson's who suffer from persistent pain. Because ultimately what we would want to develop is successful treatment strategies for those individuals who have persistent pain, while uncovering an underlying cause of the disease. So, an observation is made in an animal and then we extrapolate that to the clinic by using experimental paradigms that are identical enough, that means we know we're measuring the same pathways.

**Evans:** Let me go back a little bit. It was thought, not so very many years ago, that pain for Parkinson's people, was purely down to the aching and the tremors and all the effects from the disease itself. This is fairly new.

**Bannister:** Absolutely. What we definitely know is that constant pain is a poorly understood and a major unmet need in people with Parkinson's disease. Our research will provide new information

about the mechanisms by which these people with Parkinson's experience clinical pain, and that's true for cohorts without pain and for cohorts with pain. The mechanism, importantly, might link to the cause of disease progression. Everyone is unique, everyone is an individual. Not one of us experiences pain in the same manner and this is certainly going to be true for people with Parkinson's disease. So, we're first of all going to understand how these individuals' responses to pain tests differ in terms of, 'You're a person with Parkinson's disease, you don't have constant pain. You're a person with Parkinson's disease, you *do* have constant pain.' Then we're going to have all of the healthy age and sex match controls, and slowly but surely, we're going to build a foundation base of knowledge regarding what these experimental pain phenotypes are in these individuals. This is a step towards personalised pain management. So right now, we are busy preparing pamphlets that will give all of the information an individual would need if they wanted to consent to be part of the study. So far there's been no recruitment. We hope to begin recruitment in April and the grant will start fully in May.

**Evans:** Can people with Parkinson's volunteer themselves for the study? How will they find out about it?

**Bannister:** Absolutely. So, there's a brilliant team at Parkinson's UK who contacted me not long after I was awarded the grant and their precise role is to make sure that the Parkinson's community is aware of this study, that they can consent to be involved if they so wish. People with Parkinson's disease are at the absolute core of what it is we're trying to do, so sharing our findings with them is going to be of great importance. So even if an individual wanted to take part in the study and couldn't, they *will* learn the outcome of the study because we really believe that this is going to be a project that is going to make a real difference.

**Evans:** That's Dr Kirsty Bannister of King's College, London. Do go to the Parkinson's UK website at [parkinsons.org.uk](http://parkinsons.org.uk) to find out more about this and other studies and just about everything you need to know about living with, or with someone, who has Parkinson's disease. And go to the 'About Us' section for Scotland, Wales and Northern Ireland specific support. And on the subject of support, people have told me, and I know this to be true from my own family experience, that if you want to know anything about managing day-to-day living with Parkinson's, the Parkinson's clinical nurse specialists like Carol Vennard at the Queen Elizabeth University Hospital in Glasgow are always there to help you.

**Vennard:** We as nurses have more time with the patients. We can sit with them and talk through whatever they want as many times as they want without the pressure of having a-million-and-one

other patients with other disease processes going on. All I live, sleep, eat and breathe when I'm at work is Parkinson's disease. And there's not really many doctors who have got that luxury. So, we are able to see the patients back a bit more often, we're able to phone them back if they have problems. We're able to go and see them inside their own home or within their care home. They're able to bring a relative with them etc. I think from the patient's point of view, that's what they like, they like the accessibility of a nurse and it's not always easy for a medic to have that accessibility. I think as well that they get to trust you. They know that if you phone them, and that on my answering machine, if people get my answering machine it says I'll get back to them within 24 hours. They know that there's a safety net there for them.

**Evans:** Carol Vennard. I'll just remind you that while we in Pain Concern believe information and opinions on ***Airing Pain*** are accurate and sound and based on the best judgments available, you should always consult your health professionals on any matter relating to your health and well-being. They are the only people who know you and your circumstances and therefore the appropriate action to take on your behalf. Do check out Pain Concern's brand new, shining website at [painconcern.org.uk](http://painconcern.org.uk) where you can download all editions of ***Airing Pain*** and find a wealth of support and information material about living with, and managing, chronic pain. Last words of advice from Janet Kerr.

**Kerr:** Every morning I do a basic yoga routine, just mobilisation to lubricate my joints. Now, quite a lot of that is me going, 'Ow, ow, ow!' [laughs]. But I do it because I know otherwise I would hardly get out of bed because I'd just be that stiff and sore. But although it's sore to do, I know it's beneficial. Because I could be sitting on the couch doing absolutely nothing, in pain. If I go out on my bike, I'm in pain but I'm doing something. I'm not vegetating on the couch doing nothing. That was one thing the pain clinic actually had said, that when people are told they have a movement disorder, or they have a bulging disc in their back, or they have trapped nerves, they sometimes go into protective mode where they think, 'Oh I've got a sore back, I can't bend over and pick my slippers up off the ground. I can't reach up to get that,' when they were saying that the complete opposite should happen. Because your body needs movement. It literally seizes up if you've not moved. So, I've always kept that with me, that despite the pain, I have to move. Now, I do tend to choose things on wheels, but I don't go out walking because I think in my head, I've been a bit too self-conscious which is absolute nonsense. Because in my head people are looking at me going, 'Oh gosh, she's needing a walking aid,' when they're possibly not even looking anywhere near me. And my friend said to me, 'Janet, if you've got walking poles, for all people know you are recovering from a sprained ankle or an injury.' You know, it doesn't say, 'I've got Parkinson's.'

So, there's still a bit of acceptance with this condition. You think you've met acceptance and then a little bit of turmoil happens. I mean, I'm five years down the line and I'm still coming to terms with... a journey. I'm trying to think of the best way to word it. It is a journey and it's a rollercoaster. And I just hit a scary moment again with the walking. Because at the end of the day, Paul, I do a lot of exercise in pain and then I'm thinking, 'Well, why do I not go walking?' I'm in pain. And it's to do with the whole-, that I need an aid. So that's my *stupid* pride. But it's just me learning to come to terms with it, that's what I need to do.

## Contributors

- Carol Vennard, Clinical Nurse Specialist in Parkinson's Disease at the Queen Elizabeth University Hospital, Glasgow.
- Janet Kerr, ex-primary school teacher and Parkinson's disease patient
- Kirsty Bannister, Senior Lecturer and Principal Investigator at the Institute of Psychiatry, Psychology & Neuroscience, Kings College London.

## More Information

- Parkinson's UK: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)
- [Airing Pain 115: Neuropathic Pain 1](#)
- [Airing Pain 116: Neuropathic Pain 2](#)
- [Pain Concern's leaflet on Neuropathic Pain](#)
- [Institute of Neurological Sciences, Neurology in NHS Greater Glasgow and Clyde](#)
- [Senior Lecturer and Principal Investigator Kirsty Bannister's key publications](#)
- Finding a Parkinson's Nurse – <https://www.parkinsons.org.uk/information-and-support/parkinsons-nurses>
- [The British Pain Society](#)
- [IASP Global Year Against Neuropathic Pain 2014-15](#)
- [Stress Management Society, Stress Awareness Month April 2021](#)

*Transcription by Cara Manning*