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Fiona & Andy: Living with Parkinson's



Fiona has early-onset Parkinson's¹. Fiona and Andy shared their story about their experiences of living with this and how it has impacted on their lives.

Finding out and initial impact

Whilst most people are older (over 60) when they develop Parkinson's², Fiona was only 47 years old when she first became aware that something wasn't right. This was 8 years ago in January 2012.

The first sign that things weren't right for Fiona was when a work colleague noticed that her arm was hanging loosely by her side as she walked. As this had been something that had happened gradually, she hadn't noticed this change. Fiona had experienced tremors, but at the time had put this down to stress - through a stressful job at the time. Like most of us, Fiona and Andy 'googled' Fiona's symptoms and "*frightened themselves silly*" about what the problem might be.

Whilst they had first noticed things might be amiss as early as January 2012, it took until November that year before Fiona felt she needed to see a GP about this. Fiona recounted that the GP must have had their suspicions about the likely diagnosis, recommending her to have further tests "*to rule out the possibility of Parkinson's*". Up to that point, neither Fiona nor Andy had even contemplated that it might be Parkinson's but following the appointment with the GP they again 'googled' her symptoms against those of Parkinson's and they were very much a match. It took a further four months to get to see a Neurologist, by which time they knew that Parkinson's would be the diagnosis. No tests can conclusively show if someone has Parkinson's, but the consultant also confirmed that - based her on symptoms - that indeed this was what she had.

There are two main types of Parkinson's - Bradykinesia³ and Dyskinesia⁴. Fiona has

Bradykinesia which is characterised by movements made with lower acceleration and amplitude and with longer intervals between movements (this is the opposite to Dyskinesia which is characterised movements of normal amplitude and acceleration but with shorter periods without movement).

Impact on work, employment, and benefits

Fiona was employed as a police community support officer when she became aware that she had Parkinson's. Following confirmation from her consultant she had advised her employers about her diagnosis. Over the next three years very little changed with her work schedule as they didn't really understand her needs; although she says - in hindsight - this was probably the best thing. With a change of personnel there was a greater focus on looking at her needs. She was given access to an external Access to Work team which she said were "utterly hopeless" in helping her. Rather than looking at her specific needs they just provided a range of services and said, "pick what you want". None of the services would have been any benefit to her but would have been an expense to the workplace, so she declined the offer of the support. Over the following year, Fiona had a very difficult time with her employer which eventually resulted in her being forced into offering her resignation. This was very upsetting as she felt she still had a lot to offer within her role after 18 years of service - she did not feel her health condition would have hindered this, particularly if minor adaptations could have been made at this point. Fiona applied for redeployment, but this was not granted.

Following the loss of work role, Fiona and Andy then shared the experiences of trying to secure benefit support through Universal Credit and the Personal Independence Payment. They explained that that the last three years has been a tortuous process with no understanding of Fiona's health circumstances. Eventually Andy had to give up work, as any employment earnings he

made were deducted from their Universal Credit payments. There was no support around mortgage payments, and they have struggled considerably to make ends meet: "One of the problems with Universal Credit is that you can't speak to anyone - it's all done online". The phone lines are there but you are encouraged strongly not to phone. Their experience of Personal Independence Payments (PIP) was even worse. Fiona and Andy recounted their interview at the White Cross offices: "we were being watched as we entered the building, they noted everything we did - for example 'did we use the stairs'. This was all then included as part of our assessment. They are not health professionals, but they are making decisions that vastly affect your life". Fiona has been in receipt of PIP for some years, but to go onto a different increment as the disease progressed, they were turned down. They subsequently appealed and despite an 18 month wait they eventually got the decision overturned at a tribunal. "We've learnt the hard way - we thought there would be help for people in our position - we assumed there was, but there wasn't".

Fiona and Andy re-iterated the importance of people in similar positions staying determined to get what they might be entitled to: "So many people are too frightened to apply for benefits, because of the process involved and how they make you feel". The added value of securing these benefits also opens the door to other important entitlements including the NOW Travel Card⁵, Blue Badge parking⁶ and cinema tickets for carers through the CEA programme⁷ (a national card scheme operated by the UK Cinema Association).

Despite Fiona and Andy's determination and success in getting their entitlements it did come at a cost. Fiona recounted her experience of developing Bell's Palsy⁸ brought on by the stress of their dealings around universal credit and PIP. Fortunately, Fiona has subsequently made a good recovery, but she said, "this may not be the case for all".



Getting help

the Home Improvement Agency grant⁹ managed through the local council was a very supportive process: *“They replaced our boiler, as it was on its last legs, and being cold was very detrimental to Fiona’s condition and completely adapted our bathroom into a wet- room to assist with Fiona being able to maintain hygiene standards”.*

“The Parkinson’s Nurse, Vicky, is also fantastic - providing us with a bridge between you and the doctor or consultant”. As a carer, Andy benefited by being able to get in contact with the nurse to understand more about the medication that Fiona had been taking and how it might affect her. For Fiona the speech and language therapist has also been essential - *“Tina has been wonderful”.* Finally, they both commented that they had been very

lucky to have such a supportive GP over the last 8 years.

Looking forward:

Getting Parkinson’s is not regarded as something you get when you are younger - most people get it at an older age: *“There are over 40 symptoms associated with Parkinson’s but often hidden amongst the physical symptom are the challenges of frustration, anxiety and depression which are often overlooked. Parkinson’s is like an iceberg - most people only see the more obvious symptoms, there is so much more below the surface that you have to deal with”.*

Fiona and Andy talked about how they had to go through the stages of acceptance, learning to adapt and moving forward: *“We have had to give up all the things we used to enjoy ... motorcycling, fell-walking - these have all had to go. We have had to adapt - otherwise we would have just given up. Now we have very different activities - we both love photography and visit the zoo to take photos of the animals there. We have eventually been able to take advantage of the CEA cinema scheme (free ticket for a carer) and Fiona can access free off peak bus travel through meeting the criteria of the NOW Travel Card.”* In terms of other ways of maintaining her wellbeing, Fiona mentioned the importance of restorative yoga which she does for 10 minutes every night before going to sleep: *“this helps with stiffness which can interrupt your sleep”.* Fiona also recommends meditation and mindfulness in helping with her condition.

Overall, they feel that they have grown through their experiences: *“We have been dealt lemons but made lemonade!”*

Giving something back

Both Fiona and Andy wanted to help others going through similar experiences and have played an active role at local level attending the Bay Information Hub¹⁰ - aimed at supporting people with neurological conditions and their families.

They have also recently set up a free 6 week course to support people newly diagnosed with neurological conditions and have received kind support from Defying Dementia (University of Lancaster) and the Dukes Theatre in Lancaster to run and host the programme. The first course has been really well received with more than twenty people attending the first few weeks. The course was aimed at helping both those with new and existing conditions and to support their carers. Andy hopes to run a Carers Cafe as they saw a huge gap in the support area for Carers. They also have a 'fresher's group' where people can meet monthly to share their concerns and offer support to one another. In addition, Fiona works with Parkinson's UK¹¹ as a volunteer educator to raise awareness for this disabling, misunderstood disease.

Further post-COVID pandemic update

"There have definitely been some good and bad experiences around the pandemic for us.

In terms of the pros:

- Our cats loved having us around all the time.
- We sorted lots of gardening and DIY projects.
- We spent time baking and cooking and ate healthier.
- We followed all the rules only leaving the house for shopping down the road and the allotted exercise allowed.
- Universal Credit increased the amount we get by £100 which really helped.
- We discovered a lot of Carnforth on our daily walks and we found people very friendly greeting everyone we passed with smile.
- We watched plenty of movies and TV in the evenings.
- We enjoyed a break from the usual routine.
- We have been doing Zoom Meetings to try and keep those from the freshers' group connected.

In terms of the cons:

- Although we started watching the news daily, we quickly decided to avoid it.
- We had problems when going shopping with local shops refusing entry for Andy as my carer, because he didn't have a Carers Card. There were no toilets open anywhere even in the supermarkets. All disabled accessibility and parking was removed for queuing and no seats to rest. As a lady facilities inspector we met today at a station said 'It's 10 years of disabled right down the drain'
- Three weeks into lockdown Fiona was texted by the government to inform her she had to shield (way too late). Two months after start of lockdown we received a call from Lancaster City Council asking if Fiona was alright and whether she needed help getting food or her prescriptions. It was a good job we didn't!"

For more information please click on the links below

- [1Early onset Parkinson's](#)
- [2Parkinson's Disease](#)
- [3Bradykinesia](#)
- [4Dyskinesia](#)
- [5The NOW Travel card](#)
- [6How to apply for a Blue Badge \(disabled parking\)](#)
- [7The CEA cinema card scheme](#)
- [8Bell's Palsy](#)
- [9Applying for a Home Improvement Grant](#)
- [10The Bay Information Hub](#)
- [11Parkinson's UK](#)