

PARKINSON'S 200 PLUS

Shaping the clinical, research and care agenda for people with Parkinson's

This is a transcript of the panel "Living Better with Parkinson's" that took place as part of the Parkinson's 200 Plus conference in Oxford on 18th September 2017.

Panel members

The session was moderated by **Jo Bromley**, a Parkinson's specialist nurse based in Oxfordshire. We are very grateful to our panelists for their contributions:



John Foster is a children's poet. He has written and spoken extensively about Parkinson's and the Deep Brain Stimulation treatment he received for it.

Alex Reed is President and founder of the European Parkinson Therapy Centre in northern Italy.

Emma Lawton was diagnosed with Parkinson's aged 29. She is a designer, blogger, and author of "Dropping the P Bomb".

Further information

You can find more information about the conference content, including video screencasts of most of the presentations, at <http://www.parkinsons200plus.org/timetable.htm>

During the panel, speakers mentioned various resources of interest. Here are links to some of them:

- European Parkinson Therapy Centre: www.terapiaparkinson.it/en
- Emma Lawton's tremor-controlling "watch": <https://www.youtube.com/watch?v=R6rAlFYDffQ>
- Paul Mayhew Archer's TV documentary on BBC iPlayer: <http://bit.do/parkinsons-funny-side>
- First Steps programme for those newly diagnosed with Parkinson's: <http://bit.do/firststeps>

Jo Bromley: I thought I'd start by asking you what the most important aspect of living with Parkinson's is: the physical or the psychological? John, would you like to start?

John Foster: I think the physical was, for me – because I developed a tremor and it got very severe. I was diagnosed in 2005 and by 2010 my tremor had become so severe that I was on the brink of giving up my life as a children's poet when I visited schools. I was told very badly initially – as many of you perhaps were – by the person who diagnosed me, who said I should think about retirement, and that was the last thing I wanted to hear, because I planned to spend my retirement going round schools and performing my poems. I continued to do so between 2005 and 2010, but the tremor had become by that point so severe that I was on the point of giving up. Then I was offered DBS [deep brain stimulation] and the result of the operation is that my right hand is now totally controlled, and it gave me back my life. So I think that from my point of view it was the physical – though for the first two years I had great difficulty in accepting.

Alex Reed: Yes, I'd go along with that. I think for me it was the psychological aspect. Forty-six years old, you've kind of got your life planned out, and then Parkinson's comes along and scuppers everything. It came home to me when I read an article, soon after I was diagnosed. It said "since I've got Parkinson's I've become a better husband, a better father, and a better man." I honestly thought the man must be psychotic, because it didn't make sense until I started looking into it. What we heard earlier is very true. Parkinson's is a remarkable opportunity, in some ways, of looking at your life and reassessing it. The psychological aspects have been difficult, but also the most exciting area in which I've come to terms with Parkinson's.

Emma Lawton: For me the physical stuff is the hardest thing, but actually the thing which I have to get in check the most is the mental side of things. So I feel that the physical I have no control over, but the emotional things I have some control over.

JF: I forgot to add that I think the psychological was as important as the physical in actual fact, because I had depression before I was diagnosed and for two years I found great difficulty in coming to terms with the fact that I had got Parkinson's. And it was only when I began to accept it after a couple of years that things began to get better.

JB: Thank you. I think, as Parkinson's nurses, we do spend quite a majority of our appointments with our patients talking about the non-motor symptoms – these are the symptoms that affect things like sleep and appetite – rather than just their medication and their movement. So that comes across quite clearly in our assessment. I've just one other question to ask the panel: What's the most important thing you've changed, to live better with Parkinson's?

AR: I think that the very fact that we could make that decision to make a change was one of the most revealing factors. Parkinson's doesn't destroy; it will limit. The decision to make the change, I made – not because Parkinson's made me. The biggest decision was career. I was a business consultant before doing any of what I do now, and that was a very stressful job. Today I would say I see more of my family – I'm about to become a grandfather. I see more of what's around me. I spend a lot of time volunteering in the [European Parkinson Therapy] Centre in Italy. It's a remarkable revelation.

EL: I refused to change anything, and that's why I'm in this mess, so learn from me! Look after yourself, don't do what I did. Sleep properly, eat properly, exercise. This is what happens if you don't! I'm on the wrong panel, I think... Definitely, I think my mentality of what I want to do has changed. I think I see it as if I have X years in which things will be easy to do, so I want to live faster in that time. I think that's probably a bad way of looking at it, but that's my way of looking at it and it's true what you just said – having that

choice and deciding that you have some control over it is something you never feel that you have in life before you have Parkinson's, and then you realise that you do have control over something.

JF: The DBS gave me back my life – it really did.

JB: If you haven't had the opportunity to read any of John's books I'd really recommend it. And I think that shows the inspiration that you carried on, still visiting schools, still doing the things that you're passionate about.

JF: Yes!

JB: I'd like to hand over to the audience now.

Audience member 1: I help with the First Steps programme [for those newly diagnosed with Parkinson's] and I just wanted to say thank you to Sally for highlighting it earlier. I'm delighted to be a part of it. Some people have said kind things about me, but it's only because of people like Alex and Emma who are a total inspiration that makes you feel like you can do it as well. Paul [Mayhew Archer] did a documentary on TV that showed to a whole load of other people with Parkinson's that you can do whatever you want to do and make the best of it. What I wanted to ask Emma was about her "watch", the 2-minute video on Facebook that went viral – I was lucky enough to meet you at Christmas and talk with you about it – what's happened with the Watch, and what's going to happen with it?

EL: Firstly, it's in my handbag – oooh, I have it with me, that's quite fun! Secondly I'm working with Microsoft at the moment; we're testing it with users at University College Hospital in London, testing it with them. The results take forever to come back – it's the slowest thing ever. If you're not patient you shouldn't be doing something like this, and I'm not patient... We're waiting to see what the results are, whether it works just for me, whether it works for other people. If it does work for other people then we go back to Microsoft and we say "this is something we've got to create for other people". The clocks are ticking, things are whirring, but it's really really slow, sadly. So I can't come in and say "YES, we're launching it today" – that would be amazing – but I'm really hoping it's something we can get out there, with other things in it that would make it useful for people with Parkinson's from day to day.

Audience member 2: I'd find it interesting to know the different times that people have had Parkinson's – how many years [asks for show of hands, most audience members said under 20 years]

Audience member 3: Microsoft? Watch? I don't know what it is.

EL: I can tell you about it. I was part of a TV documentary at the end of last year [2016] on BBC2 which was around how tech, devices, science and clever engineering can make people's lives better and easier. I was lucky enough to be selected for that programme. The challenge I set them was that I couldn't write or draw because of my tremor, and they actually created a watch that vibrates into my wrist (it isn't actually a watch, it doesn't tell the time, it's more a wrist strap). It allows me to write and draw almost as if I don't have a tremor. We're not 100% sure how it works or why it works, that's a mystery, so we're trying to rationalize it now. It was done with the Head of Innovation at Microsoft in Cambridge and we've had support from the CEO of Microsoft as well. It's a really exciting project. If you haven't had a look at the clip, search for "Emma Watch" on YouTube.

Audience member 4: What is your experience of loss of memory with Parkinson's? My memory is terrible, and it's a problem. I can be asked for something, and if I don't do it instantly.... gone.

AR: The aspect of memory with Parkinson's is fairly well documented, falls into the category of "mild cognitive impairment", which is not a dementia but a cognitive limitation that a lot of people with Parkinson's have. It's connected with – normally – the short-term memory. I can't remember people's faces even though I met them this morning; I can't remember people's names; I can't remember where I put my car keys. I had a wallet with €1000, put it down somewhere and I can't find it, so... if anyone finds [laughter]... It also affects multi-tasking, doing more than one thing at one time. So I think it's about 25% of people with Parkinson's who have mild cognitive impairment problems, but normally the memory issue is to do with shorter term, not longer term. I don't know if that's the same for you.

JF: I don't know if it's just having "senior moments", because I'm 76.

Audience member 5: Could I ask you where you get your ideas for your poems?

JF: I get my ideas from what people say to me, what I observe, and my imagination. I've been writing poems for about 30 years now, and I still manage to get the ideas. I got one yesterday when I took the cat to the vet and the lady next to us had a dog that had a small pink ribbon on it, and she said that someone had come up to her in the street and accused her of gender-stereotyping her dog! [laughter]

JB: A final question: How would you explain that you have Parkinson's to someone that didn't know you?

JF: A lot of people don't recognise that I've got Parkinson's now, but I've found it very difficult when I initially had the tremor. Kids are wonderful; they accept you; but adults aren't so accepting, and I found that I was avoiding social situations in the first two years because the tremor was so obvious and I wondered if people thought I was an alcoholic. I had to explain to people, at parties and so forth: look, I've got a slight tremor, I've got Parkinson's. But many people when they are first diagnosed find that very difficult.

AR: I think the whole aspect of telling people you have Parkinson's is a very revealing factor. I remember being in a supermarket queue, and I was off my medication and a little bit slow, shall we say. The woman behind me made some fairly rude noises, not very complimentary. Now, most people with Parkinson's will turn around and say "sorry", probably have an increase in their tremor or symptoms, and will go home and think twice before going out again – and that is very, very sad and very, very wrong. What I actually did – a true story! – was to turn to the lady behind me and said "My problem is Parkinson's. Could I know what your problem is?" [laughter]

EL: Similarly I found it was really difficult when I was first diagnosed to tell people, but I've got to the point now where it's like a sport. I feel a bit mean doing it, but I drop it into conversation and then scamper off. I call it "Dropping the P Bomb" and that's what my book is called – I led into that quite nicely, didn't I! It's the whole idea that you destroy someone's day by dropping the P Bomb on them. You have to remember to do it with kindness sometimes, because it might be the tenth time you've said it that day, but it's the first time they're hearing it and it can really upset people.

JB: And John, just coming back to you because you're working a lot with children: Do you ever talk to them about your Parkinson's?

JF: Sometimes. One of the most encouraging experiences that I had was when I still had the tremor, and I went into a school and a person came up to me – one of the teachers – and said "this boy has got a shake in both his arms, and to have seen you standing up there and performing was really beneficial to him because he could see that although you had a tremor you could still do it".

AR: Can I just add one thing? At the Centre we had a gentleman who was very embarrassed to have a tremor. He was about 80 years old and he told us not to tell anyone that he was there for Parkinson's therapy; he was "just there on holiday". He was practising a speech that he was going to give his daughter, because we persuaded him that he should tell her. His daughter came on the last day and he said to her "I've got Parkinson's." The daughter's reaction was: "Papa, we knew this for two years! We were just waiting for you to tell us." We then went out to dinner, and I was sitting next to him, and the granddaughter (aged about 7 or 8) was sitting opposite. He started having a bit of tremor, and he does what all good people do with a bit of tremor: he sat on his hand. I watched the little girl. She got up and walked around and took out his hand and put it on the table, and said "Grandfather, shaking doesn't bother me; why do you hide it?" I think that expresses everything. Why do we hide it? [applause]

JB: Thank you all very much. [applause]