

First Steps

Ian Sargent

I was diagnosed with Parkinson's in April 2015. Like many I was shocked and very uncertain about what the future held for me. As luck would have it, my Parkinson's Nurse mentioned a new two day course for newly diagnosed people and their supporters being piloted in Oxford which she thought would help me. It was called *First Steps*.

My wife Ruth and I decided to give it a try and we were invited to the very first session held at the end of July 2015. We went with some trepidation, not knowing what to expect but were soon put at ease by the friendly welcome we received. The course (which was devised by Oxford's Sally Bromley and Peter Harling) is held at Witney Lakes Resort, rather than a hospital, because the focus is not on medical issues but on our wellbeing and the benefits of an active lifestyle. The first morning covers a wide range of topics including a basic introduction to Parkinson's, the importance of managing one's life and taking control. It also encompasses Parkinson's research, the effects on daily life and the multidisciplinary team of health care professionals who are there to help us. The afternoon begins with a key message about the importance of exercise followed by our Local Advisor, Delia Wells, describing the support options provided by PUK. The final session discusses six key ways in which we can take control of our lives; namely thinking positively, getting informed, staying connected, doing things, making plans and being involved. Whereas the first day is about getting across information, the second (normally six weeks later) is a

more relaxed affair with the opportunity for group discussions and sharing of experiences. The highlight of the day is a taster PD Warrior exercise session which is always very popular. The message from both days is clear – there is life after diagnosis and the quality of that life depends on you!

A key feature of the course is that it is presented by people with Parkinson's who have empathy for those attending. This allows them to share anecdotes about their own experiences and give tips and hints on how to get round problems in a way that people who don't have Parkinson's could not. My course was led by Jason Batup and Richard Tyner, two very different characters united by their desire to help people with Parkinson's and their passion for golf.

At the end of the course we were asked to identify the things we intended to do as a result of attending the course. We made some immediate decisions; I took ill health retirement from work (Ruth decided to retire too), I joined the PD Warrior exercise programme, I joined Parkinson's UK and the Oxford Branch and we booked the African Safari Holiday we had always promised ourselves. A pretty good



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outcome for two days that changed my life!

However that was not the end of it. In September 2016 Jason asked me if I would like to help host the course. I was a bit uncertain how I would fit in (especially as I don't play golf!), but after a couple of sessions watching the masters at work I was up and running and I have been helping ever since. The whole experience has been immensely rewarding and we have received great feedback. It is particularly satisfying to see how people become more relaxed and confident over

the two days and their attitudes completely change. We have already seen many new friendships develop as a result of the course. To date there have been around two hundred people who have benefited from First Steps in Oxford and the great news is that PUK have recognised its importance and agreed to roll it out across the UK starting in Southampton, Plymouth and Aberdeen this year. So it's thanks to Sally and Peter for a great idea and Jason and Richard for turning it into a reality.

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Martin Cowell

My diagnosis was a year ago, in March 2017, after I was referred to my consultant having sought some remedy for my gentle tremor. I echo what Ian says about my reaction but I was briskly re-assured that "you're not ill" and that I should continue to lead my life as fully as possible. The consultant referenced First Steps and I made immediate contact with Kathryn at Parkinson's UK to register for the programme. I was also very fortunate to chat to a great guy called Darren (Billy) Taylor, whom I had previously met via the charity Rowathon that I was helping to organise

(<https://www.rowathonoxford.co.uk/>).

Billy and his team, who have already rowed the Pacific from California to Hawaii, are now turning their attention to the Indian Ocean (they will set out in June:

<http://www.rowtheindianocean.com/>),

this time raising funds to help progress research into Early Onset Parkinson's, with which one of their four-man team has been diagnosed. Billy encouraged me to contact and meet a number of people, including Peter Harling

and not least 'our Sally', which of course was stimulating and encouraging.

So in July my wife Anne and I went to Witney for Day 1 of First Steps. I echo everything Ian says about the relaxed atmosphere and particularly the opportunities to discuss and share experiences with like-minded people. Jason was again one of the two presenters and it was helpful to hear from him as someone diagnosed with 'early onset' and who had managed to adapt his life positively. As Ian was the other presenter I must make sure to give him full credit for the tone of the two days, and especially how he drew everyone into the discussion. We were a disparate group with a wide range of experience and so there was a lot to share and to hear.



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The main things I took away were the need to maximise one's potential and particularly to do everything you felt able to do. What was stressed throughout and

especially at Day 2 was the need for a good exercise regime: it took me a while to get into this but, with the excellent encouragement of Jenny my Parkinson's physio I now have a daily (well, almost) 15-20 minutes of workouts to do.

I have tried to sign up to the PD Warrior classes at Cassington but at present am on the waiting list – Jenny tells me she is working on trying to get further classes set up. Meanwhile, fingers crossed, my condition has not worsened and I have yet to begin medication, and I have a full schedule of activities to keep me busy. Ian mentions the friendships he has seen forming, and in my case that is with Nick from Henley with whom I have arranged to go to EuPaTh in the

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Italian Lakes in early May (we are tacking on a couple of days prior to take a look around nearby Lake Iseo).

Prior to that I am heading for to the (English) Lake District for a few days of walking with another travel pal, Tony. No sooner am I back from Italy than Anne and I and a friend are off to the Azores for a week. I will be walking in Pembrokeshire with another group of regular pals in early July and then am going to Newfoundland with Tony (see above). In early September

I will be narrow-boating with my walking mates, then in late September Anne and I are going to drive the Great River Road from Minneapolis to Nashville. Well done to First Steps for setting me out on this busy path!