

The Edinburgh Parkinson's Lecture 2013

'Non-motor symptoms of Parkinson's: Important yet often neglected. Why?'

This will not be an unbiased account of this lecture. I confess here and now to being a major fan of this year's speaker, Professor Ray Chaudhuri. When I first heard him speak about non-motor symptoms, at the Parkinson's World Congress in Glasgow, I wanted to hop on the stage and shout 'Yes! He gets it'. At last someone was describing the illness I was living with as a carer. And I still think he 'gets it' and can begin to talk with solid evidence behind him.

So what did he say? He talked of non-motor symptoms (NMS for short) being the marginalised poor relations in Parkinson's. Yet they have a major impact on the quality of life of Parkinson's sufferers and may turn out to be useful early indicators of the disease. (Useful, that is when people like Tilo have found a prevention.) Professor Chaudhuri told us 99% of people with Parkinson's have NMS *and* have an average of 5 of them. 5! So they may be the poor relations but there are a lot of them. What are they?

There are the physical ones

- Fatigue
- Pain
- Day time sleepiness, violent dreams, insomnia
- Constipation
- Urinary frequency
- Sexual problems
- Loss of smell

Then the mental ones

- Apathy
- Depression
- Anxiety
- Memory loss
- Poor concentration
- Dementia

To have any 5 of the above is heavy going, never mind the motor symptoms of slowness and tremor. So why have NMS been so neglected? Even 200 years ago when the "shaking palsy" was first described the sleep disorder that goes with it was mentioned. Since then the medical profession have been blinkered, concentrating on the shaking and the palsy, thinking of it as a degeneration of the substantia nigra which controls movement. Studies in the UK and the US show that in 40% of

consultations between doctors and Parkinson's sufferers NMS don't get a mention. The doctors don't ask and the patients don't volunteer.

Professor Chaudhuri has been a persistent voice saying "recognise me so you can treat me." In his clinics a questionnaire such as the NMS Quest or MNSS is filled in by the patient (and carer) before a consultation. It does unearth more problems to be solved in a busy clinic, but a lot of them *are* solvable and the Professor takes the pragmatic approach of tackling the ones that impact the most on quality of life. But this is new. Until 2006 no one had devised a questionnaire to assess the whole picture. There was Hoehn and Yahr, but that was a scale of motor symptoms. And interestingly one study showed even early Parkinson's (Hoehn and Yahr 1) had an average of 8.9 NMS, not going up much (to 13) by the time the illness is very advanced. So these problems come early and persist. They also are more common in people who get the disease earlier in life.

We were shown diagrams of cross sections of brains. Shown where the problem with Parkinson's was always believed to be at the base of the brain (the aforementioned substantia nigra) and shown where it now is believed to start – in the part of the brain that controls smell, spreading to the bottom of the brain (brainstem, controlling sleep) and thinking part (cortex) and the limbic system (controlling emotions). Where it spreads to determines what sort of Parkinson's you have and Professor Chaudhuri suggests thinking of the illness in different sub groups. So your illness would be thought of as one that was mainly a problem with

- Cognition/thinking, or
- Depression/anxiety, or
- Pain, or
- Fatigue, or
- Autonomic (eg bowel problems)

I think this risks simplifying Parkinson's again too much. That many of you would fall into several groups. But I still think the Professor has been a hugely needed voice saying this is a hugely complicated illness. He's right that the drug companies need to wake up to the fact that more than just dopamine is needed to treat Parkinson's. Three other chemicals are already known to be involved (serotonin, noradrenaline and acetylcholine as well as dopamine).

So is he still my hero? Who made me feel I wasn't living alongside a confusing, baffling illness than bore no resemblance to the Parkinson's I'd be taught about in medical school? Yes! My husband had no tremor and no noticeable slowness and yet was disintegrating in all sorts of ways. Now we understand why. Thank you Professor Chaudhuri. Keep changing how we view and live with Parkinson's!