



‘Guides not, gods’

Most Parkinson’s experts agree that an early management of the disease is vital for a person’s quality of life. However, evidence suggests too many people with Parkinson’s are receiving an unacceptable level of care from disinterested doctors. **EPDA Plus** speaks to two prominent European neurologists who powerfully argue what services Parkinson’s diagnosticians should – and should not – be providing their patients

Leslie Findley

In the last issue of *EPDA Plus*, I expressed my concerns about the results from the first EPDA Move for Change survey [which can be downloaded at www.epda.eu.com/projects/move-for-change/move-for-change-part-i-final-report]. It confirmed that too many people with Parkinson's (PWP) across Europe are not necessarily being referred to doctors with a special interest in Parkinson's. Furthermore, it was apparent that many were not being given enough quality time to receive an accurate diagnosis. It is clearly not appreciated by many physicians/neurologists that both care and time in giving the diagnosis greatly influence the progress and future wellbeing of that person for the rest of their journey with their disease.

In short, I gave a brief history lesson about the research undertaken from the 1970s to the present – through the Oxtoby and Romford projects to the Global Parkinson's Disease Survey and finally the current Move for Change survey. I argued the case that we were going over old ground, and that many of the PWP's complaints are already understood and so much good evidence exists on what is needed for an appropriate service for people with parkinsonism. In this article I wish to verbalise my thoughts on what I believe to be a major part of this recurrent problem – the role of the diagnosticians themselves.

'FIND YOUR OWN WAY'

In recent months I have seen a number of doctors in the UK diagnose PWP's simply by giving diagnoses and medications, and in terms of explanation, merely stating that their family doctors will "be written to". For the PWP, this diagnostic process – one of the most important events in their lives to date – consisted of three minutes of the doctor's time and the hidden instruction that they were to "find their own way". I think we are all agreed that this is not the best model for looking after people with chronic complex disorders such as parkinsonism.

The doctors themselves – as diagnosticians – have to be made aware of their responsibilities. They are the critical



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advisers at the beginning of this process or 'journey'. They should set the tone, instil the confidence, reassure and be available in the future or when complications may arise. Unless they are willing to make this effort at the start then the only person who is going to suffer is the PWP. The blinkered neurologist who feels their role is complete once the diagnosis has been made is not going to be the professional friend a PWP requires.

I think we are all also agreed that the idea of the solo physician/neurologist sitting in their office, handing out diagnoses and sending PWP's out to fend for themselves is of limited value. Furthermore, directing a PWP to the internet, which has too much non-validated and silly information, may be confusing and/or frightening. The specialist doctor must help the PWP gain access to the multidisciplinary team of professionals who are best able to holistically pick up on the myriad of Parkinson's-related problems that can arise. In other words, the specialist doctor must understand their own personal strengths and weaknesses, and be humble enough to recognise and accept the skills of others to assist the PWP on their journey.

LET'S MODERNISE

Having expressed my criticisms of my peers, I have to admit there is a growing enlightenment among some neurologists, particularly the younger consultants – many of whom have been more broadly educated and have a greater appreciation of patients' diverse needs. However, surprising as it may seem, there still appears to be a large number of old-fashioned neurologists practising in Europe, and the Move for Change evidence backs up this assertion.

But rather than fit a square peg in a round hole, I think it would be better

that those doctors with a natural affinity towards being involved with providing holistic care go in that direction and identify themselves to patient groups.

Those other specialists, meanwhile, who prefer to live in their ivory towers and spend their time attending numerous meetings around the globe should focus on that activity. There has always been an assumption that if you are a successful academic in neurology then you are naturally a 'good doctor'. The truth is, however, that while many academics are very good doctors, others should avoid professional activities that involve patients – particularly PWP's.

It must be considered substandard practice if, during the diagnostic process, the PWP is not given the appropriate information – or the time to receive this information. I found much of the Move for Change evidence tantamount to clinical negligence, and this cannot be endorsed.

An accurate, accessible and early diagnosis – linked to proper multidisciplinary team management from the beginning of the process to the end – is the only way forward. As healthcare professionals, our objective must always be to provide the PWP with the best quality of life possible and the confidence that they are being properly managed – no matter what part of Europe they come from.

As a final thought, when I first undertook research into the importance of diagnosis and the early management of parkinsonism, I found it a learning process – but I did not initially realise I had anything to learn! I am sure the same is true for many other doctors: they may *feel* their education is complete but they must learn – and quickly – that every PWP is a potential teacher.

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Bastiaan Bloem



I recently gave a presentation to healthcare providers, patients and policymakers in Maastricht in the Netherlands. The presentation was entitled ‘From God to Guide’ and it called on doctors across Europe to embrace the concept of “participatory health for everyone”. My idea was simple. I wanted to tell my peers that I think it is time that doctors “descend from their ivory towers” and become a guide (or coach) in the lives of their patients.

The presentation began with me – representing the traditional doctor – rising to great heights (using a forklift and guided by singing angels and a beam of light) and talking to my newly diagnosed patient, Hans, from high up in my ‘tower’. Following a brief, disinterested discussion about Hans’s symptoms, I threw a prescription down to him where it fell feebly to the floor.

“Please, you have to take me seriously,” cried Hans. “This diagnosis is very bad news. It will change my life completely. I want good and reliable information. And I want to take part in the decision of whether to start treatments or not. Where can I find other patients like me? What can I do to make things better?” He paused, disconsolate. “This kind of medical care is not the reason you became a doctor is it?”

He walked away alone and pressed a big, red reset button. Immediately, the light went off, the angels stopped singing, and my forklift descended back to baseline level. I left the forklift, took my white coat off (in real life, I never wear a white coat!) and put my hand on Hans’s shoulder.

BRAVE NEW WORLD

That was the first part of the talk. What followed was a discussion in the new ‘world’ that Hans had now created, a world where there was “no hierarchy” between patient and doctor.

I began by playing him a film that showed the power patients have to compensate for their disease. A man with late-stage Parkinson’s and severe walking difficulties told me he could still ride a bicycle without difficulty. I was surprised by the claim and

took him outside to see for myself. I thought it would be impossible but was amazed to see him in total control of his Parkinson’s and his pedals. It was striking evidence that even though patients have severe difficulties, they often have remarkable abilities too.

I have since received hundreds of letters and emails from patients around the world who report similarly remarkable abilities to

compensate for their disease. And the most important part of it all is that they knew the truth all along. It is us – *the doctors* – who don’t know the truth, even though it stares at us in the face all the time.

I wanted the audience to witness a remarkable transition in just a few minutes, which saw a doctor who was once a ‘god’

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descend from his ivory tower to become both a teacher and an equal partner in the healthcare system. I wanted to exemplify a world where doctors and patients could work together on a mutual basis.

Make no mistake, though: this is not a world where patients are ruling the roost and bossing their doctors about – a fear that some of my more conservative colleagues hold. The truth is this isn’t what patients want. They want to be taken seriously. They want to take an active part in their own disease management process.

A CLIENT-CENTRED APPROACH

For those doctors still hesitating to make such a transition to participatory healthcare, then think about the following exciting possibilities.

Firstly, by starting to see patients as ‘clients’ we’ll begin to move the healthcare system a huge step forward. Patients can become huge sources of inspiration – just

like the patient in the bicycle video. I am surprised week in, week out by the power my patients display in overcoming all the difficulties they encounter every day of their lives. We, the doctors, are underutilising that power. Too many of us still see them as passive objects instead of active subjects who can contribute to their own health.

Engaging with your patients will also prove to be cost-effective. For example, doctors usually tell their patients to return to their clinic after a fixed period of, say, three months. But if things go wrong then that’s too late, while if things are going well then it’s too early. An interesting alternative approach was studied in a randomised clinical trial that focused on patients with inflammatory bowel disease.¹

One part of the study saw the traditional doctor call patients back in a few months’ time. In the other part, however, the patients were left to come back whenever they felt the time was right. And you know what happened? They came back less often. The number of no-shows went down and the patients always returned exactly on time because *they decided* when to come back.

These are just a few wonderful examples of how engaging patients is a simple solution to both improving the quality of care and reducing the costs. It is a simple choice. I chose my job because I am passionate about healthcare and I have compassion for my patients. For me, seeing a patient as a sparring partner in the health process is the only way forward. And working as a doctor becomes so much more pleasurable when patients are treated as active subjects.

I finished the presentation by sharing a secret ‘wish cookie’ with Hans (who is a real patient of mine). It said simply: “Participatory health for all of us.” I hope that wish comes true very soon. ■

Professor Bastiaan Bloem is a consultant neurologist at Radboud University Nijmegen Medical Centre, the Netherlands. His presentation, from which this article is based, can be viewed on YouTube by searching for “From God to Guide”. Bloem was elected the ‘national healthcare hero on patients centredness’ in his native Netherlands in October due largely to his innovative Parkinson’s-related work.

1. A Kennedy, E Nelson, D Reeves, G Richardson, C Roberts, A Robinson, A Rogers, M Sculpher and D Thompson. ‘A randomised controlled trial to assess the impact of a package comprising a patient-orientated, evidence-based self-help guidebook and patient-centred consultations on disease management and satisfaction in inflammatory bowel disease.’ *Health Technol. Assess.* 7 (28):iii, 1-iii113, 2003.