UK Parkinson's Excellence Network: time for a paradigm shift in Parkinson's care

David Burn* speaks to Daphne Boulicault, Commissioning Editor:

David is Clinical Director at Parkinson's UK, Director of Newcastle University's Institute of Neuroscience, Director of Newcastle Biomedicine's Clinical Ageing Research Unit and a senior National Institute for Health Research (NIHR) Investigator. He qualified from Oxford University and Newcastle-upon-Tyne Medical School in 1985. His MD was in the functional imaging of parkinsonism. He runs the Movement Disorders service in Newcastle-upon-Tyne which provides a large regional service. His research

interests include dementia associated with Parkinson's disease and progressive supranuclear palsy. He was a member of the Special Interest Committee Task Force of the International Movement Disorder Society for Diagnostic Criteria for Parkinsonian Disorders (2002–2003) and the Parkinson's disease Dementia Task Force (2004–2006). He was appointed NIHR-DeNDRoN Associate Director/National Lead for Parkinson's disease in July 2010. He was Clinical Reviews Editor for the Movement Disorders Journal from January 2007 before taking on an Associate Editorial role in January 2010. He is an Officer (Treasurer-Elect) of the International Parkinson and Movement Disorder Society, having previously served as Chair of the MDS Congress Scientific Programme Committee (2011–2012). He has published over 220 articles on movement disorders in peer reviewed journals.

Q What inspired you to work in the field of movement disorders, with a particular interest in dementia in Parkinsonism?

Well, in both cases, the question is not necessarily 'what' inspired me but 'who'. Having had some very positive experiences in general neurology, I made the move down to London from Newcastle and had the good fortune of meeting Professor David Brooks at the Hammersmith Hospital. He quickly became an invaluable supervisor and mentor to me throughout the process of completing my MD thesis. At the same time, David was setting up a movement disorders service in Ealing Hospital, a process in which I was able to participate. When dealing with a condition like Parkinson's, there are a myriad of opportunities for initiating and adjusting treatments, and I found this extremely satisfying as a clinician.

Upon moving back to Newcastle as a senior registrar, I began working with Professor Ian McKeith, an old age psychiatrist. Ian was a great influence on me in terms of involving me in research on dementia with Lewy bodies. Because of the similarities between this and Parkinson's dementia, it was a natural progression for me to move into research on dementia in Parkinson's.

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Q What would you describe as the biggest achievement of your career to date?

Having thought about this, I believe the words of ancient Greek statesman Pericles sum up my answer best: “What you leave behind is not what is engraved in stone monuments, but what is woven into the lives of others.” Rather than picking a paper or set of diagnostic criteria to which I contributed, I hope my greatest legacy will be my influence on other doctors and trainee doctors in building the capacity for research and services in Parkinson’s disease.

I think a prime example of this is our internationally recognized service within Newcastle-upon-Tyne Hospitals NHS Foundation Trust and Newcastle University. Given that we began from scratch here, it is really wonderful to know that my research team have all gone on to gain consultant positions in Newcastle and elsewhere. As someone who knows firsthand the value of mentorship within the medical profession, it is very rewarding to see past colleagues thriving and delivering quality service and research.

Q Have any colleagues, past or present, particularly influenced you & your career?

Of course David Brooks and Ian McKeith were big influences on my career, but there are definitely some other names I would be remiss in not mentioning.

Throughout my medical degree David Bates and Niall Cartlidge – though both retired now – were such wonderful clinical neurologists to train with, especially during the old days of ‘one night in two on call’. I can honestly say that I learned most of my trade as a neurologist from them. David Bates, in particular, was someone who motivated me to be more inquiring and research focused.

A current influential colleague of mine would be Matthew Stern, president of the International Parkinson and Movement Disorder Society. He has not only been an indispensable source of advice over the years, but a paradigm of leadership as well as reminding me never to forget the importance of a good work/life balance.

Q From your years in the clinic, how have you seen Parkinson’s care changed in the UK, both in diagnosis & day-to-day management?

While I would love to say there has been a frame shift in terms of drug treatments, this has not changed hugely. What has evolved is

our overall approach; we now focus on involving patients in the decision-making process and including other healthcare professionals (for example, physiotherapists and speech therapists) for a much more multidisciplinary approach.

I would have to agree with a previous Chief Executive of the then Parkinson’s Disease Society (now Parkinson’s UK), Mary Baker, in that there have been two major advances in the management of Parkinson’s disease over the last 50 years in the UK: levodopa and the Parkinson’s nurse specialist. The role of the Parkinson’s nurse specialist cannot be underestimated and they have had an enormously positive impact on the way that we tackle and manage people with Parkinson’s disease.

Q As the Clinical Director for Parkinson’s UK, you have recently announced the launch of the UK Parkinson’s Excellence Network, can you tell us a bit about the form this network will take?

The Excellence Network is effectively a ‘one-stop-shop’ for collaboration, evidence, education and resources with the distinct aim of empowering service improvement. The network has been founded with the Parkinson’s patient as the core driver, with the resources and infrastructure of Parkinson’s UK and the passion and commitment of healthcare providers across the UK forming a tripartite force.

Q What inspired the network’s inception?

I can take no credit for the conception of the Excellence Network; again, it was the voice of the Parkinson’s patient that was the catalyst here. Parkinson’s UK undertook a huge listening exercise to inform their 5-year strategy, which resulted in three strands: developing better treatments, empowering patients for self management and service improvement. As I have mentioned, the Excellence Network focuses largely on this third point.

People with Parkinson’s all want accessible and timely services that will not only meet but anticipate their needs. For this to happen, they and we in the healthcare industry, need these services to be integrated and multidisciplinary. I think in the past, however, there has been a tendency to be quite mechanistic and to treat people as a set of symptoms. This can disempower and dehumanize patients resulting in a less streamlined and effective healthcare service.

Q What are some of main objectives the network hopes to realize?

The state of Parkinson's care within the UK can currently be thought of as a mountain range with peaks and troughs in the standards experienced by Parkinson's patients. This was highlighted in 2012 by a Parkinson's UK audit in which 1/20 or nearly 6.5 thousand Parkinson's patients in the UK did not have access to a Parkinson's nurse specialist. In short, the goal of the Excellence Network is to raise this bar so that Parkinson's patients experience the peak standard of care across the UK.

While there are some amazing Parkinson's specialists working in the UK, there has never before been this type of vehicle for multidisciplinary communication and organization. The network has been designed, for example, to enable speech therapists and physiotherapists to collaborate with a primary clinical service.

The network will also be a repository for the wealth of education related knowledge that has been developed. Physiotherapists and other healthcare workers will easily be able to access best practice guidelines as these are among the areas that suboptimal at present.

While the primary aim of the Excellence Network is service improvement, we know from previous work that involvement of people in studies leads to an overall improvement in standard of care. With this in mind, I foresee an important proxy metric of the network's success being the opportunity for patients to be involved in research and in making informed choices to do with key management decisions.

Q Now that it has launched, what are the network's short-term goals?

In the next 2 years, we are aiming to have delivered a step change in the provision of first-class Parkinson's care. I think this will be done through effective networking in order to effectively evaluate and disseminate locally successful techniques and ideas throughout the UK.

Our 18 regional groups are essentially developing local, inclusive Excellence Networks – consisting of nurses, doctors, patients and so on – who are developing projects, for example, best care within hospitals, which can then be rolled out nationally. I am confident that harnessing the enthusiasm of relevant parties across the UK and providing them with a unified voice is the way to ensure this step change in healthcare provisioning occurs.

Q The Excellence Network is an interprofessional collaboration, how does this approach to healthcare particularly apply to Parkinson's disease?

You honestly could not find a more appropriate setting for multidisciplinary, personalized care than in Parkinson's disease. It is such a complex condition, both in terms of the symptoms and treatment strategies. For this reason, patients require support from a huge range of health and social care professionals at every stage of the disease, but no more so than in its advanced stages. It is no exaggeration to say that you cannot provide a high level of excellence in Parkinson's care unless you have fully integrated services that address all of their needs.

Q In terms of treatments for Parkinson's disease, do any recent or forthcoming advances have you excited?

I suppose, it is easy to become cynical at my stage, having been involved in trials and working as a clinical neurologist for over 20 years, because a lot of promising studies using animal models have invariably come to nothing in human trials.

However, there is one model emerging from basic biology that I find very persuasive: the idea of a passage of pathology from one cell to another to influence that cells' function and subsequent demise. To my mind, the possibility of designing a treatment to interfere with the basic transfer of 'toxic' protein from one cell to the next could have a fundamental and game-changing influence on the entire disease progression and is really exciting.

Q How do you see your field progressing in the next 5–10 years?

It is clear to me that the days of 'siloed' research are at an end and that real progress is only likely to be made as a result of national and international collaborations and data sharing. In fact, I believe this method will yield not only better results but more 'bang for the buck' in terms of research investment.

We have developed some great symptomatic treatments, but what is lacking is a strategy that affects the underlying disease progression. We need now to work with small and medium-sized enterprises and the pharmaceutical industry and basic scientists to identify tractable targets that offer real hope for disease modification of Parkinson's disease. Intervening at an early stage might not only slow down the motor symptoms

but also halt the development of some of the more feared complications such as Parkinson's associated dementia, which in my opinion is the major therapeutic unmet need in the management of Parkinson's disease at the moment.

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