

THE STANDARD OF NEUROLOGICAL TREATMENT IN THE UK IS NOT GOOD ENOUGH

David Johnston

Over the past three years I have had the dubious pleasure of consulting six different neurologists in three different areas of the country. This has not been by choice. It is due to funding; moving house; and the unusual nature of my condition. It appears likely (but not even now certain) that I have both Parkinson's and dystonia.

All the neurologists I have seen have been very pleasant; apparently concerned and apparently competent. However, they have been virtually totally ineffective in providing any real help with my condition. Over the past three years, I have had 12 different therapeutic interventions; 8 have provided real benefit to me; the other 4 have been ineffective or positively harmful. Of the 8 which have been helpful, 2 have come from ophthalmologists; 2 from charities; 1 each from a physiotherapist, my GP and my own researches. Only 1 appointment with 1 neurologist has been helpful. All 4 interventions which have been ineffective or positively harmful have been from neurologists.

I am not alone in being concerned about the standard of neurological care in England. Earlier this year the Public Accounts Committee in a critical report concluded that "Neurological conditions are not a priority for the Department of Health and NHS England". They were following up an earlier critical report in 2012 which made six recommendations, only one of which has been properly implemented and three of which have been completely ignored.

So what can neurologists do to improve their effectiveness? I suggest the following:

- 1) Listen to their patients. When seeing a new patient for the first time be sure to have a full and proper history. The only full history that I have ever had taken was as part of a research project.
- 2) Explain the pros and cons of any proposed treatment to the patient. This is never done adequately in my experience. One doctor even suggested in writing that I should not read the patient information leaflet that comes with all medication.
- 3) If a patient prepares a short concise legible document, have the courtesy to read it.
- 4) If changing medication, be sure to arrange a review system after say one month, by appointment, email or telephone to see how the treatment is going. This is not only good for the patient. It also saves the NHS drug budget wasted and unnecessary medication.
- 5) Be open to wider ideas, for example: exercise; physiotherapy; diet etc. to improve patients' lives. Do not focus on drug treatment alone.
- 6) Be better administrators or get better administrative back up staff. Two examples of many: I recently attended an NHS Centre of Excellence for the second time. I saw a different doctor. She had no idea that I had been seen previously or the outcome of the first appointment. A recent urgent letter took two and a half weeks to produce. Why in this age of email use letters for urgent communication?
- 7) Concentrate on NHS solely or give it up and be solely private. I have the uncomfortable feeling that many doctors are unconcerned about the current administrative shambles of the NHS as it boosts their private practice income.
- 8) Be humble. Acknowledge the limitations of your knowledge, your competence and the effectiveness of treatment. I understand that the only certain test for whether you have Parkinson's is to slice up your brain. This is obviously done after death and reveals that 90% of people thought to have Parkinson's had it. It also means that thousands of people thought to have had Parkinson's didn't actually have it.
- 9) Accept that medicine is uncertain and that no-one can foretell the future.

10) Involve patients fully in decisions about their care.

How can we as patients improve the care we receive? My suggestions are:

1) Be prepared for your appointment. Prepare a concise summary of your current health and concerns or questions and ensure that they are all dealt with.

2) Attend all appointments with someone.

3) Question the advantages and disadvantages of any proposed treatment. The book Parkinson's for Dummies has a very good medication check list. I confess that I haven't had the courage to use it yet.

4) Do not accept passively that Doctor knows best. There are gaps in knowledge. Medication is largely a process of trial and error. You are the expert in what works for you.

5) Attend your local Parkinson's Group and share experiences with other patients.

6) Attend a local self-management course run by Parkinson's UK.

7) Be aware of publications produced by Parkinson's UK.

8) Familiarise yourself with the NHS Constitution, which sets out a number of legal rights for patients dealing with the NHS.

9) Do not put up with substandard ineffective care. There is decent care out there. Persevere until you find it.

10) Insist that expert timely review is built into any proposed treatment change.

11) Do not rely on your neurologist alone to improve your quality of life. Explore other areas: for example: aqua-therapy; physiotherapy; singing; dancing; Tai Chi etc.

12) Get and keep copies of all correspondence from your consultant.

Finally, what can Parkinson's UK do to improve care?

As can be seen from the above, I think charities do a very important and worthwhile job in filling the gaps in NHS provision. My major concern however is that the regular magazine from Parkinson's UK in particular is full of medical success stories, with very little coverage if any of adverse events. It is important to remain positive and optimistic but you should also be realistic and accurate. As you can tell from the first three paragraphs above, I believe that the correct picture of neurological care in England is much more mixed than the rosy picture presented in the magazine.

What should be written about? Topics such as the following would be of use:

- What standard of care should patients expect?
- How to get better care?
- How to complain effectively if your care is not good enough?
- What are your rights under the NHS Constitution and how do you achieve them?
- Is it possible to set up an advocacy service to assist in resolving difficulties with hospitals? Some hospitals have websites for anonymous feedback. It is particularly important to give poor feedback as well as good.
- Could a Trip Advisor-like website be set up to rate Neurology Departments in NHS hospitals in England?

As is clear from the Public Accounts Committee report something has to be done to improve neurological care in England and I hope that these thoughts will act as a catalyst for change.