

Report for Berkshire West Long Term Conditions Board

Findings from a focus group held on Monday 14th September, 2015

'My experiences of being diagnosed with a long term neurological condition'

Purpose

The Berkshire West Neuro Steering Group is a sub-group reporting to the NHS Berkshire West CCG Federation Long Term Conditions Board. One current priority for the Neuro Steering Group is to understand and improve the pathways and methods used by the local NHS to diagnose neurological conditions. Therefore the Alliance convened a focus group entitled '*My experiences of being recently diagnosed with a long term neurological condition*', to provide a local patient perspective to inform these developments.

Findings

Those taking part in the focus group reported the process of obtaining a neurological diagnosis generally to be slow, with some GPs appearing to lack neurological knowledge, often requiring time and further information before making significant decisions, such as when to refer patients to a specialist neurologist. There were examples of diagnoses being given then subsequently changed, which was reported to have significant implications on psychological state as well as introducing the possibility of inappropriate management of the condition(s) or situation. There were suggestions of tests being ordered by clinicians that may not have been relevant against the given knowledge. There were wider suggestions that some GPs may not be clear as to the diagnostic pathway to be followed. It is apparent that when Consultants confirm a diagnosis sometimes they are then perceived as abandoning their patients, although there was no discussion as to whether or not that makes any material difference. In many cases patients receive insufficient or sometimes no useful information, resulting in some dismay, isolation, uncertainty and similar potentially avoidable feelings. The role and impact of nurse specialists was generally well-regarded, although not always.

Participants were generally of the view that the system for diagnosing neurological conditions needs to be made more systematic, more streamlined and rapid, so as to deliver an accurate diagnosis and ongoing management regime more reliably.

Peer group support from others in a similar position was regarded generally as likely to be of benefit, although everyone participating in the focus group had early experience of such support and it is known from anecdotal evidence that not everyone wants this.

Recommendations

1. A more robust and systematic approach to assessment, integrated into a well-defined care pathway for neurological diagnosis should be established and followed consistently.
2. More GP knowledge about neurological diagnostics would be welcome.
3. Better access to good quality information throughout diagnosis would be useful.
4. Wherever possible, appropriate care management options for neurological conditions should be offered and provided as early as practicable.
5. Diagnosis is the start of a long process leading to further needs. Nurse specialists and voluntary sector peer group support should both be central to immediate post-diagnosis service design, planning and delivery.

About the focus group attendees

The event was publicised widely through the voluntary sector, but only six people responded, probably because many newly diagnosed are not involved with the voluntary sector. The participants were diagnosed locally within the previous 18 months or were in the process of being diagnosed or were carers (husband, wife, or mother) of someone in such a situation. There were three males and three females, in the age range 50-65, one cared-for not taking part directly being younger than this.

Format of the Focus Group

A WBNA Trustee led the discussion. There were two independent note-takers. A written submission had been received from an individual and his wife, he being part way through a series of neurological diagnoses. This letter was used to set the scene for open discussion. Minimal further prompts were used, allowing delegates to determine their own priorities for discussion.

Limitations of this Focus Group.

The experiences raised at a two-hour focus group with only six participants cannot cover comprehensively the experiences of people recently diagnosed by the area's 150+GPs. The themes identified should not be taken to represent the full extent and nature of what it is like to be diagnosed or how consistently any part(s) of the service operate. This report provides pointers for reflection and further work.

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Focus Group
***'My experiences of being diagnosed with a
long term neurological condition'***

Appendix 1 'S and 'B's account'

First symptoms were noticed in 2012 so went to the GP who referred me to a Neurologist who suspected stress. Symptoms persisted, in 2014 had a scan and PD was suspected so prescribed Madopar. By August 2014, with no improvement on Madopar a diagnosis of PSP was given. It was a 'cold diagnosis' with no explanation given only being told that nothing could be done. Saw the PD nurse who made me feel worse. The OT was helpful, a physio suggested exercises to do at home and a very good SLT saw me for 6 weeks. Since then there has been no support or help. We would like support from the same person. We have started a PSP support group.

Appendix 2. Consolidated record, based on two sets of notes.

Focus Group
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The account sent by 'S' and 'B' was read out. (See Appendix 1.)

M has still not had a full diagnosis after 18 months but has symptoms of Parkinson's disease. Her symptoms came intermittently and were variable & doctors treated each as they appeared. Luckily she now has a new GP who has been marvelous. A friend (GP) in France diagnosed Parkinson's. It took 6 weeks to get a neurological appointment in Reading which is much too long. In France you see a GP in the morning and a consultant in the afternoon. In Reading she saw a Consultant who is the wrong consultant for movement disorders but she was just allocated to him. He upped her medication and will see her in 9 months time, all cursory and unsatisfactory.

G noticed different symptoms in M, such as her dragging feet but the first GP discounted this. 2nd GP is much better and providing continuity and understanding. But getting past the GP secretaries is a real problem and also, getting back to the Consultant is very difficult. Getting anything from the NHS is not there – M's only support has been through the Parkinson's Group. They went to the local PD group who said that drugs would help, but they hadn't so they started to research the condition and asked for a second opinion from a PD specialist in Oxford, Dr H who gave them a 50 minute appointment and really listened and is now doing tests but does not think the diagnosis of PD is correct, they don't yet know the true diagnosis but suspect PSP.

K's daughter had a vaccine & following this she felt dizzy. She saw her GP but was given no treatment. She then had another vaccine & felt even worse. She went again to the GP who thought she was depressed. Another GP thought she had Chronic Fatigue Syndrome. She then saw a consultant in Oxford who thought it was "in her head". She then had a seizure followed by another and was taken to Guys and, 4

years into things, was diagnosed with POTS, (postural orthostatic tachycardia syndrome), with other underlying symptoms. She was sent to Basingstoke, given plasma exchange and put on a massive dose of steroids. She then went to the National in London. She is not depressed. She is studying for a degree which will take 6 years. Her Mother goes with her to hospital appointments but she feels the consultants do not like her speaking. An International Medical Alert Team in Denmark has raised a "Safety Signal". K & her daughter are meeting them imminently. There is a support group—POTS.

M was told she was depressed. She gets very tired but it is not normal tiredness.

K wrote to the senior GP saying that the treatment of her daughter by various GPs was unacceptable. Alarm bells should have rung with the GP when a fit young woman was coming to see him every week for 6 weeks. She kept a diary of her daughter's symptoms but the diary was ignored.

M also kept a diary but the GP did not look at it.

K says that her daughter's blood pressure drops when she stands up but the GP ignores this.

J does not consider himself a carer but he realises that things are going to get worse and he will need to help his wife more. They notice together when symptoms develop. He thinks their surgery is good and they have recently been transferred to another Dr who is good.

J2 and his wife see their GP regularly so there is continuity of care. He said you have to know how the system works in order to see a consultant.

J does not find that there is any support for him from the NHS but the volunteer group is very helpful.

M found that there was a great deal of support when she had breast cancer and it should be the same for neurology.

G's husband has been diagnosed with dementia. A six-week course had been offered that was easy to attend. Access was given to a support worker. The support required had been difficult to identify.

J3 said clinical nurse specialists are invaluable.

J had heard about them but had not had any contact with one.

G thought that a clinical nurse specialist would have been invaluable (difficult though when you don't have a real diagnosis).

K The National Hospital did not give herself or her daughter much support.

Question What would you like to happen differently?

General discussion

- There needs to be a more systematic approach in diagnosis.
- There should be a protocol to go through so that each symptom is eliminated.

- After an initial examination, it should be clear which consultant should be seen.
- Why do consultants not refer the patient to the one who specialises in that symptom? You must be sent to the right Consultant.
- Look at each symptom in more depth.
- Doctors look at individual symptoms and not at the whole situation.
- It is too easy to suggest 'it's all in your head'.
- Too often physical symptoms are ignored and the suggestion is psychological.
- Do not say it is depression.
- No one has ever written a protocol for neurological symptoms.
- Nothing was written down by the Consultant and a letter was not sent to the GP promptly, so information on medication was not provided in time.
- GPs should have a list of volunteer groups in the area.
- A new information system is on every GPs desk and could/should be the way forward for neuro diagnostics and more. It is likely that in time more referrals will be bookable directly and not have to go through the GP.
- There's a great need for a smoother, faster appointment system to see a consultant.
- Consultants' letters sometime have incorrect information in them which can be dangerous. They should be checked.
- In hospital the medication very often has to be taken at a set time which can be dangerous in some conditions when normal protocols are not followed.
- Hospital notes should always be available.
- Put personal information in the 'Message in a Bottle' so that it is available in an emergency. (None of the delegates had heard of this system.)
- If you phone 111, your notes should be available because it would save so much time and could be critical to getting the right advice quickly.
- A lack of information. After a typical 10-minute diagnostic consultation, you are on your own and just told 'someone will be in touch'.
- Patients themselves find they have to be proactive in checking whether appointments have been made, in finding support groups, specialist nurses etc. OK for some, but what about those less able?
- Why does the NHS still use FAX instead of email?