

West Berkshire Neurological Alliance

Focus group

Monday 26th September 2016

‘My experiences of Living with a rare neurological condition’

A discussion between individuals and their carers living with a rare neurological condition.

Conducted by

West Berkshire

Neurological Alliance

Funded by

healthwatch
West Berkshire

Community 
Engagement
Programme

Purpose

The purpose of the focus group was to identify real-life experiences of living with a rare neurological condition and to identify recommendations to service providers to improve the experiences of those in such a situation.

Background

There are about 1,000 or so possible neurological diagnoses in total. There is no agreed definition of 'rare neurological condition'. However, there are defined local services in Berkshire West for some of the more common neurological conditions, including Stroke, Parkinson's, MS, Epilepsies, Pain, Dementias, Acquired Brain Injuries, Learning Disabilities and ME, in various degrees of development, most clinicians having some knowledge and experience of most of these more common conditions. The prevalence of many neurological conditions are estimates. Some sub-sets of the more common neurological conditions have low prevalence and can also be considered as rare. Statistics from the National Neurological Alliance indicate that there are more individuals with a rare neurological condition than those with Parkinson's or with MS, making the rare conditions cohort a significant number. The infrequency with which most clinicians come across patients with such conditions can lead to difficulties in reaching a diagnosis and in determining appropriate care pathways and treatment options. This situation was recognised by West Berkshire Neurological Alliance when in 2008, together with the Reading and West Berkshire MND Association and the Reading Branch of the Huntington's Disease Association, a Rare Neurological Conditions Nurse Specialist post for Berkshire West was first funded, a post now funded ongoing by the local NHS.

Findings

Those taking part in the focus group reported on a wide range of matters, entirely consistent with issues raised by those with the more common conditions, but generally in the context of longer time-scales, less knowledgeable clinicians, less information, less support and a greater sense of isolation. Matters raised included (not in any order in terms of priorities for action):

1. The wish to **be rid of their condition**.
2. The negative impact on **work and family life**.
3. The need to make **GPs more capable and supportive** when confronted with a rare neurological condition through better IT systems leading to better questioning of medical history and family medical history, appropriate care pathways, more appropriate clinical referrals, faster access to appropriate tests, particularly use of MRI and other scans, infection risk factors better information and similar.
4. The lack of a sufficiently knowledgeable **Consultants** and barriers to ongoing communications in some cases.
5. The need to 'fight for yourself', **take control** and 'do your own research', to transform the rate of progress to ensure an accurate diagnosis and treatment.
6. **Lack of information**.
7. The problems arising when there is a '**loss of my own communication skills**' arising from the condition.

8. The need for a comprehensive system of completing the network and maintaining **National Centres of Excellence** such that everyone with a rare neurological condition has appropriate access, not just some.
9. The need to upgrade the neuro facilities, physiotherapy services and patient care pathways at **the District General hospital in Swindon** and communications between there and the Oxford hospitals.
10. The need for hospitals to treat **patients who are out-of-area** equally to those who are financed by local NHS funds as regards rehabilitation and speedy discharge, to avoid delays.
11. The reality that **intensive care** is potentially more risky for those with a rare neurological condition than for others.
12. The need for more **community physiotherapy** and specialist services such as those provided by West Berkshire Therapy Centre.
13. The need to consider **nutrition and other environmental factors** and better targeted management options.
14. The lack of **research into the causes and cures** for most rare neurological conditions.
15. The sometimes **lack of urgency** when situations are clearly urgent.
16. The generally valuable inputs from the **voluntary sector**, with exercise therapy and acupuncture and other alternative therapies being mentioned.
17. The need for accessible **neuro rehab centres**.
18. The sometimes poor physical **access to some GP premises**.
19. The difficulties of arranging **longer appointment times** to have a proper GP consultation.
20. The benefits of having a **named GP** for those with a long term condition.
21. The **bureaucracy** that sometimes intervenes.
22. The sometimes lack of focus on **well-being**.
23. The lack of clarity sometimes about '**who is in charge of my health?**'.
24. The need for special support when considering **pregnancy**.

Recommendations

1. CCGs should speed the introduction of the well-thought-out **neurological care pathways** into the DXS IT system used by GPs and include information that will be relevant to rare neurological conditions. This should include aspects of genetics, nutrition and environmental risks in addition to core risks and needs such as more focus on well-being, the need for better timeliness in the case of urgency and special situations such as pregnancy.
2. The number and diversity of specialisations of **Consultant Neurologists** should be reviewed and made fit for purposes for those with rare neurological conditions.
3. Patients should be encouraged to take as fully a **self-management** role in their own care and GPs should be encouraged to identify situations and cases where patients might benefit from more support.
4. **Information** about rare neurological conditions should be available to patients in all healthcare settings.
5. The Department of Health should instruct the NHS to make proposals and to take action that will result in an increase in the number of specialist **National Centres of Excellence** of relevance and benefit to those with rare neurological conditions.
6. The services needed at the **District General Hospital at Swindon** by those with all neurological conditions including rare neurological conditions

should be the subject of a major review leading to investment and reorganization.

7. Healthwatch and other NHS regulatory bodies should make substantive enquiries into the treatment received by patients who are out-of-area, compared to those who are locally funded and determine whether or not the funding arrangements for **out-of-area patients** work against the health and well-being interests of patients.
8. The amount of provision of **community physiotherapy** and similar alternatives such as **community rehabilitation Centres** should be reviewed and improved, driven by formal NHS processes.
9. The Department of Health should review its balance of support for **research into the causes and cures** of rare neurological conditions.
10. The CCGs of Berkshire West should conduct a survey into the physical **accessibility of GP premises** and encourage improvements, based on specialist advice.
11. GP Practice teams should make it easier for those clients in need of **longer GP appointments** to have their needs met better.
12. Patients with rare neurological conditions should be offered the facility of having a **named GP** should they wish.

About the focus group attendees

The event was publicised widely through the voluntary sector, seeking those with, or caring for someone with, a condition that they regarded as rare or not very well known. Nine individuals responded. Those present included: Participant 1 (cerebellar ataxia), Participant 2 (stroke following aortic dissection) with wife, Participant 3 (sensory ataxia) with mother (Participant 8), Participant 4 (NMO or Neuro myelitis optica syndrome) with husband (Participant 10), Participant 5 (Transverse myelitis) with her mother. Participant 7 (Charcot Marie Tooth syndrome). Participant 9 (a scientific observer with a professional research interest in rare conditions). Also present were a convener (Participant 6) and two notes takers each with personal neurological involvements.

Format of the Focus Group

A WBNA Trustee (Participant 6) led the discussion. There were two WBNA note-takers. Attendees were provided with a written agenda:

1. Welcome and introductions
2. Open discussion prompted by the following:
 - When did you first realise you had a problem?
 - How long was it before you approached anyone for help?
 - How long was it before you received a diagnosis or some help?
 - What has changed for you since your diagnosis?
 - Have you been treated by people in the way you would expect?
 - Did you get information and explanations when needed?
 - How has all this impacted on you, physically, mentally or otherwise over time?
3. What would you have liked to have happened differently?
4. What recommendations do you have for clinicians, social services, the voluntary sector and others?

Within that framework, attendees determined their own priorities for discussion. The meeting was conducted using minimal prompts (shown in italics in the transcript). **Appendix 1** is a transcript of the discussion. **Appendix 2** is a written submission submitted by an individual who was unable to attend that was used to introduce the discussion.

Limitations of this Focus Group.

The experiences raised at a two-hour focus group with only a small number of participants cannot cover comprehensively the experiences of those affected by a rare neurological condition, of which there are about 1,000 possible diagnoses. The themes identified should not be taken to represent the full extent and nature of what it is like to have a rare condition. This report provides pointers for reflection and further work.

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West Berkshire **Neurological Alliance**

Appendix 1

Transcript of proceedings WBNA Focus Group on 'My experiences of Living with a rare neurological condition'

To start of the meeting an email was read out from a participant who was unable to be present, illustrating how she is managing her daughter's rare neurological condition through doing her own research and *'badgering the medics'* with her findings and concerns. See **Appendix 2**

Also as an introduction the example was given of a local person who has lived with a rare form of Motor Neurone Disease (MND) for 13 years and is now very disabled, with poor speech, hence she uses a lightwriter to communicate. She has problems with her carers who cannot understand her. Her experience of going into hospital is *'a nightmare because the nurses are so busy they get impatient with me and won't listen to my lightwriter'*. Also, many doctors and nurses talk only to her husband instead of to her which is immensely irritating and frustrating. *'They need to look at me when I am speaking because then they would have a better chance of understanding me.'*

Prompt *'When did you first realise you had a problem? And how long was it before you approached anyone for help?'*

Participant 1 started to get dizzy when aged about 35. Her uncle had ataxia so she was gene-tested and found to have a hereditary form of Cerebellar Ataxia.

Participant 2 had a stroke following an aortic dissection. His wife had been pressing for coronary investigations because of a history in the family, but was not listened to, causing a missed diagnosis. She feels if his aortic dissection had not been left so late, *'a stroke could have been avoided'*.

Participant 3 went for a medical at work and the only thing wrong were his eyes which were *'strange'*. Work colleagues noticed he had slight balance and mobility problems so he stopped going up ladders and became more desk-bound. He eventually saw a doctor and was diagnosed with sensory ataxia at age 37. His younger brother was always wobbly which was put down to his having dyspraxia, but his mother got him reassessed and he too was found to have sensory ataxia but with a different set of symptoms – he was 35 when finally diagnosed. *'He was born by c-section. Is this significant?'*

Participant 4 has Neuro myelitis optica syndrome (NMO) which started with 'pins and needles' in February 2016. This got progressively worse so she was sent to Swindon where she had to be admitted because she became paralysed from the chest down. A Neurologist is at that hospital only one day a week. Eventually she was sent to the John Radcliffe (JR) hospital in Oxford which was *'much better'*. She had a plasma exchange, then was sent to a geriatric ward at Swindon but had no physiotherapy for 10 days. She was transferred to a rehab ward thereafter. She experienced very poor communication between the JR and Swindon and vice versa.

Participant 2 said he wasn't given the option of rehab at RBH and was sent to Swindon because *'Berkshire didn't want him as there was no discharge plan'*.

Participant 4's husband said *'Swindon is a terrible hospital'*.

Participant 5 On 15th June 2016 she experienced severe chest and shoulder pain and later she got very bad pins and needles. Her GP thought it was probably a trapped nerve so she had some physio for her shoulder. Later she had an MRI scan which indicated that there was something wrong with her spine. She was then diagnosed with Transverse Myelitis, but there was *'no after care and no ongoing plan'*. She *'needs neuro physio and normal physio'*.

Participant 7 was diagnosed with Charcot-Marie-Tooth syndrome (CMT) about 15 years ago. Often 'wobbly' as a child, she has foot drop. In the last 4 years there has been a marked deterioration. Has had very little help on how to help herself and *'has had to do all the research myself'*. She has been offered, but refuses to take, anti-depressants because of being so fatigued and low and has had adrenal failure. *'There has been a complete lack of signposting.'* She has only ever been offered OT, but there has been *'no guidance about anything'*. **The Health Corner** *has helped a bit as has a dietary plan.'* A neuro physio recently offered her a vibro plate which has been a huge help. *'The facilities at West Berkshire Therapy Centre have been a godsend'* and are really helping her now.

Participant 9 *'Many neurological conditions are affected by different factors. What about trace elements, a factor in yuppie flu? If you are low in zinc you get a dry mouth and eyes and if you are low in magnesium your muscles don't work properly. Doctors rarely ask about TBI (traumatic brain injury) when taking a history – they should be aware of the many environmental factors in neurological conditions.'*

Participant 8 *'There was no information or advice from the neurologist. My daughter (Participant 5) was just put on steroids which then precluded her from any trials. She had to beg for an MRI scan.'*

Participant 7 *'I would like an MRI scan but never had one.'*

Participant 1 *'I was given an MRI scan.'*

Participant 4 Her decline was so rapid that she did have an MRI and a lumbar puncture. She had a kidney removed in November and *'any surgery can lead to infection in the spine. Was this the cause of the disease?' 'There is a theoretical link between Swindon and the JR at Oxford, but it was not much in evidence.'* The national centres of excellence for Neuro Myelitis Optico syndrome (NMO) are at Oxford and Liverpool and there are leaflets available about the condition.

Participant 2's wife Her husband has only one kidney which *'got over-hydrated when he was in intensive care which made the situation worse'*.

Participant 10 *'What triggers NMO?' 'There doesn't seem to be any research going on.'*

Participant 7 The things that have helped her have been Vibration (vibro plate), fresh air, acupuncture and improved diet. *'Why don't more Health and Social Care Professionals know about this?'*

Prompt: *'Does anyone have access to specialist neurology?'*

Participant 5 has experienced no specialist neurology, her neurologist, Dr F*****, *'is a stroke specialist'*. No ongoing help has been offered. Other members of the group suggested she *'seek a second opinion'* in Oxford.

Participant 3 was diagnosed at the John Radcliffe (JR) hospital and told *'the condition would worsen and nothing could be done'*. He transferred to a centre in London which was *'much better'*. They told him that he could get help for his condition and then sent to the Royal Berkshire Hospital for an 'urgent' appointment, but *'it took ages to get this appointment. What does 'urgent' mean?'*

Prompt *'Has the voluntary sector been helpful or not?'*

Participant 1 said there was an ataxia group in Maidenhead. There are 3 specialist centres for ataxia.

Participant 7 said *that 'the CMT Society is there but they don't do much. West Berkshire Therapy Centre (WBTC) has been 'the best thing'.*

Participant 2's wife *'WBTC is what got my husband walking again. She 'likes the sound of acupuncture but would it trigger anything as he has heart damage?'*

Participant 5 *'The Transverse Myelitis Society is good and has a good library.'*

Prompt *'What about alternative therapies?'*

Participant 5 and Participant 7. *'Acupuncture has often been suggested as being helpful and it has helped me,' Participant 4 'it is not discouraged'. Reflexology might help for pain in big toe.'*

Prompt *'What about the impact of your condition on your lives?'*

Participant 3 It has had a big impact on his work. He is *'now deskbound and may have to give up work altogether'*.

Participant 5 has had to change her job and work from home because she *'cannot sit comfortably for too long'*.

Participant 1 is a hair dressing teacher but having difficulty with coping. She doesn't feel she can go on anymore and hopes to give up work by Christmas.

Participant 4 Her illness has had a huge impact on their family business as she can no longer do HR or the accounts and her daughter has had to take over. This has led to feelings of guilt. Also, she is a JP but cannot drive now and cannot get to the Court house in time for a 10am start. 2 out of the 3 court houses are not disabled friendly. She can no longer help with her grandchildren and *'the whole situation gets me down'. 'If you develop a urinary infection for example, you need to see a GP immediately.'*

Prompt *'What should have happened differently?'*

Chorus of agreement *'Not have the condition!'*

Participant 4 *'You have to fight for everything you get. If you can't fight you get nothing. It is very difficult to get a double appointment at my GP Practice, and I need that extra time), also the Surgery is not disabled friendly.'*

Participant 2 *'wished the GP would admit he knows little about the condition.'*

Participant 4 *'To prevent relapses you have to pick up on the potential for infection – you need to follow up with someone having the knowledge.'*

Participant 6 *'GPs locally have agreed to have a named GP for long term conditions.'*

Participant 5 was given her diagnosis over the phone on a Friday evening (*'so I no-one to talk to at the weekend'*). She was promised a treatment plan that never came. She could have *'appreciated a leaflet at the very least'*.

Participant 4 *'One of my medicines can only be prescribed by the Consultant, but communicating with the Consultant is almost impossible.'*

Prompt *'What recommendations would you make?'*

Arising from discussion those present concurred that: the system is disjointed, with the need for flowcharts/care pathways for patients to show them what is available and what they can do. There should be much better use of IT.

Participant 10 feels *'there is a lot of pointless bureaucracy which gets in the way of diagnosis and treatment.'*

Participant 9 *'Are the care pathways looking at sub-sections of diseases?'*

Participant 7 *'There should be more emphasis on well being because you can't help getting depressed. You need emotional well being and not feeling tired all the time.'*

Participant 2 *'Make full use of IT technology and stop reinventing the wheel.'*

Participant 5 was surprised she wasn't asked how she was before her symptoms started. *'There should be an initial questionnaire, then a year later the current situation can be checked against it and see what helped and what didn't.'*

Participant 8 *'There is a lack of communication with the patient – who is in overall charge of her health? Why does the consultant refuse certain investigations?'*

Participant 5 *'If I can't manage my pain now, how will I manage if I have a baby?'*

Participant 1 Expressed the wish for was a centre for neurological conditions including provision of alternative therapies. She has to pay for everything but has no advice on what is likely to help – *'expensive trial and error'*.

Participant 4 *'Can NMO go in to a care pathway plan because it is considered to be a subset of MS?'*

Participant 3 reiterated that *'communication needs to improve.'*

A participant said that *'at an early stage people should be offered continence advice.'*

A participant queried *'whether it is best to contact the CEO to inform him/her of the problems experienced?'*

General comment from the convener. The participants had little opportunity to comment on each statement made by the others, but *'there was considerable empathy and agreement about the underlying issues evident throughout the session.'*

Following the meeting one attendee submitted this email: *'I thought the following link may be of interest to some (especially the young lady with myelitis). www.nmouk.nhs.uk There are a number of information booklets to download, and gives an idea of the services that are available from a specialist centre. As most of us said, it is the local services that have the gaps.'*

Appendix 2

Written testimony from a participant who was unable to attend.

'We searched through numerous research publications and were able to justify a request for tests that are not normally carried out, leading to our consultant providing treatment and ongoing investigations, putting us at the centre of a medical research project relevant to my family, also potentially useful to others affected by the same rare condition.'

Appendix 3



The funding for this research report has been provided by Healthwatch West Berkshire's Community Engagement Programme (CEP) grant scheme. The CEP grants ranged from £500-£3000, and were specifically reserved for research relating to vulnerable, hard-to-reach groups or where there is a health or social care issue that is problematic, or not working as it should. The research had to be evidence based, with outcomes that can be used to highlight and develop suggestions for service improvement.

Healthwatch seeks to understand and represent the needs of everyone and recognises the importance of getting to the voice of those who can be considered 'hard to reach', which undoubtedly applies to those with rare neurological conditions.

*You can view Healthwatch West Berkshire's priorities and current work plan, which have been developed through our Champions board, local feedback and other local Clinical Commissioning Group (CCG), Local Authority and NHS priorities on our website:

<http://www.healthwatchwestberks.org.uk/publications/>

Appendix 4

About West Berkshire Neurological Alliance

The Alliance is an umbrella organisation for neurological voluntary groups, patients and carers covering the Local Authority areas of Reading, West Berkshire and Wokingham, an area also known as NHS Berkshire West. The Alliance conducts research using a range of methodologies into the experiences of local people living with or affected by neurological conditions. This is the Alliance's fifteenth Focus Group report.

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