

Report for Berkshire West Neurology Local Implementation Team

Experiences at the time of diagnosis

Findings from a Focus Group held at Padworth on 7th October 2009

Executive summary

Attendees reported that the impact of being diagnosed with a long-term neurological condition on an individual's physical and psychological state could be anything between minor and very considerable, sometimes variable and sometimes overwhelming. Within this there are many commonly arising situations, experiences and needs. Attendees emphasised that they are individuals and appreciate being treated as such. Attendees described their experiences of local service provision as varying between excellent to very poor with most reporting inconsistent quality within the system as a whole, or having to 'work the system'.

Diagnosis was reported as being rarely quick or straightforward and for many has spanned several years, in several cases taking 10 years or more. Matters are sometimes explained well and sometimes poorly explained or not explained and occasionally answers from clinicians are 'made up' or clearly incorrect. Some patients go through a transparent and systematic process of eliminating possible other diagnoses while some are offered an interim diagnosis that turns out to be incorrect and this leads to some interim mismanagement. A proportion of patients have faced taking their own steps to find information or to find an expert clinician to secure a more accurate diagnosis. The diagnosis process is greatly dependent on the knowledge and skill of the clinician(s) involved. In particular it seems that variable knowledge among GPs about neurological conditions and variable knowledge as to referral options either slows down, stops or brings uncertainty and inconsistency to the care pathway actually followed. The actual manner of clinicians telling patients their diagnosis is important and several attendees reported poor bedside manner historically, although few had experience of a recent diagnosis.

Most attendees placed importance in ensuring there should be generally more prompt and direct referral access to a skilled clinical workforce and they mentioned variously the importance of Consultants, GpWIS and Nurse specialists, as well as the voluntary sector for non-clinical support. Almost no time was spent discussing therapy and ongoing support services, so such disciplines received no comments either way.

Other than one compliment about rehabilitation and one about crisis care, the comments on hospitalisation experiences at the Royal Berkshire Hospital were largely poor, or worse which is at complete odds with the Care Quality Commission's ratings for RBH of 'Excellent' / (more recently 'Good'). There was insufficient time to explore this in depth but the concerns were clear and strong and warrant urgent evaluation and action.

The voluntary sector was generally fairly well rated for information and peer group support and is seen as lacking in expert clinical knowledge. The voluntary sector is perceived as not receiving appropriate support from the NHS.

The consultation event did not allow sufficient time to explore some issues, particularly experiences in acquiring information, acquiring help and ongoing support and harvesting ideas for improvements for those subjects. Therefore it is proposed to hold an additional event to allow time to gather further information.

Limitations of this consultation

Neurology conditions are many and diverse and this consultation covered an incomplete cross section sample with only a small number of participants (14), a bias as regards age range, (30-87), a slight feminine bias, (9F, 6M). The time since diagnosis was mainly in the 5-10 years range with two at about the 20 years range. Four participants were wheelchair users and two were with a terminal diagnosis. Dementia and Learning Difficulties were specifically excluded. The agenda for the meeting was too ambitious and was not fully covered, so some subjects received little or no mention by default. Seven participants were from West Berkshire and seven from the East of the PCT. Neurological Alliance volunteers led and took notes of the proceedings. Care was taken to avoid use of leading questions, but these may have occurred. The purpose of the meeting was circulated in advance and attendees were asked to prepare, which most had done. The intention was that attendees would not be current committee members of any neurological representative group, but three attendees currently serve in such a capacity. This arose because the extensive and protracted recruitment campaign failed to attract non-committee attendees in some instances, or there were last minute cancellations. No individual affected by a very rare condition was present. In total, 11 patients represented 12 neurological conditions and 4 attendees had a caring role (one being both a patient and a carer).

Either individually or collectively, the patients and their carers should not be thought off as 'representative' or 'typical'. They were selected by local charities of which they are members because they are intelligent, analytical, good communicators, positive in outlook and interested in the way that services are provided. In addition to being able to describe their own experiences they all also have some understanding of how others with the same condition may be affected differently.

Purpose of the meeting

To gather patient and carer perspectives on experiences at onset and diagnosis
Experiences in finding information
Experiences in getting help and support
Experiences when in hospital
What works well and what changes would people make for services to be better?

Observers present

Berkshire West PCT Commissioning Manager for Long Term Conditions
Reading Council Physical Disabilities Commissioning Manager
West Berkshire Council Physical Disabilities Team Leader

Conditions represented and impact of the condition

| | |
|-----------------|--|
| Brain Tumour. | Given terminal (1-5 yrs) diagnosis in '04, cannot work, 'going strong' |
| Epilepsy | Described by doctors as a secondary effect, but is a primary problem |
| Stroke 1 | Initially recovered but now developing new problems |
| Stroke 2 | Slowly recovering, wheelchair bound and several other impacts |
| Fibromyalgia | Was confined to wheelchair, but now returned to work part time |
| ME | Spinal problems and fatigue, but working |
| Polio | Had polio at age 11, several late onset disabilities from 1990 |
| Spinal injuries | Paralysed from waist down for 20 yrs, recently returned part time work |
| Ataxia | Frequent wheelchair user, frustrated by movement limitations since '97 |
| Parkinson's | Former teacher. 9 years since diagnosed with PD |
| MS | Primary Progressive MS '89, walking difficulties, other MS issues |
| MND | Diagnosed in 2006, battling well, beating the odds with strong support |
| Dystonia | Was unable to self-feed, now 75% better since finding right Consultant |
| Carer 1. | Mixes caring with voluntary work |
| Carer 2. | Mixes caring with part time work |
| Carer 3. | Emerging from being a full time to a part time carer |
| Carer 4. | Was a carer for a major stroke survivor, since had one herself |

Experiences at onset and diagnosis

Brain Tumours. Patient developed problems with spelling, falling over, then had a seizure that caused partner to be falsely arrested for assault. MRI scan found tumours. Epilepsy followed. Doctors would not tell her the facts and said there was no cure. Later discovered spinal tumours. Some doctors not communicating with each other and clearly making things up at times. Other doctors have been very 'on the ball'.

Stroke. Patient could not see anything on one side. Major loss of communication skill and hence loss of communication. The hospital environment did not help his recuperation, so when the carer also subsequently had a stroke, she did not want to go into hospital.

Fibromyalgia. Car crash led to patient having neck pain. Had to wait 3 hours to be seen in A&E. Developed further pain and asthma but nurses told her to stop complaining and threatened legal action. Discharged same day without a scan, but needed neck brace. One month later developed intestinal problems, became dyslexic and falling over. GP only ordered limited blood tests and only on self-referring to another doctor she began to get any understanding and help.

ME/Chronic Fatigue Syndrome/Fibromyalgia. Patient experienced pelvic pain during the year following birth of daughter 19 years ago (1990). Adhesions noted during laparoscopy led to subsequent diagnosis with IBS by a gastroenterologist who did not inspect her notes. Given laxatives and then amitriptyline (tricyclic anti-depressant) for IBS and subsequently diagnosed with post-viral / post-natal depression in 1996 and treated with low-dose amitriptyline for 6 months. When symptoms recurred in 1999, treated with hormones for ovarian cyst, although consultant subsequently told her she did not have an ovarian cyst, despite not having carried out an ultrasound scan prior to treatment. Developed interstitial cystitis during or as a result of treatment for ovarian cyst. Developed dry-eyes, allergies,

chemical sensitisation, fatigue and post-exertion pain and investigated for thyroid problems in 2001/2. Eventually received incorrect or incomplete diagnosis of CFS in 2004 leading to recommendation of pacing as treatment, which led to worsening of symptoms and increased post-exertion pain. Referred privately to rheumatologist (in Hampshire) at own request, leading to diagnosis with fibromyalgia in 2007. This led to referral to pain specialist and subsequent referral on the NHS to 4 week rehabilitation course at INPUT (St Thomas Hospital, London) as well as treatment with calcium supplements for tremors caused by low blood calcium/VitD deficiency. Hysterectomy in 2009 confirmed long-term history of endometriosis as probable contributory cause of fibromyalgia. Regularly been told the 'good news' by GPs that tests had come back negative (or "normal") and that the condition(s) were not life threatening, despite having ongoing symptoms.

Polio. Following polio at age 11 had no further problems until 1990. Initially diagnosed with ME then contacts in the ME/CFS community led to self-investigation of possible late onset polio. Second doctor thought it was ME. Neurologist said nothing was wrong. Requested lung check and polio was suspected, but RBH 'confirmed' there was nothing wrong. Now fitted with pacemaker and feeding tube. 'Too many people are going up cul-de-sacs before they get the right diagnosis'

ME/Chronic Fatigue Syndrome. Patient experienced pain following birth of daughter, which returned after a year. Doctor who told her she was OK had not even looked at her X-rays. Given laxatives and treated for ovarian cyst. Then diagnosed with intestinal problems by a doctor who did not inspect her notes. Diagnosed with depression 8 years ago and investigated for thyroid problems. Eventually received correct diagnosis. Has regularly been told 'good news', despite having ongoing symptoms

Spinal Cord Injury. Patient knew he had jumped, fallen and broken his back but took time getting used to the many implications and restrictions. Attending a specialist Spinal Centre made a big difference to understanding and management, but 10% of those in a similar situation never have access to this. Now knows that each spinal cord patient is in a unique situation. Despite significant paralysis and care needs and always assuming he could not, he returned to employment 20 years after his injury.

Ataxia. Patient reported that every support has been there at every turn. Balance problems caused his GP to make an appropriate referral. This led to a further referral to rule out other things and the genetic problem causing Ataxia was identified and confirmed. Full information at every consultation.

Parkinson's. Took 10 years to get confirmation of Parkinson's. A brain scan result was described initially as 'all clear', but within a month it was confirmed she'd had Parkinson's for the previous 5-7 years. Preparing for today the Parkinson's group held a focus group. 27 of 35 were alone when given the diagnosis, which that group finds unacceptable. One person was diagnosed by email. Support is needed at the time of diagnosis. *The Parkinson's Society Focus Group summary notes are appended.*

Multiple Sclerosis. Symptoms started circa 1990, with problems with balance. Confirmatory tests revealed MS. Was working at the time and did not want to accept the diagnosis.

Dystonia. The carer's son went to his GP and got nowhere. So he went to her GP and got an immediate diagnosis. From there it has been a fight to get everything that has been needed, even though her son was so disabled as to not be able to feed himself. More recently he has found a consultant whose help means her son is now 75% better.

Motor Neurone Disease. On holiday in 2006 and suddenly unable to walk. Back home the GP was fantastic, but the diagnosis was accompanied with news of 'you have only 1-5 years to live'. 'You say to yourself 'Goodbye!'' One person has saved him, Carol Allen (Nurse Specialist), through listening, empathy and positive inputs. Without her support 'I would not be here now'.

Carer comments. Carers spoke less than the patients and spoke variously about difficulties in communicating with the cared-for, and difficulties in general understanding, in finding information and in offering the right support.

Experiences during hospitalisation

In a short session, the points that arose were:

- 1) 'Reading hospital is a shambles.'
- 2) 'I do not want to go back to the Royal Berkshire Hospital ever again.'
- 3) Groans of agreement from around the room.
- 4) Upon asking a leading question if anyone had a good experience in RBH, two said they had. One attendee then reported good attention but then described: - non-adherence to important long term medications; no comprehension by ward staff of interactions of drugs; lack of turning to avoid pressure ulcers and several other long-term care concerns
- 5) One reported 4 months of good care in neuro-rehab ward.

Other comments, discussion, experiences and ideas for better services in future

'We need commitment to providing quality services.'

'I want the NHS to take more responsibility for providing services.'

'We need more counselling services, especially for younger people.'

'GPs should not be able to diagnose neuro conditions or discharge them. That is for the Consultants.'

'Can you speak to your specialist direct?' 'You need one named person.'

'GPs and Consultants use different terminology to patients.'

'We need GPs with special Interest in Neurology.'

There was some discussion about the problems of being on your own with no support.

It was said that ‘many GPs do not know or understand’.

Praise was given for the West Berks Council Team under James Hamilton for making ‘good referrals’.

Two attendees said that ‘hospitals should provide space for support groups to meet’.

‘The voluntary sector is there to give advice but is not getting NHS support.’

‘Support groups are run by people with experience but people also need access to someone with medical expertise.’

‘Where to get advice is important. Need some training.’

‘The NHS could do better by helping groups to link together.’

‘In Southampton the NHS seems to offer more support.’

‘There is great value in sharing information. It can be dangerous to generalise with information.’

‘We need someone to be able to talk to.’

‘We want the NHS to recognise there are people with Polio in this country.’

‘If you have an MRI scan in Royal Berks the results take three weeks whereas in Royal Marsden you get the results on the same afternoon.’

‘Why don’t the PCT have a list of all voluntary organisations and give that information to all GPs?’

Comments on ‘Post-it’ notes collected after the meeting, or received by email

‘Direct referral to save GP time.’

‘Support groups run in hospitals free of charge.’

‘Provide Internet access for patients.’

‘We should have MRI scans ‘same day results’ to alleviate stress and worry.’

‘Increase the number of specialist rare conditions nurses (although stroke would not come into this category as it is certainly not rare) these nurses could provide the medical support to the non-professional self-help groups.’

‘Have a clear care pathway from patient to information (not the Internet) e.g. email link to specialist nurse, consultant, etc.’

Portal in every GP surgery and ‘Exhibition Corner’ in RBH where one pane is ‘contacts for local support groups’ and the other a ‘useful contacts pin up board’

Every rehab patient to leave rehab with a home physio routine learnt under supervision in rehab.

NHS contact number and help line for those seeking support to self-manage rehab.

Appendix

READING PARKINSON’S DISEASE SOCIETY AND WEST BERKSHIRE PEPS (PD Young Onset Group)

NEUROLOGICAL SERVICES QUESTIONNAIRE

Profile of participants:

| | |
|-----------------------|---|
| Date of survey | September 24 th with phone follow-up |
| Survey participants | 13 PwPs and 0 Carers |
| Age range | 47 – 65 |
| Gender | M – 4, F - 9 |
| Years since diagnosis | Mean 5.6 years |

Please answer these questions by ticking the boxes and commenting below.

1a Your experience at diagnosis

| Were you accompanied or alone after diagnosis appointment? | Who gave you the diagnosis? | Did you see the PD specialist nurse on that day? | Did you receive any information about PD on that day? |
|--|-----------------------------|--|---|
| Alone – 9 | Neurologist – 11 | Yes - 1 | Yes – 2 |
| Accompanied – 4 | GP – 2 | No - 12 | No - 11 |

1b Evaluate the support given to you by each of the following in the early days after your diagnosis.

| Health Professional | Good (+2) | Acceptable (+1) | Poor (-1) | Overall Rating (weighted) |
|---------------------|-----------|-----------------|-----------|---------------------------|
| GP | 4 (+8) | 2 (+2) | 2(-2) | +8 |
| Neurologist | 6 (+12) | 2 (+2) | | +14 |

| | | | | |
|------------------------|--------|--|--------|----|
| PD Specialist Nurse | 3 (+6) | | 4 (-4) | +2 |
|------------------------|--------|--|--------|----|

Remarks:

- The PD Nurse did not contact me despite requests from Consultant,
- GPs should be more aware of PD symptoms
- It took 3 years before the GP sent me to the neurologist (at my insistence). Previous to this they were treating me for benign essential tremor.
- I could never get through to the PD Nurse; I e-mailed the Neurologist instead and he was helpful but pushed for time.
- Services are under-resourced and GPs “under-knowledged”, but willing to learn.
- Apart from the news, not a bad experience. Too much information on that day would not be right, as it would not be taken in. It would have been good to have a follow up within 2 weeks so when the news had sunk in you could ask better/considered questions. As it was the next appt given was 6 months away. To be fair I was offered an email contact and the Newbury ISW came to see me within a month.
- I would have appreciated some follow up sooner from the PD Nurse but I understand how busy she was at the time. My family was very supportive and searched for information via the Internet and joined the PDS.
- My G.P. has been superb. However, no one from the medical profession has ever explained to me what PD is. This has not been a problem for me as my partner and I have done research ourselves but I think it's a huge issue for patients who are alone, or have no-one to help them understand the complexities of their condition, the options available to them, and so on. In my experience, the people with PD know more about the condition than many of those in the medical profession. I would strongly advise anyone who has been diagnosed with early onset PD to speak to another early onset PWP as soon as possible, and to keep off the PDS website initially.
- Doctor apologised that he had not leaflets to give me on PD. Suggested I bring questions to next appointment, and family if they had questions. Said that there would be PD nurse starting soon.

2. Information and support

Who has helped you manage PD? Please tick any box which applies.

| Health professional / organisation | Managing your symptoms and medication | Providing information on services and support | Helping you to gain access to benefits and entitlements | Overall hep rating |
|------------------------------------|---------------------------------------|---|---|--------------------|
| GP | 4 | 0 | 1 | 5 |

| | | | | |
|--------------------------|---|---|---|----|
| Neurologist | 7 | 3 | 1 | 11 |
| PD Specialist Nurse | 4 | 2 | 1 | 7 |
| PDS Support Worker (ISW) | 1 | 5 | 4 | 10 |
| PEPS | 2 | 7 | 1 | 10 |
| Internet | 2 | 3 | 2 | 7 |

Remarks:

- Most of my information come is from the PDS, sufferers and carers.
- I have found support from the PDS Support Worker (ISW) invaluable.
- At hospital appointments we only get to see the PD Nurse, not the Consultant even though I was recently diagnosed with MSA.
- Superb Oxford PD Nurse. Excellent ISW in Newbury.
- ISW in Reading is ineffective as is the PD Nurse. Now I won't go to Reading hospitals.
- PD Specialist Nurse particularly helpful.
- PD is very individual and professionals rely on patient feedback, therefore patients can influence treatment received.
- I am not impressed by the "support" given by NHS. If I had not contacted the PDS I would be on my own. A less confident person would have problems going to a new venue/meeting/association and would be really alone. It is daunting when you feel that you may see people with advanced Parkinson's who could be a glimpse of your future) I found it daunting walking in to the hall the first time but luckily people were friendly and I did not just do a runner!

3 Getting help when you have PD related problems

If you have experienced difficulties with Parkinson's and need help urgently, who have you contacted and how helpful have they been?

| Service | Good (+2) | Acceptable (+1) | Poor (-1) | Overall Rating |
|-------------|-----------|-----------------|-----------|----------------|
| GP | 3 (+6) | 1 (+1) | 1 (-1) | 6 |
| Neurologist | 3 (+6) | 1 (+1) | 0 | 7 |
| PD Nurse | 3 (+6) | 2 (+2) | 1 (-1) | 7 |
| PDS | 1 (+2) | 0 | 2 (-2) | 0 |
| Other | 1 (+2) | 0 | 0 | 2 |

Remarks:

- PD Specialist Nurse particularly helpful.
- Oxford Neurologist and Nurse very good.
- Most information comes from PDS and from people that I know who are sufferers and carers.
- There needs to be a lower patient / clinician ratio, more training for GPs and more support groups like PEPS.
- I don't often ask for help.

4. Experiences of being in hospital

| Hospital experience | GOOD | ACCEPTABLE | POOR |
|---------------------|------|------------|------|
| | 1 | 1 | 1 |

Remarks:

- I did not always get my medication on time, which is important for PD sufferers.
- Lack of support with PD
- Lack of support, understanding, knowledge and empathy towards the condition. Nurses on wards should be trained to some degree of help with PD.

5. Changes needed to make services better

Remarks:

- I have not demanded much from the services so far. There is too much focus on elderly sufferers. I would like to see more of a balance here.
- GP needs to be better informed
- GPs knowledge is out-of-date.
- GPs need further training
- Better communication required between GPs and professionals
- Reliable supplies of medication; local pharmacies have not had Azilect available on several occasions.
- Needs to be easier to get help with problems. For example, I rang the PDS help line the day before yesterday to speak to the Specialist Nurse, but none available – they have phoned me twice when I have not been at home. I have never yet seen a specialist Nurse and have had to find information for myself. More training for GPs and continuity of care are needed. Parkinson's awareness training for GPs.
- More support groups like PEPs

- Information was given but I felt that it would have been helpful if I could have spoken to another young-onset patient. Felt very alone for a long time.

Prepared for: Local implementation Team, Older People & Long Term Conditions, Care Group Commissioning, Commissioning & System Reform Directorate, Berkshire West Primary Care Trust

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