

# *West Berkshire Neurological Alliance*

Representing all people in Berkshire West affected by a neurological condition

## **Report for Berkshire West Long Term Conditions Board**

### **Continuity of care**

#### **Findings from a focus group held at Padworth on 16<sup>th</sup> June 2014**

#### **Purpose**

- To identify situations where continuity of care is important and identify personal experiences and impacts.
- To identify risks and benefits of disjointed and joined-up services
- To identify good practice for others to consider.
- To explore how services could be improved for the future

#### **Findings**

Attendees had praise for many health professionals and for some health and social care systems when they had worked well. However all delegates, for various reasons, had experienced poor continuity in care in many scenarios, resulting sometimes in significant consequences.

Many clinicians and others are not familiar with neurological conditions or what it is like to live with a neurological condition. Some health and social care services would seem to be designed more on a 'one-size-fits-all' basis, into which an individual presenting with a neurological condition may not fit well. Many care pathways are more absent than real and some services are better integrated into the wider system than others.

Some services, including diagnosis, OTs and physiotherapy are sometimes too slow to respond to need. Some such as the Wheelchair Service apply criteria that appear inappropriate, leaving easy-to-meet needs unmet.

#### **Recommendations**

- Health and Social Care staff training should include modules on 'what it is like to live with a neurological condition', also on 'improving your listening skills' and 'ensuring continuity'.
- Commissioners should review services used by neurological patients, to move on from any 'one-size-fits-all' approach still offered by some services, to providing individualised services where these are needed.

- Care pathways for neurological patients should be clarified, publicised and followed always in a timely manner.
- The statutory sector should make more effort to ensure closer working with the voluntary sector.

### **About the focus group attendees**

Ten people were present, some in more than one capacity. There were three males and seven females. The age range was 25-75+, some having been diagnosed in pre-teen childhood. Two delegates were only recently affected by a neurological diagnosis, most being affected for 15 years or much longer. One wheelchair user was present and other wheelchair users were represented. Conditions represented included MS, Stroke, Polio, MND, Epilepsy, Pain and Learning Disabilities

### **Format of the Focus Group**

Only patients, carers and neurological voluntary sector volunteers were invited. The pre-advised agenda was:

Open discussion:

situations where continuity of care is important  
personal experiences and impacts

risks and benefits of disjointed and joined-up services  
good practice for others to consider

The delegates determined their own priorities for discussion within the above.

### **Limitations of this Focus Group.**

There are perhaps 1,000 neurological conditions, such that the experiences raised at a small, two-hour focus group cannot cover comprehensively the subject of continuity. The themes identified do not represent the full extent and nature of health and social care systems and continuity needs or lapses. This report provides pointers for reflection and further work.

For further information about this focus group please contact:

John Holt,

*West Berkshire* **Neurological Alliance**, 2, Clayhill Crescent, Newbury RG14 2NP

Tel: 01635 33582 [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com) [www.wbna.org.uk](http://www.wbna.org.uk)

Registered Charity No: 1081021

## Appendix

### Consolidated notes of the Continuity of Care Focus Group (based on two sets of notes)

A Polio survivor commented that the word, which keeps coming up, is 'Criteria'. She feels that it is a hook to hang things on when medical staff do not know what to do. *'Professionals consult their 'criteria' before doing anything and then you find you don't qualify.'*

A delegate commented that staff on the NHS '111' number have a tick list which does not necessarily have any relevance to the person ringing. *'The list needs looking at by people affected by disability.'* *'When ringing 111, the respondents don't know what polio is. They should be asking 'how does this affect you? The British Polio Fellowship's membership is increasing because of the increase in immigrants who have been afflicted with polio.'*

*'The CCG should have a session about 111 in order to understand it from a patients point of view.'*

One carer would not use the 111 service because: *'I need something more responsive, to take over accurately from where I have no choice but to leave off.'*

A delegate with epilepsy stated that when he has a seizure people call an ambulance, *'presumably because they are frightened'*, but by the time it arrives he has recovered and he does not need their help.

A stroke survivor needed to call an ambulance when with a nosebleed, being on warfarin and the bleed would not stop. *'The initial response was 'why bother us with this?' until they heard the word warfarin.'*

A delegate's wife was taken to the RBH when she had a stroke, which caused a delay in the planned removal of an ovarian cyst, which then became very large. In due course she was moved to West Berks Hospital for physio. When she arrived she had been able to stand but she deteriorated and was no longer standing, so the physio did nothing for her. The couple have since employed a private physio and the wife is now standing again. She also suggested various aids, which helped. These were sometimes provided free, or they paid for them privately if there was a significant delay. The waiting time for aids recommended by an OT is about a year. The carer feels he is the key to continuity of care and there is *'no financial support'*.

A delegate described a West Berkshire patient with MND who had been assigned an OT who was retiring and who was replaced by one who lived in Cheshire! The

patient needed an arm support and there was a significant delay in providing it. The specialist nurse was off sick so there was no support.

A stroke carer's wife had had 4 different OTs in 4 years but they have all been very supportive. He has tried "Access for All" which is a portal for anyone who needs support. He thinks the stroke club, a voluntary organisation, is '*marvellous*'. His wife goes to the club at Woolhampton but had to wait for a place.

An MS delegate tries always to be very positive. '*The MS group has been very supportive. People with disability have to rely a great deal on the voluntary sector.*' Another MS delegate stated: '*The MS voluntary sector is a larger provider of support than the NHS, and is good at signposting to statutory services*'. '*Why does the statutory sector provide new services without consulting the voluntary sector better?*'

A Polio survivor had requested a powered wheel chair but was told she was only entitled to a manual one. '*How can I use a manual wheelchair with only one useable arm? I would go round in circles. And how would I carry shopping?*'

A delegate informed that the continence advisory service had once said that his wife had been assessed correctly for incontinence pads. He responded by saying '*You try it, then!*' The result was to increase immediately the supply of continence products.

One delegate requires continence pads for the bed and has found that: '*These are cheaper at "Pets at Home"*'!

A delegate described the transition from young people's to adult's services. He felt that he was carefully supervised when young but not so much as an adult and wondered why he now receives so little assessment. He became very depressed. He then found "Epilepsy Action" which '*helped a great deal to improve my confidence*'. He now fund-raises for epilepsy services.

A delegate added: '*It is so good to meet people with the same condition as it boosts one's confidence.*'

One delegate had not noticed any transition to elderly care other than: '*All the annual assessments have now stopped!*' '*Patients should have a regular check-up, to assess their situation.*'

One delegate remarked that: '*The lymphodaema service has changed dramatically. (?for better or worse?)*'

One delegate has her shoes built up and goes to the 'West Country Cobbler' who used to fix her calliper.

An MS patient stated that: '*My original GP used to send me regularly for an assessment, but that has now stopped.*'

A delegate with complex needs stated: *'I used to have an assessment by one consultant for my whole body but now I see a different one for each joint.'*

One delegate has an assessment every six months, which *'gives me confidence'*.

A delegate described a patient with MND who lives alone, whose specialist signed her off and then the district nurse did the same. She got very depressed until her GP said 'See me in 3 months'. (Typically MND has a life expectancy of about 14 months from diagnosis.)

One delegate records his interview with his consultant and plays it back to remind himself what has been said.

A delegate reported that her consultant used to have a physio in the room to assess patients with him, but not any longer.

*'When more than one agency is involved it slows everything up.'*

When his wife is in hospital one carer stated *'I always like to see the staff on all 3 shifts to ensure continuity.'*

*'There is a lack of capacity in the Voluntary Sector and a lack of a plan from the Council about the allocation of resources.'*

*'We should identify cost saving ideas which should be put to the managers so that they can consider improvements.'*

*'There are sixteen different statutory sector organisations providing Mental health services in Berkshire.'*

*'There is a new system for ordering support stockings which is very longwinded and must be more expensive as so many more people are involved.'*

*'If you have an unusual condition, getting any interest at all is a problem. There is no continuity in my care.'* (Polio survivor.)