

**Report for Berkshire West Neuro Local Implementation Team**

**Accessing physical therapies, pain management and psychological support**

**Findings from a focus group held at Padworth on 4<sup>th</sup> October 2010**

**Executive Summary**

In general, the pathway and access to therapies is unclear or not followed and this requires radical review. The training of statutory sector therapists should embrace more neurology needs-awareness. A development programme is required that would ensure the statutory sector is able to provide a wide range of therapies that would bring services into the modern era. Audit and improvement programmes should be used to drive this, built upon patient experiences and perspectives.

At this Focus Group eight different long-term neurological conditions were represented. There was general agreement that some useful, statutory sector therapy services are available, meeting some patient needs in some instances. However these services tend to be time-limited. Also, securing prompt referral and the right mix of services is generally a problem. Most of those participating mainly relied on voluntary sector or private therapy. Family, friends and the voluntary sector were very highly rated for provision of psychological support, with statutory sector services regarded in general as relatively lacking in accessibility, helpfulness, relevance or value. In particular, the tendency for many GPs to prescribe pharmacy rather than psychological support therapy is seen as unhelpful.

Sometimes NHS staff provide therapy through a multi-disciplinary team, which delegates tended to rate well and some individual therapists were rated as providing well-considered, holistic care. However many therapists have little or no knowledge of individual neurological conditions and there is clear evidence that sometimes staff assume the wrong things about patients' abilities and needs.

The problems identified by the participant who was newly diagnosed were largely around how to get the referral system switched on and most present also had experienced this problem early in their own diagnosis. In contrast, those who had long experience of their condition had tended to become increasingly expert in the range of therapies that were likely to work for them. Those present with longstanding conditions generally were well connected to others with the same condition and this was seen as one of the best ways to find out what might work. For many this had led to them now taking combinations of therapy based on long periods of experimentation, but little of this is obtainable from the statutory sector. Most present were critical that statutory sector therapists seem not to be well versed in the range of therapies from which neurology patients acquire benefits.

The key implication for PCT Commissioners is to ensure that therapy services are restructured around real patient needs, with a more extensive range of local services providing personalised packages of holistic care, drawing on a very wide range of therapies, rather than the 'one size fits all' and narrow range of services currently on offer through a poorly thought out and poorly followed care pathway.

## **Purpose of the Meeting**

The purpose was to capture the expectations, experiences and outcomes of neurology patients in using a broad range of therapy services and, from this, to identify best practice. The intention is to help local service providers to understand where there may be gaps in services and how to work towards providing more relevant or better services in future.

## **Limitations of this consultation**

Neurology conditions are many and diverse and this consultation covered an incomplete cross section, with only a small number of participants (8 conditions), a bias as regards age range, (all above 40 yrs) and a feminine bias, (5F, 2M). There was only one carer present. No participant was wheelchair-bound. There was one family support worker present. 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 two attendees were serving in such a capacity. This arose because the extensive and protracted recruitment campaign had 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.

Either individually or collectively, those taking part should not be thought of as 'representative' or 'typical'. They were selected by local charities of which they are members because they are intelligent, 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.

## **Conditions Represented:**

Parkinson's  
Myalgic Encephalitis  
Fibromyalgia  
Polio  
Multiple Sclerosis  
Motor Neurone Disease  
Brain Haemorrhage  
Stroke

## **Participants**

Brain Haemorrhage and Stroke survivor	West Berkshire
Head injury patient and PD carer	Wokingham
Motor Neurone Disease patient	West Berkshire
ME + Fibromyalgia patient	Reading
ME support admin worker	Reading
Multiple Sclerosis patient	West Berkshire
Parkinson's patient	Wokingham
Polio patient + branch support worker	Reading
Stroke family support worker	West Berkshire

There were no independent observers present apart from 3 facilitators from **West Berkshire Neurological Alliance**

**Chairman/Lead:** John Holt

**Recorders:** Gill Hall, Fred Davison

## **Experiences of Patients using Various Therapy Services**

### **1. Physical Therapies**

#### **Brain Haemorrhage and Stroke**

This participant pointed out that initial physiotherapy is very good but patients receive only 12 weeks treatment. Sometimes they feel abandoned and want better access to services. Some people even have to wait for a bed in a rehabilitation unit in order to get physiotherapy treatment. The patient found Pilates to be very good, but experience with physiotherapy has been 'hit and miss'. Although Pilates is very useful, it is not mentioned by rehabilitation staff.

#### **Stroke Care Support**

Early physiotherapy is provided but not down-line after a year, when it has to be paid for. Stroke Care pays for physiotherapy for stroke survivors in its local area.

#### **ME/FM**

This patient pointed out that physiotherapy for long-term pain conditions is not available, only being available for acute conditions. She uses an osteopath, acupuncture and also *Bowen* relaxing therapy but has to pay for it herself. Yoga classes for ME sufferers are available, funded by PCT, but this is not a long term provision. She attends community-based yoga classes and Tai Chi that are intended for fit people. The local ME Group subsidises attendance at yoga.

#### **Polio**

This polio survivor used physiotherapy initially but it was not very useful. She requires occasional physiotherapy treatment rather than on a regular basis. Hydrotherapy provides fantastic pain relief was but, at present, it is only available at the Royal Berkshire Hospital pool and users need to book a block of treatment, not just call in when treatment is needed. She pointed out that patients would like to be in control and have treatment irregularly not frequently. She attends the West Berkshire Rehabilitation Centre to keep her name on the records, but for a condition that is deteriorating she would prefer to 'dip in and out' as and when she feels she needs treatment. She uses Pilates as a soft impact exercise, which helps with movement and pain relief. She obtained advice on exercising from her doctor and has bought her own machine. She doesn't want to go out to a gym

She pointed out that for the recently diagnosed, the help of an occupational therapist (OT) could be very useful but as time goes on a patient gains in experience and knowledge and does need OT support. The patient always needs to be asking questions and needs an enquiring mind to manage her condition.

A handbook on what is available costs about £26 to obtain up-to-date information. This person considered that if you want 'kit' the critical level for eligibility is set high.

### **Parkinson's Disease**

Parkinson's Disease UK (PD UK) provides funds to use a private hydrotherapy pool and also provides physiotherapy. This patient pays privately to have treatment from a chiropractor every 2 months and she has tried using Pilates. She is also trying Speech and Language Therapy (SaLT), as she needs to prevent choking. Most useful of all has been the purchase of a Nintendo Wii to follow a personal balance and exercise regime at home. Nintendo Wii Fit is joining with PD UK to promote the provision of a gentle exercise regime that might help with balance and relieve muscle pains for PD sufferers. It also helps with weight reduction.

### **Motor Neurone Disease**

No community physiotherapy is available and the patient has been told to do Pilates exercises. He has paid for physiotherapy on a monthly basis because the NHS will not fund regular physiotherapy. Social Services provided an Occupational Therapist (OT), who is very good and helped him develop strategies to cope with activities needed for daily living, such as lifting his arm up to mouth to eat, as well as advice on installing a wet room. This OT support is available indefinitely.

### **Multiple Sclerosis**

The MS patient had suffered MS since 1990 and is now a volunteer with the MS Society. She has 6-weekly physiotherapy sessions, her GP recommends her for 6 weeks of sessions and then she has a 12-week break.

### ***Information on MS Physiotherapy Service***

*The MS Physiotherapy Service was initially pump-primed by the local MS voluntary sector, which raised money from various charities to run a service at West Berkshire Community Hospital. An impact study demonstrated its benefits and now the NHS picks up the bills.*

## **2. Pain Management and psychological support**

The discussion started with the premise that doctors prescribe pills for neurology patients rather than psychological or other forms of support. There was a clear consensus from the delegates that this seems to be the case.

### **Stroke**

This stroke survivor reported that stroke sufferers often suffer from depression but don't want to ask for help, as they would rather cope themselves. It would be more beneficial if counselling were provided as part of the standard treatment package.

This patient valued the camaraderie at the Stroke Club and felt that members can open up and even be tearful as everyone is sympathetic and supportive. The counsellor is helpful and peer support is very valuable providing a positive attitude. It is difficult to talk with partners, as they may have personal feelings that you don't want to hurt.

**Stroke care support worker** added that after stroke there can be a change in personality so it may be worth offering counselling to both partners. Sometimes it is better to talk with someone outside the family, as a stranger can say something family cannot say. In the Stroke Club they partner people, so a person can share experiences. Also a family tends to offer to do things for you.

## **ME/FM**

This patient relies on the voluntary services for psychological support and felt that pills are often 'dished out' rather than counselling being offered. It would be good if counsellors came to the home, in cases where the patient does not want to go out. She commented that support is sometimes provided by trainees who work with surgeries.

## **Polio**

Pain can be managed using a self-help approach, such as Pilates, perhaps supplemented by drugs if the pain becomes too much. She commented 'Everything has to be planned carefully.' as she needs to arrange her life to cope with feelings of tiredness and pain. The tiredness is worse later in day and made worse in winter when it is cold.

She didn't expect her GP to have full information on every condition so valued a support group which provides specialist personal information rather than information out of a textbook. Partnering with another patient can be absolutely fantastic. Fellow sufferers are more in tune and provide camaraderie, support, friendship and advice. You can open up and laugh and share a joke.

## **Parkinson's Disease**

Her pain is controlled by exercise and the odd painkiller. No one has asked about her pain or depression. After her son died it took 3 years to obtain 'emergency' counselling. The Talking Therapies' services sounded interesting but no one has got in touch after her request for such support.

The Expert Patient scheme very useful but patients need to be able to get onto it. It sets goals for the patient but these are very general. She found 'support from the NHS was zero'. Friends and family and especially friends from PD UK have been excellent.

## **Motor Neurone Disease**

This delegate suffers no pain of the kind sometimes associated with MND.

The MNDA support group meets every 2 months but even seeing people with the more advanced condition helps you understand more about the disease. He was saddened by the lack of response from his GP. After each specialist consultation the consultant writes a report for the GP but the GP never gets in touch to discuss it. 'You need to ring the GP and ask for an appointment.' He felt that support groups are much better than GPs.

## **ME/FM**

The delegate has suffered several years with ME and doctors don't understand dosages of drugs. ME and FM sufferers need only half the normal dose. She does exercises such as yoga and gentle exercise to control pain. One of her fellow ME/CFS sufferers can't do a structured course so feels excluded from getting help. Patients need better access to specialist assessments. GPs may not have sufficient specialist knowledge, whereas peer support is valuable.

## **Multiple Sclerosis**

This patient can still drive a car but walks with stick and has them 'everywhere around the house'. She commented that there is only so much energy for the day so everything has to be planned to fit in.

A group of MS sufferers and carers meets up for coffee every week. This provides excellent support through sharing laughs and friendship.

## **Discussion**

*A survey has shown that 43% of all MS patients in Berkshire West are taking pills for depression, anxiety, sleeplessness and related conditions. IAPT (Talking Therapies) was asked to provide an MS specialist talking therapy service but the PCT said that priority was diabetes - even though no one with diabetes had asked for the service. No MS talking therapy service has yet been provided.*

Several delegates responded, indicating that condition-specific, specialised IAPT services should be effective and most welcome for patients with their condition. The ME/FM patient pointed out that the CBT service is 2 hours once a week for ME patients and you need to do a 12-week course. ME/FM patients can be worn out by going to a therapist and a more flexible option would be preferable.

## **3. Discussion about obtaining Support and Advice**

### **Polio**

Make sure rehabilitation centres and GP surgeries have information about whom to refer patients to, especially support groups. You need this information at the start of your journey.

### **Parkinson's Disease**

Her GP continually tells her pills are very expensive.

### **Multiple Sclerosis**

The GP is very good at getting wheels in motion even though she has no specialist knowledge of MS.

### **ME/FM**

She did not get on with her own GP but subsequently found one in the practice that she got on with and who knew something about ME.

### **Motor Neurone Disease**

The GP didn't know about referrals when first diagnosed, so it took 6 months to almost year before he could be seen. An O/T came after 5 months. In a lot of instances like this, patients don't know what to do.

## **General conclusions from the discussion**

Families and support groups appear to be the main sources of psychological support.

NHS therapy services need to be easier to access, with skilled and knowledgeable staff, otherwise they are unlikely to have much relevance or impact, especially to patients affected by fatigue.

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

'Some [patients] have to wait for a bed in a rehabilitation unit in order to get physiotherapy treatment.'

'Physiotherapy for long-term pain conditions is not available, it is only available for acute conditions.'

'I want to have irregular physiotherapy treatment rather than on a regular basis.'

'Hydrotherapy is fantastic for pain relief was but it is only available at the Royal Berkshire Hospital pool and you need to book a block of treatment, not just drop in when you need treatment.'

'Most useful of all has been the purchase of a Nintendo Wii so I can follow a personal balance and exercise regime at home.'

'The Occupational Therapist is very good and helps me [MND patient] develop strategies to cope with activities I need for daily living, such as advice on installing a wet room and help and advice on lifting my arm up to mouth for eating.'

'Pilates is very good, but my physiotherapy experience as been hit and miss.'

'I [Polio sufferer] bought my own machine privately, having seen it on TV, a QCB Pilates machine that provides adjustable tension. I don't want to go out to a gym and don't want to use OT services.'

'...for the recently diagnosed, an OT can be very useful but as time wears on patients gain in experience and knowledge and do need OT support.'

'A patient always needs to be asking questions and needs an enquiring mind to manage her condition.'

'..... people suffering stroke often suffer from depression but they don't want to ask for help, they would rather cope with it themselves.'

'...after stroke there can be a change in personality so it may be worth having counselling for both partners.'

'..... people are often 'dished out' pills rather than being offered counselling.'

'[Post polio syndrome] is worse later in day when you become tired, or in the winter when it is cold. Everything has to be planned carefully.'

'When my son died it took 3 years to obtain *emergency* counselling.'

'ME and FM sufferers need to have only half the normal dose [of medicinal drugs].'

'[ME] patients can be worn out by going to a therapist and a more flexible option should be available.'

'At Stoke Club people feel they can open up, enjoying camaraderie, even be tearful as everyone is sympathetic and supportive.'

'Sometimes it is better to talk with someone outside the family, as a stranger can say some things family cannot say.'

'You don't expect a GP to have full information on every condition. A support group provides specialist personal information rather than information out of a textbook.'

'The MNDA support group meets every 2 months but even seeing people affected by a more advanced condition helps you understand more about the disease.'

'After each consultation at the Royal Berkshire Hospital the doctor writes a report to the GP but the GP never gets in touch.'

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*West Berkshire Neurological Alliance*

**Representing all people in Berkshire West affected by a neurological condition**

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