

**Report for West Berkshire Local Implementation Team**

**Experiences on Hospitalisation of people affected by an existing long-term neurological condition**

**Findings of a focus group held at Padworth on 17<sup>th</sup> May 2010**

**Executive Summary**

At this Focus Group seven different long-term neurological conditions were represented. There was wide agreement that excellent acute services are regularly provided in hospitals across the region. At the same time those present reported recurring and very clear evidence of the general need for hospitals to employ better trained ward staff who would be more able to provide holistic care relating to pre-existing neurological conditions. Loss of dignity (and worse) can and sometimes does arise, particularly when hospital staff are busy or perhaps assume the wrong things about patients' ability as regards their mobility, strength, exhaustion level, continence control, ability to swallow, ability to feed themselves, speaking ability or if they mistakenly appear unable to think for themselves.

When someone with a long-term condition is in hospital their care-givers' (family or friend's) input, as well as prompt access to specialist neurology staff, can make a very positive difference. Some in the Focus Group mentioned not being allowed to take important long-term medications as a problem.

The problems identified by the Focus Group participants seemed to arise almost regardless of which hospital or type of ward people had experienced. The exception seemed to be neuro-rehabilitation wards, which generally received consistent praise, perhaps because the staff there have the right specialist training and a better understanding about neurology and its impacts.

One important implication for PCT Commissioners is to ensure that contracts with secondary and tertiary care should cover not only the need to provide expert and specialised services of suitable quality but that those services should also meet the needs of patients with existing conditions or co-morbidity. Secondary and tertiary care providers must therefore gear-up to meet these co-morbidity needs and the audit and improvement programme should be configured accordingly.

## **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 (6 plus two written submission), a bias as regards age range, (all above 40 yrs) and a feminine bias, (5F, 1M). There were two written submissions and one submission made by a carer. One participant was a wheelchair user and one a support worker. 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 one attendee was serving 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.

Either individually or collectively, the patients and their carers should not be thought of 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**

The meeting was to obtain experiences of patients with a neurological condition(s) when staying in hospital with a view to improving services and information. It is intended that ideas and suggestions be fed to the neuro LIT and RBH

## **Observers present**

Andy Barlow, Reading Borough Council  
Angela Todd, Reading Borough Council  
James Hamilton, West Berkshire Council

## **Conditions represented**

Parkinson's  
Epilepsy  
Polio  
Multiple Sclerosis  
Huntington's Disease  
Motor Neurone Disease  
(ME/CFS via written submission)

## **Experiences during Hospitalisation**

### **Motor Neurone Disease (MND)**

A contribution was read by a representative of a patient in her 50s diagnosed with MND December 2009. Her severe abdominal pain was initially diagnosed as pancreatitis she attend A&E and was told no bed was available, so had to stay on a chair from 23.00 to 04.00h. When admitted she asked to climb onto a bed but was unable. Staff managed to get her into bed where she was unable turn over. Toileting was a problem and could not be managed by a single member of staff and no other staff were available which caused great anxiety. Staff shortages also meant that she was unable to get in and out of bed, so she had to sit in chair all day, which was very distressing. There was no understanding about the condition and staff appeared unsympathetic to her needs.

One good experience was recalled from a patient diagnosed with MND 9 years earlier who was severely physically disabled and used a light-writer to communicate.

### **ME/CFS:**

A written submission was provided by a patient who had been in hospital 4 times in the previous 4 years for two different conditions. The patient had used both the private sector and NHS hospitals. The issues raised were: continence, dignity and understanding. This patient felt the staff needed to listen to the patient and not just the condition for which the patient was admitted. Staff need to consider the whole person and take account their different needs.

This patient recalled that staff were not willing to understand or help the physical disabilities associated with ME. Walking to the bathroom with a wash bag and towel and using two sticks was both difficult and exhausting. In the event another patient helped. When a nurse was asked for help with lifting legs up onto the bed, the nurse could not understand why help was needed when the condition being treated was pneumonia. On a subsequent stay in hospital the staff made the patient sit in a chair and she was not able to get out of it. Luckily she was catheterised so did not have to walk to the bathroom. When her husband visited the patient said she couldn't move and felt exhausted as her feet became swollen When pain relief was requested staff could not understand why she was experiencing pain in her hips and legs.

### **Parkinson's Disease**

A carer told of his spouse with PD who managed her condition for 10 years until she broke her hip. It took 6 months to get the condition under control. Three years later the hip replacement went wrong and she was hospitalised. This time with careful preparations the GP wrote to the orthopaedic consultant and neurologist to alert them. There are problems with entry to hospital in an emergency by A&E. Later his wife broke her femur and the PD was not looked after properly and regressed. Social Services were helpful and with a care plan it took 6 months for normality to return.

In recent years the introduction of PD specialist nurses has provided more specialist advice than from GPs. A few earlier, his wife was asleep and couldn't be woken in morning. The GP aroused his wife and had her admitted to the Critical Diagnosis Unit. The PD nurse and neurologist played a full part in her treatment and the level of care was good. The PD consultant reviewed medication before discharge and provide advice on medication by e-mail, which was much quicker.

Whilst in hospital incontinence is an embarrassing problem. Some staff do not take account of patients wearing continence pads and some hospital staff rely on their use rather than taking patients to the toilet.

### **Polio**

This patient had many stays in hospital but not during previous 6 months. She commented on specialist hospital outpatient services and being fitted with orthotic shoes and callipers. After experiencing increased discomfort in her legs and feet the hospital clinic could find nothing wrong. The GP referred the patient to the Polio Fellowship (PF) for advice. A specialist in London was recommended and recommended a new form of calliper, drawing it to show the local hospital clinic. A new calliper was made but with a Caucasian colour not the natural colour of the patient. After objecting the patient was told nothing more could be done but insisted on speaking with a manager. Eventually a new manufacturer was found and a new calliper in correct skin colour was made.

The problem highlighted the fact that medical staff see few people with polio so have no experience, hence they continued prescribing an out-of-date and unsuitable calliper design. The new calliper is made of lightweight material and comfortable to wear. The old calliper could have done good deal of harm while being worn.

### **Epilepsy**

This patient described her own experiences and those of her daughter, which were, during an epileptic fit, the brain becomes scrambled and the patient can tell lies or deny truth. She described how her daughter, after having a fit, gave name and date of birth correctly but claimed that she was at a friend's house when she was actually in her own home. Also after a fit the patient has no control of their body. On another occasion the ambulance man considered there was no need for the patient to go into hospital and prepared to leave. However, her mother noticed there was blood between legs for whilst fitting, the patient had fallen and 'done splits' tearing the skin between her legs. Medical staff need to be aware that after fitting the patient can say they are feeling fine yet fail to admit they have serious injuries.

It was pointed out that there are not enough people with experience of epilepsy to understand what is wrong; 99% hospital treatment is fine but in 1% of cases can be o staff do not understanding epilepsy with potentially serious problems.

## **MS**

This patient was diagnosed with MS six years ago and taken to a general hospital ward. The ambulance service was good. She had physiotherapy treatment and was transferred to rehab ward. The O/T was prepared to allow her to go home even though it meant she her using a commode in and open plan downstairs with 3 teenage boys and a husband at home. Weighing 25 stones she was not supposed to go upstairs and therefore couldn't bathe herself. Eventually after much persuasion, a bath board was obtained from WBC social services otherwise husband had to lift her.

Later, after suffering an accident using her mobility scooter and tearing ligaments a hospital junior doctor X-rayed knee, which went into spasm and caused agony. She informed the doctor of her MS and was sent to a ward for 3-day stays. The stress and pain resulted in increased MS symptoms. Her husband visited daily and was able to catheterise, as was his practice at home. He also had to feed her. During a doctors round, she choked on toast and this was nearly fatal.

Since this experience hospital visits have needed to be planned. The patient is reluctant to go into hospital and would rather be in her own home and be able to seek advice by email. She also pointed out that continence advice is a real problem. Fortunately been able to get helpful advice but it is essential to have information about the most recent products. It would be useful to have a leaflet about the neuro-condition on helpful things to know.

## **Huntington's Disease (HD)**

This patient experience was provided by a HD support worker. Circumstances surrounding the diagnosis and treatment of a patient with Huntington's disease but who also had diabetes were described. The family began noticing small personality changes and involuntary body movements, symptoms that were put down to diabetes. The family, after searching the Internet, suspected it was HD but the patient became violent and aggressive and was arrested regularly. The diabetes went out of control. Once, on being taken to hospital by paramedics the police had to be called. After becoming progressively worse the patient assaulted his wife causing her to break her hip.

The GP refused to accept it was HD. After spending 7 months in hospital, all symptoms put down to diabetes. No tests for HD were carried out but when eventually they were done it was confirmed. Hospital was a most unsuitable place but the bad behaviour meant refusal by most homes. Eventually a place providing one-to-one care was found. He had several falls and was admitted to hospital the on to another care home. He was also threatened with 'Sectioning'.

The story shows protracted diagnosis with the patient suffering pain and frustration over a 19 yr period. The patient now has some understanding but can't feed himself or communicate. The younger son has recently diagnosed with HD.

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

'Staff shortages on the ward meant that she was unable to get up out of bed so had to sit in chair all day.'

'There was no understanding about the condition (MND) and staff appeared unsympathetic to her needs.'

'...a patient with MND for 9 years who was pretty physically disabled and uses a light-writer to communicate. This patient had to go to Critical Diagnosis Unit where he had a good experience.'

'The patient is unable to walk far to the bathroom, which makes it difficult. Walking with two sticks makes it difficult to carry a wash bag and towel and actually it was another patient who helped.'

'The staff made the patient sit in a chair and she told them that if she had to stay in the chair she would not be able to get out of it.'

'It took 4 nurses with a hoist to lift her into bed and her feet were so swollen it took a day for the swelling to recede.'

'In both hospitals she had experience this patient felt the staff needed to listen to the patient and treat not just the condition the patient had come in for. Staff need to consider the whole person and take account their different needs.'

'This time there were careful preparations and the GP wrote to the orthopaedic consultant and neurologist to warn them of the problems. '

'There are problems with entry to hospital in an emergency by A&E.'

'Over last few years Parkinson's UK has supported specialist nurses. GPs can't give direct advice because they don't have the specialist knowledge.'

'The PD nurse was at the bedside and introduced her to the neurologist who played a full part in her treatment. The doctor in charge had good knowledge of Parkinson's. He was impressed with level of care and the food that was provided etc.'

'Advice on medication was sought from the consultant by using email. He responded quickly by email and the consultant changed the medication and treatment and switching to transdermal patch for delivery of the drugs.'

'This carer pointed out that incontinence is an embarrassing problem. Some staff do not take account of patients wearing a continence pad and in some places hospital staff rely on them rather than having to take patients to the toilet.'

'The problem showed that medical staff see so few people with polio, they have no experience and so the Reading staff continued prescribing a calliper design that the patient had used since she was 14.'

'Everyone should be aware that after fitting the patient could say they are feeling fine yet fail to admit they have broken bones or other injuries.'

'She was transferred to rehab ward and the O/T was prepared to allow to come home even though it meant she had to use commode in open plan downstairs when she has 3 teenage boys and her husband at home.'

'The patient was left in bed and given meal but was unable to eat on own. Husband had to do her feeding.'

'Weighing 25 stones the staff assumed that she was too fat to get into bed.'

'The patient would rather be in her own home and be able to seek advice by email than go into hospital.'

'His GP refused to accept that it was HD.'

'A service provider representative commented that medical staff are reluctant to be inquisitive about other conditions, once one condition has been diagnosed.'

### **Some points raised during discussion**

#### **Treating the underlying neurological condition**

A service provider representative commented that medical staff are reluctant to be inquisitive about other conditions, once one condition has been diagnosed.

An attendee commented that when his wife went into hospital he provided drugs but these were not used.

Another commented that staff tend to stick to drugs round and be inflexible about giving drugs at other times even though this may be warranted by the neuro-condition.

Another problem is that self-injected medication is not allowed and hospital staff may not have been trained to carry out procedure.

PD UK reported large numbers of husband/carers take medication along and administer medication themselves to find way around the system.

#### **Lifting and transferring**

Health and Safety rules are very inflexible so many staff will not do lifting of patients.

Insufficient staffing may mean patients are restricted to staying in bed or else left in a chair all day because transfers or assistance is not possible with a single member of staff.

The consequences of prolonged immobility can be swollen joints and unnecessary pain. This can lead to further complications.

Large patients are a particular problem and hoists may be needed.

### **Patient dignity**

Staff made a patient sit in a chair even though she told them that she would not be able to get out of it. Fortunately, she was catheterised so did not have to walk to the bathroom.

Incontinence is an embarrassing problem. Some staff do not take account of patients wearing a continence pad.

On some wards hospital staff rely on patients wearing continence pads rather than having to take them to the toilet.

One patient was left in bed and given meal but was unable to eat on own. Fortunately her husband was available to help.

### **What You Need To Know About My Condition**

The Neurological Alliance has produced a document entitled '*What You Need to Know about My Condition*' see Appendix. It allows the patient to describe their needs and how they wish to be treated. The leaflet has been trialled and found to be very useful as it allows the patient to explain their requirements for treating their neurological condition and preventing it from regressing whilst in hospital. The template is available in electronic format and has been distributed to the local Patient Advisory and Liaison services. It can be downloaded from Neurological Alliance website ([www.neural.org.uk](http://www.neural.org.uk)) or WBNA website ([www.wbna.org.uk](http://www.wbna.org.uk))

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*West Berkshire Neurological Alliance*

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

Registered Charity No: 1081021



## What you need to know about my condition

Although I am in hospital for [... *insert* ... ], I also have [... *insert condition* ...], the symptoms of which vary from person to person and are different from one time to another. To help me cope while I am in your care, you need to know the following information.

**Full Name** .....

**The name I like to be called by** .....

**Address** .....

.....

**Telephone** .....

**In an emergency/for more information contact** .....

**Telephone** .....

**GP name** .....

**Surgery telephone** .....

**Specialist nurse/neurologist** .....

**Telephone** .....

### Essential information

*E.g. symptoms which may arise which require urgent attention and what to do in these circumstances, religious/cultural needs, existence of an advance directive*

**Please remember that my condition varies over time -  
ask me what my needs are now**

## Eating and drinking

I eat and drink independently yes  no

I need the following help when eating or drinking

.....

I have the following dietary needs / food allergies

.....

## Communication

My condition does  does not  affect my **intellect**

I have no  some  considerable  difficulty in **hearing**

I have no  some  considerable  difficulty in **understanding**

I have no  some  considerable  difficulty **communicating**

I have no  some  considerable  difficulty **recalling information**

How you can help when talking to me or when I am trying to tell you something

.....

## Mobility

My mobility is  is not  affected by my condition

I experience muscle weakness  muscle stiffness  tremor   
which affects my:

Upper limbs sometimes  often  constantly

Lower limbs sometimes  often  constantly

Torso sometimes  often  constantly

Head / neck sometimes  often  constantly

Hands / feet sometimes  often  constantly

I can walk unaided  with assistance

I can stand unaided  with assistance



.....

## Before I am discharged you need to plan

.....  
.....  
.....

### Other useful contacts (i.e. social worker, voluntary organisation)

Name	Role	Telephone
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....

***More about [condition]***

***Use this box as you wish, for example, to give some general information about the condition to help those who might not be familiar with it, or to highlight a particularly important piece of information about the needs of people who live with the condition, or about your organisation.***

**Thank you for helping to make my stay as comfortable as possible**

**Signed**

Patient (and specialist nurse if desired)

Dated

This leaflet was developed by the Neurological Alliance with the help of its member charities. Particular thanks are due to the Motor Neurone Disease Association, the Sarah Matheson Trust, the Tuberous Sclerosis Association and The Walton Centre.

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