



**Public Awareness &  
Consultation Event on  
neurological services**

**25 June 2009**

**Supporting your right to the best  
health and social services in England**

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## Introduction from LINK Steering Group

York LINK (Local Involvement Network) was launched in September 2008 to take over the role of the Patient and Public Involvement in Health Forum (PPI Forum) in the York Area. The PPI Forum was a group of volunteers who inspected health services in York on behalf of public. The main difference between the LINK and the PPI Forum is that the LINK can investigate issues to do with social services as well as health services.

The money to fund LINKs comes from the Department of Health and is divided between every Local Authority in England that has responsibility for providing social services. Hence there is a LINK covering North Yorkshire, a separate one for York and one for every area in the country. The City of York Council found a 'Host' organisation to help develop the LINK. The reason for this is so that the LINK is not directly managed by the Council giving the staff and volunteers freedom to investigate services without being influenced by council decisions. The Council chose a voluntary organisation based in Hull called North Bank Forum (NBF).

At the LINK launch event, 18 volunteers agreed to form an Interim Steering Group to agree the constitution containing the rules for the LINK etc before the first Annual General Meeting (AGM). The AGM was held in March 2009 and a Steering Group made up from individual volunteers from York and volunteers who are involved in community groups was established.

The role of members of the Steering Group is to discover what people in the York area think about health and social services and investigate any problem that affect more than one person. When the investigation is complete the LINK can make recommendations to organisations to improve their services. When a report is published it is sent to the organisations concerned with a letter outlining the recommendations. The organisation then has 20 working days to reply to the LINK stating what it proposes to do to implement the change.

The Interim Steering Group decided to use a voting system to prioritise the work of the LINK. A debate on various issues that were referred to the LINK from a variety of sources took place during the AGM. To try to include as many members of the community as possible, and have a recorded process that provided evidence for LINK priorities, the voting document was also sent to registered members and was available on request from the LINK office. The problems experienced by people with

Long Term conditions, including neurological conditions were voted on to the LINK work plan for 2009/10.

## **Background to the investigation**

Various problems experienced by people with neurological conditions were referred to the LINK.

Individuals and groups informed the LINK that the beds for patients with neurological conditions that had been based on one ward in York Hospital were now reduced and this was the cause of many of the problems. It was rumoured that the PCT had cut the funding for the beds, LINK Steering Group members questioned NHS North Yorkshire and York about this and was subsequently informed by the PCT Commissioner that this specific funding had not been cut. The LINK was also informed that people requiring neurological care, in the main, are assisted by community services but may need to be cared for in hospital during times of crisis and possibly at the end of their life. Anecdotal information about problems around 'end of life care' related to the reduction of the neurological beds in one area had also been given to the LINK.

The LINK was informed by patients and their carers that when the neurological beds had been based on Ward 38 the staff gained an insight into the different neurological conditions thus the patients stated they received an extremely good service. Neurology is a specialised area, and every person who has a neurological condition has individual symptoms therefore it is very difficult to train every member of staff on all wards on all conditions.

Personalised care plans for people with long term conditions, such as neurological conditions, are scheduled to be implemented in 2010. New guidance has also been issued to help NHS and Social Services staff to ensure that people who have long term conditions are more involved in decisions about their illness and treatment, including their treatment in hospital. It is widely recognised that people with long term conditions require a great many health and social services and often find difficulty in accessing the services they need at the correct time due to the variability of their condition. NHS guidance states that a care plan must be agreed between the person with the condition, their family or Carer, the NHS and social services staff. This care plan must be accessible for all to read so there is no mistake in what has been agreed (National Service Framework

for Long Term Conditions now renamed National Service Framework for Long Term Neurological Conditions).

During the first meeting with York Foundation Hospital Chief Executive and members of the LINK Steering Group it was discovered that three wards had been closed because the hospital had received a reduction in funding from the PCT. The hospital had applied for Foundation Trust status and one of the conditions is the need to show the organisation is financially sound, meaning the services they intend to provide meet with the amount of funding they will receive. In order to balance the books, a decision was made to reduce the number of wards. The 14 beds specifically for people with neurological conditions that were based on Ward 38 were reduced to 8 and moved to the Cardiology ward. Some staff were transferred with the patients but many took early retirement or moved to work in another part of the hospital. When the 8 beds on the Cardiology ward are occupied, patients with neurological conditions are allocated a bed within another ward thus patients with neurological conditions are scattered throughout the hospital. Also, staff on the Cardiology ward could not possibly gain the knowledge and experience required to nurse people with long term conditions in a short time so patients experienced an inferior service until this developed. When asked, York Hospital Patient Advice Liaison Service (PALS) stated that no complaints had been received either before or after the neurological beds were moved bringing into question why people complained to the LINK and not PALS.

The LINK was informed that beds for people with neurological conditions would eventually be reallocated to the Stroke Unit. Stroke is classed as a neurological condition therefore the staff should have more of an insight into the nursing skills required on this ward than others. However subsequent information emerged that the Stroke Unit is permanently full and could not accommodate further patients so the future of the neurological beds would come under a 'Bed Review' that was being undertaken by the Hospital. There appeared to be much confusion on what was happening with beds provided for people with neurological conditions in the hospital therefore the LINK formally requested to have copies of the minutes of all meetings regarding the 'Bed Review' and the time table for this piece of work. However, a written reply was eventually received stating that the 'Bed Review' was being undertaken by a

manager in NHS North Yorkshire and York employment. The LINK has formally requested information regarding this but had not received a reply by the time this report was published.

In order to progress matters and discover more evidence, the LINK Steering Group agreed to hold a Public Awareness and Consultation Event (PACE) on services for people with neurological conditions. Speakers from five main neurological charities were invited to speak followed by a general discussion on what is good and bad with the services available (see appendix 1). Invites were sent to individuals and groups involved with neurological conditions and statutory services.

## Jackie Chapman, Secretary, York Multiple Sclerosis Society Branch

### What is MS?

MS is not easy to diagnose due to its complexity – there is no single diagnostic test and other conditions with similar symptoms may need to be ruled out before a final diagnosis can be made.

A Neurologist is always involved in diagnosis – It is now possible to determine if a person has MS after they have had only one occurrence of neurological symptoms, so long as there is evidence of new lesions on an MRI scan at least one month after the first attack

The following are the most commonly used tests and procedures

- **Neurological Examination and History** – questions about past and current symptoms, physical examination to check for abnormalities in nerve pathways involved in movement, reflexes, sensation and vision, looks for changes in vision, eye movements, co-ordination of legs and hands, balance, sensation, speech or reflexes as well as signs of weakness
- **Magnetic Resonance Imaging (MRI)** - to get an image of the brain and spinal cord a person lies in a tunnel like centre of the MRI scanner which takes about 10 - 30 minutes. It is painless. shows changes in the central nervous system in over 95% of people with MS, shows as white areas in the brain
- **Evoked Potentials** – This involves testing the time it takes the brain to receive messages, small electrodes are placed on the head to monitor how brain waves respond, if damaged messages and responses will be slower or weaker, again painless
- **Lumber Puncture** - carried out under local anaesthetic, involves a needle being inserted into the space around the spinal cord in the lower back, a small sample of fluid that flows round the brain & spinal cord is taken and tested. Most people with MS have abnormal proteins in this fluid, this is not carried out as often as it used to be and tends only to be used where diagnosis of MS has not been confirmed by other tests



## What Causes MS?

The causes still unknown. Research suggests that a combination of genetic and environmental factors may play a role in its development

**Genes and family history.** MS is not directly inherited and unlike some other conditions there is no single gene that causes it – it seems likely that a combination of genes make some people more susceptible. While MS can occur more than once in a family it is more likely this will not happen – about 2% chance of a child developing MS where a parent is affected

**Environmental Factors.** MS more common in areas further away from the equator – relatively common in Britain (very high in Scotland), North America, Canada, Scandinavia, Southern Australia & New Zealand. It is not clear why but it is possible that something in the environment perhaps bacteria or a virus plays a role. No single virus identified but there is growing evidence that a common childhood virus, such as Epstein Barr virus may act as a trigger.

Theory remains unproven and many people who do not have MS have also been exposed to these viruses so just like genes they are unlikely to be the whole story. Some research has also suggested that Vitamin D could be a factor – low levels of Vitamin D have been linked to higher numbers of people developing many different conditions including MS – it could be one of many factors and research into this area continues

## Four categories of MS

**Benign** – mild attacks – does not worsen and no permanent disability – only classified as benign if after 10-15 years after the first onset of symptoms has not worsened – may occasionally develop disability after many years of inactivity – 10% - 30% of people with MS fit this broad description and have had MS many years without major disability

**Relapsing Remitting MS** – for most people around 85% are first diagnosed with relapsing remitting MS - this means they experience a relapse or flare up. Relapse is defined by the appearance of new symptoms or the return of old symptoms for a period of 24 hours or more, in the absence of a change in core body temperature or infection. Relapses occur when inflammatory cells attack the myelin of specific

nerve fibres, interfering with the job the nerve normally does. Remission occurs when the inflammation subsides and symptoms settle down.

**Secondary Progressive MS** - many start with Relapsing Remitting and later develop Secondary disability becoming progressively worse. Around 65% of people with relapsing remitting MS will have developed secondary MS within 15 years from onset.

**Primary Progressive MS** – affects around 15% of people diagnosed with MS. Tends to be diagnosed in older people usually in their forties or later, from outset will steadily get worsening symptoms some people do not have distinct relapse and remissions but experience steadily worsening symptoms – could level off or continue to get worse.

### **What are the Symptoms of MS?**

Very unpredictable - Fatigue, balance problems and vertigo, numbness, tingling, pain, loss of muscle strength and dexterity, stiffness & spasms, anxiety, depression, mood swings, cognitive problems, speech problems, incontinence, sexual problems.

Range from mild to severe, from brief to persistent. Some symptoms are obvious to other people eg walking, others such as fatigue or pain are not, hidden symptoms may be more difficult to understand.

### **Treatment for MS**

Modifying drugs can help to reduce the severity of relapses. Many MS symptoms can be effectively managed using a variety of treatments – OT's, Physio's, continence advisors – psychologists can help with mobility, coordination, continence and memory or concentration problems

### **Living with MS**

Having MS means living with uncertainty and adapting to changing situations. Some people feel relief after diagnosis because they finally understand their symptoms and have a name for their condition, however, shock, fear, grief, or anger are also perfectly natural reactions & it can take several months or longer before these feelings settle down. Adapting to life with MS can take some time and for many people involves compromise and adaptation but with a generally positive attitude and appropriate health and social care most people manage their condition well.

Healthy Eating = well balanced diet, low saturated fats – many diets are sold to people with MS - these tend to restrict or eliminate certain food groups or require certain supplements to be taken – can be very expensive and may be dangerous if followed without medical supervision - very little scientific evidence is available to support these MS diet claims – consult before doing it

- Exercise benefits – consult a health care professional before starting
- Stem Cell – lots of research going on
- Environment – sensitive to heat and humidity although some like it hot
- Infections – consult re immunisation such as flu – always discuss with your doctor, consultant or MS Nurse

MS has now been diagnosed in children as young as four using MRI scanners so the condition does not just affect people in the 25-40 age brackets.

# **Doreen Forster, Specialist Nurse York Against Motor Neuron Disease**

## **What is MND?**

Motor Neurone Disease (MND) is a progressive neurodegenerative disease that attacks the upper and lower motor neurones. Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. In recent years there is evidence to suggest the incidence of Motor Neurone Disease (MND) is increasing. This could possibly be due to more accurate diagnostic testing. Also, as people are generally living for longer, the incidence of a disease more common in older people will continue to increase.

## **MND Statistics**

Motor Neurone Disease is not infectious or contagious. It can affect any adult at any age but most people diagnosed with the disease are over the age of 40, with the highest incidence occurring between the ages of 50 and 70. Men are affected approximately twice as often as women. The incidence or number of people who will develop MND each year is about two people in every 100,000. Seven people in every 100,000 are living with MND in the UK at any one time.

## **Diagnosis**

**Blood Tests** - A blood test will be looking to see if there is any rise in a creatinine kinase. This is produced when muscle breaks down and can occasionally be found in the blood of people with MND. It is not specific for MND and may also be an indicator of other medical conditions.

**Electromyography (EMG)** - The EMG test is sometimes called the needle test, because fine needles are used to record the naturally-occurring nerve impulses within certain muscles, recordings are usually taken from each limb and the bulbar (throat) muscles. Muscles, which have lost their nerve supply, can be detected because their electrical activity is different from normal healthy muscles.

**Nerve Conduction Tests** - This test may be carried out at the same time as the EMG. An electrical impulse is applied through a small pad on the skin; this measures the speed at which your nerves carry electrical signals.

**Magnetic Resonance Imagery (MRI) scans** – The MRI scan will not diagnose Motor Neurone Disease, the damage caused by this disease does not show up on this scan but it is used as a tool for eliminating other conditions which can mimic symptoms of MND.

**Other tests** - The neurologist may request other tests such as a lumbar puncture or muscle biopsy if the clinical findings indicate they could be useful, but they are not always used as diagnostic tools for MND.

### **Different Types of MND**

There are four main types of MND, each affecting people in different ways. There can be a great deal of overlap between all of these forms, so in practise it is not always possible to diagnose a specific type.

### **Symptoms**

The main symptoms are:

**Pain** - Pain and discomfort are not caused directly by the MND but usually due to the cramped positions people are left in. The muscle cramps and spasms can be relieved by changing position. Stiff joints can be helped with gentle exercise.

**Incontinence and bowel problems** - Incontinence may occur if mobility is restricted and getting to the toilet becomes more difficult. The bowel may become constipated due to restricted mobility and/or changes to diet. Diarrhoea may be the overflow from a severely constipated bowel.

**Saliva and mucous** - When swallowing becomes a problem an excess of saliva may pool in the mouth or it becomes thick and sticky. Food or saliva becomes becoming lodged in the person's airway resulting in coughing and feeling of choking.

**Breathing** - Eventually the breathing muscles will become affected by the MND. When this happens a breathing assessment from a respiratory consultant is necessary.

**Cognitive changes** - For most people there will be no cognitive involvement, however approximately 20% of people will undergo some degree of difficulty or personality change. This may be very mild and will probably go un-noticed, but for others the personality change may be quite marked.

## **Complimentary Therapies**

Complementary therapies work in conjunction with conventional medicine. The treatments are becoming increasingly available on the NHS, with many general practices providing access to complementary therapy. Many of the therapies concentrate on relieving stress and anxiety by relaxing the mind and body.

There is currently no treatment or cure for MND so people must be kept as comfortable and pain free as possible.

## Linda Poole, Influence & Service Development Officer, Parkinson's Disease (PD) Society



### What is PD?

PD is a progressive neurological condition affecting movements such as walking, talking, and writing. It is named after Dr James Parkinson the London doctor who first identified Parkinson's as a specific condition.

PD occurs as result of a loss of nerve cells in the part of the brain known as the substantia nigra. These cells are responsible for producing a chemical known as dopamine, which allows messages to be sent to the parts of the brain that co-ordinate movement.

### Symptoms

The symptoms of PD can be classified as motor and non-motor. Motor symptoms define PD has three primary features:

- **Tremor** - which usually begins in one hand. This is the first symptom for 70% of people with Parkinson's
- **Slowness of movement (bradykinesia)** - people with Parkinson's may find that they have difficulty initiating movements or that performing movements takes longer.
- **Stiffness or rigidity of muscles** - problems with activities such as standing up from a chair or rolling over in bed may be experienced.

Various non-motor symptoms may also be experienced, for example: sleep disturbances, constipation, urinary urgency, depression

## **Treatment**

As there is no cure for PD at present, drugs are used to try to control symptoms. The main aims of drug treatments are to:

- increase the level of dopamine that reaches the brain
- stimulate the parts of the brain where dopamine works

In most newly diagnosed people considerable improvements can be achieved by careful introduction of anti-PD drugs. As PD is a very individual condition response to medication varies from person to person and not every medication will be considered suitable for everyone.

When patients don't get their medication on time their Parkinson's symptoms become uncontrolled and they can become very ill. If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their brains can be severely disrupted – leading to the symptoms of the condition becoming uncontrolled.

## **Prognosis**

PD is both chronic, meaning it persists for a long time, and progressive, meaning the symptoms grow worse over time. Although some people become severely disabled others experience only minor symptoms.



## Jo Rudland, Assistant Regional Services Manager, The Stroke Association



### **What is a Stroke?**

A brain attack, caused by an interruption of the blood supply to the brain. This can be due to a blood clot that blocks the flow of blood to the brain or bleeding in or around the brain from a burst blood vessel

### **What is a TIA?**

A Transient Ischaemic Attack or mini stroke is temporary and can last a few minutes or hours. It usually resolves within 24 hours but is a warning sign, don't ignore it.

### **What is the prevalence of Stroke?**

Approximately, 150,000 people have a stroke in the UK each year which is 1 person every five minutes. Most people who have strokes are over 65 but 1000 will be under the age of 30. Babies and children have strokes as well. Stroke is the third most common cause of death. 250,000 people in the UK live with disabilities caused by stroke.

The symptoms of stroke is a sudden onset of numbness, weakness of the face, arm or leg on one side of body. Slurred speech, or difficulty finding words or understanding spoken language. Sudden blurred vision or loss of sight with dizziness, unsteadiness or a sudden fall.

The effects of stroke, depends on part of brain affected. It can cause weakness on the opposite side to stroke but all strokes are different and can be mild or severe. The left side of brain governs talking, understanding, reading and writing and the right side handles perceptual

skills, making sense of what we see and hear and touch plus spatial skills e.g. distance and speed. Swallowing can be affected and an assessment by a Speech and Language Therapist is required. Reading and writing may be affected as well as loss of balance, tiredness and memory and concentration.

**The risk factors for stroke are:**

- High blood pressure
- Medical conditions
- Smoking doubles the risk
- Binge drinking (more than six units in six hours)
- Diet, high salt, saturated fat
- Inactivity

We can reduce the risks by have a regular blood pressure check. Reducing our salt intake and eating 5 portions of fruit and vegetables. We should also limit the amount of fat we eat, drink sensibly, stop smoking and increase our activity.

The National Stroke Strategy contained in the National Service Framework (NSF) for Stroke sets a framework of 20 quality markers for raising the quality of stroke prevention, treatment, care and support over the next decade.

## **Andrew Kent, Secretary, Epilepsy Action York Branch**

### **What is Epilepsy?**

Epilepsy is defined as a tendency to have recurrent seizures (sometimes called fits). A seizure is caused by a sudden burst of excess electrical activity in the brain, causing a temporary disruption in the normal message passing between brain cells. This disruption results in the brain's messages becoming halted or mixed up.

### **Types of Seizures**

There are over 40 different types of epilepsy and many different types of seizures. The two main types of seizures are Partial Seizures and Generalised Seizures.

**Partial Seizures** affect only a small part of the brain.

**Simple Partial Seizures** is when a person is alert and conscious but performs motor movements such as arm jerks or can smell or sense things that are not present. The symptoms depend on which area of the brain the seizure is located. Some people have been charged with shoplifting when experiencing a simple partial seizure because they are aware of what is going on but they cannot stop the activity because the brain not the person is in charge.

**Simple Partial Seizures can develop into Complex Partial Seizures** which is when the person still performs the activity described above but they are not aware of what is going on. This can last for a second or a few minutes and is often unrecognised as people think they are clumsy or ignorant.

Complex Partial Seizures can develop into Generalised Seizures that affect the entire brain.

There are different types of **Generalised seizures**:

**Absence Seizures** – often seen in children. The person is seen to be staring or blinking and loses consciousness for a few seconds

**Myoclonic Seizures** – The person is seen to be jerking a part of their body but not conscious

**Tonic Seizures** – this is when the person goes stiff and drops to the ground but does not convulse. People who have Tonic Seizures always

fall face down and they drop instantly not take a few seconds to fall as most people will do.

**Atonic Seizures** – this is when the person goes immediately limp and falls to the ground. This looks like a rag doll falling.

**Tonic-Clonic Seizures** (used to be called Gran Mal) – this is the classic tonic (going stiff) then convulsing (thrashing about) seizure that everyone recognises as epilepsy.

### **Living with Epilepsy**

Epilepsy changes a person's life because if you display any of the symptoms described above people think you are strange. Or if you display altered awareness people think you are on drugs or have an alcohol problem. Epilepsy is the most common neurological condition affecting approximately 1 person in the average street in Britain. However, most people hide the fact that they have the condition due to the stigma given to it by the general public. Over 75% of people who have epilepsy are controlled by medication. Another 5 % are partially controlled with breakthrough seizures occurring infrequently but the remaining 20% of people are severely affected by the condition. These are the people that are affected by lack of awareness from health and social services.

## Evidence the LINK gained before, during and after the event:

Evidence	Source
<p>Fatigue and bladder control are the most distressing symptoms for people with MS but this is not well understood by nursing and medical staff in York Hospital so people get left in wet beds and say they are 'put down' for not helping themselves.</p>	<p>Presentation from Jackie Chapman at PACE June 2009</p>
<p>It has been proven that a 6-8 week intensive exercise programme helps most people with MS. Woodlands MS Resource Centre could provide this because they have a full time MS Physiotherapist but who will pay?</p>	<p>Presentation from Jackie Chapman at PACE June 2009</p>
<p>Patients are now admitted to different wards in York hospital but 'staff have little or no understanding of MS or MND'. Patients and families find this very distressing. People reported that staff have said things such as "you are lazy, you must try to help yourself". "Why are you so lethargic".</p>	<p>Referred from members of the public to LINK, March – June 2009</p>
<p>One person stated that her mother, who had MS, received excellent nursing care in one of the Elderly Care wards.</p>	<p>Discussions at Tenants &amp; Residents meeting April 2009</p>
<p>The good practice guide for long term neurological conditions published in 2008 states that better outcomes for people with long term neurological conditions can be achieved by a 'workforce that has the right skills, knowledge and competence'.</p>	<p>Good Practice Guild for Long Term Neurological conditions, DH, 2008</p>

<p>There is a lack of suitable equipment. It is vital that MND patients have a comfortable recliner chair, preferably a riser /recliner due to weak neck muscles and lack of upper body strength. People with MND should never be sat in the high upright chairs commonly used in the hospital.</p>	<p>Presentation from Doreen Foster at PACE June 2009</p>
<p>One person refused to get out of bed whilst in hospital because he could not cope with the discomfort in the upright high chairs. The pain people experience is terrible and the positions they are sat in can lead to complications such as a further loss of mobility, chest infections etc. This particular person got a chest infection and died, his family were 'very upset because staff did not understand the need for correct seating'.</p>	<p>Referred from family member of person that died with MND to LINK, April 2009</p>
<p>York Hospital employs Specialist Nurses for many neurological conditions and they visit wards and explain to staff about the care patients require. However, 'one person was transferred around three wards in three days therefore the chance to educate staff is slim'. This is not the first time this has happened. Patients with MND and MS are very vulnerable and their families are very distressed by all of this moving about.</p>	<p>Referred from family member of person with MND to LINK, Feb 2009</p>
<p>Several people reported that they will never go into York Hospital again because the lack of understanding and knowledge of MND. Other people have said this and have kept to it, missing out on necessary interventions because of it and therefore dying sooner than they otherwise would have. One lady was terrified of going back, so much so that in her last few days she was even terrified of going to the hospice, until she arrived and spent her last few days. In the end she was</p>	<p>Referred from family member of person who died with MND to LINK, Jan 2009</p>

<p>happy that she was admitted because everyone was so kind and understanding, "not like the hospital". A sad indictment.</p>	
<p>There is a difficulty in obtaining Disabled Facilities Grants. Due to the length of time taken for means testing, applying and being granted these funds; some people die before the money is available or the alterations are complete.</p>	<p>Presentation from Doreen Foster at PACE June 2009 and Discussions at Tenants &amp; Residents meeting April 2009</p>
<p>Due to the length of time it takes to get an appropriate wheelchair, people are often kept indoors for too long. After numerous calls to the department for an assessment, someone died after weeks of being stuck with an unsuitable wheelchair. The chair was too small so the person was unable to sit in it. Another person waited nine months for a wheelchair and again died before this was delivered.</p>	<p>Information gained from discussions with people via York against MND society, Nov 2008</p>
<p>What is needed is experienced carers in the community who can handle end of life care. They also need to be able to use equipment such as hoists and understand the medications so people can die in comfort in their own homes.</p>	<p>Referred from family member of person who died with MND to LINK, Jan 2009</p>
<p>The main problem for people with PD is that they currently have their medication removed from them when they are admitted to York Hospital. These people need to take their medications at the correct time but staff are often too busy to remember.</p>	<p>Presentation from Lynda Poole at PACE June 2009</p>
<p>The facilities for stroke patients in York Hospital are very good and most of the standards contained in the Stroke NSF have been reached.</p>	<p>Presentation from Jo Rudland at PACE June 2009</p>

<p>There are two wards, one ward is for acute patients who have just experienced stroke and the other is for patients who are rehabilitating. A problem is that patients who are rehabilitating are nursed in a hospital ward therefore they have an increased risk of infection. There should be a community rehabilitation unit for people with stroke such as at White Cross Court or St Helens.</p>	<p>Discussion with member of York Hospital medical staff during community group meeting April 2009</p>
<p>In general services for people who have epilepsy are good but medical staff, including Neurology Consultants, need to take more time with consultations and listen to patients more.</p> <p>The general public need to realise that people who have epilepsy are not stupid, ignorant or slow.</p>	<p>Discussion with members of Epilepsy Action York Branch, April 2009</p>
<p>Accident and Emergency staff in particular need training on the different types of seizures and how to look after someone who is having one. The 'passport' system may help with this – if they take the time to find and read it.</p>	<p>Discussion with members of Epilepsy Action York Branch, April 2009</p>
<p>As branded drugs get older, they cease to be protected by patent. Once this happens, they can be 'copied' and produced slightly more cost effectively. These drugs are called 'Parallel Imports'. It is vital that people who have epilepsy do not swap between branded and parallel imports as often the slightest variation will result in a seizure.</p>	<p>Discussion with members of Epilepsy Action York Branch, April 2009</p>



## Recommendations from the LINK:

The MS society run an MS cafe once per week, and provides transport to enable people to attend. However, this takes a fair amount of money to fund, if the costs etc could be shared with the other neurological charities more people could benefit. It therefore makes sense that everyone should join up with each other to try to make things better.

- 1. York LINK should help to form a 'York Neurology Group' to bring people interested in all neurological conditions together to identify problems, highlight good practice and work with health and social services.**

People with most neurological conditions have suffered as a result of the designated ward being closed in York Hospital. There are also other ongoing problems such as the lack of recognition given to Carers which could be resolved by implementing the standards contained in the National Service Framework (NSF) for Long Term Neurological Conditions. The staff on the Cardiology Ward have now increased their knowledge and experience in how to treat people with neurological conditions, so the services have improved over time. However, the lack of an informed workforce in York Hospital appears to be the cause of much of the problems experienced by patients such as improper use of chairs etc.

- 2. York LINK recommends to NHS North Yorkshire & York and York Hospital that a ward designated for people with neurological conditions is made available, with the necessary equipment.**
- 3. The LINK should also work with the York Neurology Group, York Hospital staff, Social Services and NHS North Yorkshire & York to establish Local Implementation Teams (LITs) for all the NSF for Long Term Neurological Care standards.**

Many people experience problems being diagnosed with neurological conditions such as epilepsy and ongoing problems due to GP's lack of in-depth knowledge about the conditions. The Darzi review recommended that people are given 'information prescriptions' when they are diagnosed. These prescriptions should contain information about the condition as well as the contact details of local voluntary groups that people can access for ongoing support if they wish.

- 4. York LINK recommends to GP's via the York Health Group that an information event such as the LINK PACE day is made**

**available for GP's to enhance their knowledge of the various neurological conditions.**

- 5. York LINK also recommends that GP's provide 'information prescriptions' to all patients when necessary.**

Many problems that people with neurological conditions experience are as a result of staff not being aware of their fluctuating condition. Nurses and Care staff are often not given the initial training required to nurse people with specialised conditions and many would be horrified that they had treated people inappropriately. However, Hospital and Social Services managers and must recognise that this lack of knowledge does impact on the care given to patients/clients. The MS Society has produced a 'Passport' that provides information on individual peoples conditions that may help. York LINK should work with the people on the York Neurology Group to agree which information needs to be included in a 'passport'.

- 6. York LINK recommends to all concerned that the neurological charities work together to provide a programme of training on neurological conditions and this be made available to all hospital and community based staff and student nurses at York University. Particular in-depth training on Epilepsy should be provided to staff working in the A & E department.**
- 7. York LINK recommends to statutory services that a 'Passport' be used for neurological patients in York Hospital, Primary Care and Social Care services.**

Carers and families that have lost loved ones with neurological conditions should be offered the opportunity to undertake a 'Carer's Post Bereavement Course' that includes access to benefits etc.

- 8. York LINK recommends to all statutory services that a 'Carer's Post Bereavement Course' should be jointly funded and made available.**

The problems experienced by people with PD accessing medications at the correct times and people with epilepsy being prescribed and given the correct medications by pharmacist must be addressed.

- 9. York LINK recommends that lockers for patient medications should be installed in all wards in York Hospital so specifically patients with PD can self-medicate while an in-patient.**
- 10. York LINK recommends to NHS North Yorkshire & York that GP's should agree a protocol with pharmacists so patients**

**with epilepsy receive the medications on which they are commenced, whether they are branded or a parallel import.**

The problems of suitable equipment such as recliner chairs, wheelchairs etc being available to people with neurological conditions at the time of need must be addressed.

**11. York LINK recommends that a protocol be drawn up between NHS North Yorkshire & York and Social Services to ensure that a fast-track system is in place that meets the needs of people when equipment is required.**

**12. York LINK recommends that CYC Social Services department looks at the time taken to obtain Disabled Facilities Grants to ensure that no one is kept waiting.**

The training of all Home Care workers must be made more effective and fit for purpose. A robust system for ongoing monitoring would be beneficial.

**13. York Link recommends to CYC Social Services that a programme of intense training including aspects of end of life care is in place for all Home Care Workers.**

**14. York LINK recommends to City of York Council Health Overview and Scrutiny Committee that they monitor regular reports on how many members of staff have undergone the differing types of training.**

The services for people who experience a stroke are reported to be very good in York Hospital and this must be recognised. However, people who are rehabilitating from Stroke need to be cared for in the most appropriate setting. It is well known that hospital wards are not germ-free and the feeling of loss of empowerment people experience as in-patient is also well documented.

**14. York LINK should congratulate York Hospital on their acute stroke services.**

**15. York Link recommends to NHS North Yorkshire & York that they commission rehabilitation services for stroke patients in a more germ-resistant community setting outside a hospital ward.**

## **Bibliography**

Department of Health, *Essence of Care, Benchmarks for Promoting Health*, London 2006

Department of Health, *Concise Guidance to Good Practice: Number 10 Long term neurological conditions at the interface between neurology, rehabilitation and palliative care*, London 2008

Department of Health. *The National Service Framework for Long Term Conditions*, London 2005

Skills for Health, *Long Term Neurological Conditions, A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse*, Manchester 2008

**Appendix 1**

**Public Awareness & Consultation Event**

**Thursday 25 June 2009**

**Central Methodist Church, St Saviourgate, York, YO1 8NQ**

**Programme**

10.00 – 10.30	What is MS? Jackie Chapman, MS Society York
10.30 – 11.00	What is Stroke? Jo Rudland, Stroke Association
11.00 – 11.15	Coffee / tea
11.15 – 11.45	What is MND? Doreen Forster, York Against MND
11.45 – 12.15	What is Parkinson's? Linda Poole, Parkinson's Disease Society
12.15 – 13.00	Lunch
13.00 – 13.30	What is Epilepsy? Andrew Kent, Epilepsy Action York Branch
13.30 – 14.45	Discussion groups
14.45 – 15.00	Recommendations for the future

**Please note that all speakers will give details about the problems people with the conditions experience. No lunch will be provided at this event but tea / coffee will be available for anyone who wishes to bring their own sandwiches.**

**LINK meetings are open to the public**

**Everyone is welcome to attend**



## York's Local Involvement Network

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