

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

**Living with two or more long term conditions**

**Findings from a focus group held at Padworth on 25<sup>th</sup> March 2013**

**Purpose**

- To explore patient and carer experiences following onset of a second medical condition
- To discuss how services could be improved for the future

**Executive summary**

Receiving an accurate diagnosis is the key to being able to evaluate health-management options. However, securing an accurate diagnosis for a single condition can be slow and difficult and unless co-morbidity arises by obvious or sudden onset, it is more difficult to get an accurate diagnosis of the co-morbidity.

Patients reported some good experiences, but there is inconsistency in GP behaviour, with some care pathways clearly not in place or not followed. Improved accuracy and timeliness in making referral to specialists is needed.

Patients had high praise for the way the NHS deals with crises, but were much more critical about poor holistic care. Many had concerns at the lack of helpful information and poor co-ordination between clinicians. Some reported that some clinicians are too generalist to be able to help, while others identified that some clinicians who are sub-specialised sometimes overlook the obvious.

There are times when getting all the specialists together makes a difference, but it does not always happen. The ideal that one person should take overall responsibility for patient care is not always met. Care planning and coordination for those with co-morbidity is inconsistent.

Concern about poor holistic care provision on general hospital wards is widespread. Concerns were expressed that the traditional model of hospital ward structure is unhelpful in caring for patients with existing conditions or co-morbidity, and there is a need for an in-depth review of ward staff training. The tendency of clinicians to deal with the immediate crisis rather than providing holistic care is unsatisfactory.

Carers described a range of experiences ranging from poor involvement, poor information and no support, through to very full involvement and excellent support.

Nurse specialists can be particularly helpful and more are needed for neurology, for diabetes and no doubt other long-term conditions. Their condition-specific expertise makes them particularly valuable when co-morbidity presents itself.

There is likely to be an increased need for psychological support for co-morbid patients. Talking Therapies staff who are unfamiliar with underlying medical conditions are not effective compared to their colleagues who have specific health training.

Discussion on the Liverpool Care Pathway generated strong concerns about misuse. Delegates were keen to know more about how the Pathway operates locally.

One delegate recounted that, when hospitalised with a broken back, he was put in a ward where MRSA was present, which is unacceptable.

The need to maintain and develop clinician education was mentioned repeatedly.

Some cross-border issues were identified for those living near NHS boundaries.

A specific problem of incompatible PEG equipment is one that should be addressed.

The ever-increasing pressure on the NHS budget was clearly recognised.

### **Limitations of this focus group.**

It was difficult to recruit delegates with multiple conditions, as the more health issues an individual has, the less likely he or she is able to travel or participate.

There are perhaps 1,000 neurological conditions and perhaps 10,000 diagnosable conditions in total, such that the experiences raised at a small focus group cannot cover the full complexity of living with co-morbidity. Many major conditions were not covered, for example no delegate referred to having HIV, cancer, psychiatric illness or pulmonary problems, to name just a few. There was no representation from anyone under the age of 40, the majority being in the over-60s age range. There was no representation on behalf of the bed-bound. Two wheelchair users were represented. One carer recounted the experiences of a deceased relative. Several delegates had experienced life-threatening times. In contrast, some delegates had experienced only short-term co-morbidities, which is not to marginalise the challenges this posed for them.

The themes identified do not represent the full extent and nature of problems arising in co-morbidity. This report provides pointers for further work only.

### **Recommendations**

Improvements in the speed and accuracy of diagnosis of co-morbidity:

- Care pathways need to be published for all service streams to ensure appropriate co-ordination between clinicians and service users.
- Pathways need to be reviewed to account for co-morbidity.
- GPs need better desktop tools.

Best practice should be adopted more widely in care planning and coordination:

- holistic care should be provided at all times in all scenarios and cover physiological, psychological and sociological needs.
- Holistic care requires more emphasis in the education of clinicians.
- Information services should be improved at all points of contact.

Better hospital care provision is needed:

- The traditional model of hospital wards structure should be reviewed for its efficacy.
- An in-depth review of hospital ward staff training is needed.
- Some enabling measures should be in place to ensure more case conferences can happen more often, as needed.
- Carers should be fully involved and supported wherever the opportunity presents.
- Stronger efforts must be made to isolate patients with MRSA from other patients.
- Patient and carer concerns about the way the Liverpool Care Pathway is managed need to be addressed.
- The 'named clinician' or 'named co-ordinator' approach should be used more often.
- The nurse specialist role should be given higher priority in workforce planning.

The training of the Talking Therapies Service therapists should include sufficient clinical knowledge of specific long-term conditions before service is provided.

There is a need for better co-ordination between the NHS purchasing teams, wherever there is a risk of equipment incompatibilities.

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

Ten people were present, four patients, four carers and two notes takers who contributed to the discussions.

Conditions and syndromes included: Ataxia, Dementia, Fibromyalgia, ME/CFS, MS, MND, Post Polio, Sciatica, Spinal injury (2), and other pain. Non-neurological co-morbidities mentioned were, depression, diabetes (2), heart disease (2), kidney disease, knee replacement, osteoporosis (2), gastro-intestinal problems, urinary tract problems, incontinence, hearing difficulties, balance problems, serious influenza and a range of related syndromes such as speech and swallowing problems.

### **Consolidated notes of the meeting**

One present described that his wife with MS also has only one kidney that has blocked several times. The blockages are very dangerous, recovery exacerbated by her underlying condition. NHS crisis management has always been '*brilliant*', but '*problems start when she is transferred to a general hospital ward*', at which time he negotiates with the doctors to bring her home for her own safety. The likelihood of a repeat blockage makes for a life of permanent uncertainty and vigilance.

Another delegate described that because of various problems like a bad shoulder, implants in his mouth, etc, he did not realise for some time that he had a neurological condition. Eventually his GP referred him to a neurologist and was (incorrectly)

diagnosed with PSP, MSA and then finally correctly with Ataxia. More recently he has added problems, having fallen and broken his back. In the crisis situation, the hospital was very good, but the care fell off after the initial crisis. He was not told the extent of his problems and the neurological appointments were very far apart, which left him in a state of limbo. *'There are neurological centres of excellence but they don't talk to each other'* and he suggested that *'research seems often to be replicated'*. *'Some centres ask you to donate your brain and spinal cord and issue you with a donor card but others don't – why not?'* *'For everyone to be asked to be a donor would be good, as there are only 10,000 ataxia sufferers in the UK.'* This delegate is unclear if he may or may not have osteoporosis.

On behalf of his wife, who was present, another delegate described her Post Polio Syndrome that *'took 10 years to get diagnosed'*, co-morbid with sciatica, incontinence and fitted with a pacemaker. *'Everything has to be treated by different people.'* She followed the sciatica doctor when he transferred to Swindon, and when the sciatica injections started to become ineffective, the doctor recommended an MRI scan. Her surgeon was in Swindon and her cardiologist in Oxford and they agreed they could do the scan and fit a new pacemaker at the same time. However, the radiologist would not do the scan, even though the other consultants were happy to go ahead. The patient and her husband feel that the Neurologist, Radiologist and Cardiologist should have talked together to arrange a plan of action. To date nothing has happened.

A further problem concerns the PEG feeding equipment she uses. There are 2 suppliers and they don't use the same connectors. *'Royal Berks Hospital uses one supplier and the John Radcliffe hospital, Oxford uses the other.'* This causes problems when being treated in the different hospitals.

Another delegate suffers from both diabetic and heart problems and also needed a knee operation. *'I was lucky and had all three relevant consultants round my bed at the same time. However, there were problems after the operation because the nurses did not know about treating diabetes and could not read a glucometer. 'There is no Diabetic ward in Royal Berkshire and so there is no nursing expertise.'* This led to similar comments from others that: *'There are no Neurological Wards and basic nursing care for neurological patients does not seem to be available.'*

Another delegate described that her mother has diabetes but she has found that there is a lack of information for patients. Her mother had a bout of flu that sent her blood sugar 'sky high'. She had a blood test but her GP would not see her but said she should see the consultant to discuss it. Her mother now has to have insulin injections. The carer has found the information she has been given confusing.

*'There is an assumption that the patient understands the condition, but there is permanent uncertainty'*. Her mother has *'lots of questions that have not/are not being answered.'* She is now insulin dependent. *'There is no support for carers and the experts just don't inform you properly.'* *'Things have improved since the GP Surgery acquired a diabetic nurse.'*

Another delegate stated: *'there is a lot of ignorance about ME amongst the medical profession. When other illnesses come in the question arises: is this the ME or something else? Clinical Depression can result and there is a problem of accessing suitable services when you live across a border.'* She lives in Berkshire but her GP is in

Hampshire and she cannot access the Talking Therapies that are available in Berkshire. Also, she has to push to insist that problems like hearing and balance need treating. *'The tendency is to be fobbed off and told this is just ME.'* *'One needs to be pro-active, but this is difficult given the basic condition.'* She always demands a 20-minute appointment, as standard appointments *'do not allow time to cover needs'*.

A more general discussion then developed

**Referring to GPs:** *'Often GPs assume that any problem is due to the basic neurological condition.'* *'GPs have to be brave to admit they don't understand a condition.'* *'Consistency among GPs would be good, along with them knowing how to refer appropriately.'* *'It is important for the diagnosis to be correct.'*

**Care Planning and Coordination.** *'You might come across a very good doctor who understands the situation but then doesn't see the case through because of the conveyor belt system.'*

**Talking Therapies Service.** *'Talking therapies are not rated by many people with MS because the therapists do not understand MS.'* *'Are they any good for people with Diabetes?'* The reply was 'Eyes to ceiling' followed by – *'harrumph!'* A delegate with ME/CFS stated *'I need people to LISTEN to ME.'* Another delegate had tried to phone the service but *'could not get through'*. *'You should be able to self refer to Psychologists and Counsellors.'*

**Hospitalisation,** 'when a patient with multiple conditions is in ITU they seem relatively safe because of the high nurse: patient ratio. The situation changes significantly on the general wards, where the focus seems often to be on dealing with the immediate cause of hospitalisation rather than holistic care.

Several delegates identified that there is often the assumption that if a patient is hospitalised with a pre-existing, disabling condition their quality of life is 'not worth it' and therefore active intervention should not be pursued and they are put on the Liverpool Care Pathway, sometimes without consent. Several delegates had not heard of this pathway. In defence of the Liverpool Care Pathway was stated *'Trusts are supposed to implement NICE guidance'*. The more general view seemed to be that this is often inappropriate and *'should be challenged'*.

Also referring to hospitalisation, *'It is necessary to reconfigure the way the wards are set up so that specialities are understood and are grouped together.'*

One delegate recounted that when hospitalised with a broken back he was put in a ward where there was MRSA present, which *'could have killed me'*.

**Clinicians more generally,** some conflicting statements were made: *'Getting the initial diagnosis right is so important and makes the NHS more efficient.'*

*'More and more, doctors are specialists in only one part of the body. Patients need someone to explain what all the problems are which they might experience.'*

*'Some doctors are too specialised and they do not look at the whole picture. If a patient has a number of things wrong with him/her it is very difficult and becomes a real challenge getting the right treatment.'*

*'Specialisation can go too far, e.g. there are separate specialists for kidney and bladder and the one doesn't necessarily talk to the other. Or if you have a broken hand, a specialist hand doctor is involved but he doesn't seem necessarily to think about the underlying cause of osteoporosis.'*

*'With Post Polio syndrome you need someone to think about all the things that can go wrong.'*

There was considerable agreement that accessing specialist services at the nurse level can be the answer. *'The RBS are now employing a diabetic nurse.'*

**Joining up the expertise.** *'In Social Care when there are children with complex needs, they have case conferences where all the different agencies are involved. The same should happen for adults with complex medical conditions. It wouldn't be necessary for all those involved to be in one geographical place. Video conferencing or skype could be used.'* A delegate expressed that she *'would appreciate a case conference but would also like ONE person to take responsibility for her case'*.

**Education** *'It is important to educate the staff.'* **'Education, education, education!'**

**Costs of the system** *'I would like to improve the NHS and its funding. It is very different today from what it was at the beginning. Who is going to pay for it in the end? The private sector will have to be involved.'*

*Ends*

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*West Berkshire Neurological Alliance*

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