

Report for Berkshire West Long Term Conditions Board

Coping when Health and Social Care systems falter

Findings from a focus group held at Padworth on 14th October 2013

Purpose

- To explore patient and carer experiences when health and social care systems falter
- To explore how services could be improved for the future

Findings

Attendees had praise for health and social care systems when they had worked well, and criticisms and a range of concerns when they had broken down. Breakdowns were reported in a range of scenarios and settings, particularly at diagnosis and with care pathways, sometimes finding poor knowledge, understanding, attitudes and listening skills among professionals and care staff. Sometimes a neurological condition can be so debilitating that those affected know they need help to communicate their problems, but perhaps cannot arrange this, leading to missed opportunities and longer time-scales before matters are resolved. Attendees reported the challenges of coping when equipment repairs were not attended to efficiently, also reporting frustrations in finding information on a range of subjects, covering basic medical information, medications, management options, the benefits system, carers issues and similar. Poor public awareness of how neurological conditions might affect an individual was reported to have caused difficult coping situations, requiring resolve and fortitude to get through by both patients and carers.

The process of obtaining an accurate neurological diagnosis is known to be variable. Ensuring consistent and better access to specialist neuro staff is a longstanding problem overdue and needing to be addressed. When the process breaks down, for some patients it can amount to total abandonment, with no clues as to how to proceed or cope. Resourceful patients and carers are the fastest in making headway. Those who are less well or less able, either physically or psychologically, and who also lack the support of a friend, relative or peer group support are likely to take much longer in securing a diagnosis and in finding ways to cope with the attached uncertainty and worry. Attendees also expressed concerns about coping when continuity of care was uncertain.

Participants recounted current situations where they are not sure what to do and are not yet coping with specific matters such as the Occupational Therapy Service, care staff, equipment repairs, carers services and benefits. In every case other Focus Group participants could identify one or more options that would help to deliver solutions and restore coping.

Coping is influenced by several factors, in particular:

- How clear or obscure are the diagnosis and attached individual situation, as perceived by health and social care staff?
- How much information and support do patients and carers get from professionals?
- How pro-active, physically/mentally energetic and confident are the patients and their carers?
- How much peer group support is available?
- Does the way ahead appear manageable and affordable?
- Is there an ability to plan through uncertainty?

Recommendations

For commissioners

- Consider and tackle the recurring problem, that neuro patients experience a long time to get a diagnosis and do not have sufficient access to neuro specialists, in part because the care pathways are unclear.
- Design and commission pathways that embrace carer and peer group support.
- Ensure that service specifications include the need for information at all stages and allow that early psychological and coping support may be needed.
- Ensure that complaints systems are easy to find, follow and are transparent.

For professionals

- Check if you have sufficient listening skills and knowledge of the condition you think you are treating, enough knowledge of the individual and his or her specific needs, and understanding of the way your service impacts on each person.
- Ask yourself if you would happily use your own service and follow the advice and options you are recommending to others.
- Check if your patients are capable of coping in their current situation and if not arrange coping support.
- Encourage carer and peer group support unless there are reasons not to.

For patients and carers

- At the first sign that the system may seem to be failing you, take up all matters of concern with all the constructive vigour you have, in case you run out of energy before you get the service you need.
- Seek peer group support and talk about your issues, to help identify options.
- Never accept poor quality information, advice or services, as generally there are plenty of good alternatives available.
- Ask someone to look out for and speak up for you if you do not have the confidence to tackle issues on your own.
- Be aware that to be unwell could be costly, possibly beyond your means, so proceed accordingly.
- Try not to give up!

About the focus group attendees

Twelve people were present, some in multiple roles. There were four patients, seven carers, one former care and five with voluntary sector connections. Eight conditions and

syndromes were represented: MND (3), MS (3), Epilepsy (2), Ataxia, Presumptive postural tachycardia, PSP, Stroke and back pain. There were five males and seven females. The age range was 25-75, the earliest diagnosed being in their teens. Two delegates were only recently affected by a neurological diagnosis, some being affected for 5-10 years, some affected for up to 40 years. Two wheelchair users were present and two other wheelchair users represented. Two delegates represented life-shortening situations, two episodic conditions, the others being generally in a static state or in slow health transition. One delegate could not attend and submitted a note afterwards, attached as appendix 2, (not discussed at the meeting).

Format of the Focus Group

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

1. Welcome and introductions
2. Purpose and focus group 'rules'
3. Open discussion on experiences about:
 - actual examples where local care systems have faltered
 - personal experiences and impacts
 - coping and not coping
 - low and high points
 - good coping practice for others to consider
4. Recommendations for the statutory, private and voluntary sectors

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

Limitations of this Focus Group.

There are perhaps 1,000 neurological conditions, such that the experiences raised at a small, 2-hour focus group cannot cover the full complexity of coping when systems falter. The themes identified do not represent the full extent and nature of when and where health and social care systems might falter or how people might cope or perhaps do not cope. This report provides pointers for further work only.

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West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition
Registered Charity No: 1081021

Appendix 1

Consolidated notes of the meeting (based on two sets of notes)

Diagnosis:

A delegate reported she was originally told her daughter had Chronic Fatigue Syndrome so must **'go away and just adapt'**. She asked for more tests and was sent to JR Oxford where her daughter was told the problems were **'in her head'** and she needed to **'push herself'**. She did and collapsed, so was seen by a neurologist and given a different and correct diagnosis. She registered with a different GP who said she **'didn't understand the diagnosis'**. Being unhappy, she registered with another GP who said, much better, she **'didn't know the diagnosis but would do some research to find out all she could'**.

Another delegate finds that when he goes to see doctors **'my mind goes blank and I really need someone with me to ask the questions'**. However, another gets the feeling that professionals don't like her accompanying her mother to appointments **'because I ask too many questions'**. It was noted that although the posters in clinics say *'if you don't know, ask'*, it doesn't work out like that in practice **'because so many professionals don't know the answers'**. Another added that **'If you have something like cancer, there is a lot of information and doctors know it all, but if you have anything neurological, doctors don't want to know'**.

Another said **'I often interrupt professionals during my mother's appointments and this isn't appreciated'**. She has the same problem with carers who don't want to hear what she has to say. Another pointed out **that 'the opposite can happen when doctors will only listen to carers and ignore the patient'**.

Some present prepare for appointments: **'I discuss with my wife before any appointment to find out what she wants brought up.'** Another agreed: **'I make a list of questions.'**

One present stated: **'I never see the same GP twice.'**

There was broad agreement that patients can't expect too much of GPs because they specialise in being generalists, but it is reasonable to expect them to know to whom to refer. Some examples of GPs not knowing about local services were cited including the juvenile Epilepsy Specialists, of which there are three.

A delegate stated that although his GP didn't have expertise **'He did recognise that I had a neurological problem. However over a period of time I was given 4 different diagnoses: PSP, MSA, another unpronounceable condition and finally a form of ataxia – so now I have little faith in the 'experts''**.

Another added **'it took two and a half years to get my wife's diagnosis'**.

Another confirmed that **'My mother was misdiagnosed.'** A delegate recalled that local Neurology Consultant, Dr Bogdanovic, has identified that when newly diagnosed patients see the Consultant Neurologist Team, 43% of GP neuro diagnoses are changed, as are 80% of management strategies.

One present stated ***'I would rather have a misdiagnosis than be turned away.'*** In response was said: ***'I would have like our GP to have listened and looked at the context of my daughter's life and taken her more seriously.'*** And from another: ***'It is better to have a GP who can recognise his own fallibility and not think himself a god.'*** Also summed up by another with: ***'One problem in diagnosis is the slow referral to other more knowledgeable people'***.

Occupational Therapy

One present was annoyed when an OT ***'accused my mother of being drunk'*** when she knew she had problems and was particularly anxious about getting safely from the house to a car.

One delegate stated ***'I have a good OT now'***, but when he was trying to get one to come and assess his problems in getting from his house to the car, he kept phoning and being promised a response, but nothing happened. Eventually he rang and ***'asked for an emailing address so that I could record in writing the number of times I have made an unsuccessful request for help, so that when he fell and hurt himself there would be a record of the failure of the department. Within 10 minutes an OT rang me to make an appointment!'***

Another reported problem was in getting an OT for an MND patient. The patient was seen 12 months ago and then his case was closed. Now he is deteriorating and a new assessment and advice is needed. His wife tried to get the original OT from the Physical Disability Team but was told she must reapply to 'Access for All' in Newbury. She did so at the beginning of July, but there was ***'no response until I spoke to the Manager a week ago, followed by various excuses and then a promise to fast track the referral'***.

Public awareness.

A delegate with epilepsy described problems surrounding his seizures, which have caused several unnecessary dramas (e.g.: an air ambulance was once called out, his school was once closed for the rest of the day, and a cinema once had to be emptied – ***'all embarrassing and unnecessary'***). He also has the problem that his medication ***'leads to fatigue and 'rots up' my memory'***. He was asked if there had been a problem in moving from children's to adult services, as he has had epilepsy since his schooldays, but reported positively he ***'hadn't noticed any difference'***.

Carers

A delegate reported that his wife was recently in hospital with a renal infection and was not allowed home until the Intermediate Care Team had been in. They were good but he never knew about this service before. ***'It isn't a service that is advertised. Apart from this, there is no care for carers.'*** Another said: ***'I don't know what services exist to help'***. This resulted in a flow of helpful information in response to the predicaments.

A delegate asked a rhetorical question: ***'How do full time carers stay sane and get some respite? It is so expensive to get carers in to go out to the cinema – an evening out like that will cost around £70.'***

One carer said when she was younger and her mother's fulltime carer she had no money and her boyfriend had to pay for everything. ***'Then I discovered Direct Payments which paid for carers to go in 4 times a day and enabled me to take up paid work.'*** There was much agreement with the remark: ***'it is very expensive to be disabled and there should be more allowances to help people stay in the community.'*** One delegate has taken to writing articles about caring for different magazines. Some discussion followed about the respective roles of Berkshire Carers, which provides one-to-one support, Crossroads which provides a sitting service and Carers UK, the carers voice in Whitehall.

Council Tax.

A delegate asked if he could get a reduction in Council Tax, which others present confirmed he qualifies for in his situation. ***'No one at the Council will respond to my questions'***. It was suggested that he should approach the Council's Chief Executive and, if no luck, then write to his MP.

Wheelchair service.

A delegate described briefly a long story about very poor service from 'H' the wheelchair maintenance firm contracted by the wheelchair service. (Printed saga attached.) This has involved endless emails and telephone calls made on his behalf by others. Problems started on 23rd July and are still not resolved. A second almost identical story with very similar timescales was also recounted. A third delegate has also been having problems with the Wheelchair service.

Finally, when invited to say one thing about their current situations

1. ***'Everything is a battle.'***

2. ***'I have issues with my mother's carers. They show a lack of dignity and respect.'***

3. ***'I would like to praise my consultant, Dr Sultan, who comes to the house to give me botox.'***

4. ***'I think the NHS is dysfunctional.'***

5. ***'I would like more to be done for the mental welfare of carers.'***

6. ***'I would like A&E Consultants and staff to know more about neurology, and would like GPs to listen to mothers.'***

7. ***'Recently I broke my hip and received excellent care from the NHS, and am very angry that people involved with neurological illness have suffered so much.'***

Appendix 2

Postal submission from someone with Charcot-Marie-Tooth syndrome

One delegate could not attend and submitted the following, indicating a pressured situation, little or no access to peer group support and having detailed questions to which clinicians seem slow or unable to provide responses.

APOLOGIES for unavoidable non-attendance. It's important I relay my particular situation.

As a single parent, 47, with a special needs son. Two teenagers. I have CMT 1.

I appreciate the need to access information and get support.

Seven years ago, new to Newbury, I tried to set up a CMT group. Only one person applied to my adverts placed around Newbury and Thatcham. Emailed last week. No reply.

West Berkshire Community Hospital info centre had no information about CMT. CE now in charge previously from Berkshire Carers Trust. Maybe she can improve services.

I saw my doctor at X medical practice on 28th August asking for a referral to neurological department at the hospital. I've not had a reply. Detail below is my letter request I read out to my doctor as regards self help for my condition: my doctor himself to 'not hold out much hope of any help':- but I did get referred to podiatry, and biomechanics help efficiently. BUT patients are not made clearly aware that they must attend within 6 weeks for regular treatment or they get listed out of the loop then it takes a while to go back to GP for referral again. Does this apply to other services?

CMT. Dietary and physiotherapy. Help in repair of myelin sheath.

As a patient with CMT, peripheral vasodilation interests me. Any research to improve where my circulation and movement is hindered interests me. There are probably various mechanisms for affecting arteriovasodilation, which is why different drugs are used such as calcium channel blockers. Are there any mechanisms useful to increase peripheral blood flow?

What are the effects of CMT on peripheral circulation as in the mechanisms by which circulation is compromised?

Unless mechanisms for controlling arteriovasodilation are damaged it ought to be possible to improve peripheral circulation using one or more of these?

I've had no answers or support advice or signposting on the above. I self-help as much as possible. I take the omega 3,6, and 9 and vitamin B. I gym and swim, podiatry and orthotic treatment. Please put forward my comments at meeting or when discussing with forum members.

Appendix 3

'My wheelchair story' (background to the section on Wheelchairs in Appendix 1)

Anyone who has a wheelchair that they own and therefore have to pay for service/repairs may be interested in my experiences with the following 2 companies used by the X Hospital who supplied my chair. The first company I had any dealings with was Company M. After a catalogue of mistakes, misdiagnoses, ineptitude, broken promises, wrong parts given to their operatives, unreasonably long times to get spares in etc, I compiled a report on them which ran to 3 pages at the request of my neurologist at the time, Professor C. Possibly as a result of that, and at the insistence of the redoubtable Prof., the Wheelchair Clinic awarded the next contract to Company H. I was delighted, they couldn't be as bad as Company M could they?

As it turns out they seem to be worse: on Monday 23rd July my chair cut out. Company H picked it up the next day. My wife phoned on the Thursday (my own speech is failing) and was told it was unlikely to even be looked at until the following week. On the following Monday she was told that they would be bringing out a loan chair the next day as they had to order new motors. The loan chair had no seat, only the flat metal base on which we had to put a cushion. The footplates were too low and the chair slid down slopes. I actually slid into the road on 3 occasions. I got stuck several times when it slid down a lowered crossing point and the footplates hit the road.

The next time my wife phoned she was told the motor supplier was closed for 2 weeks and the new motors wouldn't be in until 6th September, nearly 7 weeks after picking up the chair, and only 10 days before we were due to go on holiday. Had they looked at it earlier and, therefore, ordered the motors earlier, I have no doubt they would have been delivered much earlier. After JK had contacted them to complain, and after I had sent a "wind-up" e-mail to shake them out of their complacency, one of the bosses phoned on Thursday 22nd August to complain about my e-mail and during the conversation she admitted the motors were in but as it was approaching the bank holiday they wouldn't be delivering the chair until the following Tuesday, some 5 or 6 days after the chair was ready, meaning we couldn't travel anywhere over the bank holiday weekend. The loan chair does not have the correct lifting brackets to fit our hoist so we couldn't get it in our car.

When returned the chair kept suddenly pulling to the left and then about a day or so later it started cutting out again. Company H arranged to come out the following Monday. No one turned up. When we phoned they said their chap was too busy and couldn't come until the Thursday, but they would make it the first call, 9.30. He turned up at 11.30. He replaced a part, said the pulling to one side was due to the motors bedding-in and that the chair was ok and left. A couple of days later, on the Saturday, it packed up again when I was about a mile from home. My wife had to pick me up and load the chair into the back of the car whilst stopped on a busy dual carriageway. We phoned Company H when we got home but apparently their emergency service engineer doesn't have access to spares, but he promised to get someone out on Monday. They came out on Tuesday – the 10th September – took the chair in saying that they would try to get it back to us on Friday, in time for our holiday on the following Monday.

We phoned them Wednesday afternoon but they still hadn't solved the problem. We contacted them again the following day and were told that they had replaced the control unit which had corrected the problem. They were still saying the pulling to the left was the motor bedding-in. The chair was returned on Friday 13th (just was well I'm not superstitious, touch wood!), and we went away on the Monday. To be fair the chair didn't cut out whilst we were away but it continued to keep pulling to the left, and 2 occasions slewed round so badly that had I been near to the kerb I would have pitched into the road. When we returned I e-mailed to ask if it was normal for bedding-in to take so long. They didn't bother to reply. I also e-mailed the head of the Wheelchair Clinic. He didn't reply either.... so I e-mailed JK (MNDA). She not only replied but promised to chase He &/or get the Wheelchair clinic to chase them. They called out Tuesday 1st October, checked the chair, said one of the new motors was faulty and that they would need to take it in again. As they were going to have to order the new motor we said they could pick up the chair when they had the new motor. At the time of writing this – just over a week later – I am still waiting for word from them that the motor is in.

At the start of this article I said you might want to avoid either Company M or Company H: during the time that Company H were groping blindly to find out what was wrong with the chair I happened to be talking to the chap from SM (another wheelchair repair company) about a different subject and mentioned the problem. He said it sounded like the control unit, weeks before Company H came to that conclusion.

If you have read through the whole of this article - and I admire your fortitude if you have – you may think it long winded but I have to say this is a shortened version: for example I omitted the number of times my wife phoned, someone promised to phone back and didn't. I have kept it as brief as I could without omitting pertinent facts.

(Signed)

Appendix 4

Other comment in response to the draft report on the focus group.

From an attendee: *'I think your scribes have done an excellent job interpreting our ramble. I thought you have captured all the relevant points. The only thing I might have added is the arrogance that can be shown by the medical world to the detriment of patients.'*