

Forward ME

Minutes of the Meeting held in the Television Interview Room

House of Lords

Wednesday 25 June 2014, 2pm

Present:

Countess of Mar (Chairman)

Dr Charles Shepherd (MEA)

Sonya Chowdhury (AFME)

Janice Kent (reMEMber)

Bill Kent (reMEMber)

Sue Waddle (ME Research UK)

Christine Harrison (BRAME)

Dr Paul Worthley (ME Trust)

Hannah Clifton (ME Trust)

1. Apologies had been received from Mary Jane Willows and Jane Colby.

2. Professor Mark Baker, NICE

2.1 The Chairman introduced Prof Baker who explained he had been in post for about two years. The Professor said he would start with an explanation of the process by which subjects come before NICE. Originally they had just responded to whoever wanted guidance. Then around 2005-6 a formal process of topic selection, with specialist panels, was set up. That process was changed around the end of 2010 when the main political parties preferred “standards” to guidelines in the NHS. In March 2012 a Library of Quality Standards Topics was established; it included a number of NICE guidelines but ME/CFS was not among them and he did not know why. It was not feasible to update or change guidelines not in the Library until at least 2017. The Library was now the responsibility of NHS England, not of the Department of Health.

2.2 Turning to the ME/CFS Guideline specifically, the Professor said that it did not meet our needs and it did not meet theirs (NICE’s) either. The pressure for guidance started in about 2002 when the then CMO, Sir Liam Donaldson, wanted the subject “put to bed” in the form of advice to doctors that ME/CFS was a real illness and what they should do about it. It did serve a purpose because it was the only bit of guidance in the NHS on ME/CFS, but it was

limited in its scope. It was designed to get patients seen and helped, but it assumed there were specialists who knew what to do – and there were not.

2.3 The Guideline had been reviewed twice, but not much change had been observed, and when it was last looked at in 2013 it was decided to put it on the static list. Subjects on the static list were still reviewed, but only every five years compared with every two years for those on the active list. If anything important were to come up in the way of evidence it could be taken off the static list. Prof Baker said he sympathised with our position. The Guideline was not comprehensive guidance and it did not promote innovation. It referred to only “passive” interventions such as CBT and Graded Exercise. There was not much of an evidence base to go on, and in NICE it was evidence that drove guidance.

2.4 In summary, Professor Baker said:

- He sympathised with the position we were in with the Guideline
- The Guideline failed to address the real issues in ME/CFS
- It does not promote innovation
- It had a disappointing impact on specialist care and commissioning issues.

3. Questions

3.1 The Chairman referred to people being given an incorrect diagnosis of ME/CFS. In the North-West of England for example such people had been found in fact to have 15 other conditions, and Jill Mizen had asked about the treatment of patients with “red flag” conditions. How could this be brought to the attention of GPs? Prof Baker said that the pendulum appeared to have swung from under-diagnosis to over-diagnosis, with some very serious conditions being misdiagnosed as ME/CFS. The Chairman agreed and mentioned Addison’s Disease and Pituitary Tumour as examples of this misdiagnosis. Prof Baker listed several conditions for which some guidance was to be developed including medically unexplained symptoms and persistent pain (as in fibromyalgia).

3.2 The Chairman then turned to the provision in NICE that people with ME/CFS have the right to refuse or withdraw from any aspect of their care plan. Suppose Social Services wanted to take a child with ME into care. What force had the NICE Guideline in law? The Professor said that a judge had ruled that you can’t ignore NICE Guidance just because you don’t agree with it. You must have carried out a robust review of the case in question. This, he said, seems to give NICE Guidance rather more force than was originally intended. He would try to find the case reference for the Chairman.

3.3 Sue Waddle asked about NICE’s position on the ICD classification. Did they apply it to all cases? Prof Baker replied that they were not necessarily tied by the

ICD. In fact they did not normally start their deliberations by saying “This is the definition of X”. Sue said that what many of us were seeking was guidance which set out the seriousness of the illness whilst still taking in the ICD provision. Prof Baker commented that whenever he read responses to any consultation on this subject his initial reaction was “We should stand this down”. But to take it away completely would probably do more harm than good. Christine Harrison added that during the development of the Guideline Tanya had done her best to have the WHO classification included to address the misunderstanding of ME and CFS.

- 3.4 Dr Charles Shepherd referred to the high number of patients who were found to be suffering from conditions other than the ME/CFS that had been originally diagnosed. There ought to be guidance which would alert doctors to the possible alternatives. He had brought an abstract of Prof Julia Newton’s paper which showed that 40% of supposedly ME patients referred to a specialist service were found to have other conditions. Other members supported that proposal.
- 3.5 Janice Kent asked if there was some way in which, without review, a passage could be put into the Guideline requiring all patients to be diagnosed by a specialist ME doctor. Prof Baker replied that you couldn’t “fiddle” with the Guideline! Following on from this Sonya Chowdhury referred to a patient decision-making aid that had been developed for stroke/atrial fibrillation. Could we work together on something similar for ME/CFS? Prof Baker commented that the stroke/AF aid was the first of its kind produced by a new body – the NICE Implementation Collaborative. It was a possibility for ME/CFS. Sonya said that AFME was prepared to put some resources into developing it as it would directly build on work they had already started on a guide for patients to use with GPs when they are diagnosed with ME or it is suspected. Prof Baker said he would look into the possibility. Anyone could develop a decision-making aid for patients and clinicians and they might develop a method of accrediting decision-making aids.
- 3.6 Christine Harrison referred to the list of possible symptoms in the NICE Guideline to consider ME/CFS which was being used erroneously as “criteria” for ME/CFS by some East of England SHAs which were surveyed in 2011, which was not appropriate. She asked whether NICE could put out a statement to that effect. Professor Baker said that he was unable to do that, but confirmed that there was no such thing as NICE criteria for ME/CFS. Christine explained the work done by BRAME and other patient representatives in Norfolk and Suffolk. She asked Professor Baker for reassurance that, in all the work they had been doing, they had done nothing wrong in not following the NICE Guideline if it addressed a local need. He confirmed that this was correct and said that a guideline is basically a tool to help professionals and patients – a decision-making aid.

3.7 The Chairman asked Prof Baker if he would take on board what Sonya had suggested. Prof Baker agreed and said that we needed something to steer patients away from “dangerous neglect” and towards expert diagnosis and treatment. Dr Charles Shepherd and the Chairman asked who we might speak to about this at NHS England. Prof Baker suggested Martin McShane. Sonya Chowdhury said she was prepared to take this project forward. Janice Kent said we would need names other than charities to promote it. Prof Baker suggested the Royal College of General Practitioners.

3.8 The Chairman wondered whether we might approach the Chief Medical Officer. Janice Kent suggested Duncan Selbie at Public Health England. Prof Baker commented that the CMO retains a lot of clout. He was not sure what interest Public Health England might have, but we could try.

3.9 The Chairman thanked Professor Baker for being so helpful and candid.

4 and 5. Minutes of last meeting (10 June 2014) and matters arising. The minutes had only recently been received. Members had until the following week to comment on them.

6. SEN Code (Special Educational Needs for children) The Chairman had brought a copy (a very large document). Jane Colby and Mary Jane Willows had contributed to it.

7. Recent action

The Chairman had e-mailed members a Parliamentary Question she had put, and the answer. She asked Janice Kent to read out the details.

7.1 Janice said that several patients had contacted her because they had asked their doctors for a referral, under the NHS, to a ME/CFS specialist (Dr Amolak Bansal) but had been refused. This seemed to run counter to the principle of Patient Choice, so she had requested the Chairman to ask a PQ seeking confirmation of patient’s rights in this area. In his reply Lord Howe had said that under the NHS Constitution and the 2014-15 NHS Choice Framework, if a patient needs to see a consultant or specialist for a physical or mental health condition, they can choose the organisation that provides their NHS care and treatment anywhere in England for their first outpatient appointment. They can also choose which consultant-led team or which mental health team led by a named health care professional will be in charge of their NHS care and treatment for their first outpatient appointment.

7.2 The reply also contained provision for patients to complain if their right of choice appeared to have been denied, but several members pointed out that normally this should not be necessary; the NHS Constitution and 2014-15 Choice Framework set out quite clearly what the commissioners of services must do. However, Sue Waddle issued a note of caution pointing out that the devil was in

the detail; the answer referred to “anyhealth service provider with whom the CCG has a commissioning contract for the service required as a result of the referral...”. This was one more hurdle for patients to overcome. Bill Kent said he was more optimistic. He believed that when they were hit with this information the local NHS bodies would give patients the choice to which they were entitled.

8. DWP

8.1 The Chairman thanked Dr Charles Shepherd and, particularly, Christine Harrison for the points to be put to the DWP about the new guidelines. Christine explained in some detail her discussions with the Minister of State, Mike Penning MP. She said that everyone agreed the guidelines were a mess, although cases were being turned round more quickly now. Her main point to the Minister was that there needed to be a further review.

8.2 Christine said there was a further meeting of the PIP ISF group on 17 June and gave an update on PIP. The Minister for Disabled People, Mike Penning MO, had accepted her invitation to attend a PIP ISF meeting to hear first-hand feedback on PIP and the PIP journey. This was welcomed by the group. She had also given the Minister a personal copy of the letter about the ESA, WCA and DLA. It was recognised that the April launch of PIP had a number of problems, some of which had been addressed.

8.3 Christine stressed the importance of supporting medical evidence copies of which should be sent with Part 2 if possible. She also reminded us to remind clients/members to ask for a personal password as an added security measure when contacted to ensure that it was the DWP asking for personal details.

8.4 The latest statistics on PIP categorised conditions. Christine had noted that sensory impairments were not included and she asked formally where ME/CFS were placed. She was told that “CFS and ME would fall into the Chronic Pain Syndrome sub-category which forms part of the Musculoskeletal Disease (General) category.” She informed the DWP Statistical Officer that ME and CFS were classified as neurological diseases by WHO ICD 10 G93.3 and should be included in the neurological disease group, not the musculoskeletal disease one.

8.5 The first DWP PIP Review was launched on 23 June and would close on 5 September 2014. Christine would be willing to feed points made by members into the review. The link to the review:

<https://www.gov.uk/government/consultations/personal-independence-payment-PIP-assessment-first-independent-review>.

She had expressed her concern that the proposed two independent reviews would be insufficient as the process had been chaotic since the PIP launch. This would be taken to the Minister.

9. Mental Health Act and Children Act

The Chairman referred to a letter from Natalie Bolton. Sue Waddle said she, Dr Charles Shepherd and Sonya had a plan. The problem was that when Natalie had contacted them her information was anecdotal and it was difficult to go forward on anecdote. Charles Shepherd said he had spoken to Natalie on the phone but had still found it difficult to get the full picture. Sonya said their plan was to devise an information sheet for people with ME who were being threatened in this way – who you could turn to, the legal position etc. They were also thinking of collating information they received from patients with this problem. Another idea was to provide information to mental health liaison workers to make them aware ME is a physical illness, not a mental one. Charles Shepherd said one of the problems as he understood it was that many doctors regarded ME as a psychiatric condition and initiated action that led to Section 47. He would like to know the legal position. He pointed out that you could not compel a person with a physical illness to receive treatment.

The Chairman explained that under the present Mental Health Act it was necessary to prove mental incompetence and that patients were a danger to themselves or others before they could be sectioned – in other words the patient had to be incapable of making a decision for themselves. In the case of children, Section 47 proceedings were taken when there was concern about the welfare of the child. Patients threatened with such action should get a good lawyer. She had referred several to Leigh Day and Co. Dr Worthley also recommended Leigh Day and added that if you say you will use a law firm those threatening Section 47 action will give in. Members discussed aspects of this subject. Dr Shepherd said there was useful information here that could go into the proposed information sheet.

10. Keith Geraghty

The Chairman stated that she had obtained more information from Mr Geraghty and had tried to arrange an urgent meeting with Professor Holgate in order to resolve the problem. Unfortunately, this was not possible and she said that she would try again in October after the parliamentary recess.

11. Any other business

Dr Shepherd announced that he would be meeting James Bolton of DWP the following week to discuss ESA and WCA.

There being no further business the meeting ended at 3.30pm