

## **Forward ME**

### **Minutes of the Meeting held in Residence 1**

#### **House of Lords**

**Wednesday 21 November 2018, 2.00 pm**

#### **Present:**

Countess of Mar (Chairman)

Carol Monaghan MP

Helena Aris (with Ms Monaghan)

Bill Kent (reMEMber)

Suzie Henson-Amphlett (TYMES Trust)

Sarah Reed (ME Action)

Esperanza Moreno (ME Action)

Sam Bromiley (AFME)

Dr Charles Shepherd (ME Association)

Jonathan Davies (MERUK)

**1. Introductions and Apologies.** The Chairman introduced new members Suzie Henson-Amphlett, Sam Bromiley and Esperanza Moreno. Apologies had been received from Sue Waddle (MERUK), Anita Williams (TYMES), Janice Kent (reMEMber), Tony Crouch (25% Group), Dr Nigel Speight, Nina Muirhead, Philip Gowan and Clare Ogden (AFME)

#### **2. Parliamentary Ombudsman's Office.**

2.1 The Chairman introduced Dr Alex Robinson and Dr Samuel Stone from the Office of the Parliamentary and Health Ombudsman. Alex Robinson said they would explain what they do and how they look into complaints about

public services, and then hear comments and questions from members. He explained that they were the final stage of the complaints process for members of the public. This includes the NHS in England but there are separate complaints bodies for health services in other parts of the UK. Last year they received about 115,000 calls and enquiries from members of the public about the services. They look to see whether something has gone wrong and if so whether or not it has been remedied. As necessary they can recommend an apology, an assurance that things will be put right and, if appropriate, payment of compensation. If such recommendations are made they are nearly always complied with although there is no legal obligation to do so. They are looking into the possibility of publishing their casework so that names and proceedings would be available to the general public. But before they intervene in any case they have to be satisfied that complaints have been investigated by the bodies involved (eg a NHS Trust).

2.2 Alex went on to explain that most of the Office had recently relocated to Manchester, and a big training programme was ongoing. Procedures had been streamlined and they were now getting through casework more quickly. They were concentrating on improving their “front line” services, and also working with the public bodies to enable them to deal more satisfactorily with complaints themselves.

2.3 Sam Stone explained that the Office had been established in 1967 and they were currently in the process of re-organising for the twenty-first century. A Bill had been introduced two years ago which, among other things, was intended to bring their office together with that of the Local Government Ombudsman. It also has the intention of introducing “own initiative investigation” – in other words an individual would be able to initiate action with the Ombudsman without having to involve a Member of Parliament. And they are looking to see how there might be a “single point of contact” for all complaints about public services, with everyone complying to the same “good practice framework”.

### **3. Questions and discussion**

3.1 The Chairman said that in the past ME people had experienced problems in trying to understand the system and having to go via their MP, so these plans were most encouraging.

3.2 Dr Charles Shepherd referred to the NICE Guideline which was being re-written. There were bits of the current Guideline which were helpful to patients but they were not being enacted, for example in the provision (or lack of provision) of NHS services. If Forward-ME were to produce a letter about these shortcomings, could the Ombudsman look into it? Alex Robinson said they would have to have a complaint on behalf of a particular individual, and he was not sure whether NICE came within the scope of the Ombudsman.

3.3 The Chairman explained that the complaint would be about the providers of the services – GPs, hospital trusts etc – who were not meeting the requirements of NICE. Alex Robinson agreed that in those circumstances the Ombudsman could become involved. The complaint would have to be by, or on behalf of, the patient concerned, and they would need to complain locally first. The Chairman pointed out that many patients are too unwell to lodge a complaint. Bill Kent asked whether the patient representative organisations could complain on their behalf. Alex said they can, and also local authorities are required to provide advocacy for people who are having problems with the local NHS.

4. Suzie Henson-Amphlett outlined the unsatisfactory way that ME patients, and parents of children with the illness, are dealt with when they complain, whether to the GP or at another level. Patients may have difficulty remembering what was said, for example; it would be helpful to have someone with them when they encounter a doctor or whoever. If incorrect or incomplete information is written down it will follow you for ever. The Chairman added that lack of understanding of the illness by GPs can lead to co-morbidities being attributed, wrongly, to ME. Alex Robinson asked whether ME patients had access to information about their rights. Are they written down anywhere? That would be very helpful.

5. Jonathan Davies asked if it appeared that the process rather than the provider was at fault, whether the Ombudsman could take up a complaint against that

process. Alex said that if this was apparent they could issue a “systemic report”. It has been done, but he stressed it did not happen often.

6. Sarah Reed asked whether the Ombudsman would only look at individual cases, or could a complaint be taken up on behalf of a group of patients who had all suffered in the same way from a particular treatment. Alex explained that there has to be an individual complainant, but that individual could refer to other patients or groups of patients who have the same complaint and the Ombudsman would take this into account. They would need to investigate to see whether there was a systemic fault, and whether that fault was already under investigation.
7. There were no further questions so the Chairman thanked Alex and Sam for their helpful presentation.

#### **4. Minutes of meeting held on 17 July and matters arising**

The minutes were agreed to be a true record. The Chairman said that the response from NHS England (ie correspondence with Professor Powis) relating to IAPT was unsatisfactory. She had not yet received a reply to her response. There were no other matters arising

#### **5. RCGP Conference**

5.1 Sam Bromiley said the conference had gone very well. Charles Shepherd agreed. He said Clare Ogden had sent round a report which he would summarise. In response to Jonathan Davies he said that the people at the top of the Royal College had got the message, and Nina Muirhead was having success with medical schools, but getting it through to all the GPs was going to be much more difficult. It was a very friendly

atmosphere. A lot of people came to the Forward-ME stand, and the workshop went extremely well. They had ideas for improving it next year. If he had a criticism it was that there was too much information by way of posters, leaflets etc. Doctors do not come in to read leaflets, they want to discuss with other doctors.

5.2 The Chairman asked whether it would be helpful to produce a Forward-ME poster/information sheet for next year's conference, with contact details for the various charities. This was agreed. Sam Bromiley said AFME had already prepared a list of requirements for the 2019 conference in Liverpool. Charles added that the College would welcome us being there again, but it could cost £1,000 to put up a stand. He added that a friendly MP in Liverpool would be helpful. Asked whether we could do another workshop, Charles said we should not do the same workshop; another "angle" was needed.

## **6. NICE**

6.1 The Chairman said she was becoming increasingly hopeful and optimistic about the project. There had been controversy about membership of the development group, and this was being reviewed on the coming Friday. She, Carol Monaghan and Nicky Morgan MP had recently met Baroness Finlay and had made their views on this subject known. She and Carol Monaghan had also met Prof Mark Baker's successor, Paul Chrisp. He had been very understanding. Carol added that P. Chrisp had spoken of a friend who has ME.

The Chairman said NICE want to work with us; she had received a letter to that effect from Paul Chrisp.

6.2 Dr Charles Shepherd had some important information about the NICE guideline. He had been in e-mail contact with Peter Barry, the Chair. He wants us to produce some new patient evidence on CBT and GET. The time limit for producing this is fairly short; they want it by March 1<sup>st</sup> 2019. What they would really like is another survey like that done by the MEA in 2014, but up-to-date and including evidence of harm (particularly from GET) supplied by the patient community. Charles had put together a skeleton for the survey which he would e-mail round to members. But developing it would mean a lot of

work – so we need to work together on this. Was there someone who could organise an online survey using Survey Monkey or something similar?

6.3 Jonathan Davies asked whether there was time to commission a third party to do this. MERUK might be able to fund it. Charles said the MEA could put in some funding as well. Was AFME able to lead on this? Sam Bromiley said he could take it on using Survey Monkey; perhaps ME Action, MEA and MERUK could give some help.

6.4 Carol Monaghan recommended we should do a paper survey too. Not everyone would be able to do it online. Charles Shepherd agreed; that might not be completed until after the 1<sup>st</sup> March deadline, but Peter Barry had said not to worry, the paper stuff could be added in later. The Chairman added that there would have to be someone to do a spot check.

6.5 Esperanza Moreno enquired about analysing the survey. Who would do it and how? The Chairman replied we would have to employ a researcher to do that. Charles Shepherd added that Baroness Finlay knows people at Cardiff University who can do this sort of analysis.

6.6 Sarah Reed asked if the survey would be published as a Forward-ME survey. This was agreed. Jonathan Davies asked what was the main aim of the survey? The Chairman said as far as she was concerned it was to get rid of the recommendation to use CBT and Graded Exercise. It had been suggested that NICE might not recommend any treatment.

6.7 Charles Shepherd added that Peter Barry had asked also mentioned that the committee would be looking at diagnostic criteria quite early in the guideline development process. Charles suggested that this is something that Forward-ME might also like to consider and possibly provide input to the committee.

**7. Public Relations.** The Chairman said we could not discuss this today as Philip Gowan was not present.

- 8. Research.** Both Dr Charles Shepherd and Jonathan Davies said they had nothing new to report at this point.
- 9. DWP.** The Chairman said she was sorry that Christine Harrison was not present. She had worked incredibly hard with the providers and had now got them to revise their training manuals. The Chairman asked members to let her know of complaints they receive about bad treatment by the benefits agencies. Carol Monaghan added that she would be meeting the DWP soon, so she could convey any complaints we wish to inform her about.
- 10. CMRC.** Dr Charles Shepherd said the Research Collaborative conference at Bristol in September had been excellent. For various practical reasons they will not hold a conference in 2019. It has been deferred until March 2020.

## **11. Any other business**

11.1. Sam Bromiley asked about the possibility of research funding for ME being considered by the Science and Technology Select Committee. Carol Monaghan MP suggested the Health Select Committee might be more appropriate, although the Chairman pointed out that the Health Select Committee was “snowed under”. There are so many things people want them to consider. She suggested perhaps the House of Lords Science and Technology Committee.

11.2. Dr Charles Shepherd referred to the APPG on Disability which had met the day before to discuss disability access. A trustee of MEA had attended; she could provide a report if any members would like it, and could represent Forward-ME at future meetings of the APPG. The Chairman approved that.

11.3. AFME Conference 28 November. The Chairman said she would be speaking there about Forward-ME.

11.4. Sarah Reed asked if there was any news about a Parliamentary Debate. Carol Monaghan said a bid for a debate in the chamber of the House of Commons had been made, but there was no news yet.

11.5. Suzie Henson-Amphlett said that National Carers Week was coming up. Was there any way in which we could publicise the work of those caring for ME patients? The Chairman said she would speak to Philip Gowan about this.

There being no further business the meeting ended at 4.00 pm