

Forward ME

Minutes of the meeting held in the Television Interview Room

House of Lords

Thursday 22 June 2017 starting 10am

Present:

Countess of Mar (Chairman)

Dr Charles Shepherd (ME Association)

Bill Kent (reMEMber)

Janice Kent (reMEMber)

Tony Crouch (representing 25% Group and TYMES)

Clare Ogden (AFME)

Professor Kamila Hawthorne (Royal College of General Practitioners)

Fiona Erasmus

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1. **Apologies** had been received from Sue Waddle (MERUK), Cath Ross (25% Group), Christine Harrison (BRAME), Jane Colby (TYMES), Dr Paul Worthley (ME Trust), Hannah Clifton (ME Trust), Gareth Tucker (ME Trust) and Sonya Chowdhury (AFME)

2. **Presentation by RCGP.**

2.1. The Chairman introduced Professor Kamila Hawthorne and Fiona Erasmus.

They explained that they have responsibility for the training and professional development of GPs. In the last two years they have become involved in undergraduate education as well as post-grad. They want to encourage doctors to become GPs. Prof Hawthorne explained that she was in GP practice herself. It was a busy practice which included a lot of homeless people.

2.2. Prof Hawthorne then moved on to the subject of ME/CFS. The College recognised it was a proper illness. Her own view was that it is an umbrella term for a number of conditions. There is no diagnostic test, which causes problems for patients and GPs. Both experience frustration because there is no specific course of treatment. Prof Hawthorne said it was very important that the doctor should listen carefully to the patient and check out their medical history. They should discuss the patient's condition with them and agree a course of action with them. There is a module on ME in the RCGP's training programme which she recently checked to see what service provision there might be around the country. This revealed there are gaps in ME services – nothing in South Wales for

example where she lives. Dr Charles Shepherd added that there was now no ME/CFS service at all in Wales; this was a disgrace.

2.3. Fiona Erasmus then introduced herself. She had staff responsibility for the College's examinations and curriculum. She had been involved in GP education for a number of years. She referred to the minutes of Forward-ME's meeting with the GMC in February which she had found very helpful. Regarding ME, their curriculum is structured along the lines Prof Hawthorne had described – listening to the patient, agreeing a course of action etc. ME/CFS is in their curriculum and among the subjects that can be included in their examinations. She explained in some detail the different methods (multiple choice questions, role play etc) that can be used in the exams.

3. Discussion and Questions

3.1. The Chairman pointed out that there may be as many as 250,000 people with ME, possibly 60,000 of whom are housebound or even bedbound and many of them never see a GP because domiciliary visits are no longer made. There are knock on effects from this. It means that arrangements are not made for a physiotherapist because a doctor has to initiate that. They have problems getting the correct social security benefits because they cannot get the certification they need from a doctor. What could be done about this?

3.2. Professor Hawthorne explained that home visits, if requested, used to be obligatory but that resulted in a lot of unnecessary visits. Now, if a home visit is requested the GP should first make a phone call to determine whether a visit is really necessary or whether the problem can be dealt with over the phone. If it is decided that a home visit is needed then it should be made. She confirmed this could apply to a patient bedbound with ME.

3.3. Tony Crouch asked whether a person who had been ill for years could be visited at regular intervals. Prof Hawthorne confirmed this could be arranged; the frequency or regularity of visits would depend on the particular circumstances of the patient.

3.4. The Chairman referred to the problem of co-morbidities. Once a person had the ME "label" the possibility of co-existing conditions was frequently overlooked. She mentioned the case of a person with ME who had collapsed in the street and who, on admission to hospital, was found to be diabetic. She had been reporting symptoms for some time but had been ignored because of her ME. Prof Hawthorne said this was a common problem, and not just with ME. There is a tendency by doctors to attribute all symptoms to the original diagnosis. The College urges doctors to consider all possibilities.

3.5. Dr Charles Shepherd added that with ME patients a number of "ologies" can be involved. Because of the wide range of a symptoms a patient may be referred to a rheumatologist or a neurologist or specialists in other areas. The danger is the specialist may overlook the possibility of a condition that is not in their particular field. For example irritable bowel syndrome can be a symptom of ME but it could also be a red flag for other serious bowel conditions including cancer. He pointed out that certainly in the past GPs have received no training about ME and it was even referred to as an hysterical condition when he was at medical school. Things may have improved somewhat, but in a website poll (2016) 46% of MEA members said their doctors had poor knowledge – or indeed no knowledge - of the condition. Early and accurate diagnosis was essential, but this was not happening. Education must improve in this area.

- 3.6. Fiona Erasmus and Prof Hawthorne explained that training in this area was given but clearly it was not always acted upon in general practice. Charles Shepherd asked if there was any way in which the Royal College could make good this deficiency. Prof Hawthorne said there were several possibilities; one way to improve knowledge would be for the College to put a link on a blog (News and Views) which goes out weekly to all RCGP members; the link could be supplied by Forward-ME.
- 3.7. Dr Charles Shepherd pointed out the GPs have no directory of the NHS local CFS/ME services; that ought to be rectified. The Chairman added that post-exertional malaise is now the signal symptom. That should be made clear in the NICE Guidance which is due to be considered for review. That would be a good opportunity for the College to target GPs to improve their knowledge of the illness and tell them where they can obtain help.
- 3.8. Tony Crouch pointed out that many GPs still believe ME is a psycho-social condition. This leads to bad outcomes – for example Graded Exercise for severely ill ME patients which results in them becoming worse. It also results in children and families being referred to social services because of interrupted school attendance. Parents and children had been treated very badly because of this. Prof Hawthorne and Fiona Erasmus said a formal complaint should be made where appropriate, and patients and carers should be encouraged to complain. The General Medical Council (GMC) makes a strong point that they are there to safeguard the patients, not the medical profession.
- 3.9. The Chairman said she could understand the frustration of GPs because their role was to try to cure patients and there was no cure for ME. Prof Hawthorne said some GPs were very good in spite of this and tried to find ways to help these patients but others seemed to think that as there is no cure there is nothing that can be done, or even that there is nothing wrong with the patient. Again, that happens in other specialties as well as ME.
- 3.10. Clare Ogden said we recognised that GPs were incredibly busy. What could we in the patient organisations do to help them? Prof Hawthorne agreed that a good time for the College to put out new guidance would be when/if the NICE Guideline is revised, although Dr Shepherd pointed out that any revision was unlikely to be put into effect before 2020. In the meantime, Prof Hawthorne suggested, we should let them have a few lines and a link for their blog. This would be subject to agreement with the College and should be linked with a relevant news story as a 'hook', such as key announcements from NICE. We could also contact Local Medical Committees (one page of A4 if possible) setting out the local problems for GPs and their ME patients and asking how we might help.
- 3.11. Dr Charles Shepherd asked whether the College had any videos that GPs could access that might be of help. Prof Hawthorne said they only had those used in the training programme which were not really suitable. GPs often referred patients to this website – patient.doc.information.uk – but the information is not produced by the RCGP. They also have a magazine GP Frontline which goes out quarterly to all RCGP members. She suggested Forward-ME submit an article for it. The Chairman suggested we all contribute to the article. This was agreed. Another possibility was the RCGP Annual Conference which she could arrange for Forward-ME to attend. It is held over two and a half days in October. We could

submit an abstract for next year's (in Glasgow) and we could perhaps have a workshop and stall.

3.12. The Chairman asked about prescriptions. Sometimes ME patients had lengthy prescriptions because of their many symptoms but the combination of drugs sometimes made them feel worse. Prof Hawthorne said it was important that doctors listen carefully to their patients and consider the possible effects of various medicines taken together. She had encountered patients who had acute sensitivity to drugs. The Chairman also referred to studies done at Newcastle and Barts where it was found that 40% of patients referred to them as having ME in fact had other conditions. Early, accurate diagnosis was essential. Prof Hawthorne agreed that empathy with the patient was extremely important.

3.13. The Chairman thanked Prof Hawthorne and Fiona Erasmus for answering our questions so fully and patiently, and asked that we keep in touch.

3.14. Tymes Trust had submitted some written information and a question on the role of GPs. The Chairman passed these to Professor Hawthorne and their response will be transmitted to the Tymes Trust.

4. Business Meeting

4.1 Tony Crouch referred to a meeting he had attended in Northern Ireland where it had been agreed a letter about ME should go out to all GPs. He would arrange for members to receive copies.

2. Minutes of meeting held on 14 March 2017

The minutes were agreed as correct record.

5. Matters arising

5.1. Isabelle Trowler (Chief Social Worker for Children and Families in England). The Chairman said she had not yet contacted Ms Trowler about CAMHS and cascading information to us, but she would do so.

5.2. PACE. The Chairman commented that this subject goes on and on! She was very concerned about a presentation that had been given to the British Renal Society in which derogatory remarks were made about ME patients. Should we complain to the GMC? Dr Shepherd said we had only seen slides of the presentation, we did not have the dialogue. The Chairman said she would think on what our response might be.

5.3. Health Select Committee Inquiry. Jeremy Quin MP had offered to take up this matter. The Chairman asked Clare Ogden to let her have any amendments. Clare agreed.

6. Any other business

Charles Shepherd referred to a film "Unrest" about people with severe ME and their problems. He thought it was well made but there was no medical or scientific content from the UK that could be regarded as educational if we are going to try to get politicians, doctors and medical students interested in watching the film.

There being no time for further business the meeting closed at 11.00 am. Business to be continued at our next meeting on 11 July.