

From Caroline Carver, who attended this meeting.

Group's Meeting with Harriett Baldwin at the Cube, Malvern on 3/6/16

At the meeting

Harriett Baldwin, West Worcestershire MP, said she is willing to help people diagnosed with ME/CFS who experience difficulties with the benefit system.

Harriett Baldwin will be following up a question concerning M.E. Research.

Harriett Baldwin will be following up a question on the number of people with a diagnosis of M.E./CFS. A recommendation in the Inquiry into NHS Service Provision for ME/CFS (March 2010) - "The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS."

Unfortunately there were only four of the group present: Ian, Esther, Karin and myself, along with Marina from the Worcestershire NHS CFS/ME service. Harriett was accompanied by her Private Secretary, Ed Davey. She came with a small folder of papers, including those that Jill had sent to her recently relating to the recent NHS Worcestershire Clinical Commissioning Groups' (CCG) meeting. She asked what our main issues of concern were.

Ian's response: research, research, research and support, support, support.

Harriett picked up on the research point and said that £1.5 million is being allocated by the Medical Research Council. Harriett was asked which organisations/individuals that money had been given to and what areas of research were being undertaken. There was concern amongst the group that it was being given to psychiatrists, and the problems caused by the condition being taken over by the psychiatrists were emphasised to Harriett.

Harriett didn't know the details of this funding, but said she would find out and let us know.

The group then expressed concerns about the benefits system and the difficulties people had experienced and continue so to do. The group hears from people who have their benefits cut, the new Personal Independent Payment (PIP) causes problems, and many people are having to go to tribunals.

Harriett said that she was very willing to help anyone having difficulty and asked that the group make this known.

The discussion then turned to the issue of support from the NHS CFS/ME service, in particular the complete lack of any kind of help for people with severe symptoms, as they were unable to make even assessment appointments and there were no facilities for home visits by the service.

Marina explained that this is something they are concerned about and looking into. She said that one suggestion that had been raised was telephone contact. Marina felt that it was important to establish a face-to-face contact first, so the possibility of making one home visit, with subsequent "consultations" being undertaken by telephone was being explored. She had experience of this working well, so was hoping it would be implemented. We didn't hear how people with severe ME would initially receive a diagnosis, whether a home visit from a CFS/ME Consultant, or whether this would have to be from their GP?

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Marina gave us a further explanation about the Recovery after Management (RAM) group - telling us that the reason for limiting it to people who had recently attended the NHS CFS/ME service was because they didn't want to be overwhelmed by numbers. Now that they know that is not going to happen the intention will be to open it up. The comments from Marina were very much that they were trying to effect change, but it would take time.

At the recent Worcestershire Clinical Commissioning Group (CCG) meeting, Ian and Jill heard that the NHS CFS/ME Service's Occupational Therapists and Psychologists are being asked to do more, but without any extra funding.

Esther raised various questions submitted by Jill, including whether the number of sufferers with the condition was known, locally and nationally. It was emphasised that the UK number of 250,000 had been broadcast for years, so was unlikely still to be accurate.

Harriet said she didn't know, but would find out.

Harriett was also asked whether she was a member of the All Party Parliamentary Group on ME, to which she answered no. As she was a Minister she was not allowed to be.

Overall the meeting was a lot more positive than I expected. Harriett seemed genuinely willing to help individuals, although her willingness and ability to address the wider issues was less in evidence! I suspect that this is due, in part at least, to her not wanting to go against Government policy. Harriett stayed for around an hour, which was good, after which the group stayed and chatted about what had been discussed.

Marina very kindly stayed on too and we had a very positive discussion with her. It was clear from what she said that notice had been taken of concerns about the CFS/ME Service and they were looking at ways in which they could change things for the better: changes which would not incur massive extra cost.

So I left feeling a lot more positive than I expected to! -

Following the meeting, Ian said - "Our points were made, and the outcome will remain to be seen".

Caroline Carver
