

Parliamentary News



Brief Report on the APPG Meeting on ME

House of Commons, 22nd January 2008

This meeting had been postponed from November 2007. Dr Ian Gibson MP stood in as Chairman for Dr Des Turner. It was attended by 4 other MPs, the Countess of Mar and around 30 patients, carers and patient group representatives. The main speaker was Ann Keen MP, Parliamentary Under Secretary of State for Health Services, supported by Dr Chris Clough (Consultant Neurologist from Kings College Hospital) and ministerial staff.

Two items arising from the minutes of the last meeting were letters from Paul Davis (he complained about inaccurate and insufficiently detailed minuting of his critical reports on inappropriate treatments for ME patients at the new CFS/ME clinics) and a Statement read out by Angela Kennedy, supported by over 500 signatories, stressing serious concerns within the ME community over treatments offered at most of the new clinics (i.e.CBT+GET). Doris Jones said her support for Paul Davis' comments made at the July 2007 APPG meeting had not been minuted - controversial comments tended not to be recorded.

A heated discussion followed; many expressed grave concerns over the current situation. Funding for many centres was uncertain. Flowcharts were given out on problems in East Anglia (one was entitled 'A fundamental failure of duty of care'); the MEA circulated a useful paper - 'Hot Topics', on the current position with regard to NICE, NHS Plus and DWP new guidelines. Included were questionnaire details on proposals for new NHS Clinical Services for ME/CFS patients.

Discussions then focused on specific questions/concerns to be put before the Minister:

- How could Ministers satisfy themselves that PCT approaches are consistent with recommendations (e.g. from NICE etc) was one suggestion.
 - Funding for local centres was another.
 - An urgent meeting with Lord Darzi was stressed; he was working on a chapter on long-term neurological conditions for a new NHS review, due to be published in June 2008. Dr Gibson supported this, suggesting a delegation should be nominated for this meeting (such a meeting has now been fixed for 28.2.2008 – Ed.).
 - Care protection cases was an issue to be placed before the Minister.
 - Another paper had been prepared on unsatisfactory services in the West Midlands.
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- John Bercow MP was still trying to arrange an Adjournment Debate in the House of Commons
 - Dr Des Turner had suggested an EDM on services and the DWP guidelines. The DWP does not deliver the service - this is subcontracted to ATOS. There was a perception that more ME patients were turned down for benefit than those with other diseases, but more got their benefit on appeal.
 - The question of amendments to the NHS+ Guidelines was still unsettled – changes may only be cosmetic.
 - The NHS Collaborative Conference arranged by AfME had been a success – it was stressed at this event that there was an over-dependence on 'evidence-based medicine' – it was necessary to listen to patients.
 - Dr David Sampson had analysed papers co-authored by Professor Peter White and noticed that the data from his studies did not support his conclusions. This critique is to be published in a peer-reviewed journal.

The Minister arrived late and spoke of her experiences as a nurse, dealing with many long-term condition patients. She was sympathetic towards patients who are not believed. A current review looked at different health service pathways and how the NHS deals with these, particularly also long-term conditions. Recognition of symptoms was vital. She asked whom ME/CFS patients wanted to have as healthcare providers and researchers. A report due by June 2008 was looking at how to get from emergency treatment to treating chronic conditions. Recognition levels for some conditions were clearer than others (e.g. stroke and diabetes).

Issues of concern then raised in discussions with the Minister included the following:

- woefully inadequate services for children with ME/CFS;
- chaos over funding and services for ME/ CFS patients in some areas and great concerns over the few new services (especially on diagnosis with only a psychologist responsible – no physician, no clinician and no neurologist);
- services for ME patients now are worse than they were some years ago;
- ME was a neurological disease which the DWP and the NHS+ refuse to acknowledge.

The Minister and Dr Clough listened sympathetically and carefully, saying the PM wants chronic long-term conditions to be recognized and treated properly; the PM and CMO want NHS moneys to be used differently. There is a problem with training of GPs - they must listen to patients and PCTs must cooperate. There are problems with all neurological disease – no figures exist. A meeting with Lord Darzi should be arranged.

Edit Comments: Another very lively APPG meeting revealed the frustration and anger of the ME/CFS