



All-Party Parliamentary Group on ME

# Inquiry into NHS Service Provision for ME/CFS

Interim Report



This inquiry arose as a result of long-term concerns that the National Health Service (NHS) provision for people with ME/CFS was not meeting their needs.

As stated in the terms of reference, the overall goal of the inquiry was to obtain information from key individuals and groups involved with ME/CFS, including patients, carers, charities and service providers. The terms of reference also seek to determine if the current service provisions offered are fit for purpose and what areas need to be improved.

ME/CFS is an extremely complex disease covering a range of symptoms and clinical presentations. There is currently no scientifically proven cause or cure. Treatments and coping strategies are therefore designed to enable patients to manage their symptoms. It is therefore important that patients receiving treatment are able to access the best possible care and support in a multidisciplinary setting. It is also vital that these services are of the highest quality across all primary care trusts (PCTs) within England.

According to the NHS, the main symptom of ME/CFS is severe fatigue following almost any mental or physical activity<sup>1</sup>. According to the NHS, this does not go away with sleep or rest, and limits usual activities<sup>2</sup>. The fatigue experienced by patients is mental as well as physical and can be described in the following ways;

- It is a different type of tiredness from what the patient has experienced before
- After sleeping patients do not feel refreshed
- It is not due to exhaustion
- It is not caused by a loss of motivation, which people with depression often experience
- Exercising beyond individual limitations will make symptoms worse<sup>3</sup>

1 Symptoms of chronic fatigue syndrome, NHS, <http://www.nhs.uk/me/symptoms/>, accessed 25/11/09

2 Symptoms of chronic fatigue syndrome, NHS, <http://www.nhs.uk/me/symptoms/>, accessed 25/11/09

3 Symptoms of chronic fatigue syndrome, NHS, <http://www.nhs.uk/me/symptoms/>, accessed 25/11/09

The APPG issued an open call for written evidence requesting submissions from patients, carers, charities and service providers, in particular PCTs. Evidence was sent to the APPG through tailored questionnaires for patients and PCTs. The patient questionnaire was published on the APPG on ME's website and was also distributed to patients through the ME patient groups. In total, more than 400 responses were received. The number of submissions and the number of people wishing to remain anonymous persuaded the APPG not to list the names of those who submitted written evidence.

All PCTs were sent questionnaires individually, personally addressed to the PCT Chief Executive. The following is a breakdown of responses.

Number of PCT responses	Number of PCTs that did not respond
42	91

The APPG held two oral evidence hearings. Below is a list of those who gave oral evidence and the members of the APPG in attendance.

#### 9th of July 2009

##### APPG Members present

Dr Desmond Turner (Chair)  
Andrew Stunnell MP  
Countess of Mar  
Tony Wright MP

##### Witnesses

###### First oral evidence session – patients' session

Catherine Fry  
Joy Birdsey  
Sally Phillippe

###### Second oral evidence session – Patient groups' session

Jill Pigott (Worcs. ME Support Group)  
Christine Harrison (BRAME)  
Sir Peter Spencer (Action for ME)  
Mary-Jane Willows (AYME)  
Doris Jones (25% ME Group)  
Dr Charles Shepherd (ME Association)

#### 16th of July 2009

##### APPG Members present

Dr Desmond Turner (Chair)  
Countess of Mar

##### Witnesses

###### First oral evidence session – patients' session

Madeline Lawrence  
Tanya Harrison

###### Second oral evidence session – expert evidence

Dr Esther Crawley (Consultant Paediatrician, Clinical Lead, Bath CFS/ME Service)  
Minister of State for Health, the Rt Hon Mike O'Brien MP

The Group would like to thank everyone for their involvement in the compilation of this report, in particular, the ME patient groups who were able to distribute the survey to their membership.

## Interim Report Recommendations

From the written and oral evidence, the Group has determined that there are a number of issues that need to be addressed to ensure ME/CFS patients receive the best quality care. These issues and the associated recommendations are outlined below.

### Recommendation 1

There were a significant number of submissions from PCTs stating that they do not have accurate patient numbers. PCTs who do offer adequate services could only supply numbers of how many people are using their particular service. There will also be an unknown number of other sufferers within the community.

**The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS.**

### Recommendation 2

It is clear from the evidence that there are probably sufficient numbers of patients involved and sufficient uncertainties about the nature and availability of services to justify a measure in addition to the NICE Guidelines.

**A national service framework should be created to complement the NICE Guidelines.**

### Recommendation 3

The APPG felt that many of the concerns and experiences submitted as evidence by patients, carers and patient organisations would have been addressed had the Independent Working Group Report to the Chief Medical Officer (CMO) of 2002 been acted upon adequately.

**The DoH should revisit the report to the CMO and ensure that the recommendations relating to service provision are adequately addressed and are implemented promptly.**

### Recommendation 4

Currently, there appears to be a lack in consistency in treatment options offered to patients in different PCTs. The Group has ascertained this from the evidence supplied by PCTs and patients. The APPG finds the degree of variation in the availability and access to services unacceptable. Patient evidence also indicates people want services that are physician led, multidisciplinary, and are situated in locations that are easily accessible to those with significant mobility problems.

**The APPG recommend the DoH take steps to remedy the variation and ensure that each PCT offers a full range of services promptly – a process that should involve meaningful consultation with local patients or patient support groups.**

### Recommendation 5

Through the evidence supplied to the Group, it is clear that there is a significant lack of services available for children and adolescents. Many services only offer treatment options to patients over 16, which has led to many children not receiving adequate care. This is unacceptable and can lead to tragic consequences.

**The APPG therefore call on PCTs, Strategic Health Authorities and the DoH to undertake a detailed review of current services for children and adolescents to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate.**

### Recommendation 6

From correspondence with the Royal College of Physicians and the Royal College of General Practitioners, the Group is not convinced that medical students receive sufficient training on ME/CFS, including how to clinically assess and diagnose these patients and advise on appropriate forms of management.

**The Group recognises that ME/CFS does not have the same obvious impact as cardiovascular disease or cancer, but that it is necessary for medical students to receive adequate training in ME/CFS. The relevant Royal Colleges should ensure that students receive training in this disease.**

### Recommendation 7

There were a large number of submissions from patients that stated their experience with GPs was poor due to lack of awareness of the disease amongst primary care givers.

**GPs should receive ME/CFS awareness training as part of their continuing professional development and ensure they are able to adequately recognise the symptoms of ME/CFS and deliver a correct diagnosis. They should also be aware of the various management pathways.**

### Recommendation 8

The Group noted evidence that there were serious concerns about acceptability, efficacy and safety with some treatments such as cognitive behavior therapy (CBT) and graded exercise therapy (GET). This may be due to the lack of training given to professionals but evidence was given that it was in part due to fixed attitudes about causation by some health professionals. The Group feel that it is inadequate for professionals to treat patients with ME/CFS when they have not been fully trained in the particular characteristic of this disease.

**It is essential that all healthcare professionals i.e. dieticians, nurses, occupational therapists, physiotherapists and psychologists, involved in treatment should have adequate training in ME/CFS and the relevant professional bodies should ensure this occurs as a matter of real urgency.**

**NICE should carry out a detailed review of their management guidance on ME/CFS, in particular the mounting evidence for the need to broaden the range of appropriate therapies beyond CBT and GET, and to specify that all such therapies should be delivered by specifically ME/CFS trained professionals.**

#### Recommendation 9

To date research in the field of ME/CFS has produced little substantive progress but there are a number of encouraging findings e.g. the XMRV research, which need to be pursued. As noted in the Gibson report, there has also been far too much emphasis in the past on psychological research and insufficient attention to biomedical research. The Group welcomes the recent MRC initiative to attract new researchers and new technologies in to this area.

**However, the Group is sure that it is vital that further biomedical research is undertaken to help discover a cause and more effective forms of management for this disease.**

#### Recommendation 10

It is clear from the evidence submitted to the Group that currently, ME/CFS patients receive little assistance in the complicated process of application for benefits and that refusal rates are worryingly high. Applying for benefits is an extremely prolonged and strenuous task, especially if patients are forced to appeal the original decision where their application was denied.

**The Department of Work and Pensions should review its guidance to decision makers to increase the awareness of the specific difficulties faced by ME/CFS sufferers. Furthermore the Group recommends that ATOS Healthcare staff should also receive increased training to ensure that they are fully aware of ME/CFS and the limitations that it places on patients**

#### Recommendation 11

The APPG is aware that many patients who are severely affected by this disease are receiving either inadequate care or no NHS care at all, which is clearly inconsistent with the NICE Guidelines.

**Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in-patient facilities for assessment and management.**