



All Party Parliamentary Group on M.E.

Chair: Des Turner MP
Vice-Chairs: Andrew Stunell MP
Tony Wright MP
Secretary: Ian Gibson MP
Treasurer: David Amess MP

Minutes of the meeting of the All Party Parliamentary Group on M.E. held at 1.30pm, Thursday 17th May 2007 Committee Room 17, House of Commons

PRESENT

Dr Des Turner MP

Sarah Vero, Office of Dr Ian Gibson MP
Koyes Ahmed, Office of Dr Des Turner MP

Sir Peter Spencer, Action for ME
Trish Taylor, Action for ME
Heather Walker, Action for ME
Dr Charles Shepherd, The ME Association
Tony Britton, The ME Association

Clive Page, father of person with ME & MEFreeForAll.org
Doris Jones, The 25% ME Group for severe sufferers
Vera Chaney, Green Network Charitable Trust
Christine Harrison, Blue Ribbon for the Awareness of ME (BRAME)
Barbara Robinson, Suffolk Youth and Parent Support Group (and East Anglia
ME Patient Partnership)
Hugh Berger, The National Forum Trust
David Butler, Sussex and Kent ME/CFS Society
Colin Barton, Sussex and Kent ME/CFS Society
Annette Barclay, Person with ME
Augustine Ryan, Person diagnosed with ME

1. Welcome by the Chairman, Dr Des Turner MP

The chairman, Dr Des Turner, welcomed visitors and in particular Dr Ira Madan, Director of the Evidence-Based Guideline Project at NHS Plus, which in October 2006 published three guidelines, "Occupational aspects of the management of chronic fatigue syndrome: evidence-based guidance" for employers, healthcare professionals and employees.

2. Main Speaker: Dr Ira Madan, NHS Plus

Dr Madan described how NHS Plus came into being, after former Health Secretary Alan Milburn set up an initiative to provide central occupational health guidance to small and medium-sized companies. She was seconded to

the Department of Health four years ago from Guy's and St Thomas' NHS Foundation Trust, where she is consultant occupational physician.

The CFS guidance had been initiated by Dr Karen Pratt, who is now specialist registrar in Occupational Medicine at BUPA Wellness in London. The guideline had been developed in consultation with stakeholders, DWP, NICE and Pat Noons at the Department of Health.

Dr Madan explained that the main purpose of the NHS Plus guidance was to answer three basic questions:

- What treatments are effective in enabling people with CFS to return to or remain in work?
- What are the predictive factors for a successful return to work in individuals who are currently absent from work?
- What is the risk of relapse and what are the risk factors for relapse in terms of non-attendance or poor functioning at work?

In response to a question from Charles Shepherd, Dr Madan said she did not consider the appointment of two psychiatrists as the external assessors to be biased. One of these assessors had been suggested by Chris Clark, former chief executive of Action for M.E., who was a member of the Guideline Development Group. The group deliberately chose not to approach Professor Simon Wessely because they realised his appointment would be contentious.

The group had used the "York Review" – produced by the NHS Centre for Reviews and Dissemination at the University of York – as the basis for its literature review.

The guidance was authorised for publication by the Health Minister Rosie Winterton.

Dr Madan said Mr Clark had signed the guidance in March 2006, shortly before he left Action for M.E., She said she then met Trish Taylor, the charity's acting chief executive, and spent an afternoon with her at the Department of Health going through the guidance. She had been informed that Action for M.E. was not happy with the guidance and could not endorse it.

Trish Taylor said the guidance was sent to her formally on July 21, and she had responded to it. Dr Madan said the reply did not reach her.

A joint charities' response to the NHS Plus guidance had been tabled. It had been signed by 23 ME charities and organisations. Dr Madan went through it point by point and responded to specific criticisms. These included:

Failures to mention that ME is classified by the WHO as a neurological disorder (in ICD10:G93.3), or to use the term ME. After some at times heated discussion, Dr Madan said this was a decision of the group, really arrived at because members did not want to confuse employers who are used

to seeing the term CFS on sick notes. There had been no intention to denigrate the term ME.

Failure to reflect any doubt or caution about the efficacy of CBT and Graded Exercise in the treatment of ME. Dr Madan said the only evidence presented to the Guideline Development Group of therapies which assisted in getting people back to work were CBT and GET, although she acknowledged that neither was curative and CBT should in no way be considered a panacea.

Advising people who feel tired to try to stay at work on the basis that otherwise they will lose 'work hardiness'. Dr Madan commented that it well known that people on sick leave from work get depressed after six weeks and people do indeed lose 'work hardiness'. Hugh Berger said such comments were deeply offensive to people with M.E.

Failure to recognise that employees who are moderately affected with ME/CFS may be ill for years and that 25% of people with the illness are severely affected and may well have their illness for life. Dr Madan said of course she realised that 25% of people with CFS were severely affected and would probably never return to work. The guidance was not intended to include them.

Failure to mention that the CMO's Report in 2002 and the full version of the NICE draft guideline both emphasise patient choice in undertaking treatment for the illness. Dr Madan said the NHS Plus guidance was totally different intended for total different audiences: " I have had an awful lot of positive feedback, particularly saying how helpful it's been".

The charities' joint response to the guidance had said that the guidance was insulting to people with the illness who had fought tooth and nail to keep their jobs and tried everything to get better. Dr Madan responded to this saying she had been in occupational health for 17 years and she had worked tooth and nail herself to keep people with CFS at work. She cited one case from her work as occupational health adviser to the Houses of Parliament.

APPG chair Dr Des Turner said the NHS Plus guidance had been produced with the best of intentions but nothing was ever totally beyond criticism. He hoped criticism would be voiced in an amicable way.

Christine Harrison (BRAME) said the evidence covered in the York Review clearly failed to reflect the growing volume of biomedical evidence on causes and pathogenesis. Barbara Robinson (Suffolk Youth and Parent Group) agreed, adding that the review also failed to reflect emerging evidence on iatrogenic illness. Dr Turner said one of the major problems was the very weak research base for ME

Sir Peter Spencer, the new chief executive of Action for M.E., said that as the guideline development group had been interested in occupational rather than clinical outcomes, it had perhaps inadvertently missed evidence and made decisions which could cause real harm for some people with M.E.

He asked if Dr Madan would be receptive to considering such evidence and open minded about amending the guidelines. Dr Madan agreed.

Sir Peter also suggested that, in the light of NHS principles on patient involvement, M.E. guideline development groups should include patient representatives who have direct personal experience of the illness.

Doris Jones (25% Group) said that many members of her group, which represented people severely affected by ME, reported that they had become bedridden or housebound after taking courses of GET. A return to work would be impossible for many of them.

Dr Madan agreed with a suggestion made by Dr Shepherd that she meet with a small group of charity representatives to discuss the criticisms in more detail, and to consider possible amendments to the published documents.

She said would like to see the evidence gathered by Action for M.E. and agreed to a meeting. She indicated that it would be easier to change some emphases in the leaflets at this point, rather than the guidance itself.

Dr Madan added, in answer to questions from Annette Barclay and Charles Shepherd, that neither of the external assessors had declared conflicts of interest.

Dr Turner thanked Dr Madan for her attendance, saying he hoped that work on the amendments would be carried out swiftly.

3. Apologies

David Amess MP, Tim Boswell MP, Peter Bottomley MP
Jim Cousins MP, Andrew Dismore MP, Clive Efford MP, Sandra Gidley MP,
Mike Hancock MP, Jim Hood MP, Kelvin Hopkins MP, Dr Brian Iddon MP,
Eleanor Laing MP, John McDonnell MP, Chris Mullin MP, Bill Olnor MP, Rudi
Vis MP, Hywell Williams MP.

Di Newman, Peterborough ME/CFS Self-Help Group; Neil Riley, The ME
Association.

4. Minutes of the Last Meeting

The Minutes of the Meeting held on 22 February 2007 were accepted as a correct record.

5. Matters Arising

Pages 2-5: The NICE discussion

Dr Shepherd said The ME Association was seeking release of the Guideline Development Group minutes under the Freedom of Information Act. The MEA

had also arranged for Professor Baker, chairman of the NICE Guideline Development Group, to address a public meeting in Peterborough on Saturday September 15.

Dr Shepherd said he and Doris Jones had attended the Commons Health Committee Inquiry into NICE earlier in the day when David Amess, APPG treasurer, had asked about the ME/CFS Guideline.

Page 6: DWP Guideline

Christine Harrison said she had been in touch with Dr Moira Henderson, principal medical adviser to the DWP. Mrs Harrison said she understood that there may be changes made to Version Nine as a result of representations, and expected to hear more in May.

Page 7 – Dr Ian Gibson’s draft EDM

Sarah Vero, Dr Gibson’s parliamentary assistant, said action on the EDM had been suspended as Dr Gibson was not prepared to promote an EDM which may well be the subject of a counter-campaign by people opposed to its wording. She suggested that the APPG itself might launch an EDM to support the recommendations of the Group on Scientific Research into ME. Dr Turner said he would discuss this with Dr Gibson.

6. Mental Health Act and Mental Capacity Bill – the implications for ME

Deferred, in the absence of Di Newman.

7. Code of Practice for the APPG on ME

Deferred.

8 Any Other Business

NHS-funded services for ME/CFS

Problems with the past (ring-fenced), present and future financing of the NHS clinical services were raised by Christine Harrison and Barbara Robinson. Both spoke about the part-withdrawal of PCT funding for the East Anglian ME/CFS service led by Dr Terry Mitchell.

Dr Turner said he would be prepared to raise the issue with the Secretary of State for Health. He wanted Dr Mitchell to be invited to speak on the matter at the next APPG, and also to invite the Health Secretary.

Dr Sarah Myhill

Vera Chaney (Green Network Charitable Trust) mentioned that Dr Myhill, a GP in Wales who offered nutritional support to people with ME, would be facing a General Medical Council hearing in September, following complaints

from doctors about the style and content of some of her practice. She needed support.

Group for Scientific Research into ME

Sarah Vero reported that, apart from Dr Gibson and David Taylor MP, no other members had attended the last GSRME meeting. Because the other members had moved on to other interests, it would not be possible to consider changing the GSRME Report published last November to incorporate alterations suggested in the feedback process. Dr Gibson was now secretary of APPG on ME, which he saw as offering the best hopes for parliamentary campaigning on behalf of people with ME.

Dr Turner said the GSRME was set up to conduct a short-term inquiry. It was never intended to have had a long life and therefore Ms Vero's news came as no surprise.

9. Date of the Next Meeting

The date was set for 12 July; the room venue will be announced later. Dr Turner said he hoped Dr Mitchell would speak on the subject of NHS Services, particularly as they affect his own area.

Dr Turner said the AGM of the group would also be held on July 12, when a quorum would be required to assure its future.

ENDS