



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 4pm, Wednesday 8 October 2008
Committee Room 17, House of Commons

Present

Parliamentary

Dr Des Turner MP (Chairman)
Andrew Stunell MP (Vice Chairman)
Tony Wright MP (Vice Chairman)
Rt Hon Tom Clarke MP
Kerry McCarthy MP
Janet Dean MP
Damian Green MP
Sir Robert Smith MP
The Countess of Mar
James Bolton, DWP
Phill Wells, PS, Mr Purnell
Koyes Ahmed, Office of Des Turner MP

Secretariat

Tony Britton (MEA)
Dr Charles Shepherd (MEA)
Sir Peter Spencer (Action for M.E.)
Heather Walker (Action for M.E.)

Organisational representatives and people with M.E.

Jane Colby (Tymes Trust)
Christine and Tanya Harrison (BRAME)
Joy Birdsey (Kent and Sussex Alternative Group for ME)
Doris Jones (25% Group)
Janet Taylor (Kirklees Independent ME Support Group)
Di Newman (Peterborough ME and CFS Self-Help Group and Cambridgeshire
Neurological Alliance)
Bill and Janice Kent (reMEMber)
Barbara Robinson (Suffolk Youth and Parent Support Group)

Sue Waddle (MERUK)
Paul Davis (RiME)
Natasha Posner
Annette Barclay
Ciaran Farrell
Augustine Ryan
Stephen Jones

Apologies

Janet Anderson MP, Tim Boswell MP, Peter Bottomley MP, Graham Brady MP, Kelvin Hopkins MP, Baroness Howe of Idlecote, Dr Brian Iddon MP, Elfyn Llwyd MP, John Leech MP, Ann McKechnin MP, Eddie O'Hara MP, Ken Purchase MP, Baroness Jo Valentine, Rudi Vis MP, Sir Nicholas Winterton MP.

1. Welcome

Dr Turner welcomed everyone to the meeting and introduced the main speaker, The Rt Hon James Purnell MP, Secretary of State for Work and Pensions, who was accompanied by James Bolton, Deputy Chief Medical Adviser at the DWP.

2. Welfare Reform

- i. Mr Purnell gave a short presentation on the reforms that are taking place:
 - a. Employment Support Allowance would be introduced this month, the Green Paper *No one written off: reforming welfare to reward responsibility* had been published and the White Paper would be produced based on the consultation currently underway.
 - b. The reform wasn't just about rules it was about people. The Minister described the case of a man in Myrtha Tydfil, who had lost his job, claimed Incapacity Benefit and thought he would never work again. Only when he did the Pathways programme did he realise that there was support available to help him back into work. His only complaint: why hadn't the DWP made Pathways available earlier?
 - c. The aim of the reform was to improve support and in return, raise expectations of claimants, by following five key principles:
 - i. Abolishing child poverty
 - ii. Improving the rights of disabled people to control their lives by introducing individual budgets so that they can choose how (on what services) money is spent
 - iii. Doubling the budget for Access to Work
 - iv. Providing better support but have higher expectations of claimants, expecting more work-related activity the longer

people are on JobSeekers Allowance. The majority of people (those in the work-related group) will do work-related activity.

- v. Devolving power to local level, so that policies could be adapted to meet local needs
- d. The Green Paper came on the back of reforms to assessment and introduction of the Work Capability Assessment (WCA), which should take account of fluctuating conditions.
- ii. Dr Turner thanked Mr Purnell for his presentation and opened questions by reading one of seventeen written questions which had been sent in by local ME support groups and people with ME. Questions were also taken from the floor.

- a. *Written question:* "How will the proposed assessments meet the needs of people with fluctuating conditions like ME?"

Minister: We are aware that some illnesses have particular characteristics that need special consideration and we have issued extra guidance on fluctuating conditions.

Charles Shepherd: Assessment is very important. People with ME cannot sustain levels of activity. Their cognitive and physical ability decreases with activity. The WCA has not been scientifically tested or validated.

Minister: We have committed to review WCA in 2009.

Di Newman: What is your definition of fluctuating conditions (quoted examples)

Minister: The WCA asks, what are your specific set of circumstances, rather than 'what is your specific condition.' But I note your points and you can submit them to the review.

- b. *Written question:* "Is the Minister aware of the deleterious effect stress, arising from applying for and benefits and appealing against refusals, has on the health of people with ME?"

Minister: To have an entitlement to benefit we have to have an assessment. I can see that there will be stress and worry that comes with that but it is necessary to see what benefit people should get. When we assess in future people in need will have a higher allocation of benefit.

- c. *Written question:* "I have had ME for 20 years. I made a partial 'recovery' and for 15 years I managed to hold down my job at the expense of forgoing all social and sporting activities. After a massive relapse, where I was unable to walk, stand, think, or tolerate light, sound or smell, I was dismissed by my employer 5 years ago on the grounds of medical incapability. What job do you think I can do?"

Minister: It is difficult for me to comment. What I can say is that if people fall back out of work, they will be able to go back to the benefit level they were on earlier.

- d. *Written question:* "Given that ME is a chronic, invisible and fluctuating condition that may last for a lifetime what guarantee can you give that sufferers will be allowed to work according to their capacity? So far the IB system has not allowed for this and the new system appears to suggest that only certain people on the higher support allowance can do this. Very few if judged able to do some work will be in this bracket and therefore only allowed to work flexibly for 52 weeks before losing all benefit. Benefit amounts could be estimated based on last years earnings as happens with WTC."

Minister: ESA allows a higher level of permitted earnings so people can combine benefits and work. We are not saying people have to take a job whatever their circumstances.

Tanya Harrison: But the system only allows people to do low level minimum wage jobs. If you try to do higher level work you lose your benefits.

Minister: It's a hard balance, providing enough support but not a disincentive to work.

Ciaran Farrell: The system tries to assess disability rather than debility. M.E. affects all body systems. If someone with performs the test and is judged fit to work, it doesn't mean they are fit to work.

- e. *Ciaran Farrell:* Is there a linking rule between ESA and DLA?

Minister: No

Tony Wright MP: The biggest problem is skepticism in the medical profession. If they are assessed by a medical professional who does not believe in ME, people with ME fall at the first hurdle. The

doctor doesn't believe there are issues around what people with ME can do.

Minister: We employ our own doctors and our guidance does recognise it.

- f. *Dr Turner:* Are you happy with your standard of medical advisers?

Minister: There is always good and bad practice in any area but we feel they do their job.

- g. *Written question:* "What measures will be in place to ensure that objective medical evidence – 'from the person that knows you best' – in my case my GP, will not be secondary to the subjective opinions of (private sector?) administrators under pressure to meet Government rehabilitation targets?"

Minister: They are not under pressure to meet targets. They are there to assess the person in front of them. The problem in part is that using people's own GPs does not provide consistency or independence.

- h. *Janice Kent:* Do you know what it's like to live on benefits, with such limited quality of life? The system does not allow people to work and work will not be available in a recession.

Minister: (Described links and local partnerships which were being developed to help people back into work).

- i. *Written question:* "The Minister has emphasised how much people on benefits say they want to work. Is he careful to make the distinction between wanting to and being able to work? If you ask the majority of people with ME if they want to work, I strongly suspect that they like me would say 'yes.' If you ask them if they are able, I for one would sadly have to say 'no.'

Minister: That's why we have ESA as well as JSA. We want to recognise that people with M.E. want to work.

Christine Harrison: One time when the ME organisations worked well together was on the DWP Guidelines on M.E./CFS. Regrettably after two years the DWP Medical Policy Unit did not accept their comments. Until there is a guideline on ME/CFS which truly portrays the reality of this illness, problems for people with ME will continue.

James Bolton: There were ten revisions at the time, trying to balance views, advice and the needs of the department. The guidance is to be reviewed in 2009.

Christine Harrison: will we be invited back to the table for this revision?

Minister: Yes.

James Bolton: Please write to us anyway to make sure.

Christine Harrison: We have been involved with Welfare Reform from the beginning I was pleased to have reconfirmed by Dr Moira Henderson and senior management of the DWP in July that the Australian model of the 104 week rule of work/benefit has been adopted. However, we are campaigning for the Government to take this a step further for people with long term conditions, allowing them to be automatically reassessed after the 104 weeks, and if necessary for the support to be extended for a further 52/104 weeks, and for this to continue to be assessed and extended if needed. This is because people with long term conditions may take many years before they find a sustainable level of work, and may continue to have future health relapses. Extending the rule would help people with long term conditions to continue to try and remain in work, with the security of knowing they can go straight back onto benefits if needed, and would give peace of mind.

Minister: This is an idea we can take back and consider.

Tanya Harrison: With the changes in benefits, what will happen to Severe Disablement Allowance?

James Bolton would inquire and write back.

Tanya Harrison questioned the amount of money people could earn without losing benefit, as to work 16 hours a week means working at a minimum wage. Although some people will never be able to work more than 16 hours per week, the message this sends out is that disabled/ill people are only capable of minimum wage work. It also means that those with high skills/expertise are unable to build up their hours.

Minister: a balance needs to be struck between providing support where necessary and giving too much encouragement to people to stay on benefits.

Peter Spencer: I would like to thank the Minister for coming because spending time at this meeting sends a powerful signal that he wants to get this right. That of course raises expectations that the views and experience of PwME will be taken into account. Through our consultation on the Green paper we have heard from about 1,000 people with ME and their carers and the results are very informative. Would there be an opportunity for us to share the statistics and rich narrative by engaging with his officials?

Minister: Yes please contact James.

- j. Doris Jones:* Will Pathways replace Work Step? Does Pathways offer the same provision for supporting people in work long term?

Minister: Pathways is different from Work Step. It will not replace it. There are a range of programmes. We are trying to introduce long-term pre-employment support.

- k. Tanya Harrison:* What will happen to people currently receiving SDA?

Minister: That will stay the same.

The Chair thanked the Minister for attending and he left.

3. Minutes of the last meeting

- i.* P3. Ciaran Farrell suggested that “If a child is suspected of child abuse” should read “If a parent is suspected of child abuse” and asked for clarification on whether Mr Webster has two daughters, Victoria and Veronica, or one daughter. He wished to make other points of language and grammar but Peter Spencer objected, saying that the Secretariat spent a great deal of time producing detailed minutes, without being resourced to do so. Unless the APPG could find funding for a stenographer to take a Hansard-style record of the meetings, time should not be wasted on unhelpful criticism about minor points.
- ii.* The Countess of Mar suggested that any changes to the minutes be put in writing to the Secretariat a week before the meeting and the Chair agreed.
- iii.* Di Newman will propose an alternative form or wording to her point on p5 which said “social workers who had ‘a psychiatric reading’ of ME.”

4. Matters arising

Matters arising were: (i) Child protection; (ii) Countess of Mar's meeting with charities; (iii) APPG inquiry into NHS service provision; (iv) M.E. Services: a template for a UK-wide module; (v) Mental Health Act and Mental Capacity Bill – detailed below.

i. Child protection issues

Jane Colby said that she and Mary-Jane Willows (CEO, AYME) were working on a briefing which would be e-mailed to charities for comment/approval, before forwarding it to the Chair for circulation at the next meeting and then to the Secretary of State and Chief Medical Officer.

ii. Countess of Mar's meeting with charities

The Countess reported that she had met with charity representatives from Action for ME., BRAME, MEA, MERUK, 25% Group, ReMEember and Tymes Trust earlier that afternoon to identify areas of agreement. AYME and Invest in ME had also been invited to the meeting but had been unable to attend. The Countess had found that agreement existed on 80-90% of issues. There was therefore a case for extending the ME Alliance into a larger grouping.

- a. Another meeting would be organised in the near future.
- b. A website would be set up in due course and papers would be posted on it to ensure transparency.
- c. In response to recent internet hostility and speculation, the Countess pointed out that she had been working with people with ME for 14 years and in the House of Lords for 30 years. She wanted to use her position to fight for people with ME as she hated injustice - but she did not need to fight the ME cause. If she was to continue, she was willing to receive reasoned and reasonable contributions from everybody, but only if there was respect for different people's views.
- d. Peter Spencer was pleased to report that the Countess of Mar had agreed to Chair the extended 'Alliance' group. This would guarantee independence.
- e. Ciaran Farrell said he was surprised to hear that the Countess would Chair the Alliance as she had denied an association with the Alliance in an e-mail to him, prior to the meeting.
- f. Peter Spencer made it clear that the charity representatives had been invited to the meeting as individuals and that the invitation to become

Chair of the new group had come at the meeting from amongst those present.

- g. Paul Davis asked why the Countess was now working with the charities, given her speeches in the House of Lords in April 2002 and January 2004, in which she had said that many of those who were severely affected by ME had felt let down by the apparent capitulation of the two major charities which appeared to have accepted the bio-psychosocial model of ME, especially Action for M.E.
- h. The Countess said that she would not countenance working with the charities if she thought they had not changed.
- i. Paul Davis asked if Action for M.E. regretted signing up to the CMO report.
- j. The Chair intervened, saying that regret or otherwise was not a matter for the current Group.
- k. Ciaran Farrell asked if the minutes of the Countess's meeting would be published
- l. The Countess said that they would be published on the website when it was set up and that Mr Farrell was welcome to have a copy of what was discussed.

iii. APPG Inquiry into NHS service provision

Dr Turner said the APPG Inquiry into NHS Services would look at what NHS services were available and make recommendations. It would consider whether there was a need for a national service framework for ME.

- a. *Terms of reference:* a draft Terms of Reference had been produced and was circulated at the meeting. The Inquiry was welcomed by Barbara Robinson, Di Newman and Christine Harrison, who all encouraged people to work with their local services. The meeting agreed to accept the draft terms of reference in principle subject to minor amendments. Sue Waddle suggested PCTs should be asked how many people were classified as having ME using Read Codes. It was agreed that this was worth considering. Any further amendments to be received by the Secretariat by early November for consideration by the Chair.
- b. *Inquiry Group:* a parliamentary team of MPs and members of the House of Lords would be invited to carry out the Inquiry.

- c. *Process*: like the Gibson Inquiry into research, the Inquiry would invite written evidence from people with ME/CFS and those involved with providing NHS services and, having considered the written evidence, it would then invite a number of people to give oral evidence. Ciaran Farrell asked if individuals would be allowed to submit their experiences and views. The Chair said they would be invited to submit written evidence in the first instance.
- d. *Funding*: resourcing the Inquiry was an issue as a great deal of work would be involved. A similar Inquiry, resourced by a special interest group, had recently cost £40k. Suggestions to raise money included issuing an appeal for funds or approaching a pharmaceutical company for sponsorship. Ciaran Farrell cautioned against this, as a pharmaceutical company might compromise independence. The Chair said he would ensure that sponsors would not influence outcomes.
- e. *Timescale*: The Chair would send out an invitation to submit written evidence before Christmas with a view to hearing oral evidence in February/March and publication before the summer recess (subject to funding).
- f. *Further points raised*:
 - a. Paul Davis said a committee member from Hereford had asked what criteria would be used for assessing clinics. He said Kent clinics criteria would exclude many people with ME. He also asked if the Inquiry would cover research. The Chair referred to the draft terms of reference and said that there was no intention of sending people to inspect the new clinics. Research had already been covered by the Gibson Inquiry.
 - b. Joy Birdsey said people with other conditions eg. Parkinsons did not seem to experience the same problems as people with M.E. Jane Colby agreed, saying some young people with mental illness were getting more home tuition than people with ME, even where ME was being classified as mental illness, possibly reflecting underlying prejudices.
 - c. Peter Spencer hoped the report produced by the Inquiry would be heavy on evidence rather than anecdote as it might then lead to a health select committee inquiry
 - d. Barbara Robinson asked if Pat Noons' replacement Patience Wilson or whoever is now responsible for ME at the Department of Health could be asked to provide evidence.

iv. M.E. Services: a template for a UK-wide module

The following represents a brief note of two presentations by Di Newman. It is hoped that the full presentation will be available as a link to this minute in due course.

- a. Di Newman reported on work undertaken by the Peterborough ME and CFS Self-Help Group and Cambridgeshire Neurological Alliance in association with local PCTs to ensure good quality permanent services for people with ME.

This included:

- i. clarifying Read Codes for ME/CFS
 - ii. working with healthcare professionals to change the language eg. from CFS to ME/CFS and to identify the numbers needed by the Strategic Health Authority to allow them to fund services (NB. These services are not stand-alone but within services for long term conditions)
 - iii. achieving recognition that instead of 23-58 cases, there were 2,400 possible cases in the region
 - iv. accepting where there is resistance to stand alone services and working within the remit of the National Service Framework for Long Term Conditions
 - v. ensuring that ME is firmly positioned in the 'neurological' arena, which provides access to a variety of consultants including immunologist etc
 - vi. supporting and promoting all the work that the Neurological Alliance has done
 - vii. seeking Scrutiny overview
 - viii. educating neurologists who do not believe in ME
- b. Janet Taylor said that the Kirklees Group was going down a similar 'neurological/long term conditions' route and would be meeting with the SHA on 2 December to ask how the service will be meeting the recommendations of the Darzi report. The Group have been told that there is money available for training GPs. Sue Pemberton's service in Leeds has been given a copy of the MEA questionnaire. It does not advocate GET and regards ME/CFS in the same way as MS.
 - d. Joy Birdsey said Medway was very lacking in services and that the progress outlined by Di and Janet sounded like Utopia in comparison. It was essential that high quality services were offered nationwide: the current provision was too patchy.
 - e. Christine Harrison said BRAME had drafted a policy statement in May, which was given to Lord Darzi. She hoped that the proposed Inquiry would recommend joined up services.

v. Mental Health Act and Mental Capacity Bill – detailed below.

- a. Di Newman proposed that the APPG invite a representative of the Mental Health Alliance to attend the APPG and discuss how the legislation will affect people with ME and how it is being implemented. In particular, there are serious concerns about misuse of powers on sectioning. Di will suggest who might be invited.
- b. Christine Harrison said there was a risk people could be sectioned for refusing treatment.
- c. The Countess of Mar agreed, citing an occasion where AYME had used NICE to overturn a case.
- d. Christine Harrison said that Criona Wilson had responded to Peter White's letter in the *Times*, in which he had said that "no patient has ever died directly as a result of CFS/ME and follow-up studies show no increased risk of dying" but her letter had not been printed. Criona's daughter, Sophia Mirza, died from acute aneuric renal failure due to dehydration as a result of CFS. When she was alive, Criona had fought for recognition that Sophia was physically - rather than mentally - ill. Sophia was sectioned for two weeks under the Mental Health Act in 2003.

v. Other business

- a. Paul Davis asked the Chair if he would sign RiME's petition. The Chair declined.
- b. Janet Taylor asked if the Ian Gibson's offer of an EDM had moved forward. The Chair said no.
- c. A person with M.E. (name supplied) said she did not think that DWP medical assessors have proper understanding of ME

vi. Date of next meeting

Proposed for early December, depending on availability of potential speaker. (Meeting since deferred, pending availability of a speaker).