



## ALL-PARTY PARLIAMENTARY GROUP ON M.E.

**Chair:** Tony Wright MP  
**Vice Chair:** Rev Martin Smyth MP  
**Secretary:** Steve McCabe MP  
**Treasurer:** David Amess MP

### **MINUTES OF THE ALL- PARTY PARLIAMENTARY GROUP ON M.E. HELD ON MONDAY 28 JUNE 2004 AT THE HOUSE OF COMMONS**

#### PRESENT

- Tony Wright MP (Chair)
- Tom Clarke MP
- Peter Pike MP
- Russell Brown MP
- Maria Eagle MP
  
- Fay Stockwell, Office of Angela Browning MP
- Chris Clark, Chief Executive, Action for M.E.
- Tony Britton, M.E. Association
- Angela Flack, Trustee, M.E. Association

#### **1. MINUTES OF THE LAST MEETING**

The minutes of the last meeting held on 20<sup>th</sup> January 2004 were agreed.

#### **2. APOLOGIES**

Apologies for absence were noted

- David Amess MP
- Harry Barnes MP
- Anne Begg MP
- Roy Beggs MP
- Bob Blizzard MP
- Tim Boswell MP
- Graham Brady MP
- Tom Brake MP
- Tony Clarke MP
- Lord Clement-Jones
- Jim Cousins MP
- Jim Cunningham MP
- Tony Cunningham MP
- Janet Dean MP
- David Drew MP
- Julia Drown MP
- Peter Duncan MP
- Clive Efford MP
- Annabelle Ewing MP
- Howard Flight MP
- Mark Gapes MP
- Cheryl Gillian MP
- Win Griffiths MP

- Ivan Henderson MP
- Paul Holmes MP
- Jimmy Hood MP
- Joan Humble MP
- Andrew Hunter MP
- Dr Brian Iddon MP
- Robert Jackson MP
- Nigel Jones MP
- Fraser Kemp MP
- Eleanor Laing MP
- Steve McCabe MP
- John McDonnell MP
- Kali Mountford MP
- Chris Mullin MP
- Eddie O'Hara MP
- Bill O'ner MP
- Lord Puttham
- Syd Rapson MP
- David Rendel MP
- Dame Marion Roe MP
- Bob Russell MP
- Rachel Squire MP
- Andrew Stunell MP
- Mark Todd MP
- Bill Tynan MP
- Robert Walter MP
- Bill Wiggin MP
- Betty Williams MP

### **3. THE BENEFITS SYSTEM AND M.E.**

The APPG invited Maria Eagle MP, Minister for Disabled People, and Parliamentary Under-Secretary of State for Work and Pensions to speak and she agreed to take questions from the group. Tony Wright MP introduced her to the group. Ms Eagle went on to explain how the Disability Living Allowance (DLA) is not a medicalised benefit. She stated that the Department of Work and Pensions does not diagnose people or dispute their diagnosis. The Department is looking at the effect a condition has on a person and, therefore, DLA is awarded to M.E. sufferers based on their ability to care for themselves. After this brief introduction to how DLA is awarded, Ms Eagle opened up the discussion so she could hear personal experiences and concerns.

### **4. QUESTIONS AND DISCUSSION**

Tony Wright brought up the possibility of the Department implementing special arrangements for those with M.E. because they do not fit with other illnesses covered by DLA. Ms Eagle reiterated the fact that DLA is not a medicalised benefit and therefore cannot implement different rules according to a medical condition.

Tom Clarke MP brought up the issue of some general practitioners (GPs) not believing in M.E, which makes getting a diagnosis difficult. Those visiting practitioners (EMPs), who come to visit M.E. sufferers in their homes to get a

report on the individual, are often reported to be unsympathetic. People with M.E. have good days and bad days and often the practitioners come on good days or ask the wrong questions. Therefore the report that the Department receives reflects the day that someone comes to visit (whether it is a good day or a bad day), how long they stay to observe and how willing they are to listen. Ms Eagle stated that the Department recognises that M.E. is a serious illness and recognises that it can lead to an entitlement to DLA. The visiting practitioners are trained and have a handbook that briefs them on the various disabilities.

The Department is willing to hear complaints and wants to know when a practitioner is less than satisfactory, and will remove those who fall below required standards. She also stressed that DLA is a subjective assessment and that those who apply have the opportunity to appeal.

Tony Wright MP then brought up the case of M.E. sufferers and appeals, highlighting the low success rate at first application matched by high success rates on appeal. Perhaps the opportunity to appeal lessens the number of complaints the Department receives. Ms Eagle stressed the subjectivity of the benefit and the availability of additional information on appeal.

Chris Clark from Action for M.E. reinforced Tony Wright's point, referring to independent published research showing high levels of failure on first application matched by high levels of success on appeal.

Chris Clark stated that people with M.E. were not seeking special treatment, just that there should be fairness in the handling of applications and equity with other illnesses of equal severity. He thought that the system was not effectively applied on the ground and stressed how easy it is for patients to get caught up in the benefits system. He also discussed the Department's handbook, which sets a tone by introducing M.E. as a controversial disease. He was very concerned by the link to the Mental Health Chapter. He talked about EMPs asking an M.E. sufferer if they can walk to the end of the path, which they often can. EMPs need to ask the better question: 'What will be the affect on your health if you walk to the end of the path?' He criticised the section on those most severely affected and stressed that the scale of complaints indicated this was not a result of a few individual EMPs who needed to be weeded out, but was a more systematic problem.

Ms Eagle replied that she was willing to adjust the handbook if there are errors and work with Action for M.E. to create a better one. She agreed that if the role of EMPs in assessing DLA is not working this should be reviewed, though she stressed that complaints against EMPs were no higher for M.E. than for other conditions. EMPs are supposed to ask what the condition is generally like. Ms Eagle invited him to write detailing the areas of concern so she could put him in touch with the relevant officials, particularly regarding the possibility of amending the handbook and improving the process.

Russell Brown MP brought up the subject of the forms required for applying for DLA. He said that due to the paperwork involved, many people give up on applying for DLA after being refused the first time. He called for the forms and the process to be reformed and made simpler. Ms Eagle said that the Department is looking at reworking the forms and have introduced some new options designed to tailor them to the patient's needs as well as reducing their length. The alterations are due to go live in September.

Angela Flack said that she was glad to hear that DLA is not a medicalised benefit and then asked, if it was not medicalised, why general practitioners need to be consulted at all. Ms Eagle said that such consultations are not required, but are often needed so that those who make the DLA decisions have all the facts about the disability. The purpose of the assessment is to evaluate the impact of the condition, not to diagnose. Ms Eagle continued to stress that the Department is looking for complaints if visits are unsatisfactory. She stated that those who make the visits have no financial interest in the outcome. The EMP's report is passed to the DLA decision maker.

Tony Wright MP agreed that it was important to pass on complaints about DLA to the Department. Tony then brought up an email he received from an APPG member, Liz Blackman MP, which discusses DLA as an indefinite award. Ms Eagle said that the reassessment of a benefit looks at the individual's entire eligibility. An indefinite award does not mean that one will receive DLA indefinitely, rather that it has no definite end date. Reviews resulting from health improvement have to look at other entitlements.

Concluding comments included the need to raise greater awareness of M.E, especially amongst general practitioners. The APPG thanked Maria Eagle MP for attending and for being receptive to comments.

## **5. CORRESPONDENCE (Additional to the large amount received that helped form the recent adjournment debate on benefits and M.E.)**

**Sheila Barry** (daughter Carli mentioned in Adjournment Debate): writing to support our work and ask if we will ask the Minister about the problems M.E. sufferers face in the initial and daunting DLA application process.

**Theresa Coe, Editor of InterAction, Action for M.E:** following an email sent to 200 randomly selected members three weeks ago, attached **31** responses, all detailing bad experiences relating to DLA from people with M.E, many of whom are severely disabled. Might be able to provide a copy of some of this evidence to Ms Eagle, so she is fully briefed on the problems faced by people with M.E.

**Simon Lawrence, 25% ME Group:** provided information in the form of a press release regarding M.E. Awareness week that details the problems of the group's members in receiving the necessary benefits they feel they are entitled to. This provides some good statistics.

## **6. ANY OTHER BUSINESS**

- a) The group discussed the possibility of asking other members what would be the best day/time to hold the APPG on M.E. meetings to ensure a better attendance rate. Tony Wright agreed.
- b) Following a long gap the ME Association had indicated they were now able to resume the joint secretariat role with Action for M.E.

## **7. DATE, TIME AND SUBJECT OF NEXT MEETING**

The next meeting will be in October 2004, reflecting feedback from members about the best day and time to meet.