

ME in Politics

REPORT ON APPG ON ME MEETINGS

The 15th January meeting concerned welfare benefits. Representatives from both ATOS and the DWP (Minister Mark Hoban MP) were expected to be present to hear problems which ME/CFS patients have with Work Capability Assessments (WCA) and in obtaining Employment Support Allowance (ESA), but neither attended. Parliamentarians present were Annette Brooke (Chair), the Countess of Mar and Ian Swales MP (Vice-Chairs).

Tristana Rodriguez outlined key points from a briefing paper on the Welfare Reforms, which had been prepared for parliamentarians:

1. Following internal reviews and independent reviews by Professor Malcolm Harrington, the government had made changes to the WCA, but the Professor had said 'pace and scope' of improvements were slower than hoped for and the WCA was still traumatic for many people.
2. In September 2012 AfME had produced a report '*Time for Action on the WCA*', highlighting continuing problems with WCA for people with ME.
3. From October 2013 there will be changes to the appeals system with a 'mandatory reconsideration' stage before an appeal can be lodged with the Tribunals Service.*
4. PIP (Personal Independent Payments) are to be rolled out as the new non-means-tested, non-taxable cash payment to disabled people to assist with the extra cost of living with long-term conditions. This replaces Disability Living Allowance for working age people (16-64). The government hopes to save £2 Billion by the transfer of DLA to PIP. As there is no equivalent to the lower rate of DLA in PIP, many ME patients may find that their benefit is cut and this is causing great anxiety.*
5. The government is consulting with relevant government departments regarding benefits like Blue Badge, public transport concessions and mobility schemes.
6. One example concerns worries over new rules on how far people can walk, which may mean people lose help with transport from April. A precedent DLA case law rule stipulated a distance of 50m as a guide to eligibility to higher level of DLA benefit, but under new rules this will apply to people who can walk less than 20m.
7. An estimated 90,000 people may lose Motability Vehicles under PIP.
8. Disability organisations representing people with fluctuating conditions have collaborated with the DWP in endeavours to ensure that the ability to carry out tasks '*reliably, repeatedly, safely and in a timely manner*' is reflected in eligibility documents.

Many critical comments followed.

Dr Charles Shepherd reported that the DWP's Evidence Based Review of the WCA was in progress. However, many points the Fluctuating Conditions Group would have made were removed from their report, as the DWP had maintained they were out of remit. Dr Shepherd said in his view the WCA was not fit for purpose. Sonya Chowdhury commented that fundamental factors were being ignored e.g. inaccessible assessment venues, and assessors who had no knowledge of ME should not assess these patients. Doris Jones circulated and read out a

brief paper *'Key Issues / Problems arising from 25% ME Group Members' ESA Experience'*, the summary of a more detailed report - which had been sent by e-mail to parliamentarians prior to the meeting.

Ian Swales MP said there was a special problem for those people who were too ill to attend assessments and Sue Waddle commented that some drop out of the process because they can't cope and lose benefits they badly need.

Christine Harrison said she is very concerned about some of the language that is used in assessment documentation intended for implementation of PIP and she had many worries about this particular change in the benefit reforms.

Sonya Chowdhury commented on the appalling lack of common sense and compassion to patients on the one hand, and an excessive amount of money being spent on appeals and tribunals on the other.

The Countess of Mar said she would send copies of AfME's *'Time for Action'* report and the 25% ME Group's summary report to Lord Freud, and Annette Brooke promised to send the same documents to a Minister in the House of Commons.

The Chair and Ian Swales MP said they would try to arrange a half hour debate on welfare benefits and ME.

Note: There was a 3-hour fierce and highly critical debate on ATOS and WCAs in the House of Commons two days later (17.1.2013). Annette Brooke and at least one other MP specifically referred to problems experienced by patients with ME/CFS. This debate was initiated by Michael Meacher MP.

The 13th March meeting, deferred from last summer, focused specifically on the severely affected. Parliamentarians present were Annette Brooke MP (Chair) and Russell Brown MP. Presenters were Professor Derek Pheby (Visiting Professor of Epidemiology, Buckinghamshire New University, AfME), Clare McDermott (University of Southampton), Sarah Frossell (Dorset Bespoke).

Annette Brooke welcomed the group. She reported that since the last meeting officers had been invited by ATOS to visit an Assessment Centre at Marylebone (to be reported on at the next meeting). She welcomed the opportunity to focus specifically on those with severe ME, and introduced Professor Pheby.

Professor Pheby said he was grateful for the opportunity to talk about severe ME. He would outline research into risk factors for severe ME, which he was involved with, funded by MEA with results published in 2009. Then he would discuss the impact which severe ME had on the lives of those affected and their families, speaking from personal experience.

1. *Prevalence of severe ME:* Conventionally this is estimated to affect 25% of people with ME – in the UK amounting to ca. 60,000 of about 250,000. But there was little empirical evidence to support these figures, which had been arrived at based on Jason et al's headline prevalence figures of 0.42%.

2. *Risk Factors:* Having a family member with ME, especially the mother. This could be due to mitochondrial dysfunction in the pathogenesis of ME, as mitochondrial DNA is entirely of maternal origin. Premorbid personality was not a risk factor. *The most important risk factor appeared to be inappropriate treatment in the early stages of the illness – a poor relationship with GPs and greater involvement of psychiatrists and social workers.*

3. *Further Research needed:* The study done was largely hypothesis-generating and needs to be tested by more research requiring larger samples and better categorization of cases. There may be multiple underlying pathologies requiring biomedical research on underlying disease mechanisms.

4. *Lack of understanding by professionals:* Better training was necessary for all professionals involved in the care of people with ME (e.g. doctors, teachers, clinical and educational psychologists, social workers etc) because lack of understanding of appropriate treatment in the early stages contributes to later morbidity.

5. *Impact on lives:* He described his family's experiences after his son developed severe ME at the age of 8, who is now 42. He said his entire family became public property, social services got involved from the start, they were threatened with care proceedings. The County Council repeatedly lied about the case and denied matters for 25 years. The experience had blighted his and his wife's lives and adversely affected his other children's social and educational developments - a tragic account of a cruel experience that took 26 years before justice prevailed.

A pdf file containing the article on Prof. Pheby's research from Biology + Medicine was circulated .

Clare McDermott, NIHR Doctoral Research Fellow at the Department of Primary Care and Population Science, University of Southampton, outlined her research: *'Designed by people with ME, for people with ME : Developing a community based intervention to improve health and quality of life in severe CFS/ME'*. She has been involved in ME research for over 10 years, on studies involving 'specialist services' within the NHS. Her particular interest is in people with severe ME, having had this in her teens and early 20s. She described some innovative pilot work for people with ME which her team has recently completed and results of which were promising. She has obtained funding for a feasibility study that she will conduct as part of a PhD. She circulated a copy of the *'Dorset Bespoke Group Model for ME/CFS'*. She has worked with Tim Stirgess (Dorset ME Support Group, who was present at the meeting) and the late Dr Tudor Thomas (previous Chair of the Dorset Group), which has helped through the steering group, financially and in the development work. People with ME had contributed ideas, skills and insights into the development process - acting as 'peer specialists'. She gave an example of a long-term bedridden patient in a darkened room who after 1 year could go out in the car again. In her view effective drug therapies could be a long way off, meantime all should be done to improve the health and quality of life for these patients. She stated that the programme regarded ME as a biomedical illness and *'worked with individuals to use strategies to put the body into a healing state'*. The intervention *'was neither CBT nor GET - the challenge was to help and equip people to do this for themselves'*.

Sarah Frossell works with Clare and spoke about the work they have done. The pilot involved 6 people; the feasibility study will comprise 20 patients fulfilling the 1994 CDC criteria.

Issues arising in the Q+A session included: separate ME from CFS; a combination of approaches found to lead to recovery; uncertainty about underlying pathology – along a continuum or different pathologies/sub-types; severity/chronicity being triggers for child protection investigations.

by Doris Jones

* *There is guidance for members on the change to the appeals system on page 23 of the newsletter; DLA and the introduction of PIP is covered on pages 16 & 17. (Ed.)*