

DRAFT

APPG on M.E. Legacy Paper (2005/6-2009/10)

The All Party Parliamentary Group on M.E. (M.E. as defined by the World Health Organisation) will formally break up for the forthcoming General Election (date to be confirmed.) The Group leaves the following legacy paper to the APPG that will be reconstituted after the election, so that the work that has been carried out over the last four years will be clear and may continue as seamlessly as possible.

The APPG operates a code of practice, circulated November 2006 (see Appendix.)

Ongoing work / areas of concern

1. Research

The Medical Research Council has highlighted CFS/M.E. as an area of high priority but says there has been a lack of high-quality research proposals on the subject. The Gibson Report, published Nov 2006, found that the research areas defined by the CMO Report in 2002 had not been addressed. It said that although some interesting biomedical research has been done in the UK precedence has been given to psychological research and definitions. It said further research is the single most important area in this field and that the UK should take this opportunity to lead the way in encouraging biomedical research into the potential causes of CFS/M.E.

Issues to address:

- a) Availability of funds in a fiercely competitive environment
- b) Need for proactive and strategic action
- c) Whether the Medical Research Council strategy is appropriate and effective
- d) Biomedical research into M.E. Review the work of Prof. Holgate expert group on research. Focus on sub-grouping.
- e) Focus on the severely affected - they are most in need, have the most challenging symptoms and are most neglected
- f) Pro-active and strategic action particularly in light of recent research findings regarding xenotropic murine leukemia virus (XMRV)
- g) At least one M.E. Research Centre providing a multidisciplinary research environment, to support access to appropriate clinical, educational and support services based on an enhanced understanding of the debilitating fatigue suffered by those with M.E.

2. Welfare benefits and social care

Problems relating to Disability Living Allowance (DLA), Incapacity Benefit and more recently, Employment and Support Allowance, have been an important issue for the APPG. Problems involved in benefit-claiming, assessment and decision-making have been illustrated by the high number of awards made at the appeal stage after rejection of the first claim. Current social care proposals will have a significant impact on people with long-term conditions, in the short term and as they get older. The current economic climate threatens the provision of welfare support to those who need it most. Issues to address:

- a) Production of accurate and appropriate guidelines for assessors and decision-makers.

- b) Monitor all changes to benefits and how those affect people with M.E. for example the impact and effectiveness of Employment and Support Allowance (ESA.)
- c) Realistic support from Government and employers for people with M.E. and other fluctuating conditions who want to stay in or return to work;
- d) Monitor the impact of National Care Service proposals and the effect of these changes for people with M.E. eg. personal budgets and direct payments of personal allowances such as Disability Living Allowance (DLA) and Attendance Allowance (AA) to Social Services.
- f) Protect the welfare of genuinely ill and disabled people *and their carers* who need support through the recession and beyond.
- g) Recommend that an “M.E. expert” should be appointed to work with decision makers in each Disability Benefits Consortium area nationally.
- h) Education of Social Services and Department for Work and Pensions (DWP) staff.
- i) Fairer criteria for CFS/M.E. patients to be issued by DWP.

3. NHS services

A Report to the Chief Medical Officer in January 2002 led to the announcement by Government in May 2003 of an investment of £8.5m over two years in a centrally planned programme to set up new clinical services for people with CFS/ME in England. In 2009, the APPG held an inquiry into NHS services in England. The Inquiry found that *(this point to be completed when the Inquiry report is published)*.

Issues to address *(to be added when the Inquiry report is completed)*:

4. National Institute for Health and Clinical Excellence (NICE) guidelines

NICE published guidance on the Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, in August 2007. Although it tells healthcare professionals to “acknowledge the reality and impact of the condition,” it has been criticised by patient groups (see issues to address). The guidance was the subject of a Judicial Review at the High Court in London, February 2009, which found in favour of NICE. In December 2008 there were reports that the Care Quality Commission intended to make NICE recommendations (for all conditions) mandatory. The NICE guideline is now eligible for review.

Issues to address:

- a) Focus on chronic fatigue not M.E. as defined by the World Health Organisation.
- b) Over-emphasis on randomised control trials based evidence regarding cognitive behavioural therapy and graded exercise therapy.
- c) Realities of interpretation and implementation which may result in what is essentially a “psychiatric” approach.
- d) Review of NICE guidelines in the light of emerging viral research, to include establishing testing services for the xenotropic murine leukemia virus (XMRV) and the other infections which may be found in people with M.E. and treatment for the XMRV if it becomes available.
- e) Review of diagnostic criteria - the Canadian Expert Consensus Panel Clinical Case Definition for ME/CFS of 2003 is regarded by Dr Neil Abbott, Operations Director of ME Research UK, as a useful starting point.

5. Child Protection Issues

Some children with M.E. and their families are caught up in unnecessary, damaging and distressing child protection conferences and care proceedings because there is misunderstanding about M.E. amongst teachers, social workers and other professionals. Guidelines published by the Royal College of Paediatrics and Child Health in 2004 have largely gone unnoticed. *Issues to address...*

Issues to address:

- a) Invite the Inspector of Social Services to the APPG to hear parents' and children's stories
- b) Consider the needs identified by children and young people's ME charities for:
 - (i) The Department for Children, Schools and Families to alert Social Services professionals to the frequency of misunderstandings in cases of M.E. There should be an investigation into the cost of pursuing these cases.
 - (ii) All parents under suspicion of putting their child at risk should be informed of their rights, and given information clarifying child protection procedures and details of organisations which can support them
 - (iii) Directive to be issued by the Royal College of Paediatrics and Child Health for all paediatricians to refer to the college's guideline when treating children and young people with M.E.
 - (iv) M.E. to be included in the training of all GPs and paediatricians.
 - (v) M.E. education for all teaching professionals.

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

Although the Government made important concessions to protect patients and their families, there have been concerns that the Bill might increase the number of people sectioned for refusing treatment. There was a risk of over-use of community treatment orders and there were concerns about the powers given to clinicians.

Issue to address: Has this proved to be the case and if so, what should be done?

Programme of work

1. Consider how to take forward **issues to be addressed** in 1-6 above.
2. Consider future **opportunities for adjournment debates** (last suggested July 2007; attempt unsuccessful)
3. Consider future **opportunities for Early Day Motions** (last suggested 2007 but deferred)
4. **Possible APPG speakers:**
 - Chief Executive of the Medical Research Council (last spoke April 2006)
 - Chair of the NHS CFS/M.E. Clinical & Research Network and Collaborative (CCRNC) Conference (last spoke Nov 2005)
 - Secretary of State for Work and Pensions (previously spoke Nov 2006, Oct 2008, Nov 2009)

- Chairman of the National Institute for Health and Clinical Excellence (last represented Feb 2007)
 - Secretary of State for Health Services (last represented by Parliamentary Under Secretary of State for Health Services, January 2008)
 - Baroness Young, Care Quality Commission
 - Inspector of Social Services
5. Review the Terms of Reference for the APPG on ME.
 6. Review the “Code of Practice for the APPG on M.E.” (See appendix.)
 7. Draw up a structured and prioritised **Work Plan** and programme and an annual schedule of meetings each year, to accompany the Work Plan, which the APPG ought to revise and review annually at the APPG’s AGM. The Work Plan should be able to be adjusted at each APPG meeting to meet the prevailing needs of the day, and there should be an item on the agenda of APPG meetings entitled “Work Plan” for this purpose.
 8. Consider making available a slot on the agenda of its meetings for members of the public to raise items of concern in accordance with the terms of reference of the APPG on ME.
 9. Work towards parity with other medical conditions, such as AIDS, multiple sclerosis.

APPENDIX: Code of practice for the APPG on M.E...

APPENDIX: Code of practice for the APPG on M.E.

1. The APPG and the Secretariat (Action for M.E. and the M.E. Association) accepts the WHO Classification of M.E. as a neurological condition and welcomes the recognition by the Department of Health of M.E. as a long term neurological condition.
2. The APPG strives to support the improvement of health, social care, education and employment opportunities for people affected by M.E.
3. The meetings of the APPG are held in public and it is expected that attendees will adhere to the principles of best practice in meetings:

Attendees will abide by the APPG Governance Procedures and Practices

This means that the attendees will honour the policies set up by the APPG to govern its own activities, including meeting protocols, committee rules etc. It is anticipated that attendees will follow basic rules of personal courtesy, attendance and being prepared. The APPG and the Secretariat recognise the connection between the behaviour of individuals in meetings and the ability of the APPG to address its business effectively. Attendees will be expected to participate so that APPG business progresses smoothly and efficiently.

- Participants will give apologies ahead of time to the Chair if unable to attend meetings
- The Secretariat will ensure that information is distributed prior to meetings, allowing participants time to read and digest important information ahead of a discussion
- Attendees will honour the authority of the Chair and respect his/her role as the meeting leader. When problems arise with meetings they should be dealt with as procedural issues rather than a personal criticism of the Chair and other officers.
- Participants will engage in debate according to procedures, maintaining a respectful attitude towards the opinions of others whilst making their own point.
- Attendees must express their views clearly when it is their turn to speak and then allow others to express their opinions in turn.
- Attendees must listen respectfully to other meeting participants, to the Chair and to other speakers. They must not attempt to silence minority opinions, nor should they talk over others.
- Attendees must not use their mobile phones in meetings or adopt any other bullying tactics.
- Attendees are invited to offer suggestions to the Secretariat or the Chair on how best to enhance the role and function of the APPG.

These guidelines are produced as a method of efficiency. If an individual attendee does not comply with the code the Chair may institute a warning system. The APPG anticipates that debate should be lively but controlled and every effort will be made to hear a wide range of different opinions and elicit the opinions of those who may be inclined to be silent.