

Current issues of concern

RECENT EVENTS

Chief Medical Officer's Report

In July 1998, former Chief Medical Officer Sir Kenneth Calman set up a multi-disciplinary group to prepare a report on ME/CFS that concentrated on clinical assessment, diagnosis and management.

This report was published in January 2002 by the present Chief Medical Officer, Professor Liam Donaldson. It concluded that ME/CFS is a genuine and disabling illness that is under-researched and often badly managed,

As a result, two important government initiatives relating to research and service provision were announced.

Medical Research Council

The Medical research Council was asked to develop a research strategy for ME/CFS. This was published in 2002.

Biomedical research into the underlying cause was not given a high priority. The main emphasis was on non-drug (ie behavioural) management.

So, while The MRC has been willing to fund research into behavioural interventions - ie cognitive behaviour therapy (CBT) and graded exercise therapy (GET) - it has not been proactive in funding or encouraging

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BACKGROUND: KEY FACTS ON ME/CFS

- ☆ ME/CFS (myalgic encephalomyelitis or encephalopathy/ chronic fatigue syndrome) is an illness whose nomenclature, definition, cause and management remains the subject of controversy and uncertainty.
- ☆ ME/CFS is probably a three-stage illness that involves **predisposing** factors (ie genetic predisposition); **precipitating** factors (includes infections and sometimes vaccinations) and **perpetuating** factors (including neurological, immunological and endocrine/hormonal dysfunction).
- ☆ ME is classified by the World Health Organisation as a neurological disorder in section G93:3 of their International Classification of Diseases, edition 10. CFS is linked to this classification. The government accepts the WHO classification.
- ☆ Epidemiological studies suggest a prevalence of somewhere between 2 and 4 per 1,000 of the UK population. This equates to between 150,000 and 250,000 adults and children.
- ☆ Onset is usually during the early twenties to early forties. However, children as young as seven and adolescents are also affected. ME/CFS is one of the commonest causes of long-term absence from school.
- ☆ All social classes and ethnic groups are affected.
- ☆ Around 25% of people with ME/CFS are severely affected. In general, they are house-bound or bed-bound, and require the use of wheelchairs, mobility scooters and personal assistance to get around.
- ☆ Overall prognosis is poor with less than 10% making a complete and permanent recovery.
- ☆ The annual cost to the UK economy of supporting such a large number of sick people has been estimated by independent commissioned research at £6.4bn. This represents lost taxes, benefit payments, hospital costs and related expenditure.

biomedical research. In recent years, The MRC has turned down a number of potentially important biomedical research applications.

All-Party Inquiry

Dissatisfaction with the lack of biomedical research led to the setting up of an all-party group of MPs and peers called the Group for Scientific Research into ME. The group was led by Dr Ian Gibson MP and included two physicians, Lord Turnberg (a former president of the Royal College of Physicians) and Dr Richard Taylor MP. They carried out their inquiry into research in 2006 by taking written evidence and holding five oral hearings.

Their report was published in November 2006. It concluded that there was an urgent need for high quality biomedical research to be carried out into various aspects of ME. A copy of the report can be downloaded at www.erythos.com/gibsonenquiry

At the same time, the All-Party Parliamentary Group (APPG) on ME was also expressing serious concerns about the lack of biomedical research and The Medical Research Council's research strategy. Professor Colin Blakemore, then chief executive of the MRC, was questioned by the APPG in April 2006.

In the absence of MRC funding, almost all biomedical research

into ME/CFS in the UK has had to be funded by charities and individuals.

The ME Association is funding a study into gene expression in people with ME (ie how genes behave and control various functions at a cellular level). Encouraging preliminary results are now being replicated by other groups, both here and overseas. The ME Association have also funded the first research study to examine multiple-risk factors that may be involved in the development of severe ME.

A high proportion of ME Association-funded research has been published in peer-reviewed scientific journals.

NHS Service Development

In recognition of the fact that there were many areas of the UK where there were no hospital-based services for either diagnosis or management of people with ME/CFS, the Department of Health provided a ring-fenced fund of £8.5m in May 2003. This was used to develop a network of 13 clinical co-ordinating centres and around 50 local multi-disciplinary services throughout England. We understand that a total of 22,000 adults and children have been referred to these services so far.

No such network was set up in Scotland, Wales or Northern

Ireland. NHS specialist services in these important parts of the UK remain few and far between.

The ring-fenced funding has now finished. As strategic health authorities and primary care trusts struggle to balance budgets and meet competing priorities, the English services are under threat.

One of the clinical network co-ordinating centres in Birmingham has now been closed, and there are large gaps in service provision. There are, for instance, no specialist NHS services in Teeside, Buckinghamshire and Hertfordshire. And there is little prospect for severely ill people in these areas being able to travel elsewhere – even if out-of-area funding is available.

The ME Association is also concerned that many of the NHS services offer management programmes based on behavioural and exercise interventions, which are inappropriate for people with severe ME.

Dr Terry Mitchell, clinical lead for ME/CFS in East Anglia, spoke about the threats facing his service when he addressed the APPG on ME in July 2007. The APPG has invited the Secretary of State for Health, Alan Johnson, to respond to these concerns and other issues at their next meeting, which we hope will be held before the winter recess.

Other current concerns

Nice Guideline

NICE (National Institute for Health and Clinical Excellence) published a guideline on the clinical assessment and management of ME/CFS in August 2007.

While it contains some helpful guidance on the need for early diagnosis and management and

makes it clear that patients must not to be coerced into taking part in treatment programmes with which they are not happy, it still fails to accept the WHO classification of ME/CFS as a neurological disorder.

The advice on management is dominated by the recommendation that everyone with mild to

moderate ME/CFS would benefit from trying a course of CBT and/or GET – which may well be based on the flawed psychosomatic model of ME/CFS whereby it is maintained by abnormal illness beliefs and behaviour.

NICE were presented with a unique opportunity to provide

practical guidance that would help to ensure that people with ME/CFS were offered management advice covering all aspects of the illness that would be acceptable and beneficial. They have failed the task that was set.

The ME Association, along with many other local and national groups, believes that the recommendations in the final version – which are basically a ‘one size fits all’ approach to management involving CBT and GET – are over-simplistic and unfit for purpose. The British Psychological Society, the professional body which represents psychologists, have also issued a statement criticising the inflexibility of the guideline. The BPS statement can be accessed on the MEA website.

If you would like to see the The ME Association’s response, please email: meconnect@meassociation.org.uk

During the drafting of the NICE guideline, members of the APPG on ME also expressed their misgivings over the version that was presented for stakeholder consultation in September 2006. At their meeting in November 2006, Dr Ian Gibson MP said: “I’ve read this damn thing. It’s hopeless.” The APPG chairman, Dr Des Turner MP, added: “I am at a loss to know why NICE are doing this and what they hope to achieve.”

The APPG expressed their continuing concerns to Professor Peter Littlejohn (clinical and public health director at NICE) and Dr Esther Crawley (a member of the ME/CFS guideline development group) at their meeting in February 2007.

Professor Richard Baker (chairman of the NICE guideline development group) and members of his team discussed the final

version of the guideline at The ME Association’s annual medical meeting in September 2007.

DWP Benefits

Problems with obtaining state sickness and disability benefits – in particular Disability Living Allowance – are a major and on-going concern for people with ME/CFS

For many people, this means having to appeal against what are regarded as very unfair initial decisions. We understand that the success rate at appeal has been around 40% – a figure that indicates a serious problem with the medical assessment and lay adjudication process.

The DWP acknowledges that there is a problem here and decided to revise the medical guidance relating to DLA and Carers Allowance. This procedure took two years and the document went through 10 drafts.

ME charities believe the new guidance, which was published in July 2007, is unfit for purpose and will not redress the current very unsatisfactory situation. A copy of this response, and the final version of the guidance, is available at The ME Association website. Visit www.meassociation.org.uk and type **DWPv10** into the search box.

The APPG on ME discussed their concerns on the issue with the then Secretary of State for Work and Pensions, John Hutton, at their meeting in November 2006.

NHS Plus

NHS Plus is the part of the Department of Health that issues guidance on occupational health matters.

Guidance to employees, employers and occupational health physicians on ME/CFS was

published in November 2006. This is available at the NHS Plus website www.nhsplus.nhs.uk

The main ME/CFS charities, and their medical advisers, again produced a joint response expressing serious objections to many of the conclusions and recommendations – some of which we believe will make matters worse rather than better when it comes to advising people on how to manage this illness in the workplace. This guidance is also available at www.meassociation.org.uk (type **NHSPlus**) into the search box.

Following a presentation to the APPG on ME in May 2007, Dr Ira Madan, director of NHS Plus guideline development project, met with charity representatives at the Royal College of Physicians to discuss possible amendments to the NHS Plus literature. The ME Association then co-ordinated charity responses to this meeting and submitted further comments. We are still waiting to hear whether these comments have been accepted.

IN CONCLUSION

People with ME/CFS feel that their opinions are not being listened to; that urgently needed research into the underlying causes of this illness is not taking place; and that government departments are providing over-simplistic information to health professionals, DWP decision-makers and employers. This information remains far too biased towards psychological rather than physical causation.

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