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To Dr Dewis

Please see below *

[Discuss c̄ Peter Dewis]

DISABILITY LIVING ALLOWANCE ADVISORY BOARD
The Adelphi 1-11 John Adam Street London WC2N 6HT
Telephone 071-962-8000
GTN 391

Dr P D White MD MRCPsych
The Medical College of St Bartholomew's Hospital
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Department of Psychological Medicine
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19 November 1993

Dear Dr White

Thank you for your letter dated 10 November 1993 addressed to Professor Rodney Grahame and Dr Mansel Aylward. They have asked me to respond briefly on their behalf.

Both, most certainly intend to take note of the comprehensive information and opinion contained in your letter and asked me to express their gratitude for the time and trouble you have taken to write to them.

Their intention is to write to you shortly in far more detail.

Yours sincerely

DR M E MCGRATH
Secretary DLAAB

*Peter, I have overlooked responding to this letter with all the other activities going on. Can we discuss so that you can reply.

Mansel 13.I.94.

Discuss with Mida

15/11

The Medical College of Saint Bartholomew's Hospital
University of London
Department of Psychological Medicine
Head of Department: Professor Ted Dinan MD PhD

10 November 1993

MA 15/xi

Mr Rodney Grahame
and Mr Mansel Aylward
Disability Living Allowance
Advisory Board
London WC2N 6HT

Dear Mr Grahame and Mr Aylward,

Description of ME in Disability Handbook

I read your letter in the British Medical Journal of 23 October this year. I was worried to learn that the Disability Handbook "will probably conclude that myalgic encephalomyelitis is a separate entity within the group of disorders encompassed by the chronic fatigue syndromes and that some affected people remain disabled, make little or no progress, or even deteriorate over time".

I am a psychiatrist who has been studying fatigue, particularly fatigue following infections like glandular fever, for nine years. From my own work, as well as my reading of the world literature, I would not agree that there is a consensus that "ME" and the chronic fatigue syndrome are separate conditions. Because of my research and clinical experience of helping to reduce disability in the chronic fatigue syndrome, I suggest that separating the two conditions may enhance disability. The reason for this is that those who believe in the separate existence of "ME" believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection, for which no treatment is available. On the contrary, I think the present evidence suggests that the chronic fatigue syndrome is a genuine discrete syndrome and treatments and rehabilitation programmes are available which address both the physical and psychological factors that maintain this syndrome.

For this reason, I would ask you to reconsider separating the two conditions. I would be happy to have further discussions with you about this.

Yours sincerely,

Dr P D White, MD MRCPsych
Senior Lecturer and Honorary Consultant Psychiatrist

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Fax 071-601 7969

CHRONIC FATIGUE SYNDROME

SUMMARY
OF THE TALK GIVEN BY PROFESSOR P K THOMAS CBE DSc MD FRCP AND DR S WESSELY BM BCh MRCP MRCPsych on 2.11.93.

AT A FULL BOARD MEETING HELD IN RICHMOND HOUSE IN THE PRESENCE OF THE RT HON NICHOLAS SCOTT MBE MP.

Professor Thomas:-

1. The term Myalgic Encephalomyelitis (ME) was introduced at the time of the epidemic in the Royal Free Hospital in 1955. There can be no doubt that this epidemic represented mass conversion hysteria. The epidemic was triggered by a small number of cases of genuine neurological disorder, such as MS or post infective acute disseminated encephalomyelitis. In 1962 when Professor Thomas started working in the Royal Free Hospital there were still a number of symptomatic cases. The dominant symptoms were weakness, fatiguability and muscle pain.

2. The cases now seen in the UK are a variety but one thing is certain they do not have Encephalomyelitis. This term means inflammation of the brain and spinal cord, for which there is no evidence whatsoever. Their symptoms are Myalgia, Fatigue and some Psychiatric symptomatology.

3. Fatigue is a symptom in a wide variety of conditions and it is vitally important to establish a precise diagnosis. Many cases have been labelled as having ME when the diagnosis on further investigation was found to be eg Myasthenia Gravis, Hypothyroidism, Brain tumour, Occult infection, Metabolic neuropathies etc.

4. There are different types of fatigue. Fatigue is the inability to maintain the necessary output of force by muscles. a). Peripheral Fatigue that is due to problems with the muscles themselves, the neuro-muscular junction or with the spinal cord.

   b). Central Fatigue refers to difficulty in maintaining an output of muscle force because of problems in the activation of the nerve pathways that run from the brain to the spinal cord.

c). <u>Objective Fatigue</u> is something that can be demonstrated by physiological recordings, which measure the declining force from the muscle.

d). <u>Subjective Fatigue</u> refers to the situation where the delivery of the required force cannot be maintained because of uncomfortable sensations, not in the muscles themselves but in an indefinable way that affects drive and motivation.

5. The features of the chronic fatigue syndrome are multifarious and variable between different parts of the world. They have also changed over time. Definition thus becomes a problem, however symptoms should have persisted for at least six months. This is arbitrary but it does exclude patients who have the fatigue that normally follows many acute illnesses.

6. The dominant symptom is FATIGUE, both mental and physical. They are unable to work and many spend most of the day in bed or resting elsewhere. They have great difficulty in undertaking even mild exercise. Careful studies, in particular by Professor Richard Edwards in Liverpool and by a group in Sydney, Australia have shown unequivocally that the fatigue these patients experience is SUBJECTIVE. That is they have no muscle weakness,there is no difference between normal and CFS subjects in the decline and recovery of muscle force/contraction.

7. The second important symptom is MYALGIA or muscle pain. Characteristically this follows exercise rather than occurring at the time, it is the same as the pain which is suffered by physically unfit people after exercise. These patients are not active and therefore experience post-exercise myalgia after quite mild activity. It is related to muscle damage during what is called eccentric contraction. MUSCLE BIOPSY shows no abnormalities other than those related to the effects of inactivity ie type 11 atrophy of muscle fibres. The symptoms of CFS are therefore NOT due to neuromuscular dysfunction.

8. MENTAL FATIGUE is associated with emotional disorder. All studies have emphasized the high rates of psychological disorder in patients with CFS. Major or minor DEPRESSION is the commonest, however the following occur as well, somatization disorder, anxiety, hypochondriasis, hyperventilation and a few hysterical conversion syndromes.There is no psychiatric disorder in 23% of cases. CFS IS NOT DUE TO MALINGERING. It must be pointed out that fatigue is a symptom of depression and can be the initial symptom of depression.

[illegible] One feature that tends to distinguish patients with CFS from other patients with depression is a lack of self blame or self deprecation which is often a conspicuous aspect. Patients with CFS are desperate to find some reason outside themselves which has caused their symptoms.

9. CFS is NOT related to chronic viral infection, previous claims have been shown to be faulty.

10 Prognosis is not clearly understood and is determined by many factors, such as :- Psychological, social and cultural influences.
Certain factors are associated with a poor prognosis, these are:- long duration of illness, high emotional distress, illness beliefs eg viral persistence or muscle disease, and poor clinical management.

11 Clinical management MUST include identification of the underlying depression and persuasion of the patient to accept this explanation. It must be treated as it could lead to suicide.
ACTIVE management is important, with graded rehabilitation towards achievable targets. Graded exercise does and will help. Patient support groups do not help as they tell patients that at all costs they must avoid exercise as it will make them worse which is totally untrue.
There is no difference between ME and CFS except in the patient's belief.

<u>Dr Simon Wessely:-</u>

1. There is no evidence of primary muscle dysfunction ie it is not a neuromuscular disorder or a neurological disorder. There is no evidence of inflammation of the CNS. There is no evidence of hysterical or feigned origin to symptoms.

2. It is associated with high rates of psychiatric disorders which are well in excess of what might be explained as a reaction to physical illness.

3. There is little evidence that it is due to a persistent virus. The only infective association is that it may be triggered by the Epstein Barr virus. Post viral fatigue after other viral illnesses should not last longer than six months.

MISC 200 F.

Benefits agency
Medical SERVICES

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13 October 1993

Dear Dr. Wessely,

Very many thanks for your welcome letter of 1st October, and my apologies for not having been able to respond earlier.

I well remember our correspondence last year about the perplexing and controversial subject of chronic fatigue syndrome. Let me assure you that, as indicated above, I welcome your letter. In some ways some of your comments and advice, far from depressing one's spirits, provides an alterative view to those which have bombarded me, my colleagues in the Department and members of the Disability Living Allowance Advisory Board (DLAAB) in the past couple of years. Both Professor Grahame (Chairman of the DLAAB) and I are most grateful for your bringing our attention to the various points you raise in your letter.

You will, no doubt, have seen the letter by Charles Shepherd of the ME Association published in the 2nd October issue of the BMJ. For completeness, I enclose a photocopy of the relevant page of the BMJ together with a copy of a letter from Professor Grahame and me which we have submitted to the BMJ for publication in the letters columns.

Our letter is self-explanatory and expresses the profound dismay and disappointment we felt upon reading Charles Shepherd's inaccurate and unauthorized disclosure of certain selected parts of a draft version of a chapter for the Disability Handbook.

You can well imagine how we now feel when reading the ME Association's leaflet which you kindly enclosed with your letter. That disturbing leaflet is a glowing expression of what the lobby would like to be the truth rather than what is the truth.

SOCIAL SECURITY
an Executive Agency of
the Department of Social Security

The prognosis for those who acquire the label of "ME" is at the moment poor. The only three prognostic studies conducted to date all suggested that poor prognosis, and failure to improve, is closely related to illness beliefs of a solely physical origin to symptoms.

5. It seems likely that the greater the disability, the more likely is the disorder to be associated with either misdiagnosed psychiatric disorder or poor illness management. Many are iatrogenic ie Doctors contribute in perpetuating the disease and its symptoms.

6. TREATMENT is difficult, extraordinary sensitivity is necessary. Great flexibility is essential in treating these patients, each case is different. It is a treatable disorder but its management is deplorable at present, the worst thing to do is to tell them to rest.
Rehabilitation is essential, exercise is good for these patients, prolonged inactivity causes adverse physical and psychological consequences.
Most cases can be expected to improve with time.

7. As regards benefits:- it is important to avoid anything that suggests that disability is permanent, progressive or unchanging. Benefits can often make patients worse.

Dr M McGrath
Secretary DLAAB

The draft version of the Handbook's chapter was sent to groups representing people with ME as part of the customary confidential consultation procedures followed by the DLAAB when soliciting the views of interested parties on provisional revisions of the text of the Disability Handbook. The DLAAB, and the DLAAB alone, is charged with advising the Secretary of State on the contents and format of chapters for the Handbook. The DLAAB has not yet reached a decision on the final text of the chapter mentioning ME which it will recommend to the Secretary of State for inclusion in the Handbook.

A plenary session of the DLAAB will take place at 10.00a.m. on Tuesday, 2nd November at Richmond House when the Minister of State, The Rt. Hon. Nicholas Scott MBE MP, will be attending. Among other matters on the agenda will be a talk by Professor Thomas of the Royal Free Hospital on the subject of chronic fatigue syndrome. Professor Thomas's contribution will also assist the DLAAB in its deliberations on the final text of the chapter concerned with ME. Both Professor Grahame and I would be delighted if you could attend too. If you are able to come could you please get in touch with Dr. Mida McGrath (Tel: 071 962 8045) at the above address who will be pleased to give you details of the agenda and copy you with the relevant papers.

I am sure that the matters you raise, and in particular your views on the listing of chronic fatigue syndrome under "Other Neurological Disorders", will serve to fuel the debate at that meeting.

With kind regards,

Yours sincerely

Mansel Aylward

Dr. Mansel Aylward

pattern of pain is of no value in localising the site of the lesion.[4]

We advocate consultation with a senior doctor and [illegible] of early computed tomography for patients with a good history of neck rotation at the time of impact. This increases the chance of bony injury, particularly between the occiput and C2, which is often poorly visualised in plain films. Computed tomography should also be considered in those with a fixed abnormal neck position, particularly if pain does not seem to be the restricting factor, and those with definite neurological signs and symptoms, even if their presentation is delayed.

K E JONES
J N RAWLINSON

Bristol Royal Infirmary,
Bristol BS2 8HW

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1 Brown JN, Lenarz NL. Acute soft tissue injuries of the cervical spine. BMJ 1993;307:439-40. (14 August.)
2 Macnab I. The whiplash syndrome. Orth Clin North Am 1971;2:389-403.
3 Jones DM, Sevens. Hyperextension–flexion injuries of the cervical spine. Mayo Clin Proc 19[illegible].
4 Miles KA, Finlay D. Is prevertebral soft tissue swelling a useful sign in injuries of the cervical spine? Injury 1988;19:177-9.

Infantile colic and parental stress

EDITOR,—Piiri Rautava and colleagues suggest an interesting association between infantile colic and parental stress.[1] In their study, however, colicky symptoms were assessed by the parents themselves. It would not be surprising if stressed parents perceived their baby's crying as worse than did those under less pressure. Thus the authors' screening procedure is likely to have picked up infants with genuine colic and those whose parents had an exaggerated awareness of their child's screaming. The only way to avoid confusing these two groups is for continuing tape recordings to be made of the infant. Otherwise, results such as this may led to the premature conclusion that all instances of excessive, paroxysmal screaming of uncertain organic aetiology are a consequence of parental tension.

SIMON THACKER

Birmingham B14 1EH

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1 Rautava P, Helenius H, Lehtonen L. Psychosocial predisposing factors for infantile colic. BMJ 1993;307:600-4. (4 September.)

Description of ME revised in disability handbook

EDITOR,—Anthony David's contribution to Medicine and the Media contains several factual errors concerning myalgic encephalomyelitis.[1] Firstly, the all party lobby of nearly 100 members of parliament, which is working with patients' organisations on problems with state benefits and other matters of concern, has been concentrating on the disability living allowance, not invalidity benefit as stated. As a result of this joint action the Disability Living Allowance Advisory Board has agreed to important changes to the clinical description of myalgic encephalomyelitis in its "disability handbook." The next revision of this will make it clear that myalgic encephalomyelitis is a separate clinical entity from the chronic fatigue syndrome (although they have several features in common), is not hysterical in origin, and can result in severe and permanent disablement. In common with the tenth revision of the *International Classification of Diseases* the handbook will also refer to myalgic encephalomyelitis as a neurological disorder.

Secondly, there is no evidence to support David's view that myalgic encephalomyelitis has become "a no go area" in the quality press. During August and September both the *Times* and the *Independent on Sunday* devoted a total of three pages to the subject, with four separate views being expressed.[2,3]

CHARLES SHEPHERD

ME Association,
Stanford le Hope,
Essex SS17 8EX

---

1 David A. Camera, lights, action for ME. *BMJ* 1993;307:688. (11 September.)
2 Marcovitch H, Sharpe M, Wessely S. What exactly is the chronic fatigue syndrome called ME? *Times* 1993 Sept 14:16.
3 Wyndham A. Stop the world, I want to get off. *Independent on Sunday Review* 1993 Aug 29:40-1.

Discharging patients into the community

EDITOR,—Jane Yeo reports the problem she experienced earlier this year with a patient newly discharged from an old fashioned institution to the community.[1] This problem, however, should be considered in the context of the relocation of 240 patients with learning difficulties from a hospital condemned as unsuitable for their care into many small and friendly homes across the district, West Berkshire. This relocation, which was completed in March, has produced, on one hand, two complaints (of which Yeo's was one) and, on the other, a dramatic improvement in the quality of life for most of the patients.

Meanwhile the process of change continues and two full time consultants in learning difficulties were recently appointed to lead the community team. This trust is committed to designing the best possible service for these patients and, despite hiccups in the transitional phase, wishes to work closely with general practitioners towards this aim.

JANE KNOWLES

Priority Services Trust—West Berkshire,
Reading,
Berkshire RG1 4EG

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1 Yeo J. Neuroleptics in learning disability. *BMJ* 1993;307:620-1. (4 September.)

Provision of highly specialised services

EDITOR,—The current purchaser-provider arrangements are designed to ensure, as far as possible, that the health care needs of local people are met by local services. Luisa Dillner's report on the initial findings of the Clinical Standards Advisory Group[1] and Nick Kitson's letter[2] highlight the difficulties that patients with highly specialised needs face in getting access to appropriate services. But in addition to the threat to the provision of services there is a more insidious threat.

By bringing together professionals with highly specialised skills, many highly specialised services provide both services and training. Training offered in such units ensures the continuity of services and allows services to develop new methods of treatment. It is by this means that the supraregional deaf mental health services have established a unique outpatient child psychiatric service for deaf children and their families and pioneered family therapy for deaf people in Britain.

Thus the possible demise of highly specialised services threatens not only the immediate provision of services but also the gathering together of skilled professionals that ensures that their skills are further developed and disseminated. Because these professionals' patients are often widely spread across Britain, however, they do not represent a large enough constituency in any single district health authority to register effective protest against threats to services.

Some district health authorities have developed consultative processes between the users and providers of services to ensure that local health needs are adequately met. Such arrangements are of no use to patients with highly specialised needs, such as those described by the Clinical Standards Advisory Group and Kitson. The advisory group offers important professional advice to the Department of Health with regard to a small group of such patients. But there is a growing need for monitoring bodies that can represent users and providers of services and the Department of Health and can ensure that district health authorities and general practitioner fundholders make adequate provision for people who require highly specialised services.

PETER HINDLEY

Deaf Child and Family Team,
Springfield Hospital,
London SW17 7DJ

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1 Dillner L. NHS reforms deny patients specialist services. *BMJ* 1993;307:151. (17 July.)
2 Kitson N. Availability of specialist services. *BMJ* 1993;307:567. (28 August.)

Prioritising resources

EDITOR,—The question of the prioritisation of resources in health care is clearly of utmost importance.[1] One of the main factors that should be taken into account in prioritisation is the evidence that interventions do more good than harm—that is, effectiveness. One of the few instruments available to purchasers that provides objective evidence on effectiveness is the series of bulletins *Effective Health Care*. Thus we were disappointed by Chris Ham's dismissal[1] of some of the topics that we have chosen to study—namely, the treatment of persistent glue ear and screening for osteoporosis to prevent fractures. When Ham questions the relevance of these topics he surely misses the point: it is the impact of changes in decision making at the margin that is the most important consideration,[2] not simply the total volume of activity or the prevalence of the condition.

Topics assessed in *Effective Health Care* are selected on the basis of their implications on resources, uncertainty about their effectiveness, and their likely impact on health status. The selection process entails considerable market research and discussion by a steering group comprising senior health service managers, directors of public health, and academics.

Glue ear is the commonest reason for elective surgery in children, yet large geographical variations in treatment rates exist and doubts remain about the appropriateness of surgery in many cases. These doubts are strengthened by the finding in a recent randomised controlled trial, in which surgery was undertaken on the basis of clinically determined need, that around a third of children were operated on unnecessarily.[3] Similarly, doubts exist about the likely impact of population screening programmes for osteoporosis. Estimates suggest that such screening is unlikely to prevent more than 5% of fractures in elderly women. The two *Effective Health Care* bulletins on these subjects have aided commissioning authorities in allocating resources towards proved therapeutic activities. There is considerable evidence that this information has been used around Britain in setting standards and changing decisions on commissioning.[4]

Commissioning in the health service is (and will probably always be) an uncertain science in which some of the most important decisions are taken around the margins of activity. Information based on evidence raises the level of debate in com-

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The Editor
British Medical Journal
BMA House
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LONDON WC1H 9JR

Date: 7 October 1993

Dear Sir

I enclose a letter from Professor Rodney Grahame, Chairman of the Disability Living Allowance Advisory Board, and myself for consideration for publication in your Letters column.

If possible could it be published in the 15th October edition.

Thank you.

Yours faithfully

Mansel Aylward

Mansel Aylward MD FFPM

enc

DESCRIPTION OF MYALGIC ENCEPHALOMYELITIS IN THE DISABILITY HANDBOOK[1]

Redacted under FOI Exemption S 40 (2) & (3) closed Until 2072

EDITOR - We were distressed and disappointed that [redacted] felt that he was free to make an unauthorised disclosure of some of the contents of a draft version of the Disability Handbook's revised chapter on Myalgic Encephalomyelitis (ME)[2]

A provisional draft had been sent to the ME Association for comment as part of the normal consultation process followed by the Disability Living Allowance Advisory Board (DLAAB) prior to its advising the Secretary of State on a final text for publication. The letter summarizes selected parts of the draft's text but lacking completeness it may have misled your readers.

It is hoped that the final text of the section on ME will provide a balanced account of current knowledge about, and thinking on ME. It will likely conclude that ME is a separate entity within the group of disorders encompassed by the Chronic Fatigue Syndromes, and that some affected people remain disabled, make little or no progress, or even deteriorate over time. However, the revised chapter will also provide information about the majority of people affected by ME in whom disablement is neither severe nor permanent.

Rodney GRAHAME
Mansel AYLWARD

(1) Aylward M, Dewis P, Scott TP. The Disability Handbook.
LONDON: HMSO, 1992

(2) Charles Shepherd. Description of ME revised in Disability Handbook.
BMJ 1993; 307:869 (2 October).

MISC 200 F

benefits agency
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13 October 1993

Dear Dr. Wessely,

Very many thanks for your welcome letter of 1st October, and my apologies for not having been able to respond earlier.

I well remember our correspondence last year about the perplexing and controversial subject of chronic fatigue syndrome. Let me assure you that, as indicated above, I welcome your letter. In some ways some of your comments and advice, far from depressing one's spirits, provides an alterative view to those which have bombarded me, my colleagues in the Department and members of the Disability Living Allowance Advisory Board (DLAAB) in the past couple of years. Both Professor Grahame (Chairman of the DLAAB) and I are most grateful for your bringing our attention to the various points you raise in your letter.

You will, no doubt, have seen the letter by Charles Shepherd of the ME Association published in the 2nd October issue of the BMJ. For completeness, I enclose a photocopy of the relevant page of the BMJ together with a copy of a letter from Professor Grahame and me which we have submitted to the BMJ for publication in the letters columns.

Our letter is self-explanatory and expresses the profound dismay and disappointment we felt upon reading Charles Shepherd's inaccurate and unauthorized disclosure of certain selected parts of a draft version of a chapter for the Disability Handbook.

You can well imagine how we now feel when reading the ME Association's leaflet which you kindly enclosed with your letter. That disturbing leaflet is a glowing expression of what the lobby would like to be the truth rather than what is the truth.

The draft version of the Handbook's chapter was sent to groups representing people with ME as part of the customary confidential consultation procedures followed by the DLAAB when soliciting the views of interested parties on provisional revisions of the text of the Disability Handbook. The DLAAB, and the DLAAB alone, is charged with advising the Secretary of State on the contents and format of chapters for the Handbook. The DLAAB has not yet reached a decision on the final text of the chapter mentioning ME which it will recommend to the Secretary of State for inclusion in the Handbook.

A plenary session of the DLAAB will take place at 10.00a.m. on Tuesday, 2nd November at Richmond House when the Minister of State, The Rt. Hon. Nicholas Scott MBE MP, will be attending. Among other matters on the agenda will be a talk by Professor Thomas of the Royal Free Hospital on the subject of chronic fatigue syndrome. Professor Thomas's contribution will also assist the DLAAB in its deliberations on the final text of the chapter concerned with ME. Both Professor Grahame and I would be delighted if you could attend too. If you are able to come could you please get in touch with Dr. Mida McGrath (Tel: 071 962 8045) at the above address who will be pleased to give you details of the agenda and copy you with the relevant papers.

I am sure that the matters you raise, and in particular your views on the listing of chronic fatigue syndrome under "Other Neurological Disorders", will serve to fuel the debate at that meeting.

With kind regards,

Yours sincerely

Mansel Aylward

Dr. Mansel Aylward

King's College School of Medicine & Dentistry and the Institute of Psychiatry
Academic Department of Psychological Medicine

KING'S College LONDON *Founded* 1829

Rec'd: 6/10/93.

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Professor Robin M Murray
Dr Anthony S David
Dr Simon C Wessely

↓ Oct.

18 OCT 1993

Dr Mansel Aylward,
Department of Social Security,
The Adelphi,
1-11 John Adam St.,
London WC2N 6HT.

Dear Dr Aylward,

You may recall we corresponded last year over the ever controversial subject of chronic fatigue syndrome, or ME as it is sometimes known. I wrote to express some dissatisfaction with the then DLA entry, feeling it did not accurately reflect the state of medical knowledge on the subject. I am afraid I feel obliged to write again following the receipt of the enclosed leaflet from the ME Association, which triumphantly states that CFS/ME will now be listed under "Other Neurological Disorders".

I regret to say that it seems to me that in order to be fair to the ME Association you have now gone to the other extreme. I am disturbed that this disorder should be listed as a neurological disease. I enclosed an editorial that I had written last year for a neurological journal reviewing the evidence on this subject, and concluding that there was little to point to a neurological origin of symptoms. Since then more research has been published in the leading neurological journals, and nothing has happened to alter those conclusion.

Instead I feel this decision represents the triumph of an effective lobby over scientific evidence. If CFS/ME is to be listed as a neurological disorder, I for one will begin to campaign via the mental health charities for schizophrenia and manic depression to be also listed under the same heading. Indeed, there is far more evidence suggesting that these disorders have a neurological origin than does CFS/ME.

I also feel that this decision, if it has been made, reflects an undesirable stigmatisation of psychiatric disorders. The main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry.

It is also a most unfortunate message to send sufferers. It colludes with the erroneous belief that this is a severe disorder of neurological functioning, for which there is little effect treatment, and a poor prognosis. It will discourage any sensible efforts at rehabilitation. As we, and now many other groups, have shown that the **only** determinant of outcome in this condition is strength of belief in a solely physical cause, then it will also itself contribute to disability and poor outcome. I cannot believe that is the intention of the Department, if only on grounds of cost!

I believe that the Department is making an error if it accepts the partisan views put forward by pressure groups as a basis for making medical decisions. I also believe that it is a decision that the Department will come to regret, since it seems likely the result will be an ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery.

I am sorry to write to you again on this subject, and I know all too well how your spirits may well sink at receiving another letter on the topic. I also know from personal experience that coming to any decision on this subject that conflicts with the "party line" is not a recipe for a quiet life. Nevertheless, I would value your comments.

With kind regards,

Yours sincerely,

Dr Simon Wessely,
Senior Lecturer in Psychological Medicine.

ME
ASSOCIATION

DLA VICTORY!

DLA HANDBOOK ENTRY

As you are all aware, one of the purposes of the Parliamentary campaign has been to persuade the DSS to change the entry on ME in the handbook which DSS officials use when determining the applications for the Disability Living Allowance, so that it reflects the reality of disability for those affected by ME. In June of this year we sent the DLA Advisory Board our own suggestions for a revised entry which placed ME within the chapter on "Certain Neurological Disorders", and explained the levels of disability and chronicity in ME in terms of four bands of severity.

We have just received, for our comments, the official DLA Advisory Board revision of this entry. They have agreed to the replacement under "Certain Neurological Disorders" and while there are still instances where the phraseology leaves room for improvement, much of the text is taken verbatim from our suggested draft and reflects the reality of the severity of the illness.

A MAJOR STEP FORWARD

This represents a major step forward in our battle for recognition. Whenever we come up against instances of the misunderstandings and prejudice with which we are continually confronted, we can point to this entry and say, "this is the official stance on the severity of ME". We now have a good reason for optimism and this is due in no small part to your own efforts in involving your MPs in our campaign.

THE WAY FORWARD

We must recognise that there is no room for complacency, that attitudes will not change overnight, and that the campaign for recognition must continue. We are now in a much better position to insist that we be given equal access to all benefits, and that the DOH disseminates authoritative information, agreed by us, to all doctors while funding helpful research into cause and treatment.

Over the next few months our activities in Parliament will continue, with a reception in the House for MPs and Ministers at which we can put forward our views, further mailings to MPs, and even more Parliamentary questions, Early Day Motions and debates.

Please continue to give us your full support. It is your determination which has brought us this far, and it will be your determination that will ensure our final victory.

Registered Office: Stanhope House, High Street, Stanford Le Hope, Essex SS17 0HA
Charity No. 801279. Company No. 2361986

COPIED TO DR. LLOYD
M.J. 6-2-96

MISC. 200 7

DISABILITY LIVING ALLOWANCE ADVISORY BOARD
The Adelphi 1-11 John Adam Street London WC2N 6HT
Telephone 071-962-8000
GTN 391

The Editor
British Medical Journal
BMA House
Tavistock Square
LONDON WC1H 9JR

Date: 7 October 1993

Dear Sir

I enclose a letter from Professor Rodney Grahame, Chairman of the Disability Living Allowance Advisory Board, and myself for consideration for publication in your Letters column.

If possible could it be published in the 15th October edition.

Thank you.

Yours faithfully

Mansel Aylward

Mansel Aylward MD FFPM

enc

②

Redacted under FOI Exemption S 40 (2) (3) closed Until 2072

DESCRIPTION OF MYALGIC ENCEPHALOMYELITIS IN THE DISABILITY HANDBOOK[1]

EDITOR - We were distressed and disappointed that [redacted] felt that he was free to make an unauthorised disclosure of some of the contents of a draft version of the Disability Handbook's revised chapter on Myalgic Encephalomyelitis (ME)[2].

A provisional draft had been sent to the ME Association for comment as part of the normal consultation process followed by the Disability Living Allowance Advisory Board (DLAAB) prior to its advising the Secretary of State on a final text for publication. The letter summarizes selected parts of the draft's text but lacking completeness it may have misled your readers.

It is hoped that the final text of the section on ME will provide a balanced account of current knowledge about, and thinking on ME. It will likely conclude that ME is a separate entity within the group of disorders encompassed by the Chronic Fatigue Syndromes, and that some affected people remain disabled, make little or no progress, or even deteriorate over time. However, the revised chapter will also provide information about the majority of people affected by ME in whom disablement is neither severe nor permanent.

Rodney GRAHAME
Mansel AYLWARD

(1) Aylward M, Dewis P, Scott TP. <u>The Disability Handbook.</u>
LONDON: HMSO, 1992

(2) Charles Shepherd. Description of ME revised in Disability Handbook.
<u>BMJ</u> 1993; <u>307</u>:869 (2 October).

practice. Secondly, attempts can be made to capture current thinking in documentary form. Annual business plans and longer term strategic direction statements are tangible expressions of the organisation's vision.

These manifestations of the organisational vision are complementary rather than interchangeable approaches. Too great a reliance on documents runs the risk of them being seen as "tablets of stone" and may stifle imagination. On the other hand, alone informal communication and "networking" can result in wasted effort through lack of coherence: the vision is overwhelmed by indiscriminate and uncoordinated brainstorming. Each practice will need to strike a balance between these contrasting approaches which suits its size, personnel, and management style.

How do you know if you've still got it?

We have suggested that the practice vision needs to be broadly defined and regularly refreshed. This can come about only if individuals invest time and effort in the process. To justify and sustain this investment the quality of the resulting vision needs to be monitored. So how does an organisation know if its vision continues to be sound? Surprisingly, the answer is straightforward: if vision guides the organisation's planning, then as the future unfolds there are numerous reference points against which the meaningfulness (strictly, the predictive validity) of the vision can be checked and appropriate adjustments made. Without careful monitoring of this kind the organisational vision will sooner or later fail, perhaps catastrophically. Failure will be evident in two ways: external change will hit the practice with little or no warning; and rigorous organisational audit will reveal that significant objectives are not being achieved.

The next time you get angry about a "bolt from the blue" in the form of a decision by the Department of Health, General Medical Services Committee, family health services authority, regional health authority, etc, ask yourself: Should I have anticipated this? If when judged honestly the answer is yes, then something is wrong with your organisational vision. If the answer is no, take stock of any implications and build into your strategic plan sufficient resilience to cope with the (very) occasional surprise.

1 *Holy Bible.* Genesis xxxvii, 5-11, xl-xli.
2 Stephens GG. The intellectual basis of family practice. *J Fam Pract* 1975;2:423.
3 McCormick J. The vision thing: try it, you'll like it. *Business Month* 1990;135 (May):66-9.
4 NHS Management Executive. *Integrating primary and secondary health care.* London: NHSME, 1991.
5 Spiegal N, Murphy E, Kinmonth AL, Ross F, Bain J, Coates R. Managing change in general practice: a step by step guide. *BMJ* 1992;304:231-4.

(Accepted 17 May 1993)

FILE: ME

Patients with fatigue in general practice: a prospective study

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Kay Osler, *general practitioner*

Correspondence to: Dr Ridsdale.

BMJ 1993;307:103-6

Abstract

***Objective*—To describe the characteristics of patients attending their general practitioners and complaining of fatigue or being "tired all the time."**

***Design*—Prospective study of cohort aged 16 years and older with follow up at two weeks and by questionnaires at two and six months.**

***Subjects*—220 patients (164 women) with mean age 43 years and an age-sex matched comparison group.**

***Settings*—Doctors and patients in four practices in Lancashire, Mid Glamorgan, Suffolk, and Surrey.**

***Main outcome measures*—General clinical data, results from standard group of laboratory tests, fatigue questionnaire, and 12 item general health questionnaire.**

***Results*—Over twice as many patients with fatigue had high scores on the health questionnaire compared with the comparison group (156 (75%) *v* 69 (34%)). Results of laboratory tests were abnormal and contributed to the diagnosis in 19 patients. 59 out of 102 patients who responded had high fatigue scores six months later. Patients with persistent fatigue were more likely to have a history of anxiety or depression and to have had fatigue for more than three months on entry to the study.**

***Conclusions*—Women are particularly at risk of fatigue. The outcome is better if patients have had symptoms for three months or less or there is no history of emotional illness.**

Introduction

Fatigue is a common subjective experience. Hannay reported on responses to interviews at home with patients from one practice and found that nearly a quarter of responders felt more tired or run down than usual.[1] After respiratory symptoms this was the most common physical symptom described. Only a small proportion of those who experience fatigue as a problem come to the doctor. Morrell and Wale linked symptoms reported in women's diaries to their consultations in one practice and found a ratio of 400 episodes recorded to one consultation for fatigue.[2]

Fatigue may be the main complaint or a "supporting" symptom. Jerrett found about 75 per 1000 registered patients attended with fatigue as a presenting or supporting symptom in one year.[3] Morrell found about 13 per 1000 registered patients presented with fatigue as their main complaint, and fewer than 2% were referred to secondary care.[4] General practitioners can probably gain no useful information from research on fatigued patients in secondary or tertiary care.

During medical training clinical teaching is often focused on problems in which the diagnoses can be defined and there is some evidence from research to guide management. General practitioners often see patients with tiredness, but there is little scientific evidence from research done in primary care.[5] In this context practitioners experience uncertainty, which may impair their confidence and relationships with patients.

We aimed to describe the characteristics of patients who consulted their general practitioners with a main complaint of fatigue or being tired all the time; compare their symptoms of fatigue reported on questionnaires with those reported by a comparison group matched for age and sex from the practice lists; and compare their symptoms of psychological distress reported on questionnaires with those of the comparison group. We also analysed the results of standard laboratory tests; measured the change in symptoms at intervals over a six month follow up period; and determined the characteristics on entry which predicted patients' fatigue symptoms six months later.

Subjects and methods

Ethical committees approved the study in the four districts. Doctors recruited patients in separate practices in Lancashire, Mid Glamorgan, Suffolk, and Surrey. The practice populations lived in urban, suburban, semirural, and rural locations. The doctors' combined list sizes consisted of about 21 420 patients in the middle of the year during which recruitment took place. Patients were recruited to the study if they were 16 years or older and their main reason for consulting was fatigue or synonyms like "being knackered, lethargic, run down, or tired all the time." When patients complained of more than one symptom, doctors asked what the main symptom was which led them to consult that day. The symptom must have been present for two weeks or more. Patients could be recruited only once, but the consultation for fatigue need not necessarily have been their first for this problem. The doctors in the study each carried out pilot trials in applying the entry criteria, and their performance was tested by using case vignettes. They received feedback before the study began and were reassessed during the course of the study year.

For each patient entering the study the doctor completed a structured data collection sheet which required the doctor to provide information from the patients' records about history of physical and psychological problems, and they arranged a standard group of laboratory tests. These measured haemoglobin concentration, white blood cell count, erythrocyte sedimentation rate or plasma viscosity, and concentrations of urea, electrolytes, thyroid stimulating hormone or thyroxine, and blood or urine glucose. Patients under 40 years old were also tested for glandular fever.

On entry to the study patients completed a questionnaire on duration of symptoms and a 14 item fatigue questionnaire which has been validated in general practice by Chalder *et al.*[6] To measure the change in symptoms over the six months' follow up period we divided patients into two groups on the basis of a cut off score between 3 and 4. Choice of threshold is to a certain extent arbitrary. It alters the sensitivity and specificity of the questionnaire when comparing results to a standard structured interview. A high sensitivity by using the questionnaire means that few true cases are missed but the false positive rates are high. Chalder *et al* found this cut off gave a sensitivity of 75·5% and a specificity of 74·5% when the questionnaire results were compared to results from the revised clinical interview schedule.[6]

On entry to the study patients also completed the 12 item general health questionnaire.[7] This does not contain any questions about physical symptoms such as fatigue. The choice of threshold with the questionnaire in estimating the number of patients with psychological distress has the same implications as it does with the fatigue questionnaire. We used a threshold between 2 and 3, which Goldberg (personal communication) found to give a sensitivity of 86% and a specificity of 74·8% when he compared scores on a sample of patients by using the questionnaire with the scores from the composite international clinical interview.

When a patient was recruited a person of the same sex and the nearest younger by date of birth was selected from the same practice register. If this patient was found to have moved away or died the subsequent patient was chosen. This patient was sent the same questionnaires as those completed by fatigued patients on entry to the study.

All patients were asked to return for a follow up appointment two weeks later, and at this time they completed the fatigue and general health questionnaires a second time. Patients were also sent a fatigue and general health questionnaire to complete at eight weeks and six months.

Statistical analysis was by the test of proportions, the χ^2 test for trend, and multilinear logistic regression. In some instances patients or doctors, or both, did not fill out all the items on the questionnaires. When cross tabulations were undertaken the denominator changed slightly, and so each denominator is stated for the data provided.

Results

RESPONSE RATES

Most patients were pleased to participate in the study as they thought the doctors were taking their symptoms seriously and might be able to help similar patients more as a consequence. Two patients refused outright, and doctors completed initial clinical data collection sheets on 220 patients. Two hundred and seven of these patients returned completed questionnaires after the consultation at which they entered the study. Two hundred and twenty age-sex matched patients were identified from the doctors' lists. Two hundred returned completed questionnaires. At two weeks 195 (89%) of the study group returned for a follow up visit. At eight weeks 182 (83%) returned their questionnaires, and at six months 172 (78%) returned their questionnaires.

CHARACTERISTICS OF PATIENTS AND THE COMPARISON GROUP

Fifty six (25%) of the study group were men and 164 (75%) were women. The mean (range) age was 43 (17-88) years. Women patients with fatigue were over five times more likely to report that they had no paid work than women in the comparison group.

The patients' physical symptoms of fatigue and health questionnaires were initially scored in the same way as described by Wessely and Powell in a study of patients with chronic fatigue who attended the National Hospital for Nervous Disease and in whom a physical cause had not been found.[8] The scores of the matched comparison group and for consulters with fatigue in primary care are shown in table I, together with the mean scores of patients reported by Wessely and Powell in tertiary care.

Two hundred and seven patients reported on the duration of their fatigue on entry. Thirty four (16%) patients had had their symptoms for between two weeks and one month, 66 (32%) for one to three months, 34 (16%) for four to six months, and 74 (36%) for longer than six months. There was a significant trend for those who on entry reported symptoms of longer duration to have had a previous episode of depression or anxiety recorded by the doctor (table II).

TABLE I—*Mean scores (95% confidence intervals) for fatigue and on general health questionnaire in three groups*

Group	Physical fatigue	General health questionnaire
Matched comparison group	2·5 (2·0 to 3·0)	2·4 (1·9 to 2·8)
Patients with fatigue in general practice	8·7 (8·2 to 9·2)	5·2 (4·7 to 5·7)
Tertiary care[8]	11·8 (10·8 to 13·0)	7·0 (5·8 to 8·1)

TABLE II—*Number of patients with fatigue and previous episode of depression or anxiety and duration of fatigue on entry*

Duration of fatigue	No (%) with previous episode of depression or anxiety	Total No of patients
<1 Month	5 (15)	33
1-3 Months	25 (38)	65
4-6 Months	12 (36)	33
>6 Months	34 (46)	74

χ^2 Test for trend 6·776, df = 1, p = 0·009.

Sixty nine (33%) patients had one or more abnormal results on laboratory tests when the laboratories' criteria for abnormality were used (table III). One laboratory changed the method it used to test for glandular fever during the course of the study as it yielded too many positive values, so little confidence can be placed in this result. The doctors judged that an abnormal result was clinically important in 19 of 210 (9%) patients. The clinical diagnoses were anaemia (eight), hypothyroidism (three), infection (three), glandular fever (three), diabetes (one), and carcinomatosis (one). In three additional cases the doctors were uncertain about the clinical importance of an abnormal result.

CHARACTERISTICS OF PATIENTS WHO DID AND DID NOT RESPOND AT FOLLOW UP

More women than men responded to questionnaires at six months but the difference was not significant. Patients who responded at six months were older (mean age 44 years; 95% confidence interval 42 to 47) than patients who did not respond (38; 34 to 41). There was no significant difference in the mean fatigue scores on entry of those patients who failed to respond to questionnaires at six months.

CHANGE IN SYMPTOMS

All patients had self defined cases of fatigue on entry, but to describe the change in symptoms over the follow up period we divided the patients into two groups by using a cut off between 3 and 4 on the fatigue questionnaire[6] and between 2 and 3 on the general health questionnaire.[7] An estimate of likely cases was made for patients on entry, at two weeks, eight weeks, and at six months on the basis of scores. This is shown in table IV with data on high scorers in the age-sex matched comparison group. By using this threshold more than half of the patients who consulted for fatigue had high symptom scores six months after entry to the study.

TABLE III—*Proportions of abnormal results of laboratory tests in patients with fatigue*

Test	No (%) with abnormal result
Haemoglobin	11/210 (5)
White blood cell count	9/210 (4)
Erythrocyte sedimentation rate/plasma viscosity	17/206 (8)
Urea	18/207 (9)
Electrolytes	5/206 (2)
Glucose (serum or urine)	4/206 (2)
Thyroid stimulating hormone/thyroxine	8/198 (4)
Monospot	8/83 (10)

TABLE IV—*Number (%) of patients with high fatigue and general health questionnaire scores*

Patients	High fatigue score (4-14)	High general health questionnaire score (3-12)
Comparison group	71 (35)	69 (34)
Fatigue patients:		
On entry	195 (94)	156 (75)
2 Weeks	158 (81)	123 (63)
8 Weeks	121 (66)	96 (53)
6 Months	102 (59)	80 (47)

TABLE VI—*Factors independently associated with high fatigue scores (≥4) at six months according to linear logistic model*

Variable	Odds ratio*	95% Confidence interval	χ^2	Degrees of freedom
Age (years)§	1	0·98 to 1·02	0·01	1
Sex:				
Men†	1			
Women	0·44	0·19 to 1·02	3·80	1
Occupation:				
Non-manual†	1			
Manual	1·73	0·72 to 4·19		
Unemployed	1·04	0·39 to 2·75		
Others	1·37	0·52 to 3·59	1·84	3
Previous episodes of anxiety/depression:				
No†	1			
Yes	2·98	1·45 to 6·13	9·27‡	1
Duration of tiredness:				
≤3 Months†	1			
>3 Months	2·11	1·08 to 4·11	4·89‡	1

*Each adjusted for other factors in model.
†Baseline category.
‡χ^2 Statistic (for reduction in deviance) significant at $p \leq 0·05$.
§Analysed as a continuous variable.

CHARACTERISTICS ASSOCIATED WITH HIGHER FATIGUE SCORES AT SIX MONTHS

Of the 220 patients who were initially recruited, 172 returned questionnaires at six months. Among this group 102 (59%) had high fatigue scores (see table IV). The characteristics of the patients on entry were related to high fatigue scores (4 or more) at six months by using linear logistic regression analysis (table V).

Age as a continuous variable was not associated with high fatigue scores at six months. Men were more likely to have high scores at six months, but the difference was not significant. When patients were grouped according to their occupation, those in manual occupations, particularly men, were more likely to have high fatigue scores after six months. The numbers in occupational subgroups were small, and this difference was not significant. The persistence of a high score on the fatigue questionnaire at six months was significantly associated with a history of fatigue of

TABLE V—*Associations of variables with high fatigue scores (≥4) at six months*

Variable	No of patients	No (%) of patients with high fatigue scores (≥4)	Unadjusted odds ratio	95% Confidence interval	χ^2	Degrees of freedom	Adjusted odds ratio*	95% Confidence interval
Age (years)¶	172	102 (59)	1·01†	0·99 to 1·03	0·50	1		
Sex:								
Men‡	39	28 (72)	1					
Women	133	74 (56)	0·49	0·23 to 1·07	3·37	1		
Occupation:								
Non-manual‡	45	23 (51)	1					
Manual	49	32 (65)	1·80	0·79 to 4·12				
Unemployed	34	20 (59)	1·37	0·56 to 3·35				
Others (and no data)	44	27 (61)	1·52	0·65 to 3·52	2·06	3		
Previous episodes of anxiety, or depression:								
No‡	107	54 (50)	1				1	
Yes	65	48 (74)	2·72	1·42 to 5·41	9·42§	1	3·15	1·54 to 6·44
Duration of tiredness:								
≤3 Months‡	85	40 (42)	1				1	
>3 Months	87	60 (69)	2·27	1·22 to 4·23	6·86§	1	2·27	1·18 to 4·34
General health questionnaire scores on entry:								
<3‡	46	25 (54)	1				1	
≥3	126	77 (61)	1·32	0·67 to 2·61	0·63	1	1·55	0·76 to 3·17

*Adjusted for age, sex, occupation.
†Increase in odds per unit increase in age.
‡Baseline category.
§Significantly different from baseline category at $p \leq 0·05$.
¶Analysed as a continuous variable.

Practice implications

- General practitioners manage 98% of patients who present with fatigue, and refer less than 2% to specialists
- This study shows that three quarters of patients with fatigue also have symptoms of emotional distress; 9% had a physical illness
- 59% of patients still had high fatigue symptom scores six months later
- History of anxiety or depression increased threefold by the risk of fatigue symptoms persisting over six months

three months or more on entry and with a history of anxiety or depression. High score on the general health questionnaire (of 3 or more) at entry was not associated with high fatigue scores six months later.

As age, sex, and occupation might a priori be expected to be confounded with the other effects of interest, they were retained in the multiple logistic model used to assess the independent effects (table VI). A history of depression or anxiety on entry and a duration of fatigue of more than three months were independently associated with high fatigue scores at six months.

Discussion

In our study women were three times more likely to consult with fatigue, and when compared to the age-sex matched group they were more likely not to be in paid employment. A history of psychological disturbance was positively associated with the duration of fatigue before entry to the study. Patients with fatigue as a main symptom were more than twice as likely to report psychological symptoms above a threshold level as those in the comparison group. From this evidence we suggest that doctors need to consider and open up a discussion of psychosocial issues when patients present with tiredness.

One third of patients consulting for fatigue had a blood test which yielded abnormal results when the laboratories' own criteria were used. Except for three tests, the prevalence of individual abnormal results was compatible with a 95% normal range. The doctors judged that laboratory abnormalities were clinically important in 19 (9%) patients and treated them in the usual way. This proportion of abnormalities was higher than that reported in patients with chronic fatigue[9] and underlines the importance of vigilance for physical as well as psychosocial causes. The fact that common physical causes of fatigue have been identified and treated may conrtribute to the low yield of laboratory tests when patients with chronic fatigue are investigated by specialists.

Almost 40% of patients consulting for fatigue had low fatigue scores six months later, the rest still had high scores. This persistence of symptoms has been reported in North America.[10,11] A positive history of anxiety or depression and a longer duration of fatigue on entry were each predictors of poor outcome at six months. Knowing what to expect may help doctors and patients understand and come to terms with the problem. It is therefore worth inquiring about the duration of symptoms and noting the psychiatric history before discussing the prognosis. A short duration of symptoms and no history of anxiety or depression make the prognosis better.

We thank the Scientific Foundation Board of the Royal College of General Practitioners for funding this study and Professor D C Morrell, Dr S Wessely, Miss S Chinn, and many patients and colleagues for their help.

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(Accepted 13 May 1993)

A PATIENT WHO CHANGED MY PRACTICE

Maintaining dignity above all

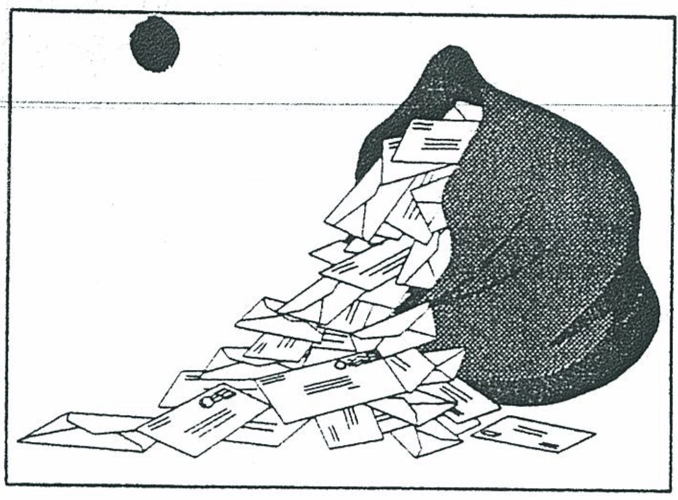
In the days when a junior partner waited 10 years for equality and was given the unattractive jobs my partner insisted that I apply for a job that no one else wanted to bring a little more money into the practice. This was for a medical officer in a council run home for 39 elderly, mentally infirm residents.

The home had a container in which visitors left old clothes that might fit the residents, most of whom slept in chairs facing a poorly tuned television. Medication was handed out as an unthinking routine. The morale of the nurses was low, and they seemed incapable of behavioural analysis, relieving their dissatisfaction by verbal abuse. I found this regimented environment and negative work attitudes intolerable until one day a head nurse, made desperate by staff shortages, asked me to look at a new resident who took half an hour longer than the others over her meals and made a terrible mess. She was 69, had been unable to cope living alone, and had been admitted by a social worker.

Examination showed an obese woman, with coarse features, thin hair, deep voice, and a tremor. Thyroid failure was diagnosed, confirmed, and replacement treatment begun. It was clear later that she had Parkinson's disease, and she responded well to anticholinergics in the days before levodopa. Ten weeks later she was once more doing the daily crossword and asked to go home. This was impossible because her house had been sold.

The effect of this on me was electric. The director of social services agreed with me that no admission should take place without prior medical assessment, and that all residents should wear their own clothes in order to maintain their individuality. An occupational therapist was engaged to encourage handicrafts. Finally, on my weekly visit I saw patients in the office with two nurses present, helping them to understand, for instance, that an old man who urinated against the wall was simply indicating that he did not know where the facilities were. Within a month I had reduced the drug bill by £250 with noticeable patient benefit. I decided then that care of the elderly was the most challenging and interesting feature of general practice.—KEITH THOMPSON *is a retired general practitioner in Croydon*

We are delighted to receive submissions of up to 600 words on *A paper (or patient or book) that changed my practice, A memorable patient, The one message I would like to leave behind,* or related topics.



FACSIMILE TRANSMISSION

DR M E MCGRATH
MEDICAL OFFICER
POLICY & CENTRAL SUPPORT
ROOM 11-28, THE ADELPHI
1-11 JOHN ADAM STREET
LONDON WC2N 6HT

TEL NO: 071-962-8045/8757
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Date: 6 July

Number of Pages: This plus 6

To: Miss C. Mayoh

Room and Building: Norcross.

Division:

Extension: 63375

From: Dr. Mida McGrath

Room and Building: Rm. 626, ADI.

Division: DLAAB Extension: 28045.

MESSAGE

I believe Miss Mayoh did not receive a copy.

Please - would it be possible to obtain comments as soon as possible.

Thank you,

Mida McGrath.

Mr N Ward	A2
Ms C Edwards	A2B
Ms C Mitchell	A2A
Mr K Bellamy	CAO
Mr D Revell	CAS
Miss C Mayoh	DLAU
Dr Mansel Aylward	
DR Peter Dewis	
Dr Tim Scott	
Mr Moira Henderson	
Dr Jon Buchan	

From: Dr M McGrath
MO, DLAAB

Date: June 28, 1993

CHAPTER ON "CHRONIC FATIGUE SYNDROMES" IN THE DISABILITY HANDBOOK

1. In response to the latest campaign by the Myalgic Encephalomyelitis (ME) lobby it was decided to redraft the section on ME in the Handbook.

2. The section on ME will now be included in the chapter "Certain Neurological Disorders" in accordance with the International Classification of Diseases.

3. There is a commitment to have the final draft ready for the Full Board meeting on Tuesday 27 July 1993.

4. Please would you send any comments or suggestions to me. I would very much appreciate receiving them by the 2 July.

5. Thank you.

DR M McGRATH
ROOM 626 ADI
GTN 391
EXT 28045

DRAFT

CERTAIN NEUROLOGICAL DISORDERS

11.12 Myalgic Encephalomyelitis

11.12.1 CONTENTS

PARAGRAPHS

11.12.2 Introduction

Myalgic Encephalomyelitis (ME) is a chronic disabling condition in which the dominant symptom is exercise induced muscle fatigue. It is thought to affect 20-30 per 100,000 of the population. Onset can occur at any age but is most common in those aged 30-40 years.

ME is not a new condition, but its incidence has increased over the last 50 years. A variety of names has been used for disorders which include, as one of their symptoms, disabling fatigue. These names reflect the perceptions of the condition at the time they were coined and include Neurasthenia, Effort Syndrome, Fibrositis, Fibromyalgia, Post Viral Fatigue Syndrome, Chronic Fatigue Syndrome, and Myalgic Encephalomyelitis. None of these names is wholly satisfactory for a condition which clearly has a variety of causes and encompasses a wide range of effects.

There is some recent research to suggest that amongst this group there is one condition which may be a separate entity in which the symptoms are related to persisting or reactivated viral infection. It is desirable that the term M.E. is restricted to this cause of fatigue. However it is necessary to emphasize that the disability suffered by these people is not distinguishable from that due to other causes.

There is as yet no treatment which has proved uniformly successful and therapy consists of a wide range of treatments.

11.12.3 General

It is well recognised that a viral illness can be followed by weakness and depression, lasting a few weeks, eg. post influenzal lethargy and depression. In ME these symptoms persist for months, years or even indefinitely.

The predominant symptom is severe muscle fatigue and pain following exercise. Many other symptoms may also be present such as abnormal exhaustion unrelieved by sleep, poor concentration, loss of short term memory, clumsiness, disturbed balance, sensitivity to light and other problems with vision, sensitivity to noise, misjudgment of distance, problems with bladder control and bowel disturbance. Anxiety and depression are common symptoms which may be related to the overall effect of persistent disability. All of these symptoms are exacerbated by mental and/or physical over exertion.

To experience fatigue as a result of exertion is normal. People with ME or chronic fatigue syndromes have a significantly greater perception of exertion than others after even mild exertion. The fatigue which is experienced by these people is a disabling symptom, whatever the precise underlying cause.

11.12.4 Care Considerations

During the acute stage or relapse the extreme fatiguability can be very debilitating. Adequate rest is recommended and help may be needed with daily activities and bodily functions. However during remission sufferers should be encouraged to carry out as many of their daily tasks as they can without help from other people. Most tasks relating to personal care eg. dressing and undressing, have a low energy requirement and can be achieved without haste and be followed by a period of rest.

The outcome in any particular case is extremely difficult to predict. During the acute stage and in severe relapse any form of sustained physical and/or mental activity may become impossible. Overall, so far as levels of disability are concerned, people tend to fall into one of four bands:

i. Approximately 35 per cent will improve slowly, although the process may take several years, and be punctuated by periods of relapse. Of these, perhaps half will achieve a full recovery in time.

ii. The majority, approximately 40 per cent, will make variable progress, with fluctuating levels of disability, and never achieve full recovery although they may at times reach 70 to 80 per cent of former functions. Some may be able to work, possibly part time, and carry out most household duties, despite their inability to perform strenuous physical or mental tasks to their former levels of ability. Relapses may be severe and prolonged.

iii. A significant minority, approximately 15 per cent, remain disabled and make little or no progress. They may require daytime assistance, particularly in the preparation of food and in performing household tasks. They may also require help with toileting and dressing although this is likely to be less frequent because of the less strenuous nature of these activities.

iv. A smaller number, perhaps 10 per cent, steadily deteriorate, becoming chair or bed bound for much of the time. This group is likely to require a great deal of nursing, medical, and social support.

11.12.5 Mobility Needs

Exercise induces muscle fatigue, pain and weakness. If these symptoms are severe, and especially if they are associated with visual disturbance, poor balance and misjudgment of distance, walking ability may be markedly restricted. When walking, increasing severity of the symptoms may result in the person having to stop and rest more and more frequently. Some may require walking sticks, home adaptation, a frame or even a wheelchair.

11.12.6 Duration of Need

The course and effects of ME vary widely and are unpredictable. After some time it may be apparent that a person falls into one of the four bands of disability listed under 11.12.4. However it should be noted that even those in the first two bands may be subject to relapse which can be variable in duration.

11.12.7 Additional Evidence

In a condition where disability varies over a period of time, it can be difficult to get an accurate picture of a person's overall needs. A factual report from the GP may greatly assist in this situation. A report by an Examining Medical Practitioner may help the affected person to properly identify the level and extent of care and mobility needs.

Dr McGrath DLAAB

From: C Fuller A2A

Date: 5 July 1993

Copies: Mr Pendergast A2B
Mr Revell CAS4D
Dr Aylward

DISABILITY HANDBOOK: CHAPTER ON CHRONIC FATIGUE SYNDROMES

1. Your minute of 28 June refers. I am sorry for missing your deadline for comments.

2. The following remarks take into account discussions I have had with A2B.

Section 11.12.3

3. **First paragraph:** It says "in ME these symptoms persist for months, years, or even indefinitely." Do the symptoms generally continue for so long? Or is it the case that they **may** persist for longer than a few weeks?

4. **Final paragraph:** I think the phrase "a significantly greater perception of exertion" could be misunderstood. I take it you mean that people suffering from ME believe they have exerted themselves greatly even when they have not. Readers may think you mean they have a "greater perception of fatigue".

Section 11.12.4

5. **First paragraph** mentions the "acute stage or relapse"; **second paragraph** mentions "severe relapse". It would be helpful to have a clearer description of the various stages through which the condition goes. For example - what is the difference between relapse and severe relapse, and between the acute stage and other stages?

Section 11.12.4

6. **Sub-paragraph (ii)** - although those who make variable progress form the largest group, at only 40% they are not in the majority.

Section 11.12.7

7. One of the symptoms is misjudgment of distance (section 11.12.3 and 11.12.5). That, coupled with sufferers' abnormal perception of exertion will make it difficult for Adjudication Officers to decide mobility needs and could cast doubt on the reliability of information about mobility in the claim pack.

8. It might be helpful if the potential difficulties could be mentioned in the section on additional information. And, under the circumstances might not a factual report from someone who knows the person be preferable in the first instance to a report from an EMP.

Charles Fuller

Charles Fuller
6th Floor ADI
Ext 28869

Dr T Scott
BAMS PACS
4E26
Quarry House

From: Em Gratrex
CAS 4D

Date: 30 June 1993

CHAPTER ON "CHRONIC FATIGUE SYNDROMES" IN THE DISABILITY HANDBOOK

1. We have received a draft of this new section for comment. As agreed with you previously, I am sending our comments directly to you rather than to the DLAAB.

2. In the covering minute from Dr McGrath, she states that the section on ME is being moved to Chapter 11. Does this mean that Chapter 12 will be deleted altogether, or are the references to ME being removed? The advice given on care and mobility considerations in Chapter 12 at present differ quite markedly from the new section. Is this because medical thinking on the cause and effect of these syndromes has changed? This could lead to confusion for AOs.

3. In the section on mobility needs (11.12.5), is it possible to expand this to give AOs more advice on whether the effort of walking is likely to endanger life or cause the condition to deteriorate? Without straying into adjudication, it is not clear from the text whether it is the effort of walking which causes the symptoms to deteriorate or the other way round.

4. I hope these comments are helpful.

Em Gratrex

MRS M A GRATREX
Room GS36
QH
GTN 513 ☎24938

21/6

WESTCARE
Hope & Help for M.E.

15 Queen Victoria Road,
Redland, Bristol,
BS6 7PE.
Tel: 0272 738317
Fax: 0272 744701

Registered Charity No. 900619

WITH COMPLIMENTS

Richard Sykes

Westcare provides information and services for people with
M.E. (Myalgic Encephalomyelitis),
P.V.F.S. (Post-Viral Fatigue Syndrome)
and C.F.S. (Chronic Fatigue Syndrome).

③

The National Archives

LETTERCODE/SERIES BN 141

Extract/Item 1/1

Extract/Item Details:

1 page(~~s~~)

Sub folder

Closed under FOI Exemption(s)

Section: 40(2) & (3)

Closed until: 2072

Initial & Date

SA
23/3/12

Difficulties in claiming DLA encountered by people with ME

1. The after-effect of walking is not taken into consideration.

2.. In the claim form under section 2, there is no mention of the possibility of serious deterioration in health as a result of walking (merely a reference to it being "dangerous").

3. In severe and chronic cases awards are not made for a sufficient length of time and hence people with ME cannot take advantage of motability (for which there is a minimum requirement of three years).

4. People still encounter difficulty because of the diagnosis of ME. Mrs. Crawley, an experienced welfare rights worker, writes: "Had they been suffering from some other disease such as MS with exactly the same degree of impairment, we feel they may well not have had such a struggle to convince the authorities of their entitlement to benefit".

5. As a result of these difficulties people with ME can give up the struggle.

6. There are still long delays in the processing of claims.

7. A doctor's report is called for far more frequently than in other illnesses.

8. In examining, doctors frequently do not have up to date knowledge about ME. Some do not believe that ME exists, or think that ME is "pyschological".

9. There are still difficulties resulting from the old system.

Information Sheet December 1992

TASK FORCE ON CFS/PVFS/ME

STEERING GROUP

Background

There is much confusion and uncertainty among doctors and health care professionals about the diagnosis and management of the disorders known as Chronic Fatigue Syndrome, Post Viral Fatigue Syndrome and Myalgic Encephalomyelitis.

Following a meeting on 17th January 1992 between the Rt. Hon. William Waldegrave, then Secretary of State for Health, Dr Anne Macintyre and Dr Richard Sykes, a joint meeting was arranged for 30th March 1992 between representatives of the ME Organisations, (ME Association, ME Action Campaign and Westcare) and doctors from the Department of Health (DH) and the Department of Social Security (DSS). At that meeting the ME Organisations requested that the DH send out guidance in the form of a circular as soon as possible, and set up a working party to produce more detailed information at a later date. In reply the DH suggested that a Task Force should be set up, comparable to the existing Task Force on Asthma, to produce this information.

Feasibility Group

Following this suggestion a Feasibility Group was set up, representing a wide variety of specialisms and perspectives. Three meetings have been held in London on 29th June, 14th July and 28th September 1992. The group has taken a broad look at major issues which need to be addressed and has identified constructive and significant roles for a Task Force, both in compiling reports and guidelines and in stimulating appropriate action.

Steering Group

A small Steering Group has now been assembled under the chairmanship of Dr David Tyrrell, CBE,FRS,DSc,FRCP,FRCPath, with the aim of establishing a Task Force. An application has been made to the DH to provide funding for the Task Force.

Richard Sykes
Secretary,
Task Force
Steering Group
11/12/92

Richard Sykes, MA,PhD,
Westcare, 15 Queen Victoria Road,
Redland, Bristol. BS6 7PE
Tel: (0272) 738317

CERTAIN DISORDERS

11.12 - Myalgic encephalomyelitis

11.12.1

11.12.2 Clinical Description 11.12.5

Myalgic Encephalomyelitis (ME) also known as Post-Viral Fatigue Syndrome is a disabling condition, whose incidence has increased over the last 50 years. It is thought to affect 20-30 per 100,000 of the population. Onset can occur at any age but is most common in aged 30-40 years.

It is well recognised that a viral illness can be followed by weakness and depression; lasting a few weeks. In ME these symptoms persist for months or even years. Current thinking suggests that in true ME there is persistent viral infection and disturbance in immune response.

The most prominent symptoms are extreme fatiguability and muscle pain. Other symptoms include poor concentration, loss of short term memory, clumsiness, disturbed balance, sensitivity to light and noise and bowel problems.

11.12.3 Care Considerations

This extreme fatigualibility can be very debilitating and in established cases (approx. 1 in 4) help may be needed with daily activities for quite some time. However most tasks relating to personal care have a low energy requirement and with time it should be possible to dress and undress however slowly. These daily and nightly activities eg such as using the toilet can be achieved without haste and can be followed by a period of complete rest.

11.12.4 Mobility Needs

Exercise induces muscle fatigue and pain, if they also have problems with balance, walking ability can be markedly reduced. Some people, therefore may need frequent stops and rests prior to continuing. It must also be remembered that over-exertion may lead to relapse.

11.12.5 Duration of Need

Duration of need is variable.

35% improve slowly, punctuated by relapses but about half will recover fully
40% make variable progress with fluctuating levels of disability and may reach 70 - 80% recovery.
15% remain severely disabled and make little or no progress towards improvement.
10% deteriorate steadily requiring a great deal of assistance and social support.

11.12.6 Additional Sources of Evidence

A report from an EMP would greatly assist in helping the person to detail the unavoidability of ME over a period of time. The level of care needs and the extent of impaired mobility could be clearly identified.

CERTAIN ~~neurological~~ Disorders

11.12 - ~~ME~~ Myalgic Enceph

11.12.1 Contents.

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care 11.12.3.
mob needs 11.12.4
11.12.5 11.12.6.

11.12.2. Clinical Description.

Myalgic Encephalomyelitis (M E) also known as Post-Viral Fatigue Syndrom (PVFS) is a ~~chronic~~ disabling condition, whose incidence has increased over the last 50 years. It is thought to affect 20-30 per 100,000 of the population. Onset can occur at any age but is most common in ~~persons~~ people aged 30-40 years ~~Ou~~ It is well recognised that a viral illness can be followed by weakness + depression, lasting a few weeks. In ME these symptoms persist for months or even years. Current thinking suggests that in true ME ~~there~~ is persistent viral infection + disturbance in immune response. The most prominent symptoms are extreme fatiguability and muscle pain. Other symptoms include poor concentration, loss of short term memory, clumsiness, disturbed balance, sensitivity to light + noise & bowel problems.

11.12.3. Care considerations:-

This extreme fatiguability can be very debilitating and in established cases (approx. 1 in 4) help may be needed with daily activities for quite some time. However most tasks relating to personal care have a low energy requirement and with time it should be possible to dress + undress however slowly. These daily ~~activities~~ and nightly activities eg. such as using the toilet can be achieved without haste + can be followed by a period of complete rest.

11.12.4. Mobility Needs.

Exercise induces muscle fatigue and pain, if they also have problems with balance, walking ability can be markedly reduced. Some people, therefore may ~~have may~~ ~~have freq~~ need frequent stops & rests prior to continuing. It must also be remembered that over-exertion may lead to relapse.

F

benefits agency Medical SERVICES

Dr Mansel Aylward
Principal Medical Officer
Policy: Medical Services
Room 6/25, The Adelphi
1-11 John Adam Street
LONDON WC2N 6HT

Tel: 071-962-8757
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Ms Sandra Howes
ME Association
91 Gordon Crescent
Morland Road
Addiscombe
CROYDON CRO 6NW

Date: 8 June 1993

Dear Ms Howes

Very many thanks for your letter of 3 June with which you kindly enclosed copies of your letter to Dr Jon Buchan and your suggested re-draft of the chapter on Myalgic Encephalomyelitis and other related documents.

I have already forwarded the enclosures to those who will be involved in the revision, updating, and augmenting of the Disability Handbook, and I have asked them to give full consideration to the texts you have provided.

Kind regards,

Yours sincerely

Mansel Aylward

Mansel Aylward BSc MD FFPM

cc: Dr Jon Buchan
Dr Mida McGrath

Duration of need

11. 12. 5 < Duration of need is variable.

35% improve slowly punctuated by relapses but about half will recover fully

40% make variable progress with fluctuating levels of disability and may reach 70 - 80% recovery

15% remain severely disabled + make little or no progress towards improvement.

10% deteriorate steadily requiring a great deal of assistance + social support.

11. 12. 6. Additional sources of evidence.

A report from an EMP would greatly assist in helping the person to ~~expla~~ detail the variability of ME ~~nature of the~~ over a period of time. The level of care needs ~~of~~ and the extent of impaired mobility could be clearly identified.

5/6

ME
Myalgic Encephalomyelitis
ASSOCIATION

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MA
07/VI

Dr Mansel Aylward
Principal Medical Officer
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Room 6/25
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1-11 John Adam Street
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Please reply to:
91 Gordon Crescent
Morland Road
Addiscombe
Croydon CRO 6NW
Tel: 081 656 3447

3 June 1993

Dear Dr Aylward

As I believe Nick Anderson has explained, I have taken over from Richard Sykes as the contact between the DLA Advisory Board and the national ME organisations.

I am informed that you have very kindly offered to ensure that our re-draft of the DLA Handbook guidelines reaches those engaged in re-writing the various Chapters, and I am therefore copying to you my letter to Dr Buchan, and the enclosures.

My colleagues and I are most grateful for your help in this behalf. Please do not hesitate to contact me should you wish for further information.

Yours Sincerely

SHowes

SANDRA HOWES

Dr J Buchan
Medical Secretary
DLA Advisory Board
The Adelphi
1-11 John Adam Street
London WC2 N6HT

Please reply to:
91 Gordon Crescent
Morland Road
Addiscombe
Croydon CRO 6NW
Tel: 081 656 3447

3 June 1993

Dear Dr Buchan

As I believe you are aware, I have taken over from Richard Sykes of Westcare as the contact between the Advisory Board and the national ME organisations, and I am now writing with reference to points arising from the meeting on 4 May.

As you know, the Chairman, Professor Grahame, agreed that we should submit a re-draft of the DLA Handbook guidelines on Myalgic Encephalomyelitis for onward transmission to those currently engaged in re-writing sections of the Handbook. This re-draft has now been completed, and a copy is enclosed, together with a brief rationale. Also enclosed, for ease of reference, is a copy of the original entry, and our critique.

We would be grateful if this re-draft could be given speedy and full consideration, and await your comments with interest. We are, as always, very willing to share our expertise with the Board, and are ready to discuss all points arising at an early date.

With this in mind, we would be pleased if you would now confirm the meeting previously arranged for 27 July, or suggest another date in the near future. We would also be grateful for a copy of the minutes of the last meeting.

We look forward to hearing from you shortly. Please do not hesitate to contact me should you require further information.

Yours Sincerely

SANDRA HOWES

11. CERTAIN NEUROLOGICAL DISORDERS

11.12 MYALGIC ENCEPHALOMYELITIS

11.12.1 *Introduction*

Myalgic Encephalomyelitis [ME], also known as the Post-Viral Fatigue Syndrome [PVFS], is a chronic disabling condition affecting the immune and central nervous systems. It is not a new disease, but its incidence has increased over the last 50 years, and it presents in both epidemic and sporadic form.

11.12.2 *Incidence*

Myalgic Encephalomyelitis is thought to effect 20-30 per 100,000 of the population. Onset can occur at any age, but it is most common in persons aged 30-40 years.

11.12.3 *General*

Onset is linked in most cases to an acute infective episode, and there is evidence implicating various common viruses in the development of the syndrome. The person with ME experiences a disabling, exercise-induced muscle fatigue, muscle pain, [myalgia], often severe, a 'flu-like malaise, an abnormal exhaustion unrelieved by sleep, and various symptoms which indicate disturbance in brain function [encephalitic symptoms] including loss of concentration and short-term memory, dyslexia, clumsiness and disturbed balance [dysequilibrium], particularly at night, sensitivity to light [photophobia] and other problems with vision, sensitivity to noise [hyperacusis], misjudgment of distance [spatial disorientation], and problems with bladder control and bowel disturbance. All of the symptoms are exacerbated by mental and/or physical over-exertion.

Current research suggests that the symptoms may be related to persisting or re-activated viral infection, disturbances in the immune systems response, and consequent changes in the normal activity of muscle and the central nervous system.

There is as yet no treatment which has proved uniformly successful, and therapy consists of a range of treatments [eg oil of evening primrose, magnesium injections, and anti-depressants]. It seems that the patients who make the most significant improvement are those who take adequate rest during the acute stage of the illness and during relapse.

11.12.4 *Care Needs*

The outcome in any particular case is extremely difficult to predict. During the acute stage and in severe relapse any form of sustained physical and/or mental activity becomes impossible. Overall, so far as levels of disability are concerned, people with ME tend to fall into one of four bands.

1) Approximately 35% will improve slowly, although the process may take several years, and be punctuated by periods of relapse. Of these, perhaps half will achieve a full recovery.

2) The majority, approximately 40%, will make variable progress, with fluctuating levels of disability, and never achieve full recovery although they may at times reach 70-80% of former function. Some may be able to work, possibly part-time, and carry out most household duties, despite their inability to perform strenuous physical or mental tasks to their former levels of ability. Relapses may be severe and prolonged.

3) A significant minority, approximately 15%, remain severely disabled and make little or no progress. They invariably require daytime assistance, particularly in the preparation of food, and in performing household tasks. They may also require help in toileting and dressing, particularly at night, when visual and balance problems are exacerbated by darkness.

4) A smaller number, perhaps 10%, steadily deteriorate, becoming chair or bed-bound for much of the time.This group requires a great deal of nursing, medical, and social support.

11.12.5 *Mobility Needs*

The exercise induced muscle fatigue, weakness and pain have both central nervous system and muscle components, and this, together with dysequilibrium, inevitably places marked restrictions on walking ability. These restrictions may well be compounded by visual disturbance and spatial disorientation. When walking, escalating severity of the symptoms may result in the person having to stop and rest more and more frequently. Even minimal over-exertion may lead to relapse. These restrictions affect both daily living activities, and the prospects of resuming employment. The person with ME may require walking sticks or a frame, and a considerable number require wheelchairs, and home adaptations.

11.12.6 *Duration of Need*

The course and effects of ME vary widely from one person to another, and are unpredictable. After some years it may be apparent that the person falls into one of the four bands of disability listed above. However, it should be noted that even those in the first two bands may be subject to severe and prolonged relapse.

11.12.7 *Additional Evidence*

A factual report from the person's general practitioner or hospital consultant is essential where the needs over a period of time are not clear because of the variable nature of the disease.

RE-DRAFTED GUIDELINES FOR MYALGIC ENCEPHALOMYELITIS IN THE DLA HANDBOOK

RATIONALE

CHAPTER HEADING

Since Myalgic Encephalomyelitis is a distinct clinical entity, it is necessary to differentiate between it, and other causes of chronic fatigue.

The most dominant feature of ME is the number of symptoms resulting from disturbances in the function of the central nervous system. Myalgic Encephalomyelitis is therefore properly placed within Chapter 11, Certain Neurological Disorders, in accordance with the classification used by the World Health Organisation.

11.12.1 INTRODUCTION & 11.12.2 INCIDENCE

These sections reflect current knowledge, and are common ground amongst experts in the field.

11.12.3 GENERAL

The symptoms listed are those which are most likely to give rise to care and mobility needs.

As explained in our critique of the original entry, whilst several studies show alteration in muscle function, it seems likely that the major component in muscle pain, fatigue, and weakness lies within the central nervous system, and the methods used in many studies will therefore be inappropriate, and prove nothing.

As also explained, "graded exercise" is known to precipitate relapse, as reported by those ME patients involved in such studies as Stokes et al, and we do not therefore include it amongst therapies now in use. [Some clinicians do use graded exercise as a means of differentiating between ME and other causes of chronic fatigue, but this is not a course that we would advocate, since relapse may be severe and prolonged and familiarity with the symptoms and disease process renders such measures unnecessary.]

11.12.4 CARE NEEDS

The bands of disability outlined in this section are in accordance with the findings of clinicians working in this field, leaves no-one in doubt of the potential severity of the illness, and should be helpful to officials in deciding the degree of disability suffered by individual claimants.

11.12.5 MOBILITY NEEDS

This section reflects the severe disability suffered by patients, and the consequences of over-exertion.

11.12.6 DURATION OF NEED

This section reflects the chronicity and variability of ME, and its uncertain prognosis.

11.12.7 ADDITIONAL EVIDENCE

The reason for the requirements laid down in this section is self-evident. In an illness such as ME, where the severity of the symptoms fluctuate from day to day and the results of over-exertion may not be immediately apparent, an EMO seeing the patient for half an hour or less will be unable to make a fair assessment of the patients needs.

Appendix C

Disability Living Allowance Handbook

Section 12

Chronic Fatigue Syndromes and Myalgic Encephalomyelitis

12.1 Contents

Paragraph

12.2 Clinical Description

Fatigue is the dominant feature of a group of conditions known as chronic fatigue syndromes. These include Royal Free Disease, Icelandic Disease and the post-viral fatigue syndrome. Myalgic Encephalomyelitis, which is currently the subject of much attention and research, may be included in this group. People with these syndromes complain of weakness, lethargy and fatigue after even moderate or slight exertion. Other symptoms such as intolerance of light and noise and depression may be present. Symptoms usually start after an acute viral illness in the form of an upper respiratory tract infection or gastro-enteritis, although in some individuals no such history is forthcoming. It is well recognised that viral illness can be followed by weakness and depression (e.g. post-influenzal lethargy and depression); but symptoms rarely last beyond a few weeks. In chronic fatigue syndromes symptoms persist for months or, in some cases, indefinitely.

As far as Myalgic Encephalomyelitis (ME) is concerned, a case has been made for its consideration as a distinct clinical entity within the spectrum of chronic fatigue syndromes (CFS) - it may well be that only a small proportion of people with CFS fulfil the criteria which have been used by some doctors to describe ME which must follow a feverish illness. In some persons whose disease pattern conforms to a diagnosis of ME a persistent viral infection in muscles may occur, and there may be some evidence of minor muscle damage.

12.3 Care Considerations

12.3.1 Some studies have shown an association with an allergy to or intolerance of certain foods, food-products and additives but other studies have not confirmed this.

12.3.2 A great deal of help may be expected by, and is often given to, a sufferer from CFS or ME. Sufferers are sometimes advised to rest completely but muscles which are not used deteriorate rapidly. There is however another school of thought which advocates graded exercise of muscles to assist the return to normal muscle function and power. In some studies of people affected by chronic fatigue syndromes objective tests of muscle power have shown it to be normal or near normal. A person affected by these syndromes may therefore be able to attend to bodily functions without the assistance of another but each case must be considered in the light of the available evidence.

12.4 Mobility Considerations

In some controlled clinical studies some people with chronic fatigue syndromes have been shown to have adequate muscle power. They may however refrain from walking because they are fearful of the consequences.

12.5 Additional sources of evidence

A report by an Examining Medical Practitioner may greatly assist in helping the affected person properly identify the level and extent of care and mobility needs.

Appendix D: CRITIQUE OF DLA HANDBOOK ENTRIES BY SECTION

Section 12.2 - Clinical Description

The entry on Myalgic Encephalomyelitis in the Disability Living Allowance handbook makes no attempt to explain the very real differences between ME and other Chronic Fatigue Syndromes in terms of respective causes, symptomatology and severity. It is this failure to make the distinction between ME and CFS which has flawed many studies, particularly in the fields of epidemiology and psychiatry, some of which were obviously favoured when compiling the entry.

The inclusion of depression in the clinical description when many more typical symptoms are not mentioned is a clear indication of bias. A study conducted by Walter J. Gunn of the U.S. Centers for Disease Control (1) found that half of the patient group had no depressive symptoms at all, whilst much of the depression which did occur was deemed to be a response to the limitations imposed by the illness itself rather than the cause. It should also be noted that while anti-depressants are often advocated as a treatment for ME, there have been no placebo-controlled studies to confirm their effectiveness.

The existence of objective abnormalities in the brain, as proven by varied brain scan studies, (such as those by Daugherty et al (2) & Buchwald et al (3)), and the role of a persistent viral infection is minimised here. Studies by Landay et al (4), Cunningham et al (5), Gow JW et al (6) and Klimas et al (7), all indicate a continuing viral presence in the tissues of brain and body.

The statements that "some persons" may show persistent infection in muscles with "some evidence of minor muscle damage" hardly reflects the study by Behan et al (8) showing damage to the mitochondria (organelles vital to the energy cycle) in 80% of the patient group.

Section 12.3.2 - Care Considerations

It is implied that complete rest is harmful, whilst 'graded exercise' will effect a cure. Empirical evidence, however, shows that complete rest is often essential to recovery during acute episodes of the illness, whilst the exercise therapies advocated by some researchers can precipitate a prolonged relapse. The only study of the effect of graduated exercise was an open (not a controlled) trial, flawed, again, by a failure to differentiate between CFS, ME and other illnesses, and by a high drop out rate.

There is reference to 'objective tests' showing that patients have normal muscle power, implying a lack of motivation for self-help or activity. However, there are many studies showing that this is a fallacy. Lloyd et al (9) showed conclusively that lack of motivation played no part in the loss of force-generating capacity, and the conclusion was that the cause lay within the central nervous system (CNS). It has been suggested that on the basis of the study by Behan PO and Bacheit AMO (10) that fatigue originating in the CNS is made worse by exercise, and the paper by Demitrack et al (11) of the US National Institutes of Health bears out Behan's research into impaired activation of the Hypothalamic-Pituitary-Adrenal Axis. A study by Mena (12) using SPECT scans show abnormalities following exercise in ME patients which differ from these seen in healthy people.

Further evidence that the Disability Living Allowance handbook seeks to minimise the serious physical nature of ME (and therefore the need of ME sufferers for Care Allowance) is that no mention is made of the balance problems, exacerbated by darkness, and the spacial disorientation experienced to varying degrees by almost all patients. It is the unsteadiness resulting from this that puts patients in need of aid at night and whilst toileting, dressing, etc.

Section 12.4 - Mobility Considerations

The material given in Section 12.3.2 covers the issue of 'adequate muscle power'. The suggestion that ME patients may refrain from walking because of fear of the consequences is unproven. There is a great deal of anecdotal evidence showing that if anything, ME patients tend to overestimate their abilities so far as walking, exercise and other activities are concerned.

Section 12.5 - Sources of Evidence

This paragraph implies that all EMO's will be experienced in the diagnosis and assessment of ME, which will certainly not be the case. As is well known, both diagnosis and assessment of disability in ME is difficult and time consuming for practitioners experienced in this field, not least because the effect of over-exertion may not become apparent for some time afterwards. An EMO not versed in ME, seeing a patient for the first time, and for half an hour or less, will rarely be capable of judging the needs of that patient.

An EMO's ability to diagnose ME is seriously impaired, moreover, by the complete lack of authoritative information on the disease available from Government sources.

References:

1. Walter J Gunn, Center for Disease Control - Treatment proposed for CFS - research continues to compile data on this disorder JAMA, 1991, Vol 266, 2667-2668
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5. Cunningham et al - Persistence of Enteroviral RNA in CFS is associated with the abnormal production of equal amounts of positive and negative strands of enteroviral RNA. Journal of General Virology, 1990, 71, 1399.
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10. Behan PO & Bakheit AMO - Clinical spectrum of the Post Viral Fatigue Syndrome. British Medical Bulletin, 1991, 47, 793-808.
11. Demitrack MA et al - Evidence for Impaired Activation of the Hypothalamic - Pituitary - Adrenal Axis in Patients with Chronic Fatigue Syndrome - Journal of Clinical Endocrinology and Metabolism, 1991, 73, 6, 1224-1234.
12. Mena I - paper presented at Conference on CFIDS - Los Angeles, California, 18-19 May 1991

For further information, please contact:

Dr. Charles Shepherd,
Priors Cottage,
Queens Sq.,
STROUD,
GL6 8EH.

Tel.: 0453-885462

2714.

FILE: ME. 45G.

WESTCARE
Hope & Help for M.E.

15 Queen Victoria Road,
Redland, Bristol BS6 7PE.
Tel: 0272 738317
Fax: 0272 744701

Registered Charity No. 900619

Dr M McGrath
Department of Social Security
The Adelphi
1-11 John Adam Street
London
WC2N 6HT

26th April 1993

Dear Dr McGrath,

Further to our recent correspondence, I am writing in connection with the forthcoming meeting with the DLA Board at 12 noon on Tuesday, 4th May.

The colleagues who are coming with me are :-

Dr Anne Macintyre - Director designate IFMEA (International Federation of ME Associations).

Dr Nick Anderson - Director, ME Action Campaign

The items which we wish to discuss, with reference to ME, are :-

1. The judgment in the case Page vs Smith.
2. The mobility component of the DLA allowance.
3. The entry in the DLA Handbook.
4. Some difficulties encountered in making claims.

Some notes on the judgment are enclosed.

Since 2 key colleagues, Dr Charles Shepperd and Mr John Broderick, Chairman of the ME Association, are unable to be present on 4th May, we appreciate the opportunity of a further meeting with the DLA Board on Tuesday 27th July.

After the meeting on 4th May correspondence relating to the representation of the views of the joint ME Organisations should be addressed to Ms Sandra Howes, 91 Gordon Crescent, Morland Road Croydon, Surrey CR0 6NW (Tel 081-856-3447). I would be grateful, however, if you could keep me in touch with developments.

Westcare has now withdrawn from the joint ME Organisations Parliamentary Lobby, but we are, however, fully committed to the aims of achieving more understanding of ME and better services for ME sufferers. We remain very involved with proposals to establish a Task Force on CFS/PVFS/ME.

I look forward to the meeting on 4th May.

Yours sincerely,

Richard Sykes

Patrons:
The Earl Baldwin of Bewdley
The Bishop of Bristol

Director:
Richard Sykes M.A. (Cantab),
Ph.D. (Princeton), C.Q.S.W.

Westcare provides information and services for people with M.E. (Myalgic Encephalomyelitis), P.V.F.S. (Post-Viral Fatigue Syndrome) and C.F.S. (Chronic Fatigue Syndrome).

485

The National Archives

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Closed until: 2072.

Initial & Date

23/3/12

E.R.

DLAAB was highly instrumental in the production of the Handbook; Members include not only eminent clinicians from the whole range of medical specialisms but also people who are themselves disabled or involved in the care of people with disabilities. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

During the preparation of the Handbook DLAAB were fully consulted and articles and papers across a wide range of disabilities and illnesses studied. Experts in particular conditions were consulted and drafts of the Handbook were circulated to outside specialists, and organisations, for comment, to ensure accuracy and consistency of medical opinion.

On the subject of ME; this section of the Handbook was written following careful study of papers and articles on this condition in several scientific journals. DLAAB was also consulted, and met with members of the ME Action Group to discuss the drafting of this chapter. Many of the suggestions made by the ME Action Group were incorporated. The Handbook acknowledges the condition is not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for ME is recognised.

The Handbook also recognises that there is as yet no consensus with regards to advice given to sufferers. Some doctors advise complete rest, but there is another large consensus of medical opinion which advocates graded exercise of muscles to assist the return to normal.

It is the Department's intention that the Disability Handbook should be regularly reviewed and revised so as to ensure current medical opinion is accurately reflected for the benefit of AOs. DLAAB, which has the function of advising on the contents of the Handbook, is carefully monitoring the Handbook and I am sure that they will take fully into account the points Dr Sykes and his colleagues have to make before advising any necessary revision on the section of the Handbook that deals with ME.

I should like to thank you for your interest in this important area and hope this reply helps to reassure you and explain the position fully.

Yours ever,

Nick.

NICHOLAS SCOTT

FILE: ME.

DEPARTMENT OF SOCIAL SECURITY
Richmond House, 79 Whitehall, London SW1A 2NS
Telephone 071-210 3000
Fax 071-210 5415

Minister for Social Security and Disabled People

CC: Mrs Brennan.
Miss Edwards
Mrs Sigmaszko
Ms Mitchell
Mr Pendergast
~~Dr Aylward~~ MA
Dr Buchan 15/iv
Dr McGrath
Miss Mayoh

The Rt Hon William Waldegrave MP
House of Commons
SW1A 0AA

14 APR 1993

Dear William,

Thank you for your letter of 23 March on behalf of Dr Richard Sykes of 15 Queen Victoria Road, Westbury Park about a meeting he is to have with the Disability Living Allowance Advisory Board (DLAAB) concerning Myalgic Encephalomyelitis (ME).

I can reassure you that both this Department and the Department of Health recognise ME as a debilitating and distressing condition affecting many people. I welcome the fact that Dr Sykes will be meeting DLAAB to discuss the effects of this condition and I can assure you that the valuable information and insight that he can provide will be considered seriously by the Board.

It might be helpful if I explain some of the background to our contact with Dr Sykes and the ME Action Group. Disability Living Allowance (DLA) was introduced in April 1992. Entitlement to DLA does not depend on each person's need for attention with personal care, or supervision/watching over to avoid~~s~~ substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

To assist Adjudication Officers (AOs) in the assessment of entitlement to DLA a handbook - the Disability Handbook - was compiled to set out the care needs and mobility requirements likely to arise from various disabilities and chronic illnesses. The Handbook provides general information about these conditions and is not intended to be prescriptive, nor is it intended to be used as authoritative information in any other context.

F

benefits agency Medical SERVICES

From: Principal Medical Officer
Policy: Medical Services
Room 06/25
Adelphi
1-11 John Adam Street
London
WC2N 6HT
Tel: 071 962 8082
Fax: 071 962 8785

Your Ref: HS/C/MCG/1/93

Mr Eddie McGrady MP
14A Scotch Street
DOWNPATRICK
Co DOWN
Northern Ireland

Date: 13 April 1993

Dear Mr McGrady

RE: MYALGIC ENCEPHALOMYELITIS ASSOCIATION AND THE DISABILITY HANDBOOK.

Your letter of 8 March to Mr Wylie asking for changes to the Disability Handbook in regard to Myalgic Encephalomyelitis (ME) has been passed to me for reply. I note that Mr Wylie had informed you of this and I apologise for not having been able to respond earlier The chapter on ME in The Disability Handbook was written following very careful study of papers and articles on this, and related conditions, in various scientific and medical journals. Drafts of the handbook were circulated widely for consultation among organisations representing disabled persons before it was published. My colleagues and I in Benefits Agency Medical Services met with people affected by ME and others representing the interests of those with this illness when we were preparing the final draft of the Disability Handbook. Moreover, we also consulted the Disability Living Allowance Advisory Board (DLAAB) when preparing the Handbook. Indeed, the DLAAB also met with members of several organisations representing people with ME who discussed the Chapter on ME with them.

Many of the suggestions arising out of these meetings with interested groups resulted in our modifying, and adding to, the first drafts of the Chapter dealing with ME.

The Handbook acknowledges that the condition is not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. A physical cause for ME is recognised. The Handbook also recognises that there is as yet no consensus with regards to advice given to people affected by ME. Some doctors advise complete rest, but there is another body of medical opinion which advocates graded exercise of muscles to assist the return to normal.

The Handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help Adjudication Officers in deciding claims to Disability Living Allowance (DLA) and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

The Disability Handbook will be regularly reviewed and revised. The DLAAB, which has among its responsibilities the function of advising on the contents of the Handbook, will examine and evaluate all research material on ME submitted to it, or to the Department of Social Security. I am sure that the DLAAB will take full account of any published research findings both now and in the future when it exercises its important advisory role on the contents of the Handbook.

Let me further assure you that the classification of Benign Myalgic Encephalomyelitis (Post Viral Fatigue Syndrome) under "Diseases of the Nervous System" in the International Classification of Diseases will be taken into consideration by this Department and the DLAAB in subsequent revisions of the Disability Handbook.

I very much hope that you will have found this letter helpful and informative.

Yours sincerely

Mansel Aylward

MANSEL AYLWARD BSc MD FFPM

Silent copies of this to

(1) Mr F J Johnston
Chief Executive's Office, Stormont etc
(2) Dr Brian Brolley
(3) Dr Jon Buchan.
(4) Trevor Pendergast Mansel
12/iv

The Rt Hon William Waldegrave MP

Thank you for your letter of 23 March on behalf of Dr Richard Sykes of 15 Queen Victoria Road, Westbury Park about a meeting he is to have with the Disability Living Allowance Advisory Board (DLAAB) concerning Myalgic Encephalomyelitis (ME).

X I can reassure you that both this Department and the Department of Health recognise ~~Myalgic Encephalomyelitis~~ (ME) as a debilitating and distressing condition affecting many people.

X The chapter on ME ~~Myalgic Encephalomyelitis~~ in the Disability Handbook was written following careful study of papers and articles on these conditions in several scientific journals. Drafts of the Handbook were circulated widely among organisations representing disabled persons for consultation before it was published. The DLAAB was also consulted, and met with members of the ME Action Group to discuss the drafting of this chapter.

Many of the suggestions made by the ME Action Group were incorporated into it. The Board itself includes eminent clinicians from the whole range of medical specialties and members who are either disabled themselves or involved in the care of disabled people. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

INSERT A

The Handbook acknowledges that the condition is not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. ~~Hence~~ A physical cause for ME is recognised. ~~The Handbook does not suggest that "it is all in the mind"~~. close up

The Handbook also recognises that there is as yet no consensus with regards to advice given to ~~sufferers~~ people affected by ME. Some doctors advise complete rest, but there is another ~~large consensus~~ body of medical opinion which advocates graded exercise of muscles to assist the return to normal.

INSERT B

The Handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help Adjudication Officers in deciding claims to Disability Living Allowance (DLA) and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

Entitlement to DLA does not depend on a particular illness, disease or diagnosis. It depends on each persons need for attention with personal care, or supervision/watching over to avoid substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

F

benefits agency Medical SERVICES

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Mr F J Johnston
Chief Executive's Office
Social Security Agency
Castle Buildings
STORMONT
BELFAST BT4 3SJ

Date: 2 April 1993

Dear Mr Johnson

RE: MYALGIC ENCEPHALOMYELITIS AND THE DISABILITY HANDBOOK
[Letter from Mr Eddie McGrady MP to Chief Executive]

Thank you for your letter of 23 March on the above topic with which you kindly enclosed copies of Mr McGrady's letter to Mr Wylie, dated 8 March, and Mr Wylie's reply of 22 March, 1993.

We have received a number of letters along similar lines from Members of Parliament in Great Britain. I shall be replying directly to Mr McGrady and will copy you and Dr Brolly with my letter.

Yours sincerely

Mansel Aylward

Mansel Aylward BSc MD FFPM

cc: Dr Jon Buchan DLAAB
Dr Brian Brolly DLA.NI

30/3

MA 31/iii/93

SOCIAL SECURITY AGENCY
CASTLE BUILDINGS · STORMONT · BELFAST BT4 3SJ · TELEPHONE 763939 · FAX 761053
CHIEF EXECUTIVE'S OFFICE

Dr Mansel Aylward
Principal Medical Officer
Benefits Agency Medical Service
11th Floor
Adelphi
1-11 John Adam Street
LONDON

23 March 1993

Dear Dr Aylward

Please see the attached letter from Mr Eddie McGrady MP to Mr Alec Wylie Chief Executive of the Social Security Agency, in which he askes for changes to the Disability Handbook in relation to Myalgic Encephalomyelitis.

As discussed with your office I am passing the enquiry to you to reply to Mr McGrady on this matter. A copy of Mr Wylie's reply to Mr McGrady is attached and all documents have been copied to Dr J Buchan of the DLA Advisory Panel and to Dr B Brolly of the DLA Advisory Board in Northern Ireland for their information.

Yours sincerely

F J Johnston

W147/3 10/3/93.

Letter acknowledged - 10/3

HOUSE OF COMMONS
LONDON SW1A 0AA

14A Scotch Street
DOWNPATRICK
Co Down
BT30 6AQ

Downpatrick 612882

Our Ref: HS/C/MCG/1/93

8 March 1993

1/ Mr Johnston
2/ Mr Cunliffe
This is probably one for HQ (and indeed for DSS Policy) but pl note & deal as necessary. I would need to reply if only to say where the matter has been referred too!
AW
10/3.

Mr Alex Wylie
Chief Executive
Social Security Agency
Castle Buildings
Stormont
BELFAST BT4

Dear Mr Wylie

re: Myalgic Encephalomyelitis Association

I refer to the above named subject matter.

I am writing to advise that I have received on-going communication from the Myalgic Encephalomyelitis Association about the need to revive the description of ME in the Disability Handbook. I would respectfully request the following measures:-

- the current Disability Handbook guidelines on ME be immediately revised to reflect both the severe, disabling nature of ME and the latest research findings now and in the future.
- the entry on ME in the Disability Handbook be removed from the Chapter on Chronic Fatigue Syndromes and placed within the chapter on "Certain Neurological Disorders" in line with the current World Health Organisation listing for the illness.

Perhaps the whole problem in relation to ME could be adequately investigated and research and proper cognizance given to it in the Disability Handbook?

I await a reply in due course.

Yours sincerely

Eddie McGrady

Eddie McGrady MP

SOCIAL SECURITY AGENCY
REC'D 12/3/93
TIME pm
CHIEF EXECUTIVE'S OFFICE

ref no: 62/3

SOCIAL SECURITY AGENCY
CASTLE BUILDINGS · STORMONT · BELFAST BT4 3SJ · TELEPHONE (0232) 520520 · FAX (0232) 523337
CHIEF EXECUTIVE

Mr E McGrady MP
14A Scotch Street
DOWNPATRICK
Co Down

22 March 1993

Dear Mr McGrady

You wrote to me on 8 March 1993 asking for changes to the Disability Handbook in relation to Myalgic Encephalomyelitis.

The Handbook, which does not come within my responsibilities, is produced by the Benefits Agency in Great Britain and its contents are approved by the Disability Living Allowance Advisory Panel there. Accordingly, I have passed your letter to Dr Mansel Aylward, Principal Medical Officer, Benefits Agency Medical Service, 11th Floor, Adelphi, 1-11 John Adam Street, London, who will reply direct to you on this matter. A copy of your letter has also been sent to the Advisory Panel and to the Advisory Board here in Northern Ireland.

Yours sincerely

A WYLIE

W147/3 10/3/93.

Letter acknowledged - 12/3

HOUSE OF COMMONS
LONDON SW1A 0AA

14A Scotch Street
DOWNPATRICK
Co Down
BT30 6AQ

Downpatrick 612882

Our Ref: HS/C/MCG/1/93

8 March 1993

1/ R Johnston
2/ R Cunliffe
This is probably one for HQ (and indeed for DSS Policy) but pl note & deal as necessary. I would need to reply if only to say where the matter has been referred too!
AW
10/3.

Mr Alex Wylie
Chief Executive
Social Security Agency
Castle Buildings
Stormont
BELFAST BT4

Dear Mr Wylie

re: Myalgic Encephalomyelitis Association

I refer to the above named subject matter.

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I await a reply in due course.

Yours sincerely

Eddie McGrady MP

SOCIAL SECURITY AGENCY
REC'D 12/3/93
TIME pm
CHIEF EXECUTIVE'S OFFICE

ref no! 62/3

30B

ME.
File :- ME

b 18/9/92
Copy both ~~by~~ to Dr Aylward for possible follow up action
Then file C4.1

Dr Castaldi CMA/DSS

From: Dr J S Metters DCMO
16 September 1992

Copies to: Dr Hilton
Dr Hangartner
Dr Aylward DSS

ME : WESTCARE

1. I have just been looking through the 'DH Westcare' file and find that you have not yet received a copy of the note of the meeting we held with them on 6 July. I am sorry for the delay in sending this to you. May I draw attention to paragraphs 2 and 9 which mention DSS interests.

2. A copy of the note has gone to Mr Waldegrave in view of his constituency interests.

3. Most of the follow-up action rests with the Task Force Feasibility Group. We will keep you in touch with further DH action as and when it occurs.

JSM

J S METTERS
Room 509
Richmond House

232/YdeS

130/9

JH77

NOTE OF A MEETING ON CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS HELD ON 6 JULY 1992 AT THE DEPARTMENT OF HEALTH

Those present:

Dr J Metters (Chairman)	DH
Dr D F H Pheby	Westcare
Dr C Shepherd	ME Association
Dr R Sykes	Westcare
Dr R Hangartner	DH
Dr J Hilton	DH

1. This meeting was a follow-up to one held on 30 March 1992. Apologies were received from Dr A McIntyre, Medical Adviser to the ME Action Campaign. Dr Hangartner was present for only part of the meeting.

2. A DH note of the previous meeting had been prepared and circulated to all participants. The ME organisations expressed disappointment that their letter requesting a follow-up meeting with DSS officials had not yet been answered.

FOLLOW-UP OF ACTION POINTS

3. Dr Metters explained that a CMO letter on the subject of ME would be inappropriate. The Department was trying to restrict CMO letters to matters of urgent public health concern. They were not an educational series. He suggested that the ME organisations should consider an article for Health Trends. Dr Shepherd agreed to consider writing such an article.

4. Exploration of the circumstances in Sidmouth with colleagues in the Department did not suggest that there was any action which the Department could appropriately take. Dr Shepherd reported that one partner in the practice now seemed to be more sympathetic to ME patients. Westcare has arranged study days in Exeter and Plymouth and it was suggested that the Regional Postgraduate Dean should be contacted in order to publicise the meetings to GPs in the area. Dr Shepherd and Dr Sykes were advised to continue pursuing the matter through the Community Health Council (CHC). The Chairman of the CHC

is a patient of the practice in question but it was suggested that some other member of the CHC might be approached. Failing that, there are informal channels of communication between DH and FHSAs and these could be used if a satisfactory resolution was not obtained.

5. A Task Force Feasibility Group had been established. Dr Hilton had attended the first meeting of this Group and it was pointed out that her status must be clearly registered as that of an observer. There is no physician on the Feasibility Group and the potential problems of finding someone of standing within the RCP who would be sympathetic to the aims of the task force required sensitive handling. DH officials agreed to explore the matter with the College and were also prepared to discuss appropriate representation with the RCGP once the Task Force Feasibility Group had completed its work. There was no ready means whereby DH could provide funding for the Task Force but the possibility of seeking funding via a Section 64 Grant was suggested.

6. The Department's developing research strategy had only identified the top tranche of priorities and ME/CFS research did not sit among those priorities. The new concordat with the MRC highlighted the importance of obtaining the support of DH policy divisions for research so that those divisions could identify their priorities in discussion with MRC.

TREATMENT

7. The ME organisations described a project at the Harold Wood Hospital where Leslie Findlay, a neurologist and honorary consultant at Queen's Square, was providing a programme of rehabilitation and behavioural management. There had been problems in having patients referred to his unit because of the view that there was no accepted treatment for ME/CFS. The ME organisations undertook to find out the details of this apparent problem since DH officials were unable to take the matter forward without such information. It was suggested that an article on the treatment programme could also be submitted to Health Trends and that the Regional Director of Research could be approached to discuss the possibility of a study to evalute its effectiveness.

8. Westcare also had a proposal for an approach to treatment but were experiencing difficulties in obtaining funding. They were also advised to make an approach to their local Regional Research Director.

OTHER BUSINESS

9. Dr Metters explained that neither he nor other DH officials could express an opinion as to whether disability could exist in the absence of clinical signs. Whilst the DLAAB could express views on diagnostic criteria this was an area in which DH would seek guidance from its network of advisory bodies and would wish that guidance to be endorsed by professional bodies such as the Royal Colleges.

ACTION AGREED BY DH

10. It was agreed that a note of the meeting would be sent to Dr Castaldi and Dr Ayleward of the DSS.

11. Dr Metters would raise the possibility of articles on ME diagnosis and management in Health Trends with the Chairman of the Editorial Board. Dr Hilton would also let the Editor of Health Trends know of the proposed articles.

12. DH would facilitate contacts with the RCP/RCGP when the Task Force feasibility group had completed its work.

13. Dr Hilton would consider any basic research projects for which MRC funding was sought to see if they merited customer support from her division.

14. It was agreed that a further meeting would not be necessary until the Task Force feasibility group had completed its work.

cc. Dr Costaldi
Dr Hilton
Dr Hangartner
Dr Aylward

18/9/92

The Rt Hon William Waldegrave MP
House of Commons
LONDON SW1A 0AA

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16 September 1992

Dear Chancellor

WESTCARE

In my letter of 11 June I mentioned that officials from DH would be holding a further meeting on 6 July with Dr Sykes of Westcare and representatives of other support organisations for patients with Myalgic Encephalomyelitis (ME).

As you may remember, Westcare's original approach was prompted by difficulties in Sidmouth where it was suggested some general practitioners were not sympathetic to or even recognised ME as a clinical entity.

We have gone carefully into the situation at Sidmouth, and do not believe there is anything that the Department of Health can do centrally. It is primarily a matter of medical education and Dr Shepherd of the ME Association told us that one of the partners in the practice at Sidmouth now seem to be more sympathetic to the problems of ME patients. Westcare was arranging study days in Exeter and Plymouth and would be contacting the Regional Postgraduate Dean.

Following the previous meeting in the Department, a Task Force Feasibility Group had been established, and this Group was investigating ways of making contact with the Royal College of Physicians as a way of influencing medical attitude to ME.

We also discussed the possibility of evaluating treatment and rehabilitation programmes for ME. In this context the difficulties of evaluating treatment methods without a proper comparative controls was mentioned.

In view of the Westcare's interest in disseminating information on the diagnosis and management of ME, we suggested that the Department's "Health Trends" as a possible publication. Acceptance of the article would of course be subject to the Health Trends Editorial Board.

I enclose a copy of the Department's note of the meeting and will keep you informed of our future contacts with Westcare. Dr Sykes is separately in touch with colleagues in DSS.

Yours sincerely

Jeremy Metters

J S METTERS
Deputy Chief Medical Officer

Enc.

233/YdeS

30B

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Follow up of patients presenting with fatigue to an infectious diseases clinic

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Abstract

***Objectives*—To determine the symptomatic and functional status during follow up of patients referred to hospital with unexplained fatigue and to identify patient variables associated with persistent functional impairment.**

***Design*—Follow up by postal questionnaire six weeks to four years (median 1 year) after initial clinical assessment of patients referred to hospital during 1984-8.**

***Setting*—Infectious diseases outpatient clinic in a teaching hospital.**

***Patients*—200 consecutive patients with fatigue of uncertain cause for at least six weeks; 177 fulfilled the inclusion criteria.**

***Main outcome measures*—Findings at initial assessment; current symptoms, beliefs about the cause of illness, coping behaviours emotional disorder, social variables including membership of self help organisations, and degrees of recovery and functional impairment from questionnaire responses.**

***Results*—144 (81%) patients returned completed questionnaires. Initial assessment did not indicate the cause of fatigue, other than preceding infection. The proportion of patients with functional impairment was significantly smaller with longer follow up (33% (11/33) at two to four years, 73% (29/40) at six weeks to six months; χ^2 for trend = 12·5, df=1; p<0·05). Functional impairment was significantly associated with belief in a viral cause of the illness (odds ratio=3·9; 95% confidence interval 1·5 to 9·9), limiting exercise (3·2; 1·5 to 6·6), avoiding alcohol (4·5; 1·8 to 11·3), changing or leaving employment (3·1; 1·4 to 6·9), belonging to a self help organisation (7·8; 2·5 to 23·9), and current emotional disorder (4·4; 2·0 to 9·3).**

***Conclusions*—Short term prognosis for recovery of function was poor but improved with time. Most patients had made a functional recovery by two years after initial clinic attendance. Impaired functioning was more likely with certain patient characteristics. Prospective studies are required to clarify whether these associations are the consequences of a more disabling illness or indicate factors contributing to impaired function.**

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Introduction

In recent years there has been renewed interest in the causes and management of the symptom of fatigue. Although fatigue is a symptom of many medical conditions, identifiable organic disease is rarely found in patients referred to hospital with fatigue as a major complaint.[1,2] The fatigue is then considered to be "idiopathic." Clinical concern has focused on patients whose fatigue is idiopathic, persistent, and associated with impaired physical and mental functioning, who have been referred to as having a "chronic fatigue syndrome" if the fatigue has been present for at least six months.[3] The patient group thus defined is almost certainly aetiologically and prognostically heterogeneous. Several more specific syndromes have been proposed, including more restrictively defined chronic fatigue syndromes,[4,5] postviral fatigue syndrome,[6] and myalgic encephalomyelitis.[7] Although each has its advocates, none of these specific syndromes has yet been shown to have clinical utility.

The literature includes several studies of patients with idiopathic fatigue, most of which have selected patients according to one of the above criteria. However, there is still a paucity of information concerning unselected patients referred to non-specialist units. The patient samples of previous studies have been obtained from self referrals,[5 8] primary care,[9 11] or tertiary referral centres.[5 6 12 13] The generalisability of the findings to a general hospital outpatient clinic is therefore in doubt.

The prognosis for such patients is also uncertain. Conflicting findings have been reported for patients with idiopathic fatigue in primary care,[9-11] whereas the prognosis for patients referred to hospital with "post-viral syndrome" has been reported as poor.[6] There are no long term follow up studies of large series of patients with idiopathic fatigue, and the factors associated with persistent illness are unclear. It has been suggested that patients may fail to recover from acute fatigue if they become trapped in a vicious circle of avoidance of activity, belief in an infective cause outside their control, and emotional disorder.[14] Though patients who regard their illness as physical rather than psychological in origin respond less well to psychological treatment,[15] the significance of such beliefs and consequent behaviours in an untreated population is unknown.

In this report we present findings from a large consecutive series of patients who presented with a major complaint of fatigue to a single physician working in an infectious diseases clinic. Patients were subsequently followed up by postal questionnaire. The study attempted to answer two questions: (*a*) What is the outcome for patients with fatigue in terms of symptoms and limitations on their functioning? and (*b*) What patient factors are associated with persistent functional impairment?

Patients and methods

CLINIC REFERRALS

Two hundred consecutive patients with a major complaint of fatigue of at least six weeks' duration were assessed in an infectious diseases clinic between November 1984 and December 1988 by one consultant physician (GP) as part of his routine clinical practice. The referrals were unsolicited from general practitioners. All patients had a major complaint of fatigue and had impaired physical and mental function because of this. A minimum of six weeks' fatigue was required for their inclusion in the study.

INITIAL ASSESSMENT

In all cases age, sex, marital status, and the date of onset of the illness reported by the patient were recorded, a detailed history was taken, and a full physical examination was performed. In almost all patients a full blood count and biochemical testing were carried out. (Specific tests including antibodies to acetylcholine receptor,[16] large undifferentiated cell counts which might suggest recent viral infection,[17] and detection of VP1 antigen[18] were performed only in selected patients.)

MANAGEMENT

Most patients were seen only once after the initial assessment, to give them the results of investigations. Treatment consisted principally of establishing the absence of treatable disease; acknowledging the reality of the patient's illness; diagnosing "post infectious" or "idiopathic" fatigue; and optimistic reassurance about prognosis. Twenty (10%) patients were admitted to the infectious disease ward for further investigation.

FOLLOW UP QUESTIONNAIRE

After 12 patients who were aged under 16 years, 10 patients for whom the reported onset of illness was less than three months before follow up, and one patient who was blind were excluded, 177 patients remained. These patients were all sent a previously piloted questionnaire in February 1989. The study was approved by the local ethics committee.

The questionnaire (available from the authors) asked patients about their health over the previous month on four point scales. The questions were based on clinical experience intended to determine the patients' current state and experience of treatment and also to inquire about factors perpetuating illness, as suggested by a cognitive behavioural model of the chronic fatigue syndrome.[14] It included the following items: symptoms such as fatigue and muscle pain (rated as "absent" to "present most of the time"); functional impairment in terms of patients' premorbid performance in walking, social life, hobbies, and occupation (rated as "not impaired" to "impaired a great deal"); social factors such as changes in employment or studies and membership of a patient organisation; the patients' beliefs about the cause of their illness (three point scales from "not a cause" to "definitely a cause"); the methods of coping with symptoms they had found helpful when ill, including limiting exercise and avoiding alcohol (four point scale from "no help" to "very helpful"); and finally, patients' evaluation of any treatment received (four point scale from "no help" to "very helpful"). Patients were also asked to rate their degree of recovery (three point scale from "none" to "fully recovered").

Included in the questionnaire was the hospital anxiety and depression scale.[19] This scale was designed to assess emotional disorder in physically ill subjects and is relatively free from somatic items. The total score was used with a threshold of 11/12[20] (calculated both including and excluding the fatigue related symptom of "I feel as if I am slowed down").

ANALYSIS

The questionnaire responses were collapsed into dichotomous categories: symptoms were rated as present if reported as occurring "frequently" or "most of the time" over the past month; each belief was scored as present if it was rated as a "possible" or "definite" cause of illness; specific areas of activity were rated as impaired if affected at least "moderately"; and each coping behaviour was rated as present if it was reported "moderately helpful" or "very helpful."

Functional impairment was used as the principal measure of outcome. Patients were considered to have impaired functioning if one or more of the activities assessed (housework, sport, walking, social, hobbies, occupation, or studies) had been impaired by the illness during the preceding month. The associations between impaired overall functioning, duration of follow up, demographic variables, beliefs, emotional disorder, coping behaviours, and social variables were examined by logistic regression fitted using generalised linear interactive modelling.[21] Each of these possible explanatory variables was fitted both unadjusted and after adjustment for other variables. For confounding associations the significance of the association was assessed by the increase in deviance found when that variable was excluded from the regression (the change in deviance was approximated to a χ^2 statistic). Odds ratios for functional impairment at follow up are reported relative to a reference value of each variable and were calculated as the exponential of the parameter of the fitted model.

Results

INITIAL ASSESSMENT

All 200 patients were judged on clinical assessment to have fatigue with impaired functioning as their major complaint. Of these, 131 (66%) had reported disabling fatigue for six months or more at presentation and so would have met the accepted time criteria for the chronic fatigue syndrome.[3]

Of the whole sample, 166 (83%) patients related the onset of symptoms to an acute illness. The most common initial symptoms, reported by 93 (47%) patients, were those of an upper respiratory tract infection (that is, sore throat, fever, and swollen glands). Other retrospectively reported symptoms suggesting an initial infection were diarrhoea in 17 patients (acquired while abroad in 13) and chest pain in four. An initiating disease (or treatment) had been recorded in a small number of patients: pneumonia, viral meningitis, epididymitis, immunisation against tetanus, and a fracture (one patient each); 35 (18%) patients reported no initiating illness.

Physical examination disclosed no major abnormalities. Minor abnormalities were found in 18 (9%) patients (soft systolic murmurs in nine, blood pressure >140/90 mm Hg in three, and minor cervical lymphadenopathy in six), none of which enabled a firm physical diagnosis to be made. Psychiatric assessments were not performed at presentation.

Laboratory investigations added little to the clinical assessment. A full blood count was obtained in 184 (92%) patients; three patients had white counts $>10\times10^9/l$; five had eosinophil counts $>0\cdot5\times10^9/l$; five had an erythrocyte sedimentation rate >30 mm in the first hour; and five had platelet counts $>3\cdot5\times10^{12}/l$. Biochemical variables were studied in 192 (96%) patients and disclosed minor abnormalities in bilirubin (three patients), aspartate transaminase (six) and alkaline phosphatase (five). The large undifferentiated cell counts were normal (0·2% to 1·1%) in 16 patients tested. Nine of 20 (45%) patients with the chronic fatigue syndrome were positive for VP1 antigen.[18] Only two patients had slightly raised creatinine kinase concentration (264 and 274 IU/l respectively; reference value <200 IU/l). None of 24 patients complaining of severe muscle weakness had acetylcholine receptor antibodies.[16] None of these findings led to specific treatment.

QUESTIONNAIRE FOLLOW UP SAMPLE

Of the 177 questionnaires sent out, 144 responses were available for analysis (response rate 81%). Five patients could not be traced (questionnaire returned) and 28 questionnaires were either not returned or were inadequately completed. The patients in the final sample had a median age of 34 years (range 16 to 79 years); 94 (65%) were female. The median duration of fatigue at presentation to the clinic was 25 months (range 6 weeks to 25 years), and the time that elapsed between presentation and questionnaire follow up ranged from six weeks to four years (median one year). The characteristics of the follow up sample were as follows.

Functional impairment and employment/studies—In all, 130 (90%) patients reported having reduced their normal activities by at least half for a month or more at some time during their illness. Fifty five (38%) had left or changed their job (or studies) because of their illness and 93 (65%) were functionally impaired at follow up.

Beliefs about the cause of the illness—Many patients attributed their illness to more than one cause. One hundred and thirty five (94%) believed that infection had been a factor, 120 (83%) suggesting a virus as the infective agent. However, 97 (67%) considered "stress" to have played a part in causing their illness.

Symptoms—The only symptoms reported as frequently present over the previous month by at least half the sample were fatigue (115, 80%) patients and muscle pain (61, 42%).

Ways of coping with symptoms—Seventy one (49%) patients had found limiting exercise helpful when they were ill, and 46 (32%) had found it helpful to avoid alcohol. Many respondents commented that they tried to avoid "all kinds of stress" as failure to do so tended to cause a "relapse" of symptoms. A minority of patients (41, 28%) had joined a patients' organisation (ME Association or ME Action Campaign).

Emotional disorder (anxiety and depression) as defined by a total score of greater than 11 on the hospital anxiety and depression scale was present in 95 (66%) patients, and in 81 (56%) if the scale item "slowed down" was excluded.

Treatment—In addition to the attendance at the infectious diseases outpatient clinic many patients had sought further treatment for their fatigue. Twenty three (16%) had attended a psychiatric outpatient clinic but only five patients found it more than "slightly helpful." Fifty five of the sample (38%) had taken an antidepressant drug, of whom only four reported that they had been "greatly improved" whereas 13 patients felt they had been "made worse" by the drug. Other forms of therapy included dietary advice, principally concerning diets to control candida infection (39, 27%), homeopathy (29, 20%), physiotherapy (18, 13%) and hypnosis (7, 5%). None of the above treatments were reported to have been "very helpful" by more than 30% of the patients who had received it. However, 71 (49%) patients reported finding the initial outpatient medical assessment "very helpful."

FUNCTIONAL IMPAIRMENT AT FOLLOW UP

At the time of follow up only 19 (13%) patients regarded themselves as "fully recovered." The remainder reported excessive fatigue and varying degrees of functional impairment. Ninety three (65%) were functionally impaired according to our definition, most reporting impairment in several different activities (walking 90 m (100 yards) (72), social activities (44), hobbies (53), and occupation (44)). Most patients (68, 73%) had experienced days during the past month when they had been entirely unable to work or study because of fatigue.

All the functionally impaired patients complained of "excessive fatigue;" 54 (58%) reported frequent muscle pain, 53 (57%) frequent headache, and 42 (53%) poor concentration. Most (64, 69%) complained of problems with sleep, 50 (53%) of disturbed sleep, and 39% (36/93) of an increased need for sleep. Emotional disorder was present in 69 (73%) and in 64 (69%) if the item "slowed down" was excluded.

Dividing the patient sample into subgroups according to duration of follow up (table I) disclosed that the percentage of patients functionally impaired by the illness was smaller in patients with longer periods of follow up (χ^2 for trend = 12·5, df=1; $p<0\cdot05$). Though functional impairment was present in 73% (29/40) of patients who completed their follow up questionnaire within six months of the initial clinic assessment, only 33% (11/33) of patients followed up at two to four years were so affected. Despite this indication of improvement in functioning with time, most of these longer term follow up patients (23, 70%) continued to consider themselves unwell and to complain of fatigue (see table I).

TABLE I—*Persistence of fatigue and functional impairment by duration of follow up*

Duration of follow up	No of patients	No (%) with symptoms	No (%) functionally impaired
<6 Months	40	36 (90)	29 (73)
6 months-1 year	42	39 (93)	33 (79)
1-2 years	29	27 (93)	20 (69)
2-4 years	33	23 (70)	11 (33)
Whole sample	144	125 (87)	93 (65)

TABLE II—*Association of patient variables with functional impairment at follow up*

Variable	No of patients	No (%) of patients with functional impairment	Odds ratio	95% Confidence interval	Degrees of freedom	χ^2	Adjusted odds ratio†
Duration of follow up:							
<6 months‡	40	29 (73)	1		3	18·6*	
6-12 months	42	33 (79)	1·4	0·5 to 3·9			
1-2 years	29	20 (69)	0·8	0·3 to 2·5			
2-4 years	33	11 (33)	0·2	0·1 to 0·5			
Onset of symptoms to initial assessment:							
<6 months‡	32	19 (60)	1		3	4·1	
6-12 months	32	21 (66)	1·3	0·5 to 3·3			1·0
1-2 years	31	18 (58)	0·9	0·4 to 2·4			0·6
2-4 years	29	23 (79)	2·6	0·9 to 7·6			0·9
Sex:							
Male‡	51	32 (63)	0·1	1	1	0·1	
Female	93	61 (66)	1·1	0·5 to 2·3			1·3
Age (years):							
16-25‡	36	24 (67)	1·9	1	2	1·9	
26-40	60	35 (58)	0·7	0·3 to 1·7			0·9
41-79	48	34 (71)	1·2	0·5 to 3·1			1·9
Marital status:							
Single‡	58	39 (67)	1		2	1·3	
Married	77	61 (47)	0·8	0·4 to 1·6			0·9
Divorced or separated	9	78 (7)	1·7	0·3 to 9·3			1·9
Belief in virus infection:							
No‡	24	9 (37)	1		1	8·8*	
Yes	120	84 (70)	3·9	1·5 to 9·9			3·3
Limitation of exercise:							
No‡	73	38 (52)	1		1	7·6*	
Yes	71	55 (77)	3·2	1·5 to 6·6			2·9
Avoidance of alcohol:							
No‡	98	54 (55)	1		1	13·1*	
Yes	46	39 (85)	4·5	1·8 to 11·3			4·1
Changed job or stopped work:							
No‡	90	50 (56)	1		1	9·0*	
Yes	54	43 (80)	3·1	1·4 to 6·9			2·9
Member of patient organisation:							
No‡	103	56 (54)	1		1	19·0*	
Yes	41	37 (90)	7·8	2·5 to 23·9			6·5
Emotional disorder (total hospital anxiety and depression score):							
<12‡	49	24 (49)	1		1	7·8*	
≥12	95	69 (73)	2·8	1·3 to 5·8			2·5
Emotional disorder (hospital anxiety and depression score, excluding item "slowed down"):							
<12‡	63	29 (46)	1		1	4·2*	
≥12	81	64 (79)	4·4	2·0 to 9·3			4·2

*Significantly different from reference category at 5% level. †Adjusted for duration of follow up. ‡Reference category.

TABLE III—*Factors independently associated with functional impairment at follow up according to logistic models*

		Model I			Model II		
Variable	Degrees of freedom	χ^2	Odds ratio	95% Confidence interval	χ^2	Odds ratio	95% Confidence interval
Duration of follow up:							
<6 months†	3	9·8*	1		7·2	1	
6-12 months			1·4	0·4 to 4·4		1·6	0·5 to 5·1
1-2 years			1·0	0·3 to 3·3		1·0	0·3 to 3·5
2-4 years			0·3	0·1 to 0·9		0·3	0·1 to 1·1
Belief in viral infection:							
No†	1	5·6*	1		3·6	1	
Yes			3·6	1·2 to 11·0		3·0	0·9 to 9·9
Avoidance of alcohol:							
No†	1	7·5*	1		7·1*	1	
Yes			3·9	1·2 to 11·1		4·0	1·3 to 12·1
Member of patient organisation:							
No†	1	10·4*	1		9·9*	1	
Yes			5·6	1·7 to 18·3		5·7	1·7 to 19·3
Emotional disorder (hospital anxiety and depression score):							
<12†	1	NA	NA		11·4*	1	
≥12						4·3	1·8 to 10·3

*χ^2 statistic (for reduction in deviance) significant at 5% level. †Reference category.

The number of referrals to the clinic increased over the four years (table I), raising the possibility that there were initial differences between follow up groups. This is unlikely, however, as there were no significant differences on any of the independent variables between those patients seen more than two years before follow up and those seen more recently.

Interestingly, there seemed to be little difference in functional impairment at follow up between patients who had been ill for more than six months at initial assessment and hence met the criteria for the chronic fatigue syndrome[3] at this time and those with shorter histories (see table II).

ASSOCIATIONS WITH FUNCTIONAL IMPAIRMENT AT FOLLOW UP

Age, sex, and marital status were not significantly related to functional impairment. Significant associations were found with patients' beliefs, coping behaviours, and social factors. The specific factors were the belief that fatigue was a consequence of an initial viral infection; coping with illness by limiting exercise and by avoiding alcohol; changing or leaving a job or studies, and joining a patient organisation (see table II). Emotional disorder at the time of follow up was also associated with functional impairment.

Two further analyses were undertaken to examine these associations. Firstly, as time since initial clinic attendance may have been a confounding factor the analysis was repeated after adjusting for this variable. The adjustment had little effect on the odds ratios for the associations reported above (table II). Secondly, because the explanatory belief, behaviour, and social variables were correlated, the associations of each with functional impairment was re-examined after adjustment for all the others. When this was done the following associations remained: duration of follow up (χ^2 for trend = 6·1, df=1; $p<0·05$) and a belief in an initial virus infection, avoidance of alcohol, and membership of a patient organisation. Table III (model I) shows the odds ratios and χ^2 values for exclusion of each term obtained from the logistic model containing these variables as main effects.

The association of emotional disorder with functional impairment remained significant after adjustment for all other measured variables. Including emotional disorder in the logistic model resulted in minor changes to the estimated odds ratios as shown in table III (model II). The association for duration of follow up was no longer significant for the specific follow up categories, although χ^2 for trend remained so (χ^2=4·1, df=1; p=0·05). The value of χ^2 for the association of belief in viral infection (p=0·07) was reduced to below that for significance. However, the association of avoidance of alcohol and membership of a patient organisation remained significant after adjustment, suggesting that their association with functional impairment is independent of emotional disorder.

Discussion

This study is the first systematic follow up of a large number of consecutive patients with fatigue referred by general practitioners to an infectious diseases clinic in the United Kingdom. Its principal weaknesses are the reliance on questionnaire responses and the fact that many patient variables were assessed only at follow up. These findings therefore require confirmation in a prospective study. Furthermore, though our sample may be typical of patients referred to infectious diseases clinics, it may not be representative of patients referred to other specialist clinics or those with fatigue who are not referred to hospital.

The results of the initial clinical assessment confirm that physical examination and routine laboratory investigations rarely yield evidence of treatable disease other than "post infectious fatigue syndrome."[1,2] Our findings also illustrate that despite this absence of abnormalities on routine laboratory investigation the functional and occupational morbidity in these patients is considerable. Most patients had been unable to work for prolonged periods and a significant proportion (38%) had abandoned employment or studies altogether.

Perhaps not surprisingly for patients attending an infectious diseases clinic, most believed that their illness had been caused by infection, most commonly a virus. It was, however, impossible to determine the veracity of this belief in more than a few patients. Attributions for the cause of the illness were frequently complex, and many patients also referred to the role of "stress." Most patients had found limiting exercise helpful as a method of coping with their symptoms. Other behaviours commonly avoided included eating certain foods, drinking alcohol, and doing anything that might lead to "stress." In addition most patients had emotional disorder as defined by their total score on the hospital anxiety and depression scale.

FUNCTIONAL IMPAIRMENT AT FOLLOW UP

Our findings confirm a previous report from primary care suggesting a poor prognosis for the first year after clinic attendance.[9] However, the longer term follow up suggests that the proportion of patients remaining functionally impaired falls as time passes, with most patients no longer having impairment after two years. On the other hand, it is noteworthy that most patients remain symptomatic, and one third remain functionally impaired for as long as two to four years after their initial clinic attendance.

We have no reason to suppose that patients who were referred to the clinic more recently had a different degree of disability from those referred earlier. Indeed, there was no substantial difference in length of history, age, or sex distribution over the period studied. However, because disability was not formally measured at the initial clinic assessment, initial differences between the follow up groups cannot be entirely excluded.

ASSOCIATIONS WITH FUNCTIONAL IMPAIRMENT AT OUTCOME

Length of history at presentation did not predict functional impairment at follow up. We did not find any difference in prognosis between patients who met the time criteria for the chronic fatigue syndrome by having been ill for more than six months at presentation and those with shorter histories. This result casts doubt on the utility of the existing time criteria for the syndrome.[3-5]

Functional impairment was associated with several patient factors, including belief in a viral cause, leaving or changing employment, coping with illness by avoidance of exercise and alcohol, membership of a patient organisation, and emotional disorder. These factors are themselves associated but the last three remain independently associated with impairment after all the others have been controlled for. Though these results are of interest and relevant to a cognitive behavioural explanation of the perpetuation of the chronic fatigue syndrome, they should be interpreted with caution for the following reasons. Firstly, the confidence intervals around the odds ratios are wide, and hence there is considerable uncertainty about the strength of the associations. Secondly, the independent variables were assessed at the questionnaire follow up, not at the initial clinic assessment, and cannot therefore be regarded as predictors of poorer outcome. Thirdly, other patient variables which were not measured, such as dysfunction of the immune system,[22] may be important. Finally, the findings do not indicate the direction of cause underlying the associations.

With these caveats in mind we will briefly consider the clinical significance of the findings. Although the analysis suggests that the findings are unlikely to be simple reflections of chronicity, the associated factors may be consequences of a more severe form of illness. Alternatively, they may indicate factors that tend to maintain functional impairment. Thus membership of a patient organisation may be an understandable consequence of a more disabling illness or, alternatively, could be a marker of beliefs in physical causation and the need to limit activity which may perpetuate illness. Emotional disorder, which has a prevalence in the functionally impaired patients in this sample similar to that found in previous studies,[8,12,13] may be a consequence of the distress resulting from severe disability or may be a factor contributing to the functional impairment.[23] It is of course possible that the cause underlying the above associations could act in both directions; thus emotional distress may be both a cause and consequence of functional impairment.[14]

The strong association between avoidance of alcohol and functional impairment is intriguing. It may be a marker of physiological abnormality or of avoidance of an activity that exacerbates the feeling of fatigue. It merits further investigation.

MANAGEMENT

This study is not able to evaluate specifically the effect of the physician's explanation and reassurance. However, though most patients reported finding it helpful, the poor short term prognosis indicates its ineffectiveness. Many patients had taken "alternative" remedies but with little benefit. Notably, despite the high prevalence of emotional disorder few patients had attended a psychiatric outpatient clinic and even fewer found their contact with psychiatric services beneficial. Although commonly recommended as a treatment for chronic fatigue,[24] antidepressant drugs were found by few patients to be beneficial. Hence it seems that currently available forms of treatment, including psychiatric outpatient care, are not meeting the needs of this patient group. More effective treatments are therefore required.

In conclusion, routine laboratory assessment is unlikely to yield evidence of treatable disease in patients referred to hospital with unexplained fatigue. The functional impairment of patients with the chronic fatigue syndrome is severe, but our results suggest that the prognosis for functional recovery by two to four years after clinic assessment is good. Many patients remain symptomatic, however, and a significant minority remain chronically disabled. Functional impairment at follow up is not predicted by demographic variables or by length of history at presentation.

Patients who are functionally impaired are more likely to have emotional disorder, to believe in an infectious cause for their illness, to avoid alcohol, and to be members of a patient self help organisation. Prospective studies are required to determine the aetiological importance of these associations.

We thank Penny Hagar and Susan Simkin for handling and scoring the questionnaires, and Oxfordshire Health Authority for financial support.

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(Accepted 8 May 1992)

Association between postpartum thyroid dysfunction and thyroid antibodies and depression

Brian Harris, S Othman, J A Davies, G J Weppner, C J Richards, R G Newcombe, J H Lazarus, A B Parkes, R Hall, D I W Phillips

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S Othman, *research associate*
J A Davies, *senior registrar*
G J Weppner, *senior registrar*
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J H Lazarus, *senior lecturer*
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D I W Phillips, *lecturer*

Department of Obstetrics and Gynaecology, Caerphilly and District Miners' Hospital, Caerphilly, Mid Glamorgan
C J Richards, *consultant obstetrician*

Correspondence to:
Dr Harris, Department of Psychological Medicine.

BMJ 1992;305:152-6

Abstract

***Objective*—To define the relation between mood and autoimmune thyroid dysfunction during the eight months after delivery.**

***Design*—Double blind comparison of the psychiatric status of women positive and negative for thyroid antibodies. Clinical examination and blood sampling for free triiodothyronine and thyroxine, thyroid stimulating hormone, and thyroid antibody concentrations at four weekly intervals. Psychiatric assessment at six, eight, 12, 20, and 28 weeks post partum.**

***Setting*—Outpatient department of district hospital.**

***Patients*—145 antibody positive women and 229 antibody negative women delivering between August 1987 and December 1989.**

***Main outcome measures*—Thyroid status. Number of cases of mental ill health by the general health questionnaire, research diagnostic criteria, Hamilton 17 item depression scale, hospital anxiety and depression scale, and Edinburgh postnatal depression scale.**

***Results*—Six weeks after delivery the general health questionnaire showed 62 (43%) antibody positive women and 65 (28%) antibody negative women had mental ill health (χ^2=8·18, p<0·005). Follow up of 110 antibody positive and 132 antibody negative women showed significantly greater depression by research diagnostic criteria in antibody positive women (47%) than antibody negative women (32%) regardless of thyroid dysfunction. Antibody positive women showed higher mean scores for depression on the Hamilton (6·01 *v* 3·89, p=0·0002), Edinburgh (7·45 *v* 5·92, p=0·031), and hospital depression scales (4·95 *v* 3·79, p=0·003).**

***Conclusion*—Depressive symptoms are associated with positive thyroid antibody status in the postpartum period.**

Introduction

Transient postpartum thyroid dysfunction associated with autoimmune thyroiditis was first reported in 1976 when Amino *et al* described six cases in women presenting three to four months after delivery with signs of mild hypothyroidism.[1] The symptoms included swelling of the neck, cold extremities, and weight gain. Profiles of serum thyroid hormone concentrations showed the women to have hypothyroidism accompanied by raised titres of thyroid antibodies. A larger prospective study of over 500 women presenting for delivery showed the commonest clinical conditions to be mild hypothyroidism, hyperthyroidism, and occasionally hyperthyroidism followed by hypothyroidism.[2] Other studies have confirmed this,[3-6] and since thyroid disorders are associated with mood disorders,[7-10] transient thyroid dysfunction could possibly be associated with postnatal depression.

Postnatal depression occurs in 10% to 20% of women in the postpartum year.[11-14] Although there is overwhelming evidence that factors such as marital disharmony, lack of a confiding relationship, previous psychiatric illness, housing problems, and other socioeconomic problems are strongly associated,[12 13] a subgroup of women may have a hormonal basis for their depression.[12 15] Anecdotal support for this has been provided by the finding that the mood of some women with post partum thyroid dysfunction mimics that of "depressive psychosis."[2] Hayslip *et al* found that women positive for thyroid antibodies

FILE: ME
30B.

Dr Aylward

RE: WESTCARE

Please see the attached minute from Dr Hangartner.

He would like a reply by the end of the week.

TRACY

19/6/92

fax to FRH
on 10/6/92.
TC

Discussed a reply
c Dr. Henderson
who will prepare draft.
MA 11/6/92

1. Dr Alywood DSS
2. Dr Castaldi DSS

From: Dr R Hangartner HC(M)1

Date: 9 June 1992

cc: Dr Hills HC (M) 1
Dr J Hilton HP (M)

WESTCARE/ Dr Richard Sykes: Minute from Rt. Hon. William Waldegrave PCMP to Dr J Metters

1. The attached minute refers.

2. I think it is unfortunate that Mr Waldegrave now has the impression that DSS is being unhelpful, particularly in view of your willingness to meet Dr Sykes and his colleagues in the future and to look at the operation of the Board's guidance in the light of practical experience.

3. I think there is an opportunity here to redress that balance and I presume you will wish to let me have a few paragraphs and a short briefing note to offer Dr Metters.

4. I will have to put the record straight in respect of the Task Force.

5. If possible I will be grateful for a rapid response as Dr Metters would like to reply to Mr Waldegrave by the end of this week.

Dr Hangartner
Room 409 Eileen House
Ext 22826/22825

From: The Rt. Hon. William Waldegrave, MP

Dr Hangartner

Before I reply to this could we have a word on the phone please

JSM 5/6/92

1st June 1992

I hope you will forgive me writing to you direct and cashing in on our old relationship! You and your people have been very helpful to Dr Richard Sykes, who is a constituent of mine, who has been leading an organisation called Westcare trying to bring support to ME sufferers and to get recognition of ME, particularly amongst GPs. I believe that you have had a meeting with him and his people and there is now a proposal for a task force.

Dr Sykes came to see me full of praise for the co-operation he had received from the Department of Health, but rather more baffled by how to approach the medical advisers in DSS. It is often they who play a crucial role in judging whether or not a person can be awarded sickness benefit and, in many cases, according to Dr Sykes, they are very tough in relation to people who are alleged to have ME. If I am right that a task force is to be set up, could the DSS advisory service be involved in it in some way? Obviously, this is always going to be a difficult matter because diagnosis in this sort of case is going to be difficult and subjective but, presumably, one part of your intention would be to try to produce guidelines for the benefit, not only of GPs but of the DSS. I would be most grateful for any help and advice you can give to me or to Richard Sykes. He seems a sensible and level-headed person.

Dr Jeremy Metters
Deputy Chief Medical Officer
Room 509
Richmond House
Whitehall S W 1

ME 30B ME

Dr Castaldi
Dr Aylward
15/VI/92
File: ME.

Dr R Hangartner HC(M)1
Room 409
Eileen House

From: Dr M Henderson
Secretary DLAAB

Date: 12 June 1992

RE: WESTCARE/ Dr Richard Sykes: Minute from Rt. Hon. William Waldegrave PCMP to Dr J Metters

1. Your minute of 9 June to Dr Aylward refers.

2. Apologies for the delay in providing you with the requested information; both Dr Aylward and I have been out of the office for the past two days.

3. If I can be of any further help please let me know.

Moira Henderson

DR M HENDERSON
ROOM 11-26
ADELPHI
EXT 28794

Suggested Paragraphs for inclusion in reply to William Waldegrave.

The involvement of the DSS and in particular the Benefits Agency Medical Services with Westcare has been confined to considerations of Disability Living Allowance, and the information provided on Myalgic Encephalomyelitis and Chronic Fatigue Syndromes in the Disability Handbook. The Handbook provides information to Adjudication Officers on the effects on care needs and mobility requirements which are likely to arise from disabling conditions or chronic illnesses.

The Disability Living Allowance Advisory Board (DLAAB) advised on the contents of the Handbook and has responsibility for reviewing and updating it as required. It is not accurate to imply that either the DSS or the DLAAB are uncooperative or intransigent on the question of Myalgic Encephalomyelitis in relation to benefits for disabled people, nor that they ignore the opinions of groups representing disabled people.

Full consultation with ME Action Campaign, including Westcare, took place during drafting of the Handbook. This was both by correspondence and at a face to face meeting between the parties on 22 October 1991. Many suggestions made by ME Action Campaign were in fact incorporated into the final draft.

A letter dated 17 January 1992 from ME Action Campaign on the subject of the Handbook was circulated to and discussed by all DLAAB members at a meeting of the Board on 25 February.

Dr Castaldi, Director of Medical Services and Dr Aylward, Principal Medical Officer in the Benefits Agency Medical Services, also participated in the joint meeting between DH, DSS and Westcare on 30 March.

The DLAAB has expressed willingness to meet again with Westcare but is firmly of the opinion that such a meeting will be more productive if it is held after sufficient time has elapsed to allow for an evaluation of the impact of the introduction of DLA on sufferers from Myalgic Encephalomyelitis. Time is also required in order to evaluate the usefulness of the Handbook. It is recommended therefore that a further meeting take place no earlier than the Autumn of this year.

In the meantime the Board has undertaken to keep records of those cases of ME and Chronic Fatigue Syndromes referred to them for advice. They will document the advice given to Adjudication Officers together with the basis upon which such advice is given.

To date only one claim made on the grounds of ME has been referred to the Board for advice, and in that claim the Board advised that the disabled person had significant mobility needs. This underlines a principle of paramount importance in assessment of disablement; that each claim must and will be considered individually on its own merits.

Background Briefing for Dr J Metters

1. ME Action Campaign and Westcare in particular accused the authors of the Handbook of selectivity in citing papers on ME, choosing to take into account only those which support their attitude. The same accusation could be made of Westcare who appear to choose to ignore the growing body of opinion that there is a high prevalence of psychiatric disorder in ME/CFS sufferers.

2. As far as DLA is concerned, it matters not whether disablement arises from physical or mental causes; it is the degree of disablement which determines entitlement to benefit, not the underlying cause.

3. The Chapter on ME/CFS in the Disability Handbook will be revised but as has already been said, not until sufficient time has elapsed to allow for a full and proper evaluation of its use.

4. As you know DH and DSS have cooperated in drafting a joint standard reply to ME Action Group's Parliamentary Round Robin; the total number of such replies to date is some 600. In addition the DLAAB Secretariat has dealt with some 70 items of individual correspondence on the same topic.

5. Dr Aylward as principal author of the Handbook has been the subject of abusive and defamatory correspondence from certain individual members of ME Action Group. This correspondence was issued without the full knowledge of the ME Association. He has since received an official apology and disclaimer from the ME Association which refers to the "harmonious working relationship" between Benefits Agency Medical Services/DLAAB and the ME Association.

1. Dr Alywood DSS
2. Dr Castaldi DSS

From: Dr R Hangartner HC(M)1

Date: 9 June 1992

cc: Dr Hills HC (M) 1
Dr J Hilton HP (M)

WESTCARE/ Dr Richard Sykes: Minute from Rt. Hon. William Waldegrave PCMP to Dr J Metters

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5. If possible I will be grateful for a rapid response as Dr Metters would like to reply to Mr Waldegrave by the end of this week.

Dr Hangartner
Room 409 Eileen House
Ext 22826/22825

fax: 071-972-2844. (dir)
7.396.22844 (gtn)

Dr Hangartner

Before I reply to this could we have a word on the phone please

JJM 5/6/92

1st June 1992

I hope you will forgive me writing to you direct and cashing in on our old relationship! You and your people have been very helpful to Dr Richard Sykes, who is a constituent of mine, who has been leading an organisation called Westcare trying to bring support to ME sufferers and to get recognition of ME, particularly amongst GPs. I believe that you have had a meeting with him and his people and there is now a proposal for a task force.

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Dr Jeremy Metters
Deputy Chief Medical Officer
Room 509
Richmond House
Whitehall S W 1

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ME C21 H
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c.c. Dr Hangartner
Dr Hills
Dr Castaldi - DSS
~~Dr Aylward - DSS~~
19vi

DEPARTMENT OF HEALTH

Richmond House
79 Whitehall
London SW1A 2NS
Telephone 071 210 3000

The Rt Hon William Waldegrave MP
House of Commons
LONDON SW1A 0AA

11 June 1992

Dear Secretary of State

WESTCARE

Thank you for your letter of 1 June about Dr Richard Sykes and Westcare. As you know, I arranged a meeting in March with Dr Sykes and some of his colleagues. This was to discuss with officials of DH and DSS the various recognition problems that faced ME sufferers. Unfortunately, at the last moment due to sickness, I was unable to chair the meeting. Colleagues told me it went reasonably well and I was pleased to hear this confirmed by Dr Sykes' conversation with you. I enclose a copy of the Department's record of the meeting that may be of interest.

We have a further meeting between Westcare and Department of Health planned for 6 July when we hope to make further progress, but I should introduce a note of caution, in that it is the medical profession at large who need to be persuaded of the salient diagnostic features of the disease, if the sort of problems that exist in Sidmouth are to be overcome. One way of enlisting the professions' interest in an educational programme would be to follow the route that another disease specific interest group has charted. This was a leading asthma charity's joint approach to the Royal College of Physicians and the British Thoracic Society which resulted in a joint Task Force to address problems facing asthma sufferers.

We suggested to Dr Shepherd, the Vice President of the ME Association, that a similar approach to the Royal Colleges could lead to a ME Task Force whose role would be predominantly educational. DH officials offered to facilitate the process. However, we feel the initial proposal for a Task Force would preferably be made by Dr Shepherd and his colleagues, rather than through the Department. If a Task Force is set up, we will most certainly explore with DSS colleagues whether and how they could participate.

I should also mention a complicating factor for colleagues in DSS, as they are not free agents over the recognition of ME. The Disability Living Allowance Advisory Board has advised DSS to retain the guidance in the Disability Handbook in an unmodified state, until

9896.

experience has been gained in its use during the first six months of the newly introduced DLA benefit. Clearly the Advisory Board would take note of any professionally backed advice that came from a Task Force set up on ME by the Royal Colleges, but that will take some time to emerge. In the meantime DSS officials have offered to arrange a meeting with Westcare and representatives of various other ME Associations and the DLA Board. This is referred to in paragraph 8 of the meeting note.

The meeting on 6 July will give us a further opportunity to discuss some of these difficult issues with Dr Sykes. I will certainly do all I can to help Dr Sykes and Westcare, but when it comes to agreement over diagnostic criteria and changing entrenched attitudes by some sections of the profession, it can be hard struggle in which we need all the help we can elicit from the Royal Colleges. I will, of course, keep you informed of progress.

Yours sincerely

Jeremy Metters

J S METTERS
Deputy Chief Medical Officer

Enc.

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(6)

The National Archives

LETTERCODE/SERIES	BN 141
Extract/Item	1/1

Extract/Item Details:	Initial & Date
1 page(s) Sub folder **Closed under FOI Exemption(s)** Section: 40(2) & (3) Closed until: 2072	SA 23/3/12

> While the guidelines are often oblique and their precise meaning obscure, they create the impression that people with ME can manage on their own (and so they do not qualify for attendance allowance) and that their difficulties in mobility are due to fear rather than to real disability (and so they do not qualify for mobility allowance).

Can you help us in these difficulties? Specifically,

1) Are there any ways tof bring pressure on doctors to recognize the genuineness and seriousness of ME?

2) Is there a possibility of initiating a process which would lead to an authoritative statement from the DOH about ME (comparable to statements about AIDS)?

3) Can the Department make it clear that absence of clinical signs on routine examinations is not in itself sufficient ground for denying the genuineness of the disability or for withholding benefit?

4) Is it possible to initiate a process which would lead to a review of benefit decisions on ME?

5) Can support be given to the suggestion that new guidelines on ME are postponed until further discussion takes place?

Any assistance which you can give, or suggestions which you can make, on these points would be much appreciated.

Yours sincerely,

Richard Sykes

RICHARD SYKES M.A.(Cantab),Ph.D.

P.S. Thank you very much for your offer to be present at a fund-raising event for Westcare. We hope to arrange one later in the year.

We have not had further news about our application for funding under Section 64.

/enc.

(6a – 6d)

The National Archives

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Extract/Item	1/1

Extract/Item Details:

4 page(s)

Sub folder

Initial & Date

Closed under FOI Exemption(s)

Section: 40(2) + (3)

Closed until: 2072

SA
2/4/12

ME

This EDM has been cleared with DSS who have the lead responsibility on the handbook. They have undertaken to handle all future enquiries

Feb

1) Mr Freeman
2) Mr Sharpe 4/6
3) Mr I Jones
Parliamentary

From: K O'Leary HP(A)3B
Date: 4 June 1992
CC: Dr Henderson DSS
Dr Hilton HP(M)1
Mr Wilson (O/R)
Dr Scott DSS

MA
8/6/92

EARLY DAY MOTION 164: MYALGIC ENCEPHALOMYELITIS

I attach a draft reply to this EDM plus background note.

K O'Leary

K O'LEARY
WEL 425
EXT 24180

** Please photocopy for Dr Castaldi for information; then file (ME).

8/vi

LINE TO TAKE

Both the Government and the NHS recognise Myalgic Encephalomyelitis (ME) as a debilitating and distressing disease affecting many thousands of people.

The Disability Handbook was written following consultation with the Disability Living Allowance Advisory Board, which comprises a wide range of experience of disablement and expertise in managing it. Many organisations involved in the care of the disabled, including the ME Action Group, were consulted.
It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for ME is recognised. The Handbook does not suggest that "it is all in the mind". The Handbook will be regularly reviewed and revised and all representations received will be carefully considered when the Handbook is next revised.

BACKGROUND NOTE

The Disability Handbook is primarily intended for Adjudication Officers of the Benefits Agency, who determine eligibility to DLA. It is not intended to be used in preference to the evidence available in individual claims, each of which must be considered on its own merits.

The Disability Living Allowance Advisory Board which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of DLA claims over the next few months advising any revision of the Handbook.

We are aware of several wide ranging research studies taking place into the possible causes of ME and methods of treatment which already have funding from private sources. The Medical Research Council (MRC), which is funded by the Government to support clinical research, is funding a study at the Institute of Psychiatry to investigate chronic fatigue in general practitioners attenders. The results of these studies, together with those of earlier epidemiological studies, will form a basis for deciding whether further studies are required and what nature they should take. The MRC and the Department of Health are always willing to consider soundly based scientific proposals in competition with other applications.

It is not the Government's practice to issue clinical guidance to doctors, and, until such a time as more is known about the illness and its epidemiology, I do not believe that the Department is in a position to send out more authoritative information than is provided already by the Medical Profession.

164 *MYALGIC ENCEPHALOMYELITIS* 3.6.92

Mrs Anne Campbell
Jean Corston
Dawn Primarolo
Mr Jimmy Hood
Dr Tony Wright
Glenda Jackson

Alice Mahon Mr Bill Etherington Mr Jim Marshall ★ 9

✓ That this House agrees with the honourable Member for Loughborough's statement, made in his former capacity as a Parliamentary Under Secretary of State for Health, that myalgic encephalomyelitis (ME) is a debilitating and distressing disease affecting many thousands of people; considers that the disability living allowance handbook recently published by the Department of Social Security undersestimates the physical and physically disabling nature of ME, ignores the growing body of scientific evidence showing brain cell abnormalities, damage to muscle tissue and persistent viral presence of sufferers and that this should be corrected; and urges the Department of Health to fund research into physical causes, possible treatment or cures of ME and send out authoritative information about ME to the medical profession.

File: ME.
MA 8/vi

164 *MYALGIC ENCEPHALOMYELITIS* 3.6.92

Mrs Anne Campbell
Jean Corston
Dawn Primarolo
Mr Jimmy Hood
Dr Tony Wright
Glenda Jackson

★ 9

Alice Mahon Mr Bill Etherington Mr Jim Marshall

✓

That this House agrees with the honourable Member for Loughborough's statement, made in his former capacity as a Parliamentary Under Secretary of State for Health, that myalgic encephalomyelitis (ME) is a debilitating and distressing disease affecting many thousands of people; considers that the disability living allowance handbook recently published by the Department of Social Security undersestimates the physical and physically disabling nature of ME, ignores the growing body of scientitific evidence showing brain cell abnormalities, damage to muscle tissue and persistent viral presence of sufferers and that this should be corrected; and urges the Department of Health to fund research into physical causes, possible treatment or cures of ME and send out authoritative information about ME to the medical profession.

LINE TO TAKE

Both the Government and the NHS recognise Myalgic Encephalomyelitis (ME) as a debilitating and distressing disease affecting many thousands of people.

The Disability Handbook acknowledges that ME is not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for ME is recognised. The Handbook does not suggest that "it is all in the mind". The Handbook will be regularly reviewed and revised and all representations received will be carefully considered when the Handbook is next revised.

Background note

The Disability Handbook has been written by senior medical staff of the Benefits Agency Medical Services. The Disability Living Allowance Advisory Board, comprising a wide range of experience of disablement and expertise in managing it, was extensively consulted. Many organisations involv~~ing~~ed in the care of the disabled, including the ME Action Group, were consulted.

The Disability Handbook is primarily intended for Adjudication Officers of the Benefits Agency, who determine eligibility to DLA. It is not intended to be used in preference to the evidence available in individual claims, each of which must be considered on its own merits.

The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of DLA claims over the next few months before advising any revision of the Handbook.

We are aware of several wide ranging research studies taking place into the possible causes of ME. The Medical Research Council (MRC), which is funded by the Government to support clinical research, is funding a study at the Institute of Psychiatry to investigate chronic fatigue in general practitioners attenders. The results of these studies, together with those of earlier epidemiological studies, will form a basis for deciding whether further studies are required and what nature they should take.

It is not the Government's practice to issue clinical guidance to doctors, and, until such a time as more is known about the illness and its epidemiology, I do not believe that the Department is in a position to send out more authoritative information than is provided already by the Medical Profession.

30B

DEPARTMENT OF HEALTH
Eileen House
80-94 Newington Causeway
London SE1 6YX
Telephone No 01-972-2000

File: ME.

Your reference
Our reference

Room 409
Direct Line: 071 972 2826
Fax No: 071 972 2844

Dr R Sykes
Director
WESTCARE
15 Queen Victoria Road
Redland
Bristol BS6 7PE

29th May 1992

Dear Dr Sykes

Further to our telephone conversation of today I am writing to confirm arrangements for the meeting on the 6th July at 3.00pm in Dr Metters' office (Rm: 509) in Richmond House. I understand that in addition to yourself Dr McIntyre, Dr Pheby and Dr Shepherd will also be attending.

I look forward to seeing you again then.

Yours sincerely

Dr R Hangartner
Principal Medical Officer

Hidden Copies:

Dr Meters
Dr Hilton
Dr Hills

Dr Aylward } For Information only.
Dr Castaldi }

20/6

File: ME Associations etc MA 25/V/92

DEPARTMENT OF HEALTH
EILEEN HOUSE
80-94 NEWINGTON CAUSEWAY
LONDON SE1 6YX
TELEPHONE 01-972 2000

Your reference
Our reference MAY\EH-WESTC.E20

Please copy: Dr Henderson. 28/5

Room 409
Direct Line: 071-972 2826
Fax No: 071-972 2844

Dr R Sykes
Director
WESTCARE
15 Queen Victoria Road
Redland
Bristol BS6 7PE

20th May 1992

Dear Dr Sykes

Thank you for your letter of 27th April to Dr Metters and your letter to me of the same date. Dr Metters has been out of the office for much of May and asked me to reply on his behalf. Please will you also take this as a reply to your letter to me.

First thank you for sending your detailed comments on our note on behalf of yourself, Dr Pheby and Dr McIntyre, and for the copy of your aide memoire. I note you in turn invite us to comment on your comments. Dr Shepherd accepted the Department's notes of the meeting with two minor correction which we have accepted. Might I enquire if you have sent him a copy of your comments?

I understand that Dr Castaldi has written to you regarding the DSS position on the note of the meeting. From the DH our point of view there are a few points which I and colleagues feel need clarification. In respect of your paragraph 3.2, however, you are quite correct I did say I would explore another possibility and I have that action in hand.

As I am sure you will recall I expressed doubts both about the appropriateness and the effectiveness of the DH issuing any circular or CMO letter about the diagnosis and management of ME. As I am sure you will also recall, as is reflected in paragraph 5 of our note, I did suggest that Dr Shepherd should consult the Royal Colleges to enlist their help with professional educational which I considered to be the route which is most likely to produce a lasting solution to the various problems that those that suffer from ME encounter. I will ask you to bear those points in mind when you read my comments on your paragraph 8.2.

<u>Research</u>

On the matter of research on ME I think 6.3 gives slightly the wrong impression. What I offered to do was to explore where ME might sit in the context of the Department's research strategy.

<u>DH information on ME</u> (Paragraph 8.2)

Personally I think this paragraph, which reflects your closing comments, takes certain key points of the earlier parts of your note and changes the context somewhat.

I think the pragmatic solution is if DH modifies certain parts of its note and we try to reach agreement on our note as a basis on which to go forward. I attach a revised draft of our note which I have amended to incorporate the omission in respect of Sidmouth, pick up the point on the research strategy and to expand our rather brief reference to your concluding remarks into something more akin to a summary. I have not altered any of the parts of the note referring to DSS interests.

On a general point we feel the meeting was of benefit in increasing understanding between yourselves and the Department of Health and the Department of Social Security. We did of course agree to meet with you again separately. On that point the 8th June is not convenient with Dr Metters who does wish to meet with you. The following dates are convenient both for Dr Metters and for Dr Hilton as well as for other colleagues here - 16 June (am); 17 June (am); 26 June (pm) and 6 July (pm). As you know Dr Hilton together with her immediate administrative colleagues have a specific interest in ME on behalf of the Department of Health. Perhaps you would telephone Dr Hills' secretary on 071-972 2850 and let her know the best date for you and your colleagues.

I apologise for the length of these comments but I am sure you would agree that it is important that we try to agree a note in advance of the next meeting. I look forward to seeing you and your colleagues again in due course. I have arranged for a copy of our revised note to go to Dr Shepherd with a brief covering letter explaining that we are seeking to reach an agreed note.

Yours sincerely

Dr R Hangartner
Principal Medical Officer

cc: Dr Metters DCMO
Dr Aylward
Dr Hills
Dr Hilton

Redacted under FOI
Exemption S 40 (2)
(3) closed Until 2072

MAY\EH11.92

NOTE OF A MEETING ABOUT MYALGIC ENCEPHALOMYELITIS
30 MARCH 1992, 3.30 P.M.

Present:

Dr R Hangartner - DH (for Dr Metters)

Dr C Shepherd, Vice-President of ME Association

Dr R Sykes, Director of Westcare

Dr A McIntyre, Medical Adviser, ME Action Campaign

Dr D F H Pheby, Westcare

Dr M Aylward, Benefits Agency Medical Services, DSS

Dr P Castaldi, DSS

Dr E Hills, DH

1. Dr Hangartner welcomed the visitors. He explained that Dr Metters was ill and unable to take the meeting. He understood that the problems to be discussed were the DLA Handbook and difficult relationships with the GPs in Sidmouth.

2. Dr Sykes asked that CMO be thanked for arranging the meeting.

2.1 He explained that Westcare provides a clinic where patients can see a doctor or obtain counselling, and also arranges educational meetings.

2.3 He said that Westcare and the Department had shared concerns -

(a) to help patients to get better

(b) to help genuine sufferers to get State benefits. There were no clear markers of disease and they must be distinguished from patients with the wrong diagnosis.

2.4 He claimed there were thousands with the disease who suffered injustice from lack of understanding and ridicule.

2.5 There was little provision of care or rehabilitation.

2.6 In the context of claim for benefits, the necessary decision was whether the disability was genuine and posed needs for attention or supervision, rather than whether it was possible to determine whether it was organic or psychiatric.

2.7 ME support groups sought continued discussion of problems with the Departments of Health and Social Security and joint exploration of solutions.

3. Dr Shepherd reported a survey of GPs in Scotland where 10% denied the existence of ME. He described the difficult situation in Sidmouth where patients have alleged that there was only one group practice where the GPs did not recognise ME. One patient was known to have registered with a practice in another town using a false address. It was likely that this situation could occur in rural areas.

4. He asked that the CMO circulate a letter informing doctors that the Department recognised the diagnosis. It would give salient features of the disease and be designed to produce better understanding and a sympathetic attitude to sufferers. The chairman commented that the Department did not give clinical advice, he had doubts about the educational value and effectiveness of such a communication. Nevertheless the request would be considered. The Chairman said he would explore another possibility in respect of the events described in Sidmouth and asked Dr Shepherd to provide any additional information that came to his attention. It was agreed that if a letter were produced, the ME advisers would be consulted before it was circulated.

5. Dr Hangartner suggested that Dr Shepherd consult the Royal Colleges to enlist their help in an educational programme. The Chairman considered the educational route was more likely to produce a lasting solution to the various problems of those with ME encountered (in their dealings with health care professionals). There was at least one current example where the a leading asthma charity was working with the Royal College of Physicians and the British Thoracic Society in the form of a taskforce to address a number of issues facing asthma sufferers. A similar action might be an appropriate way forward. The Department would be prepared to explore bringing the parties together if those concerned thought it would be helpful.

Redacted under FOI
Exemption S 40 (2)&
(3) closed Until 2072

[redacted]

7. Westcare considered the "guidelines" in the Disability Handbook to be unacceptable and that they should be changed immediately. Section 12.3.1 should include a statement that conventional muscle tests may be normal, but this does not exclude disability and real needs. Section 12.4 was ambiguous. Dr Wesseley's work was mentioned. It was claimed that DSS had misinterpreted his work. He had included people with chronic fatigue syndromes. There were other causes of this from which people had recovered with exercise, whereas ME was made worse by exercise. The ME representatives had not seen the Board's reply to Dr Wesseley. They were supplied with a copy by Dr Aylward during the meeting.

8. Dr Aylward said it was impossible to change the guidelines immediately. They had recently been endorsed by the Disability Living Allowance Advisory Board (DLAAB). They would be reviewed after 6 months' use and revised in collaboration with interested parties. The DLAAB will keep records of those cases of ME and Chronic Fatigue Syndromes referred to them for advice, and they will document the advice given to Adjudication Officers together with the bases upon which such advice is given. The DLA Board are keen to meet with representatives of disabled people and a meeting with ME representatives will be arranged. The DLAAB had advised DSS to retain guidance in the Disability Handbook unmodified until experience had been gained on its use during the first 6 months of the newly introduced DLA benefit.

9. The visitors said the only research into ME is funded by their own Associations and finance obtained from various charitable trusts. The DSS had spoken of MRC- funded research into the chronic fatigue syndrome, but this was not ME. They had not made any application to the Department of Health or MRC for funding and looked for guidance. The chairman explained that Professor Peckham had recently taken over as Director of Research and Development. The Department Research Strategy was still under consideration and it was not yet known where the priorities would lie. Clinical research was a matter for the MRC. Health Services (Operational) Research was more a matter for DOH and the NHS. Dr Pheby suggested that health services research was required rather than fundamental scientific research. The Chairman agreed to explore where ME might sit within the context of the Department's developing research strategy.

10. It was decided that a further meeting should be arranged after about 3 months. It was agreed that it was appropriate to separate DSS issues from any DH issues. It was noted that the next meeting should be arranged to enable Dr Hilton to be present.

11. Dr Sykes summarised his points again and the meeting closed.

12. <u>Action agreed by DH</u>

i. The Department will consider the request to issue a CMO letter on the subject of ME, though the Chairman had doubts about the appropriateness, educational value and effectiveness of such action (paragraph 4).

ii. The Chairman would explore the circumstances in Sidmouth with colleagues (paragraph 4).

iii. Should the charities decide to approach the Royal Colleges the Department would see what it could do to bring the parties together. A task force between the charities and the profession might be one way forward (paragraph 5).

iv. The Chairman would establish where ME sat within the Department's developing research strategy (paragraph 9).

File: ME Associations etc.

25/v/92

Dr Aylward DSS - as requested.
Dr Castaldi DSS
Dr Hilton HP(M)1
Dr Hills HC(M)1

From: Dr R Hangartner HC(M)1

Date: 19 May 1992

MEETING WITH WESTCARE

1. I have reflected on Dr Sykes' comments and the tactics over the weekend. I think the better solution is that if we offer to make some small amendments to the DH part of the note rather than to in any way accept or refer to his note which in my draft reply I now refer to as comments on our note.

2. I also attach a revised note of the meeting in point of fact there are a couple of omissions from our note but they refer to actions on my part on behalf of DH rather than DSS. The revisions are to paragraph 4 and 9. I have also taken the opportunity to expand slightly on paragraph 5 in order to make a point in the summary about the need for them to talk to the profession rather than for us to do it for them. The summary is an addition and is my attempt to get round having to deal in any detail with Dr Sykes' summing up.

3. Grateful for any comments as soon as possible preferably by 4pm today.

Dr R Hangartner
Room 409 Eileen House
Ext 22826/22825
BT Gold NHS:223
Radiopager:a) dial 081-884 3344
b) quote callsign DHSS 2
c) give message to operator

Ref: MAY\EH-WESTCARE.E20
File:

142/5

DRAFT REPLY

Dr R Sykes
Director
WESTCARE
15 Queen Victoria Road
Redland
Bristol BS6 7PE

May 1992

Dear Dr Sykes

Thank you for your letter of 27th April to Dr Metters and your letter to me of the same date. Dr Metters has been out of the office for much of May and asked me to reply on his behalf. Please will you also take this as a reply to your letter to me.

First thank you for sending your detailed comments on our note on behalf of yourself, Dr Pheby and Dr McIntyre, and for the copy of your aide memoire. I note you in turn invite us to comment on your comments. Dr Shepherd accepted the Department's notes of the meeting with two minor correction which we have accepted. Might I enquire if you have sent him a copy of your comments?

I understand that Dr Alyward will be writing to you regarding the DSS position on the note of the meeting. From the DH our point of view there are a few points which I and colleagues feel need clarification. In respect of your paragraph 3.2, however, you are quite correct I did say I would explore another possibility and I have that action in hand.

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Yours sincerely

Dr R Hangartner
Principal Medical Officer

cc: Dr Metters DCMO
Dr Aylward
Dr Hills
Dr Hilton

rf. MAY\EH-WESTCARE.E20

(9)

A:EH11.92 at ~~23.4.92~~ 19.5.92

DRAFT

NOTE OF A MEETING ABOUT MYALGIC ENCEPHALOMYELITIS
30 MARCH 1992, 3.30 P.M.

Present:	Dr R Hangartner - DH (for Dr Metters)
	Dr C Shepherd, Vice-President of ME Association
	Dr R Sykes, Director of Westcare
	Dr A McIntyre, Medical Adviser, ME Action Campaign
	Dr D F H Pheby, Westcare
	Dr M Aylward, Benefits Agency Medical Services, DSS
	Dr P Castaldi, DSS
	Dr E Hills, DH

1. Dr Hangartner welcomed the visitors. He explained that Dr Metters was ill and unable to take the meeting. He understood that the problems to be discussed were the DLA Handbook and difficult relationships with the GPs in Sidmouth.

2. Dr Sykes asked that CMO be thanked for arranging the meeting.

2.1 He explained that Westcare provides a clinic where patients can see a doctor or obtain counselling, and also arranges educational meetings.

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(3) closed Until 2072

2.3 He said that Westcare and the Department had shared concerns -

(a) to help patients to get better

(b) to help genuine sufferers to get State benefits. There were no clear markers of disease and they must be distinguished from patients with the wrong diagnosis.

2.4 He claimed there were thousands with the disease who suffered injustice from lack of understanding and ridicule.

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2.7 ME support groups sought continued discussion of problems with the Departments of Health and Social Security and joint exploration of solutions.

3. Dr Shepherd reported a survey of GPs in Scotland where 10% denied the existence of ME. He described the difficult situation in Sidmouth where patients have alleged that there was only one group practice where the GPs did not recognise ME. One patient was known to have registered with a practice in another town using a false address. It was likely that this situation could occur in rural areas.

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5. Dr Hangartner suggested that Dr Shepherd consult the Royal Colleges to enlist their help in an educational programme. The Chairman considered the educational route was more likely to produce a lasting solution to the various problems of those with ME encountered (in their dealings with health care professionals). There was at least one current example where the a leading asthma charity was working with the Royal College of Physicians and the British Thoracic Society in the form of a taskforce to address a number of issues facing asthma sufferers. A similar action might be an appropriate way forward. The Department would be prepared to explore bringing the parties together if those concerned thought it would be helpful.

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Exemption S 40 (2)
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immediately. Section 12.3.1 should include a statement that conventional muscle tests may be normal, but this does not exclude disability and real needs. Section 12.4 was ambiguous. Dr Wesseley's work was mentioned. It was claimed that DSS had misinterpreted his work. He had included people with chronic fatigue syndromes. There were other causes of this from which people had recovered with exercise, whereas ME was made worse by exercise. The ME representatives had not seen the Board's reply to Dr Wesseley. They were supplied with a copy by Dr Aylward during the meeting.

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9. The visitors said the only research into ME is funded by their own Associations and finance obtained from various charitable trusts. The DSS had spoken of MRC- funded research into the chronic fatigue syndrome, but this was not ME. They had not made any application to the Department of Health or MRC for funding and looked for guidance. The chairman explained that Professor Peckham had recently taken over as Director of Research and Development. The Department Research Strategy was still under consideration and it was not yet known where the priorities would lie. Clinical research was a matter for the MRC. Health Services (Operational) Research was more a matter for DOH and the NHS. Dr Pheby suggested

that health services research was required rather than fundamental scientific research. The Chairman agreed to explore where ME might sit within the context of the Department's developing research strategy.

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11. Dr Sykes summarised his points again and the meeting closed.

12. <u>Action agreed by DH</u>

i. The Department will consider the request to issue a CMO letter on the subject of ME, though the Chairman had doubts about the appropriateness, educational value and effectiveness of such action (paragraph 4).

ii. The Chairman would explore the circumstances in Sidmouth with colleagues (paragraph 4).

iii. Should the charities decide to approach the Royal Colleges the Department would see what it could do to bring the parties together. A task force between the charities and the profession might be one way forward (paragraph 5).

iv. The Chairman would establish where ME sat within the Department's developing research strategy (paragraph 9).

(11 - 21)

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LETTERCODE/SERIES BN 141

Extract/Item 1/1

Extract/Item Details:	Initial & Date
11 page(s)	
Sub folder	
Closed under FOI Exemption(s)	
Section: 40(2)+(3)	SA 26/3/12
Closed until: 2072	

BH

AA 13/V/92.

Dr E Hills HC(M)1

From: Dr R Hangartner HC(M)1

Date: 12 May 1992

cc: Dr Castaldi DSS
Dr Aylward DSS
Dr Hilton HP(M)1
Mr Wilson HP(A)3B

MYALGIC ENCEPHALOMYELITIS: MEETING WITH WESTCARE

1. Your suggested draft reply to Dr Sykes and Dr Hilton's minute of 6th May refer.

2. In fact I think Dr Sykes' amendments have made a substantial difference to the sense of many of the points that were discussed in the meeting and are frankly unacceptable.

3. I note Dr Hilton has picked up the sentence in paragraph 3.2 "Dr Robert Hangartner said that he would explore another possibility." I think on this point Dr Sykes is correct. As I recall what I had in mind was to enquire of colleagues in HCD-SD whether a blanket refusal on the part of a practice to recognise the existence of a condition was contrary to "terms and conditions of service". I certainly would not wish that to appear in the record which is why I did not elaborate at the meeting. It would of course be an entirely different matter if the GPs concerned recognised the existence of ME but did not consider it was the correct diagnosis in a particular individual case. My recollection is that Dr Shepherd was referring to the former set of circumstances rather than the latter.

4. I have absolutely no recollection of 6.3 at all. It is in any event subsumed within 6.1 i.e the development of the research strategy.

5. I think Dr Sykes' 8.2 is a rehash of Dr Hills' paragraph 4. I think the most pragmatic solution is to amend Dr Sykes' draft to reinsert our paragraph 4 and our paragraph 5 and add that in principle the Department would be prepared to consider using its good offices to get such discussions of the ground. I understand that Dr Aylward has considerable reservations about the sense that is now conveyed by Dr Sykes' alterations to the parts of the note dealing with DLA and ?also certain aspects of Dr Sykes' letter to Dr Metters.

6. I think there are two options, one a brief acknowledgement indicating that we reserve our position over the amendments to the note and will respond more fully in the near future or a more detailed reaction.

7. My instinct is to go for the latter course of action which has the advantage of flagging our discontent early rather than later.

71/5

8. Grateful for any comments on the attached draft reply* which I must send Friday morning else there is no reason for me to reply on Dr Metters behalf.

Dr R Hangartner
Room 409 Eileen House
Ext 22826/22825
BT Gold NHS:223
Radiopager:a) dial 081-884 3344
b) quote callsign DHSS 2
c) give message to operator

Ref: MAY\EH-WESTCARE.E20(44/4, 36/13)
File:

*(and for amendments to Dr Sykes' draft)

DRAFT REPLY

Dr R Sykes
Director
WESTCARE
15 Queen Victoria Road
Redland
Bristol BS6 7PE

May 1992

Dear Dr Sykes

Thank you for your letter of 27th April to Dr Metters. Dr Metters is away from the office until 20th May and he has asked me to reply on his behalf. Please will you also take this as a reply to your letter to me of 27th April.

First thank you for sending your detailed additions to our notes on behalf of yourself, Dr Pheby and Dr McIntyre, and for the copy of your aide memoire. I note you in turn invite us to comment on your amendments to our draft note and these are set out below. Dr Shepherd accepted the Department's notes of the meeting with two minor correction. My I enquire if you have sent him a copy of your amendments?

On a general point we feel the meeting was of benefit in increasing understanding between yourselves and the Department of Health and the Department of Social Security. We did of course agree to meet with you again separately. On that point the 8th June is not convenient with Dr Metters who does wish to meet with you. The following dates [ ] are convenient both for Dr Metters and for Dr Hilton as well as for other colleagues here. As you know Dr Hilton together with her immediate administrative colleagues have a specific interest in ME on behalf of the Department of Health.

On the detail of your amendments to the note of the meeting there are a few points which I feel need clarification. In respect of your paragraph 3.2 you are quite correct I did say I would explore another possibility and I have that action in hand. As I am sure you will recall I expressed doubts both about the appropriateness and the effectiveness of the DH issuing any circular about the diagnosis and management of ME. As I am sure you will also recall, as was reflected in paragraph 5 of our original note, I did suggest that Dr Shepherd should consult the Royal Colleges to enlist their help in an educational programme which I considered to be the route which is most likely to produce a lasting solution to the various problems that those that suffer from ME encounter. I will ask you to bear those points in mind when you read my amendments to your paragraph 8.2.

On the matter of research on ME I think 6.3 gives slightly the wrong impression. I thought what I offered to do was to explore where ME might sit in the context of the Department's research strategy.

DH information on ME I suggest we delete 8.2 in its entirity and replace with "The Chairman commented that the Department did not give clinical advice and that he had doubts about the educational value and effectiveness of such a communication. The request would be considered. It was agreed that if a letter were produced, the ME organisation advisors would be given an opportunity to comment before it was circulated. Dr Hangartner suggested that Dr Shepherd should consult the Royal Colleges to enlist their help in an educational programme. The Department would of course be prepared to see what it could do to facilitate matters. This might include some form of task force similar to that established the profession and the leading asthma charity. Such a task force would not be led by the Department but could be facilitated by it."

I attach a revised draft of your note which also incorporates changes made by colleagues in DSS at paragraphs [xxxxxxx].

[Finally I think it might be helpful if I explained a little more fully the purpose and function of CMO letters. The Department of Health itself does not issue guidance on clinical matters. The normal mechanism where a particular issue is deemed to be suitable for a CMO letter is to either set up an Expert Advisory Group or to take the advice of for example a Royal College. It is a mechanism which is used relatively infrequently in order to bring a particular matter urgently to the attention of doctors in England which cannot be appropriately dealt with through other channels. As I indicated, and as both notes of the meeting accurately reflect, this is a matter that we have agreed to consider. I think it is appropriate that Dr Metters should have an opportunity to hear the views that were expressed at the meeting.]

I apologise for the length of these comments but I am sure you would agree that it is important that we try to agree a note in advance of the next meeting. I look forward to seeing you and your colleagues again in due course.

Yours sincerely

Dr R Hangartner
Principal Medical Officer

cc: Dr Metters DCMO
Dr Aylward
Dr Hills
Dr Hilton

rf. MAY\EH-WESTCARE.E20

[illegible] Hills

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Exemption S 40 (2)
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(22)

DRAFT

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30 MARCH 1992, 3.30 P.M.

Present:
Dr R Hangartner - DH (for Dr Metters)
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Dr A Macintyre, Medical Adviser, ME Action Campaign
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(23)

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Richard Sykes
27/4/92

Dr J S Metters
DCMO
Richmond House

From: Chief Medical Adviser
BA medical Services

Date: 12 May 1992

c.c: Dr Hangartner
Dr Aylward

19/V

ME : WESTCARE

1. In reply to your minute dated 30.4.92 about this subject I confirm that separate meetings between DH AND DSS with the ME organisation will be perfectly satisfactory.

2. Richard Sykes has written to me separately and I have attached a copy of my response for your information. In that response you will see that I accept our account of the meeting and not theirs.

P CASTALDI
FRH 131 EXT 23286

127/5

DEPARTMENT OF SOCIAL SECURITY
Friars House, 157-168 Blackfriars Road, London SE1 8EU
Telephone 071 972 3286
From the Chief Medical Adviser (Social Security)

12 May 1992

Dr R Sykes
Westcare
15 Queen Victoria Road
Redland
Bristol
BS6 7PE

Dear Dr Sykes

Thank you for your letter dated 27 April 1992. Dr Aylward and I also appreciated the opportunity of a discussion with you.

I am afraid that I must begin in a negative way by not accepting your account of our meeting. For example DSS are not in a position to have views on the provision of health-care in Sidmouth, or anywhere else for that matter. That falls outside the DSS remit. No doubt you will, by now, have received a copy of the DH/DSS note about the meeting. I am of the opinion that it is an accurate account of the proceedings.

I note your request for a meeting with the DLA Advisory Board and have taken steps to put it before them. How they conduct their business is, you will understand, a matter entirely for them. I must say, however, that there has been wide consultation with special interest groups both in DLA and in its predecessor Attendance Allowance. The Board's record is outstanding especially in this field and there are many, many examples of views being modified by such meetings. I would add however that certain topics raised in the penultimate paragraph of your letter do not fall within the Board's remit.

Yours sincerely

P CASTALDI

M4/v/92

DISABILITY LIVING ALLOWANCE ADVISORY BOARD
The Adelphi 1-11 John Adam Street London WC2N 6HT
Telephone 071-962-8000
GTN 391

Professor J Marshall
203 Robin Hood Way
London
SW20 OAA

Date: 5 May 1992

Dear Professor Marshall

Please find enclosed copies of correspondence sent to Dr Aylward by Richard Sykes of Westcare in connection with M.E.

With regard to the draft notes of the meeting held on 30 March 1992, Section 5 in relation to the Disability Handbook is not wholly accurate. As you know, Dr Wessley's main concern was that people with M.E. exhibiting primarily psychiatric symptoms should not be denied benefit to which they were entitled because their disability arose from M.E. rather than from any other cause of depression.

I am also not aware that either Dr Castaldi or Dr Aylward undertook that the full DLA Board would meet with representatives of Westcare; to my knowledge, the agreement was that representatives of the Board would meet with them. There was certainly no suggestion endorsed that such a meeting should be chaired by anyone other than yourself.

Dr Aylward suggests that you, he and I should discuss this further when you are next at the Adelphi for a Board session on 12 May. He and I will also discuss it with Dr Castaldi, so that a common approach may be agreed.

I believe you have received all the background correspondence on this matter, but if there is anything further which you need, I am as always at your service.

Yours sincerely

Moira Henderson

cc: Dr. Aylward.

DR M HENDERSON MRCGP
Secretary

19/5

MA 04/v/92

Dr Hangartner

From: Dr J S Metters DCMO
30 April 1992

Copies to: Dr Castaldi
Dr Aylward
Dr Hills
Dr Hilton

ME : WESTCARE

1. Dr Sykes' letter of 27 April, which was copied to all, requests a further meeting to discuss DH action on ME. I see from their note of the meeting it was agreed that the ME organisations would meet separately with DH and DSS. I assume this is satisfactory to our DSS colleagues.

2. I do not know what arrangements were made for circulation of a note of the meeting but did we (unusually) agree to accept their record. I have to say I am not keen on this as a principle. Instead, I would prefer to let them have a copy of our meeting note.

3. They suggest the week of 8 June for the next meeting with DH. This is not particularly good for me. Could you liaise with Mrs de Sampayo about a suitable date.

4. As I will be away from the office until 20 May, at the World Health Assembly, would you respond directly to Dr Sykes on my behalf to avoid a prolonged delay.

pp Y de Sampayo
J S METTERS
Room 509
Richmond House

221/YdeS

375

Re: ME

Mr C G Blake
Office of the Solicitor
Room 412
New Court

From: Dr Mansel Aylward
PMO, P&CS, BAMS

Date: 29 April 1992

cc: Dr Moira Henderson PACS

Re: DLA HANDBOOK AND THE CHAPTER ON: CHRONIC FATIGUE SYNROMES AND ME

(1) Very many thanks for your kindly copying me with the letters you have written to Dr H Milton and Mr T J Heatley. More importantly, I am most grateful for your dealing so ably with these unpleasant letters and your vigorous defence of me!

(2) Unfortunately, I have another. Attached you will find a copy of Mr David Pratt's letter of 22 April. I could reply along these lines of your letters to Milton and Heatley, but would value your counsel before doing so.

Mansel Aylward

DR MANSEL AYLWARD
ROOM 11/26
ADELPHI
EXT 28082

MA 28/iv/92.

63 Stanfell Road
Leicester
LE2 3GE

Dr Mansel Aylward
Principal Medical Officer
Central Policy & Support Services
Benefit Agency Medical Services
1/11 John Adams Street
London
WC2N 6HT

22 April 1992

Dear Sir

The Disability Handbook

12.4

"In some clinical contolled studies people with chronic fatigue syndromes have been shown to have adequate muscle power. They may however refrain from walking because they are fearful of the consequences."

1) Can you please confirm in writing that, as editor of the above handbook, you are responsible for the above wording?

2) Can you please advise whether yours is a political appointment or a medical one? If the wording in the handbook proved to be politically unacceptable, who would have the final say?

3) If you are not responsible for the wording given above, can you please advise who is?

Yours faithfully

David Pratt

D A Pratt

89/4

File.

Westcare
15 Queen Victoria Road, Redland, Bristol BS6 7PE (Tel. 0272 - 738317)
Registered Charity. No. 900619

MA 29/IV/92

April 27 1992

Dr Aylward
DSS
The Adelphi
1-11 John Adam Street
London WC2N 6HT

Dear Dr Aylward,

Enclosed is a copy of a letter to Dr Castaldi, together with a draft record of the meeting on 30th March.

I do hope that progress can be made over the various points of difficulty with ME.

Yours sincerely,

Richard Sykes

RICHARD SYKES

/encs.

1037/4

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Dear Dr Castaldi,

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I am writing now to ask for a meeting with the full DLA Board to be arranged at the earliest possible opportunity, as was agreed at the meeting.

We were encouraged by the progress made in the clarification of some issues. We were glad to hear that the DSS recognises (a) that the disabilities of people with ME are genuine, (b) that a person with ME may be seriously disabled even though no clinical signs are apparent on routine investigation and (c) that disability claims relating to ME are no more suspect than those relating to any other illness. We were also encouraged to learn that the DSS considers the situation at Sidmouth unacceptable.

We were disappointed that the DSS was not willing to support the proposal that the current guidelines on ME be withdrawn. It seems clear that they can be construed in such a way as to prejudice claims for benefit. It is also clear that there is opposition to them from all quarters; not only from the ME Organisations but from independent scientists such as Dr Stuart Butler, Scientific Director of the Burden Neurological Institute, and even from psychiatrists such as Dr Simon Wessely who has written to express his opposition.

In this situation it would seem to be in the interests of the DSS to support the proposal that the guidelines be withdrawn, rather than invite the storm of criticism and protest which would seem almost inevitable, and which would reflect badly on the Department.

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We also ask that consideration be given to the appointment of an alternative chairman for this particular meeting. We are aware that Professor Marshall's views on ME are at one end of the spectrum and in view of his undoubted eminence there could be difficulties in fully considering a contrary point of view.

I look forward to hearing from you.

Yours sincerely,

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Copy to:
Dr Aylward.
Dr Metters

25

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DRAFT

NOTE OF A MEETING ABOUT MYALGIC ENCEPHALOMYELITIS
30 MARCH 1992, 3.30 P.M.

Present:

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Dr C Shepherd, Vice President of ME Association

Dr R Sykes, Director of Westcare

Dr A Macintyre, Medical Adviser, ME Action Campaign

Dr D F H Pheby, Westcare

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2.7 They hoped to be able to demonstrate a constructive and rational approach in the meeting, which could be the basis for further co-operative work in the future. They hoped that the need for urgent action on some matters and longer term action on others could be accepted.

3. Sidmouth case A man suffering from ME was not able to get a sick note, despite support from a consultant, because none of the doctors in the single group practice which serves the small town of Sidmouth recognizes ME or PVFS as a long-lasting condition.

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/Cont'd...

27

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4.1 While no comments could be made on this particular case, the doctors from the DOH and DSS agreed that lack of clinical signs on routine examination does not necessarily imply lack of disability. Sufferers from ME do not have muscle paralysis.

4.2 The right of ME patients to Attendance Allowance and Disability Living Allowance depends on their disability. Adjudication officers are independent of the Department. Dr Pheby felt that they required more guidance.

5. New guidelines on ME Dr Charles Shepherd and Dr Anne Macintyre suggested that the new guidelines could be construed in an unfair and damaging way which would prejudice claims for benefit. A request was made for their withdrawal.

5.1 Particularly prejudicial was Section 12.4, which stated:-

> "In some controlled clinical studies some people with chronic fatigue syndromes have been shown to have adequate muscle power. They may however refrain from walking because they are fearful of the consequences".

This could be read as implying that people with ME had normal muscle power and that, therefore, they were able to walk; but that they refrained from walking through fear rather than because of genuine disability.

5.2 Dr Wessely's work was mentioned. He had expressed his dissatisfaction with the guidelines and had written to the Board to this effect. It was claimed that the DSS had misinterpreted his work. He had included people with chronic fatigue syndromes. There were other causes of this from which people had recovered with exercise, whereas ME was made worse by exercise. The Board had replied to Dr Wessely and a copy of their reply was supplied to the ME representatives at the meeting.

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5.3 Dr Castaldi and Dr Aylward were not willing to support the proposal that the guidelines be withdrawn, and they did not agree that the guidelines could be construed in an unfair and damaging way.

5.4 Dr Aylward said it was impossible to change the guidelines immediately. They had recently been endorsed by the Disability Living Allowance Advisory Board (DLAAB). They would be reviewed after 6 months' use and revised in collaboration with interested parties. The DLAAB will keep records of those cases of ME and Chronic Fatigue Syndromes referred to them for advice, and they will document the advice given to Adjudication Officers together with the bases upon which such advice is given. The DLA Board are keen to meet with representatives of disabled people and a meeting with ME representatives will be arranged. The DLAAB had advised DSS to retain guidance in the Disability Handbook unmodified until experience had been gained on its use during the first 6 months of the newly introduced DLA benefit.

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6.1 The chairman explained that Professor Peckham had recently taken over as Director of Research and Development. The Department Research Strategy was still under consideration and it was not yet known where the priorities would lie. Clinical research was a matter for the MRC. Health Services (Operational) Research was more a matter for DOH and the NHS.

6.2 Dr Pheby suggested that health services research was required rather than fundamental scientific research. He said that there was a need for clarification of terminology a the use of definitions which incorporated diagnostic criteria. There was a need for rigorous research to characterize the disease, to establish its epidemiology, to assess the burden of disability and to establish a strategy for providing appropriate treatment and care facilities and support programmes for sufferers.

6.3 Dr Hangartner said that he would explore the possibility of reviewing the way in which research

/Cont'd...

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MA 29/iv/92

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WESTCARE aims to make available information about M.E. (Myalgic Encephalomyelitis) and similar conditions and to help in the provision of services and care for ME sufferers in Bristol and the West of England.
Director: Richard Sykes M.A. (Cantab) Ph.D., C.Q.S.W.

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6. Research on ME Dr Anne Macintyre suggested that research into ME was urgently needed. The only research into ME is funded by their own Associations. The DSS had spoken of MRC-funded research into the chronic fatigue syndrome, but this was not ME. (Only a very small proportion of those with chronic fatigue had ME). They had not made any application to the Department of Health or MRC for funding and looked for guidance.

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6.2 Dr Pheby suggested that health services research was required rather than fundamental scientific research. He said that there was a need for clarification of terminology a the use of definitions which incorporated diagnostic criteria. There was a need for rigorous research to characterize the disease, to establish its epidemiology, to assess the burden of disability and to establish a strategy for providing appropriate treatment and care facilities and support programmes for sufferers.

6.3 Dr Hangartner said that he would explore the possibility of reviewing the way in which research

/Cont'd...

on ME was currently classified.

7. <u>Treatment for ME</u> Because of time pressures this item was not discussed.

8. <u>DOH Information on ME</u> Dr Charles Shepherd pointed out that even among doctors who accept ME/PVFS there is much confusion and uncertainty about how to diagnose and treat it.

8.1 There was the need for a DOH circular now (in the same way that circulars on AIDS had to be sent out) and for a working party to produce more detailed information later.

8.2 Dr Hangartner said that he would explore the possibility of sending out a circular soon; the ME Organisations would be consulted before any such circular was sent out. He also said that he would explore possible ways in which to facilitate the establishment of a Task Force, similar to the task forces on asthma and other conditions. Such a task force would not be led by the Department but could be facilitated by it. It would be important that the Royal Colleges and other bodies were involved.

9. <u>Follow Up</u> It was agreed that the ME Organisations Group (The MEO Group) would meet with each of the Departments separately in future. A meeting with the DOH was to be arranged within 2 to 3 months, at a time when Dr Hilton could be present. The DSS would ask the DLA Board for the full Board to meet the MEO Group as soon as possible.

<u>Richard Sykes</u>
27/4/92

(31 - 35)

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LETTERCODE/SERIES BN 141/1

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Extract/Item Details:

5 page(s)

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Section: 40(2)+(3)

Closed until: 2072

Initial & Date

SA
27/3/12

Dr Elizabeth Hills
SMO/HC(M)1
405 Eileen House

From: Dr Mansel Aylward
PMO, PACS BAMS

Date: 9 April 1992

cc: (plus enclosures)
Dr P Castaldi CMA
Dr M Henderson
DLAAB

RE: MYALGIC ENCEPHALOMYELITIS - NOTE OF MEETING HELD ON 30 MARCH 1992

1. Very many thanks for kindly providing Dr Castaldi and me with a copy of your draft notes of the meeting which accompanied your minute of 7 April 1992.

2. I am responding for both Dr Castaldi and me.

3. I enclose your draft which I have annotated in red ink with respect to corrections and additions. I hope you will find my handwritten notes legible but please let me know if you need further clarification or amplification.

4. I would be most grateful if you could let me have a copy of the final note which you will circulate.

Mansel Aylward

DR MANSEL AYLWARD
ROOM 11/26
ADELPHI
EXT 28082

50/18

A:EH11.92

Dr Castaldi
Dr Aylward

From: Dr Elizabeth Hills
Date: 7 April 1992

MYALGIC ENCEPHALOMYELITIS - NOTE OF A MEETING HELD ON 30 MARCH 1992

1. I enclose draft notes of the meeting with representatives of ME organisations.

2. Please let me have any corrections/additions before they are circulated by 15 April.

Elizabeth Hills

ELIZABETH HILLS
SMO/HC(M)1
405 Eileen House
Ext 22821

A:EH11.92

DRAFT

NOTE OF A MEETING ABOUT MYALGIC ENCEPHALOMYELITIS
30 MARCH 1992, 3.30 P.M.

Present:
Dr R Hangartner - DH (for Dr Metters)

Dr C Shepherd, Vice-President of ME Association

Dr R Sykes, Director of Westcare

Dr A McIntyre, Medical Adviser, ME Action Campaign

Dr D F H Pheby, Westcare

Dr M Aylward, Benefits Agency Medical Services DSS
Dr P Castaldi, DSS

Dr E Hills, DH

1. Dr Hangartner welcomed the visitors. He explained that Dr Metters was ill and unable to take the meeting. He understood that the problems to be discussed were the DLA Handbook and difficult relationships with the GPs in Sidmouth.

2. Dr Sykes asked that CMO be thanked for arranging the meeting.

2.1 He explained that Westcare provides a clinic where patients can see a doctor or obtain counselling, and also arranges educational meetings.

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Exemption S 40 (2)
(3) closed Until 2072

2.3 He said that Westcare and the Department had shared concerns -

(a) to help patients to get better

(b) to help genuine sufferers to get State benefits. There were no clear markers of disease and they must be distinguished from patients with the wrong diagnosis.

2.4 He claimed there were thousands with the disease who suffered injustice from lack of understanding and ridicule.

2.5 There was little provision of care or rehabilitation.

2.6 In the context of claim for benefits, the necessary decision was whether the disability was genuine, and posed needs for attention or supervision rather than whether it was possible to determine whether it was organic or psychiatric.

2.7 ME support groups sought continued discussion of problems with the Department of Health and of Social Security and joint exploration of solutions.

3. Dr Shepherd reported a survey of GPs in Scotland where 10% denied the existence of ME. He described the difficult situation in Sidmouth where there was only one group practice where the GPs did not recognise ME. One patient was known to have registered with a practice in another town using a false address. It was likely that this situation could occur in rural areas.

4. He asked that the CMO circulate a letter informing doctors that the Department recognised the diagnosis. It would give salient features of the disease and be designed to produce better understanding and a sympathetic attitude to sufferers. The chairman commented that the Department did not

give clinical advice, he had doubts about the educational value and effectiveness of such a communication. The request would be considered. It was agreed that if a letter were produced, the ME advisers would be consulted before it was circulated.

5. Dr Hangartner suggested that Dr Shepherd consult the Royal Colleges to enlist their help in an educational programme.

[redacted]

7. Westcare considered the ~~guidelines~~ information on ME and Chronic Fatigue Syndromes in the ~~DLA~~ Disability Handbook to be unacceptable and that they should be changed immediately. Section 12.3.1 should include a statement that conventional muscle tests may be normal, but this does not exclude disability and real needs. Section 12.4 was ambiguous. Dr Wesley's work was mentioned. It was claimed that DSS had misinterpreted his work. He had included people with chronic fatigue syndromes. There were other causes of this from which people had recovered with exercise, whereas ME was made worse by exercise. The ME representatives had not seen the Board's reply to Dr Wesley. But they were supplied with a copy by Dr Aylward during the meeting.

8. Dr Aylward said it was impossible to change the guidelines immediately.*) They would be reviewed after 6 months' use and revised in collaboration with interested parties. [~~A record will be kept of cases failed.~~] The DLA Board are keen to meet with representatives of disabled people and a meeting with ME representatives will be arranged.

* They had recently been endorsed by the Disability Living Allowance Advisory Board (DLAAB. The DLAAB had advised DSS to retain guidance in the Disability Handbook unmodified until experience had been gained on its use during the first six months of the newly introduced DLA benefit.

9. The visitors said the only research into ME is funded by their own Associations. The DSS had spoken of MRC- funded research into the chronic fatigue syndrome, but this was not ME. They had not made any application to the Department of Health or

→ Please rephrase this to: The DLAAB will keep records of those cases

MRC for funding and looked for guidance. The chairman explained that Professor Peckham had recently taken over as Director of Research and Development. The Department Research Strategy was still under consideration and it was not yet known where the priorities would lie. Clinical research was a matter for the MRC. Health Services (Operational) Research was more a matter for DOH and the NHS. Dr Pheby suggested that health services research was required rather than fundamental scientific research.

10. It was decided that a further meeting should be arranged after about 3 months. It was agreed that it was appropriate to separate DSS issues from any DH issues. It was noted that the next meeting should be arranged to enable Dr Hilton to be present.

11. Dr Sykes summarised his points again and the meeting closed.

MISC 200

File MA

A:EH11.92

~~Dr Castaldi~~
Dr Aylward

From: Dr Elizabeth Hills
Date: 7 April 1992

MYALGIC ENCEPHALOMYELITIS - NOTE OF A MEETING HELD ON 30 MARCH 1992

1. I enclose draft notes of the meeting with representatives of ME organisations.

2. Please let me have any corrections/additions before they are circulated **by 15 April**.

Elizabeth Hills

ELIZABETH HILLS
SMO/HC(M)1
405 Eileen House
Ext 22821

A:EH11.92

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	Dr C Shepherd, Vice-President of ME Association
	Dr R Sykes, Director of Westcare
	Dr A McIntyre, Medical Adviser, ME Action Campaign
	Dr D F H Pheby, Westcare
	Dr M Aylward, DSS Dr P Castaldi, DSS
	Dr E Hills, DH

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2.6 In the context of claim for benefits, the necessary decision was whether the disability was genuine rather than whether it was organic or psychiatric.

2.7 ME support groups sought continued discussion of problems with the Department and joint exploration of solutions.

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give clinical advice, he had doubts about the educational value and effectiveness of such a communication. The request would be considered. It was agreed that if a letter were produced, the ME advisers would be consulted before it was circulated.

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DEPARTMENT OF HEALTH
Eileen House
80-94 Newington Causeway
London SE1 6YX

Telephone No 01-972-2000

Your reference
Our reference

A:EH11.92

Copy: Dr Castaldi
Dr Henderson.
Prof Marshall.

Dear Dr Aylward

DRAFT MINUTES OF A MEETING ON MYALGIC ENCEPHALOMYELITIS 30 MARCH 1992

I enclose a draft set of minutes of the above meeting, which has been agreed by Department of Health and Department of Social Security colleagues.

Would you be kind enough to let me know if you agree with this record of our meeting - a telephone call would suffice if this is easier. My direct line is 071-972- 2821.

Yours sincerely

Elizabeth Hills

ELIZABETH HILLS
Senior Medical Officer
Health Care (Medical) 1

Phoned Dr Hills to confirm that draft was a fair & accurate account of our meeting.

Mansel Aylward 14/iv/92

A:EH11.92

DRAFT

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30 MARCH 1992, 3.30 P.M.

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8. Dr Aylward said it was impossible to change the guidelines immediately. They had recently been endorsed by the Disability Living Allowance Advisory Board (DLAAB). They would be reviewed after 6 months' use and revised in collaboration with interested parties. The DLAAB will keep records of those cases of ME and Chronic Fatigue Syndromes referred to them for advice, and they will document the advice given to Adjudication Officers together with the bases upon which such advice is given. The DLA Board are keen to meet with representatives of disabled people and a meeting with ME representatives will be arranged. The DLAAB had advised DSS to retain guidance in the Disability Handbook unmodified until experience had been gained on its use during the fi~~r~~st 6 months of the newly introduced DLA benefit.

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Meeting at DOH, Richmond House, 30/3/92

Dr Metters (DOH), Dr Aylward (DSS) Dr Castaldi (DSS)
and Dr Macintyre (ME Action), Dr Pheby (Westcare)
Dr Shepherd (ME Assoc.), Dr Sykes (Westcare)

PROPOSED AGENDA

1. Introduction
2. Sidmouth case. Refusal of sick note by GP.
3. N's case. Lack of disability inferred from lack of clinical signs.
4. New DLA Guidelines for ME.
5. Research on ME.
6. Treatment for ME.
7. DOH Information on ME.
8. Follow up.
9. Summary and Review of meeting

41a - 41e

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SA
2/4/12

[illegible]ta Neuropathol (1991) 83: 61 – 65

Acta Neuropathologica

Mitochondrial abnormalities in the postviral fatigue syndrome*

W. M. H. Behan[1], I. A. R. More[1], and P. O. Behan[2]

Departments of [1]Pathology, and [2]Neurology, University of Glasgow, Scotland

Received February 1, 1991/Revised April 24, 1991/Revised, accepted August 5, 1991

Summary. We have examined the muscle biopsies of 50 patients who had postviral fatigue syndrome (PFS) for from 1 to 17 years. We found mild to severe atrophy of type II fibres in 39 biopsies, with a mild to moderate excess of lipid. On ultrastructural examination, 35 of these specimens showed branching and fusion of mitochondrial cristae. Mitochondrial degeneration was obvious in 40 of the biopsies with swelling, vacuolation, myelin figures and secondary lysosomes. These abnormalities were in obvious contrast to control biopsies, where even mild changes were rarely detected. The findings described here provide the first evidence that PFS may be due to a mitochondrial disorder precipitated by a virus infection.

Key words: Postviral fatigue syndrome – Branching and fusion of mitochondria – compartmentalization – Mitochondrial vacuolation

The postviral fatigue syndrome (PFS) is a disease of unknown aetiology, developing after a definite viral infection and characterized by severe fatigue and myalgia, together with a variety of psychiatric and other symptoms [1, 6, 17]. About one-third of patients also complain of palpitations and/or unsteadiness [1,6]. Routine laboratory tests are normal but specialised investigations of muscle reveal myopathic features on single fibre electromyography [20, 21] and an unusually early intracellular acidosis on exercising using nuclear magnetic resonance testing [4]. About 70 % of muscle biopsies reveal moderate atrophy of type II fibres with no other specific features [6]. Auditory brain stem and eye motility responses have also been recorded as abnormal [29, 30]. Formal psychological tests in our laboratory have revealed defects in sustained concentration and a curious sensitivity to visually disturbing patterns (in preparation).

The lack of specific diagnostic criteria has made it very difficult to study the disease and, until recently, it has not been the subject of scientific investigation. Attempts have now been made to set strict guidelines for diagnosis, with a working case definition [18]. Unfortunately, the term "chronic fatigue syndrome" has been selected and this will certainly lead to severe problems since fatigue is a feature common to so many, diverse, medical and psychiatric diseases. We prefer the term "postviral fatigue syndrome" and select all our cases on the basis that the muscle fatigue and myalgia started at the time of a viral infection and have been continuous since then. The fatigue appears to have a central nervous system component because there is no lack of power on testing but the patient has to make a determined effort to carry out simple routine tasks. It is also invariably accompanied by depression, a reduced ability to concentrate and a decrease in intellectual performance.

There are some clues as to the aetiology of the syndrome: viruses have been isolated in rare cases [10, 19] and high titres to coxsackie antibodies have been detected in a few, small series [6, 8, 13], although results in a later, larger study were not convincing [23]. Nucleic acid hybridisation studies have provided additional support for a viral aetiology: 20 % of 96 cases were found to have enteroviral RNA sequences in samples of their muscles [2], while another 10 % had sequences which hybridised to an Epstein-Barr virus-specific probe [3]. Finally, using the more sensitive polymerase chain reaction we have confirmed that enteroviral-specific sequences can be found in 53 % of cases [15].

In spite of this evidence of viral involvement, muscle biopsies from our carefully selected group of patients showed none of the histological features of inflammation or necrosis. Ultrastructural examination, however, revealed obvious mitochondrial damage, suggesting for the first time that this may be the pathogenesis of PFS.

---

* Supported by the Barclay Research Trust

Offprint requests to: P. O. Behan, Department of Neurology, Institute of Neurological Sciences, Southern General Hospital, 1345 Govan Road, Glasgow G51 4TF, Scotland

Methods

Patient selection

Fifty patients were studied, 19 males and 31 females. The ages of the men ranged from 17 to 49 years (mean 34.2 years) and that of the women from 16 to 50 years (mean 3.5 years). They were selected because of the severity of their symptoms which had been present for 6 months to 17 years, (mean 4.1 years). They were all investigated to exclude the many other conditions which enter into the differential diagnosis of PFS [17]. Each one reported that a febrile illness, of such severity that he or she had been confined to bed for 5–7 days was the precipitating factor, with the illnesses as follows: a influenza-like illness with headache, sore throat and myalgia (35 cases), infectious mononucleosis (8), Bornholm's disease (4), diarrhoea and vomiting (1), labyrinthitis (1) and chickenpox (1). In three of the influenza-like illnesses, rising titres of anti-coxsackie antibodies had been documented while the diagnosis of infectious monoculeosis was based on typical clinical and laboratory findings.

The symptoms that they complained of have been described in detail elsewhere [6]. They consisted of overwhelming fatigue made worse by exercise, myalgia, a reduced ability to concentrate, loss of short-term memory and depression. The majority had also had palpitations at some stage and unsteadiness. Their symptoms started at the time of the original illness and had persisted since then. Seven cases had been admitted to hospital at their initial presentation because of the severity of the symptoms.

No patients were taking medication when they were studied. Previously they had all had good work records: there were 3 full-time housewives among the 31 women but all the rest had additional jobs. The occupations of the patients ranged from teachers (8 cases, including a university professor) to hospital workers (9, including a chief pharmacist and a physicist), engineering workers (9) and office workers (5). The teachers included 3 who taught physical education and there were 6 other keep-fit enthusiasts including a marathon runner and a county class badminton player. No patients had previously been referred to a psychiatrist. Two patients reported siblings developing infectious mononucleosis at the same time as themselves but recovering completely, while in 4 cases, other family members had had the influenza-like illness but again recovered. There were, however, 2 cases who had affected relatives – a woman whose mother and brother developed the disease after her, and a man whose niece was ill. Five patients had identified another 1 or 2 people at their work place who had developed the same illness after themselves.

A detailed physical and neurological assessment was carried out. The nutritional state was confirmed as satisfactory. The routine laboratory investigations carried out included urinalysis, complete blood count, sedimentation rate, serum electrolytes, liver function tests, muscle enzymes, thyroid function tests, chest X-rays, electrocardiography and serological tests for common viruses, including influenza A and B, coxsackie B group, herpes 1 and 2, cytomegalovirus, hepatitis B and the Epstein-Barr virus. Immunological studies included immunoglobulin concentrations, complement component estimations, antinuclear antibodies and rheumatoid factor determinations. A detailed evaluation of hypothalamic function was also made. Percentage populations of T and B lymphocytes were determined in 35 of the patients. Electromyography and needle muscle biopsies were carried out. Lumbar punctures, testing of visual evoked responses, a CT scan and nuclear imaging of muscle were done in 5 cases where an alternative diagnosis had been raised. No patient was admitted to the study if he or she had any other condition which might explain even some of the findings.

Muscle biopsies

Three cores of skeletal muscle were obtained from each case from the right or left vastus lateralis muscle, under local anaesthetic (lignocaine 2 %), taken with the UCH biopsy needle as described [12]. One fresh tissue cube, 1 mm diameter, was placed immediately in cold (4 °C) 2 % EM grade glutaraldehyde in Sorensen's phosphate buffer (pH 7.4) and another, taken into a tube under sterile precautions, was frozen in liquid nitrogen for later examination by enteroviral probes using the polymerase chain reaction. The main parts of all three cores were examined under the dissecting microscope at the bedside, orientated on cork discs, surrounded by Tissue-Tek and frozen in Arcton, precooled in liquid nitrogen [12]. Sections (5 μm) were then prepared, using the following stains in the order given: haematoxylin and eosin, modified Gomori trichrome, adenosine triphosphatase at pH 9.4 and 4.3, NADH-tetrazolium reductase, succinate dehydrogenase, adenylate deaminase, oil red O, PAS and PAS with diastase. Appropriate controls for the histochemical stains were used in the sequence. For electron microscopic examination, the specimens were left at 4 °C overnight. Then, after washing and treatment with 1 % OsO_4, the tissue was dehydrated using graded alcohols, impregnated with Araldite resin and polymerised in fresh resin mixture overnight at 60 °C. Sections (80–90 nm) were cut, stained in the conventional manner using uranium and lead and examined in a Philips CM10 electron microscope.

As control samples, 50 1-mm^3 samples of skeletal muscle were obtained over the same period of time, from the operative site of patients undergoing various surgical procedures and treated in the same manner as above. The samples were from pectoralis major, rectus abdominis and vastus medialis muscles. The patients consisted of 30 females aged from 24 to 71 years (mean 51.4 years and 20 males, from 18 to 73 years (mean 59.8 years). The women were all undergoing either lumpectomy or mastectomy for benign (12) or malignant (18) breast disease, while the men had hernial repairs or vascular surgery. None of these patients had a muscle disease.

Results

Routine histology

Light microscopy examination revealed only one consistent abnormality, present in 39 cases, and that was type II atrophy which ranged from mild and focal (6 cases) to moderate and diffuse (33). Four cases also had mild type I atrophy. One or two necrotic fibres were identified in three of the specimens, a tiny inflammatory focus in another two, and evidence of regeneration in a further four. One case had two ragged-red fibres on the Gomori stain: in 25 other cases, this stain identified unusually prominent mitochondria, especially in the type I fibres, but the typical ragged-red appearance was not present. The enzyme stains revealed 1 patient with adenylate deaminase deficiency and 24 cases with a mild to moderate excess of lipid present.

Electronmicroscopic findings

Evidence of mitochondrial abnormalities was present in 40 of the cases (80 %) with the commonest change (seen in 70 %) being branching and fusion of cristae, producing "compartmentalisation". Mitochondrial pleomorphism, size variation and occasional focal vacuolation were detectable in 64 %, together with secondary lysosomes.

Groups of mitochondria, together with the nucleus and abundant glycogen, were present in a sub-sarcolem-

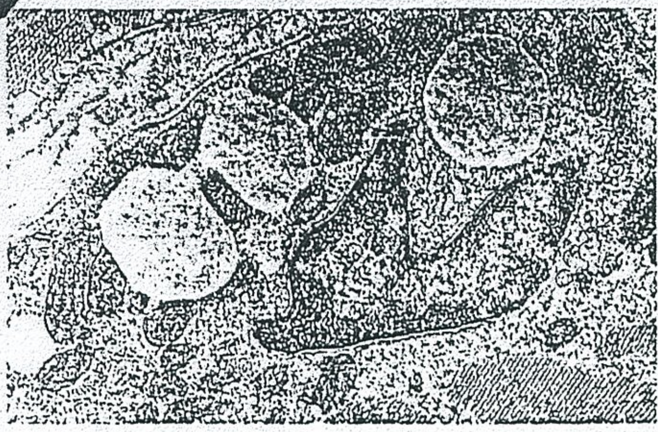

Fig. 1. Pleomorphic mitochondria related to lipid, × 15,500

mal position and also scattered between muscle fibres with their long axis parallel to that of the fibres. They showed severe pleomorphism of shape and size (Fig. 1). Their sizes ranged from 0.3 µm to 1 µm in maximum diameter, while the shape was rounded, angulated or sinuous. Expanded areas of variable shape were continuous with more conventional long sinuous types. In some instances, however, they were grossly irregular with pseudopodia-like projections thrown out at right angles to the main body of the mitochondrion.

The cristae were conventionally transverse in some cases but in others, longitudinally orientated cristae predominated; in a proportion, both forms were found. In many mitochondria branching of the cristae was a prominent feature, such that the interior of the mitochondrion was converted into a series of compartments (Fig. 2a, b). These compartments varied in appearance, the majority being rounded although some were angular. In some instances, they were of a uniform size within a given mitochondrion, whilst other showed a marked size variation. Some compartments could be seen to fill the whole body of the mitochondrion while others were confined to the outer membrane area. At the sites where the branching or fusion of cristae took place there was some loss of the parallel arrangement of the membranes of the cristae. No true zig-zag or concentric cristae were seen. No crystalline or paracrystalline inclusions were found and mitochondrial granules were scanty.

Vacuolation of mitochondria was frequent although variable in extent. In some cases there was swelling of the whole mitochondrion with rupture of the outer membranes and continuity of the matrix space with the general cell cytoplasm. In others, only a portion of the mitochondrion was swollen, centered quite obviously on one of the compartments formed as described above (Fig. 3). Such limitation of the swelling suggested that these were closed compartments, subject to selective damage, although it is true to say that usually the rest of the mitochondrion was also damaged but to a lesser extent.

Lipid globules were commonly found ranging in size from 0.2 µm to 3 µm in diameter. They were scattered at random through the cell or in small groups in association with the sarcolemnal membranes.

Secondary lysosomes were prominent in some of the worst-affected cases, associated with the mitochondria, nucleus and glycogen at the cell periphery. The varied in size from 0.5 µm to 3.5 µm and in appearance containing lipid of variable density, membranes, granular debris and vacuoles. Rare areas of myofibrillary degeneration were present where the mitochondria were found with their long axes at right angles to their normal orientation as well as in the more usual positions.

Examination of the 50 control biopsies revealed no mitochondrial pleomorphism. There was minor size

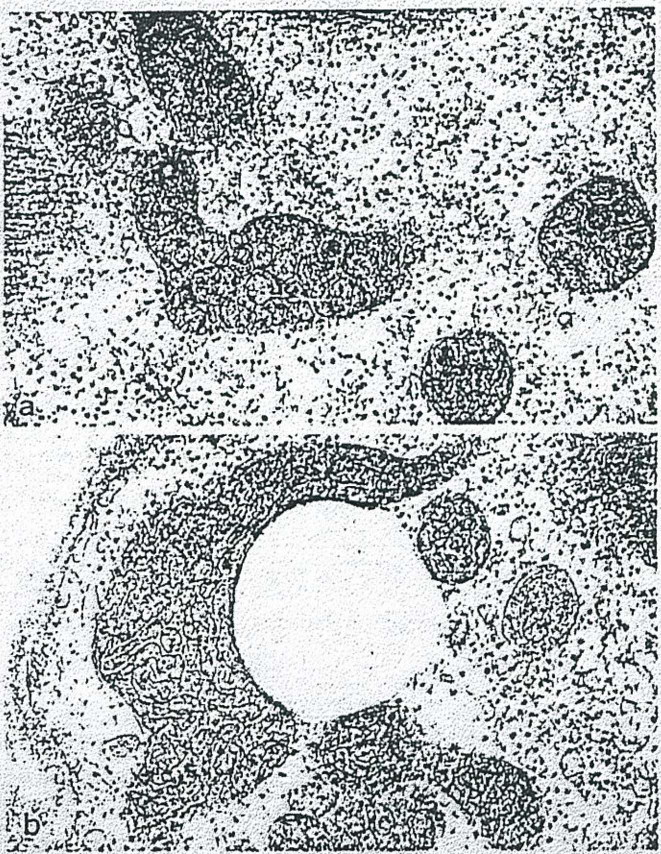

Fig. 2a, b. Mitochondria showing conspicuous compartmentalisation and granules, × 39,000

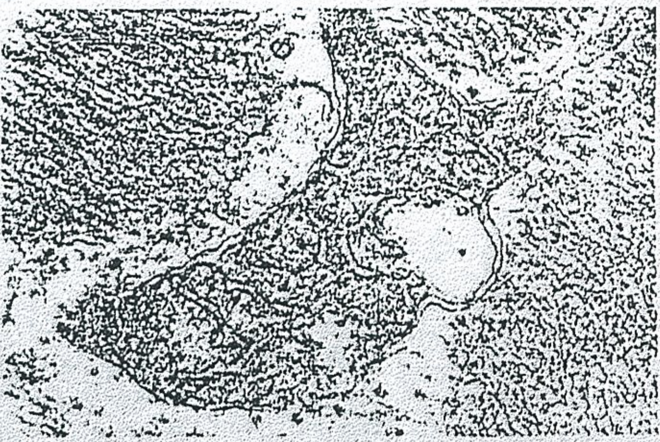

Fig. 3. Focal vacuolation in a mitochondrion with compartmentalisation, × 49,000

variation, as expected since both type I and type II fibres were examined. Rare focal vacuolation was detectable in 52 %, of very mild degree and not comparable to the gross change visible in the patient biopsies. With regard to compartmentalisation, none of the samples revealed the severe changes seen in patients with PFS but on careful examination, some occasional compartments in a rare mitochondrion could be found.

The pleomorphism of the mitochondria in the patients' muscle biopsies was in clear contrast to the findings in the normal control biopsies.

Discussion

Scientific study of the postviral fatigue syndrome (PFS) has been bedevilled by the difficulty in diagnosis and the absence of fibre necrosis on routine histology. Nonetheless, diffuse or focal atrophy of type II fibres has been reported, and this, although non-specific, does indicate muscle damage and not just muscle disuse [9]. In addition, specialised tests have revealed electrophysiological [20, 21] and metabolic muscle abnormalities [4, 7] and recent reports suggest that a persistent local enteroviral infection may be present [2, 3, 15].

In the study reported here we found that the mitochondria in 80 % of the biopsies from patients with PFS showed an unusual appearance, consisting of branching and fusion of the cristae which produced the appearance of compartmentalisation within the organelle.

In general the number of cristae within a mitochondrion is thought to reflect its level of activity; normal muscle mitochondria have more cristae than those of liver [32]. Branching and fusion of cristae (compartmentalisation) or a honeycomb appearance, along with other structural abnormalities, are seen at their most frequent and florid in the mitochondrial myopathies. Indeed, although not correlating with any specific metabolic lesion, defects involving the respiratory chain or components of the energy conservation or transducing systems have consistently shown major alterations in mitochondrial structure and number [11, 25]. It is assumed that the usual sequence of metabolic steps is disturbed in these cases, leading to accumulation of a metabolite and attempts at compensation.

The morphological changes which occur in mitochondrial myopathies do have one feature in common: they all represent an increase: the organelles are more numerous, larger and pleomorphic, developing abundant, branched cristae, show an increased matrix and are surrounded by more and larger triglyceride droplets [22]. Sometimes crystalline or paracrystalline structures are found [22]. These changes are similar those we detected in our cases of PFS except that we found no inclusions.

One of the problems in studying the ultrastructure of muscle mitochondria is that similar abnormalities can be found, although very rarely, in normal muscle, and can be induced experimentally by ischaemia or mitochondrial poisons [16, 25]. They may also form a minor feature of diseases such as muscular or myotonic dystrophy or polymyositis, although in these cases, the changes are overshadowed by other diagnostic features [11, 25]. In muscle, as elsewhere, these organelles obviously have a limited range of responses to injury.

What is described in the literature as "non-specific changes due to cell injury" [14] have also to be distinguished from artefactual injury produced during preparation. We excluded this artefact by collecting the muscle specifically for electron microscopy with no delay in fixation and processing the samples according to a well-recognized schedule in a laboratory which handles some 900 specimens per annum. We also took the precaution of examining 50 muscle samples, processed in exactly the same way, from patients with no muscle diseases. The changes we describe here were present only in the muscle samples of the patients, never in the surrounding connective tissue. In addition, they were often associated with an excess of lipid or with foci of myofibrillary degeneration, features not associated with preparative artefact.

We have not yet carried out any functional studies of the mitochondria in PFS, but other workers have reported mild depression of state 3 respiration rates using sites I and II substrates in two cases [7]. P^{31} nuclear magnetic resonance tests on patients [4] have shown an abnormally rapid fall in phosphocreatine during light aerobic exercise, similar to cases of coenzyme Q reductase deficiency [26].

Can mitochondrial damage follow a viral infection? The obvious comparison to make is with Reye's syndrome, which follows influenza or varicella virus infection and is characterized by mitochondria described as structurally disrupted or abnormal, oddly shaped or swollen with a diffuse matrix and loss of cristae. Dense bodies are absent but peroxisomes are increased [27]. These changes, which are seen in liver and muscle, occur in the absence of any inflammation or cell necrosis and are completely reversed if or when the patient recovers. Apart from compartmentalisation, these features are similar to those we describe here. Others have also reported virtually identical mitochondrial damage (again except for compartmentalisation) in acute viral infections of muscle [5, 28]. We confirmed these results in a small series of biopsies from patients with acute viral illnesses.

How might a virus produce the mitochondrial damage shown here? Workers suggested originally that the Kearns-Sayre syndrome, now shown to be due to deletions in mitochondrial DNA [24], was due to a viral infection [31]. Three patients (not included here) whom we examined and were later confirmed to have mitochondrial myopathies, were referred to us originally as cases of PFS. It is tempting to speculate that a persistent virus might interfere with mitochondrial DNA, leading to muscle fatigue.

Mitochondrial disorders are expressed in other tissues, although because of its special metabolic demands symptoms in muscle may predominate. Similar damage to the central nervous system might account for the psychiatric features described in this syndrome and for the hypothalamic dysfunction which we have recently identified.

In summary, we are not putting forward the muscle damage found here as specific for PFS but suggest our results show that mitochondrial lesions may be present in the muscle, that they may explain many of the clinical and laboratory features and that they suggest a new way of investigating the disease.

References

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Mr T Heatley
Membership Secretary
Myalgic Encephalomyelitis Association
Leicestershire Group
36 Scraptoft Lane
Leicester
LE5 1HU

18 March 1992

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I can reassure you that both this Department and the Department of Health recognise Myalgic Encephalomyelitis as a debilitating and distressing condition affecting many people.

The chapter on Chronic Fatigue Syndrome and Myalgic Encephalomyelitis in the Disability Handbook was written following careful study of papers and articles on these conditions in several scientific journals. Drafts of the handbook were circulated widely among organisations representing disabled persons for consultation before it was published. The Disability Living Allowance Advisory Board was also consulted, and met with members of the M.E. Action Group to discuss the drafting of this chapter. Many of the suggestions made by the M.E. Action Group were incorporated into it. The Board itself includes eminent clinicians from the whole range of medical specialties and members who are either disabled themselves or involved in the care of disabled people. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

The Handbook acknowledges the two conditions are not fully understood. It recognises that in some persons with Myalgic Encephalomyelitis there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for Myalgic Encephalomyelitis is recognised. The Handbook does not suggest that "it is all in the mind".

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In summary, we are not putting forward the muscle damage found here as specific for PFS but suggest our results show that mitochondrial lesions may be present in the muscle, that they may explain many of the clinical and laboratory features and that they suggest a new way of investigating the disease.

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The Handbook acknowledges the two conditions are not fully understood. It recognises that in some persons with Myalgic Encephalomyelitis there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for Myalgic Encephalomyelitis is recognised. The Handbook does not suggest that "it is all in the mind".

The Handbook also recognises that there is as yet no consensus with regards to advice given to sufferers. Some doctors advise complete rest, but there is another large consensus of medical opinion which advocates graded exercise of muscles to assist the return to normal.

The Handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help Adjudication Officers in deciding claims to Disability Living Allowance and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

The Handbook is not intended to be used in preference to evidence available in individual cases. The introduction to the Handbook (para 1.1.1) clearly explains this.

Entitlement to Disability Living Allowance does not depend on a particular illness, disease or diagnosis. It depends on each persons needs for attention with personal care, or supervision/watching over to avoid substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

The Disability Handbook will be regularly reviewed and revised. The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of claims to Disability Living Allowance over the next few months before advising revision of any of the chapters in the Handbook. The Board will be closely observing the situation. Although there will be no immediate changes, all representations received will be carefully considered when the Handbook is next revised.

As far as providing information for the medical profession is concerned, the Department of Health inform me that it is encouraged by the increased number of informed articles on ME appearing in professional journals and by the number of regional health authorities approving courses for GPs in ME; the various ME groups do valuable work in this area too. It is not that Department's practice, however, to issue clinical guidance to doctors, and, until such time as more is known about the illness and its epidemiology, the Department of Health does not believe it is in a position to send out more authoritative information than is provided already.

Several studies are already taking place into the possible physical causes of ME, while the Medical Research Council is funding a study at the Institute of Psychiatry to investigate chronic fatigue in GP's attenders. Researchers at the Institute are attempting to find ways to help ME sufferers cope with their disease and regain their health, which then can be used in a primary care setting. All evidence suggests that, whilst the primary trigger may be viral, the determinants producing the condition are more complex.

The source of such a study should not be assumed to imply any preconceived ideas about its likely findings. The Institute's study is an initial exercise which will enable us to assess the feasibility of further studies as well as providing some information on the epidemiology of ME. The Department of Health advises me that it would wish to have an opportunity to consider the results of that study, together with any problems encountered in carrying it out, before deciding what further studies are feasible.

Turning now to the payment of invalidity allowance with invalidity pension, I can confirm that invalidity allowance has not been abolished. However, from November 1985 the amount of invalidity allowance payable has either been reduced or extinguished by the amount of any additional pension and/or guaranteed minimum pension also due.

There is also a change in the calculation of the amount of additional pension payable where entitlement to basic invalidity pension starts on or after 6 April 1992. From this date no entitlement to additional pension will arise on earnings paid after the 1990/91 tax year. However, all existing rights are preserved. All earnings between 1978/79 - the first tax year to count in the calculation of additional pension - and 1990/1991 (both years included) will continue to count for additional pension entitlement. The earnings for these tax years will also be adjusted to keep pace with the general rise in earnings.

The Secretary of State is grateful for the opportunity to explain the position.

Yours sincerely

VAL WIDDICOMBE
DLAAB SECRETARIAT

Lewis Nunn
A3C
Room 11/39 ADI

From: Val Widdicombe
DLAAB Secretariat
Room 11/39 ADI

Date: 18 March 1992

LETTER FROM ME ASSOCIATION - LEICESTERSHIRE GROUP

Many thanks for your helpful notes concerning IVA.

I have incorporated your suggested contribution on this matter in my reply, a copy of which is attached for your reference.

VAL WIDDICOMBE
Ext 28056

Mrs V Widdicombe
AAB(Sec)
Room 11-39
Adelphi

From: Lewis Nunn A3C
Date: 18 March 1992

Letter from MYALGIC ENCEPHALOMYELITIS ASSOCIATION (Leicestershire Group)

1. Thank you for letting me see the letter from the above Association.

2. A contribution towards your reply is attached.

3. As you will see invalidity allowance (IVA) has not been abolished. The only recent change in the amount of IVA payable occurred in November 1985, almost 2 years before the 1987 election.

4. The only major change to IVB since the last election has been the curtailment of additional invalidity pension (AP) for new claims starting on or after 6 April 1992. I wonder if this is what the writer is on about? In case it is, I have mentioned this change in my contribution.

5. Because we are in between Governments I have kept my contribution factual, and not gone into the reasons behind the changes.

L W Nunn
Room 11-39
Adelphi
Ext 28081

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TO: General Office
ARD
Rm 11-33
API

Date: 2 MAR 1992

TREAT OFFICIAL CORRESPONDENCE

The attached correspondence has been received in Private Office. Please acknowledge immediately and send an official reply indicating that the Minister has asked you to reply.

If it later transpires that this is not for your Agency, please pass to the appropriate section or division.

If it is for another Department, please transfer to the Private Office of that Department. It is not necessary to inform Private Office of the transfer.

L A Walker

LOUISE WALKER
Private Office
Correspondence Section
Richmond House
Room 239

ME
MYALGIC ENCEPHALOMYELITIS ASSOCIATION
GROUP
Address:

LEICESTERSHIRE GROUP

Membership Secretary:
36, Scraptoft Lane,
LEICESTER
LE5 1HU
Tel: 766998

Mr Tony Newton,
Secretary of State for
Social Security,
House of Commons,
LONDON SW1A OAA

5th March 1992

Dear Mr Newton,

M.E. Definition Errors in the DLA Handbook

I have just received a copy of the contentious paragraph of the DLA handbook (enclosed) in which it is quite apparent that rather than trying to extend the social security benefits for people you are in reality deliberately attempting to disqualify many thousands of people who would currently be entitled to mobility and other benefits. Since you have been well-briefed by M.E. Associations both nationally and locally this political ploy is nothing short of fraud and is an attempt to mislead doctors and adjudicators.

As you must well know by now, the reason that sufferers are fearful of the consequences of walking is because from past experience they KNOW the consequences. The question is not merely to do with muscle power but equally with the devastating effect on subsequent energy levels that walking will have, and in that I mean the high risk of major relapse lasting over a period of weeks or months. Since this scenario is similar to that of heart patients why is it so difficult for you to understand? As exercise is believed to increase virus replication (the cause of M.E.) is it no wonder that people don´t want to be made worse by aggravating this. Brynmoor John, one of your ex-colleagues, died as a result of doing too much while trying to recover from M.E. Surely this is a lesson to you.

One of my members last year in a desperate attempt to exercise her way out of the rut she was in decided to walk 20 yards to the corner of her road and back to her house. This she achieved quite successfully. However, later in the day she became quite ill and the next day had gone into a severe relapse. This unfortunately is all too common an occurrence. I am amazed and appalled at the number of wheelchair sufferers and desperately ill people that have recently been turned down for benefit. Exploiting the sick by rigging the health criteria for benefits is as low as any politican can get particularly when he is trying to convince the electorate otherwise. Many M.E. sufferers will remain housebound because of this.

12.5.2 CHRONIC FATIGUE SYNDROMES AND MYALGIC ENCEPHALOMYELITIS

12.3.2 A great deal of help may be expected by, and is often given to, a sufferer from CFS or ME. Sufferers are sometimes advised to rest completely but muscles which are not used deteriorate rapidly. There is however another school of thought which advocates graded exercise of muscles to assist the return to normal muscle function and power. In some studies of people affected by chronic fatigue syndromes objective tests of muscle power have shown it to be normal or near normal. A person affected by these syndromes may therefore be able to attend to bodily functions without the assistance of another but each case must be considered in the light of the available evidence.

12.4 Mobility considerations

In some controlled clinical studies people with chronic fatigue syndromes have been shown to have adequate muscle power. They may however refrain from walking because they are fearful of the consequences.

12.5 Additional sources of evidence

A report by an Examining Medical Practitioner may greatly assist in helping the affected person properly identify the level and extent of care and mobility needs.

Science report

Post-viral fatigue explained

By Pearce Wright Science Editor

A remarkable discovery by a medical research team at Oxford explains why people can feel tired, listless and exhausted for many days and even weeks after they have recovered from a virus infection such as influenza. When people say: "I have no energy to do anything", they are probably right. The intricate chemical reactions which breakdown the fuel to be turned into muscle power have gone wrong.

The discovery was made by a new procedure in medical diagnosis. For the first time, it allowed doctors to obtain a biochemical analysis of what was happening in the arm muscle of a patient at the instant he was asked to exercise.

A report on the discovery in *The Lancet* says the abnormality could not be identified with traditional methods, and the findings point to a newly identifiable mechanism of disease.

However, the detection of this abnormality depends on an examination using a method known as nuclear magnetic resonance, NMR, which is available at only a few medical centres, for making body scan pictures without using X-rays.

The new application of NMR for biochemical analysis of organs, without taking as much as a blood smear, not to mention a biopsy, is a tremendous advance.

The case report in *The Lancet* describes how it was used to measure the changes which took place in the high-energy phosphates in a patient. He had been suffering prolonged exhaustion and fatigue after a viral infection. Coincidentally, the patient was a general practitioner aged 30 who had been in good health until an attack of chickenpox at the age of 26.

Recovery hed never been complete. He was left with a general malaise. He was easily fatigued both physically and mentally and had a persistent feeling of unsteadiness.

Although most people get over the fatigue and exhaustion associated with viral illness, a small number of patients never recover and investigations have failed to provide an explanation of the symptoms.

The diagnosis of the doctor's syndrome was made by specialists at the Radcliffe Infirmary, Oxford, working with Professor George Radda, FRS, who has pioneered clinical magnetic resonance techniques.

The method works because elements and compounds have a distinct magnetic signature which can be produced by surrounding an object, in this case the arm, with a coil in which an intense magnetic field is generated.

In the new diagnostic procedure, the analysis allows doctors to compare the concentration of chemical compounds in the tissue with the values that should exist under normal conditions.

(42)

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26/3/12

42/10

Westcare
15 Queen Victoria Road, Redland, Bristol BS6 7PE (Tel. 0272 - 738317)
Registered Charity. No. 900619

March 25 1992

Dr J Metters
Deputy Chief Medical Officer
Richmond House
79 Witehall
LONDON SW1

cc. Dr Castaldi
Dr Aylward

26/3

Dear Dr Metters,

I am writing to confirm our meeting at 3.30 pm on Monday next (March 30th). I understand that Dr Castaldi and Dr Aylward from the DSS will be present.

Three doctors will be coming with me, Dr Charles Shepherd, Vice President of the ME Association, Dr Anne Macintyre, ME Action Campaign and Dr Derek Pheby (Westcare - Director of the Cancer Epidemiology Unit, University of Bristol).

In order to have a fruitful discussion, we ask that up to one hour thirty minutes should be available for the meeting. I do hope that it will be possible to make progress on the issues which we are bringing to your attention.

Yours sincerely,

Richard Sykes

RICHARD SYKES

5/45

WESTCARE aims to make available information about M.E. (Myalgic Encephalomyelitis) and similar conditions and to help in the provision of services and care for ME sufferers in Bristol and the West of England.
Director: Richard Sykes M.A. (Cantab) Ph.D., C.Q.S.W.

APPENDIX B

CORRESPONDENCE

CORRESPONDENT	DATE
Westcare	11.11.91
ME Action Campaign	30.10.91
Westcare	14.09.91
International Federation of ME Associations	06.09.91
ME Action Campaign	04.09.91
ME Association	28.08.91
Royal Association for Disability and Rehabilitation	23.08.91
Standard letter from the general public produced by ME Association and ME Action Campaign	April 91
ME Association	18.08.90
ME Association	20.08.90
ME Action Campaign	16.03.90
Dr G A Jamal Dept of Neurology, University of Glasgow	08,03.90
Dr Anthony Pelosi MSc MRCP MRCPsych Dept of Psychiatry, University of Edinburgh	29.02.90 (probably 01.03.90)
ME Association	12.06.89
ME Action Campaign	25.10.89
ME Association	23.12.88

APPENDIX A

ARTICLES

TITLE	AUTHOR	JOURNAL	DATE	VOLUME
Evidence for Impaired Activation of the Hypothalamic-Pituitary-Adrenal Axis in Patients with Chronic Fatigue Syndrome	Mark A Demitrack et al	Journal of Clinical Endocrinology and Metabolism	1991	73 Part 6 Pages 1224-34
Editorial - Chronic Fatigue Syndrome	Dr Simon C Wessely	Journal of Neurology, Neurosurgery and Psychiatry	1991	54 Pages 669-671
History of Chronic Fatigue Syndrome	Dr Stephen E Straus	Reviews of Infectious Diseases	1991	13 (Supp 1) Pages S:2-7
Chronic Fatigue Syndrome: Clinical condition associated with immune activation	Alan L Landay et al	The Lancet	21.9.91	338 No 8769 Pages 707-12
Enteroviral RNA sequences detected by polymerase chain reaction in muscle of patients with postviral fatigue syndrome	J W Gow et al	British Medical Journal	23.3.91	302 Pages 692-6
Post-Viral Fatigue Syndrome: Evidence for Underlying Organic Disturbance in the Muscle Fibre	Goran A Jamal et al	European Neurology	1989	29 Pages 273-6

Persistence of enterviral RNA in chronic fatigue syndrome is associated with the abnormal production of equal amounts of positive and negative strands of enteroviral RNA	Louise Cunningham et al	Journal of General Virology	1990	71 Pages 1399-1402
ME and Psychiatric Illness	Ellen Goudsmit	Perspectives	1990	Pages 11-13
Muscle strength, endurance and recovery in the post-infection fatigue syndrome	A R Lloyd et al	Journal of Neurology, Neurosurgery and Psychiatry	1988	51
Myalgic Encephalomyelitis - A brief review of the literature	Ellen M Goudsmit		July 91	
IFMEA - Medical Update	Ellen Goudsmit et al		1991	3 No 2
Consensus on research into fatigue syndrome	Alexander Dorozynski	British Medical Journal	31.3.90	300 Page 832
IFMEA - Medical Update	L Davies et al		1991	3 No 1
Digging for clues to fatigue	Phyllis Shaw	International Federation of Multiple Sclerosis Societies - UPDATE	Summer 1990	4 No 2 Page 3
Myalgic Encephalomyelitis: Postviral Fatigue Syndrome	Peter O Behan MD FACP FRCP	Diagnostic and Clinical Guidelines for Doctors		

History of Chronic Fatigue Syndrome	Stephen E Straus	Reviews of Infectious Diseases	1991	13 (Supp 1) S2-7
Chronic fatigue syndrome: clinical condition associated with immune activation	Alan L Landay et al	The Lancet	21.9.91	338 No 8769 Pages 707-12
A dose of salts for ME	Dr Thomas Stuttaford	The Times	11.4.91	
Postviral Fatigue Syndrome	Anthony J Pelosi et al	British Medical Journal	7.5.88	296 Pages 1329-30
Electrophysiological studies in the post-viral fatigue syndrome	Goran A Jamal et al	Journal of Neurology, Neurosurgery, and Psychiatry	1985	48 Pages 691-94
Campaign for Benefits - Time to Act Against Prejudice and Ignorance	-	'InterAction', the Journal of M.E. Action	Autumn 1989	3
Please believe ME, I'm ill	John Illman	The Guardian	8.12.89	
Myalgic Encephalomyelitis: A Baffling Syndrome with a Tragic Aftermath	A Melvin Ramsay MA MD			
Myalgic Encephalomyelitis - A Brief Description		The Observer		

Myalgic encephalomyelitis - a persistent enteroviral infection	E G Dowsett et al	Postgrad Med J	1990	66 Pages 526-30
Cardiac Function at Rest with Exercise in the Chronic Syndrome	Terence J Montague et al	Chest	April 1989	Pages 779-83
Symptoms and Signs of Chronic Fatigue Syndrome	Anthony L Komaroff et al	Reviews of Infectious Diseases	1991	13 (Supp 1) S8-11
Detection of Epstein-Barr Virus DNA in Muscle from Patients with the Postviral Chronic Fatigue Syndrome, Myalgic Encephalomyelitis	L Archard et al	J Exp Clin Cancer Research	7.3.88	Supplement Page 142
Chronic Fatigue Syndrome in Northern Nevada	Sandra A Daugherty et al	Reviews of Infectious Diseases	1991	13 (Supp 1) S39-44
Postviral fatigue syndrome: persistence of enterovirus	L C Archard PhD et al	Journal of the Royal Society of Medicine	June 1988	81 Pages 326-29
Loss of form in young athletes due to viral infection	J A Roberts BSC MRGP	British Medical Journal	2.2.85	290 Pages 357-58
CD8 Deficiency in Patients with Muscle Fatigue Following Suspected Enteroviral Infections (Myalgic Encephalomyelitis)	J R Hobbs et al	Protides of the Biological Fluids	1989	36 Pages 391-98

Thank you for your letter of on behalf of about the entry on Myalgic Encephalomyelitis (ME) in the recently published Disability Living Allowance Handbook.

I can reassure you that both this Department and the Department of Health recognise Myalgic Encephalomyelitis as a debilitating and distressing condition affecting many people.

The chapter on Chronic Fatigue Syndrome and Myalgic Encephalomyelitis in the Disability Handbook was written following careful study of papers and articles on these conditions in several scientific journals. Drafts of the handbook were circulated widely among organisations representing disabled persons for consultation before it was published. The Disability Living Allowance Advisory Board was also consulted, and met with members of the M.E. Action Group to discuss the drafting of this chapter. Many of the suggestions made by the M.E. Action Group were incorporated into it. The Board itself includes eminent clinicians from the whole range of medical specialties and members who are either disabled themselves or involved in the care of disabled people. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

The Handbook acknowledges the two conditions are not fully understood. It recognises that in some persons with Myalgic Encephalomyelitis there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for Myalgic Encephalomyelitis is recognised. The Handbook does not suggest that "it is all in the mind".

The Handbook also recognises that there is as yet no consensus with regards to advice given to sufferers. Some doctors advise complete rest, but there is another large consensus of medical opinion which advocates graded exercise of muscles to assist the return to normal.

The Handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help Adjudication Officers in deciding claims to Disability Living Allowance and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

The Handbook is not intended to be used in preference to evidence available in individual cases. The introduction to the Handbook (para 1.1.1) clearly explains this.

Entitlement to Disability Living Allowance does not depend on a particular illness, disease or diagnosis. It depends on each persons needs for attention with personal care, or supervision/watching over to avoid substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

The Disability Handbook will be regularly reviewed and revised. The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of claims to Disability Living Allowance over the next few months before advising revision of any of the chapters in the Handbook. The Board will be closely observing the situation. Although there will be no immediate changes, all representations received will be carefully considered when the Handbook is next revised.

As far as providing information for the medical profession is concerned, the Department of Health inform me that it is encouraged by the increased number of informed articles on ME appearing in professional journals and by the number of regional health authorities approving courses for GPs in ME; the various ME groups do valuable work in this area too. It is not that Department's practice, however, to issue clinical guidance to doctors, and, until such time as more is known about the illness and its epidemiology, the Department of Health does not believe it is in a position to send out more authoritative information than is provided already.

Several studies are already taking place into the possible physical causes of ME, while the Medical Research Council is funding a study at the Institute of Psychiatry to investigate chronic fatigue in GP's attenders. Researchers at the Institute are attempting to find ways to help ME sufferers cope with their disease and regain their health, which then can be used in a primary care setting. All evidence suggests that, whilst the primary trigger may be viral, the determinants producing the condition are more complex.

The source of such a study should not be assumed to imply any preconceived ideas about its likely findings. The Institute's study is an initial exercise which will enable us to assess the feasibility of further studies as well as providing some information on the epidemiology of ME. The Department of Health advises me that it would wish to have an opportunity to consider the results of that study, together with any problems encountered in carrying it out, before deciding what further studies are feasible.

I am grateful for the opportunity to explain the position.

42a

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4/3/92

Dr Castaldi CMA

From: Dr J S Metters DCMO
3 March 1992

Copies to: Dr Aylward
Mr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE : PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. Thank you for your minute of 27 February. I am grateful for your offer to join me for the meeting with Westcare's representatives. It would be helpful if Dr Aylward can also join us.

2. I am asking my secretary to find a mutually convenient day for Dr Sykes and his colleagues to meet us.

pp YdeSampayo

J S METTERS
Room 509
Richmond House

314/YdeS

Reference..

Mansel.

Peter Castaldi may have mentioned this latest ME campaign. These are the key papers – Peter has the originals.

The specific AA case is no great problem: the RD was the standard defence, & the SSC appeal succeeded on a technicality [copy of early DS4 not sent to claimant].

Peter wants to attend the meeting + you ~~or me~~. I think I can prepare full briefing.

I doubt if Prd. will want to attend – & A2 certainly don't! (They were invited to become involved & politely declined the honour)

26.2.92

CODE 18-78

24/12

Dr Castaldi CMA

From: Dr J S Metters DCMO
3 March 1992

Copies to: Dr Aylward
Mr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE :
PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. Thank you for your minute of 27 February. I am grateful for your offer to join me for the meeting with Westcare's representatives. It would be helpful if Dr Aylward can also join us.

2. I am asking my secretary to find a mutually convenient day for Dr Sykes and his colleagues to meet us.

pp YdeSampayo

J S METTERS
Room 509
Richmond House

314/YdeS

Dr J S Metters DCMO

From: Chief Medical Adviser

Date: 27 February 1992

Copy: Dr M Aylward BAMS-3
Dr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE: PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. Thank you for sending me the papers about this subject.

2. I would be happy personally to accompany you to meet Westcare's representatives, although I would like to bring along Dr Aylward the PMO who has been very actively involved in the development of the new Disability Living Allowance. He was involved especially in the process of consulting a large number of special interest groups on a wide variety of subjects.

P CASTALDI
FRH 211 EXT 23286

25-2-92
Discuss with
AA/DLAA Board Secretariat
in first instance

Dr Castaldi
FRH 213

From: Dr J S Metters DCMO
24 February 1992

Copies to: Mr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE : PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. You will wish to see these papers which begin with a letter from Dr Richard Sykes dated 15 January. Dr Sykes is Director of "Westcare", a charity concerned with Myalgic Encephalomyelitis.

2. The Secretary of State has asked that direct contact be established with "Westcare" to discuss some problems about ME-related matters in the Sidmouth area.

3. It has been agreed that I and a "Senior Social Security Doctor" should meet Westcare's representatives. I would appreciate your advice about which senior social security doctor should join me for this meeting.

pp. Y de Sampayo

J S METTERS
Room 509
Richmond House

283/YdeS

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26/3/12

Dr P. Castaldi DMS
Room 211/212
Friars House

Dr M. Aylward PMO

From: Dr M. Henderson
Secretary DLAAB

Date: 5 March 1992

Secretary of State for Health's Constituency Case: Provision of Services for care of ME sufferers in the South Western Area.

1. I have been dealing with various items of Parliamentary correspondence in relation to the Disability Handbook and M.E.

2. The enclosed data may be of use to you as briefing for your forthcoming meeting with Westcare. It includes the official line taken by the Department of Health on various issues.

3. The line which I have taken on the Disability Handbook has been approved by Professor Marshall on behalf of the DLAAB.

4. Please let me know if there is any further information which I can provide.

Moira Henderson

DR M. HENDERSON
ROOM 11/26
ADELPHI
EXT 28794

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POS

Thank you for your letter of on behalf of about the entry on Myalgic Encephalomyelitis (ME) in the recently published Disability Living Allowance handbook.

I can reassure you that both this Department and the Department of Health recognise ME as a debilitating and distressing condition affecting many people.

The chapter on Chronic Fatigue Syndrome and ME in the disability handbook was written following careful study of papers and articles on these conditions in several scientific journals. Drafts of the handbook were circulated widely among organisations representing disabled persons for consultation before it was published. The Disability Living Allowance Advisory Board was also consulted, and met with members of the ME Action Group to discuss the drafting of this chapter. Many of the suggestions made by the ME Action Group were incorporated into it. The Board itself includes eminent clinicians from the whole range of medical specialties and members who are either disabled themselves or involved in the care of disabled people. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

The handbook acknowledges the two conditions are not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence, a physical cause for ME is recognised. The handbook does not suggest that "it is all in the mind".

The handbook also recognises that there is as yet no consensus with regards to advice given to sufferers. Some doctors advise complete rest, but there is another large consensus of medical opinion which advocates graded exercise of muscles to assist the return to normal.

5375a+/

The handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help adjudication officers in deciding claims to Disability Living Allowance and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

The handbook is not intended to be used in preference to evidence available in individual cases. The introduction to the handbook (para 1.1.1) clearly explains this.

Entitlement to Disability Living Allowance does not depend on a particular illness, disease or diagnosis. It depends on each person's needs for attention with personal care, or supervision/watching over to avoid substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

The disability handbook will be regularly reviewed and revised. The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the handbook, considers that the best approach at present would be to wait and assess the outcome of claims to Diability Living Allowance over the next few months before advising revision of any of the chapters. The Board will be closely observing the situation. Although there will be no immediate changes, all representations received will be carefully considered when the handbook is next revised.

The other issues raised concerning research and information on ME are the responsibility of the Department of Health , to whom I am copying this correspondence for separate consideration.

I am grateful for the opportunity to explain the position.

1. Mr Sharpe
2. Mr I Jones
   Parliamentary

From : R M Freeman HP(A)3B
Date : 27 February 1992
cc : Dr Henderson DSS
Dr Hilton HP(M)
Mr Wilson

EARLY DAY MOTION 759 : MYALGIC ENCEPHALOMYELITIS

I attach a line to take - provided by Dr Henderson (DSS) - plus background notes on the three points made in the EDM.

R M FREEMAN
AREA 425
WELLINGTON HOUSE
EXT 24178

759 *MYALGIC ENCEPHALOMYELITIS* 26:2:92

Mr Edward O'Hara
Mr Peter Kilfoyle
Mr Martin Flannery
Mr Harry Barnes
Mr Ted Leadbitter
Mr David Clelland

★ 19

Mr Jimmy Dunnachie
Mr Dennis Turner
Mr George Howarth
Mr Joe Benton
Mr Gordon McMaster
Maria Fyfe
Mr Peter Hain
Mr Martyn Jones
Mr Terry Rooney
Mr John Battle
Mr Derek Enright
Mr Robert Parry
Mr Ian McCartney

✓ That this House notes the statement of the Parliamentary Under Secretary of State at the Department of Health that myalgic encephalomyelitis is 'a debilitating and distressing disease affecting many thousands of people'; regrets therefore the entry in the recently published Disability Living Allowance Handbook, which suggests that myalgic encephalomyelitis may be 'all in the mind' and that many, if not most, myalgic encephalomyelitis sufferers will have no new need of benefits; and calls upon the Secretary of State for Health to (i) arrange for the current Disability Living Allowance Handbook text to be corrected immediately to reflect the seriously disabling nature of myalgic encephalomyelitis and the latest scientific knowledge, (ii) send out to the medical profession authoritative information about myalgic encephalomyelitis and (iii) fund from the Department of Health budget research into the physical causes of myalgic encephalomyelitis and possible treatments.

★ *The figure following this symbol gives the total number of names of Members appended, including those names added in this edition of the Notices of Questions and Motions.*

LINE TO TAKE

The relevant chapter in the Disability Handbook was written following study of relevant scientific papers and consultation with the Disability Living Allowance Advisory Board and The ME Action Group. The Handbook does not suggest that ME is all in the mind. The Handbook provides general information about care needs and mobility requirements resulting from disabling conditions, but each claim to benefit is decided on the basis of the individual circumstances of that claim.

Background note

The Disability Handbook has been written by senior medical staff of the Benefits Agency Medical Services. The Disability Living Allowance Advisory Board, comprising a wide range of experience of disablement and expertise in managing it, was extensively consulted. Many organisations involv~~ing~~ed in the care of the disabled, including the ME Action Group, were consulted.

The Disability Handbook is primarily intended for Adjudication Officers of the Benefits Agency, who determine eligibility to DLA. It is not intended to be used in preference to the evidence available in individual claims, each of which must be considered on its own merits.

The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of DLA claims over the next few months before advising any revision of the Handbook.

It is not the Department's practice to issue clinical guidance to doctors; that is a matter for the medical profession. However, we are encouraged by the increasing number of informed articles on ME appearing in professional journals and by the number of Regional Health Authorities approving courses for GPs in ME; the various ME groups do valuable work in this area too.

The Medical Research Council is funding a study at the Institute of Psychiatry to investigate chronic fatigue in general practitioner's' attenders. The Institute's study is an initial exercise which will enable us to assess the feasibility of further studies as well as providing some information on the epidemiology of ME. We would wish to have an opportunity to consider the results of that study, together with any problems encountered in carrying it out, before deciding what further studies are feasible.

To MR WILSON
HP(A)3B
RM 402 WELL

From: Eva Davison (PRU)
Date: 2/3/92

Please find attached a copy of your new standard ~~letter~~/paragraphs about:-
Myalgic Encephalomyelitis and The Disability Handbook

[ ] Minister has approved

[✓] Minister has approved with amendments

[ ] Minister would like a redraft

[ ] Your amendments have been incorporated

Your standard is called ME and this must be quoted clearly on all drafts.

If you are using paragraphs you must also quote the number of the paragraph.

Please check the draft **VERY** carefully for errors and notify me if any amendments are necessary. Hold on to any yellow jackets relating to this standard until all amendments have been made and checked.

If any of your yellow jackets are coming up to, or are past, their due date please send me a list of the numbers.

Thank you

Eva Davison
Correspondence Section
Room 226 Ext 5075

ME

MYALGIC ENCEPHALOMYELITIS
WILSON
HP(A)3B ROOM 402
WELLINGTON HOUSE
EXTENSION 24177
27/1/92

ME1

The chapter on Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME) in the Disability Handbook was written following careful study of papers and articles on these conditions in several scientific journals. Drafts of the handbook were circulated widely among organisations representing disabled persons for consultation before it was published. The Disability Living Allowance Advisory Board was also consulted, and met ~~with~~ members of the ME Action Group to discuss the drafting of this chapter. Many of the suggestions made by the ME Action Group were incorporated into it. The Board itself includes eminent clinicians from the whole range of medical specialties and members who are either disabled themselves or involved in the care of disabled people. The Board members therefore have a wide expert knowledge of disability and its effects on everyday life.

ME2

that The Handbook acknowledges the two conditions are not fully understood. It recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence a physical cause for ME is recognised. The Handbook does not suggest that "it is all in the mind".

ME3

The Handbook also recognises that there is as yet no consensus ~~with regards to~~ advice given to sufferers. Some doctors advise complete rest, but there is another large consensus of medical opinion which advocates graded exercise of muscles to assist the return to normal. on

ME4

The Handbook describes the care needs and the mobility requirements likely to arise from various disabilities and chronic illnesses. It provides general information about these conditions. It is primarily intended to help Adjudication Officers in deciding claims to Disability Living Allowance and Disability Working Allowance. It is not intended to be used as authoritative information in any other context.

ME5

The Handbook is not intended to be used in preference to evidence available in individual cases. The introduction of the Handbook (para 1.1.1) clearly explains this.

ME6

Entitlement to Disability Living Allowance does not depend on a particular illness, disease or diagnosis. It depends on a person's need for care, or supervision to avoid substantial danger, or on the difficulty in getting around which arises from disablement. Each claim is considered individually, and is judged solely on whether the eligibility criteria applicable to the benefit are satisfied in that particular case.

ME7

The Disability Handbook will be regularly reviewed and revised. The Disability Living Allowance Advisory Board, which has the function of advising on the contents of the Handbook, considers that the best approach at present would be to wait and assess the outcome of claims to Disability Living Allowance over the next few months before advising revision of any of the chapters in the Handbook. The Board will be closely observing the situation. Although there will be no immediate changes, all representations received will be carefully considered when the Handbook is next revised.

ME8

As far as providing information for the medical profession is concerned, we are encouraged by the increased number of informed articles on ME appearing in professional journals and by the number of regional health authorities approving courses for GPs in ME; the various ME group/ s/ do valuable work in this area too. It is not the Department's practice, however, to issue clinical guidance to doctors, and, until such time as more is known about the illness ~~of~~ its and/ epidemiology, I do not believe that the Department is in a position to send out more authoritative information than is provided already.

ME9

Several studies are already taking place into possible physical causes of ME, while the Medical Research Council is funding a study at the Institute of Psychiatry to investigate chronic fatigue in GP's attenders. Researchers at the Institute are attempting to find ways to help ME sufferers cope with their disease and regain their health, which can then be used in a primary care setting. All evidence suggests that, whilst the primary trigger may be viral, the determinants producing the condition are more complex.

ME10

The source of such a study should not be assumed to imply any pre-conceived ideas about its likely findings. The Institute's study is an initial exercise which will enable us to assess the feasibility of further studies as well as providing some information on the ~~epidemilogy~~ of ME. /* We would wish to have an opportunity to consider the results of that study, together with any problems encountered in carrying it out, before deciding what further studies are feasible.

* epidemiology

** TOTAL PAGE.005 **

E.5.1.

Dr J S Metters DCMO

From: Chief Medical Adviser

Date: 27 February 1992

Copy: Dr M Aylward BAMS-3
Dr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE: PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. Thank you for sending me the papers about this subject.

2. I would be happy personally to accompany you to meet Westcare's representatives, although I would like to bring along Dr Aylward the PMO who has been very actively involved in the development of the new Disability Living Allowance. He was involved especially in the process of consulting a large number of special interest groups on a wide variety of subjects.

P CASTALDI
FRH 211 EXT 23286

25-2-92
Discuss with AA/DLAA Board Secretariat in first instance.

Dr Castaldi
FRH 213

From: Dr J S Metters DCMO
24 February 1992

Copies to: Mr Padwick
Dr Nicholas

SECRETARY OF STATE FOR HEALTH'S CONSTITUENCY CASE : PROVISION OF SERVICES FOR CARE OF ME SUFFERERS IN THE SOUTH WESTERN AREA

1. You will wish to see these papers which begin with a letter from Dr Richard Sykes dated 15 January. Dr Sykes is Director of "Westcare", a charity concerned with Myalgic Encephalomyelitis.

2. The Secretary of State has asked that direct contact be established with "Westcare" to discuss some problems about ME-related matters in the Sidmouth area.

3. It has been agreed that I and a "Senior Social Security Doctor" should meet Westcare's representatives. I would appreciate your advice about which senior social security doctor should join me for this meeting.

pp. YdeSampayo

J S METTERS
Room 509
Richmond House

283/YdeS

49—112

The National Archives

LETTERCODE/SERIES BN 141

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Initial & Date

8/A
26/3/12

(Social Security Act 1975 section 35 (1) and (2))

Medical conditions

To be entitled to Attendance Allowance, a person must be so severely disabled physically or mentally that,

By day — he requires from another person, frequent attention throughout the day in connection with his bodily functions;

or

he requires from another person continual supervision throughout the day in order to avoid substantial danger to himself or others;

At night — he requires from another person prolonged or repeated attention in connection with his bodily functions;

or

in order to avoid substantial danger to himself or others he requires another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over him.

This extra condition applies to claims for children up to age 16

In the case of children, the attention or supervision or watching over they require must be substantially in excess of that normally required by a child of the same age and sex. (Social Security (Attendance Allowance) (No 2) Regulations, regulations 6(1) and 6(2)).

To qualify for Attendance Allowance you must satisfy one or more of the medical conditions for at least 6 months.

Making a fresh claim

If you make a fresh claim for Attendance Allowance you may not have to wait 6 months to qualify again if there was a certificate of attendance needs in issue within the past 2 years.

The special rules

The allowance can be paid to a person (including a child under 16) who, at the date of claim, suffers from a progressive disease and whose death, in consequence of that disease, can reasonably be expected within 6 months.

If you are claiming under the special rules, you do not need to satisfy the 6 month qualifying period.

The rates of the allowance

There are 2 rates of Attendance Allowance. The lower rate is payable if you need a lot of help during the day **or** the night. The higher rate is payable if you need a lot of help during the day **and** the night **or** if you satisfy the special rules.

The law about Attendance Allowance reviews

The law about Attendance Allowance reviews is set out in Social Security (Adjudication) Regulations 1986 (Regulations 38 and 39) and the Social Security Act 1975, Section 106(1). You can find copies of these at your Social Security office, a Citizens Advice Bureau, main Library or local law centre.

Typeset and printed for [illegible]

Westcare
15 Queen Victoria Road, Redland, Bristol BS6 7PE (Tel. 0272 - 738317)

Registered Charity No.900619

21 February 1992

Dr J Metters
Deputy Chief Medical Officers
Richmond House
79 Whitehall
LONDON SW1

Dear Dr Metters,

Thank you very much for your phone call this afternoon.

As suggested on the phone, copies of the papers being sent to Mr Waldegrave are enclosed herewith.

I shall be away next week but I look forward to a meeting in the near future.

Yours sincerely,

Richard Sykes

RICHARD SYKES

/encs.

WESTCARE aims to make available information about M.E. (Myalgic Encephalomyelitis) and similar conditions and to help in the provision of services and care for ME sufferers in Bristol and the West of England.
Director: Richard Sykes M.A. (Cantab), Ph.D., C.Q.S.W.

Westcare
15 Queen Victoria Road, Redland, Bristol BS6 7PE (Tel. 0272 - 738317)
Registered Charity No.900619

17 February 1992

Corinne Short
Editor
Medical Monitor
The Quadrant
118 London Road
KINGSTON-UPON-THAMES
Surrey KT2 6QJ

Dear Madam,

Our registered charity Westcare has been providing medical and counselling support for people with Post Viral Fatigue Syndrome/ M.E., for the past 2½ years. Our experience is quite the reverse of that expressed by the anonymous doctor (14 March). What we encounter is genuine disability, often severe, and great suffering.

Our knowledge of patients is derived from working with them over extended periods and there are many reasons for believing that what they tell us is true. Before their illness they had no need or desire for an "escape route". When ill they feel intense frustration (not relief that they no longer have to work). Periods of remission bring tantalising joy (not despondency that their excuse for avoiding their problems has gone). Those that recover are delighted to be able to work again and put the misery of the illness behind them.

We would be glad to share our experience with the anonymous doctor and with any other doctor who wishes to learn more about this complex illness. We find it sad that the writer has chosen to dismiss and deride patients with M.E.: they have enough to endure already.

Yours sincerely,

Richard Sykes

RICHARD SYKES M.A. Ph.D
Director, Westcare.

DR DALRYMPLE'S DILEMMAS

the right to cut them. Published letters will receive an honorarium of £15. Please write to: Corinne Short, Editor, *Medical Monitor*, The Quadrant, 118 London Road, Kingston-upon-Thames, Surrey, KT2 6QJ. Letters can also be sent by fax: 081-541 4746

Myalgic encephalomyelitis — my eye

ME is a disease of the spirit, believes Theodore Dalrymple, who sees the middle classes escaping on the back of 'Yuppie flu'

A short time ago, I published an article about myalgic encephalomyelitis. I broke no new scientific ground: I merely suggested that the condition was akin to the neurasthenia of old, and — unlike real diseases — was more common among the semi-intellectual middle classes.

To my surprise, I received scores of letters from sufferers: despite the fatigue which had prevented them from going to work, washing up, shopping and so on, they managed to write several pages of impassioned prose.

I went to a symposium on the illness (if that is what it is) last week. As the participants gathered just before it began, I heard anxiously whispered questions among them as they tentatively sounded each other out: 'Do you believe in it?' Care had to be exercised, because two sufferers were in the audience, pale and thin-lipped ladies of vengeful appearance, waiting to pounce neurasthenically on those who dared to suggest that their sufferings were other than virally induced.

From time to time I see cases of this mysterious condition, and in my heart of hearts I believe it to be a sickness not of the body but of the spirit. I am rarely the first doctor the sufferers have consulted: more frequently I am the 46th.

The patients come armed with sheaves of papers, pamphlets, documents and so forth to persuade me that there was never suffering like theirs, and that it is viruses that cause it. The whole episode is more like an attempt at religious conversion than a normal consultation.

'What's your position on ME?' they say, more like an accusation than a question.

'I don't think ME is incompatible with a long life,' I remark, as mildly and dryly as I can.

Quite often I am handed a photocopied page of laboratory results, in the way that candidates for rather minor positions hand over educational certificates or personal testimonials. The results are of antibody tests ordered by doctors convinced of the reality of ME (by reality I mean, of course, the physical causation).

> *“My experience of ME sufferers is that they suffer triumphantly, and that their claim that the disease has ruined their lives is not to be believed”*

The antibody tests demonstrate that at some time in the past the patient has been infected with one or several viruses. The presence of these antibodies reinforces the conviction of the patient that he or she has an indubitably physical illness.

In vain do I tell the patients that my blood carries antibodies against hepatitis A, but that this does not account for the tiredness against which I — like most of humanity — have long struggled. Koch's postulates are not fulfilled by the mere presence of antibodies (or even of the allegedly causative viruses themselves). Until someone can demonstrate that viral infections produce the same effects in a population that has never heard of ME, I shall remain sceptical.

By now, it will be obvious to the reader that I do not have a completely open mind on the subject. I have my own, admittedly rather ill-formed, theory about ME. It is an escape route for the middle classes, especially teachers and paramedics such as physiotherapists, occupational and speech therapists.

I do not in the least blame them for wanting to escape. Anyone who has dealt with modern British youth or the public at large must often want to do that. But the desire to escape is not something they can easily admit to themselves, especially if they see themselves as carers (horrible word).

ME offers not just an escape but something better still: a cause. You can suffer and, by joining one of the pestilential self-help or pressure groups, believe that in some way your suffering is not entirely in vain, but is helping to bring about a better world.

Almost everyone I spoke to at the symposium agreed with me, but only in secret and only in hushed tones. Of course, the ME groups will take this as yet another sign of the medical profession's criminal blindness and lack of understanding (how delicious it is to be misunderstood by everyone!) But in my opinion, the unwillingness of the medical profession to speak plainly on this matter is a sign of pusillanimity, not of obduracy. My experience of ME sufferers is that they suffer triumphantly, and that their claim that the disease has ruined their lives is not to be believed.

I could write a great deal more on this fascinating subject, but unfortunately I had the flu four years ago and am feeling rather tired.

Theodore Dalrymple is the pen name of a practising doctor

9-213

RECEIVED
5 FEB 1992
DR. D. WALFORD

Dr Abrams
Dr Metters
Dr Walford

From: Jane Verity APS/CMO
Date: 4 February 1992

SECRETARY OF STATE'S CONSTITUENCY CASE: PROVISION OF SERVICES IN CARE FOR ME SUFFERERS IN THE SOUTH WESTERN AREA

Please find enclosed a copy of the papers we have received from Secretary of State's office about "Westcare" - a charity which deals with the problems of ME sufferers in Bristol and the South West.

Secretary of State has asked for CMO or a DCMO to establish direct contact with Westcare to discuss ME related matters. CMO would be grateful for your advice but feels that perhaps he should meet Westcare.

cc Dr Abrams
Dr Walford

Ms Verity
I agree with Dr Walford about the need to involve DSS. However I would suggest that CMO delegates the meeting to myself & a DSS senior doctor.
JM 11.2.91.

Jane Verity.

ENC.

cc Dr Abrams
Dr Metters o/r

JANE VERITY
Rm 109, Richmond Hse
Ext 5151

Ms Verity
This is definitely a "health" and other government depts issue and not NHS matter so it would fall to Dr Metters, if a DCMO were to meet Westcare. However, the issue is as much for DSS as for us and CMO might like a) to seek advice from Dr Eggington (or his replacement if he has retired) and, (b) when he or the DCMO meet Westcare, perhaps Dr Eggington should be in attendance
Diana Walford
5/2

~~Corr. with DLAAB~~.
M.E.

Dr M. Aylward PMO
11/26
Adelphi

From: Dr M. Henderson
Secretary DLAAB

Date: 31 January 1992

cc: Professor J. Marshall
Dr T. Scott
Mr K. Palmer
Mr I. Rogers

RE: ME Action Campaign

1. Thank you for your minute dated 30 January 1992.

2. Identical data has been sent to me, for distribution to Professor Marshall and all members of the DLAAB.

3. I have discussed the matter with Professor Marshall, and we consider that the most appropriate action would be for the Full Board to discuss the papers at it forthcoming meeting (25 February). They will therefore be sent out to all members together with the other papers for the Board.

4. I am writing to Angela Henderson and to Nick Anderson, who sent me a covering letter, to inform them of this.

5. I have also responded to the letter from Simon Wessely, which was sent to you directly at an earlier date, and which you forwarded to me for action. Many of the points which he raises are constructive, and I am holding his letter on file for consideration when the chapter on CFS is next reviewed.

Moira Henderson

DR M. HENDERSON
ROOM 11/26
ADELPHI
EXT 28794

CMO.
Would you like to do this yourself or pass to the DCMOs?
Jane
30/1

3.2.92

CMO Routine in tray

— DCMO advice, but perhaps I had better see Westcare
KC

29 JAN 1992

Dr Nicholas PS/CMO

From: Chris Padwick

Date: 29 January 1992

SECRETARY OF STATE'S CONSTITUENCY CASE: PROVISION OF SERVICES IN CARE FOR ME SUFFERERS IN THE SOUTH WESTERN AREA

I attach correspondence to the Secretary of State from Dr Richard Sykes, Director of "Westcare", a charity that deals with the problems of ME suffers in Bristol and the South West. As you can see, the Secretary of State met Drs Sykes and MacIntyre at a recent surgery were they discussed the ME-related matters, as laid out in Dr Sykes' letter of 23 January to the Secretary of State. The Secretary of State has commented:

> "I would like CMO or a DCMO to establish direct contact with "Westcare" to discuss what seems to me very real issues."

I should be grateful if you could set this in hand and keep me posted as things progress. I shall of course let you have the papers concerning Dr Newman, as mentioned in Dr Sykes' letter of 23 January as soon as they arrive.

Chris

CHRIS PADWICK
Room 407
Richmond House
Ext 5798

The National Archives

LETTERCODE/SERIES BN 141

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Extract/Item Details:

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SA
26/3/12

King's College Hospital and the Institute of Psychiatry

Department of Psychological Medicine
King's College Hospital,
Denmark Hill,
London SE5 9RS

071 - 326 3014

Professor Robin M. Murray
Dr Anthony S. David
Dr Simon C. Wessely

Dr Mansel Aylward
Department of Social Security
The Adelphi
1 John Adams Street
London WC2N 6NT

10 January 1992

Dear Dr Aylward

Dr Richard Sykes, of Westcare, has sent me a draft version of the revised guidelines for dealing with sufferers of chronic fatigue syndrome (CFS) that are being considered for the new Disablement Living Allowance handbook. This is an area that I have had a considerable interest in and have carried out a number of research studies. I have been particularly concerned in the area of rehabilitation of CFS patients and was therefore most interested to read the proposed guidelines.

I must admit to some concern about certain aspects about these guidelines, in particular as, at least in part, I think they are based on a misinterpretation of some of the published research, including my own studies. I note that you state that studies of CFS have essentially found normal muscle function. This is indeed correct. However, you go on to state that patients may "refrain from walking because they are fearful of the consequences". It is certainly true that I and my colleagues consider that anxiety about the consequences of activity is one factor perpetuating disability in CFS patients. However, I should point out that, unlike the studies of muscle function, this is by no means proven. Furthermore it is probably only one of many factors contributing to disability, and even then may only be of importance in a small sub group.

I also feel that the guidelines have failed to point out the second conclusion from the studies of muscle function in CFS. The evidence of normal muscle dynamic function in controlled conditions is indeed incompatible with theories of primary neuromuscular origin to CFS symptoms. However, it is also equally incompatible with theories of a hysterical origin to symptoms, or indeed any theory that suggests motivational factors in CFS. Perhaps the leading researcher in this field, Andrew Lloyd recently wrote in an important paper in Brain that "neither muscle contractile failure or abnormal motivation are the cause of fatigue in CFS". My reading of the proposed guidelines is that these second set of conclusions have not been adequately emphasised.

The guidelines also suggest that because laboratory testing of muscle function is normal, a person should be able to be self caring without the assistance of another. I believe that this is a non sequitur. There are many illnesses in which muscle function is objectively normal, but nevertheless a person abilities to look after themselves are severely impaired. For example in the field of psychiatry, patients with severe depressive illnesses are often completely unable to look after themselves, and yet have totally normal neuromuscular functions. There are also many disorders of cerebral function in both the psychiatric and non psychiatric fields in which this is also true. Given that research shows a considerable overlap between depression and CFS, that the two are often difficult to distinguish, and that cerebral dysfunction is almost certainly present in both. I think it is essential that the guidelines should not suggest that any forms of benefits are denied to a patient with CFS that would be available if the diagnosis was of depression. This would appear to be both unjust and inconsistent.

My final point concerns the prognosis of CFS. This is a very difficult subject, but I hope that the guidelines will not perpetuate the idea that CFS is both of poor prognosis and untreatable. Research is at an early stage, but the prospects for rehabilitation look promising, and there are undoubtedly many major medical discoveries to be made, all of which may have dramatic effects on treatments. I have previously been involved in advising the DSS that as CFS in undoubtedly a genuine condition and is as legitimate an illness as any encountered in the field of both medicine and psychiatry, CFS sufferers should be entitled to the full range of benefits. In particular it should be emphasise that symptoms and disability are genuine, and suggestions to the contrary ill founded. On the other hand I have also advised that CFS should not be grounds for permanent disability but provision should be made for regular reassessment of what may well be changing circumstances.

I hope these comments are of use. I certainly do not envy you your task, as I have found out to my cost just how controversial and difficult an area this is. However, I think that gives us all the duty to be extremely cautious in any public statements on this illness, and in particular take great care to not go beyond the evidence available.

With kind regards.

Yours sincerely

Dr Simon Wessely
Senior Lecturer in Psychological Medicine

cc: Dr Richard Skyes
Westcare
15 Queen Victoria Road
Redland
Bristol BS6 7PE

Ms Angela Henderson
ME Action Campaign
PO Box 1302
Wells
Somerset BA5 2WE

King's College Hospital and the Institute of Psychiatry

Department of Psychological Medicine
King's College Hospital,
Denmark Hill,
London SE5 9RS

071 - 326 3014

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1 John Adams Street
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I must admit to some concern about certain aspects about these guidelines, in particular as, at least in part, I think they are based on a misinterpretation of some of the published research, including my own studies. I note that you state that studies of CFS have essentially found normal muscle function. This is indeed correct. However, you go on to state that patients may "refrain from walking because they are fearful of the consequences". It is certainly true that I and my colleagues consider that anxiety about the consequences of activity is one factor perpetuating disability in CFS patients. However, I should point out that, unlike the studies of muscle function, this is by no means proven. Furthermore it is probably only one of many factors contributing to disability, and even then may only be of importance in a small sub group.

I also feel that the guidelines have failed to point out the second conclusion from the studies of muscle function in CFS. The evidence of normal muscle dynamic function in controlled conditions is indeed incompatible with theories of primary neuromuscular origin to CFS symptoms. However, it is also equally incompatible with theories of a hysterical origin to symptoms, or indeed any theory that suggests motivational factors in CFS. Perhaps the leading researcher in this field, Andrew Lloyd recently wrote in an important paper in Brain that "neither muscle contractile failure or abnormal motivation are the cause of fatigue in CFS". My reading of the proposed guidelines is that these second set of conclusions have not been adequately emphasised.

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With kind regards.

Yours sincerely

Dr Simon Wessely
Senior Lecturer in Psychological Medicine

cc: Dr Richard Skyes
Westcare
15 Queen Victoria Road
Redland
Bristol BS6 7PE

Ms Angela Henderson
ME Action Campaign
PO Box 1302
Wells
Somerset BA5 2WE

9M.

ATTENDANCE ALLOWANCE BOARD
The Adelphi 1-11 John Adam Street London WC2N 6HT
Telephone 071-962-8000
GTN 396

Dr S. C. Wessely
Department of Psychological Medicine
Kings College Hospital
Denmark Hill
London SE5 9RS

Date: 28 January 1992

Dear Dr Wessely,

Dr Aylward has asked me to reply to your letter dated 10 January 1992, concerning the guidelines on chronic fatigue syndrome in the Disability Handbook for the Disability Living Allowance. Thank you for taking the trouble to write, and for your very helpful observations and comments.

The Disability Handbook has now gone to print, but one of the important functions of the DLA Advisory Board will be to update and revise it from time to time, and to advise on changes which should be made. Your letter will be held on file until the next time that the chapter on CFS falls for review, when the points you raised will be given careful consideration.

Perhaps it would be helpful if I were to make some general comments at this stage. First of all, it cannot be emphasised too strongly that the Disability Handbook is intended as a guideline only. Each claim must be considered individually on its own merits.

It was certainly not the intention that the Handbook should give the impression that CFS is not a genuine condition. However, I think you will agree that the degree of disablement arising from it can vary considerably from person to person. In assessing entitlement to Disability Living Allowance, as indeed to its predecessor Attendance Allowance, it is the degree of disablement present in the individual which must be considered, not the disabling condition of itself. Furthermore, the legal criteria demand that the disablement be due to a physical or mental disorder, and that in consequence the claimant should be in need of frequent attention throughout the day in connection with bodily functions, or of prolonged or repeated attention at night, or in need of continual supervision to avoid substantial danger. The criteria for the new lowest rate of care for DLA are that attention is required for a significant portion of the day, or in order to prepare a cooked main meal: this latter criterion applies to those aged over 16 only.

A depressive illness of sufficient severity to result in significant lack of motivation for self-care could certainly satisfy the legal criteria for an award. As you rightly point out, the fact that such an illness was associated with CFS should not preclude entitlement. In this context I thank you for your suggestion that greater emphasis should be placed on the complex relationship between CFS and depression, as highlighted in the copy of your editorial which you so kindly sent.

With regard to prognosis, again it was not the intention that the Handbook should suggest that CFS carries a hopeless prognosis. It makes the point that post viral fatigue syndrome rarely lasts beyond a few weeks. Of CFS it states that "symptoms persist for months, or in some cases indefinitely". Almost by definition the CFS sufferers claiming benefit are those, admittedly at one end of the spectrum, in whom disability has persisted for months, and sometimes for years. The Attendance Allowance Board has considerable experience of claims from persons, usually describing themselves as sufferers from M.E., in the majority of whom symptoms have persisted for very prolonged periods.

I hope that you will find these comments helpful, both in reply to your letter and in any future contacts you may have with Westcare or the M.E. Action Campaign.

The DLA Advisory Board is of course always willing to meet with representatives of disabled persons for discussion of points of interest or concern.

Once again many thanks for your contribution.

Yours sincerely

Moira Henderson

Dr M. Henderson MRCGP
The Secretary
Attendance Allowance Board.

King's College Hospital and the Institute of Psychiatry

Department of Psychological Medicine
King's College Hospital,
Denmark Hill,
London SE5 9RS

071 - 326 3014

Professor Robin M. Murray
Dr Anthony S. David
Dr Simon C. Wessely

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1 John Adams Street
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With kind regards.

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cc: Dr Richard Skyes
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GTN 396

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Department of Psychological Medicine
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M.G.

Dr. Charles Shepherd

Friars Cottage Surgery, Queens Square, Chalford Hill, Glos. GL6 8EH
Tel: Brimscombe (0453) 885462

The Melvin Ramsay Memorial Lecture

"Postviral Neurological Syndromes"

Dear Dr Aylward

I am writing to let you know that Peter Behan, Professor of Neurology at the Institute of Neurological Sciences, Glasgow will be delivering the above lecture in the Edward Lewis Theatre, Windeyer Building, University College and Middlesex Hospital School of Medicine, Cleveland Street, London W1 at 6.15pm on Friday December 6th 1991.

The lecture has been organised by members of the Melvin Ramsay Society - an independent study group set up to promote scientific understanding into postviral fatigue syndromes, particularly myalgic encephalomyelitis/ME.

You are most welcome to attend this lecture, and I would be grateful if you could also inform any other colleagues or members of your department who may be interested in this subject. No advance tickets are required and we shall be providing some light refreshment.

Yours sincerely

Charles Shepherd

Dr Charles Shepherd
Treasurer, Melvin Ramsay Society

October 20th 1991