ME Alliance ME Diagnosis

ME Diagnosis: Delay Harms Health

Early diagnosis: why is it so important?

A report from the ME Alliance

ME Alliance

ME Diagnosis

This is an ME Alliance publication: lead author is Dr Charles Shepherd

Charities belonging to the ME Alliance are:

Action for M.E. www.afme.org.uk
Association of Young People with ME www.ayme.org.uk
Case History Research on ME (CHROME) www.chromesw6.co.uk
The ME Association www.meassociation.org.uk
The National ME Centre www.nmec.org.uk
The Young ME Sufferers (Tymes) Trust www.tymestrust.org

Contents

1 Introduction: the current situation

Despite official government acceptance, in their response to the 2002 Report to the Chief Medical Officer (CMO) for England[1], that ME/CFS is a genuine and disabling illness, many people still experience a considerable delay in obtaining a firm diagnosis from a doctor. The importance of having an early diagnosis was a key issue highlighted by patients who gave evidence to the CMO report, particularly in relation to the potential harm done by late diagnosis.

Diagnostic delay is often as long as several years

Diagnostic delay is often as long as several years according to a survey carried out by the charity Action for M.E.[2]:

- 33% had to wait more than 18 months
- 6% were only diagnosed after 10 years

When asked what significance an earlier diagnosis would have made, 52% stated that it would have made 'a huge difference.'

Two recent website surveys were carried out as part of this ME Alliance campaign:

1 In adults:

53% took over a year to obtain a diagnosis
22% were diagnosed between six months and a year
25% were diagnosed within six months

2 In children and young people:

45% took over a year to obtain a diagnosis
29% were diagnosed between six months and a year
26% were diagnosed within six months

In addition to the issue of delay to diagnosis, other people have to rely on the continuing uncertainty of self-diagnosis and never have this properly confirmed or corrected by a doctor.

2 The ME Alliance campaign

The ME Alliance has produced this report to highlight the importance of early diagnosis.

an early and accurate working diagnosis is an essential first step in a patient's journey

Establishing an early and accurate working diagnosis is an essential first step in a patient's journey as it provides a name to put to the problems the person is experiencing.

Obtaining a diagnosis should then lead to a step-wise process of acceptance, understanding, adjustment, and enablement, to maximise the prospects for early improvement and recovery. As with any potentially long-term illness this can also help to reduce the social and psychological impact and is an important aspect of secondary prevention.

In a wider context, early diagnosis leads to economic and social gains as a result of reducing the duration and burden on society that an illness such as ME/CFS inevitably creates.

The Department of Health clearly accepts the need for early recognition of potentially long-term medical conditions, followed by prompt diagnosis and treatment, as it lists this as a specific Quality Requirement in its new National Service Framework for Long-term Conditions[3]. However, these are expectations rather than guarantees, and delivery will depend on local health service priorities over the next ten years.

In March 2005, the National Institute for Clinical Excellence (NICE) started work on the production of guidelines for the diagnosis and management of ME/CFS. However, this information will not be made available to doctors until 2007 at the earliest. In the next two years the ME Alliance estimates that over 50,000 people will develop ME/CFS, many of whom will continue to experience serious delays in obtaining either a diagnosis or appropriate advice on management.

The importance of early diagnosis is such that for the sake of people who are currently becoming ill, urgent action needs to be taken.

In the next two years the ME Alliance estimates that over 50,000 people will develop ME/CFS

3 A call for action

While we can be certain that around 25,000 people per year will develop ME/CFS[4], the likelihood is that the real figure is very much larger, possibly in the region of 50,000. The ME Alliance therefore believes that organisations and agencies responsible for patient care; undergraduate and postgraduate medical education; and medical research, should all be examining ways in which they could improve the current situation.

The ME Alliance has identified three specific areas where action needs to be taken:

- **Recognition and awareness**
  General Practitioners should seriously consider the diagnosis of ME/CFS, at an early stage, in patients where there is no obvious explanation for persisting ME/CFS-like symptoms. This is especially relevant in those who are not recovering normally from an infection.
- **Education**
  Undergraduate medical schools, and those responsible for postgraduate medical education, should ensure that the curriculum properly covers the diagnosis and differential diagnosis of ME/CFS.
- **Research**
  A carefully planned epidemiological research study to estimate the true prevalence and natural history of ME/CFS, funded by government and commissioned by the Medical Research Council, should be carried out. Such a study should include investigation of some of the uncertainties that currently surround diagnosis, and factors affecting prognosis. The ME Alliance is also calling for much more research into the underlying cause of ME/CFS in order to try and identify a consistent abnormality that could act as a diagnostic marker.

4 How the ME Alliance can help

Charities belonging to the ME Alliance are keen to work in partnership with health professionals and to assist agencies involved with patient care, medical education and research. We hold a large amount of evidence relating to the patient experience of this illness and have medical advisers with longstanding interest in both clinical and research matters. We also produce in-depth information, suitable for patients and professionals, which is a rich resource on all aspects of the diagnostic and management processes referred to in this report.

5

Why early diagnosis is so important: the patient experience

people can be given totally inappropriate and harmful recommendations on management

Imagine being a fit and healthy person who picks up a simple viral infection but fails to return to a normal pattern of health. You develop a classic range of ME/CFS symptoms: exhaustion after minimal amounts of activity, severe problems with memory and concentration, and other disabling neurological symptoms. Your doctor is either dismissive of your symptoms, or is unable to provide a satisfactory explanation as to what is going wrong, and so fails to offer any form of effective management advice. This situation is all too common.

Diagnostic delay creates frustration, even despair, because of the resulting lack of appropriate management advice in the crucial early stages. Worse still, people can be given totally inappropriate and harmful recommendations on management, especially in relation to striking the correct balance between activity and rest.

Organising dealings with family, friends, employers or schools becomes very difficult. One common consequence is that people in the very early stages of ME/CFS are told to return to work or school far too quickly, instead of benefiting from a period of convalescence followed by a gradual and flexible attempt at returning to education or occupational activities.

State and private sickness benefits can be very difficult to obtain in the absence of a clear diagnostic opinion that can be written on a sick note. As a consequence, people are denied the appropriate sickness benefits, practical help with their care or mobility needs, and access to social services.

Case study

Joanne is 26. Her diagnosis of ME/CFS took over two years, after failing to recover from a viral illness.

Doctors were unable to explain her illness and she continued working, falling into a repeated pattern of collapse and recovery. Eventually, Joanne could go on no longer and became so ill she was confined to bed for several months. She underwent numerous doctor and hospital appointments, including MRI, CT and ultrasound scans and blood tests, before eventually being diagnosed with ME/CFS. "The delay in a diagnosis has led to a prolonging of my illness. Because I didn't know what was wrong, I pushed myself and dragged my body even further down," said Joanne, who has now had ME/CFS for five years.

In the case of children and adolescents, a guideline recently produced by the Royal College of Paediatrics and Child Health (RCPCH) noted that 'Diagnostic delays can cause anxiety in the patient and family and delay the initiation of an appropriate management programme'[5].

In this age group, diagnostic delay produces serious educational consequences, especially when it results in prolonged absence from school without home tuition, virtual education, or special arrangements regarding examinations.

Case study

Vikki, now aged 20, first became ill when she was nine years old, with the viral infection glandular fever.

Dismissive doctors told her to 'pull herself together', and it wasn't until a serious worsening of her condition at the age of 16 that ME was officially diagnosed. During this time she pushed herself to attend school but eventually withdrew. After battles with the education authorities Vikki managed to get permission to take five GCSE exams at home.

Later she tried to start her A-Levels. "I fully intended to take some A-levels but had to give up on that idea when I went into relapse after just two days." Now Vikki is mostly confined to bed, only managing to get downstairs once every few months or so. She has always wanted to be an electrical engineer and to travel round the world after leaving school. Becoming severely ill with ME has put paid to those dreams.

The ME Alliance shares the view of many doctors that early diagnosis is an extremely important factor in determining the outcome in ME/CFS and believes that continuing diagnostic delay makes it increasingly likely that the illness will become more serious and prolonged. This is all the more tragic because in most instances a diagnosis of ME/CFS should be a relatively straightforward process that can be carried out in general practice/primary care.

6

The role of delayed diagnosis in the development of severe ME

Around 25% of people with ME/CFS are severely affected i.e. they are wheelchair-bound, house-bound, or bed-bound, often with severe and even continuous pain. Of particular concern to the ME Alliance is the role of diagnostic delay in the development of severe ME.

severity is linked to the length of time before a diagnosis was made

Research epidemiologist Dr Derek Pheby has carried out a study which has examined how various factors might be involved in the development of severe ME. Data on possible risk factors obtained from questionnaires received from 111 severely affected people with ME/CFS was compared to that obtained from a control group of mild or moderately affected.

A key finding from preliminary analysis of the results is that severity is linked to the length of time before a diagnosis was made:

- Those who were ill for more than a year before receiving a diagnosis from a doctor were more likely to be severely ill than those who waited less than a year.
- Only 27% of severe cases were diagnosed within a year compared to 54% of those who were mild or moderately affected.

Results from this research study, which was funded by the ME Association, have now been submitted for publication.

7 Why people are not receiving an early diagnosis

There are a number of important reasons why this situation has developed, many of which relate to the historical context in which ME/CFS existed before the government fully recognised it to be a real and severely disabling illness:

- Many doctors have not been taught about ME/CFS at medical school or have incomplete, distorted, misleading or outdated views about the illness. Sadly, a few still believe that ME/CFS is a non-existent disease or even a form of hysteria. As a result, they may adopt a dismissive, disbelieving or even hostile attitude to the suggestion that someone might have ME/CFS. Sadly, it can take a long time to undo attitudes gained whilst in training.
- Some doctors are reluctant to make a diagnosis of ME/CFS because they believe it is an ill-defined condition which may be associated with unhelpful patient beliefs about cause and management[6]. This attitude has been robustly challenged by evidence collected by the patient organisations[7].
- Although experienced clinicians have provided clear guidance through various publications, such as the CMO report, there are no validated or universally accepted clinical criteria for diagnosis. The published criteria currently available for research purposes have a design that is far more rigid than is appropriate for ordinary clinical practice. One of the major obstacles to early diagnosis using strict research based criteria is the presumption that symptoms have to be present for at least six months before the diagnosis can be made[8].
- Positive diagnosis depends primarily on the presence of characteristic symptoms and the exclusion of other conditions that resemble ME/CFS. As yet, there is no specific blood or other marker that can be used as a confirmatory diagnostic test. However, it must be remembered that ME/CFS is not the only condition for which there is no defining laboratory test.

48% of GPs did not feel confident with making a diagnosis of ME/CFS

- Uncertainty amongst some doctors as to how to make a clinical diagnosis of ME/CFS has been compounded by the very limited availability of specialist referral services for ME/CFS patients. The most recent survey of GP attitudes and knowledge about ME/CFS[9] reported that 48% of GPs (811 GPs were surveyed) did not feel confident with making a diagnosis of ME/CFS and 41% did not feel confident in treatment. With specialist hospital services for ME/CFS patients still almost non-existent in some parts of the UK, obtaining a second opinion from a physician with knowledge of ME/CFS remains a significant problem for some.

Attitudes are now starting to change for the better

Instead of focusing on the problems of the past, the ME Alliance wishes to concentrate on improving the lives of those who become ill in the future. Attitudes are now starting to change for the better and we are delighted that many of the historical myths surrounding ME/CFS are no longer acceptable.

With £8.5 million Department of Health initial funding to establish new ME/CFS services in 50 locations across England, access to experienced health professionals for the purpose of both diagnosis and management will start to improve. However, no equivalent initiative to provide specialist services has taken place, or is due to take place, in Northern Ireland, Scotland and Wales. The ME Alliance believes that continuing lack of action in these parts of the UK is unacceptable.

8 What *should* happen: how a diagnosis is made

8.1 What ME/CFS is – what ME/CFS is not

ME/CFS is a clinically characteristic entity, that can be recognised as readily as many other conditions. As a considerable number of other illnesses have symptoms which overlap with ME/CFS, establishing a diagnosis will depend on a careful assessment of the symptoms. This may need to take place over the course of several consultations. The diagnostic process also requires various investigations to rule out other possible explanations.

The aim is to provide a positive diagnosis of ME/CFS, whereby a person is considered to have the characteristic features and pattern of the illness, as opposed to arriving at a diagnosis solely through the exclusion of other possible causes.

It is also vital to recognise and manage any other illness that may be present in the same person, as there may be more than one diagnosis.

ME/CFS is not depression or anxiety – although these may co-exist, as in other chronic conditions. Neither is ME/CFS deconditioning as a result of reduced activity.

Some people present with symptoms that superficially appear to be ME/CFS, but who actually have another explanation. It is equally important that they receive an appropriate diagnosis and treatment.

8.2 Acute onset post- infection cases: when should ME/CFS be considered?

Around 75% of people with ME/CFS describe a sudden onset to their illness, often dating back to an acute viral infection. This could be an episode of bronchitis, gastroenteritis, tonsillitis, or viral meningitis. Sometimes it is a more specific infection such as chickenpox, glandular fever, or rubella. ME/CFS occasionally occurs following other types of infection such as mycoplasma, Q fever, salmonella or toxoplasmosis. Instances have also been reported where ME/CFS has been triggered by a vaccination, or exposure to toxins or pesticides.

Around 75% of people with ME/CFS describe a sudden onset to their illness, often dating back to an acute viral infection

Regarding the timing of when a diagnosis of ME/CFS should first be considered, the ME Alliance agrees with two important conclusions contained in the 2002 Chief Medical Officer's report, namely:

- 'Current diagnostic criteria are useful only for research purposes' (4.2.1.1) and
- **'six months (duration of symptoms) should be viewed as an endpoint for the diagnostic process'** (4.2.1.5).

A key principle for effective management is to establish a working, or provisional diagnosis early on, and certainly before symptoms have persisted for several months. People then have a name for their various symptoms, and a plan of management can be put into place as soon as it becomes apparent that they are not recovering from an initial infection.

Equally important is providing an explanation of their illness, especially regarding diagnosis and initial management, so that people understand their situation and how the consequences of their illness are being addressed.

It is no longer acceptable for people to be left feeling abandoned by the medical profession because of a lack of willingness to make a diagnosis.

Diagnostic timeframe

- At four to six weeks of persisting undue fatigue and other ME/CFS-like symptoms following an acute infection, a diagnosis of a post-viral/infectious fatigue syndrome should be considered.
- After three to four months of persisting symptoms, and where other possible causes of ME/CFS-like symptoms have been excluded through investigation, a provisional diagnosis of ME/CFS should be considered. Initial approaches to clinical management can be instituted at this stage.
- By six months, if symptoms persist, the provisional diagnosis should have been confirmed, provided all other explanations have been properly excluded, and further advice on management given.
- In children, a positive diagnosis can often be made earlier, at around three months - as recommended in the RCPCH guideline.

On the issue of establishing an early working diagnosis, and confirming a provisional diagnosis by six months in adults, the ME Alliance is emphasising a much shorter timescale than that suggested in clinical diagnostic guidelines produced in other countries. In this we echo the recommendations contained in the Report to the CMO, and in the guideline produced by the RCPCH for children and adolescents.

8.3 Diagnosis in gradual onset cases

Around 25% of people present with no obvious precipitating/triggering event. People in this group develop their ME/CFS symptoms in a more gradual and insidious manner.

Confirming a diagnosis when there is no clear triggering event or starting point for the onset of symptoms is obviously more difficult. In cases such as this, further investigations may well be required, as well as a second medical opinion.

In some instances a doctor may not be able to go any further than listing ME/CFS as one of a number of possible diagnostic explanations. However, if the nature and pattern of clinical features remain characteristic of ME/CFS, a diagnosis can be made in most cases.

8.4 Diagnosis in children and adolescents

children of any age can develop ME/CFS

The Royal College of Paediatrics and Child Health (RCPCH) guideline recognises that children of any age can develop ME/CFS. Many will describe an acute infective onset. Although the main symptoms are very similar to those seen in adults, children with ME/CFS may have additional symptoms such as abdominal pain, nausea, and sinus congestion. The ME Alliance agrees with the recommendations on clinical assessment and investigation of children with a suspected diagnosis of ME/CFS contained in section 2.2 of the RCPCH guideline. We also endorse the conclusion contained in section 2.3.1 that 'A positive diagnosis of CFS/ME should be made as soon it becomes clear that, having excluded all other causes for symptoms, the symptoms are continuing to cause significant functional impairment.'

8.5 How does a doctor confirm the diagnosis?

In making either a provisional or firm diagnosis of ME/CFS, a doctor will piece together clues from three sources of information:

8.5.1 The clinical history

Medical history usually provides vital clues, not only about the nature and characteristics of symptoms, but about how they vary with activity and other events. This information on personal experiences of an illness can also provide useful clues for future management.

A history of previous illnesses should be taken along with occupational, personal and social events. This helps to ensure that no other explanations for ME/CFS-like symptoms are missed.

For example, in its early stages hepatitis C infection can cause an illness which is very similar to ME/CFS, so a history of blood transfusion or liver test abnormalities would be relevant. A history of being bitten by a tick should raise the possibility of Lyme disease. The presence of dry eyes should raise the possibility of Sjögren's syndrome – a condition which has several overlapping features with ME/CFS. If any ME/CFS symptoms are particularly prominent – apart from the classic exercise-induced fatigue and cognitive dysfunction – other explanations will need to be pursued (e.g. lupus/SLE in the case of someone with a lot of joint pain).

In the case of children and adolescents, more unusual explanations which may need to be considered include infections such as toxoplasmosis, Ehlers Danlos syndrome in children with joint hypermobility, hypogammaglobulinaemia, and childhood muscular disorders.

8.5.2 Examination

A relevant clinical examination should always be performed before the diagnosis is made. In particular, this should include a full examination of those systems that are indicated by the history. This is mainly to exclude other diagnoses because physical signs in ME/CFS itself are limited and subtle in nature.

A relevant clinical examination should always be performed

In children, particular attention should be paid to any signs suggestive of growth delay (i.e. height, weight, head circumference), glandular or tonsillar enlargement, evidence of chronic sinusitis (which appears to be linked to ME/CFS in children), and postural orthostatic tachycardia syndrome.

8.5.3 Investigations

The following basic investigations should always be carried out before a diagnosis of ME/CFS is confirmed:

- Full blood count and differential
- ESR or acute phase protein changes
- Blood biochemistry (calcium, sodium, potassium, urea)
- Blood glucose
- Creatine kinase (to exclude muscle disease)
- Thyroid function tests
- Liver function tests
- Urine tests for renal disease and diabetes

If any significant abnormalities are identified during this process, then the provisional diagnosis must be re-assessed.

Second line tests which may be appropriate in certain circumstances are many and varied, and will rest on clinical judgement. These may include:

- Antibody screening tests for specific infections (eg hepatitis B/C, Lyme disease, parvovirus) – some of which may need treatment if active. Antibody screening tests are, however, of very limited value in the routine diagnostic assessment.
- Screening for coeliac disease if gastrointestinal symptoms, evidence of malabsorption, or unexplained anaemia are present.
- Autoimmune and rheumatology screen if joint pains are prominent.
- MRI scan if another neurological illness such as multiple sclerosis seems possible on the basis of symptoms and signs.
- Pituitary and adrenal function tests if there is evidence that suggests a specific endocrine disorder.

9 Research into diagnosis: why this can no longer be ignored

there is a vital need to carry out a thorough epidemiological study here in the UK

The ME Alliance believes that there is a vital need to carry out a thorough epidemiological study here in the UK to establish, amongst other things, the true extent, range and natural history of this illness. Such a study could also be used to help resolve some of the uncertainties surrounding the diagnostic process and the effect that diagnostic delay has on outcome.

Among the more important questions that this, and other research, now needs to address are:

9.1 How long does it take people to obtain a diagnosis?

Strong evidence collected by the ME Alliance indicates that many people are still waiting months or even years before a diagnosis of ME/CFS is either queried or confirmed.

9.2 What is the effect of diagnostic delay on prognosis?

a good prognosis is indicated by an early diagnosis

Although a government expert group on prognosis and chronicity has already reached a consensus that a good prognosis is indicated by an early diagnosis, and that a poor prognosis is indicated by delayed diagnosis[10], this conclusion was largely based on the opinions of the doctors involved rather than evidence in the published literature.

9.3 Is ME/CFS being under-diagnosed in minority ethnic groups?

Anecdotal evidence indicates that members of minority ethnic groups are being under-diagnosed[11]. Epidemiological evidence from the USA suggests that ME/CFS is just as common, if not more so, in people of different racial origins who are born and brought up in the same country.

9.4 Can a diagnostic test be found?

The ME Alliance believes that the top priority in future must be biomedical research into the underlying physical cause of ME/CFS. Better knowledge of the pathology of ME/CFS will be the most effective way of achieving an early and accurate diagnosis based on a blood, urine, cerebrospinal fluid, or neuroradiological test which identifies an abnormality that is unique to ME/CFS. The ME Alliance accepts that in the current state of scientific understanding this is unlikely to be achieved in the short term. However, we believe that there are abnormalities being detected which should now be investigated as potential diagnostic markers.

References

1 A report of the CFS/ME Working Group: Report to the Chief Medical Officer of an Independent Working Group. 2002. Available online at the Department of Health website: www.doh.gov.uk – search under CFS/ME.

2 Severely neglected – M.E. in the UK. Action for M.E., 2001. Available online at www.afme.org.uk

3 The National Service Framework for Long-term conditions. Department of Health, 2005. Available at www.dh.gov.uk/longtermnsf.

4 Gallagher AM, Thomas JM, Hamilton WT, White PD. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. Journal of the Royal Society of Medicine 2004; 97: 571 – 575.

5 Evidence based Guideline for the Management of CFS/ME (Chronic fatigue syndrome/Myalgic Encephalopathy) in children and young people. Royal College of Child Health and Paediatrics, 2004. Available online at www.rcpch.ac.uk

6 Chronic Fatigue Syndrome: Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996.

7 Your Experiences 2003 Action for M.E. membership survey, available online at www.afme.org.uk

8 Fukuda K, Strauss S, Hickie I, Sharpe M, Dobbins J, Komaroff A. The chronic fatigue syndrome: a comprehensive approach to its definition and study. Annals of Internal Medicine 1994; 121: 953 – 959.

9 Bowen J, Pheby D, Charlett A, McNulty C. Chronic fatigue syndrome: a survey of GPs' attitudes and knowledge. Family Practice, 2005 (in press).

10 Aylward M. Government's expert group has reached consensus on prognosis of chronic fatigue syndrome. British Medical Journal 1996; 313: 885. Summary available online at http://bmj.bmjjournals.com/cgi/content/full/313/7061/885/a

11 SAMEC Report, commissioned from the SAMEC Trust Research Centre by Action for M.E., April 2000, available online at www.afme.org.uk

12 Dowsett EG, Colby J. Long-term sickness absence due to ME/CFS in UK schools: an epidemiological study with medical and educational implications. Journal of Chronic Fatigue Syndrome 1997; 3: 29 -42.

13 Bibby J and Kershaw A. How much is ME costing the country? Report prepared by the Survey and Statistical Research Centre, Sheffield Hallam University for Action for ME 2003, and Action for M.E. and The ME Association, 1996.

Executive summary

Despite official government acceptance that ME/CFS is a genuine and disabling illness, and recommendations that the illness should be diagnosed within 6 months[1], many people still experience a considerable delay in obtaining a firm diagnosis from a doctor. This has serious implications for health and wellbeing, employment and education, and access to welfare benefits.

An ME Alliance survey has found that:

- 53% of people with ME/CFS waited over a year for a diagnosis of their illness
- Only 25% of people were diagnosed within the recommended six months
- 45% of children and adolescents waited over a year for diagnosis, despite the recommended timeframe for diagnosis in this age group being three months

The importance of early diagnosis

- Establishing an early and accurate working diagnosis provides patients with a name for the problems they are experiencing and enables a plan of management to be developed. Recognising and accepting the illness early on maximises the potential for improvement and recovery.

Preliminary findings from a study into risk factors for severe ME/CFS show that severity is linked to the length of time before a diagnosis was made: those who were ill for more than a year before receiving a diagnosis from a doctor were more likely to be severely ill than those who waited less than a year. Only 27% of severe cases were diagnosed within a year compared to 54% of those who were mild or moderately affected.

Delayed diagnosis: the consequences

Lack of diagnosis causes frustration, even despair, and impacts on all areas of life:

- Patients can be given inappropriate and harmful recommendations on management, particularly in relation to striking the right balance between activity and rest
- Relations with family and friends can be strained and arrangements with employers or schools become very difficult
- State and private sickness benefits can be impossible to obtain, leaving people without financial help, home-based education, or practical care
- In the wider context, ME/CFS becomes an increased social and economic burden

The ME Alliance campaign

Urgent action needs to be taken to improve the diagnosis of people with ME/CFS. New guidelines from The National Institute for Clinical Excellence will not be available to doctors until 2007 at the earliest.

In the next two years, the ME Alliance estimates that over 50,000 people will develop ME/CFS, and many will experience considerable delay in their diagnosis.

Call for action

The ME Alliance believes that organisations and agencies responsible for patient care, undergraduate and postgraduate medical education, and medical research should take action:

1 **Recognition and Awareness:** GPs must consider the diagnosis of ME/CFS at an early stage

2 **Education:** the diagnosis of ME/CFS must be properly covered in medical training

3 **Research:** government must fund an epidemiological study, commissioned by the Medical Research Council, to investigate the true prevalence and natural history of ME/CFS. Further research is needed into the underlying cause of ME/CFS to try and identify a consistent abnormality that could act as a diagnostic marker

How the ME Alliance can help

The member charities are keen to work in partnership with health professionals and to assist agencies involved with patient care, medical education and research. We can provide evidence on the patient experience and information on all aspects of the diagnostic and management process.

ME/CFS

Key facts

- ME (myalgic encephalomyelitis/encephalopathy) and CFS (chronic fatigue syndrome) are diagnosed on the basis of their characteristic symptoms – the most prominent being profound mental and physical fatigue.
- ME is classified as a neurological disorder by the World Health Organisation (WHO) in section G.93.3 of their International Classification of Diseases, 10th revision (ICD – 10). CFS is linked to ME in the WHO classification. All of the UK national Departments of Health accept this WHO classification and regard ME/CFS as a genuine and disabling illness.
- Epidemiological research suggests that around 240,000 people in the UK have ME/CFS – of which as many as 25,000 are children and adolescents.
- Onset commonly occurs during the 20s to 40s in adults, and between 11 and 14 years in children.
- ME/CFS is the most common cause of long-term sickness absence from school[12].
- All social classes and ethnic groups are affected.
- The annual cost to the UK economy has been estimated to be around £3.5 billion[13].

Symptoms

ME/CFS is characterised by severe, disabling physical and mental fatigue, both of which are markedly exacerbated by relatively small amounts of exertion. This fatiguability is accompanied by what is termed 'post-exertional malaise' whereby there is a delayed impact so that symptoms are at their worst later the same day, or the next day, following activity. The way in which fatigue is described in ME/CFS is very different to normal everyday tiredness and to that seen in other medical conditions.

There are several other characteristic clinical features which can assist in diagnosis, including:

- Cognitive impairment, particularly relating to short-term memory, concentration and attention span, word finding abilities, and ability to properly organise thoughts.
- Pain, which is often persistent and may be severe. This can be muscular, rheumatic (joint pain), or neuropathic (nerve pain).
- Neurological dysfunction presenting as dizziness, increased sensitivity to stimuli, postural hypotension (a significant fall in blood pressure upon standing).
- Headaches, which may be migrainous in character.
- Sleep disturbance which may range from hypersomnia (increased sleep requirements) early on, through to insomnia as the illness becomes chronic.
- Immunological dysfunction presenting as sore throats, enlarged glands, flu-like feelings.
- Endocrine and hypothalamic dysfunction presenting as disturbances in temperature control.
- Alcohol intolerance, drug and chemical sensitivities.

More serious neurological symptoms occur in a minority of patients, particularly those at the severe end of the spectrum. These may include double vision, blackouts, atypical convulsions, loss of speech, and loss of swallowing – which may require assisted feeding.

ME Alliance
ME Diagnosis