Chapter 1

What is M.E.?

There are various names for this disease which causes profound exhaustion, pain, and mental confusion, and which leaves so much disability and suffering.

These are some of the names used:

Yuppie Flu - because it is mistakenly thought to affect mainly people who are high achievers

Chronic Epstein Barr Virus - in USA - used less commonly now

Chronic Fatigue Syndrome - CFS

Chronic Fatigue and Immune Dysfunction Syndrome -

CFIDS

Icelandic Disease - from an outbreak in Iceland

Tapanui Flu - from an outbreak in New Zealand

Epidemic Neuromyesthenia

Royal Free Disease - from a 1955 London epidemic

Myalgic Encephalomyelitis

Whatever it is called, it is a very unpleasant condition. The main symptom is of ***profound fatigue***, mental and physical, ***made worse by exercise***, in combination with a variety of more bizarre symptoms, in a person who may look well, and in whom there are usually no abnormal signs on examination.

The effects of this disease can be devastating to someone who was previously active and led a full life. Not only are jobs lost and early retirement is necessary for many, but marriages may founder, relationships and friends be lost, and many hobbies and interests dropped. Even the most basic tasks of daily living may require such herculean effort that the patient cannot survive without help. Some M.E. people are prisoners in their bodies, and so the condition has been referred to by some as 'A living death'.

Added to all this suffering is the fact that for decades the disease was not recognised by the medical profession, apart from a few perceptive doctors, and patients were labelled as malingerers, neurotic, or mad.

Not surprisingly, a few who suffered from this condition have taken their own lives. They were not only very ill, but were denied the basic recognition of their illness and proper medical support.

Here is a fairly typical case history of M.E.:

Jean's Story

Jean is a dentist, married with two teenage sons. She was 41 when she had a bout of diarrhoea following a meal out at a hotel ...

'I didn't seem to recover from that, I felt very weak. I was very overworked, looking after sick and elderly grandparents. This was about five years ago. I'd had a hysterectomy a year previously, which was followed by various complications, and I'd had a very nasty bout of flu just before the operation.

'After the diarrhoeal illness, my energy levels went down and up, and I would get attacks of "flu", low-grade fever, with tremendous exhaustion and weakness, lasting for several days.

'It was over a year before I was sent to hospital for tests.

During this time my main symptoms were complete and utter exhaustion, severe aching muscle pains, inability to concentrate, inability to function normally - I was trying to run a job and a family. My ears became very irritated and sensitive to sound. I got very depressed, and iller and iller, and was more or less bedridden for about two years. I could just about get out to the shops and back, then collapsed in bed. I had to give up my job.

'I developed allergies to various foods which had not upset me previously. After becoming more and more ill for over a year following the diarrhoea illness, my GP referred me to an infectious diseases unit for tests. I had various blood tests, and the consultant thought I'd had a Coxsackie virus. He heard my story and told me I was ill with Myalgic Encephalomyelitis, and that he did not know how to make me better. I was too ill at the time to take much in, but at least, knowing I was ill, I could rest.

'The rest has been the main cure. For over two years I was so weak that all I could do was get out of bed and collect the things to prepare a meal and take them back to bed. I found cutting a carrot hard work. If I put coal on the fire it took so much energy I had to go back to bed again. I had great difficulty sleeping, because of the pain. I had two admissions to a psychiatric unit because of severe depression. Sometimes I was so tired that it was an effort to breathe. Once when I felt very ill my temperature went very low for a few weeks.

'It was about a year after I got a diagnosis before I started to get better. My improvement has not been steady - the relapses always occur after physical effort. Once, when I was a bit better, I had to stand in queues at a hospital clinic with a grandmother whom I was accompanying, then foolishly had to push the car, which wouldn't start, to take her home. I thought, with the adrenaline of the moment, that I could do it! I came home, collapsed into bed, and could not get up for a month. My brain packed in, I couldn't function, and it took me months to get over it.

'Last year I began to get a bit better. My GP thought that a little physiotherapy would do me good because I was so weak. It was disastrous, even hydrotherapy, although I felt great for the first week, but after 10 days the aching and slight fever came back.

'When I was very ill I had dreadful ulcers in my mouth, and Fungilin lozenges helped enormously. It was thought to be a Candida infection.

'I am now on a total "no exercise" campaign. As long as I lie or sit, I can function mentally. Even when I was at my worst, I tried to put clothes on every day, this kept my circulation going, and provided enough exercise to stop me seizing up.

'I found that complete bed rest when my temperature was up was beneficial, but only for a short time; when my temperature had settled I tried to get dressed every day.

'The first year of the illness I kept fighting it, so of course I just got worse. To begin with it was physical exhaustion. In the second year, I found the mental problems got worse. I couldn't finish a sentence I had started, and my brain switched off. It was so frustrating, I just wept. I felt completely useless, I was just a burden to everybody. I used to say to the boys “put me out for the dustmen in a black plastic bag!"

Jean is now in the eighth year of the illness, but is slowly and steadily getting better. She works one half-day a week, and is able to go out some evenings with her family. Her food allergies have improved, but she finds that sticking to a wholefood diet with plenty of salads, not a lot of meat, and no bread, sugar or cakes, helps her. A large meat meal robs her of energy.

Her husband and children were very supportive. 'He got me better through the emotional side of it. When you are very ill, you need lots of love and support. The members of my church have been very helpful, and I had several healing sessions’.

What Should We Call It?

The term *Myalgic Encephalomyelitis* describes these main symptoms:

Myalgia = muscle pain
Encephalitis = affecting the brain
Myelitis = affecting the spinal cord and nerves

However, the term is not medically accurate, as 'itis' implies inflammation, and there is no evidence of active inflammation nor of infection of the brain or spinal cord, apart from maybe occasionally during the initial acute early stage.

Some doctors prefer to use the term *Post-viral Fatigue Syndrome,* as it usually follows an apparent viral infection. There are many post-viral fatigue states, including fatigue for weeks after influenza, post glandular fever debility, and debility for months following hepatitis. Myalgic Encephalomyelitis differs from other post-viral syndromes in its severity, the type of muscle fatigability, and chronicity.

An illness which has fatigue as its core symptom is now called *Chronic Fatigue Syndrome* in the USA and increasingly elsewhere in the world. Many doctors argue that this name is preferable since it does not imply any viral cause, nor involvement of the brain or muscles.

M.E. is the name commonly used by patients in the UK and recognised by the general population. Apart from anything else, 'M.E: is easier to say than 'CFS' or 'PVFS'!

Chronic Fatigue Syndrome may be a disease-picture with various causes (a 'heterogenous condition’), and its definition is slightly different from that of M.E. Some people with CFS may have a post-viral syndrome. Some cases of post-viral fatigue have M.E.

Therefore, I regard the illness called Myalgic Encephalomyelitis as a post-viral fatigue syndrome, and also as one of a number of chronic fatigue syndromes; however, probably not all people diagnosed with Chronic Fatigue Syndrome have got M.E.

I address this book mainly to those with M.E., but also to people with any chronic fatigue syndrome for whom there is no clear diagnosis. When I quote research documents the terms M.E. or PVFS or CFS may be used, depending on the name used by the researchers.

Diagnosing M.E.

Myalgic Encephalomyelitis is recognised in a patient with these features:

1. Gross, abnormal muscle fatigue, which occurs after a relatively small effort, and which may take days to be overcome. This is quite unlike any fatigue the patient has ever experienced before.

2. A variety of neuropsychiatric ('encephalitic') symptoms, most prominent being cognitive loss - of memory, concentration and comprehension - and disturbances of sensation.

3. Unpredictable variation in the severity of symptoms from week to week, day to day, even hour to hour.

4. A tendency for the symptoms to become chronic, i.e. lasting many months or years.

Other post-viral fatigue states do not continue for years. The diagnosis of M.E. should not be made unless the patient has the above features. Everyone feels tired when hit by a bout of influenza, a cold, or any infection. Most people who get a severe dose of influenza will be under-par for weeks, possibly months. Glandular fever and hepatitis are well known for the debility they cause, which persists for months. These conditions that require prolonged recovery are accurately called 'post-viral fatigue states'.

Many doctors say they find M.E. hard to diagnose, or to distinguish from a state of chronic depression. Some may still label the patient as malingering or hysterical. However, for most GPs, it is a condition that, once seen, is never forgotten. The post-exertional malaise after mild or moderate exertion is the most unique feature:

> Typically, the patient tolerates the physical exertion reasonably well, and may even feel energized during and immediately after the exertion. However, 6-24 hours later the patients feel ill; the used muscle groups feel sore and weak . . . and most patients experience marked worsening of their fatigue, cognitive function, adenopathy, pharyngitis and fever. In our experience, this post-exertional malaise is unusual in healthy people, and in those with other diseases that have some resemblance to CFS.
>
> (Komaroff 1991)

M.E. usually starts after an infection of some kind, with a sore throat, sore glands in the neck, fever, often pain in chest or neck, maybe vomiting and diarrhoea (gastric flu). There may be a period of apparent recovery, lasting a few weeks. This is followed by strange symptoms such as sudden collapse, vertigo, severe chest pain, abdominal symptoms, or recurrence of the flu symptoms.

At this stage, no one knows what is going on, and the patient may be put on antibiotics, sent to a cardiologist or other appropriate specialist, and given a few weeks off work. Complete rest for several weeks at this stage may lead to recovery.

But most people expect to be back to normal a few weeks after an infection. So the patient struggles back to work or school when the expected time-limit for recovery expires; then follow months of exhaustion, an inability to perform life's daily tasks, and a struggle to keep going, all the while believing that mind-over-matter will win - and it doesn't. The patient's symptoms get worse, he or she may be depressed or even suicidal. The patient cannot believe that this pathetic creature whose muscles don't work, whose brain is like porridge, who cries from pain and exhaustion after doing nearly nothing - maybe trying to get upstairs - can be the same fit and active individual he or she was before.

It is now realised that battling on and trying to get back to normal, in the acute stage, is *the worst possible thing to do.* This is why it is so crucial that people know about the existence of M.E., because if complete rest is allowed early on, before the illness becomes chronic, then there is a better chance of early recovery.

Unfortunately, most people expect a cure for nearly every illness nowadays. Old-fashioned principles of allowing the body to heal with rest, good food, fresh air and tranquillity have been forgotten; the majority of people only allow themselves one or two weeks to recover from a viral infection. If you had tuberculosis, or double pneumonia, or rheumatic fever, would you expect to be back working full-time after one or two weeks? Of course not.

It appears that a common mechanism that triggers off the development of M.E. is getting a viral infection while one is exhausted or highly stressed. However, some sufferers cannot pin-point the onset of their illness, and have gradually become more tired and ill over a period of time. On careful questioning, though, a history of having had an infection some time around the date of 'when were you last well?' will be remembered. The triggering infection may have seemed innocuous at the time. Occasionally the triggering incident is an immunization. It is easy to remember an attack of influenza; however, one of the most common viruses now implicated in M.E. (in the UK) is the group called 'enteroviruses', which may entail only a day or two of mild 'summer flu', or be symptomless and therefore overlooked.

Most of the earlier observations about M.E. have been based on patients studied in epidemics. In fact, M.E. occurs in both epidemic and endemic (isolated cases) form, and obviously a cluster of cases in one area will attract more attention than single, apparently unconnected cases scattered about. There is a history of recorded outbreaks going back to 1934, when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. This was the first of no less than 52 recorded outbreaks from various parts of the world, up to the present time.

A diagnosis of 'neurasthenia' was popularized by an American psychiatrist, George Beard, in 1869, for a condition with some resemblances to Chronic Fatigue Syndrome today. The diagnosis became popular and fashionable, and probably some of the patients labelled neurasthenic had M.E. But the diagnosis came to include so many non-specific symptoms that it fell out of favour. However, it exists in the *International Classification of Disease,* having now a narrower definition than Beard's original one.

Florence Nightingale became ill after returning from her heroic work in the Crimean war, and spent years housebound and too exhausted to speak to more than one visitor at a time. She certainly had something like M.E.; she also had a high-risk career.

The Los *Angeles Epidemic*

The Los Angeles epidemic (1934) had features which initially resembled poliomyelitis. At the Los Angeles County General Hospital 198 staff became ill. The main features which differed from those of polio were:

- Lack of severe muscle wasting, as would be expected in polio.
- Longer-lasting muscle pain and tenderness, and sensory symptoms.
- Memory lapses, loss of concentration, sleep disturbances, emotional instability, and inability to walk a short distance without fatigue.

Over 50 per cent of the staff were still unable to work six months after the peak of the epidemic.

The Royal Free Epidemic

The best known outbreak of M.E. in Britain took place in 1955, when nearly 300 members of hospital staff at London's Royal Free Hospital developed what was obviously an infectious illness, over a period of four-and-a-half months. Of the ill hospital staff, 255 had to be admitted to hospital, and yet only 12 of the patients who were already in hospital during the epidemic developed the disease. It is probable that the patients were protected from developing the muscle and neurological symptoms of M.E. because they were resting in bed, whereas the hospital staff were busy and physically active when they became infected. In this way, M.E. behaves like polio in an epidemic.

The clinical features of this epidemic among Royal Free Hospital staff (doctors, nurses, ancillary workers, and administrative personnel) were as follows:

- Malaise, headache, sore throat, abdominal pain, nausea, enlarged glands.

These were the initial symptoms, and they fluctuated for several days.

- Severe pain in the back, neck, limbs, or between ribs; dizziness or vertigo.

These symptoms developed after a few days.

- Neurological signs and symptoms developed by week three or four. 74 per cent of patients showed evidence of involvement of the central nervous system. Symptoms included double vision, difficulty swallowing, paralysis of the face, weakness of arms and legs, twitching or spasms of muscles, and bladder problems.

- Spontaneous pains with muscle tenderness and weak limbs were common features.

There are some of these Royal Free hospital staff who still suffer today from the illness, which was called *epidemic neuromyesthenia.* The infectious agent responsible was not isolated. A full account of the many outbreaks since 1934 has been written by Dr Melvin Ramsay in his book *The Saga of Royal Free Disease.*

The Iceland Epidemic

The outbreak in Iceland in 1948-9 is very interesting, because in 1955 there was a poliomyelitis epidemic on the island, which did not produce cases in the districts where the epidemic neuromyesthenia had occurred in 1948. This implied that whatever virus was responsible for the M.E. provided immunity against polio.

Common Features

The clinical features of many outbreaks world-wide (for example Los Angeles 1934, Iceland, Adelaide 1949-51, Coventry 1953, Durban 1955, which all corresponded with epidemics of poliomyelitis) had certain features in common:

- An obvious infection
- Involvement of the central nervous system
- Prolonged fluctuating course
- Marked muscle fatigability
- Exhaustion

A proportion of patients were left physically incapacitated for many years.

The Symptoms of M.E.

In a recent questionnaire (one of several) of people who gave a typical history and had the cardinal M.E. symptoms, the following were the various symptoms given, in rough order of frequency:

Made worse by exercise - 100 per cent
Exhaustion and severe malaise - 85 per cent
Muscle weakness after using muscle, lasting days
Muscle pain - commonest in back of shoulders, upper arms, and thighs
Blurring of vision - sometimes actual double vision
Sensation of pins and needles, or numbness
Loss of concentration
Headache
Muscle twitching
Speech difficulties - e.g. using the wrong word, or being unable to come up with the word needed
Poor circulation - cold hands and feet
Pain in the back of neck

Abnormal sweating - often with a sour smell
Impairment of memory, especially for recent events
Breathing difficulty - sensation of lack of air
Extreme sensitivity to sound - called 'hyperacusis'
Noises in ears - called 'tinnitus'
Sleep disturbance
Palpitations, and/or racing heartbeat
Difficulty standing for any time - (classic symptom of M.E.)
Vivid or bad dreams
Joint pains - which may move from joint to joint
Feeling 'spaced out', disorientated
Depression
Loss of interest in sex
Nausea
Chest pains
Emotional lability - crying easily, rapid mood change
Constipation or diarrhoea
Recurrent sore throats
Enlarged or painful lymph glands
Altered sense of taste and/or smell
Difficulty with balance and/or true vertigo
Difficulty walking, or walking having to be limited to very short distances
Panic attacks
Poor temperature control
Poor co-ordination - clumsiness
Pallor when ill - quite common
Poor bladder control
Skin very sensitive to touch
Spontaneous bruising, skin rashes
Great thirst

These symptoms are not present all of the time, but the features common to all are: Exhaustion, and symptoms made worse by exercise.

Age and Sex Distribution - from Questionnaire

Male : Female	1: 3
Age: Under 20	3.5%
20-29	15.0%
30-39	28.5%
40-49	23.0%
50-59	20.0%
Over 60	10.0%

Duration of Illness - At Time of Response

Less than 2 years	35.0%
Over 2 years	65.0%
Over 5 years	33.0%
Over 10 years	12.0%
Over 20 years	4.0%

Various other studies have produced slightly different figures, but it seems that, from the date of onset of the illness one has a 30 per cent chance of still having symptoms of M.E. after five years. Of course many of the chronic sufferers may not be as badly affected after five years as they were at the outset. Also, most will not have been continuously ill, but will have had remissions and relapses.

Another way of predicting the future is this: If you are in the first year of the illness, the chances of getting better are:

50 per cent in 2 years,

60 per cent in 5 years, and 90 per cent in 10 years.

However, 'better' is an inexact word. What most patients mean by 'better' is being able to live a nearly normal life for much of the time, but avoiding strenuous exercise. I know of very few people who had typical post-viral M.E. who have returned 100 per cent to their pre-illness fitness level.

Of the long list of symptoms given above, most occur in many other diseases, and are non-specific. Are there 'typical' M.E. symptoms?

- History of a virus infection before onset
- Exhaustion out of all proportion to the effort made
- Symptoms which suggest a chronic or recurrent infection - intermittent fever, tender lymph nodes, sore throat.
- Muscle problems:

  Muscle weakness brought on after minimal effort, which may take several days or weeks to go away. Inability to stand - the legs shake and ache after standing for a short time, and the patient has to sit down, on the ground if necessary.

  Inability to hold arms up - cannot hang up washing, difficulty carrying bags or even holding telephone receiver.

  Aching back or neck if sitting in unsupporting chair. Intermittent blurring of vision - due to fatigue of the eye muscle which alters the focus (ciliary muscle); or of the muscles which keep the eyes moving together to give a clear single image - failure of these may produce double vision.

  Aching in the face after chewing; inability to write for long.

  General muscle tenderness, with some acutely sensitive local spots.

  Note that problems arise from *sustained* muscle use; the muscle function may be normal to start with, e.g. in the morning, but pain and weakness develop after using the muscles for a short time. Slow walking may be easier than standing. The muscles most commonly affected are the girdle muscles - the back of the shoulders, the buttocks and thighs.

- 'Encephalitic', or brain symptoms:

Poor concentration - typically concentration cannot be sustained for long, whether you are listening to the radio, reading, or having a conversation.

Poor memory - forgetting the name of someone you know well, forgetting what has just been said, not knowing where you are or why you are there (e.g. if driving, being totally disorientated and lost, though in a familiar place).

Nominal aphasia - inability to find the word for something.

Muddled or even slurred speech when tired.

Hypersensitivity to sound - maybe so severe that voices, radio, clocks ticking are all unbearable.

Hypersensitivity to light, also to touch - e.g. clothes hurt if they touch your skin. Maybe tingling sensations, or pins and needles.

Transient blurred or double vision.

Increased sense of smell, or smelling bizarre odours that cannot be traced to their source.

Nightmares, sleep disturbance, deficiency in certain levels of sleep.

- Autonomic nervous system (controls all involuntary body functions - also part of brain disturbance):

  Sudden racing heartbeat, or palpitations. Profuse sweating, even when cold.

  Pallor - often an ashen grey colour - at onset of feeling ill.

  Poor temperature regulation.

  Poor circulation to hands -and feet - maybe only affecting one side.

  Alternating diarrhoea or constipation. Poor blood-sugar control.

  Difficulty passing urine, or incontinence.

- Acute neurological events happen in only a few patients:

  'Primary seizures (7 per cent), acute profound ataxia (6 per cent), focal weakness (5 per cent), transient loss of vision (4 per cent). These were mostly during the first year of the illness: (Komaroff 1991)

Other Symptoms

- Sudden mood changes, untypical of the person.
- Development of new allergies - particularly to chemicals and some foods.
- Difficulty breathing - especially at night - the 'I wake up feeling I cannot get enough oxygen' symptom.
- Joint pains, sometimes with swelling.
- Prostatic symptoms in men.

The Progression of the Illness

The natural progression of the illness is a slow improvement, *if proper rest is allowed.* Most M.E. people relapse because they are active by nature, and as soon as they start to feel better they do too much, then become ill again.

Main Causes of Relapse

- Physical exercise beyond the safe limit for the day.
- Mental overwork, particularly intense concentration, e.g. studying for exams.
- Developing another infection.
- Hormonal changes - such as during menstruation, or after childbirth.
- Major stresses - moving house, divorce, bereavement, etc.
- Exposure to chemicals - e.g. new paint.
- Extreme change of climate.
- Winter - not only the cold, but the lack of daylight.
- Surgery, anaesthetics, dental treatment.

There are a small number of sufferers who do not seem to have any remissions, and who gradually deteriorate, but these are relatively few. More often the illness fluctuates, with relapses and remissions occurring, sometimes quite unpredictably. This is one of the features of M.E. that makes it so hard to assess clinically, especially in any trial of treatment. The marked variations in symptoms and in the degree of illness felt by a sufferer also leads to disbelief on the part of family, friends and one's doctor. People find it hard to accept that you have a genuine illness if they see you in a wheelchair one week, and walking the next. What they don't see is that you can still only walk a short way, and they don't observe your collapse when you get home!

Chronic Fatigue Syndrome

In order for this condition to be recognisable, and also to improve the basis for clinical research, a working case definition was required - one which could be accepted world-wide. In the USA, a number of physicians have together drawn up the criteria for a case definition of Chronic Fatigue Syndrome. Another name used in the USA is Chronic Fatigue and Immune Dysfunction Syndrome - CFIDS.

Major Criteria for CFS

1.New onset of persistent or relapsing debilitating fatigue, or easy fatigability in a person with no such previous symptom, that does not resolve with bed rest and is severe enough to reduce daily activity below 50 per cent of what it was before the illness, for at least six months.

2. Other clinical conditions which could cause this fatigue must be excluded by history, examination, and appropriate investigations.

Both of these criteria need to be met for a diagnosis of CFS to be given.

Minor Criteria

The following symptoms must have persisted or recurred over six months, and have developed at or after the onset of fatigue.

- Mild fever or chills
- Sore throat
- Painful lymph glands
- Muscle weakness
- Muscle pain or tenderness
- -Prolonged (24 hours or more) fatigue following a level of exercise that previously caused no problems
- Headaches different in type to the kind experienced before the illness
- Joint pains
- Neuropsychologic complaints (encephalitic) - one or more of the following:
  light sensitivity
  blind spots in vision
  loss of memory
  irritability
  confusion
  poor concentration
  inability to think clearly
  depression
  Sleep disturbance

Physical Criteria

These symptoms have to have been observed by a doctor at least twice, and to have occurred at least a month apart:

- Low-grade fever
- Inflamed throat
- Palpable or tender lymph nodes in neck or armpits

At least eight symptom criteria need to be fulfilled; or at least six symptom plus two physical criteria.

In the USA, chronic Epstein Barr virus was thought to be the cause of M.E./CFS - which used to be called CEBV syndrome. There is also more emphasis in the USA on the fever, sore throat, and tender lymph gland symptoms. In the UK most cases are probably triggered by an enterovirus, and the clinical picture, with the muscle symptoms predominant, is more specific than that for CFS. I believe that a diagnosis of M.E. should be reserved for patients with the clinical features listed earlier, and that M.E. is probably just one type of chronic fatigue syndrome.

In 1988 Dr A. Lloyd and others of New South Wales, Australia, developed a set of diagnostic criteria after reviewing 100 patients, for a diagnosis of chronic fatigue syndrome (the term they prefer to M.E.):

1.Chronic or relapsing fatigue, made worse by very minor exercise, causing disruption of daily life, and of over six months' duration;

2.Neuropsychiatric dysfunction, including impairment of concentration, short-term memory loss; and/or

3.Evidence of abnormal cell mediated immunity.

They consider the following findings supportive to the above three main criteria:

Muscle pain, joint pain, headaches, depression, tinnitus, paraesthesiae (abnormal sensations), sleep disturbance, tender lymph glands, sore throats.

These observations, coupled with the laboratory evidence of disordered immune function in many patients, suggests that something triggers off the disease, most commonly a viral infection, in a person whose immune system is already damaged in some way. It is possible that some as yet unidentified infectious agent - call it agent X - affects the immune system, and this together with an inherited susceptibility allows either a common viral illness to trigger the illness, or a latent infection to be reactivated.

Current contenders for agent X include the recently discovered HHV-6, (human herpes virus 6) and a retrovirus related to HTLV-2 (the one implicated in HIV/AIDS), but these claims are not yet substantiated. Or could agent X be the damage caused by global pollution on an increasing scale? This might explain why the incidence of M.E. and CFS seems to be increasing, although the illness is not new.

Incidence of M.E./CFS

There is great need for careful epidemiological surveys to establish the true incidence of M.E. in the UK. In Australia (Lloyd and others, 1990) a study of a population of 114,000 found 42 cases of chronic fatigue syndrome which fulfilled strict diagnostic criteria. This gives a prevalence of 37.1 cases per 100,000 (for Multiple Sclerosis this figure is 36.5 per 100,000, in New South Wales). In 75 per cent of cases the onset of M.E. followed an acute 'viral' illness.

The Controversy - is M.E. a Disease, or All in the Mind?

In 1970, two psychiatrists at the Middlesex Hospital, London, produced two papers in the *British Medical Journal:* 'Royal Free Epidemic of 1955: a reconsideration', and 'Concept of Benign Myalgic Encephalomyelitis'.

In these papers they gave their reasons for considering that the Royal Free epidemic of 1955 had been an outbreak of mass hysteria, and that other outbreaks in the world also had features of hysteria. They admitted that those outbreaks which showed a resemblance to poliomyelitis probably weren't cases of mass hysteria, but took no account of the clinical features of those affected.

In spite of the fact that there were obvious flaws in their reasoning - such as the signs of infection and neurological involvement, which could not be hysterically-produced - this hypothesis about M.E. given by McEvedy and Beard was taken up by the media, and has unfortunately been accepted without question by many within the medical profession since that time.

The damage done to people who have had this illness, both those of the Royal Free outbreak and others since, has been incalculable. Of course it is much more convenient to label the condition as hysterical; there is then no need to research the illness, patients can be ordered to pull their socks up and go back to work, and those who have no experience of the devastating symptoms can rejoice in being far too well-balanced to get 'that sort of complaint'.

Thanks to the tireless efforts of certain doctors, who never doubted the reality of the disease, in the last few years evidence has emerged, through various research studies, of the real and organic nature of the illness. Special credit is due to Dr Melvin Ramsay, who was consultant in infectious diseases at the Royal Free Hospital at the time of the 1955 outbreak, and who devoted a large part of his long working life to striving for the recognition of and research into M.E. Sadly Dr Ramsay died in March 1990; he is greatly missed by the many people he helped during his long battle to get M.E. recognised. During the last two years, many soundly-based research projects have got under way; some of these are discussed in Chapter 3.

Not only some doctors, but also patients themselves have campaigned for better recognition and understanding. The M.E. Association, founded in 1976, and the more recently formed M.E. Action, have provided support and information to sufferers, and have worked to educate doctors, politicians and those working in the social services about the nature of the illness and its debilitating effects. What we still lack is an accurate figure for the incidence of M.E. in the UK population.

It is salutary to note that about 20 years ago, unfortunate victims of that most disabling condition Multiple Sclerosis were labelled as neurotic or hysterical. Now MS is recognised, and yet its diagnosis is largely a clinical one; there is still no single specific test for MS which is widely available.

Modern medicine relies increasingly on laboratory tests and X-rays for diagnosis, and less and less on each patient's history. A problem for doctors trying to evaluate a patient's history lies in defining the main symptom - *fatigue.* This complaint may come from someone who 'feels tired a lot, doesn't feel like getting up in the morning'. Fatigue may also be a complaint of someone who collapses and feels very ill after minimal exertion, but who has a previous history of great energy and activity. So 'fatigue' can mean many things ...

This confusion of the symptom of 'chronic fatigue' with M.E. and CFS may be seen in some well-argued recent papers published in the last two years in medical journals, which tend to emphasize the psychiatric symptoms of chronic fatigue. Depression is a symptom, not a disease itself, and is frequently a prominent and disabling part of M.E. It is also a common symptom in other organic brain disorders, including MS, Alzheimer's disease, and Parkinson's disease; reactive depression can develop in any chronic illness. Psychiatric symptoms in M.E. should be treated where appropriate - but do not in themselves mean that the disease is psychological in origin.

Much excellent research is being done, looking at the evidence of persistent virus and at immune dysfunction. However, every time some new evidence of the organic nature of M.E. appears, someone writes an indignant letter pointing out flaws in the research, and providing a psychological explanation for the results.

Here is an extract from an article called 'Chronic fatigue, viruses and depression' - note the use of the term chronic fatigue, which could be interpreted as meaning the same thing as M.E.

> It is important to recognize that, in a society where M.E. is portrayed as a mysterious, rather glamorous, and disabling illness, people who have acquired this diagnosis may obtain attention and sympathy from friends and relatives, and perhaps also a justification for not fulfilling career ambitions or coping with the demands of everyday life. They may therefore lead less unhappy lives with their symptoms and their diagnosis than they could do otherwise.

This person's view is not based on any scientific study of numbers of ill people, it is an unfounded opinion.

There are of course a number of people who have needs that are satisfied by the invalid role, to be found in any chronic illness group. But to print this biased opinion, in a way that seems to apply to M.E. in particular, can only have far-reaching, harmful effects on ill people who are struggling to cope.

One of the characteristics of people with genuine M.E. is that they are highly motivated, frustrated by not being physically able to do things, and try by any means to get better. The loss of careers, breakdown of marriages, loss of ability to function in nearly every aspect of life - these devastating results of the disease cannot lead to ‘less unhappy lives'. In addition, many people with M.E. get neither sympathy nor support from family or friends. However, if M.E. is portrayed as nothing more than being chronically tired, then misconceptions such as that quoted above are bound to persist.

> Fatigue is a common complaint of patients presenting at general medical practice. Many such patients probably are suffering from a primary psychiatric illness. A few may have a well-recognized organic cause of chronic fatigue, such as hidden malignancy, thyroid disease, anaemia or other illness. Probably only a few of many patients seeking medical care for chronic fatigue have M.E./CFS.

(Komaroff 1991)

It is therefore very important for doctors to understand the difference between the complaint of chronic fatigue, and the features of M.E.

In case any of you doubt that the McEvedy and Beard (hysteria) diagnosis is still around, let me relate the account of a mother's difficulty when her daughter became ill:

'My daughter, aged 11, fell ill with a virus which was going round her school. She did not recover properly, and for months she kept on having swollen glands, a sore throat, and a slight fever. After eight months she was keen to go to school, but some days she would fade out by mid-morning and have to come home. If she tried any sports or gym she collapsed. She was referred to a paediatrician, who did blood tests and found nothing wrong. We then took her to another children's doctor, privately; he said he could find nothing wrong, and that she should be encouraged to go to school (which she was keen to do). We took her to see a consultant rheumatologist, because she had these awful pains in her muscles and legs, and he told us that she just needed to exercise and get fit!

'Then I saw an article in the *"Telegraph* which described her condition exactly. We were so relieved to find out what was wrong. I went back to see the private specialist and showed him the newspaper article, saying - "Look at this, our daughter has got post-viral Fatigue Syndrome." He just dismissed it, and said "That is Royal Free Disease, that's been proven to be hysteria."

'We were upset and angry. I knew she was ill and not putting it on. The trouble was that we needed a doctor to give a diagnosis so that she could rest from school if unwell, and be excused from having to do any sport.'

It was at this stage that this worried mother told me the story, and fortunately I was able to put her in touch with a knowledgeable GP, who recognised the illness with no difficulty. Happily the girl is now gradually improving, and a year after having the virus is able to go to school, provided she does not exercise.

But here were *three* specialists, all in one small city, who could not recognise that this child was ill, in part because they relied on blood tests rather than her history.