

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

Testing for M.E.: Plan D (Draft version)

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A correct diagnosis is half the battle won. However, being medically assessed by a knowledgeable doctor who is able to diagnose M.E. correctly is unfortunately far easier said than done. Scientific diagnostic methods and ethical concerns have been skewed by politics and financial concerns.

For more information on why this is the case, please see: [Who benefits from 'CFS' and 'ME/CFS'?](#), and [What is Myalgic Encephalomyelitis?](#)

On a purely scientific level we have more than enough information to diagnose patients with M.E. using objective tests, by taking detailed case notes and conducting a detailed physical exam etc. within just a few weeks of the onset of the disease. If the will and the funding were there, doctors could right now be given the information to diagnose all cases of suspected M.E. Scientifically, it would be no more difficult to do this with M.E. than with other diseases such as Multiple Sclerosis or Lupus.

A series of tests can confirm or eliminate a diagnosis of M.E. If all tests are normal then a person does NOT have M.E. **M.E. is no more difficult to diagnose through using a series of tests than MS.** In fact, it has been suggested that diagnosis of M.E. is significantly less difficult and more reliable than that of MS.

The problem is not that tests for M.E. don't exist. They do, but doctors – and many patients – are unaware of this. The information on testing is not generally known and accepted due to the nefarious influence of political and financial vested interest groups. There are overwhelming financial and political incentives for researchers to IGNORE the evidence on the diagnostic tests for M.E. in favour of the bogus and untestable 'CFS' (or 'subgroups of 'ME/CFS') construct, and so on. Thus doctors who gain their understanding of M.E. from such flawed research – as almost all do – wrongly believe that the disease cannot be diagnosed by tests.(tested for).

Diagnostic tests for M.E. exist, as described in [Testing for M.E.](#) Despite the existence of these tests, the unfortunate reality is that many people who suspect

they have M.E. do not have access to the appropriate tests or to doctors who are able to make a diagnosis. There are probably four main routes a patient's quest for a confirmation of the diagnosis of M.E. can take. For the purposes of this paper I've labelled them Plans A, B, C and D:

Plan A. A very small number of lucky patients will be able to see a M.E. specialist such as Dr Byron Hyde, and have their suspicion of an M.E. diagnosis either confirmed or denied, with a very high degree of accuracy, by appropriate testing and taking a detailed case history. This is the best possible scenario.

Plan B. The second best option would be to have a doctor who is not an M.E. expert but is sympathetic and intelligent and willing to use Dr Hyde's new testable Nightingale Definition of M.E. to make a diagnosis, again by appropriate testing and taking a detailed case history. This also has a high degree of accuracy.

Plan C. The patient may be unable to get a doctor to follow the Nightingale Definition of M.E. to make a correct diagnosis. The doctor may, however, agree to perform some tests which are relevant to M.E.; the doctor may not be willing to order expensive brain scans, but may perform cheaper and simpler tests. These tests may add significant weight to a suspected M.E. diagnosis. Unfortunately the doctor may or may not be able to interpret the results of these tests. Plan C can be subdivided into:

Plan C(a) in which the doctor can be trusted to interpret the results of the tests, and

Plan C(b) in which the doctor is ignorant, so the patient is forced to interpret the results for themselves.

This method may have a high degree of accuracy, if a series of these tests are done and most or all are highly indicative of M.E., and if the patient's case history and core symptoms and illness characteristics also fit M.E.

See appendix 1 for a brief description of the case history, core symptoms and illness characteristics which fit M.E.

Appendix 1:

Case history:

- Acute onset
- Virus infection evident 1-4 weeks before onset

Core symptoms:

- Significant neurological symptoms
- Significant cognitive problems which worsen with overexertion (problems with speech and talking, reading and writing, basic mathematics, memory and memory recall and learning new tasks)
- Problems coping with orthostatic stress
- Problems coping with sensory inputs such as noise, light and movement
- Lack of temperature regulation
- Muscle weakness, paralysis, pain (affecting all muscles including the heart and which may also affect breathing and vision)
- Blood pressure and pulse abnormalities due to overexertion
- Problems with balance, vertigo and proprioception
- Sensitivities to many different foods, drugs and chemicals
- Significant gastrointestinal and digestive disturbances
- Sleep disorders (reversed sleep/wake cycle, difficulty initiating sleep, lack of deep sleep etc.)
- Temporal lobe seizures and other types of seizures

Illness characteristics:

- Patient is immediately able to maintain 50% or less of their pre-illness activity level
- Severity of symptoms waxes and wanes markedly over the course of a day and a week
- Many symptoms are caused by reduced circulating blood flow of up to 50%
- Muscle strength is normal at first, but muscles quickly become weak/paralysed with use
- Delayed exacerbation of symptoms after overexertion (typically 48 hours)
- Severe exacerbation of symptoms with only minor activities beyond the patient's limits
- Overexertion can seriously harm or kill the patient
- Rest in the early stages of the disease brings the most positive long-term outcome
- A long-term or lifelong disease affecting children and adults
- Occurs in outbreaks as well as sporadically

If only a small number of these tests are done however, or the results are inconclusive or the case history/symptom profile doesn't fully tally with M.E. then the patient may still be left uncertain as regards a M.E. diagnosis.

Tests which patients may find doctors more willing to do, compared to expensive brain scans etc., and which are indicative of M.E. (particularly when done in combination) include the following:

- Romberg test or tandem Romberg test (positive in more than 95% of M.E. patients) – this is a test which can be done in your doctor’s rooms.
- Neurological examination – this is a test which can be done in your doctor’s rooms.
- Poor man’s tilt table test – this is a test which can be done in your doctor’s rooms. This involves taking your blood pressure and pulse while sitting and then while standing in order to tests for POTS etc. See [Testing for M.E.](#) for details.
- Low natural killer cell numbers/percentage and function (cytotoxicity) – this is a blood test. This test is abnormal in most M.E. patients, often strikingly so. The level of NK cells and NK Cells function also seems to correlate with illness severity.
- Apoptosis is often raised (this is programmed cell death: known to be raised in infection) – this is a blood test
- Abnormal ANA (indicates autoimmune disease) – this is a blood test
- Glucose tolerance test – this is a blood test
- An unusually low sedimentation rate of <5mm/hr is common in M.E. and can occur in 40% or more of patients (although there may also be brief periods where there is an elevated rate >20mm/hr). ESR rates as low as 0 have been documented in M.E. patients, and levels of 1 and 2 are very common. This is a blood test and this test is included if you have a full blood count test done. [Dr Byron Hyde](#) reported in 1989 that, “To my knowledge, there are only five diseases that have a pathological low sedimentation level: Myalgic Encephalomyelitis, sickle-cell anemia, hereditary sperocytosis, hyper-gammaglobulinemia [and] hyper-fibrogenemia.’
- A 24 hour Holter monitor (a type of heart monitor) may show repetitively oscillating T-wave inversions. It is important that doctors know what they are looking for with this test or else patients may be given a falsely normal report. See [Testing for M.E.](#) for details. This test may be able to be conducted at a patient’s home. If you are housebound, ask the people fitting/supplying the Holter monitor if this is possible.
- Physical exam. See [Testing for M.E.](#) for details.

Patients may also find that once abnormalities are shown on some of these tests, doctors may then be more willing to do more expensive or involved tests such as brains scans.

Note that of course none of these tests are unique to M.E. and the results are of course abnormal in other diseases. Many of the symptoms of M.E. are also seen in many other diseases; a person must have the core/ unique symptoms and features of M.E. (and combinations of symptoms and features) to be given a correct M.E. diagnosis.

It is the combination of a series of these abnormal test results, combined with a case history and core symptom profile that fits M.E., that strongly indicates M.E., not merely abnormalities shown on a small number of these tests, or a patient merely having some of the same *minor* symptoms as a M.E. patient.

Plan D: Sadly, all most patients are left with is plan D. They have little or no appropriate medical care at all. Patients may only be given the most basic of general tests, and when these show no abnormalities (as is the case with up to 90% of M.E. patients) further testing is denied, and often the very concept that the patients is ill at all is denied. (This despite the facts that as with all illnesses, of course tests will come out ‘normal’ if completely the wrong tests are done!)

Alternately, sometimes minor abnormalities are found in basic testing, for example hypothyroidism, and these minor issues are incorrectly assumed to be the sole or primary medical problem. When the patient exhibits little improvement in their condition as these minor secondary issues are given standard treatments, patients are often bizarrely accused of exaggerating (or even outright faking) their symptoms and disability.

With no access to appropriate medical care or testing at all, all a patient that suspects that they have M.E. can do is read as much as possible about M.E., and carefully evaluate their own case study to see how well it fits, or doesn’t fit, detailed and accurate accounts of M.E. This can be very useful, up to a point, as accurate descriptions of M.E. which describe the unique features of M.E. will resonate very strongly with genuine M.E. patients. (Most notably, descriptions by Dr Byron Hyde, Dr Elizabeth Dowsett and Dr Ramsay)

The biggest problem with this endeavour, however, is that much of what is written about M.E. is of questionable or very poor quality, and almost all of it is tainted by the concept of ‘fatigue’ and ‘CFS.’ Many patients will relate to poor quality or inaccurate information given about M.E. – or ‘CFS’ or ‘CFIDS’- that do not have M.E. but instead some other disease which is often misdiagnosed as ‘CFS.’

The concept of ‘ME/CFS’ and vague mixed definitions such as the Canadian ‘ME/CFS’ criteria confuse the issue even further. Many patients qualify for a ‘ME/CFS’ diagnosis (or rather, misdiagnosis) and relate to information given about ‘ME/CFS’ that do not have M.E. (This would include patients with Fibromyalgia, Lyme disease, Athlete’s over-training syndrome, various post-viral fatigue syndromes, Behcet’s disease, Multiple Sclerosis, B12 deficiency and so on.) The Canadian ‘ME/CFS’ criteria is not a definition of M.E., merely

another meaningless and unhelpful ‘CFS’ definition which happens to add in a small amount about some of the least important aspects of M.E. As with the ‘CFS’ definitions, it selects a heterogeneous (mixed) patient population.

Patients unsure of their diagnosis are recommended to look carefully at descriptions of some of the illnesses most commonly misdiagnosed as ‘CFS’ (or M.E.). See: [The misdiagnosis of CFS](#). If you aren’t sure what your diagnosis is, but you are sure it isn’t M.E., then you need to find a good doctor, preferably a skilled diagnostician. You do NOT need to see any type of ‘CFS’ expert, and in fact should avoid such individuals! A diagnosis of ‘CFS’ can only ever be a misdiagnosis.

For some patients however, this may still leave not quite 100% sure of whether or not M.E. is the correct diagnosis. The ‘D’ in plan D, may as well stand for ‘desperate.’ Plan D, means having no plan at all and having access to no appropriate medical testing at all. Being left in ‘no man’s land’ as regards your suspected M.E. diagnosis. Fairly sure but... not quite certain, due to a lack of appropriate supportive objective testing.

So what do you do if you are in this terrible situation? This is a question I am asked very often. It is very hard to know how to reply.

I am not a doctor, and have no medical training. I’m a very well-read patient that has M.E. and has spent a lot of time talking and listening to many hundreds of M.E. patients over the last decade. All I can really advise is that patients read as much about M.E. as possible (or about illnesses misdiagnosed often as ‘CFS’), and that they keep trying to get the tests and care they need, to try different doctors and to try giving doctors information from the HFME website, from M.E. experts such as Dr Hyde and Dr Dowsett – and that they participate in activism as much as possible to try to change this situation for themselves and all other patients.

But if a desperate friend were to say to me something like ‘How can I get some real objective confirmation of if this is M.E. or not, or if it’s even likely to be M.E. or not, when my doctor wont do any tests? If I don’t have M.E., I really want to know as soon as possible because I don’t want to waste YEARS missing out on getting a correct diagnosis for something that may be more treatable. I am utterly desperate for at least some type of indication either way. Some proof...’ In that scenario, where there really is **no other option for any type of appropriate care or testing at all**, and I am asked for my opinion as a M.E. patients and patient advocate, then I’d ask them the following 21 questions.

(Page breaks have been inserted before each part of the questionnaire so that patients can print out this entire document and then staple it into 3 booklets, making looking up the answers to each question much easier.)

21 point informal M.E. questionnaire: Part 1

Be as honest as you can in responding to these questions. There is no benefit at all in claiming a M.E. diagnosis publicly or even privately if it is not correct. This can be to your serious detriment in many ways. Think about your answers carefully and objectively, BEFORE looking to see if your response fits the facts about M.E. as explained in part 2 of the questionnaire. Note that these questions will not tell you whether or not you have M.E. and will only provide general information on how probable or improbable this diagnosis may be for you.

Question 1. Did you become ill suddenly, or did you become ill slowly over months or even a period of years? Was the onset of your illness sudden (acute), or more gradual?

If your onset of neurological and other symptoms was sudden, was a viral infection evident 1-4 weeks previously? (This may have been experienced as a flu-like illness, gastrointestinal upset or an unusual flu-like headache accompanied by sensations of vertigo.)

Question 2. Is your illness primarily neurological? Do you have significant cognitive problems and changes? Severe problems thinking and with memory? Problems completing simple tasks?

Question 3. Are you reduced 50% or more in your ability to do things, and did this occur within the first month of illness?

Question 4. When you are resting in the daytime, does it make an enormous difference if you lie down as opposed to sitting in a comfortable chair? What happens when you stand still for a few minutes?

Note: If you aren't sure, give it a try for 5 minutes. Remember not to sway or fidget or move at all. Just stand perfectly still with your arms and legs straight, and observe your body's response. If you know standing causes you some problems, you may want to have someone there to catch you. Stop the test immediately if you start to feel very seriously ill. If you are fine after 5 minutes, try a 12 minute time period instead.

If you are very severely ill and you know standing even 5 minutes would send your pulse and blood pressure absolutely crazy, and make you very ill for a long time afterward, of course you should NOT do any type of standing test for the purposes of this questionnaire; just mark this question as a positive and

leave it there. Perhaps the next time you have stood for too long, and are feeling very unwell, however, you might like to measure/evaluate your pulse and blood pressure readings at that time instead.

Question 5. Has your ability to tolerate alcoholic beverages changed markedly since you became ill? Did this change suddenly within a few months of the onset of your illness?

Question 6. Do your muscles seem to work normally at first, but over time lose all strength/ability to move as you repeat certain actions? Do you sometimes experience paralysis as a result of this?

Or is your muscle strength always weak or even extremely weak, without much change?

Question 7. What is your morning temperature? Is it low, or high, or normal?

Question 8. Do you have shiny red fingertips? Is the skin on your fingertips very thin and does it tear/scar/break easily?

Question 9. Do your feet go purple or even blue when you stand for more than a few minutes at a time?

Question 10. Do you sometimes notice brown or black splinter-like marks under your nails, so that it looks as if you have tiny splinters trapped under your nails (going down the nail)?

Question 11. Do you now have significant problems with balance? Do you have worsened balance problems when you have your eyes closed, or in the dark? Do you experience vertigo, extreme dizziness or spatial disorientation?

Question 12. Do you become far more ill generally depending on how much you do each day? If you do more mental activity, physical activity or spend more time upright than usual, do you really pay for it later? While you feel

some symptoms worsening right away, is the onset of the severe worsening of your symptoms caused by overdoing it often delayed by 48 hours?

Question 13. If you do become ill with overexertion, does it occur after merely minor tasks? Is the after effect often completely out of all proportion with the activity which caused it?

Question 14: Does overexertion make all your cardiac, neurological and other symptoms worse? Do you sometimes feel as if you were about to die? Do you sometimes experience severe cardiac problem such as tachycardia or a feeling as if you were having a heart attack? Do you experience breathlessness on overexertion? Flu-like symptoms?

Do you feel bone-crushing exhaustion at times? Do you suffer with extreme exhaustion all the time or almost all the time?

Question 15. Can you pass the shopping mall test? Do you have seizure-like problems, problems thinking, extreme pain or mental confusion and proprioception problems in that environment? Have you had to severely limit your exposure to light and noise and places like large shops?

Question 16. Does your level of rest play a huge part in determining how ill you are and how much you can do? Can what you did 2 weeks ago have a huge impact on how you feel today? Do you have to seriously rest for weeks or months before big events?

Is your illness stable from one month, week, day or hour to the next?

Question 17. Do you have severe pain? Do you have painful joints? Swollen glands?

Question 18. Has your handwriting changed since you became ill? Did you suddenly start writing differently? Does your handwriting change markedly/deteriorate from the start of a page to the end?

Question 19. Do you have a new onset type of 'headache' unlike anything you have felt before? Does it cause pain and pressure at the base of your skull (where your skull meets the top of your neck), and behind your ears and eyes?

Question 20. Can you tolerate sugar and carbohydrate-rich foods the same way as pre-illness? Do you have sensitivities to foods and chemicals? Changes in bowel habits? Does it feel at times as if your food just sits painfully in your stomach after you eat it rather than being digested?

Question 21. Has the way you sleep changed a lot since you become ill? Do you feel as if you sleep far more lightly? Do you feel as if no matter how long you sleep you wake up feeling as if you need far more rest?

Do you go to bed and wake much later than you used to, and have your circadian rhythms been disrupted or even reversed? Do you find that you cannot complete tasks or be active before midday as you used to?

21 point informal M.E. questionnaire: Part 2

M.E. fact 1: The onset of M.E. is acute/sudden. M.E. patients become very ill suddenly from one hour, day or week to the next.

A gradual onset of symptoms points overwhelmingly to a non-M.E. diagnosis. M.E. is not a gradual onset disease.

Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The onset of M.E. is frequently very dramatic, M.E. patients can very often tell you not just the day that they became ill, but the exact *hour* they became ill.

M.E. is an acute brain injury. Some patients say the onset of M.E. feels like having a stroke.

M.E. is an acute onset illness, however it should be noted that: (a) some sufferers will be unsure of their onset type (they may not recall it, or may not recall it accurately, for various reasons) and (b) in some cases, acute onset M.E. is preceded by a series of unrelated minor infectious episodes (in a previously well patient) which may be misinterpreted as being a gradual onset of the M.E. (These minor infectious episodes may be due to the immune system being under temporary or chronic stress from events such as; recent immunisation, repetitive contact with a large number of infectious persons, or the effect of travel; as in exposure to a new subset of virulent infections. This pre-existing temporary or chronic immune system weakness is not seen in all patients and is *not* what causes M.E., although a compromised immune system will of course make the body more vulnerable to all types of infections, including M.E.)

M.E. can commonly be diagnosed within just a few weeks if the doctor has experience with M.E.

The vast majority of M.E. patients will have had a viral infection evident 1-4 weeks before illness onset. Some patients may also be aware of being part of an infectious viral outbreak. Thus the presence of a viral infection along with an acute onset of the disease, adds significant weight to a suspected diagnosis of M.E.

For more information on the viral infection evident at onset in people with M.E., and the outbreaks of M.E. etc. see: [The outbreaks \(and infectious nature\) of M.E.](#)

M.E. fact 2: M.E. is primarily a neurological illness. Significant neurological symptoms are evident immediately after onset. This ranges from common problems such as seizure- and stroke-like episodes, problems with balance/vertigo, visual disturbances, strange tingling or burning sensations, significant problems with thinking and memory, absence seizures, sleep paralysis as well as some combination of more unusual and hard to describe neurological problems. (It has been suggested that it should be a prerequisite for qualifying for M.E. that patients have all sorts of weird and unusual neurological/CNS symptoms!)

Dr Byron Hyde explains that, ‘M.E. is an acute onset biphasic epidemic or endemic (sporadic) infectious disease process, where there is always a measurable and persistent diffuse vascular injury of the CNS in both the acute and chronic phases.’

The cognitive problems caused by M.E. are nothing at all like the ‘brain fog’ you might experience when you have had the flu or glandular fever/mono, haven’t slept well or are very tired, or are run down or hung-over. It is a completely different problem of a far greater magnitude. The two experiences are chalk and cheese.

If you have M.E., you will have felt nothing even remotely like these new onset cognitive problems before. You will feel sure you have suffered some sort of serious brain damage. It may feel like a stroke or as if part of your brain is missing, or parts of your brain just cannot communicate with each other anymore, or that the language or math centres in your brain have been completely scrambled or that you can no longer hold two thoughts in mind at the same time anymore, making complex reasoning almost impossible.

Patients may forget how to drive, or forget where they live, or suddenly become unable to do very simple tasks such as reading or using the telephone. Patients may be unable to remember which end of the phone to pick up, where to place it and what to say when they have picked it up. Words are forgotten or don’t make sense, or can no longer be understood when spoken by someone else. Faces even of close family members may be forgotten and facial recognition in general may become impossible. Patients completing higher education may suddenly find themselves unable to do basic coursework. From one day to the next, the whole way your brain works profoundly changes. Some deficits are constant, while others lift or become more severe depending on your activity levels. At times patients may be unable to think or speak almost at all or may become mentally confused or disoriented.

If your disease has few neurological features, or no neurological features, or does not cause severe cognitive deficits and changes, then it does not fit a diagnosis of M.E. These features are always a part of M.E. M.E. is primarily a neurological disease and neurological abnormalities are essential for the diagnosis. (Ideally these are tested for using brain scans such as MRI and SPECT scans.)

M.E. fact 3: Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change.

If you are in the acute stages of the disease and still managing full-time work, or full-time work and also extra study or volunteer work, then it is strongly recommended that diagnoses other than M.E. are looked at.

M.E. fact 4: Patients with M.E. cannot maintain normal blood pressure on standing. Most often the heart rate speeds up immensely to try to cope and patients feel very ill. If you felt very weak and as if you would pass out, or you even began to black out or grey out, or felt like you were having a heart attack, this would very much be consistent with M.E.

Do you find yourself moving (swaying, leaning and fidgeting) a lot when you are waiting in queues? Do you feel less faint when you are walking as compared to when you are standing still? M.E. patients often find that if they move and fidget about when they stand, or if they walk around, they can tolerate being upright somewhat better.

M.E. patients suffer with a type of cardiac insufficiency. Most M.E. patients qualify for a diagnosis of POTS (postural orthostatic tachycardia syndrome). Almost 100% of M.E. patients have NMH (neurally mediated hypotension).

POTS involves excessive rapidity in the action of the heart (either an increase of over 30 beats per minute or greater than 120 beats per minute during 10 minutes of standing); and a fall in blood pressure occurring upon standing. Syncope can but usually does not occur. NMH involves disturbances in the autonomic regulation of blood pressure and pulse. There is a precipitous drop that would be greater than 20-25 mm of mercury of systolic blood pressure

upon standing, or standing motionless, with significant accompanying symptoms. The patient feels an urgency to lie down.

A tilt table test is often used to diagnose POTS and NMH. But if this is not available, a ‘poor man’s tilt table test’ can be used, which involves using a blood pressure monitor in the following manner:

Description of poor man's tilt table testing procedure: Ask the patient to lie down and rest quietly for 15 minutes, then take the first blood pressure and pulse readings. Ask the patient to sit up for 10 minutes (or as long as they can manage without severe problems) and then take another set of readings. Direct the patient to stand up for 10 minutes (leaning against a wall, but without fidgeting or moving or talking which can affect the result) and then take another set of readings. After another 10 minutes of standing, take the readings again. Many patients will not be able to tolerate this much time upright and will need to stop the test partway through. If this happens, take another reading (if possible) and then ask the patient to lie down again. Failure to stop the tests when the patient becomes severely ill can lead to a loss of consciousness, or severe relapse lasting days, weeks or even months in the very severely affected. Someone should always be standing near the patient to catch them if they fall and serious requests to stop the test must be acted on in a timely manner.

Patients may also want to take their blood pressure reading when they are feeling very ill (in particular when this is due to orthostatic or physical overexertion). Often blood pressure readings are very low when M.E. is severe, e.g. 84/48 or 75/35. They may even be so low as to be unmeasurable by some blood pressure monitors and come up only as an ‘error’ reading. This occurs routinely in M.E.

A positive finding of NMH and/or POTS, combined with the other core features of M.E., is consistent with a diagnosis of M.E. *Thus this is one of the most important issues in determining a correct M.E. diagnosis.*

Dr Hyde says, ‘All the physician has to do is have each M.E. patient stand for 8-12 minutes to realize that a large number of these patients simply cannot maintain a normal blood pressure and normal heart rate. Compare this to non-M.E. patients and one immediately can tell the difference.’

M.E. fact 5: The vast majority of M.E. patients quickly become unable to tolerate even small amounts of alcohol. This may occur right away or over several months. The ‘hangover’ effect is fairly instant and can last for many hours afterward, or even for several days, and can be severe and completely

incapacitating. Patients may feel as if poisoned or may experience a worsening of many different symptoms. A patient that could previously drink an entire bottle of wine over an evening with few ill effects may with M.E. have a ‘hangover’ far more severe and longer lasting than any they have ever had before just from drinking half a glass of wine, for example.

This is not an allergic reaction to alcohol causing a red flush of the face and neck, as is seen in MS. Some less severely affected M.E. patients may be able to tolerate one or two drinks on occasion without severe effects, but this is very uncommon.

M.E. fact 6: The muscles of M.E. patients function fairly normally to start with, but when actions are repeated over time, muscles become very weak or paralysed. It often takes 3 to 5 days for full function to be returned, far longer than is normal (200 minutes is normal in sedentary controls). All muscles are affected, including the brain, the heart and the eyes and so on. M.E. authority Dr Melvin Ramsay explains that this unique symptom: ‘is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made.’

A person may be fine lifting a spoon to eat soup, brushing their hair, or carrying in heavy shopping bags for the first two minutes or so, but will then often find that suddenly all strength is gone and the task must be stopped or else paralysis of the muscles occurs and/or the symptoms of the illness worsen generally.

Muscle weakness that is constant (or which is not severely affected by repetitive minor actions in this way) points to a non-M.E. diagnosis.

Professor Malcolm Hooper recommends testing for this feature by observing the patient repeatedly lifting something weighing around 2 pounds or one kilogram for a period of time. He explains that, ‘M.E. patients can often manage a small number of repeats but performance rapidly falls off and recovery is very slow compared to healthy controls. More sophisticated treadmill tests will also show the same effect.’

The mitochondrial abnormalities seen in every M.E. patients can be tested for without a referral from a doctor, although the tests are expensive. (See Testing for M.E. for details.) Every M.E. patient will have abnormalities visible on mitochondrial testing. Abnormalities on this test will also be present in a variety of other diseases however, and so this test is not useful in determining a correct M.E. diagnosis. Probably the only reason to have this testing done is if you are

desperate for some concrete proof that you are physically ill and this is your only option. This test may be useful in that regard.

M.E. fact 7: A low morning temperature is almost universally seen in M.E. due to hypothyroidism. M.E. undermines the thyroid gland and hypothyroidism may be present immediately or may develop over time.

The author of the book The Brainpower Plan explains that:

One way to check thyroid status is the Barnes method. This is a self administered thyroid temperature test. Upon waking, before getting out of bed, place a thermometer under your armpit and take your temperature. The result is your AM basal temperature. Normal is between 97.8 and 98.2 Fahrenheit (36.5 and 36.7 Celsius). If your temperature is below 97.8 F (or 36.5 C) for 4 days, then this indicates that your thyroid output is low and that you should see your doctor who can prescribe the correct amount of natural thyroid etc. for you (which will likely make a significant difference to how you feel!). Note that women should not do this test during their period as this can alter the results.

A finding of hypothyroidism is very common in M.E., but this will also occur in other diseases.

M.E. fact 8: This finding is very common in M.E., although it does also occur in other diseases.

M.E. fact 9: This finding is very common in M.E., although it does also occur in other diseases (such as Raynaud's phenomenon).

M.E. fact 10: The book 'Prescription for Nutritional Healing: Fourth edition' by James Balch (a medical doctor and a certified nutritional consultant) contains a chart which lists various nail abnormalities and which diseases they signify. This book explains that black lines under the nail resembling splinters are 'a sign of infectious carditis (a serious heart infection), other heart disease or a bleeding disorder.'

In discussing this comment with many different M.E. patients, HFME contributors have discovered (anecdotally at least) that this finding appears to be very common in M.E. (M.E. is a disease which involves the heart and circulation as so this would very much tie in with the book's description.) It

also seems as if these marks will most often appear in M.E. patients during periods of severe illness or relapse.

As this abnormality also occurs in other diseases, it is not a sign of illness specific to M.E. but does appear to be one of the possible physical signs of M.E. which should be looked for during a physical examination. These splinter-like marks seem to be caused by small haemorrhages under the nails.

M.E. fact 11: M.E. patients experience problems with balance and vertigo, which are often severe. The body compensates for the damage to the vestibular or proprioceptive systems by instead relying almost totally on vision. Thus when you can't use your vision, balance problems become far worse.

The relevant test here is a Romberg test. The Romberg test is a useful test of brain stem function. This test is usually conducted by a doctor, but can also be done at home with a trusted friend or family member. From Wikipedia:

Ask the subject to stand erect with feet together and eyes closed. Stand close by as a precaution in order to stop the person from falling over and hurting themselves. Watch the movement of the body in relation to a perpendicular object behind the subject (corner of the room, door, window etc). A positive sign is noted when a swaying, sometimes irregular swaying and even toppling over occurs. The essential feature is that the patient becomes more unsteady with eyes closed. The essential features of the test are as follows:

1. The subject stands with feet together, eyes open and hands by the sides.
2. The subject closes the eyes while the examiner observes for a full minute.

Because the examiner is trying to elicit whether the patient falls when the eyes are closed, it is advisable to stand ready to catch the falling patient. For large subjects, a strong assistant is recommended. Romberg's test is positive if the patient sways or falls while the patient's eyes are closed.

If this test is normal, or inconclusive you may wish to attempt the tandem Romberg test which will allow detection of more subtle balance deficiencies that would otherwise be missed on the standard test. The difference in this test is that the patient stands heel to toe rather than with feet together.

See also neuroexam.com which includes a link to a Romberg video. The Romberg test is abnormal in over 95% of M.E. patients. This test is also often abnormal in other neurological disorders such as MS.

M.E. fact 12: M.E. patients react very differently to cognitive, physical and orthostatic exertion than healthy people or those with other diseases. The bodies of people with Myalgic Encephalomyelitis respond inappropriately to anything that forces the body to have to react in some way or work harder in some way, in order to maintain internal homeostasis, including: physical activity, cognitive exertion, sensory input and orthostatic stress.

The onset of the worsening of symptoms caused by overexertion is sometimes be acute but often will not peak until 48 hours or more afterward (this is particularly true with regard to physical, cognitive and orthostatic exertions). Symptoms will then persist for hours, weeks or many months, or longer. For many M.E. sufferers, the effects from significant overexertion will very often peak on day three.

Sometimes there is a significant worsening of symptoms evident at the time of overexertion. At other times, there may only be a minor worsening of symptoms at the time of overexertion, but the delayed effects will be severe. Sometimes the acute effects and the delayed effects will both be severe. It varies depending on the type and severity of the overexertion involved.

If you sometimes find you need 24 hours to recover from a certain physical activity, this is not at all the same thing as what is being discussed here, which is a 48 hour delay in these major symptoms even *appearing*. Taking 24 hours to recover from an activity is common, and may occur in many different non-M.E. diseases.

M.E. fact 13: When there is talk of ‘overexertion’ leading to an exacerbation of symptoms in M.E. what is being referred to is not hard exercise, it is not anything resembling what healthy people would recognise as ‘overexertion.’ This term just refers to any activity which goes beyond a person’s individual post-M.E. limits.

There is a lot of variation from patient to patient but very often the levels of activity required to cause relapse are trivial compared to a patient’s pre-illness tolerances and abilities. For example, what constitutes overexertion for someone with severe M.E. could be something as small as rolling over in bed, walking or talking for a few minutes, or eating a meal. The severity and duration of relapses varies depending on the severity of a person’s illness, but relapses in M.E. are very often way out of all proportion to the actual activity. Relapses can be very severe and prolonged (or even permanent) even if a person with M.E. has only gone past their individual limits in a seemingly minor way.

This extreme and out of all proportion reaction to even trivial levels of activity is just not seen in those illnesses causing fatigue (and other symptoms) after exertion which may commonly be misdiagnosed as ‘CFS.’ People with post-viral fatigue syndromes, Fibromyalgia and Lyme disease etc. are not affected by small activities for many weeks, months, or permanently, in this way. It is also potentially fatal in M.E., which is just not the case in these other diseases.

M.E. fact 14: When a person with M.E. is active beyond their individual post-illness limits, the result is not tiredness, fatigue or even exhaustion – nor is ‘malaise’ an accurate word to describe what occurs. There simply is no one symptom caused by overexertion in M.E. What does happen is that there is a worsening of all sorts of different symptoms and of the severity of the illness generally with overexertion. (Repeated or severe overexertion can also cause disease progression, permanent damage (e.g. to the heart), or death in M.E.) It is an entirely different problem of a much greater magnitude.

Overexertion causes an exacerbation of all sorts of combinations of neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms which can be mild, moderate, severe, or even life threatening (e.g. seizures and cardiac events). Many of the symptoms involved are present at a lower level at rest, but overexertion causes them to worsen. (Although some patients may also have some symptoms that only appear after overexertion.)

Patients commonly experience a combination of the following symptoms:

Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of co-ordination, dyspnea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if ‘poisoned,’ feeling cold and shivering one minute and hot and sweating the next, anxiety (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. Often the patient will feel an urgent need to retreat from all homeostatic pressures. The types of symptoms triggered vary widely from patient to patient, but some combination of these is common. There may also be an accompanying exacerbation of other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E. and can be profoundly incapacitating. At its most severe, the patient feels as if

they are about to die.

Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty whether they be; seizures, cardiac events, labile blood pressure, tachycardia, shortness of breath, muscle pain, muscle weakness or muscle paralysis, facial paralysis, black outs, flu-like symptoms, nausea, inability to speak or to understand speech, problems with memory, and so on. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere ‘fatigue.’ To say that all of these very different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere ‘fatigue,’ ‘malaise’ or ‘exhaustion’ is absurd.

If you experience severe exhaustion (as might be felt during a flu) rather than very distinct neurological, cardiovascular and cardiac symptoms and so on, and if this exhaustion is fairly constant and linked only minimally to physical activities, then this would very much suggest a non-M.E. diagnosis.

‘Fatigue’ and feeling very ‘tired all the time’ are not at all the same thing as the very specific type of *paralytic muscle weakness* or *muscle fatigue* which is characteristic of M.E. (and is caused by mitochondrial dysfunction) and which affects every organ and cell in the body; including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as; cardiac insufficiency (a type of heart failure), orthostatic intolerance (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, vision disturbances, breathing difficulties, and so on.

These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual limits. People with M.E. are made very ill and disabled by this problem with their cells; it affects virtually every bodily system and has also lead to death in some cases.

Many patients are housebound and bedbound and unable to do many basic tasks of daily living and often are so ill that they feel they are about to die. This state can last for many years. Sometimes patients must spend all or almost all of their time in dark quiet rooms, unmoving and alone. People with M.E. are very severely ill, not fatigued or severely exhausted.

Fatigue or post-exertional fatigue /malaise/exhaustion may occur in many different illnesses such as various post-viral fatigue states or syndromes, flu, Fibromyalgia, Lyme disease, Behcet's disease, Athletes over-training syndrome and many others – but what is happening with M.E. patients is an entirely different (and unique) problem of a much greater magnitude.

M.E. fact 15: It has been said that one way to diagnose M.E. is to put patients in a busy shopping mall and to observe the response.

M.E. patients become completely overwhelmed, confused and disorientated in this environment and may become unable to do simple mental or physical tasks. Patients may even be unable to stay upright and may fall over due to the conflicting and overwhelming visual and audio inputs. They may lose all proprioception skills and become unable to balance or be sure of where their body is in space. The constant noise and bright light may cause low-level seizures. M.E. patients will often find being in shopping malls suddenly completely unbearable and agonising.

M.E. fact 16: M.E. is *not* a stable illness. This instability and variability separates M.E. clearly from many other conditions such as post viral fatigue syndromes, which do not share this characteristic.

One can probably observe people with some illnesses carefully for an hour or so and collect a lot of good information about what they can and can't do, how severe their illness is, and what their usual symptoms are from day to day, and so on. However M.E. is not one of those illnesses.

Observing the average M.E. sufferer for an hour – or even a week or more – will not give an accurate indication of their usual activity level because the severity of M.E. can wax and wane throughout the month, week, day and even hour. Also, people with M.E. can sometimes operate significantly above their actual illness level for short periods of time thanks to prolonged rest periods beforehand, and surges of adrenaline – albeit at the cost of severe and prolonged worsening of the illness afterward. Relapses and worsening of symptoms are also very often also significantly delayed (there may be both an acute AND a delayed reaction).

Just observing someone with M.E. do a certain task should not be taken to mean (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they wont be

made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task.

Often a considerable rest period is needed before and after a task, which may be hours, days, weeks or months long. For example, someone may need 2 weeks rest before an outing, for example, and may then spend 3 weeks extremely ill afterwards recovering from it. Just observing them in the 2 hours they were 'out and about and mobile' is of course not at all representative of their usual ability levels.

For those with M.E., the amount of rest they get plays a huge part in determining how ill they are and how much they can do, both in the short term and the long term. How well you feel each day depends on how active you were and how much rest you got in the previous days, weeks, months and even years.

This very long-term effect from seemingly minor overexertion in past weeks and months etc. is just not seen in Fibromyalgia and Lyme disease etc.

M.E. fact 17: Severe widespread muscular pain is seen virtually universally in M.E. although it also occurs in many different diseases, such as Fibromyalgia.

Painful joints are a symptom not at all associated with M.E. The presence of this symptom points to a non-M.E. diagnosis such as arthritis or Lyme disease. The same is true of swollen glands. This is a symptom not generally associated with M.E. and only very rarely seen in M.E.

M.E. fact 18: The finding of changes to handwriting or deteriorating handwriting is often seen in M.E., although it may also occur in other neurological diseases and brain injuries.

M.E. fact 19: This unusual type of headache is often seen in M.E. and may be unique to M.E. It can be very disabling and severe.

Dr Hyde explains that M.E. can cause a unique type of 'severe headaches of a type never previously experienced.' There is a feeling of intense pain or pressure at the base of the skull, where the skull meets the neck (occipital pain). This may also occur with neck rigidity and/or retro-orbital eye pain (pain behind the eyes) and/or blackouts or a loss of vision. This head pain is most often brought on by overexertion, particularly orthostatic.

Vascular headaches such as this are well documented in M.E. from the earliest reports (for example Leon-Sotomayer) and are recorded as ‘long-term residuals’ in 100% of patients with M.E. (M.E. patients often report that non-M.E. patients rarely know what they are talking about when they describe these M.E. vascular headaches. They really are nothing like anything experienced pre-M.E.)

This very distinct type of ‘headache’ will often occur in M.E. patients after or during severe overexertion.

Other types of headaches seen in M.E. but also other diseases include: sinus, pressure or tension headaches (dull continual headaches which are not actually caused by anxiety as the name may suggest) and hypoglycaemia headaches (generalised prickly ache over the top of the head).

M.E. fact 20: M.E. patients will often find that their ability to handle high carbohydrate or high sugar foods has reduced markedly post-illness. You may feel jittery after eating high-sugar foods and feel very irritable and weak if you haven’t eaten for a few hours. Hypoglycaemia is very common in M.E., but will also occur in many diseases other than M.E. Symptoms of hypoglycaemia, as Dr Wilson explains, include:

- Extreme hunger or irritability at or before mealtime, especially for sweets and to some degree carbohydrates.
- Inability to skip meals.
- If one is late for a meal, one can become shaky, cranky, confused and even violent.
- Eating sugary meals often causes a roller coaster effect in people with hypoglycemia because the sugar level climbs steeply and then declines rapidly in several hours.

Cellular energy starvation produces other symptoms that may include fatigue, anxiety, confusion, tremors, irritability, fainting, headache, hunger, and even psychosis and other behavioral abnormalities.

M.E. patients often exhibit abnormal glucose tolerance curves on testing. However, this test (and finger-prick tests of blood glucose levels) may also be normal in M.E. (and other diseases involving problem with ATP production such as post-polio syndrome) despite very clear problems with foods high in carbohydrate and sugars. Patients with M.E. may also have a delayed effect with the GGT, registering a normal test result during the three hour duration of the test but then feeling extremely unwell and collapsing for an entire day an

hour or more later. As Dr Wilson explains in his excellent article on Hypoglycemia,

Confusion occurs regarding the definition of hypoglycemia. The standard medical definition is a serum glucose level of less than about 65 mg/ml. However, many patients undergoing a glucose tolerance test or GTT experience symptoms of hypoglycemia in spite of normal serum glucose levels.

I heard of one case in which a patient undergoing a 5-hour GTT ripped off her clothes and ran naked through the streets, although her serum glucose level was normal. In a less dramatic example, another patient fainted right in their chair during the test when the serum glucose was normal. Clearly the GTT is missing something.

What is missing is a better definition of hypoglycemia. It is not just low glucose in the blood. It is really related to *low energy production at the cellular level*. What happens during a GTT is that just giving a dose of sugar by mouth, as is done for this test, upsets glucose metabolism sufficiently that the entire glucose regulatory mechanism is occasionally thrown out of kilter and this produces the bizarre symptoms. It also produces false positives, false negatives and other aberrations on the GTT. If the laboratory measured the insulin levels during the test, as Dr. Robert Atkins, MD and others have suggested, it would give a much clearer picture. But even with this, it is only measuring sugar in the blood.

What is required for energy production? Adequate cellular energy production requires that enough glucose reaches the cells, not only an adequate supply of glucose, but also that it finds its way into the cells through the cell membranes. Once in the cells, it also requires that the mitochondria of the cells are able to burn or metabolize the glucose to form ATP. It also requires that the ATP is able to be utilized, meaning consumed or metabolized to ADP, and then recycled or reprocessed again into ATP. In short, any problem in these chemical pathways will cause hypoglycemic symptoms.

As the GTT is such an incomplete test and many patients know very well before the test that fasting and drinking the sugar solution will make them feel terribly ill, M.E. patients are also most likely best off avoiding the relapse-inducing GTT and instead having a simple finger-prick blood glucose level test.

Have you suddenly become either very constipated or do you have diarrhoea, or do you have both at different times? Are you experiencing new-onset stomach pains and upsets and perhaps also bloating and gas that just won't go away? Do you feel particularly unwell after eating certain foods, for example bread, dairy products and fermented products such as vinegar? Do you feel you don't digest

food as easily as you used to? All of these symptoms may indicate general gut problems and food intolerances due to M.E., although gut problems and food intolerances also occur in other diseases. You may want to do a food allergy test. Such tests are available without the need for doctor's permission, but are somewhat expensive. See [Testing for M.E.](#) for details.

M.E. patients will very often suddenly become unable to wear perfumes or other toiletries that they previously had no problem with. They may also be unable to tolerate previously used cleaning products and other common chemicals. Headaches and rashes may occur and the ability to think clearly may also be affected, or you may feel as if poisoned. This problem is very common in M.E., but also occurs in other diseases such as Multiple Sclerosis and multiple chemical sensitivity syndrome.

M.E. patients will often suddenly be unable to tolerate many different drugs and even supplements, particularly those which act on the CNS. Or patients may only need much smaller doses of these drugs to get the same effect., and may not tolerate normal doses. This problem is very common in M.E., but also occurs in other diseases.

M.E. patients commonly report that food just sits in the stomach after being eaten, rather than being digested. This is due to lack of blood supply to the stomach in M.E. and worsens with overexertion in the disease.

M.E. fact 21: Sleep disorders are a common part of M.E. M.E. patients often report being unable to sleep as deeply as they used to. Patients may sleep so lightly that they are woken by the slightest noise, or in severe cases may feel they sleep so lightly as to rarely even become fully asleep. In the early stages of the disease, patients may also have problems maintaining consciousness and may sleep (or be passed out) for 20 hours or more at a time. Also common are problems initiating sleep and maintaining sleep; sleep may be very fragmented. Another common finding in M.E. is a very changed type of dreaming. Patients may experience very vivid dreams or even nightmares (possibly due to seizures occurring during sleep). Sleep paralysis may also occur on waking in M.E.

Circadian rhythms are very often reversed in M.E. Patients often sleep much of the day and cannot sleep until very late at night/early in the morning. Patients may be unable to function in the morning as well as they do in the afternoon and may become very unwell if forced to do activities earlier than they can cope with or not in the few hours a day that they are more able than for the rest of the day. The time of day a task is completed has a profound effect on how much the patient 'pays' for it later.

These findings are very common in M.E., but may also occur in many other diseases and so aren't specific to M.E.

How to interpret your results

In short, if none of this or not much of this rings a bell with you or fits you, then it really isn't a stretch to say that a diagnosis of M.E. is not just unlikely but is in fact NOT a viable option.

If about half of your responses strongly tally with M.E. as described here, then a diagnosis of M.E. may be a possibility – depending on whether or not you have the core characteristics of M.E. and not just some of the more minor features. (Having a large number of neurological problems, and having a condition that worsens when standing upright and with minor physical and cognitive activity and sensory inputs and makes doing all the tasks you did before you were ill completely impossible, is essential for a correct diagnosis of M.E. to be considered.)

If most of your responses, or all, or almost all strongly tally with M.E. as described here, then a diagnosis of M.E. isn't a certainty but is a very strong possibility that should be further investigated via testing if at all possible.

There is no numerical score to add up here that puts you in any particular category, as what is important is that you have the core features of M.E. and the complex of symptoms seen in M.E., not merely some of the minor symptoms also seen in other diseases. The questionnaire includes questions about core M.E. features as well as some of the more minor symptoms and signs.

This questionnaire is not intended to be an alternative to appropriate testing by a qualified doctor. I cannot vouch for the accuracy of results, particularly as some patients may misinterpret my explanations.

Common misinterpretations to be aware of

Most notably, the severe and unique reaction to activity seen in M.E. is often not at all understood by non-M.E. patients. Patients with illnesses such as Fibromyalgia, post-viral fatigue syndromes, athlete's over-training disorder, adrenal exhaustion (or other thyroid or adrenal disease), Lyme disease or Bechet's disease and so on often say they relate to this and share this exact same symptom, but this can only be because they have not fully understood the severity and *difference* of what is being described and how different it is to post exertional fatigue/malaise or exhaustion.

What is happening in M.E. is utterly different to what is happening in these other diseases as evidenced by the fact that minor overexertion can cause severe disability or even death in M.E. and never in these other diseases. None of these diseases involves cardiac insufficiency and reduced blood volume of up to 50% - and these problems are what cause most of the symptoms in M.E. and the disability of M.E. Unfortunately, some patients read about the unique effects of overexertion in M.E. and seem to take from it nothing more than that what is being experienced is 'very severe' exhaustion, just the same as they are experiencing – missing the point entirely that it isn't mere exhaustion at all and has a very different CAUSE and PATHOLOGY to what they are experiencing.

The health and ability level of an M.E. patient at any minute depends entirely on how active they have been in the preceding hours, days week and years. *One day's* severe overexertion can take *a year or more* to recover from, or a person may not be recovered from it after several years. The difference is NOT just of severity. Being upright for a short period or being exposed to bright lights or noise, making a short phone call or just speaking for a short period or even just having to think can cause relapse just as easily as physical overexertion. The relapse caused is nothing like severe fatigue or exhaustion. It is so much more than that, although of course these minor symptoms may be some of the many which make up the whole in the disease. When M.E. is moderate or severe, this relapse makes the patient feel as if they are dying. One's whole life revolves around preventing the enormous and extended relapses caused by the smallest of activities and trying desperately to try and rest as much as possible in order to have any quality of life at all. It seems it is hard to understand the difference if one does not have M.E., perhaps. The experience is so profoundly new and overwhelming that expressing it in words can be difficult. Patients unsure of their diagnosis must analyse their symptoms and reactions to activity and the description of genuine M.E. very carefully and without bias.

M.E. is not the same disease as Fibromyalgia, post-viral fatigue syndromes, athlete's over-training disorder, adrenal exhaustion (or other thyroid or adrenal disease), Lyme disease or Bechet's disease and these diseases are not subgroups of M.E. nor causes of M.E., nor diseases with 'virtually all the same symptoms' as M.E.

Other misunderstandings may also occur. For example, the mild allergic reaction to alcohol, as seen in MS, may also be confused with the inability to tolerate alcohol seen in M.E. Or NMH/POTS may be present, but may be caused by a period of being bedbound instead of being an organic part of the disease as it is with M.E. The list goes on.

Final comments

I write this informal paper NOT because I feel I am in any way qualified to do so. Of course I am not. I write this paper because this is a question I get asked very often, and I know people are asking me as a last resort, and they are truly desperate for even a tiny bit of objective evidence to back up their suspicions about a M.E. diagnosis and to have some level of certainty. They are asking for my *opinion* as a well-read and experienced M.E. patient. I wish so much such a paper wasn't necessary and I hope that very soon it will not be. That people could go to any doctor and be correctly diagnosed with M.E. with no more fuss than occurs with other diseases. That would be beyond wonderful. That is the goal of HFME's advocacy.

The information given here is based on information given by the world's leading M.E. experts. For references, please see: [Testing for M.E.](#) and [What is Myalgic Encephalomyelitis?](#)

Again, this questionnaire is for a patient's use only, as an absolute last resort. It is not designed to be used by doctors, and of course (as if proper) it will have no weight at all if shown to a doctor (this is NOT recommended!). You may wish to instead show your doctor the fully-referenced [Testing for M.E.](#) paper or Hyde's Nightingale Definition of M.E. This IS recommended!

You may wish to talk to your doctor about some aspects of your case study discussed here which are important and you feel should be highlighted (e.g. sudden alcohol intolerance, significant cognitive deficits, abnormal blood pressure and pulse readings, or acute onset of illness associated with a virus and so on) but it would probably be best if you explained these things in your own words, without attaching your own interpretations as to their cause, or mine. Again, you may also wish to show your doctor the [Testing for M.E.](#) paper or the Nightingale Definition of M.E.

Additional notes on this text

- See the [Testing for M.E.](#) paper or the Nightingale Definition of M.E. for more information on M.E. diagnosis, and for references for this text. See also: [Finding a good doctor when you have M.E.](#)
- Note that many different illnesses may share a percentage of the individual neurological, gastrointestinal or cognitive features of M.E., (and so on) but there is no other illness which encompasses each of the specific neurological, cognitive, immunological, gastrointestinal, cardiac and cardiovascular, endocrinological, respiratory, hormonal and other features

and symptoms which make up M.E. While patients with all sorts of different diseases may share 20%, 30% or even 70% or more of the individual symptoms listed as M.E. symptoms, this specific combination of a particular onset, symptoms and pathology (test results) is not seen in any other illness. There are also a number of characteristics of M.E. which are unique to the illness. The acute onset of M.E. in particular sets it apart from many other illnesses commonly associated with a gradual onset, as do many other characteristics. See: [The misdiagnosis of CFS](#) for more information.

- If after reading this paper you no longer suspect M.E. as your correct diagnosis but all you have so far is a 'CFS' misdiagnosis to go on, please see: [Where to after a 'CFS' \(mis\)diagnosis?](#)
- For more information about the significant similarities between M.E. and Multiple Sclerosis see: [M.E. vs MS: Similarities and differences](#)
- *A further comment on the misinterpretation of the effects of overexertion in M.E.* This misunderstanding is also helped immeasurably in a different way by the many 'CFS' and 'ME/CFS' websites (or even worse, sites actually using the term M.E.) which feature descriptions which claim to be about M.E. and written by M.E. patients but which are not, and which will often use terms such as 'fatigue' and 'exhaustion' to describe the main features of their illness. The 'ME/CFS' definition also plays a role here as many mistake it to be a true definition and description of M.E., which it is not.

This is all also not helped by the fact that people with all sorts of diseases seem to want to consider their disease to be similar to M.E., perhaps to justify their long-held claim of a 'ME/CFS' or M.E. diagnosis (based on the 'CFS' or 'ME/CFS' definitions) or their years of involvement in 'CFS' or 'ME/CFS' etc. advocacy. But the only thing worse than having been misdiagnosed and misdirecting advocacy efforts for many years is doing so for one moment longer than you have to. Learning that one does not have 'CFS' nor M.E. is overwhelmingly a very positive development, and embracing it is far more likely to bring personal and general benefits than is holding on to a misdiagnosis and/or subverting and bizarrely twisting M.E. information to try to make it fit the non-M.E. disease you have or supporting the unscientific 'ME/CFS subgroups' nonsense. This also negatively affects M.E. advocacy and the welfare of all patients misdiagnosed with 'CFS' that do not have M.E. See: [Where to after a 'CFS' \(mis\)diagnosis?](#)

- *What is CFS?* CFS was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist. All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue (a symptom

seen in many illnesses but not a defining feature of M.E. nor even an essential symptom of M.E.).

The disease category ‘CFS’ has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various unrelated psychiatric fatigue states and post-viral fatigue syndromes (etc) for the benefit of various (proven) financial and political interests.

M.E. and ‘CFS’ are not synonymous terms. The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which are of primary importance. *The distinction must be made between terminology and definitions.* To summarise:

1. **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as ‘CFS’ is ‘medically unexplained.’ A diagnosis of ‘CFS’ does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with ‘CFS’ is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a ‘CFS’ (mis)diagnosis. Every diagnosis of ‘CFS’ can only ever be a misdiagnosis.
2. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining or even an essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

The problem is not that ‘CFS’ patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with ‘CFS’ actually *do* have psychological illnesses. ‘CFS,’ as a wastebasket diagnosis, includes all sorts of fatiguing illnesses including psychiatric illnesses.

‘CFS’ is associated with psychiatric illness; for many patients this is inappropriate, but some patients misdiagnosed with ‘CFS’ actually *do* have psychological illnesses. *There is no such disease as ‘CFS’* – that is the entire issue. The vast majority of patients misdiagnosed with ‘CFS’ *do not* have M.E.

The bogus disease category of ‘CFS’ must be abandoned (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS,’ ‘CFS/ME,’ ‘ME-CFS,’ ‘CFIDS,’ ‘Myalgic Encephalopathy’ and others), for the benefit of all patient groups involved. Information on M.E. must be published using only the term M.E. and must involve a 100% M.E. patient group. Science, logic and ethics must finally prevail over mere financial and political concerns.

For more information on this topic see: [The misdiagnosis of CFS, Who benefits from 'CFS' and 'ME/CFS'?, Where to after a 'CFS' \(mis\)diagnosis?, Smoke and mirrors, The Terminology Explained and Why the disease category of ‘CFS’ must be abandoned.](#) The truth about the organic and distinct neurological illness M.E. must not be allowed to be buried under cover of ‘fatigue’ and ‘CFS’ for another 20 years.

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The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

A one-page summary of the facts of M.E.

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- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were ‘atypical multiple sclerosis’ and ‘atypical polio.’
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation’s International Classification of Diseases since 1969 as a distinct organic neurological disease.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level

amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.

However, the hearts of M.E. patients only barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: [What is M.E.? Extra extended version](#). Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.