

## **What it feels like to have M.E. A personal symptom list and description of M.E. – Condensed version**

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I put together The ultra-comprehensive Myalgic Encephalomyelitis symptom list in 2004 using references from the world's leading M.E. experts. For some time however I've wanted to create a second M.E. symptom list; one which combines the available research with a detailed personal description of the illness and which might more accurately describe what it really *feels like* to have M.E., far more than a purely clinical list of symptoms (even an accurate one) ever could.

### **The symptom list is divided into three categories:**

**Section 1:** The myths about M.E. and the symptoms of M.E.

**Section 2:** Descriptions of individual symptoms

**Section 3:** On the pattern/cause of symptom exacerbations, relapses and disease progression in M.E.

### **Section 1: The myths about M.E. and the symptoms of M.E.**

Because of the vast amount of inaccurate information being propagated about Myalgic Encephalomyelitis by various vested interest groups (helped immeasurably by the creation of the bogus disease category of 'Chronic Fatigue Syndrome' as well as a number of vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and Myalgic 'Encephalopathy' etc.) it is important to explain briefly the myths about M.E., and the symptoms of M.E.

Myalgic Encephalomyelitis is not synonymous with being tired all the time. If a person is very fatigued for an extended period of time this does not mean they are having a 'bout' of M.E. To suggest such a thing is no less absurd than to say that prolonged fatigue means a person is having a 'bout' of multiple sclerosis, Parkinson's disease or Lupus. If a person is constantly fatigued this should not be taken to mean that they have M.E. no matter how severe or prolonged their fatigue is. Fatigue is a symptom of many different illnesses as well as a feature of normal everyday life – but it is not a defining symptom of M.E., nor even an essential symptom of M.E.

There are a number of post-viral fatigue states or fatigue syndromes which may follow common infections such as mononucleosis/glandular fever, hepatitis, Q

fever, Ross river virus and so on. M.E. is an entirely different condition to these self-limiting fatigue syndromes however (and is *not* caused by the Epstein Barr virus or any of the herpes or hepatitis viruses), the science is very clear on this point. People suffering with any of these post-viral fatigue states or fatigue syndromes do not have M.E. M.E. is also not the same condition as Lyme disease, athletes over-training syndrome, burnout, depression, somatisation disorder, candida, multiple chemical sensitivity syndrome or Fibromyalgia, or indeed any other illness. M.E. is a distinct neurological illness with a distinct; onset, symptoms, aetiology, pathology, response to treatment, long and short term prognosis – and World Health Organization classification (G.93.3) (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d.a, [Online]).

M.E. is also not defined by ‘fatigue following exertion which can last up to 24 hours’ as the bogus definitions of ‘CFS’ describe. Fatigue following activity (or post-exertional fatigue or malaise) is a common symptom of a large number of different illnesses – but what is happening in M.E. is quite different.

Overexertion does not cause fatigue in M.E. but instead a worsening of the severity of the illness generally and of various neurological, cognitive, cardiac, cardiovascular, immunological, muscular and gastrointestinal (and other) symptoms. The severity of these symptoms can range from mild to severe to life-threatening. The effects of overexertion can last for hours, days, weeks or even many months in M.E., or can even be permanent. The onset of these post-exertional effects are very often significantly delayed so that very often the worsening of the illness caused by overexertion has not even *begun* within 24 hours in M.E., let alone been completely resolved in that time.

The reaction people with M.E. have to physical and mental activity, sensory input and orthostatic stress not only has nothing to do with mere fatigue (or ‘malaise’) but is in fact unique to M.E. in a number of ways. This reaction is so abnormal in fact that exercise testing is one of the series of tests which can be used to help confirm a M.E. diagnosis, as are various tests which measure the abnormal responses to orthostatic stress seen in M.E. This is simply not the case in post-viral fatigue syndromes, Lyme disease, Fibromyalgia and so on. These patient groups do not exhibit the same measurable pathological abnormalities as M.E. patients in these (and other) tests. Recent research has also shown that postural stress exacerbates cardiac insufficiency in M.E. and that this cardiac insufficiency is the cause of many of the symptoms and much of the disability of M.E. This pathology is also not seen in any of those illnesses causing fatigue after exertion which are commonly misdiagnosed as ‘CFS.’ The way people with M.E. respond to physical activity and orthostatic stress (etc.) is profoundly

different than in these other illnesses; it is an entirely different problem, of a much greater magnitude (Cheney 2006, [video recording]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]).

What defines M.E. is not ‘chronic fatigue’ but a specific type of acquired damage to the brain. Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name Myalgic Encephalomyelitis.) Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS dysfunction is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process.

Myalgic Encephalomyelitis is a loss of the ability of the CNS (the brain) to adequately receive, interpret, store and recover information which enables it to control vital body functions (cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance etc). It is a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits. This dysfunction also results in the inability of the CNS to consistently programme and achieve normal smooth end organ response. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs. Some individuals also have damage to skeletal and heart muscle.

This diffuse brain injury is initiated by a virus infection which targets the brain; M.E. represents a major attack on the central nervous system (CNS) by the chronic effects of a viral infection. M.E. is an infectious and primarily neurological disease process which occurs in epidemic and sporadic forms. There is a history of recorded outbreaks of M.E. going back to 1934, when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. A review of M.E. outbreaks found that clinical symptoms were consistent in over sixty recorded epidemics of M.E. spread all over the world. M.E. has been linked to Poliomyelitis (Polio) since 1934 and for a number of years M.E. was referred to as ‘atypical Polio.’ The world’s leading M.E. experts (namely Ramsay, Richardson, Dowsett and Hyde – and others) have all indicated that M.E. is caused by an enterovirus, the same type of virus which causes polio. The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling. For example: M.E. epidemics very often followed Polio epidemics, M.E. resembles Polio at onset, serological studies

have shown that communities affected by an outbreak of M.E. were effectively blocked (or immune) from the effects of a subsequent polio outbreak, evidence of enteroviral infection has been found in the brain tissue of M.E. patients at autopsy, and so on. (See: [The outbreaks of M.E.](#) and for more information.)

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically. Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond a M.E. patient's individual post-illness limits causes a worsening of the severity of the illness (and of symptoms) which can persist for days, weeks or months or longer. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (eg. to the heart), disease progression and/or death in M.E.

M.E. is not stable from one hour, day, week or month to the next. It is the combination of the chronicity, the dysfunctions, and the instability, the lack of dependability of these functions, that creates the high level of disability in M.E. (It is also worth noting that of the CNS dysfunctions, cognitive dysfunction is one of the most disabling characteristics of M.E.)

At first glance a list of M.E. symptoms it may seem that every symptom possible is mentioned, but the seemingly random list of symptoms in fact form unique and distinct patterns – they are anything but 'random' for those with knowledge of the illness and/or of how the illness effects the body's various systems. Different people have a lot of different symptoms but the general pattern and evolution of major symptoms are remarkably coherent from patient

to patient in M.E.; they fit a precise pattern that is nearly identical from one patient to the next.

M.E. is a distinct, recognisable disease entity which contrary to popular belief is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease (within just a few weeks) – providing that the physician has some experience with the illness. (The usual case of M.E. is so distinct that people with M.E. can recognise fellow sufferers almost in an instant.) Although there is (as yet) no single test which can be used to diagnose M.E. there are a series of tests which can confirm a suspected M.E. diagnosis. If all tests are normal, if specific abnormalities are not seen on certain of these tests (eg. brain scans), then a diagnosis of M.E. cannot be correct (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett n.d.a, [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92). (See Testing for Myalgic Encephalomyelitis for more information.)

All of this is not simply theory, but is based upon an enormous body of clinical information which has been published in prestigious peer-reviewed journals all over the world and spans over 60 years. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis. Myalgic Encephalomyelitis is neither ‘mysterious’ nor ‘medically unexplained. Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on.

Myalgic Encephalomyelitis is a debilitating illness which has been recognised by the World Health Organisation (WHO) since 1969 as an organic neurological disorder. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio. M.E. affects all races and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages.

M.E. can be extremely disabling, and is not a self-limiting or short term illness. 25% of M.E. sufferers are severely affected and housebound and bedbound. In

some cases Myalgic Encephalomyelitis can also be progressive, or fatal. Governments around the world are currently spending \$0 a year on M.E. research.

M.E. is an infectious neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of medically unexplained ‘chronic fatigue’ (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Cheney 2006, [video recording]) (Hyde 2003, [Online]) (Hooper 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43).

## More information

- For a referenced version of this test see: [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#)
- For more information about the medical and political facts of M.E. see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [What is Myalgic Encephalomyelitis?](#), [M.E. vs MS: Similarities and differences](#) and [Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#). See also: [Putting research and articles into context](#), [The misdiagnosis of CFS](#), [Smoke and mirrors](#) and [Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename 'CFS' as 'ME/CFS' and Problems with 'our' M.E. \(or CFS, CFIDS or ME/CFS\) advocacy groups.](#)

See also those papers created exclusively for M.E. patients including: [Problems with the use of 'ME/CFS' by M.E. advocates](#) and [Are we just 'marking time'?](#)

- For information on how to treat M.E. see: [Treating M.E. - The Basics](#). See also: [Why patients with severe M.E. are housebound and bedbound](#), [The importance of avoiding overexertion in Myalgic Encephalomyelitis](#) and [Hospital or carer notes for M.E.](#)
- This website has become so large that its features can no longer all be taken in at a glance. In order for site visitors to find the information they need more quickly, the [Information Guides](#) page features guides relevant to each of the different types of visitors to the site including M.E. patients, doctors, ‘CFS’ misdiagnosed patients, friends and family of patients and so on.

## Section 2: Descriptions of individual symptoms

This is not a complete list of all the M.E. symptoms on record, nor is this even a complete list of my own symptoms, I would estimate that I’ve probably described roughly 70 - 80% of all my symptoms here. Along with some of the descriptions of individual symptoms I have also included some background and

contextual information. Also note that symptoms are listed in no particular order.

“I went from having a very normal tolerance for alcohol, to having **no tolerance for alcohol** at all. This happened over a period of just a few weeks right after the day I got M.E. (on March the 19<sup>th</sup> 1995) when I was just 19. On each occasion I drank I could drink less than on the one before. It soon got so that if I drank even half of a standard drink, I would get an extreme hangover within about 20 minutes that would continue 24 - 48 hours afterward. 12 years later I still can't really even drink a tiny (one mouthful) alcoholic drink on special occasions.”

“Some nights I would **black out** every time I turned over in bed. A few seconds after turning over I'd feel my eyes roll back in my head, the room would spin wildly, and I'd lose consciousness. It felt just horrible. The experience was made so much worse though by the fact that my memory was so bad. I'd roll over, black out, swear to be more careful about moving for the rest of the night, but then forget the whole thing entirely a few minutes or so later – so of course I'd roll over again and black out again. This would just go on and on and I remember some nights doing it 10 – 15 times or more. I just couldn't remember not to do it for more than a few minutes or so at a time, no matter how hard I tried. I'd alternate between dreading the next black out (while I could still remember them), and having the awful realisation of how damaged my memory really was (while I could still remember that too).”

“One of my very first M.E. symptoms (I had it from day one and I still have it now) was to feel very **vertiginous and disoriented in the dark** or when I had my eyes closed. I would have no sense of up or down, or sense of where I was in space and often I would experience vertigo as a result. I would be fine if there was a low level light but pure darkness was suddenly a real problem for me. I'd be lying normally on a bed but then I'd turn the light off and I'd find myself holding tight onto the edge of my bed so as not to fall off; I'd be so sure my bed was suddenly tilting at a wild angle and that I must be about to roll right off it. Getting to sleep began to become really difficult.

I just couldn't work out what was happening at first. I even thought I might be somehow 'scared of the dark' for a little while, as ridiculous as that sounds now. (That was all I could come up with! I just had so little accurate information about my illness at the time... well, no accurate information at all to be more precise as I was misdiagnosed as suffering with depression and anxiety for many years, despite the fact that I had no feelings of depression or

anxiety – and that I did have a whole host of symptoms which couldn't possibly be explained by any mental or behavioural condition.) Through a lot of trial and error however, I finally found out what was really happening: that my systems of balance (my vestibular systems) and sense of where I was in space (my proprioception) were damaged – or at least no longer working as well as they did, or reliably. I also worked out that my body had adapted to this damage to some extent (as the brain will often do) by using my vision to compensate. This was great, but of course it meant that if it was dark or if I closed my eyes, I'd be back to square; which was exactly my problem! Once I'd worked all this out, I started going to sleep with a night-light which helped immeasurably, although I have to try to go to sleep without having my eyes closed for very long beforehand, which is difficult. (Incidentally, the fact that my vestibular systems are severely damaged, and that I use vision to compensate, has been verified by objective scientific testing through the administration of a Romberg test by a physician. A Romberg test is a useful test of damage to the vestibular systems and of brain stem function. See [Testing for M.E.](#) for more information.)”

“Some days as soon as I first stand up (upon waking) I can feel that my **balance** is even worse than usual. I'll start walking to the bathroom having to hold onto both sides of the hallway walls as I go to try to keep myself from falling. The weird thing though is that I am not fighting to avoid falling over forward. My internal sensors are telling me that in fact I'm walking almost upwards (as if I were walking UP the wall) and that I am in danger of falling backwards, and about 10 degrees or so to the right. I can see clearly where the real up and down is, but my body (my vestibular system) is telling me something very different. It is disconcerting to feel as if you are walking up a wall and are about to fall backwards, when in reality you are leaning quite far forward as you walk and are in far more danger of falling forwards onto your face than anything else! This balance problem typically lasts all day but does slowly improve as the day goes on usually as the system is able to reset itself somehow.”

“Aside from the many different neurological problems, **cardiac problems** are probably my worst symptom right now and they are certainly the scariest symptoms. They are caused by my being upright for too long (orthostatic stress) but also from too much mental or physical activity. The symptoms are much the same independent of whether I have overexerted physically, mentally or with orthostatic overexertion. The pattern is the same too; some moderate to severe symptoms right after it happens and a far more severe worsening of symptoms starting anywhere from 8 to 48 or more hours later. The delayed onset symptoms or relapse can last one day, or a week or several weeks if the incident was bad enough (or even 4 – 6 months or more if it was extreme. I also might



never regain my previous level of health if it was an extremely severe overexertion, as has happened before.)

(Two recent Holter monitors I had (a type of heart monitor) showed that my heart-rate went up to 170 bpm when I was having these kinds of attacks (among other abnormalities). I didn't have anything like a severe attack while having the monitor on either, but 170 bpm is quite scary enough and I don't want to know really if it gets much worse than that. (Cardiac problems are one of the most common causes of death in M.E.). My blood pressure is also abnormal (low and labile) in response to these same exertions, which is also quite scary. I can feel my blood pressure get very low, then return closer to normal and then go all strange again a few seconds later and so on. I've also had this problem objectively and scientifically verified many times by blood pressure monitor. Tests show that my blood pressure, as well as my heart rate, goes haywire when I stand up even for very short periods of time)."

“The problem of a very fast heart rate, of **my heart fluttering in my chest**, is one of my worst symptoms. It feels like the heart can't pump properly, so it has to beat much faster to make up the difference. (So you have a lot more ineffective beats instead of the normal number of proper ones.) Certain levels of physical or mental activity, sensory input or orthostatic stress make it a lot worse both immediately and 8 – 48 hours later as well. No matter what the type of overexertion, this tachycardia and fluttering of my heart is always the first symptom I get, and very often the most severe symptom caused also. This problem is also there at a lower level all the time, even at rest.

(Like just about every other M.E. sufferer, I was blown away when the research about cardiac insufficiency came out a few years ago. ‘That explains so much!’ and ‘finally some attention on the obvious cardiac problems of M.E.!’ we all thought. According to this research, mitochondrial dysfunction leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don't fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.) So the tachycardia – fast heart rate – seen in M.E. in response to orthostatic stress etc. is actually compensating for low stroke volume to help increase cardiac output; the heart doesn't fill with enough blood so it is forced to beat faster to try to make up some of the shortfall, but we are still left with reduced cardiac output which leaves us very ill and

disabled, and if severe enough can result in death. As one M.E. advocate explains: ‘Cardiac output is sometimes too low to meet the demands of movement, and any attempt to exert oneself beyond one's own capacity for cardiac output - that is when demand exceeds cardiac capacity - would indeed result in death. Studies on dogs have shown that when the demands of the body exceed cardiac output by even 1%, the organism dies. M.E. patients [must] reduce demand and reduce their exertion level to stay within the bounds of their low cardiac output to stay alive.’ (MESA) Click on the ‘Dr Cheney’ link above to read more about this new research.)”

“I can currently only be **upright/out of bed** for a few minutes at a time, for no more than 15 – 25 minutes a day without experiencing severe cardiac symptoms. That is just enough time upright for me to get dressed, take the trips to the bathroom I need, walk to the kitchen a few times to get food – *if* I plan things very carefully and am very quick. Some days if I’m lucky I’ll have a few minutes spare standing or sitting up time that I can use either to wash my hair, get something off a shelf, have a drink of water sitting up, or brush my teeth or my hair sitting up etc. Even sitting up in bed with a few pillows also causes these problems. I also have to raise my legs slightly when I am lying down to reduce the load on my heart because my heart struggles a lot more if I don’t. Wearing knee-high compression socks helps to a certain extent too. (Blood pools in the lower legs and feet when you have M.E.; research has shown that the average person with M.E. has only 75% of the circulating blood volume they should have.) I dream of one day being well enough to sit up to use an electric wheelchair a bit now and then, that would be just wonderful but I would have to improve *immensely* for that to happen (not just with being able to sit but with being able to cope with movement, light and noise sensitivity, and much more). Being able to use a wheelchair is something I hope for very much, in the future. But I am far too ill to use a wheelchair at all now, or anytime even remotely soon.”

“The symptoms and sensations caused by **being upright longer that you should be** when you have M.E. are intense, and make you feel profoundly ill. When I’ve been upright for too long, it feels like every organ is failing, like I am having the equivalent of a heart attack in every organ. My whole body feels as if it is in crisis and really struggling, my heart most of all. It feels like my heart is under immense pressure and not dealing with it well. It will thump very forcefully or do a strange type of fast fluttering motion. The heartbeat also seems to be very irregular. It feels like a heart attack. I feel incredibly ill, as if I might drop down dead right then and there. My head feels the wrong pressure and as if it might burst, as does my whole body. My thinking is affected too; I

can't think at all, sometimes I can't speak in sentences any more, or at all. It feels like my body and brain are in a state of shock from lack of blood flow.

If I have a severe orthostatic attack however, I know that these acute symptoms were only the start of it – the tip of the iceberg – and that the delayed effects will be even worse and last far longer. The delayed effects always occur even though by then I have always been lying down properly and not standing up for longer than I should for many hours. (No amount of resting afterward prevents the delayed after effects, it is far too late by then.) For me, the delayed effects of orthostatic overexertion usually hit when I'm trying to sleep at night (from about 1am – 3am usually) and can last anywhere from 1 – 6 hours or more. One minute I'm fine and the next it hits me like a sledge hammer; heart problems similar to those that I experienced earlier in the day, but far more severe. Again my heart alternates between fluttering wildly and beating very fast and very shallowly, and pounding so hard that I can actually see my feet shake with the force of it. Again it feels like a heart attack. The pain in my heart is intense. It really does feel like a heart attack, like my heart is really struggling and as if something heavy is sitting on my chest making it very hard to move, or to breathe.

Each time this happens very severely and I feel that death could be a possibility, I wonder if I should call an ambulance. (A large percentage of the deaths from M.E. are cardiac related, so this is not an irrational fear). I try to weigh up whether I might regret not calling an ambulance in a half hour or so when it might be too late with the fact that if I do call one the trip is guaranteed to set my health back severely for 6 months or more (and my cardiac problems will be made a lot worse), and that I might not actually get any medical treatment anyway even if I do go. (Which is what happened the one time I did call for an ambulance and go to the emergency room. See: [Emergency room, 2004](#) ).”

“If you have the **orthostatic intolerance** of M.E. but have not yet been correctly diagnosed as such, you learn very quickly, or your body does, how to stop yourself passing out from it; there is a bit of a knack to it. (I was only correctly diagnosed as having orthostatic problems 6 or 7 years after I became ill and the symptom started, in all the years before that my doctor had unfortunately misdiagnosed them as being ‘panic attacks.’) If it was one of the ‘milder’ attacks I eventually worked out that I could stave off the worst of it by rocking backwards and forwards on my feet and then changing the way I was standing a lot, or by leaning all the way forward onto something. If it was a bad attack however these strategies weren't enough and I'd have to crouch on the

floor leaning all the way forward as much as I could, while also changing position and fidgeting a lot, to keep from blacking out.

I'd also have to fight against having **black outs when I was driving my car**. Of course I couldn't really crouch down on the floor and fidget in a car! What I'd do instead was tilt the car seat back as far as it could be tilted, and drive the car that way. That helped a lot, but nowhere near enough. After about 10 minutes of driving I'd be in a really bad way. I'd feel extremely ill, and very hot and feverish. I'd be having feelings of immense pressure in my chest and trouble breathing, and my heart would be just going crazy and I'd feel as if I were about to black out. I'd quickly be overwhelmed by how ill I was and wonder how I was going to manage the rest of the drive... But then suddenly, or so it seemed, I'd be pulling up in the driveway of my house, with no memory at all of how I'd got there. I've since learned that this could only have been what is known as an absence seizure (a phenomenon known to occur in M.E.).

**A brief note on driving a car while so ill:** If I could go back in time and know then what I know now I would NOT have continued to drive in this condition and to and put myself and others on the road in such potential danger. But at the time I couldn't justify to myself (or my family, friends and doctor) not driving because I was (supposedly) anxious and depressed and lacked motivation – my misdiagnosis at the time. I was told by my doctor in no uncertain terms that only willpower, pushing through my symptoms and forcing myself to do things – no matter how ill I felt or what symptoms I had – could or would get me better. I was very physically ill at the time but I had no problem at all with motivation or willpower, unfortunately. (I'd have been far better off with LESS willpower actually. I did myself so much permanent bodily damage pushing on through all the hellish symptoms so hard and for so long.) The doctor who gave me this bad advice has so much to answer for. I don't think it's an exaggeration to say that she ruined my life. If a prescription drug had anything like the appalling track record exercise has with people with M.E. (or really, even 5% of it) it would be a huge worldwide scandal. The drug would be immediately banned and serious criminal charges would be laid. Yet the rate of people with M.E. recommended or even *forced* to exercise continues to rise, with the full support of government etc. It is a gross violation of basic human rights. (See [Smoke and mirrors](#) for more information.)”

“If I am upright for too long I also get **Raynaud's type symptoms**. My feet and lower calves start turning very pink, then they go purple with very clearly defined white spots all over, and then they go blue. They really burn and tingle painfully when this happens and it gets worse the longer I keep myself upright.”

“Sometimes after severe exertion I get a **strange and horrible sensation at the back of my head, as if I had lost all the pressure in my head in that area.** It is like suddenly feeling as if I had been hit in the back of the head, where the base of the skull meets the top of the neck, with a shovel. It feels as if the blow has caved in the back of my skull and that all my blood and bits of my brain are draining out down my back. The sensation is so powerful that I often find myself automatically raising my hand up to cover the ‘hole’ I can feel in the back of my head! I also experience a marked loss of intelligence and cognitive function with these attacks. Years after I started getting these awful attacks I found out that this is the part of the brain that is most damaged in M.E. (the lower parts of the brain near the neck and the spine, the brain stem etc.) and that made so much sense to me. I felt like I knew that already, because of these attacks. (I’ve heard many other M.E. sufferers describe this same sensation, in response to the same stimulus.)”

“From the first day I became ill and every day since then for the last 12 years, **I haven’t been able to think** a single thought in the normal way. Because of the way my brain was suddenly damaged, thinking is now a completely different process than it used to be, even if sometimes the outcomes may be the same or similar. Normal thought lets you think of more than one thing at a time. There is a kind of ‘holding area’ or ‘working memory’ part of the brain (or function of the brain) where you can look at, and analyse, a variety of different thoughts and memories at the same time to actually work things out. To think. It lets you hold 2 or 3 or 5 or more different thoughts in your mind at once so that you can compare them to one another, and also see if anything you’ve learned in the past is relevant and perhaps apply one of those ideas to the problem as well. You can jump from one thought to the next, to the next, and back again. You can think of A and B, and then combine the best elements of both to get C. Then you can think about it some more and come up with options D and E, but then decide to do back to C after all when you recall a situation in the past where this sort of strategy worked really well and where a strategy similar to D failed spectacularly. When you have a normal ‘working memory’ you are easily capable of this kind of complex thought.

Since I’ve had M.E., I no longer have access to my ‘working memory’ or to my ‘control room.’ Thinking of more than one thing at a time is very difficult for me now, if I can do it at all. I can think of a question for a little while, and on a very good day I might even get to conclusions A and then B, but more often than not, the second I come up with any answers I’ve completely forgotten the question. Then I have to work backwards to come up with the question again, by which time, I’ll have completely forgotten both A and B.

This can go on and on until, if I'm well enough and lucky enough, I can shorten the gaps between thinking separately of A and B so that they overlap for a second or so. I try to think of both of them for a few seconds each, trying to trick my brain into letting them 'hit' each other in the middle and so letting me comprehend the two things at once for just a few short seconds or fractions of a second. This process is every bit as difficult as it sounds, especially as I'll keep forgetting both A and B throughout and have to start again over and over. Eventually, if I'm lucky, I'll be able to perceive A and B at the same time and on a very good day I might come up with C. Then I'll have to work hard to try to compare A and C to each other, and then B and C. (With a lot of work I can comprehend two things at a time, sometimes, but three at once is just beyond me now no matter how hard I try). Then I just have to hope I have a notebook handy to write it all down or else I have to start all over again.

Usually when I 'think' now however, I just make do with my single train of thought. I'll think of a problem I need a solution to and an answer will just pop in my head without there being any conscious thought process. I can't analyse what I've come up with at all, I just have to go with it. I don't have the ability to think about something for a longer time period and come up with a better answer; my first answer is often my only answer (if I can come up with an answer at all). If I try and see if I can come up with another solution or think through the one I already have, nothing happens. My brain just goes blank. (It is the same with memory. I either immediately recall something or I don't, thinking about it harder and longer just doesn't give me any more memories than I had initially.) I can come up with good ideas sometimes, (and remember things accurately sometimes), but I can't actually ever THINK like I used to. I am incapable of the kind of complex thought that I took for granted before my brain was damaged – except in small amounts and with a lot of hard work. I miss having a normal brain more than almost anything. (The fact that I have objectively measurable changes to my brain – typical of the damage known to occur in every person with M.E. (and which must be present for the diagnosis to be made) – has been verified by an MRI scan of my brain; see [Testing for M.E.](#) for more information.”

“I can sometimes **remember** the most random facts but I very often also forget common words I've known and used for decades etc. I come up with a lot of 'can we have the thingy from the thingy today?' type sentences. I'll say, 'Can I have a ....? Not a spoon or a knife, a... ? Yes, a fork! Thank you!' I just forget really simple words a lot. I also substitute strange words for other words sometimes too. I might say, 'I'll heat that up in the radio...what? Oh, yes, microwave, that's what I said wasn't it?' I feel only marginally in control of what words come out of my mouth; sometimes my brain will substitute one

word for another and most of the time I don't even realise I've done it. Yet 10 minutes later I might be able to remember (and accurately quote) a weird or trivial fact I saw on TV several weeks ago that is perfectly relevant to the conversation and which everyone else has long forgotten. My memory is very deficient and damaged in a number of different ways and is always unreliable. But a small part of the very good pre-illness memory I had still works sometimes (albeit quite randomly and only for very short periods of time).”

“My **cognitive abilities**, at a glance, may seem to be quite contradictory as I am able to do some very difficult tasks but unable to do many seemingly simpler ones. The reason for this is that with larger and more complex tasks I find I can easily break them down into many much smaller parts until the tasks are so small that I am able to complete them, bit by bit over a long period of time. Many seemingly simple tasks however, cannot be broken down into smaller parts and done over a longer period of time and so I find them very difficult or even impossible to accomplish. For example, the simple task of making myself a cup of instant coffee is intellectually beyond me now yet I can put together logical and complex, fully researched and referenced essays on my website. I'll explain:

The thought process involved in making a cup of coffee for myself goes something like this. ‘I want a coffee. I'm going to make myself a coffee. I'm going to walk to the kitchen, okay done! So I'm making coffee, what do I need first? I need a cup. Okay I have a cup in my hand now, no problem. What's next? (My brain goes completely blank for 10 seconds). Why am I holding a cup? What am I doing? (My brain goes completely blank for 5 seconds). I'm making a cup of coffee. How do you do that? What do I need? A cup. I have one in my hand. It hurts to hold so I'll put it down in front of me. Okay I have a cup, what do I need next? To boil the kettle. How do I do that? I have to press the button on the kettle, but first I need to make sure it has water in. (Brain goes completely blank for 20 seconds). So how do I get water in, can I lift it? How heavy is it and how strong is my arm right now? I could just try it first couldn't I? (My brain goes completely blank for 10 seconds). What am I doing in the kitchen? (My brain goes completely blank for 5 seconds). Okay I'm making coffee. How do you do that? First I need a cup.....’ This usually goes on and on until I get so mentally overwhelmed and confused that I have to give up and lie down and rest. (I can usually only ever get to about half way through when I forget where I'm up to and what I'm doing before I have to start the thought process all over again). Occasionally I do manage to make myself a coffee. But by then I've made myself so very unwell doing so that I am way too ill to actually drink the blasted thing. I'm too weak to lift the cup, or to half sit up to drink it, so even too mentally confused to remember how to drink it. I can't

move and can't think at all. I need to rest for several hours, I am too ill to do anything else and I feel very unwell. If I've remembered to bring the coffee to my room with me I'll drink it cold a few hours later usually, when I'm feeling a little better and have recovered from the worst of it.

When I write however, things are very different and I can break each task down into very small parts that I can complete over a long period of time. Not only are each of these tasks broken down to their smallest components, but I also have a lot of micro-rests, and bigger rests, in-between each tiny bit of progress within each stage. I can work for 30 seconds, blank out for 10 seconds, work for a minute, blank out for 20 seconds, work for 3 minutes, blank out for a minute etc. I can also do a half hour of work one day, then have 3 days off, the work for an hour a day for 5 days, then have a month off, and so on. (So that is why my seemingly contradictory abilities aren't really a contradiction at all. It is just that I can't really do a small task like making a coffee over a month or 3 months or a year and a half, like I can with the small tasks which make up a big task like writing an essay for my website.)”

“I read an interesting comment recently about how people with M.E. need **mental micro-rests** to be able to cope cognitively. This really helped explain a number of weird things I had been experiencing, for example: When I listen to the radio in the morning occasionally (to block out the noise that woke me up so I can go back to sleep) they'll do a quick nationwide weather report every half an hour, and I just hate it! They read out the details for each city really fast and with not even the smallest pause between words, to get through it quickly. ('Adelaide 27 degrees and sunny Hobart 21 degrees some showers in the morning clearing in the afternoon' etc.) My brain struggles to take in so much input with no breaks or rests, it feels completely overloaded and overwhelmed to the point of a seizure of some sort. I feel more and more unwell as the uninterrupted audio input goes on and soon I find I cannot move at all; my brain is using 100% of its capacity to cope with the audio input and it feels like there is nothing left to be used for anything else, like controlling movement etc. This means that I can't get away from the noise or turn the radio off! When it finally stops my brain feels totally burned out, like it just blew every fuse. Yet listening to someone talking on the radio at a normal speed etc. is fine and I can often do so for up to an hour with few ill effects.

The need for micro rests also explains why, or at least part of why, I find phone calls so difficult compared to face-to-face communication. You just don't have those same long comfortable pauses on the phone that you do in real life meetings. Of course you only get these silences when you've known someone a long time, but these are the only people I am well enough to see anyway, people



I've known 10 or more years and who it is very easy to be with because we know each other so well. That's why I can see a good friend for an in-person conversation (preferably with the TV on so I can sneak the rests I need in) for up to 2 or 3 hours once a fortnight or so, with only minimal after effects for the next few days (so long as I am well rested beforehand) and why even a half-hour phone call can make me extremely ill for an entire week afterward or sometimes even longer. I only am very, very rarely able to use the phone at all now and those calls I do make (almost exclusively phone consults) leave me very ill afterward for a week usually."

"Every now and then suddenly I've lost my train of thought and it is as if I had just come to after being unconscious. **There is a sudden FLASH of regained consciousness.** I can't feel my brain stop working, all I am aware of is the sensation of when it starts suddenly working again, of when I 'come to' again and for a second don't know how I got where I am or what has happened in the minutes before or that day etc. This is what I need those 'micro-rests' for I suppose, so my brain can go 'offline' every now and again. Although more often than not my pre-flash thoughts do come back to me, sometimes I completely lose my train of thought when these flashes happen and it never returns.

Initially I'd estimated that these flashes probably happened every few minutes. But then I re-read what I'd written about how the 30 second weather report on the radio made me so ill within about 10 seconds and I realised that if I could go minutes at a time between flashes, then I should be able to handle 30 seconds without one easily. The fact that I can't do this seems to me to point to the fact that I'm actually having these flashes far more often, perhaps even every 10 or 15 seconds. In the earlier stages of my illness I remember this problem being far worse however. Sometimes it got to the point that these flashes of regained consciousness would happen every 5 or 10 seconds or so, and I wouldn't remember what had just happened previously really at all. I'd have time to think 'what's happening? That was horrible, maybe I should try to...' and then FLASH! I'd come to again and think, 'what's happening? That was really awful, I wonder if maybe..' and then it would happen again, and so on. This could last for an hour or more a day, or on and off all day sometimes when I was really ill. Sometimes I'd alternate been having a lot of these little periods of unconsciousness with longer periods of unconsciousness that would last for hours at a time."

"I cannot wear loose-fitting shirts or tops – they make it difficult for me to walk, strangely enough! I used to be able to walk pretty much automatically. I

was, like most people, not aware of any conscious mental effort that went into it. But that has changed since I became ill, and now my walking is ‘manual’ and a large part of my brain has to be free to think through each step. (Most often this is unconscious thought, unless I am really struggling.) **When there is a distraction, I forget how to walk.** I just can’t mentally work out how to walk, or how to make my legs obey my commands. Things like noise, movement in my visual field, bright light, or even a baggy shirt moving against my skin and then away again as I walk are enough to overwhelm my brain and stop me being able to walk. This is also why I must always tie my hair up, with not a strand left free. If I walk with my hair down the thought process is; step, step, step, (pause), hair, step, hair, (pause, difficulty taking next step), hair, hair, hair – and then all I can think of is the way the hair feels falling on and off my shoulders as I walk and I can’t walk any more. I can only think of one thing at a time and now that walking counts as a thinking task I need to remove all distractions when I walk or else I can’t do it at all. (My intellectual abilities also suffer markedly when there are distractions, anything to do with memory or thinking in particular.)”

“I sometimes **forget how to do simple tasks.** The phone might ring, for example, and sometimes I can’t remember what I am meant to do. I can’t remember if I am supposed to speak first or wait to be spoken to, or what I am meant to say if I do speak. I often can’t remember that I have to pick up the receiver first, or even HOW you pick up the receiver. Sometimes I’m lucky if I even get that far and I just go completely blank and can’t even remember vaguely what I should be doing or even if I should be doing anything when the phone rings. Making calls can be just as impossible sometimes. (I’ve heard many different M.E. sufferers describe this exact same intermittent inability to remember how to use the phone, or how to even lift the handset of a phone. It seems quite common.)

Sometimes I also **forget simple facts**, like what the colours of a traffic light mean. I had this happen maybe 10 or so times when I was driving (as well as having absence seizures and semi-black outs while driving, as if that weren’t dangerous enough.). It was terrible. It wouldn’t be until I was right up close to the traffic light that I would realise that I didn’t know what the lights meant and so I’d have only a few seconds really to work out what to do. Most of the time I just looked at what other drivers were doing and copied them, although I know I went through at least one or maybe two red lights. I remember slowing down at green lights and getting beeped at by other drivers a few times as well. (Again, if I knew then what I know now I would NOT have continued to put myself on the road. I’m so lucky I didn’t kill anyone, or myself.)”

“Sometimes I **can’t understand speech**. I get severe attacks of this symptom (where I can’t understand any speech at all) with severe exacerbations of my illness, and also just randomly sometimes, but I also suffer from this problem at a lower level constantly. I used to sometimes get a delayed version of this language problem too. Someone would say something to me and because I couldn’t understand a word of it, I’d immediately ask them to please repeat what they’d said. The person would start to do so, but then a few minutes or so into it I’d instantly understand exactly what they’d said the first time. I’d automatically interrupt them and say ‘oh yes I know’ and then respond to what had been said. It was like the decoder in my brain was stuck on a one or two minute delay. It wasn’t that it was slow; I would understand nothing then suddenly understand every word instantly in a second. Unsurprisingly I got a lot of very strange looks when this happened as people just didn’t know what was going on any more than I did at the time. It was embarrassing but I couldn’t help it or find any way to stop it happening. Thankfully now that I no longer overexert myself, I only suffer with this symptom at a lower level most of the time.”

“Sometimes I also **can’t remember how to speak**, how to form words. I can think the words in my head, but intellectually I can’t work out how to verbalise them. There is nothing wrong with my voice, but the part of my brain that turns thoughts and words in my head into spoken words is just not working. Sometimes I can speak but it is very difficult. At the moment I have two main windows of opportunity each day to talk. One is in the late afternoon for about 15 to 30 minutes, the other is early in the evening, around 7.30 to 8.30pm. At these times I can talk quite normally if I am well-rested enough. (As long as there are long pauses in the conversation and I don’t have to think very much about what I am saying). Most days I manage to talk and be in company for a little over an hour a day all up. (An hour is much more than I used to be able to talk for many years previously. For several years I spent almost all of each day silently by myself, and with only an hour once-a-month (or less) internet access. I could speak only a few words or sentences a day during a lot of that time. Most days I’d probably only have company for maybe 10 minutes a day or less. It was terrible.) I still wish I could talk a lot more now (especially with my friends on the phone sometimes, or ever) but I am a lot better now than I was at least, thanks to less forced overexertion and more rest each day.”

“Aside from the need for constant cognitive micro-rests, the other reason that I find phone calls so much harder than face-to-face communication is that I am far **more disabled with my audio capabilities than I am visually**. (Perhaps

this is because I was (and am) a visual artist and designer and spent much of my time honing my visual skills before I was ill?) The difference between my audio and visual capabilities is so large that my brain automatically uses my visual skills to help make up for my lack of audio interpretation skills. Analysing body language and facial expression and lip reading helps me work out communication far more easily than just trying to listen to the words alone.”

“When I can talk, **sometimes I talk very fast**. I am not well enough to talk most of the time, but sometimes I’m forced to talk anyway (or I force myself) by calling up a huge surge of adrenaline. When I’ve done this I often talk very fast, and I’ve been told that I kind of babble. If I am talking this way, it means that I am very unwell, and have been operating far beyond my limits which means that I will be very ill and suffering immense payback for doing so in the near future. Conversely, if I’m talking fairly slowly (or at a normal speed), my speech is a bit slurred and I forget a lot of words, then that actually means I am doing really well health-wise! It means I am actually well enough to talk naturally, without calling up a big adrenaline rush, and without paying for the conversation with a day or week long (or longer) relapse. This is counter-intuitive on the surface of things of course so people are always making incorrect assumptions about the state of my health because of it. I am always being commiserated with when I’m doing quite well physically (relatively), and congratulated on my health when I am about as ill as I could be and am imminently headed for a hugely painful and prolonged relapse.”

“I’d always been able to do calculations in my head fairly effortlessly pre-illness. Now even very **simple additions and subtractions are very difficult** or even impossible for me to work out without writing them down and really taking my time over them. I make a lot of silly mistakes when doing simple calculations too, even if I have written them down. Often these mistakes involve simple one or two figure additions and subtractions (particularly subtractions).”

“Like so many other things, my **handwriting** also changed completely when I became ill. (As is known to happen with an acute brain injury such as M.E.) When I am very ill, I cannot write at all, not even a few words.”

“I have similar **problems with reading** as I do with understanding speech. Many times I’ve looked at a page of text and not been able to decipher any of it. At other times I can read the individual words okay but I can’t make the

meaning of each sentence or paragraph sink in, no matter how many times I re-read it. My biggest problem with reading however is not with reading the words themselves, but that I can only read things which don't force me to think too much. I can read a light (but intelligent!) novel for a few hours at the right time of day (after midnight) with few ill effects yet become ridiculously ill for many hours after reading a non-fiction book for only 10 or 15 minutes. I have to be so careful with a non-fiction book because before I know it I can have caused myself a huge worsening of my symptoms that can last for many days. I can only very rarely, and at times when I'm feeling much more able mentally than usual, read a non-fiction book and even then it must be done slowly over many days and I still can't do it without making myself a lot sicker. But even with light reading I still have to really limit how much I read and I can't read anything like as much as I used to pre-illness."

"Sometimes I can't recognise faces, I have **facial agnosia**. You don't immediately look at a face and know whose it is, the information must be sent from your eyes to your brain for interpretation first. Scientists now know that there is actually a specific area of the brain devoted solely to the recognition and reading of faces. When that part of your brain isn't working properly or is damaged, you get facial agnosia. I have had a handful of full-blown attacks of facial agnosia where I haven't been able to recognise close family members or friends. Mostly though, facial agnosia is a problem that I have constantly at a lower level but as with some of the other neurological damage, I've found that I can use my general visual literacy skills to compensate for it to a certain extent. One of the main ways I do this is by recognising people primarily by their hair, or other easily discernible obvious feature instead of by their face (for example particular clothing, a mole or freckles, a big nose or big eyebrows etc.)."

The skin on the tips of my fingers is quite unusual. It is very thin and my fingertips are very red and shiny. The skin is also very delicate and gets torn very easily, so I have a lot of little scars on the tips of my fingers. Because the skin is so very thin there has been some loss of the depth of my fingerprint ridges and so the fingerprint is far less pronounced. I suppose this is the **destruction of fingerprints** I've heard M.E. experts talking about for years."

"Sometimes I get what I refer to as a **cold fever**. I wake up, and straight away I know that I've woken up 'wrong.' I can feel that something in my brain isn't functioning as it should. I soon start to get really cold too. It gets steadily worse and I become colder and colder. The coldness starts to become painful and to be so severe that it is all I can think about. I am rigid with the cold and I shiver and

shake. I get colder and colder still, and then suddenly I can feel the coldness not just all over in the usual way but deep in my bones. It feels as if my bones are made of ice. But then things change again and my skin and the flesh around my bones starts to feel very hot and feverish. I'm hot and feverish on the outside but still frozen solid on the inside. Then my brain starts to become hot and feverish and feel like it is slowly boiling in my skull and I become somewhat delirious. I'm delirious, sick and poisoned, very cold and very hot and feverish all at the same time but in different parts of my body. I'm still locked up physically and can't move so I keep the blanket on even though by now I'm sweating profusely. After about 20 – 30 minutes of this, the delirium has become a lot worse. Finally the delirium gets so bad that I black out.

I usually come to several hours later feeling very wrong again, but in a different way this time. I feel better than on my first waking, but not by much. I try to move my arms but they aren't responsive. I realise I have my eyes open, so I try to look around and to blink. That all works fine, but my arms simply won't move. Nor will my legs. I'm paralysed. After maybe 10 minutes of lying there and trying on and off to move, finally an arm moves a little and soon I have full movement back – but I don't have normal movement back; my arms especially are heavy, weak and very clumsy. They don't obey my commands properly and are very slow and awkward. There seems to be a mistiming of brain to body communication. I'll then often look at the clock and marvel yet again how these fevers always knock me out for almost exactly 2 hours every single time, almost to the minute. For the rest of my day I feel 'off' mentally, and I can do only very basic cognitive tasks. I particularly loathe cold fevers. At my worst I'd have them 3 or 4 days a week.”

“The shirts and tops I wear have to be made of thin breathable fabric and sleeveless. I wear the same tops all year round, regardless of the weather. This is because I am very **sensitive to heat**, on the top half of my body especially. Feeling even a little bit hot makes me feel far more ill. I feel slightly less ill when I'm cooler too, less nauseous and poisoned.

I do feel the cold in winter, but if I try to wear a jacket to warm myself up, it just doesn't work. It feels nice and warm for a short time (if I'm lucky), but before long it makes me feel either very hot or very cold – much colder than I would have been if I had never put it on in the first place. My internal thermostat is broken, it feels as if I have to regulate my temperature manually and there is only a very small window between too hot and too cold so it is quite complicated. But what makes it even more complicated is that different parts of my body regulate temperature differently to others. So quite often I might have a cold pack over my eyes to help cool my hot and feverish head and at the same time have a heat pack on my back, and thick pants, socks and a blanket

covering my lower half. Even then my head will still feel very hot and my feet will be really cold. Often I can't even tell if I'm hot or cold because I seem to be both too hot and too cold at once. This affects me the most at night because it makes it so hard to go to sleep. I have to take my blankets on and off every few minutes because I feel either very cold, or very hot and sickly every few minutes."

"I **can't tolerate hot weather** at all. It just makes me feel so ill that I might as well have spent the day running. I feel ill and poisoned and all my symptoms are made worse, especially all my cognitive problems. It feels like the heat melts my brain. Very hot days are the worst but even warm days can be pretty bad."

"Extreme **sensitivity to noise** was for years one of my most debilitating and painful symptoms. When it was at its worst what used to happen was this: When there is a very loud noise, I forget everything I was thinking or doing beforehand and I am surrounded by nothing but pain. Each second seems to last for an hour or even a day. I can't remember anything I've said or seen that day or in the previous weeks. The noise causes such neurological disturbance and overload it seems to dissolve all my recently laid down memories so that I am unable to access them while this attack is happening, or at any time after it. I lose those memories completely. I also forget how to walk, talk and also to understand speech while the attack is happening. It feels like every cell of my body and brain is just screaming. I'm in unbelievable agony but unable to work out who I am and what is happening, or how to stop it – my brain is completely overwhelmed with the pain and the seizure-like effects.

Eventually the noise stops. Often I'll be told later that it only went for about 5 minutes, though to me it felt like about 3 days. I usually can't really remember much from before the noise, or remember what it's like not to feel this ill. Often I can barely remember my own name, but worse than that, I can't remember *who* I am - what I like, what I think, things I've done, what's important to me, anything. This is more pain than anybody should have to go through ever. It feels inhuman. (This was a condensed version of my [A day in the life of severe M.E.](#) piece, click on the link to read on). That is what happens when there is very loud noise. But even very small noises are so difficult to cope with now as well. I just get so ill and so much pain from even low level noise. Loud noises hurt but noises of a certain pitch hurt too. High pitched noises like pouring water are just excruciating. Anything to do with water hurts; the sound of a tap being turned on, the whine of water going through old pipes, the sound of someone pouring a glass of water. This problem with tolerating noise played a

big part in making my life a living hell for years. Thankfully, my family are now very good at warning me so I can leave the room if they are going to use a tap or a blender or something else noisy and just being more quiet generally – 99% of the time anyway. Their efforts to be considerate of my health needs in this area has raised my quality of life enormously in the last few years. (I wish everyone with M.E. were as lucky.)”

“The **pain in my ears** from noise can be so intense that I can feel the pain radiating out from the ear about 10cm all around. (Maybe it is just too much pain for one ear to deal with!) It can be real 10/10 pain this ear pain, it is just excruciating. It is pain that I’ve described before as ‘being eaten alive by a tiger would NOT hurt more than this does’ type pain. It really is that bad. Sometimes all I can do is cry because of the sheer intensity of it. I can’t speak, or think, just cry in pain. It feels a bit like skewers being jabbed in your ears, and then there is the seizure-causing aspect of the noise on top of that as well, from the neurological over-stimulation (ie. low level seizures). Even quite little noises can cause extreme levels of pain, especially if they are constant or of a certain (high) pitch. For years my most desperate wish was for access to a soundproof room. That would have been heaven for me. It still would.”

“Even low levels of **light hurts my eyes**. It hurts right away but my eyes also continue to burn afterwards for the rest of the day if the light was bright enough or the exposure time was long. But it isn’t just that my eyes are affected, I feel like I just ‘wilt’ under bright light (or even in moderate light that lasts for a while including looking at TV or computer screens). My brain become overloaded (like a low level seizure) and I can’t think, and sometimes it even makes me quite confused mentally. All my neurological problems become a lot worse too, including my problems with balance and co-ordination. It is like my brain is just using everything it has to cope with the light and there is nothing left for doing anything else. I also become physically weak and unable to move in bright light. It makes me very ill and far more disabled and less capable of managing even simple tasks. It seems to exacerbate my cardiac problems too. (This problem is made about 10 times more severe when it is a fluorescent light that is involved incidentally, instead of daylight or light from a normal globe.) I’ve spent the last 6 years almost entirely in a very dimly lit room.”

“I’m very **sensitive to movement and vibration**. Just like with noise and light, too much movement or vibration is unbearable and makes me very ill for long time afterward. This makes travelling by car either impossible, or if not impossible at least very unwise. One of the last times I pushed myself to travel



was to attend a medical appointment. I really shouldn't have done it, I was just too ill. The drive there was hell, and the drive home was even worse. When I finally got in to see the doctor I was so ill I couldn't speak a word, I couldn't move the muscles in my face and I could barely understand anything anyone said to me. So it was pointless in the end anyway, and then I spent over a month much more ill than usual recovering from it all.

That is what people with M.E. mean when they say they're housebound. Either they are just too ill to leave the house, or they could leave the house if they really pushed themselves but doing so would be a really stupid thing to do because of the severe and ridiculously extended payback that would last for months afterward (not to mention the fact these relapses can be PERMANENT if you push yourself too often or too hard). Sensitivity to vibration/motion is only part of what makes leaving the house difficult of course, there is also; the need to not be upright at all or for more than a few minutes at a time, light and noise sensitivity, limits to how much you can talk or listen to speech, limits to how much you can think, limits to how much you can tolerate looking at things that move (or even looking at new and/or interesting environments), limits to how much you can move or walk, and so on. There just isn't much point seeing a doctor in hopes of improving your health (for example) when you have to cause yourself a 6 month long relapse, or injure yourself permanently to do so. (Like many with severe M.E. leaving the house is impossible for me now.)”

“I often experience similar movement and cognitive problems as with a cold fever if I let myself **sleep** in the afternoon. An afternoon nap is anything but refreshing for me now. Even just 20 or 30 minutes of sleep in the daytime makes me feel terrible neurologically, like I've had a small stroke. I always feel much worse than before I did it. I always go to bed feeling far better than I do when I wake up too. I don't know what happens exactly when I sleep but I am at my worst physically, just after I have slept. (Studies have shown that people with M.E. don't go through all the stages of sleep properly, they miss out on some of the deeper stages of sleep. I've also read about small seizures occurring during sleep in people with M.E. But it seems unlikely to me that these are the only problems.) I can't not sleep though as if I do that, if I get even a little less sleep than I need, I am even more ill; very much so.

I also have a lot of difficulty initiating sleep, especially if I have overexerted myself. When I am well rested and have been living within my physical limits I go to sleep quite easily and I always sleep right through the night without waking. But when I've overexerted getting to sleep is very hard, and when I finally do it is far less refreshing (even less so than usual). I'm also likely to wake up on and off all night feeling absolutely terrible. (That is yet another

reason the whole ‘fatigue’ myth is so ridiculous. The more I do the more I suffer with cardiac and breathing problems or seizure-like symptoms – both of which make me feel very UN-fatigued and make getting to sleep very difficult. To say exertion causes fatigue in M.E. is just stupid. If anything it causes the opposite problem.)

“I feel ‘wired’ a lot of the time, particularly after I have been too mentally active or been subjected to a lot of sensory input. It’s a brain state that feels like the exact opposite of fatigue. It feels like **a constant low-level seizure**, like all my neurons are constantly over-firing. Too much (even very little) sensory input can make it a lot worse, and so can thinking much at all. It feels like my brain is frying. It’s horrible, and the severe version of this symptom can last for days, weeks or months at a time or longer. This brain state makes resting really hard – it makes me feel anything but restful or relaxed – but resting is the only way to make it go away or at least to improve it significantly. It takes a LOT of resting to really see an improvement too, which is just so annoying and frustrating. But even with a lot of rest, I’m always stuck with this problem at a low level. It’s just constant, and quite unpleasant even at a low level. This symptom makes getting to sleep really difficult a lot of the time too. (This symptom is undoubtedly a type of seizure).”

“Every day for many years I would wake up with **sleep paralysis**. When this happens the first sensation I’m aware of as I wake up is stillness. Everything feels too still. My brain quickly becomes fully awake, but my body feels as if it is still asleep. I can feel a strange lack of coordination between my brain and my body, as if they aren’t connected properly. (It isn’t that I can feel this communication when it *is* working, this is something you can only really be aware of it when it *isn’t* working.) I also feel quite dizzy and vertiginous (as I always do when I am in darkness or have my eyes closed). With great concentration and effort I try to open my eyes. I can only manage to open them a little bit usually, but it is enough to stop the room spinning and so I feel immense relief. The light hurts my eyes, and they burn, but I can’t close them for long or the vertigo will come back. I try to move myself out of bed but no matter how hard I try nothing moves. I have sleep paralysis. It feels like my body isn’t mine anymore. I lie there working on keeping myself calm, knowing as I do that worrying about the situation or thinking about it while it is happening will only make the experience feel even worse, even scarier. The feeling that I need to urinate quickly becomes quite bad and after about 5 or 10 minutes I feel that I cannot hold on too much longer. Then I start to feel very weak and dizzy from lack of food (hypoglycaemia). More time passes this way,

perhaps another 10 minutes, until the next thing I know I'm waking up again having fallen asleep once more.

I wake up this time feeling ill in all the usual ways but able to move finally, albeit in a somewhat more clumsily and jerkily way than usual. I can walk okay as well so I do a quick shuffle to the bathroom. I feel 'off' mentally for the rest of the day, as if I were not properly conscious and still in a milder kind of abnormal brain state, like I'd had a mild stroke. Sleep paralysis is horrible. I used to have it virtually every day for years and it never really got any easier to live through as time went on – although FINALLY reading about sleep paralysis and finding out that it was common in M.E. and it wasn't just me that had it really helped a lot. It was such a relief to just know what was happening! The feeling of powerlessness is so intense, I think sleep paralysis is kind of traumatic in a way.”

“I wake up in the morning, **completely alert**. There is no sense of waking up slowly, no period of sleepiness or drowsiness at all. I don't wake up feeling or functioning at 100%, I wake up physically and neurologically impaired of course but no part of this impairment is sleepiness or drowsiness or anything similar. When I go to bed at night it is the same. I go from being completely alert to being asleep with no discernible change in between. I wake up feeling hot and ill and in pain and there is no point staying in bed any longer than I have to as it just feels sickly and hot from me being in it all night and I want to get up and dressed as soon as I can, even if it is just to go to my day bed.

Like many with M.E., I've found I very rarely get fatigued since I became ill. When I do it is nothing to do with M.E. and either just normal everyday fatigue or because I have the flu (which can both be quite nice). I miss fatigue a lot. (I hear the same thing from M.E. sufferers again and again, they wish they actually had some of this supposed fatigue everyone is always endlessly waffling on about!) I miss that lovely soft, sleepy, drowsy feeling so much. That feeling when you wake up and feel so nice you decide to luxuriate in bed a bit longer to enjoy it, and to enjoy waking up slowly and to savour the happy sleepy feeling in your blissfully warm bed. I also miss the fatigue and exhaustion that comes with doing a hard days work, where you are just completely worn out and know you'll sleep well from it that night. M.E. is never anything at all like either of those feelings. Unfortunately.”

“It wasn't always the case that M.E. made me alert all the time. When I was first ill, I still didn't get drowsy or fatigued but I didn't become fully conscious and alert so quickly either. I used to have a lot of **difficulty maintaining**

**consciousness.** When this happened I'd wake up feeling 'wrong' neurologically and unable to move, then I would become unconscious again soon after. I'd wake up again a bit later still feeling wrong but somewhat less so, but I'd still be too ill to get up and then I'd pass out again. This could continue for half the day sometimes, and often did. (Sometimes, at my worst, I would do this on and off all day.) It was a real difficulty or inability to maintain consciousness, something not at all the same or similar to being sleepy, tired, fatigued or exhausted. The periods of full consciousness would most often get longer and longer until finally I would be able to get up and get dressed, eat and move myself to my day bed. (Although some days I would only have about 3 or 4 hours of consciousness.) This symptom has changed for me over time, but never have I experienced morning fatigue since day one of my illness.”

“**My sleep/wake cycle is completely reversed.** My body now thinks the appropriate time to go to bed is 9am. I found out that this symptom had got this bad when I ran out of melatonin capsules a few years ago. (Melatonin is the hormone that regulates sleep and like many with M.E. I take it to help me get to sleep at a more reasonable hour). It was hell, I'd go to sleep at 9am (after lying there for 8 hours) and wake up around 7 or 8pm, but wouldn't be well enough for any type of conversation until around 10pm – just when everyone else in the house was going to bed. Melatonin is essential. It lets me get to sleep at about 2 or 3am usually which works pretty well for me. My body functions at a much lower level if I get up any earlier than I do. I also have these same problems if I am woken up early or unnaturally and if I can't get back to sleep. I feel terrible and 'off' neurologically and cognitively all day (a bit like I've had a small stroke), and far more ill if I'm not allowed to wake up naturally and get as much sleep as I need.”

“On a good day I can easily move something moderately heavy for a short amount of time, for example move a small set of drawers, or even a bigger unit of shelves, or a 10kg (22 pound) sculpture even – from one end of my room to the other. But I am always unable to do even a very light lifting task repetitively, such as lifting a soup spoon enough times to eat a small bowl of soup for example. If I try such a repetitive task it leaves me in a bad way; I can't move or think for hours afterward, all my symptoms are made worse and my arms are often useless for several days (or longer). Sometimes all my muscles just twitch afterward too, quite visibly (or sometimes just one particular muscle will twitch all by itself). There is also a lot of pain in the affected muscles for a long time afterward. In contrast I feel almost no ill effects at all from moving the much heavier furniture for a full minute or even three minutes. **I have a fairly normal amount of muscle strength to begin**

**with, but my muscles very quickly become weak or paralysed after repetitious actions**, even small ones. I can far more easily lift something heavy once or twice than lift something light 10 or 20 or more times. The recovery period for my muscles is very long. They don't recover in a few hours like they used to (like normal muscles), the recovery period is now measured in days (3 days or more is fairly common, depending on the level of overexertion).”

“The muscle problems I have affect all my muscles, including the muscles in my eyes. I usually start the day off (unless I have not been resting enough in the weeks beforehand) with fairly normal vision, but by the end of the day I need glasses and even then I often can't make my eyes focus enough to see anything clearly. Sometimes I also discover on waking that I can't see properly. **My vision is blurry and I can't focus**. I get this problem with my vision when I have used my eyes significantly too much the day before. When I have read a book, watched TV, or been on the computer far, far longer than my body (and the muscles in my eyes) can handle. I now know to be far more careful with my activity levels so I can avoid this horrible problem, thankfully.”

“It can only ever be counterproductive to go beyond your limits if you have M.E. A lot of people (some of them doctors, unfortunately) think this means that so long as we don't do aerobic activity that we'll be fine, and that any type of stretching will be well tolerated, for example. This is just not the case, **even gentle stretching can cause severe problems and relapse in people with M.E.**”

“The muscles around my lungs are very sensitive to touch. Even a gentle touch can be excruciatingly painful and make them go into spasm, making it very **difficult for me to breathe**. I can take only very shallow breaths and I can't get enough air. (The whole back area is affected but there are also two clearly visible, small lumpy areas – about mid-back and either side of my spine – that are especially sensitive.) It is pretty scary when this happens, especially when it gets to the point that I grey-out from it, as I have done many times in the past. I also get very short of breath sometimes after very minimal activity such as 2 or 3 minutes of walking. Sometimes I become short of breath when I am resting too. (Incidentally, this isn't happening because I am unfit or deconditioned. Research has shown that this is actually primarily a metabolic or mitochondrial problem affecting the muscles around the lungs.) This problem also affects me at a lower level constantly. I breathe far more shallowly that I used to.”

“I have **numbness and tingling** in the extremities; in my feet, my hands, sometimes my arms, or the top of my head or one small area on one side of my nose.”

“Sometimes I wake up and there is a feeling of **intense pain in all the bones of my body**, all at once. I feel as if I had fallen from a multi-storeyed building and landed on my back; not just breaking but *crushing* every bone in my body into tiny fragments all at once. It is utter agony. I can feel the pain in and around every bone. Moving makes it worse but so does staying too still. I also get another version of this where my bones feel fine but suddenly all my muscles really hurt and feel very tender. I feel bruised all over, like I’d been beaten up the day before and was just one big bruise. (I also have this sort of pain at a lower level, pretty much constantly.)”

“When I have been doing too much thinking or too much physical activity, sometimes **the skin on my face just burns**. The skin feels tight and just raw. My eyes burn too, it feels like my face has been cooked. Sometimes I get **shooting pains in the veins** of my upper arms, and in my lower legs. I can feel where certain veins are and it is usually the same veins each time that hurt. It is really painful sometimes.”

“Another symptom I had for only a few years in the early years of being ill was **the ‘claw.’** My hands and wrists would form a ‘claw’ and become locked in that position, all curled up and painful. It was as if all the tendons had shrunk and my hand had become paralysed in that position. I’m really lucky my ‘claw’ was only a mild version, and fairly short-term. (I know of several sufferers who have had this problem get worse and worse until they need splints to keep their hands or feet straight. I even know of one case where the bones had to be broken to get them to become straight again and to fit into the splints.)

“I don’t suffer from (organic) anxiety as part of my illness as some sufferers do. Nor do I have depression. But that is not to say **my personality** and the way I express myself has not been affected by the illness, of course it has. That it could be unaffected would just be impossible considering the amount of damage to the brain caused by M.E. (Because of course the emotions are controlled by certain parts of the brain, just like the ability to speak or to interpret images are and so on – they aren’t controlled by a shiny ball of golden light, or by your ‘heart’ etc! They also depend to a large extent on your cognitive abilities; your ability to think complex thoughts and your memory.

When your cognitive abilities change profoundly, so too do your emotional responses and personality to some extent.)

The more I think about it though the more I think that the minor changes to my emotions and personality are almost entirely due to the cognitive problems I have now. My inability to think of more than one thing at a time, my warped sense of time, my inability to think one thing and say another, my inability to remember events for more than a short time afterward and so on. I would estimate that these cognitive deficits account for probably at least 90% of my emotional changes, if not more. You just couldn't have your ways of thinking and your memory changed so profoundly and not have this have an effect on your personality.”

“I feel **poisoned** almost all of the time, and much more so when I have overexerted myself, or been forced to do more than I should. I feel poisoned, ill and sometimes also very nauseous. When it is really bad the smallest thing makes me feel as if I will throw up – even someone just mentioning food. (Even food I really like, or used to). If I have to eat, I would much prefer to stick to only fairly bland things like toast and crispbreads, mashed potato, porridge, muesli and other cereals, pasta and rice, all types of bread, plain sandwiches, fruit smoothies, milk drinks and yogurt etc. but I am intolerant of ALL these foods in some way unfortunately, which seems completely unfair!”

“Eating is quite complicated for me now. It also takes a lot of planning. Food I eat has to run the gauntlet of:

- Food has to not make me so nauseous I can't get it down.
- Food has to be easy to physically eat.
- Food has to be easy for me to digest. Eating raw vegetables just hurts so much, they are so hard for my stomach to digest; partly due to the lack of blood flow to the stomach in M.E. It feels like I've eaten a brick when I eat raw vegetables.
- Food has to be something that I am not intolerant or allergic to. (I have a whole host of new allergies and intolerances to all sorts of different foods)
- Foods I eat have to be not just low glycaemic index, but have quite a low glycaemic load as well.
- Most foods have to be things that I haven't eaten recently. (I have to have a rotation diet where I don't eat the same food more than once in a four day period.)
- Food has to be balanced in a certain way for protein, fat and carbohydrate content.

It is no wonder that so many of us with M.E. just want food pills! Every day I have to have 7 or 8 small meals. Fasting or even having a meal or snack 5 minutes later than I need to makes me ridiculously ill (with hypoglycaemia-like symptoms). Working out what to eat and eating it takes up a lot of my day as you can imagine. Physically getting the food down is hard too. My swallowing reflex is very weak, and so I must be careful to think through and pay attention to each swallow. If I try to swallow automatically or my mind wanders away from concentrating on chewing and swallowing, I soon end up with the food going down the wrong way making me cough and splutter or choke. Swallowing liquid is also quite difficult now and I have to really pay attention as I do it, or else I have problems. Often I am not well enough to be able to make the muscles work to have a drink until late in the evening. I also sometimes just choke for no reason, which is scary. It feels like the swallowing muscles are in spasm or paralysed or something and I can't stop choking and coughing to try to clear it. I have to be very careful eating or drinking anything because of this problem – another reason I want food pills!”

“I had no unusual **reactions to chemicals** at all before I was ill, but now I react to all sorts of household cleaning products, personal care products, paints and solvents, glues, and insecticides. Far more troublesome for me however is the way **I react badly to all sorts of drugs**, particularly those which act on the central nervous system (the area of the brain most damaged in M.E. and from which the chief disability of M.E. arises). Some medications I can get away with by taking a much smaller dose than usual, but others I have had to stop taking before I've even had time to work out if they were going to do what my doctor and I were hoping they'd do, because my reaction to them was so severe. I've had reactions from taking 1/24 of a normal dose of a medication.”

“I have different types of **headaches** now. They feel different to the headaches I used to get occasionally pre-illness and they last much longer. They often last several days or even a fortnight. These headaches can be quite severe and can stop me doing just about everything, especially anything involving thinking. A lot of the time they are directly related to overexertion, particularly cognitive overexertion.”

“Sometimes when I'm very unwell (due to significant previous overexertion) I **can't move the muscles in my face**. My eyes are wide open and stare blankly ahead, my jaw is completely slack, and my mouth is open. I can't move my eyes normally, nor close my mouth, no matter how hard I try. I look like I've had a stroke, and I kind of feel like I have too. I cannot move my eyes (except



to slowly open and close them), and cannot move my neck at all either so I have to move my whole body to look at anything that is not right in front of me. I really hate when this happens, I hate feeling so powerless and looking so disabled. I make sure nobody sees me when I'm like this if at all possible.”

“I have a **sore throat** a lot; on and off from day to day and for years at a time sometimes. I get **pain in my glands** as well; mostly the ones in my neck, but also the ones under my arms and the ones in my groin. I knew where all these glands were, way before I actually knew I had glands there. I could just feel them. The pain in my glands can be constant and also quite severe.

I have both types of pain almost constantly at a mild-moderate level, but when I have overexerted myself, the pain in the glands in my neck especially becomes extremely sharp and severe. They feel like throbbing basketballs in my neck and as if they'll burst. (Sometimes one side is much worse than the other.) When the pain levels in my glands suddenly go up like this it is one of my first warning signs I need to stop doing what I'm doing immediately, if I haven't already. It means that I have overexerted myself in some way and need to rest immediately if I don't want to make the relapse any worse. The flu-like symptoms most often remain present (or worsen) throughout the worsening of symptoms as well. (That my immune system is abnormal/deficient in the ways well documented in M.E. has been verified by objective scientific testing. One of the most marked abnormalities was in my percentage of natural killer (NK) cells. Mine were at just 3%, the normal range is between 6% and 25%. So at best my reading is half what it should be, and at worst I have *less than one eighth* of the percentage of NK cells that I should have. (Natural killer cells are a form of cytotoxic lymphocyte which constitute a major component of the innate immune system.) The function of natural killer cells (the cytotoxicity) is also known to be severely reduced in M.E. (9%). See Testing for M.E. for more information.)”

### **Section 3: On the pattern of symptom exacerbations, relapses and disease progression in M.E.**

Just looking at each of the individual symptoms of Myalgic Encephalomyelitis only tells you half the story. What characterises M.E. every bit as much as the individual neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the central

nervous system) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made.

The symptoms of M.E. are not solely exertion related however; along with the metabolic deficiencies of M.E. (etc.) there are also several other features and characteristics of M.E. which play an equally important role in determining the severity of the illness, the patterns of symptoms, and what it is like to live with M.E. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) include:

**A. When you have M.E. you very quickly find out that you are unable to be anything like as active as you were pre-illness. This is an acute change, not a gradual one; M.E. patients can only achieve 50%, or less, of their pre-illness activity level immediately upon becoming ill with M.E.**

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. In my case I went from being a very healthy, happy and active teenager one day to being able to do less than 40% of what I did pre-illness, literally overnight – or from one hour to the next, in effect. The virus also suddenly left me with a very damaged brain to cope with, and my heart and a whole host of other organs and bodily systems no longer worked like they used to from that point onward either. My brain, my body, and my whole life changed in an instant.

- These sudden pathological changes seen in M.E. patients, including the damage to the brain, can be tested for using objective scientific testing. M.E. can commonly be diagnosed within just a few weeks if the doctor has experience with M.E. It is not true that M.E. is difficult to diagnose, or that 6 months must pass before the diagnosis can be made, or that M.E. is only a diagnosis of exclusion, or that there are no tests which can be done to confirm a M.E. diagnosis. These ‘facts’ relate only to the bogus ‘CFS’ definitions, not to authentic M.E. patients. If all your tests are normal, you *do not have* M.E. – see: [Testing for M.E.](#) for more information. For more information on the viral infection evident at onset in M.E., and the outbreaks of M.E. etc. see: [The outbreaks \(and infectious nature\) of M.E.](#)

**B. As well as no longer being able to be as physically active as you were pre-illness, you are also limited in a similar way with; cognitive exertion, sensory input and orthostatic stress.**

M.E. is not just about being made sicker by exercise or by certain levels of physical activity. When you have Myalgic Encephalomyelitis the body responds 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 (but not limited to): cognitive exertion, sensory input, orthostatic stress and emotional stress. It should also not be assumed that a person with M.E. will necessarily react more severely to (or have greater limits on) physical activity than with cognitive exertion, sensory input or orthostatic stress. I am fairly equally affected by physical, cognitive, sensory and orthostatic exertions/inputs most of the time, although at certain times one of these in particular will be more of a problem than the others.

- *What is Homeostasis?* Homeostasis is the property of a living organism, to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits.

**C. Being active beyond your individual (physical, cognitive, sensory or orthostatic) limits causes a worsening of all sorts of different neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.**

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 (eg. to the heart), or death in M.E. It is an entirely different problem of a much greater magnitude.

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 specific – and in some cases very serious – symptoms can be accurately summarised as being mere ‘fatigue’ ‘malaise’ or ‘exhaustion’ is just absurd.

A large number of illnesses cause significant fatigue or malaise after activity (for example post-mononucleosis or glandular fever fatigue syndromes, Lyme

disease and Fibromyalgia and so on) but what is happening in M.E. is simply not the same thing; the symptomatology and pathology – and the effect of physical, cognitive and orthostatic overexertion on long-term prognosis – is very different in M.E. (See the ‘*A note on M.E. and other illnesses*’ sections below for more information.)

**D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.**

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.

- *A note on M.E. and other illnesses:* 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 etc. are not affected by small activities for many weeks, months, or permanently, in this way. While people with M.E. and people with these other illnesses may all not improve with a graded exercise regime, that does not mean that these other patient groups have the potential to be so severely negatively affected in the long term by such an intervention, as does every M.E. patient. The way people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress is profoundly different than in these other illnesses.

**E. The severity of M.E. waxes and wanes throughout the hour/day/week and month. (Periods of intensive rest before events, and surges of adrenaline, can also sometimes allow people with M.E. to do things beyond their usual limits for a short time – albeit at the cost of future relapse and/or disease progression.)**

You 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. But M.E. is not one of those illnesses! M.E. is anything but a stable illness.

Because of the lack of stability in M.E. you simply cannot know a M.E. sufferers usual ability level or severity level unless you have observed them

over a very long period of time, or actually asked the person detailed questions about what their average daily activity limits, abilities and symptoms are. 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 won't be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task. Most importantly, you also can't tell by looking if a particular activity was so far beyond a M.E. patient's individual limits that they will end up having made themselves severely or permanently more ill by pushing themselves to do it (or being forced to push themselves to do it).

- What is an adrenaline surge? Adrenaline is often referred to as the 'fight or flight' hormone as it kicks into action in situations of potential danger. Adrenaline also kicks in when the body is in physiological difficulty however, which is what is happening with M.E. sufferers very often. Adrenaline surges make the heart pump faster and raise your blood pressure, forcing blood around the body with greater force to supply the muscles with more oxygen, so that they can make a greater effort. (This is also associated with a diversion of blood away from certain areas of your brain and internal organs and into your muscles – so although your body is more capable your ability to think in complex ways can sometimes be lessened). Surges of adrenaline increase your metabolism, to supply more energy to the body. They also relax and dilate the airways so that we can take in more oxygen than usual. Adrenaline surges can also decrease the amount of pain you feel. As a result of all of these factors, adrenaline surges – while they last – have the ability to increase your physical speed, strength and other physical abilities. For more information on adrenaline surges in M.E., and the different order in which certain bodily systems may be affected by M.E. (and by overexertion), see the Dr Cheney section in The effects of CBT and GET on patients with Myalgic Encephalomyelitis or Treating Myalgic Encephalomyelitis - Avoiding Overexertion.
- *A note on M.E. and other illnesses:* This is another one of the characteristics which clearly differentiates authentic M.E. from various post-viral fatigue syndromes and so on – the striking variability of symptoms not only in the course of a day but often within the hour. As many M.E. experts have noted, this variability of the intensity of the symptoms is not found in post-viral fatigue states or syndromes (etc).

**F. The worsening of the illness caused by overexertion can be acute, but often does not reach its peak until 24 - 48 hours (or more) later.**

Another reason that short-term and superficial judgements of ability and disability levels in people with M.E. are often very misleading – and are in fact almost guaranteed to give a falsely more optimistic view of daily ability levels – is because the relapses caused by exertion very often do not appear until 48 or more hours afterward, when the average observer is long gone. Symptoms will then persist for hours, weeks or many months, or longer. For me and for many other M.E. sufferers, the effects from significant overexertion will often peak on day three.

- *A note on M.E. and other illnesses:* The ‘CFS’ definitions state that post-exertional symptoms ‘may take up to 24 hours to resolve.’ But to say that this is true of M.E. patients is absurd and betrays an ignorance of the most basic facts of M.E. Post-exertional symptoms very often take far longer than 24 hours to even APPEAR in people with M.E., let alone be completely resolved in that time. These symptoms can take days, weeks, months or even several years to resolve (or they may never resolve, or they may cause death). Those groups and individuals who claim that the results from overexertion involve ‘fatigue’ or ‘malaise’ and ‘may take up to 24 hours to resolve’ clearly show that they are referring to, and familiar with, patients suffering various fatigue syndromes – including post-viral fatigue syndromes caused by mononucleosis/glandular fever and so on – and not authentic M.E. patients.

**G. If you push past your individual limits too deeply or too often, the effects of overexertion can also accumulate over longer periods of time and lead to disease progression, or death.**

In addition to the effects of overexertion commonly being delayed by 48 hours or so, the worsening of symptoms caused by overexertion can also sometimes be delayed (and accumulate) over weeks or even many months at a time until they are realised in a ‘crash.’ This is a period of intense worsening of the overall condition followed by a gradual return to the patient’s base level of illness over weeks, months or years.

When the body is confronted with activity (or inputs) beyond the patient’s individual limits severely and/or repeatedly over time, these effects can also become cumulative in the long term; you can become unable to return to your base level of illness at all. Long-term or permanent worsening of the overall severity of the condition is caused. Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise or to be more physically or mentally active etc. five, ten, fifteen or more YEARS afterward and for some patients the damage caused is permanent. Overexertion has also resulted in death in some cases of M.E.

Strong evidence exists to show that overexertion can have extremely harmful effects on M.E. patients. Patient accounts of leaving exercise programs much more severely ill than when they began them; wheelchair-bound or bed-bound or needing intensive care or cardiac care units, are common. (Recent research has shown that postural stress and physical and mental overexertion exacerbate cardiac insufficiency in this disease; see the section below for more information.) There have also been reports of sudden deaths in M.E. patients following exercise.

- Recent research shows that mitochondrial dysfunction leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don't fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.)
- *A note on M.E. and other illnesses:* It is sometimes claimed that while exercise programs are not safe or appropriate for the severely affected, that mild or moderately affected M.E. sufferers can benefit from such interventions. But this assertion is NOT supported by the evidence. (Some miscellaneous 'fatigue' sufferers have been shown to benefit from graded exercise programs, but the results of these studies are no more relevant to mild M.E. sufferers than they are to severe M.E. sufferers; people with 'fatigue' do NOT have mild M.E. any more than they have mild multiple sclerosis, mild Lyme disease, mild cancer or any other illness.) Recent studies have shown that graded exercise programs are the actual reason many with M.E. are so severely affected in the first place, thus exercise programs should not be considered safe for M.E. sufferers of any severity.

**H. The activity limits of M.E. are not short term (they are not being perpetuated by 'deconditioning' – a gradual (or sudden) increase in activity levels beyond a patient's individual limits can only cause relapse, disease progression or death in patients with M.E.)**

There are a lot of claims made about how people with 'CFS' can get their symptoms stable through correctly balancing activity and rest (pacing), and then gradually start increasing their activity levels until they have regained all (or at least a significant proportion) of their pre-illness abilities. This theory claims that the cause of the initial loss of ability was a short-term problem – caused either by a period of depression or other mental or behavioural illness, or a self-

limiting viral infection such as mononucleosis or glandular fever etc. – and that the barrier to increased activity either no longer remains or can only be overcome by a gradual increasing of activity levels. ie. the only barrier to returning to normal levels of activity is the deconditioning of the muscles caused by the initial period of inactivity. This theory may or may not be accurate with regards to some proportion of the people with certain psychological or behavioural illnesses, or those with various post-viral fatigue syndromes, but what is certain is that it is completely inaccurate with regards to patients with authentic M.E.

Increasing the activity levels of someone with M.E. beyond their individual limits, can only ever be counterproductive. Raising the limits gradually may well delay the onset of the relapse in some patients, but the end result will still be relapse and/or disease progression, or death. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular, and other abnormalities present in M.E. sufferers – which together cause the high level of disability associated with M.E. – can be explained by mere ‘deconditioning.’ *Patients who improve with graded activity programs simply do not qualify for a diagnosis of M.E.*

M.E. is not a short-term or ‘hit and run’ viral attack; it is not a self-limiting post-viral fatigue syndrome caused by mononucleosis/glandular fever or any other common infection. Nor is M.E. a psychological condition. These theories have been comprehensively disproven many times over with regard to authentic M.E. patients.

- There is no legitimate scientific debate about whether or not M.E. is a ‘real’ illness or not, or whether or not it has a biological basis. The (politically and financially motivated) psychological or behavioural theories of M.E. are pure fiction; they are no more scientifically viable than are the theories of a ‘flat earth.’ The reality is that anyone, whether medically qualified or not, who looks at the worldwide published medical evidence on M.E. could not fail to recognise that the psychological or psychiatric theories could not possibly explain any of the many different and profound physical abnormalities seen in M.E. – nor any of the other characteristics of the disease which are simply not consistent with psychological or behavioural illness (or with a self-limiting post-viral fatigue syndrome). There are only two ways that a person could reach a different conclusion: (1) Bias due to vested political or financial (or other) interests, or (2) Lack of access to a truly representative selection of the evidence (ie. an individual has only availed themselves of the pseudo-science provided by financial stakeholders and not a representative selection (or indeed *any*) of the legitimate and unbiased science.)



- *A note on M.E. and other illnesses:* M.E. can be progressive, degenerative, chronic, or relapsing and remitting. As many M.E. experts have noted, the chronicity of M.E. is another characteristic which clearly separates the illness from various self-limiting post-viral fatigue syndromes.

**I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion, there is also a base level of illness which can be quite severe even at rest.**

The claims that ‘CFS’ can be improved by a gradual return to normal activity levels are often accompanied by additional claims that symptoms will always resolve with rest in these patients. The theory is that if these patients can just find the right balance between rest and activity, then they will cease to be ill. Again these theories may or may not be correct with regard to certain other patient groups which may qualify for a misdiagnosis of ‘CFS,’ but they are certainly not true for patients with authentic Myalgic Encephalomyelitis.

There is a base level of illness that is always present in M.E., no matter how much you rest. (This is true of all sufferers except perhaps that small percentage who have improved enough over time to be only mildly affected, or who have had a total or almost total remission of their M.E.) This is because the metabolic problems of M.E. are only one part of M.E., they are not the only cause of symptoms or of the worsening of the illness. Virtually all bodily systems are affected in some way by both the damage to the central nervous system and the metabolic problems of M.E. (including the cardiac insufficiency this causes) etc. so it is no wonder people with M.E. feel so ill, have such a reduced level of functioning in so many different bodily systems and have so many restrictions and limits on how active they can be. Even with complete rest – and some people with M.E. can do almost nothing else – many M.E. sufferers are still very ill and disabled.

**J. Repeated overexertion can harm your chances for future improvement in M.E. M.E. patients who are given advice to rest in the early stages of the illness (and who avoid overexertion thereafter) have repeatedly been shown to have the most positive long-term prognosis.**

It is vital that M.E. patients are never encouraged to be active beyond their individual limits, as this can only ever be counterproductive. As Dr Melvin Ramsay explains; ‘The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, *those patients who are given a period of enforced rest from the onset have the best prognosis.* Since the limitations which the disease imposes vary considerably from case to case, the

responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.’

For example, when I was first ill I was reduced to only being able to achieve 40% of my pre-illness abilities. Years later, thanks to a lot of (stupid and ill-advised) physical, cognitive and orthostatic overexertion, I am now at the level where I can do far less than even 5% of what I did pre-illness – as I have been for the last 6 years. If I had been diagnosed correctly and given the appropriate advice to rest in the early stages of my illness I would still probably be at least at that 40% level, if not improved even further (as have fellow sufferers who were given the benefit of this correct medical advice etc.) The importance of getting appropriate rest and avoiding overexertion in M.E. cannot be overstated.

- Avoiding overexertion and getting appropriate rest is essential in M.E., but these are not the only things that can be done to ensure the most positive prognosis and improve quality of life in the illness. (Resting and avoiding overexertion are not treatments for M.E., they are just management strategies or survival strategies, aimed at minimising damage etc.)
- For more information about the effects of overexertion on M.E. patients, including statements/research from some of the world’s leading M.E. experts about why overexertion is so physically harmful, see: [Smoke and Mirrors](#).

**L. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness, this is not the case for the very severely affected.**

Even the most basic actions – speaking a few words, being exposed to moderate light or noise for a few minutes, turning over in bed, having hair or body washed in bed by a carer or chewing and swallowing food – cause severe and extended symptom exacerbations in very severely affected patients. Either sufferers are just too ill to do these things at all, or they cannot tolerate the very long and severe relapses that come after such activities. The payback for even very minor activities can be profound when M.E. is very severe. Even the smallest actions can take the pain and other symptoms of the illness from a constant 8/10 – 9/10 level to a 10/10 level for minutes, hours, days or weeks or longer afterward. This is pain on a level that I’ve described before as ‘being eaten alive by a tiger would not hurt more or feel more terrible, than this does.’ Severe M.E. can leave sufferers for months, years or even decades at a time; completely and utterly alone in a private agony. The illness can cause a level of disability and isolation that is just unimaginable to anyone not familiar with very severe M.E.

- As if the physical burden of M.E. wasn't enough to deal with, many people with severe M.E. also have to deal with medical neglect, appalling medical abuse and abuse (or even ridicule) from their families and as well – thanks to all the misinformation about M.E. produced by vested interest groups and supported by government and the majority of the media. Many people with M.E. have literally been submitted to what amounts to torture. Deaths have also occurred in M.E. sufferers due to this abuse and neglect. See: [Smoke and Mirrors](#) for more information. For more information on severe M.E. see [The severity of M.E.](#) and [M.E. Fatalities.](#)

### **Clarifications and acknowledgments**

This paper contains a lot of anecdotal information about my own personal experience of M.E. However, the vast majority of the symptoms and characteristics of the illness listed have also been described in detail in the scientific literature on M.E. for many decades, and many times over. The vast majority of these same symptoms and characteristics have also been described in very similar ways many times over by lots of individual M.E. sufferers. The vast majority of the symptoms and characteristics of the illness I've described here (and all of the core features) have been well documented by the world's leading M.E. experts and by many thousands of individual sufferers – thus they cannot be dismissed as merely relating to my own (unimportant) case study of one.

I think it's only when you add in people with all sorts of other non-M.E. illnesses into the mix that you see such huge variation from patient to patient. Although people with M.E. have a lot of different minor symptoms because of the way the central nervous system (which controls virtually every bodily system) is affected, the major symptoms of M.E. really are quite distinct and almost identical from one patient to the next. To read a fully referenced description of M.E. symptoms based solely on information/research produced by the world's leading M.E. experts (several of whom have been studying M.E. for more than 20 years and have each seen thousands of individual patients) see: [The ultra-comprehensive Myalgic Encephalomyelitis symptom list](#)

- To read descriptions of many more symptoms, and more information on each of the points in section 3, see the (twice as long) full-length version of this paper: [What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E.](#)
- For more information about the medical and political facts of M.E. (and for references for the comments made throughout sections 2 and 3) see: [Testing for Myalgic Encephalomyelitis](#), [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#) and [What is Myalgic Encephalomyelitis?](#)

- This is not just a description of severe M.E. I had almost all of these same symptoms (some of them severely) when I ‘only’ had moderate M.E. for the first 4 years of my illness, as well as when my M.E. became severe and then very severe (due to overexertion). Of course severe M.E. is even worse, but moderate M.E. can also cause severe symptoms and a high level of disability.
- I currently have severe M.E. but note that there are many M.E. sufferers who are far more severely affected than myself, I am far from being the most severe case of M.E. See: [The severity of M.E.](#) for more information.
- I am pedantic about fatigue not being the defining symptom of M.E. (and so on) but I think we all have to be – every M.E. sufferer and M.E. advocate – if we are ever to have the distinct illness M.E. separated out from all those unrelated fatiguing conditions and post-viral fatigue syndromes and so on. The incorrect use of the term ‘fatigue’ in relation to M.E. also harms all of those who have been misdiagnosed with ‘CFS’ (or who mistakenly believe they have M.E.) because of their severe fatigue. For more information on why the bogus disease category of CFS must be abandoned (including confusing and misleading terms such as ‘ME/CFS’, ‘CFS/ME,’ ‘CFIDS’ and others) see: [Why the disease category of ‘CFS’ must be abandoned](#), [The misdiagnosis of CFS](#) and [Smoke and Mirrors](#)
- To read more personal accounts of M.E. online see: [What M.E. feels like to me](#) and [M.E. case studies](#)
- To read some of the best descriptions of M.E. (written by both experts and individual sufferers) in print see: [The Clinical and Scientific Basis of Myalgic Encephalomyelitis](#) edited by Dr Byron Hyde., [Stricken](#) edited by Peggy Munson, [Shattered: Life with ME](#) by Lynn Michell, [Verillo and Gellman’s Treatment Guide and Osler’s Web](#) by Hillary Johnson, [In the Shadow of Memory](#) and [The Night Side](#) by Floyd Skloot. Many excellent articles and descriptions of M.E. are also available online on the [Research & Articles](#) page.

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The descriptions of my own symptoms in this paper are not intended to form a definitive definition of M.E. This paper is not intended for use as a diagnostic tool. To read a description of M.E. and the symptoms of M.E. based solely on information/research produced by the world's leading M.E. experts (and which is fully referenced) see: [The ultra-comprehensive Myalgic Encephalomyelitis symptom list](#)

This paper will be continue to be updated regularly (at least annually). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.

*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 with the ICD code G.93.3.
- 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 pump 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.