

## *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.*

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

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Taken from [www.hfme.org](http://www.hfme.org)



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.

It is important that the scientific facts of M.E., including an accurate general idea of the symptomatology of the illness, become widely known by the media and the wider medical community, as well as the friends and families of sufferers and the public at large.

There is also a real need for more of this type of information to be available to the M.E. community. So many of the emails I get from people with M.E. (and the conversations I see in M.E. support groups), have to do with sufferers trying to find out whether the textbook M.E. symptoms they are experiencing are common in M.E. or not. It's completely unacceptable that despite the abundance of good research available dating back to the 1950s (and earlier), most people with M.E. today – thanks to the financially and politically motivated creation of the bogus disease category of 'CFS' in the 1980s – have little or no information about the various neurological, cognitive, cardiac, cardiovascular, immunological, muscular and gastrointestinal (and other) symptoms which characterise M.E.

#### **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](#)

What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. [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.

#### **Additional notes on this text**

- Note that many different illnesses may share a percentage of the individual neurological, gastrointestinal or cognitive features of M.E., (and so on) but there is no other illness which encompasses each of the specific neurological, cognitive, immunological, gastrointestinal, cardiac and cardiovascular, endocrinological, respiratory, hormonal and other features and symptoms which make up M.E. This specific combination of symptoms/pathology is not seen in any other illness. There are also a number of characteristics of M.E. which are unique to the illness. The acute onset of M.E. also sets it apart from many other illnesses commonly associated with a gradual onset, as do many other characteristics. See: [The misdiagnosis of CFS](#) for more information. For more information about the significant similarities between M.E. and Multiple Sclerosis see: [M.E. vs MS: Similarities and differences](#)
- *What is CFS?* CFS was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist. All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue (a symptom seen in many illnesses but not a defining feature of M.E. nor even an essential symptom of M.E.).

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

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

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

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with 'CFS' actually *do* have psychological illnesses. 'CFS,' as a wastebasket diagnosis, includes all sorts of fatiguing illnesses including psychiatric illnesses. 'CFS' is associated with psychiatric illness; for many patients this is inappropriate, but some patients misdiagnosed with 'CFS' actually *do* have psychological illnesses. *There is no such disease as 'CFS'* – that is the entire issue. The vast majority of patients misdiagnosed with 'CFS' *do not* have M.E.

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

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

## 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. This problem remains unchanged 12 years on and I can't really even drink a tiny (one mouthful) alcoholic drink on special occasions. (It makes me feel slightly intoxicated for a few minutes and then I get a huge headache and feel terrible for hours afterward so there really is no point)."

"For a few years I had this awful symptom where 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'd feel so stupid every time I came to again, but 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). The nights I spent like this felt like a nightmare that just kept endlessly repeating itself."

"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. ('Vertigo' means a sense of spinning or feeling of disequilibrium.) 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. The fact that I had no feelings of depression or anxiety – and that I did have a whole host of very physical symptoms which couldn't possibly be explained by any mental or behavioural condition – didn't seem to bother my doctor at all strangely enough.)

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. (Your vestibular systems control your sense of balance

and tell you which way is up etc. Proprioception is the ability to sense the position and location and orientation and movement of the body and its parts, from stimuli within the body itself.) 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. I started off with a big light but soon found I could make do with a very small one thankfully. (The room is still very dark but there is just one small corner of the room lit up so that I can see it well enough to tell which way is up.) It is still quite awkward though as I have to keep my eyes open and looking at where the light is for as long as I can when I am trying to sleep. I have to go to sleep without having my eyes closed for very long beforehand, which is difficult as you can probably imagine.

Another problem was/is that I very much need to rest throughout the day with my eyes closed, or else my eyes hurt too much and I am overstimulated neurologically. I found I just couldn't do it though, closing my eyes made me so vertiginous. It made me sit bolt upright with a huge JOLT every few minutes to stop myself 'rolling off the edge' of my perfectly flat bed. But eventually I found a way around this too; I found that I must put a weighted bag over my eyes to cover them when I rest with my eyes closed. The weight of the bag tells my body which way is up, compensating for the lack of (already compensating) vision when I close my eyes. It is a very happy day when you finally work out how to 'outsmart' a symptom like this!

(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. At least 95% of M.E. sufferers have been shown to have a positive Romberg test. See [Testing for M.E.](#) for more information.)"

"Another problem with having a vestibular system that is no longer working normally, and that is using visual input to compensate to a large extent, is that **I lose all spatial orientation if there is movement in my field of vision**; I have no sense of up and down, and of where I am in space. For example, if I am walking down the hallway and someone else starts walking down it too, my brain misinterprets this movement as being relevant new information on which to base my sense of where up and down are. What usually happens then is that the room feels like it is spinning or tilting and I have to hold on to the walls to keep myself standing upright. Usually I'll just look at the floor in front of me until the person has passed my field of vision, only then can I continue my walk.

I have a lot of trouble completing tasks (including walking) when there is any other movement in the room. If I want to use the microwave for example, or get myself something out of the fridge even, I need to ask everyone else in the room to sit down and not get up until I'm finished. Such requests don't make me very popular (understandably) but it is the only way I can get around this problem. It is either that or I can't do the task at all, and (like anyone) I prefer to do things for myself if at all possible, of course."

"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! I eventually worked out that I can sometimes trick my wonky vestibular system to think I'm listening to the mad signals it is sending me by holding my head at a weird (specific) angle (so my vestibular system thinks my head is perfectly upright) and walking like that. If that works, I can walk pretty much normally, I just look very odd and walking is still difficult (in no small part because I often can't really see where I'm going as my head is at the wrong angle!). But this trick doesn't always work. 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. It is just a horrible feeling, for want of a better word. (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.) It's hard to explain but you can feel that each beat isn't as full or as deep as it should be, the beats feel 'shallow' or something. Sometimes, when it's very bad, it feels like the beats are so shallow that my heart is just shaking or vibrating in my chest instead of beating. You can just tell something is very wrong, it feels just terrible. The more fluttery and vibrate-y my heart beats get, the faster my heart rate becomes it seems. (I also sometimes feel a strange sensation in my heart as if it has a big air bubble in it. I don't think it actually does, but that this the only way I can think of to explain the feeling.) 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. I have several moderate – severe episodes of tachycardia every day usually. 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 important 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. Any more time spent upright than this and I experience severe cardiac episodes (and other symptoms) both right away and even worse ones 8 - 48 hours later that can last many days, weeks or months afterward (or which can even be permanent).

Even sitting up in bed with a few pillows also causes these problems, so I have to lie pretty much completely flat almost 24 hours a day. I can only use quite flat pillows. 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 while severe sufferers have been shown to have only 50% of the expected circulating blood volume.)

I have to lean up on one arm and raise myself slightly to eat in bed as I'd choke and couldn't manage it if I were lying completely flat. I have to try to eat very quickly though as I can't manage it for long without getting heart problems later. I'd give anything to be able to eat and drink sitting up, or even just to be able to sit up a few hours a day. I haven't been able to sit at a table to eat for at least 6 years now. 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 (along with most other severely affected M.E. sufferers)."

"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. A lot of the symptoms I have been describing have been difficult to put into words but I think my cardiac and orthostatic problems really are some of the hardest to describe. (Many of us just can't put it any better than to say 'It feels like I am dying.')

I've had these same orthostatic problems since day one of my illness and every day since. (Orthostatic stress is caused by maintaining an upright posture, ie. sitting or standing.) This is not a perfect description but is the best I can come up with:

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. (When Dr Cheney explained recently that when someone with M.E. stands for too long they are 'on the verge of organ failure' I wasn't at all surprised or shocked, I just thought YES! that is exactly what it feels like!) 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. (It feels like it can only beat pathetically weakly and so it needs to go very fast to try to make up for it. It feels like it is only beating in the most light, quick and superficial of ways, and that it is really struggling to do even that.) The heartbeat also seems to be very irregular. It feels like a heart attack. My heart feels like it is under such immense strain that it could stop at any time. 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 negatively 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 my brain are in a state of shock from lack of blood flow. Sometimes, when it is very severe, I notice that my body is shaking uncontrollably. I have to lie down very quickly or else fall down where I stand. (The immediate effects of standing or sitting up too long are severe, but I also know that the after effects will be more severe and long lasting every extra second I stay upright during the attack, so getting myself back in bed and lying flat as quickly as possible is vital.)

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. Sometimes I manage to get to sleep before the attack starts and I am woken up with a huge JOLT by the force of it. (Just when you're thought, 'oh great, I got away with what I did today' WHAM, you suddenly know you didn't get away with anything at all.) It really does feel like a heart attack, like my heart is really struggling and as if something very 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. The doctor

just laughed in my face, despite the fact something additional/unusual really was wrong and was seriously affecting my heart and could potentially have been fatal if my own doctor hadn't picked it up later. See: [Emergency room, 2004](#) for more on this). I don't think I'd chance an emergency room visit again. I just hope that my luck won't run out. So far so good but I know I have no guarantee that this will always be the case."

"Lying on my side in a relaxed way is impossible because this makes **my heart and lungs feel as if they are being crushed** by the ribcage (or something) somehow. My whole chest feels under pressure, I can't breathe and it feels like my heart is really struggling to beat. I can lie on my back with no problems, but I can't stay in that position all day and night so I do have to try to lie on my side. I have to kind of lean backwards when I do it, so I am half lying on my side and half lying on my back. It is really awkward and uncomfortable. I have to hold myself so stiffly so that my chest muscles don't relax and squeeze my heart and lungs the wrong way. I keep forgetting to be constantly careful about how I lie but then WHOMP! my heart and lungs really protest about it and I have to get all uncomfortable again. I often wake myself up struggling to breathe and having heart pain when I've got in the wrong position when I'm asleep too. This symptom is just ridiculous and it makes things so difficult. (Although I have recently finally found a medication which lessens this symptom for me at least to some extent, thank goodness)."

"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.')

Orthostatic intolerance is at its worst when you are standing or sitting very still, walking or moving around or fidgeting makes it slightly better, so things like waiting in queues, having haircuts or standing up during conversations would often cause an attack. I would be waiting in a queue for example and suddenly start to feel very hot, shaky, light-headed and dizzy. My heart and heart-rate would start going crazy. It would feel like my heart was really struggling to beat and was about to explode out of my chest. I could feel my blood pressure doing very strange things too, changing from one second to the next and then I'd feel myself start to black out; to lose consciousness. 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. (For the first few years I often used to pretend that I had to adjust a shoe, or get something out of my bag or whatever while I was crouching on the floor, so I wouldn't look completely nuts. But in the later years, I didn't care what people thought anymore or if I got stared at and I just did whatever I had to do to stay conscious, as unobtrusively as possible.)

At around the same time, in the first 6 or 7 years of illness when I was misdiagnosed as having mental health problems, 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 (with me still being able to reach the steering wheel), and drive the car that way. That helped a lot, but nowhere near enough. My usual drive (to and from university once a week) was half an hour each way, about 20 minutes more than I could really cope with at the time. 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. Sometimes I would actually grey out for a few seconds. I'd quickly be overwhelmed by how ill I was and wonder how on earth I was going to manage the rest of the drive. It was all I could do to just keep myself going from one second to the next... 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. Very scary. 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.). With an absence seizure you go into 'automatic pilot' mode; you can keep doing repetitive tasks automatically though you will have no memory of anything you've done as you weren't really fully conscious at the time.

**A brief note on driving a car while so ill:** It scares me so much to know that I was not fully conscious or fully aware while I was driving, and that this happened so many times. 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. That I did this for so long horrifies me now, 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. I had quite a lot of both, unfortunately. (For example, even when I was down to only being able to take one class a week at university and when it was taking me four, five and then six days to recover from the class, I still kept going. I'd barely manage the three hour class, then I'd drive home trying not to black out and having absence seizures every day, and then spend the rest of that day and the following four or five days going in and out of consciousness and episodes of paralysis. I'd be incapable of speech and very impaired mentally and able to do nothing but be in bed very, very ill and in extreme unrelenting pain. I was unspeakably ill. I finally stopped studying not because the pain and horrific symptoms were at frightening levels – I'd passed that threshold a very long time ago, years ago – but because it was physically *impossible* for me to keep going. I had completely physically collapsed to the point that I couldn't keep going no matter what. Six years later I have still not been able to get up from this collapse and to return to study.)

The ironic thing is that 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. I made myself far more ill, and caused myself permanent damage. I am still paying for the way I pushed myself to do more than I should have after six years, and I probably will continue to do so for the rest of my life. (If only I had trusted in myself and in what I knew what really happening with my health instead of trusting my doctor so much more, and thinking that she must know what she was talking about because she was a doctor and so certain and seemed to have science behind her (almost all my tests were normal but, well they would be, because she did completely all the WRONG tests)... and if only I'd been less motivated to get myself well at any cost, if I'd given up sooner, I would be so much better off now too.)

The arrogant and ignorant 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. The worst part of all this however is knowing that even today so many people are *still* having their lives ruined by ignorant advice to exercise, or are even dying from it (including young children). If a prescription drug had anything like the appalling track record exercise has with people with M.E. (or really, even a small fraction of it; even 5%) 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. This is also despite the fact that legitimate research clearly shows that it has a ZERO percent chance of providing any benefit to people with authentic M.E. as well. That this can be allowed to go on in such a supposedly enlightened day and age as ours defies belief. It is a gross violation of basic human rights, to say the least. (See [Smoke and mirrors](#) for more information on this.)”

“If I am upright for too long (more than 2 or 3 minutes at a time) 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. I have to lie down as soon as I possibly can and then the symptoms slowly disappear. I've noticed a milder version of this in my hands too, the tips of my fingers and sometimes my whole hand will go purple.

Another orthostatic problem I've had is with my vision going black or grey for a minute or so whenever I stood up quickly from a lying down or sitting position. When this happened I would have to bend at the waist and do a weird kind of crouch for a while until I could see properly again (to try and get blood back into my head again I suppose). Getting up also made me feel very faint and on the verge of fainting for a long time even after I'd lay down again.”

“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. (That might sound extreme but it really does feel just like that.) 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. (It is a very hard sensation to describe. It just feels very wrong and very different to any type of headache or even migraine I've ever had.) 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; it feels like something is very physically wrong with my brain. Sometimes I feel like it is going to make me black out. Sometimes it made my vision go all grey or black for minutes at a time too.

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 now also know that when people with

M.E. overexert mentally or physically there is a significant drop in blood flow to the brain afterward, and that also seems to (potentially) make a lot of sense in regard to this symptom. (I wonder if this awful feeling could be what not having enough blood getting to your brain feels like?) Small strokes are also known to occur in M.E. (78% of patients have punctate lesions which are most consistent with small strokes) maybe this is what they feel like? (I've heard many other M.E. sufferers describe this same sensation affecting the same area of the brain too, 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 level of ‘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.’ (Or perhaps I do have access, but only to a very much smaller and malfunctioning version – where the controls are labelled in Russian and are all manual instead of automatic too!) 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 also suspect that I have lost 10, 20 or maybe even 30 IQ points since the day I became ill. These kinds of losses of IQ points are well-documented in M.E., although I have not had the appropriate tests done either before or after my illness, so this is purely a guess or estimation on my part. Sometimes it feels like I've lost about half my usual IQ; for minutes, hours, days or sometimes even weeks at a time.)”

“I can sometimes **remember** the most random facts, from something I read, or a TV show I saw a week or even a month earlier etc., but I very often also forget common words I’ve known and used for decades and I often have to be told something simple many times so I can take it in, and even then sometimes it doesn’t ‘take’ no matter how many times it is repeated for me.

For example, not long ago I saw a news report on TV that was about farming and mentioned ‘lamb.’ What is a lamb I wondered? Is it a baby cow, or something else? But if it is a baby cow, then what is veal? I just couldn’t work it out. I felt like a complete idiot but I asked someone, what is a lamb? I just had to know. Very embarrassing. (What makes this worse is the fact that I actually grew up with a (rescued) pet lamb/sheep...that we had imaginatively named ‘Lambie!’)

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, which is interesting (albeit quite randomly and only for very short periods of time).”

“I need to write everything down, or else **I forget** to do it. I have two notebooks, two whiteboards and a calendar going. I didn’t used to need lists at all before I was ill and I could remember phone numbers and all sorts of different things. Now I forget everything. I used to lose my keys every single day (and just about everything else), and burn anything I put in the oven every single time too when I was first ill (and I could still cook and drive). Everyone forgets things sometimes, but this is a world away from that.”

“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 in front of me, 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 finish the task and 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 remember how I make my brain tell my body and arms and hands what to do, or remember how you lift a cup etc.) 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. I can’t cope with any light or noise or stimulation so I have to make the room completely dark and quiet. 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. Writing a new essay goes something like this: Think of an idea, write down some rough points on paper, add to the notes over the next few weeks as I think of more things I could add to it, type out the notes, do a spell check on the notes (correcting anywhere from one in ten to one in every three words I've mistyped), do more research, elaborate on each point one by one in sentences, turn the sentences into paragraphs, work on making each sentence make sense, move sentences and paragraphs around so the essay has a coherent structure, do more research, re-read it and fix any mistakes, re-read it again and again making small changes each time (10 or more times), add the reference list and references, check it again for errors, print it out and check again for errors etc.) 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."

"As well as breaking large and complex intellectual tasks up into smaller tasks and having a lot of micro-rests, I also do most of the complex thinking and reasoning for anything I'm writing in my **short periods of (relative) 'intellectual clarity.'** I most often get these around 2 or 3am (or sometimes later), they usually last for around an hour or so and occur once a month or sometimes a few times a week (occasionally). My thinking is still quite impaired of course but far less so than usual. It is when I have these periods of clearer than usual thinking that I make all the big decisions about my website, about what I'm writing, about where I stand on certain M.E. related medical and political issues (and what makes logical and analytical sense and what doesn't) and also just about my whole life. I'd be lost without them; I write copious amounts of notes when they happen, telling myself exactly what to do when I go back to being my much more stupid self again! (Thinking so much and writing so much, particularly so late at night, leaves me feeling very ill afterward but I just have to take advantage of these moments of clarity when they come. My website and my writing would not be anything like what they are now without them).

To be able to write anything I also have to be really passionate about the topic and about what I'm saying about it. (Like most people, I'm far more likely to be able to remember a particular fact if it really shocked me, or I had some other very strong emotional reaction to it. Surges of emotion enhance the ability to make facts memorable somehow.) I have to have some real insight into the issue already too. I can't just decide out of the blue what to write about, I couldn't just decide that this month I'm going to write about breeding miniature poodles or the history of train timetables instead of M.E. for example, it just wouldn't work."

"I have a **problem with making new long term memories**, with learning new tasks. For example, when I first started writing for my website I realised that I'd forgotten some of the finer points of grammar. (I remembered 90% of it, but those rules that I used less often and would have had to have thought about for a second or two pre-illness were gone, probably just because I went 5 years without writing anything more complicated than a shopping list.) I decided to try to relearn what I'd forgotten so I bought a nifty little grammar book online and started to read it. I couldn't make any of it sink it at all at first, but eventually, after reading the relevant sections over and over and over again I found that I could remember all of the 4 or 5 rules I'd lost. I used my newfound knowledge on the current paper I was working on and it was fairly effortless. But then I went 2 weeks without writing anything and all my newfound knowledge completely disappeared. I learned it all over again, but then I lost it again too. Very frustrating! Unless I use a new skill virtually every day (or at least every week or so) the memories just disappear. (I think that constantly reading new things about M.E. is what allows me to retain as much of my current knowledge about M.E. as I do.)"

"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! (This isn't so bad when it's the weather report on radio as this only lasts 30 seconds or so, but is very bad when it's a fast talking TV ad or even worse a fast talking TV show as these can last much longer and the longer it goes on the more ill it makes me, and the more ill I am afterward.) When it finally stops my brain feels totally burned out, like it just blew every fuse. After that, the only thing it/I can cope with is complete dark, quiet and rest for a long time after – yet listening to someone talking on the radio with normal length gaps between words and at a normal speed is fine and I can often do so for up to an hour with few ill effects. Those micro rests just make all the difference.

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. (This is especially true if you put the TV on, as I often do when I have a guest, so the guest can alternate between watching TV and talking to you, and you can alternate between talking and resting – while ignoring almost all of what is on the TV – all without your guest noticing, usually). 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. The less well I know the person (ie. the more I have to actually think when I'm talking and listening) the sicker it makes me – if I can manage it at all. 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 at least several days if not a whole week. (I've never been so ill as after the two phone interviews I did about M.E. They made me so ridiculously ill afterwards it was horrendous.)”

“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. The more I think about it the more I realise that this must be true. It also explains why I have to write or type long words really fast so I don't get mentally 'lost' in the middle of them, and why when I cut a paragraph in an essay (on my laptop) to move it to another location in the text I have to paste it and then cut it again many times over as I'm scrolling through the document because I forget what the text is and what I'm doing with it every few seconds.

In the earlier stages of my illness I remember this problem being far worse. 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.)

I have worked out that this is what is happening because when there is the slightest distraction when I am walking, I end up unable to walk a step further until the distraction ceases. **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.) At my worst I've actually had to get around by rolling across the floor or crawling, although this hasn't happened for a few years thankfully."

"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.)"

"**My sense of time is off.** I can remember the previous two days or so fairly well usually, but if something happened a week ago or several months ago it will always seem to me to have occurred 'ages ago.' It is hard to explain but basically things feel like they have either happened to me very recently, or 'ages ago.' The down side of this is that if something really good or fun happens, after a few days it feels like it occurred many months ago. But the opposite is also true, sometimes I forget negative things that have happened quite quickly as well, which sometimes isn't all bad."

"Sometimes I **can't understand speech.** When someone talks, you don't immediately know what they are saying; the information must be sent to a particular area of your brain to be decoded first. My brain's decoder seems not to work properly or at all sometimes. When this happens I can hear the sounds perfectly well, but there is no meaning attached to them. I can't even make out the occasional word, I may as well not know any English at all. 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 find myself subconsciously lip-reading a lot to compensate, as well as paying more attention to tone of voice and body language. When someone says something to me in the wrong tone, when they are being sarcastic or trying to be funny, it really throws me. I'm very literal now. If the tone of what is being said doesn't match the words I get confused and it takes me a while to work out the real meaning of what was said.

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. (It was especially embarrassing as it

happened a lot in front of my lecturers when I was still studying. I suspect this was because my lecturers were the only people I really spoke to while I was standing up; I've never had it happen when I was lying down.)

Thankfully now that I no longer overexert myself, I only suffer with this symptom at a lower level most of the time. Right now the problem with language I'm having most often is missing random words when someone is speaking to me. I miss every tenth word or so. I usually try to just muddle through rather than asking people to repeat themselves endlessly (which people really hate), but I can tell that I guess wrong a lot."

"Sometimes I **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'm feeling quite good (relatively) when this happens and it's a real surprise that I can't speak. This symptom, like all of them, is at it's worst when I have been overexerting myself, but it does seem to come on randomly sometimes as well.

In extremely severe episodes of illness in the past, sometimes I can think only of single words one at a time, in a kind of primal way. Words like pain, cold or stop. When this happens all I am aware of is the immense pain and that I want it to stop, need it to stop. There is no memory or thought other than these words, the brain is just almost completely physically shut down."

"Talking can be impossible for me sometimes, and a lot of the time when I can talk it is very difficult. **Talking can be very difficult**, but in a way that is hard to explain and that has nothing to do with my voice. Again it is as if the part of the brain which turns thoughts or feelings into speech isn't working, or is really struggling to work. The difficulty is hard to describe. It is like... perhaps a bit like someone who hates mathematics (and has no aptitude for it) having to do a complex tax return. Sometimes I think it feels like it makes my brain want to vomit! These descriptions really don't get all that close, it is so difficult to describe. It is a hateful task trying to speak when I am not well enough to do so neurologically. It can be difficult, frustrating and intellectually painful.

I have had to ask (and beg!) my family to not ever ask me questions before late afternoon. If I am forced to answer a question with even a single word at that time of day the payback of doing that can last many hours. Doing such a thing feels like one big seizure, like it completely fries all my brain circuits. This leaves me in a catatonic-type state where I can't move, or think, and can feel only pain; physical and neurological pain. This can also happen throughout the day suddenly; after I have been talking for a little while the ability can suddenly disappear and I must resume resting again, as soon as possible or else risk being made quite ill by just a few extra words.

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 freely and normally if I am well-rested enough. (As long as there are long pauses in the conversation and what I am talking about isn't something that means I 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. (That figure of an hour includes the long pauses of course.)

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).

I would love so much to be able to use hand signals with my family. They would be such a relief and would avoid the awful seizure-like sensations and the completely out of proportion payback from talking when I shouldn't. But I feel silly asking for them as I can talk fairly normally each day, at least for short periods at certain times of day."

"My brain has a lot of **problems deciphering multiple audio inputs**. I can only have one guest at a time and talk to one person at a time or else I'm unable to follow the conversation or contribute to it and it makes me feel so mentally overloaded that within a short time that I soon have to go back to having complete rest again, alone."

“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 doctor who did some neuropsychological testing on me about six years ago seemed to think this was a distinct possibility incidentally, as I scored well above average on tests of visual literacy and well below average on various other tests of memory etc.) The difference between my audio and my visual capabilities is so large that my brain automatically uses my higher level of visual literacy to help make up for my lack of audio interpretation skills. Analysing body language and facial expression helps me work out communication far more easily than just trying to listen to the words alone. I also lip-read quite a lot. Talking and understanding speech is still something I have difficulty with neurologically but far less than I would have without these visual ‘tricks’ to lighten some of the load for my malfunctioning audio systems. (I do all of these things unconsciously by the way, or rather my brain does. They aren’t conscious strategies, I was doing them for years before I realised what was happening; the brain is very clever in the ways it finds to compensate for a damaged part of the brain, luckily.)”

“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. (I say whatever I’m thinking, and I’m thinking about lots of different things very fast thanks to all that adrenaline. My mind jumps happily from one subject to the next and back again constantly). 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 and congratulated on my health (and a non-existent improvement in 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. When I was 15 and still at high school I got a part-time job as a cashier at my local fast food restaurant. I would always do the calculations in my head rather than by using the till when I was working because it was just quicker that way, and not once in more than four years did I make a mistake. Things changed completely the day I got M.E. though. 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.) My handwriting is less uniform now and more scrawled, it degenerates significantly the more I write. I sometimes make strange squiggles instead of letters and there are also all kind of reversals; leaving off the first letter of words, writing words in the wrong sequence, swapping the first letters of two words, writing letters more than once, mistyping words randomly and sometimes also the same way each time (pseudo-dyslexia), leaving out sections in the middle of a word, writing down something someone says to me as I’m writing (or something I’m thinking about as I write) without knowing I’m doing it. I make a lot of these same errors when I’m talking or typing too. Occasionally, when I am not so ill as usual (for a short period) a bit of my old handwriting style sometimes comes back to some extent, which is interesting. 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. Although I can still read far more than many people with M.E., I'm very lucky in that respect. (Note too that all of these problems with reading, writing, talking and thinking etc. have nothing to do with cognitive 'fatigue' in any way. These are distinct and sharp edged individual problems with the brain, which occur together and/or separately, rather than a problem of general cognitive 'fatigue.' Physical exertion doesn't cause physical fatigue, cognitive exertion doesn't cause mental fatigue, sensory input doesn't cause sensory fatigue and orthostatic exertion certainly does not cause cardiac fatigue! If only.)"

"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. All you can do when this happens is bluff your way through it; see if you can recognise some of their clothing, try to pick up how the other people in the room are relating to them and try to do the same, or relate to them in the same way they are relating to you, or simplest of all just smile and make only very general comments if you have to speak at all. (People are most often far more concerned with themselves and how they are being perceived than in analysing you, you'd really be amazed what neurological problems you can 'get away with' experiencing without anyone else even noticing! The same is true of cognitive deficits; unless someone is really paying close attention, most of the time people don't even notice that sometimes my IQ just about halves mid-conversation or that I say very illogical and silly things sometimes and I really like it that way!)

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.). I worked out that my brain was doing this when I saw a film where everyone had a shaved head. It was an army movie, and I couldn't tell any of the 6 or 7 different characters apart! Even though their faces and voices were each quite different, the fact they had the same hair made it impossible for me to tell them apart. I also use voice recognition to some extent to tell people apart on TV and in film as well as in real life, although this is much harder and more prone to error as my audio skills are not so good these days either."

The skin on the tips of my fingers is quite unusual and quite changed from how it was pre-illness. 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, though of course I still do have fingerprints, just shallower ones. I also have at least 6 or 7 other miscellaneous new-onset skin conditions, which I will refrain from describing here. (Although I have taken a series of close-up photographs of each of them that you can view online at..... Just kidding!")

"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 am fully conscious but at the same time in a somewhat altered state of consciousness. It is hard to explain but I can just feel that there is something very wrong going on neurologically. (My personality is there the same as ever but I'm stuck in this malfunctioning brain and body.)

I'm able to get up as usual, and do the usual getting up things and then go to my day-bed to lie down again (as I must every day) but I soon start to get really cold. 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. Then my teeth start to chatter and become kind of clenched, then I start to visibly shiver and shake. I turn my heater up and tuck my blanket in all around me to try to get warm and my body curls itself into a ball instinctively (to reduce my surface area) to try to keep me warm. The ball gets tighter and tighter and my joints and muscles become stiff and immobile. If I have to move my arm out of the blanket to get something it is stiff and moves very jerkily and just shakes the whole time. Before long having even a small part of my neck or arm or hand out of the blanket is unbearable. I am rigid with the cold and I continue to 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, ice that can't move or bend but can only shatter. 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. The room spins horribly and I feel my eyes roll back in my head again and again until 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'm less intelligent and much slower than usual. My arms remain not quite my own for the rest of the day and are pretty much useless, and my legs move even more stiffly and awkwardly than usual. 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. It makes me so cold that I can't get my body to warm up again with any amount of blankets and I need to put myself in a warm bath (or else it may turn into a horrible cold fever and make me pass out). Instead all I can do when it is cold is use blankets. I think I get away with using blankets because I can micro-adjust the warmth very regularly and quite easily. I can pull the blanket all the way up, then a minute later take it off, then a few minutes later put it on only around my feet, then pull it all the way up again etc. I have to adjust my blankets a lot to not get either very hot or very cold. 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. The only relief is when it is really cold and I can just leave a big blanket on all night. I love really cold nights, although of course I have to be very careful not to get too cold or my body can't warm me up by itself and it is another annoying big drama to get back to normal temperature again and to avoid a cold fever."

"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. (An air conditioner is essential in summer if you live somewhere hot like Australia and you have M.E., or even somewhere a bit warm)."

"Just like the top half of my body is far more sensitive to being hot than my lower half, I also have very **different pain responses** in the top half of my body as compared to the lower half. My head, neck and particularly my

upper back and upper chest are extremely sensitive to touch. I have to be really careful scratching an itch when it is on that part of my body, as even a very light scratch feels like being scored with a knife sometimes. (I remember to use an especially light touch in these areas about half the time, the other half of the time I forget and have to deal with burning pain in the affected area.) Yet the exact same touch on my lower body doesn't hurt at all."

"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, it feels like the world stops suddenly. 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.

For a few minutes I am in this state, 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 neurological effects. Then, slowly, two words will fight their way through the swirling pain... "make stop...." It's primitive. I don't think them so much as feel them bubbling up from deep inside me. I repeat them over and over in my mind knowing somehow they are the key to stopping this pain but not really understanding what they mean, or how they can help, or even really understanding the abstract concept of words at all.

I realise that the only way to stop the pain is suicide. I don't want to die in any way, I just need desperately for the pain to stop and dying is the *only* possible way to do that. This is physical pain so extreme that it would make any sane person have this same thought flicker through their mind. Even the idea of it really shocks me though, as I have never in my life been suicidal and I have never (and still don't) have any wish to die. The pain is *that* unbearable though and each second of it feels like it lasts a lifetime. But my will to live is so very strong too and so my thoughts can only go around in circles - offering up no solution (except for this one unusable one) just more and more desperation and pain.

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. I've lost access to my personality. My brain is completely unable to access all the happy thoughts I keep there, the memories that tell me who I am. The sense of humour that always keeps me going is lost. This intense reaction usually continues for five more days, although it does get slowly less severe as time passes. This is more pain than anybody should have to go through ever. It feels inhuman. (This description 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 I am now somewhat less sensitive to noise (a low sugar diet helped lessen my sensitivity a little) and just as importantly, 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. (They have also had special thick soundproof doors installed on my rooms etc.). I am still very vulnerable to relapse by noisy neighbours etc. but the way my family has done everything they could to minimise the noise they make has made such a huge difference. 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. (I also get a similar amount of ear pain if I get a single drop of water in my ears, I don't know why and I haven't met a single M.E. sufferer that shares this symptoms with me either.) 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. Fluorescent globes may well be better for the environment but they aren't better for a lot of people with M.E., and others, unfortunately.) 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. Sometimes it is physically impossible to leave the house, and at other times it is 'just' that you SHOULD'N'T leave the house rather than that you physically can't. There just isn't much point seeing a doctor in hopes of improving your health (for example) when you have to cause yourself a month long or 6 month long relapse, or injure yourself permanently (and significantly or permanently ruin your chances of a future improvement in your health), to do so. (We really need more medical services for the housebound, or really ANY services for the housebound in some areas. 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, I have to do all of those 'sleep hygiene' things to get to sleep at anything like a reasonable hour. I also have a lot more difficulty sleeping 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. Most people I know with severe M.E. suffer with insomnia quite badly, I'm very lucky I sleep as well as I do.)

"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. (I do keep myself calm but it *is* disturbing, the feeling of utter powerlessness that paralysis causes, and very unpleasant.) I tell myself over and over that this will pass and that I just have to wait it out again. I lie there for perhaps 10 minutes like this. I hear noises from inside the house and from the neighbours. They make me feel more alone than ever, reminding me as they do of the fact I am not out there living my own life and making my own noise like they are. The noises distract me from my task of distracting myself too and so I find each noise intensely irritating. (The fact that even the smallest noises causes me pain thanks to severe noise sensitivity doesn't help either).

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. So my mind game changes again and the focus is now mainly on distracting myself from my urgent need to go to the bathroom. After more time passes I start to panic a little that I really can't hold on much longer. The paralysis has worn off before I've ever had an accident in the past, but I wonder if maybe this time my luck will run out, finally. (As it has for many fellow sufferers unfortunately.) I work out in my mind what I would say and do if an accident did happen; how I could best deal with it and minimise the effects. Luckily, thinking all this through distracts me from the problem for a few more minutes! I'm starting to feel very weak and dizzy now 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! I haven't had sleep paralysis at all for about 6 – 12 months now, which is just wonderful. The feeling of powerlessness is so intense, I think sleep paralysis is kind of traumatic in a way.

I have had experiences of sleep paralysis that have lasted at least an hour and a half at times. (I'm judging this by my sense of time passing, what I know about the rate at which my hypoglycaemia worsens over time without food, and by the different noises I can hear.) I've had sleep paralysis for at least a solid half hour, almost every

day for many years. (I know of many M.E. sufferers who have had very similar experiences of sleep paralysis, it isn't uncommon). Incidentally, if I have a short period of sleep paralysis I'm usually going through periods of waking and sleep but when sleep paralysis lasts longer or all day, the periods of sleep soon turn into periods of unconsciousness. I never sleep all day even with sleep paralysis, but unconsciousness can last many hours."

"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. (Perhaps it does occur for a short period but if it does it is too brief for me to perceive it). 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 (as I always have to do each day now).

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 (and not at all unpleasant or troublesome) or because I have the flu (which also isn't so bad and can even be quite nice). I miss fatigue a lot. The whole fatigue and M.E. thing is just a myth, or more correctly, pure propaganda. (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 severe fatigue and exhaustion that comes with doing a hard days work – or play! – 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. After a while I'd start to get quite light headed and faint from the lack of food but still I would be unable to get up. 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 sometimes I'd have been unconscious for so long that by time I could finally get up it was almost time for me to go back to bed to go to sleep for the night! I would only have about 3 or 4 hours of consciousness some days.)

This symptom has changed for me over time, but never have I experienced morning fatigue or sleepiness since day one of my illness. The reason I sometimes can't get up in the morning is NEVER because I am too tired, it is always because I am too ill. The house could be burning down around me and I still wouldn't be able to get up.

I find it easy to tell the difference between unconsciousness and being asleep incidentally. The two sensations feel very different to each other, the onset is very different, the time it lasts is different, the events preceding both are different, and when I sleep in the daytime I can't get to sleep until a bit later than usual whereas when I've been unconscious for a period of time that day (whether it is for 2 hours or even 10 hours or more) I still need to go to bed and go to sleep at the same time, even if I've just had a long period of unconsciousness right before bedtime. Unlike extra sleep, unconsciousness has no effect on how much sleep I need, I still need the exact same amount of sleep no matter how much of the day I've spent unconscious. Sometimes when I come to after being unconscious my heart races and feels fluttery, which doesn't happen after sleep. The two states are quite different."

"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 carers get the entire morning to do what they want with, and I avoid all the early morning noise by sleeping through it.) I have tried to get the sleep/wake cycle a bit more normal several times and while sometimes I could get to sleep earlier, I would always wake up ‘wrong’ neurologically if I woke up before 12pm, every single time. I’d be far more disabled, less mentally capable, and far less able to tolerate noise/talking etc. than I would be otherwise and these deficits would affect me all day. My body just 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 (7 – 10 hours a night most often). I need to be allowed to wake naturally to have any real quality of life that day.”

“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). Sometimes I experience muscle paralysis. 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). (This muscle problem in M.E. affects all muscles including the heart.)”

“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 blurry vision a lot, on and off throughout the day but I can usually clear it – at least for a short period – by rubbing my eyes with my fingers or by focusing very hard and squinting. But when I wake up unable to see properly these things don’t work at all and it is a much more severe problem I’ll probably be stuck with all day (or at least most of the day). 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 longer than my body (and the muscles in my eyes) can handle. I’ve only had this happen perhaps 6 or 7 times or so as I have worked out that it is entirely exertion related and I now know to be far more careful with my activity levels so I can avoid this horrible problem, thankfully.”

Just like my eyes don’t work properly if I’ve been using them too much or for too long, the same is true of my brain. **I have to carefully monitor and limit how much I think** just as much as I limit how physically active I am, if not more. (The brain requires a huge amount of metabolic energy to function, more than just about any other organ. So do the eyes and muscles, incidentally. That is why mitochondrial diseases such as M.E. affect the brain so profoundly).”

“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.** I have tried many times to do a small series of set stretches each day, but it always ends badly. My muscles have a set amount of activity they can do in a day and this is very close to the amount I need to do the basic tasks of everyday living. Every time I tried to add in extra stretches I ended up being too ill to do basic things I really needed to do like lifting myself out of the bath, or brushing my teeth. I would also end up in a lot of pain and with many of my symptoms made a lot worse.

It is just stupid when you are unable to do (or only barely able to do) so many basic tasks – and virtually no fun tasks! – to waste any of your precious strength doing these sorts of exercises and they just end up making you much weaker instead of stronger anyway! When stretching goes beyond your physical activity limits it achieves nothing and is just completely counterproductive. (Until you have had some significant recovery and are able to handle it physically that is. I've never yet met a M.E. sufferer not willing to do as much as they are well enough to do; the problem is always of people with M.E. doing too much rather than too little, if anything. It's just human nature.)

“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. I have to lie down straight away when this happens, and then it almost always goes back to normal. But sometimes I become short of breath when I am already resting. I'll be breathing okay for half the day and then suddenly I'm short of breath. I can't rest any more than I already am so it's much harder to know what to do when it occurs when I'm already resting. (Incidentally, this isn't happening because I am unfit or deconditioned as it occurs some days and not others and this dyspnoea was also one of the symptoms I had right from the very beginning of my illness when I was very fit, and nobody becomes deconditioned overnight or has deconditioning suddenly disappear only to come back again a week later! 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 than I used to. (I end up very short of breath after drinking a glass of water for example.) I've tried to retrain my muscles to let me breathe more deeply, more from the diaphragm, but it just leaves me even more short of breath afterward and has even made me grey out a few times afterward too. I just don't have the muscle power to spare to take deeper breaths now.

Thankfully I eventually found a few things that help with this problem, including a particular prescription drug and keeping an electric hot pack pressed against my back all day, so it has never gotten to the point of needing resuscitation etc. (as it has with more than one friend of mine with severe M.E.) I can never get a real hug though, as these were always what caused my worst grey-out episodes in the past. Friends and family now all know that when they hug me they have to let me hug them without touching me at all themselves, just letting their arms hover over my back without actually making any contact.”

“If I'm in one position too long I get **gelling of my joints**; they lock in position and it takes a while to get them to move properly again and unbending them can be a bit painful. This problem mostly just affects my legs and hips. It means that I have to change positions fairly often to stop it happening. I'm not sure how often I do change position, I just do so when I start to feel the first twinges of stiffness in the joints. Sometimes when I'm on the computer (which I use lying down on a special stand) I'll have been concentrating so hard I'll have blocked out these early warning signs and it will take quite a while to get flexibility back in my joints.”

“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.

I've tried using eye drops to stop the burning in my eyes, and they worked quite well, but they also made the burning skin around my eyes hurt more in contrast. It felt like I was wearing a burning hot mask with the eyes cut out. Because my eyes didn't burn it just made the area around my eyes where the pain started even more noticeable so I found I was really better off without eye drops at all and 'just' living with the original pain. It was easier to mentally block out the pain that way."

"Sometimes I feel like I have no skin on any part of my body so every part of **my skin burns**. I feel totally raw. Everything is agony; the lightest touch, the softest noise, the softest light, the smallest movement I see. My whole body over-reacts to these inputs."

"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."

"Sometimes suddenly one of my hands becomes **agony**. It feels as if I have broken or crushed all the bones in my hand. Over time (and trial and error) I've learned that I need to put my hand on a flat surface so that it lies completely flat and the pain completely disappears. I usually forget about keeping my hand flat after a while, and I move it and the pain returns. I sit it flat again and I once more find relief. After about 10 minutes or so, I don't have to move my hand back once I forget (as I always do) as it no longer hurts and the pain has gone as suddenly as it came."

"I used to get a strange **ache in both wrists** that was only relieved by bending my wrists backwards as far as they would go. I remember waking in the night to bend my wrists back so I could get back to sleep. This unusual symptom lasted for a few years early on in my illness and then disappeared."

"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.)

One of the main changes I have noticed is that I find all my emotions have become much closer to the surface now. I get emotional fast, when something happens where it is appropriate, then I vent it right away and the emotion goes away very quickly and I return to my very-positive-most-of-the-time baseline. There is no blocking out emotion, no suppressing what I am feeling until lots of small hurts are released in one big gush and no storing emotions up to deal with later when I'm by myself. My emotions are almost on a kind of child-like level in a way, I sometimes think. I really live 'in the moment' emotionally (and cognitively), like young children do, to some extent. The memory loss really comes into play here as I often simply can't remember what I was mad or sad about if it didn't happen that day or the day before etc. or even 10 minutes before sometimes. (Although I still have my normal deep emotional responses too, they haven't changed; there is just this additional superficial level now.)

Before I was ill, it was rare that I'd cry even at a very 'weepy' film, now I cry far more easily – not great big can't-breathe noisy sobs, just quiet watery crying. (I cry easily but I don't get truly sad or upset more easily, if that makes sense.) When I cry and I'm not really upset at all I usually just smile and say, 'I'm fine, I'm just crying, don't worry about it.' I can still laugh when I'm crying (and I often do) which must look a bit weird, but really my

crying is on such a hair trigger it just doesn't mean much when I cry. Sometimes it's just a release of tension I think, more than anything.

Another of the changes to my personality caused by the M.E. brain damage is that I'm no longer smart enough, or sophisticated enough, to make my face show any other expression than exactly what I am feeling. You can read me now like an open book and that is not always a good thing! Tact and little white lies are important social skills, skills which I now lack (to some extent). I simply cannot think one thing and say another any more either. That would require being able to think two things simultaneously, which I can no longer do. I'm also very impulsive now in the way I'll often just blurt out whatever I'm thinking. All I can really do to prevent myself saying the wrong thing sometimes is to try very hard to say nothing at all when anything a bit complicated comes up. (Don't get me wrong though, I still have quite a lot of control and knowledge of what is and isn't appropriate. Noticeably less than pre-illness, but more than enough not to be completely socially inept or deranged or to say or think anything explosively offensive or inappropriate. Like all of my emotional changes, this is only a mild problem, not a severe or profound one.)

These emotional changes vary somewhat depending on how ill I am to some extent (as in they can sometimes get a bit worse when I'm very ill) but mostly these changes have been the same since day one. The way my brain deals with emotion is different to how it was pre-illness, but that is not to say that all of the changes are necessarily bad. There are actually some advantages to this, something I can't say about any other symptom! I get over things far more quickly than most people and I don't (and really physically can't) store up resentments and so I am very willing to forgive. This more natural, open and 'in the moment' way of being is very emotionally healthy in a lot of ways and has let me form much deeper and more positive relationships with some of my closest friends and family too. It isn't all positive though of course, sometimes it would have been far better if I could have just not said anything (for my benefit and sometimes theirs too). Plus I really hate crying in front of people. I particularly hate the thought anyone might think I am doing it on purpose to be manipulative or to get my own way in an argument (when that has never been why I've cried either before or after becoming ill).

The more I think about it though the more I think that the 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."

"As well as having to limit how much I am physically active and how much I think and how long I am upright etc. I also **have to monitor my emotional activity level**. Strong emotion is too much for my body and my brain to cope with post-illness and so I have to be very careful not to feel any emotion too strongly, or for too long. This isn't just about being made sicker by stress, anxiety or feelings of sadness, ALL strong emotions come at a high price physically, not just negative ones. For example the emotion that makes me sicker than just about anything is not anxiety but feelings of excitement and happiness, such as when it is my birthday or Christmas and I am opening and/or giving presents. I now have to do the presents thing on a different day otherwise I miss my whole birthday etc. because it takes me all day to recover just from that. Crying is also something I have to minimise as much as I can, it just leaves me feeling so ill afterward now, it feels like my whole head becomes dehydrated after I've cried. I need to drink copious amounts of water afterward even if I have just cried for a few minutes. My eyes really burn after I cry as well. Crying can be quite painful now.)

When you get very physically ill after being upset or anxious however, it makes you learn very quickly how best to minimise these emotions, as you might imagine. You become very good at not letting yourself get worked up over small things or things that are out of your control – a bit like a normal person would if they were electrocuted every time they cried or got upset, I sometimes think. You're forced to become far better than your average person at dealing with negative emotion and with not being any more upset over things (or worrying about things) than you really have to. Learning to limit strong *positive* emotions that make me ill is a lot harder as it is just such an unnatural thing to do. Although sometimes positive emotions do make me ill, limiting or eradicating them isn't something I'd really want to be too successful with for obvious reasons."

"I have a **problem with volition** a lot of the time; difficulty starting, stopping or switching tasks. (People with depression have a lot of problems with volition too: they lose the *desire* to want to do things, although there is no physical reason that the tasks can't be done. In depression, volitional problems are entirely a motivational or psychological problem. This is very different to the type of volitional problem seen in M.E., in fact the problem is quite the opposite.)

The volitional problems seen in M.E. are entirely neurological. You are entirely willing and able to do things psychologically, but there are real problems neurologically; physically. For example, I take different medications at about 5 or 6 different times of the day. Sometimes, I just can't take the appropriate medication at the appropriate time. It is like coordinating all those complicated physical movements is just too overwhelming for my brain and it can't cope. I try to make my brain tell my body what to do so I can take the medications I should be taking but nothing happens. There are just so many steps; picking up the pillbox, getting in a position where I can reach a glass of water, picking up a glass of water and getting it ready, opening the pillbox, taking a few pills out and putting them in my mouth, picking up the glass of water and taking a sip, and so on. There are just so many complex actions my brain has to coordinate my body to do, that it is just too much. (Sometimes I end up taking a lot of medications all in one hit at the end of the day when I'm at my best neurologically, which isn't ideal.)

Simple tasks like this that I used to be able to do so automatically without any real thought now need to be thought through at each little stage it seems, and even worse, often my brain is just not up these sorts of calculations so I can't do things at all. But even when I can do these sorts of tasks, they are a real mental effort and take a lot out of me. I also have difficulty switching or stopping tasks sometimes. I don't want to have a break in the middle of a task a lot of the time because getting started again is just so hard neurologically. (There is a good description of this symptom in Dr. Hyde's brilliant [M.E. textbook](#) if you want to read more about this.)"

"Proprioception is the ability we all have to sense the position and location and orientation and movement of the body and its parts, from stimuli within the body itself. I have had **problems with proprioception** since the day I became ill. It makes me kind of clumsy; I walk into doors a lot, and I drop things sometimes. (The fact that I suddenly lose all the strength in my muscles sometimes also makes me clumsy). I always have bruises on my arms and legs, mostly from walking into walls, or misjudging the distance from things and accidentally kicking the furniture. (Perhaps I also bruise easily; I usually only remember where about half my bruises came from but this could be due to memory problems rather than bruising easily)."

"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). I'd give anything not to have to eat, but the hypoglycaemia I have doesn't care one bit how poisoned or nauseous I feel, and so I still have to get through the 7 or 8 small meals I need everyday. Every bite is a fight to get the food down. 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! I usually get through my meals by putting the TV on for a few minutes and putting as much of my concentration on that as I can so I can distract myself from the fact that I am eating. It is still difficult and I hate it but hypoglycaemia is even worse so I just have to make myself do it anyway. (Several different medications have helped to reduce my nausea significantly in recent times, luckily – although it's still a significant problem.)"

"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. All sorts of foods that smell or taste a certain way, or have a certain texture make me feel like I will throw up. Some foods I really just can't keep down and I do throw up if I eat them eg. pumpkin.
- Food has to be easy to physically eat. Soup is impossible for me because of the muscle work required, eating dishes where all the bits are different sizes and you have to hunt around to get any on your fork is out too and I have to have things like steak or chicken pieces cut up for me).
- 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 had no allergies or intolerances pre-illness and ate pretty much everything but now I have to avoid or limit: tomato, capsicum, potato, eggplant (nightshade family of vegetables), yeast and fermented or mouldy foods and condiments (eg. cheese, vinegar), soy, wheat, dairy products, artificial sweeteners, artificial preservatives colourings and flavourings, eggs, stimulants (coffee, tea, caffeinated soft drinks), fruit (difficult to digest and the high levels of fructose can trigger hypoglycaemia and other problems) and nuts.

- Foods I eat have to be not just low GI, but have quite a low GL as well. (My diet is low GI and GL and high protein and moderate in fat.) Foods with a low glycaemic index (GI) are foods that release their sugar and carbohydrate content into the body slowly. But just eating a low GI diet isn't enough (not for me anyway) as many of the foods allowed on a low GI diet are very high in carbohydrate and my body just does not seem to be able to deal with carbohydrate or sugar at all well. The fact that it is released slowly just isn't all that helpful! I also need to only eat foods that don't have much carbohydrate or sugar in them to start with, foods with a low glycaemic load (GL). This was to stop me gaining weight like crazy (even with a low GI and low fat/low calorie diet I was putting on weight) and to stop extreme sensations of hypoglycaemia; extreme mood swings, feeling woozy or passing out after eating sugary foods etc. (I just feel so much better now than I did before my doctor put me on this low GI, low GL and high protein diet, plus I have been able to lose most of the weight I put on before this problem was diagnosed. I have been diagnosed with hyperinsulinism, a pre-diabetic condition, by blood test. Abnormal insulin responses etc. are well documented in M.E.)
- 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. The only foods which I can eat as much as I like of (intolerance-wise) are: meats (all of them), celery, cabbage, carrots, and spinach (and a few other vegetables).
- Food has to be balanced in a certain way for protein, fat and carbohydrate content. I have to have something with either fat or protein with every meal or snack, with just a little bit of carbohydrate added. Even when I eat a very low GI and low GL fruit such as a strawberry, I need to eat it together with something with some fat or protein in it to help mediate the effects of the sugar/carbohydrate so that I don't feel faint, dizzy and hypoglycaemic afterward. (It feels like I have to manually balance my own blood sugar!)
- Foods have to be readily available and affordable (eg. I can tolerate seafood very well but that doesn't matter much because I can't afford to eat lobsters and scallops etc. very often.)

It is no wonder that so many of us with M.E. just want food pills! It is ridiculously complicated to know how to eat, especially when you're first ill and you haven't done all that trial and error to see what exactly you can and can't eat and it feels like every single food makes you ill.

I have to eat every half an hour when I first get up, and no less than every three hours by the end of the day too. Every day I have to have 7 or 8 small meals. Fasting or even having a meal or snack 5 or 10 minutes later than I need to makes me ridiculously ill. It's hard to explain the feeling... I feel very faint and weak and as if I might lose consciousness. (If I have gone too long without food I have actually lost consciousness at times.) It feels like my body and brain just shut down when I haven't eaten enough or often enough (or when I've eaten something with too much sugar or carbohydrate in it). I'm invariably made extremely irritable when I need food too. When it is severe I also become a bit mentally confused, I just can't think at all or remember anything or do or say anything. These feelings/symptoms all last for a long time afterward even after I have finally got food too (except for the irritability, luckily!) so this is something I try very hard to avoid if at all possible. (I'm not sure if what I have is true hypoglycaemia though. The mechanisms/pathology may or may not be the same as with true hypoglycaemia, it may be more a problem of hypoglycaemia-like symptoms.)

Working out what to eat and eating it takes up a lot of my day as you can imagine. I'm too ill to do any of the food preparation though and I have to rely on others totally for this which is bad enough anyway without all the complicated food rules I have as well, but I really have no choice.

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 (which is especially annoying as I need to drink almost 3 litres of water a day now). I really want a drink but the muscles just won't move or I can't co-ordinate them to do the swallowing motion properly. (Swallowing water seems to be harder than eating food, as I can always eat food before late 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. Sometimes it is really hard to draw breath while I am choking so hard and all I can get is a quick loud wheeze of air between coughs. That is why it is so scary. 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. I have a superhuman sense of smell when it comes to certain chemicals. I can tell now if someone is wearing perfume way before they are anywhere

near me because I get symptoms so quickly from it. Luckily I am able to avoid most of these chemicals in my house most of the time and I only have a fairly mild reaction to these things compared to many. They usually cause; headaches, difficulty thinking, and a burning sensation in my nasal passages and throat (etc.)”

“Far more troublesome for me 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. (But thankfully I have found some drugs I can tolerate. Unfortunately not everyone is so lucky. Some M.E. sufferers haven’t found any medication or supplement they can tolerate.)”

“When I’m put in a **situation that is beyond what I can cope with physically**, for example a visit from someone that I didn’t plan for or agree to, it inevitably goes very badly for me physically. Sometimes I have to really fight to stay conscious. When I’ve had uninvited guests in the past, I can remember trying to listen to them talk, but not really being able to take in anything they were saying. It was all I could do to guess when to make one word replies occasionally. I would try to keep my eyes open (not wanting to appear rude), but if I did my eyes kept rolling back in my head and the room would spin. Having my eyes open made me feel like I was in imminent danger of blacking out and so I’d explain to my guest that my eyes hurt and that I had to close them. Closing my eyes helped a little, but not nearly enough, it was still just too much stimulation and too much work for my damaged brain. When the person would finally leave, I’d be left extremely ill not just for the rest of that day but for several weeks afterward. (Surprise visits can be an absolute nightmare for a M.E. sufferer. I still remember vividly some of the occasions I had this happen, they were so very horrible. I needed significant warning before any visits because at the time I needed to have complete rest for about a week before I could see anyone for even a short visit, and even then sometimes that wouldn’t be enough and I would have to cancel.)”

“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. I don’t remember ever having headaches that lasted more than half a day or a day before, and they were usually pretty responsive to mild analgesics. Now analgesics do nothing to help them and 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 they feel more like a feeling of strange pressure in the head rather than headaches, I’m not sure if these sensations are really headaches at all.)”

“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. My face is often very pale when I have this problem too, the pallor can be so extreme my face can look almost white. 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. Sometimes the warning signs encompass other flu-like symptoms too, most commonly; a mild fever of 0.1 to 1.0 degree, a bad flu-like taste in my throat/mouth, and joint and muscle aches. When I am too active (mentally, physically or with sensory or orthostatic stress etc.) it feels just like I am getting the flu, I get a handful of the usual symptoms (except the fatigue, unfortunately). But it

isn't flu, it is 'just' the M.E. (The symptoms of a flu are not caused by the flu virus but by the way your body responds to the virus, so flu symptoms are symptoms of an immune response rather than specifically flu-virus related).

If it has got to the point where I'm having flu-like symptoms, this is a sure sign that I have seriously overdone it and that I am really going to pay for it in the coming days and weeks (etc.) with a severe exacerbation of symptoms. The flu-like symptoms most often remain present (or worsen) throughout the worsening of symptoms as well. (My immune system, along with many other bodily systems, responds inappropriately to activity now. The immune system is inappropriately activated in response to physical activity etc. in M.E. There are also post-illness changes in gene expression in response to physical activity in M.E., among others.)

(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%); so we not only have far fewer NK cells than we used to but they are also far less effective than they should be, making this immune system deficiency even more serious. 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.
- 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.
- 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.
- 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.
- 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.)
- F. The worsening of the illness caused by overexertion can be acute, but often does not peak until 24 - 48 hours (or more) afterward.
- 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.
- 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.)
- 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.

- 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.
- K. 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.

To illustrate each of these points more clearly, what follows are some examples of how each of these statements relate both to my own case of M.E., and to M.E. sufferers generally:

**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.**

Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is virtually universal in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The same is true of the other changes to the brain and body caused by M.E. – these changes also appear suddenly or acutely, and not gradually over weeks or months.

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. (I can pinpoint the exact hour I became ill.) 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. They have never been correct with regard 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.](#)
- M.E. is an acute onset illness, however it should be noted that: (a) some sufferers will be unsure of their onset type (they may not recall it, or may not recall it accurately, for various reasons) and (b) in some cases, acute onset M.E. is preceded by a series of unrelated minor infectious episodes (in a previously well patient) which may be misinterpreted as being a gradual onset of the M.E. (These minor infectious episodes may be due to the immune system being under temporary or chronic stress from events such as; recent immunisation, repetitive contact with a large number of infectious persons, or the effect of travel; as in exposure to a new subset of virulent infections. This pre-existing temporary or chronic immune system weakness is not seen in all patients and is *not* what causes M.E., although a compromised immune system will of course make the body more vulnerable to all types of infections, including M.E.)

**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. Some patients find that their most severe relapses come from orthostatic stress, while others will have to be more careful with their levels of sensory input or cognitive exertion as compared to physical activity. Other patients may be equally limited with each of these activities or stimuli, and so on. It varies from patient to patient and can also change over the course of the illness.

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. Emotional stress, however, is nowhere near as large a problem as the others (probably in part because emotional stress is far easier

to avoid, control or minimise compared to the others, and is less an essential part of daily life). Far fewer than 1% of my symptom exacerbations or relapses would be caused by emotional stress.

- *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.

M.E. causes 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. There is a loss of normal internal homeostasis; the individual can no longer function systemically within normal limits. (Metabolic problems also contribute to this inability to maintain homeostasis.)

- Physical activity in this context does not just mean aerobic exercise; it includes any physical movement or activity, including stretching. Cognitive activity refers to any type of thinking, or mental processing. Sensory input includes exposure to light, noise and movement etc. Orthostatic stress or postural stress includes sitting or standing, but also things like having a few pillows under your head when lying down or sitting up in bed; orthostatic stress is caused by any posture other than lying down flat (perhaps with legs raised to reduce the load on the heart also).

### **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.

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

The types of symptoms produced in response to certain levels of physical activity, cognitive activity, sensory stimuli or orthostatic stress may or may not vary depending on the type of the activity or stimuli involved. Sometimes specific symptoms will be provoked by each activity/stimulus. (For example too much cognitive exertion can cause headaches, too much noise can cause ear pain, and so on.) But very often the types of symptoms worsened or produced by overexertion are fairly similar regardless of which exertion or input was involved. (For example, the heart problems of M.E. are made worse by all of these activities/inputs.) Sometimes this may be a worsening of one or two or perhaps even five or so different symptoms, but sometimes it is quite a large cluster of symptoms that are worsened. The cluster of symptoms made worse by exertion or stimulus is often very similar from patient to patient, as generally it is a worsening of the most common symptoms of the illness. My own most common symptom cluster is as follows:

“I like I have a fever. My eyes and my brain feel like they are slowly cooking in my head, and the skin on my face just burns. I feel like I have been poisoned. I’m very hot and very cold all at once. My throat and the glands in my neck are quite painful. I feel very overstimulated and wired mentally as if I were having a constant low-level seizure. My brain is hyper-responsive to any sort of stimulus. (I feel the exact opposite of drowsy or tired or fatigued). Even dull light hurts my eyes; the agony is intense and comes on after just a second or two of exposure to the light. The smallest noise makes me jump and makes my heart shudder, painfully, and makes my ears agony. To see anything moving makes my low-level seizure even worse and makes me feel like my eyes are rolling back in my head and as if the room is spinning. I feel very nauseous and vertiginous. Any type of input makes every symptom a lot worse. (I have to have complete rest and be completely alone but even then the symptoms are all still intense, very often.) I even have to try hard not to think at all as I lie there, or the symptoms all intensify severely again – not that I can think, my brain is mostly shut down. I can’t move almost at all. My heart feels under a lot of pressure and as if it is struggling to keep beating. It is beating very fast (tachycardia) but feels like it is just fluttering in my chest instead of beating properly. Maintaining even a slightly upright posture for even a few seconds makes my heart problems immediately a lot worse. My blood pressure is very labile as well and so I feel quite faint and weak. The pressure on my chest also affects my lungs and makes it hard to breathe.”

These symptoms combine to create an overwhelming experience of terrible illness that is also profoundly incapacitating. When these symptoms are at their most severe, you feel as if you are about to die. But at a lower level, these are also all the same symptoms that I suffer with constantly, every day since I first became ill.

Overexertion causes them to worsen, but they can be also quite severe even at the base level, at rest. (The exact combination of symptoms will vary from person to person, but some combination of the symptoms listed above is fairly common.)

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

- *An additional note on 'fatigue':* Just as some M.E. sufferers will experience other minor and non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms (and so on) – the presence or absence of mere 'fatigue' is irrelevant. In addition to these other (far more serious) symptoms, some M.E. sufferers may also suffer with mild, moderate or severe fatigue some of the time, while others will not. Thus the symptom of fatigue is not an essential symptom of M.E. and does not define M.E. (Although the symptom of fatigue *is* essential to qualify for a misdiagnosis of 'CFS'). For more information see: [M.E. is not defined by 'fatigue'](#) and [The definitions of M.E. \(and CFS\)](#).

**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.

There is a lot of variation from patient to patient but very often the levels of activity required to cause relapse are trivial compared to a patient's pre-illness tolerances and abilities. For example, what constitutes overexertion for someone with severe M.E. could be something as small as rolling over in bed, walking or talking for a few minutes, or eating a meal. Someone with moderate M.E. however may tolerate all of these things perfectly well but may become more ill after walking for more than 20 minutes, talking for more than an hour, or watching a few hours of TV, and so on.

The severity and duration of relapses of symptoms are also often out of all proportion compared to the level of overexertion involved. You might assume that a half hour phone call couldn't possibly take more than an hour or two to recover from, or that a few days should be more than long enough to recover from a short shopping trip or a visit to a doctor, for example. That might seem reasonable, but M.E. is not a reasonable illness unfortunately; even going slightly over your limits can cause severe and prolonged relapses of symptoms in M.E. For example, I recently spent 5 days recovering from a half-hour phone call. The worsening of the illness was very severe; for each of those 5 days the severity level of my symptoms went from my usual base level of 6/10 to a constant 9/10 and I was only able to do about a quarter of my usual activities. I was ridiculously more ill than usual for a long time afterward relatively – all from a mere half-hour phone call. I also end up having a severe (delayed) cardiac episode which lasts for 4 hours or more, if I stand up during the day more than I should; even if this is only for around an extra 5 minutes or so. As I explained in section 2, I've also spent 5 days very ill recovering from 5 minutes or so of extreme noise. (These out of all proportion relapses happen over and again and again with M.E, they aren't isolated incidents.)

As another example, I recently spent a week in hospital for tests. If I'd had almost any other illness I'd have been fine; I wasn't forced to be more physically active or to stand up much more than usual, although I did miss a lot of sleep and have to talk to people a lot more than I usually would have, and there was a lot of noise in the ward all day and night and on the last day I was exposed to extreme noise for half an hour. I was extremely ill when I left hospital however, my pain levels were at 10/10 and I was almost in a catatonic-type state. I couldn't speak or even think almost at all, and I couldn't bear to even have anyone talk to me either. My symptom levels and pain levels

were at about 9.5/10 for about a week afterwards and I couldn't do almost anything. It took me 6 full months after that to regain my previous level of health and ability, or most of it at least (two years later I still haven't fully recovered, I'm still nowhere near as 'well' as I was when I went in unfortunately).

The severity and duration of relapses varies depending on the severity of a person's illness, but relapses in M.E. are very often way out of all proportion to the actual activity. Relapses can be very severe and prolonged (or permanent) even if you've only gone past your individual limits in a minor way or for only a short period of time.

- *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 reaction people with M.E. have to activity 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 abnormal responses to orthostatic stress. This is simply not the case with these other unrelated patient groups. Recent research has also shown that certain levels of postural stress and physical activity exacerbate 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. Needless to say that this pathology is also not seen in those illnesses causing fatigue (etc.) after exertion, including post-viral fatigue syndromes, Candida, Lyme disease and Fibromyalgia and so on. 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. The cause is different, the symptomatology is different, the pathology is different and the effect on long-term prognosis is different. The two problems are quite distinct.

**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!

Observing your average M.E. sufferer for an hour – or even a week or more – will not give an accurate indication of their usual daily activity level because the severity of M.E. waxes and wanes throughout the hour/day/week and month and people with M.E. can sometimes operate significantly above their usual illness level for short periods of time – albeit at the cost of severe and prolonged worsening of the illness afterward. M.E. is anything but a stable illness.

M.E. is not stable over the course of a day, or even from one hour to the next:

- People with M.E. will very often have several ups and downs in ability levels, and in symptom levels, throughout the day. You might wake up feeling and functioning at about a 2/10 level, improve slowly over several hours to about 7/10 for an hour or so, then slowly worsen to spend a few hours at 4/10, then improve again to 6/10 for an hour, then worsen to 4/10 again for four or five hours before improving to a 5/10 level just before bed. After that you might spend the last hours before sleep very ill again at about 3/10. There is often so little stability in M.E. symptoms, severity and ability levels throughout the day that the question; 'what is your normal activity level or severity level?' can be just about impossible to answer for many people with M.E.
- Your ability levels for different tasks can also change significantly throughout the day with M.E. For example I have a best time of the day for talking, being exposed to hot or cold temperatures, for thinking, for reading, for listening to music, for being upright, for being physically active, and so on. They're all different. Some activities that would make me very ill for many hours afterward if I were to attempt them when I've just woken up, I can tolerate perfectly well in the late evening, for example. Other activities are impossible for me to do 23 hours of the day, but I can sometimes do them at one specific time of day (or once a week or a month) when my ability levels for that task are much higher than usual for half an hour or an hour. Timing is everything with M.E. very often.
- Sometimes M.E. sufferers are at their best at one specific time of day. Any difficult tasks that they need or want to do need to be done within that 30 minute - 3 hour period of time (etc.) where they are able to perform at a much higher level than for the rest of the day, or else they cannot be completed at all.
- M.E. can vary so much within the hour; you can be fine one minute, doing slightly better than usual even, and then suddenly you can become very ill or one symptom or more will become far more severe or disabling, for no discernible reason. That sort of change happens very often with M.E. You can't plan to do things even a few hours ahead, or even half an hour ahead sometimes; so much can change in that short period of time.

- Sometimes you just don't know what you're going to have to deal with when you wake up, with M.E. You might be fairly stable over a couple of days but then suddenly wake up the next day and out of nowhere your balance is much worse than usual, or your nausea is, or your problems with speech – or whichever other symptom or symptoms. Sometimes the general severity of all your symptoms can just get worse suddenly. (Even if you've been resting enough, and doing everything right, very often M.E. will just kick you in the teeth now and then anyway just for no reason. Sometimes all you can predict is that it will be unpredictable!)
- Timing really is everything with M.E., in so many ways. There can be so much variation in M.E. even from one 5 or 10 minute period to the next. For example, I am able to talk quite normally for a short period of time about half an hour after I've eaten my evening meal. Yet if anyone tries to talk to me even 5-10 minutes before that time, my speech is slurred, I am sometimes quite vague mentally, and even speaking a few words leaves me feeling very ill for an hour or more afterward. Even a few minutes either way can make an enormous difference in M.E. with different tasks and abilities.
- Your ability levels can also change from one minute/hour/day/week etc. to the next without warning if you have M.E. One day you might do a particular task with no problems at all yet you might be unable to complete the exact same task a few days later, or even a few minutes later. Just because you've done something one minute/hour/day, doesn't mean that you'll necessarily be able to do the same task again anytime soon; your ability levels can wax and wane constantly with M.E.
- Because of the way M.E. is always waxing and waning, you can't really commit to anything with any confidence even a few hours ahead of time, let alone days ahead of time. You just never know how ill you'll be in a few hours or days time, or how disabled you'll be then. Things can change so much in a few hours with M.E. It can be –and very often is – so unpredictable and unstable, just constantly.

The same way that M.E. isn't stable from one hour or day to the next, it also isn't stable from one week or month to the next. You can be fine one week, doing slightly better than usual even, and then suddenly you can become very ill or one symptom (or more) will become far more severe for the next week – even if you've been resting enough and doing everything right. You have good weeks and months and bad weeks and months sometimes, and you can't always predict which one you'll get, the worsening of the severity of the illness isn't always overexertion related; the illness also waxes and wanes a lot for no discernible reason. You often can't really commit to anything with any confidence even a few days or weeks ahead, you just never know what state you'll be in or what severity of illness you'll be dealing with a day or a week later. (Which makes arranging medical appointments and so on very difficult, as you can probably imagine. People with M.E. are very often forced to cancel plans they've made which can be really frustrating for everyone involved.) Things can change so much in a few days, or weeks, or months.

M.E. can be unpredictable and seem to have a mind of its own a lot of the time, and then you also have the severe ups and downs caused by overexertion to deal with. The severity of M.E. also waxes and wanes depending on your activity levels, and how much you have overexerted yourself recently. The levels of activity/input you can cope with, and the severity level of your illness, changes minute to minute and hour to hour depending on how much you have been overexerting yourself in the previous minutes, hours, days and so on. You can be feeling relatively okay one minute and then WHAM! you're suddenly hit with a massive worsening of a lot of different symptoms because of overexertion, or the delayed effects of overexertion.

With M.E. you can also sometimes use intense periods of rest before tasks to let you do something that would usually be outside your ability limits, at least for a short time. (The function of this period of intensive rest is that it allows you to be far more capable of calling up a huge surge of adrenaline than you might be otherwise.) For example a few years ago the amount of activity I could sustainably do each day was about 10 units (this being roughly 10% of my pre-illness ability level). Making it to a doctor's appointment required at least a 30 activity units however, yet I still managed to make those appointments for a number of years. For 2 weeks before the appointment I would only let myself use up around 5 activity units a day so that by the time it was the day of my appointment I'd be well rested enough to push myself to make the trip by calling up a huge surge of adrenaline. I would probably look fairly normal during my consult (compared to usual), but by the time I was being driven home the adrenaline would be starting to wear off and I'd begin feeling very ill. I'd then spend the next month recovering from the trip; I'd be much more ill and much more symptomatic than usual and only capable of about 3 activity units a day. After about a month I'd finally get back to my 10 units a day baseline. (Or at least that is what happened at first, after a while though I no longer did fully recover, I'd only get back to a baseline of 9 units, then it was 8, then it was 7, and so on, until after a few years I was too ill to push myself to go to see my doctor anymore, as I had made my base level of illness far more severe.) So it took me 6 weeks of my life and a very long painful relapse – and a worsening of my overall base level of illness over time – just to attend one half hour appointment. But all my doctor would see was that during the half hour I spent with him I looked, if not well, at least easily able to handle making the appointment without difficulty. This is a perfect example of how superficial judgements based on appearances can be so completely misleading with M.E.

Sometimes you can also call up a huge surge of adrenaline not by resting beforehand but by being put in a situation way beyond what your body can cope with (ie. putting your body in physiological difficulty). For example, a trip to the emergency room may be too much for your damaged body to cope with. It might make you feel unbelievably ill or even as if you might die. Things might get steadily worse and worse until your body is suddenly forced to release a huge surge of adrenaline just to cope. The adrenaline soon makes you feel a lot better, maybe even better than you've felt for a long time in some ways. (Which of course may often be misinterpreted as a positive sign by ignorant or misinformed emergency room staff, unfortunately.) But when the crisis is over and you return to resting, the adrenaline rush soon wears off – as it must – and you are left far more ill than before for days, weeks, months or longer. You might also not return to your previous base level of illness at all, or it might take many years to do so.

Adrenaline surges can last 5 minutes, an hour, a day or even a week or more. Some people with M.E. can sustain a low level adrenaline surge for several months before they crash. (Students with M.E. for example may be able to push themselves to just barely manage a 10 week school term, and then spend the mid-term break completely collapsed and extremely ill. I did this for several years, until one year I just didn't recover from the collapse at all.) Other sufferers may avoid long periods of running on adrenaline, but may need to use adrenaline surges to be able to do several smaller tasks in the day. It varies a lot from person to person. How much someone can operate beyond their limits thanks to surges of adrenaline varies significantly from person to person and can also change over the course of the illness depending on how much you have overexerted yourself in the previous months and years etc.

(The bursts of adrenaline produced in M.E. in response to physiological difficulty aren't anything to do with being anxious by the way. You feel calm and stronger and healthier than usual and you can do a lot more when you have an adrenaline surge, it isn't about feeling anxious or having a panic attack. Many of your bodily systems are working at their peak; so it can make you feel quite good, quite well. When you have M.E., these adrenaline bursts can mask some of your pain and symptoms to some extent, so that sometimes you feel better than you have for a long time, maybe even years. This 'improvement' can be so marked that sometimes M.E. sufferers mistakenly think that it means they are having a remission – at least until it wears off and leaves them far more ill than previously. Finally having a little spark of hope that finally your illness is improving and then suddenly not only having this hope snatched away again but also ending up far sicker than you were in the first place can just be devastating emotionally, as you can imagine.)

This ability to harness surges of adrenaline (to a certain extent) is a useful ability in some ways as it allows people with M.E. do things we would otherwise never have been able to do, and also to get through some very tough times without just dropping dead. (If cardiac insufficiency is severe enough, death is the result). For a certain period of time you can use adrenaline surges to get you through things and to artificially raise your ability levels for short periods of time, but you can't go on doing so indefinitely. After a while it just doesn't work anymore. Your relapses get worse and last longer and longer until finally you stop bouncing back to your previous base illness level and you become permanently more ill. You pay many, many times over for any small short-term gain so that in the end you'd have been able to be far more active all up (and far less ill and disabled) if you had just stayed within your limits in the first place. For example, with the trip to the doctor that I described earlier the amount of activity units I would have been able to do in those 6 weeks if I had stayed within my limits the whole time would have been up around 450. But that one day of overexertion reduced the amount of activity units in those 6 weeks to just 190 – plus I spent a whole month far more ill than usual and caused a worsening of the base level of my illness over time. It just doesn't pay to push yourself to do things beyond your limits with M.E., either in the short term or the long term.

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

Most importantly, because the worsening of the illness caused by overexertion very often does not even begin until 48 or more hour afterwards 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](#).

- M.E. is very unstable, but it can become somewhat more stable over time in some sufferers. For me, I started to see some small signs of this happening to me after about 10 years, thankfully. My illness is still very unpredictable now, but markedly less so now than it was initially (although my relapses from overexertion are the same as ever).
- *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).
- There is also a waxing and waning of the *physical signs* of M.E. throughout the day, as [Dr Hyde](#) and [Dr Jain](#) explain, “A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day.”

#### **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.

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

Sometimes there is a significant worsening of symptoms evident at the time of overexertion, and sometimes these symptoms are so severe and disabling that they force you to stop what you are doing and rest immediately. At other times, by the time you can feel even a minor worsening of particular symptoms, you will know from experience that you have really overdone it and are in for a very severe and prolonged relapse of symptoms over the next few days, weeks, or months or longer. (The minor worsening of symptoms evident at the time of overexertion would be very easy to push through a lot of the time, but people with M.E. often know from experience that to do so would only be counterproductive and very STUPID, as you would pay a huge price for doing so in the days, weeks, months or even years to come.) Sometimes there are no acute symptoms at all and the first time you realise that you have overexerted yourself (and that you didn't actually 'get away with' what you were doing like you thought you had) is 8, or 24 or 48 hours afterward when you suddenly get hit with a severe worsening of your illness, or your cardiac problems, or whatever else. Sometimes you will get both severe acute and delayed symptoms. It varies depending on the type and severity of the overexertion involved.

- *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. Overexertion can also cause a worsening of the base level of illness in M.E. and so the effects of overexertion can also be semi-permanent or permanent. Death can also occur due to overexertion in M.E.

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 types of fatigue syndromes – including post-viral fatigue syndromes caused by mononucleosis/glandular fever and so on – and not authentic neurological M.E. patients. This significant delay in the onset of post-exertional symptoms is simply not seen in those illnesses causing fatigue (etc.) after exertion. Nor do the effects of overexertion very often last for weeks, months, years or permanently in people with these various fatigue syndromes as they do with M.E. sufferers. Nor do these patients have anything like the same severe negative effects (exacerbated cardiac insufficiency etc.) from orthostatic stress and sensory input that are seen in M.E. There is also not the same risk of overexertion leading to death in these other illnesses, as there is with M.E.

(The term 'overexertion' in the context of M.E. very often refers to the most minor and trivial of activities. Even very small levels of physical and cognitive activity, sensory input and orthostatic stress can have devastating effects on M.E. sufferers over time. Again, this is simply not the case with these various fatigue syndromes (etc.) which may commonly be misdiagnosed as CFS.)

**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. What this means is that 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. (That is what happened to me; I'm still paying for ignorant advice to be as active as I could and to push through my symptoms as much as possible *12 years later* for example. See section J for more information.) 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.) In addition to the risk of relapse, permanent damage (eg. to the heart), and disease progression, there have also been reports of sudden deaths in M.E. patients following exercise. As M.E. expert Dr. Elizabeth Dowsett explains, '20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise. Prompt recognition and advice to avoid over-exertion is mandatory.'

- 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.) 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 important new research.
- *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. Graded exercise *cannot* improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E.

**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. (The supposed evidence for this theory is far from convincing at this stage, and has been widely criticised for being significantly flawed and biased.) But what is certain is that it is completely inaccurate with regards to patients with authentic Myalgic Encephalomyelitis.

Increasing the activity levels of someone with M.E. beyond their individual limits, can only ever be counterproductive. It really doesn't matter if you do this gradually or all at once. 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, Q fever or hepatitis, or any other common infection. Nor is M.E. a psychological or behavioural condition. Authentic M.E. cannot be improved through psychotherapy or graded exercise therapy. These theories have been comprehensively disproven many times over with regard to authentic M.E. patients (as have the many other similar theories; see below for details). M.E. is a chronic illness which affects the vast majority of sufferers for many years or decades at a time, or for the rest of their lives. A person who has been correctly diagnosed with M.E. will naturally raise their activity levels when/if they have had an improvement in their illness – but it can never work the other way around.

- Despite popular opinion, there is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' illness or not, or whether or not it has a biological basis. A large body of scientific evidence spanning over 60 years exists to show that it is simply not possible that somatisation, secondary gain, malingering, aberrant illness beliefs, too much focus on normal bodily sensations, irrational fear of exercise leading to deconditioning, being rich and white, being poor and from an ethnic minority, being lazy and unwilling to work, being too highly driven and perfectionistic and working too hard, faulty thought processes, lack of motivation, long-term stress, acute stress, abuse in childhood, a genetic inability to deal with normal levels of stress, inadequate coping strategies and contagious sociological hysteria – or any or the other ridiculous and often contradictory 'theories' put forward by vested interest groups – play a role in either causing or perpetuating authentic M.E. Evidence that M.E. is a distinct, infectious and organic neurological illness has existed since the 1930's and 1950's. 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. (So the continuing disability is entirely the fault of the patient for being either too highly or too poorly motivated to get themselves well, supposedly. This type of contradiction and lack of logic is fairly typical of the 'CFS' research produced, incidentally.) 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. There would seem to be at least four different causes (or exacerbating factors) of symptoms and disability in M.E.:

1. There is a base level of illness which is always present (caused by the acute damage to the brain, the muscles etc.)
2. The severity of the illness, and your ability levels, also fluctuate constantly from one hour/day/week and month to the next because of the waxing and waning nature of M.E.
3. The severity of the illness, and your ability levels, can worsen if you've gone past your individual physical, cognitive, sensory or orthostatic limits (ie. if you have overexerted yourself.) In the short term overexertion causes a worsening of symptoms, over time the base level of illness and disability is made more severe by continued overexertion. (For some patients these metabolic symptoms are also present at rest.)
4. Symptoms can also be worsened for other miscellaneous reasons (eg. being woken up early, not getting enough sleep, exposures to certain chemicals or mould, getting a cold or flu, not avoiding foods you are intolerant of or allergic to, drinking alcohol, and so on.)

But even those symptoms which are caused by the metabolic problems of M.E. (etc.) do not always resolve with rest. For severely affected patients, just keeping the body going at the lowest possible level can count as 'overexertion' unfortunately – not only can the bodies of these people not cope with extra activity, but they also cannot even cope with keeping the bodily systems and organs going at the lowest possible level – at rest. Because of course even when we are resting as much as we can be; our hearts have to keep pumping, our lungs have to keep drawing air in and out constantly, our kidneys have to keep working, and so on. It takes a lot of metabolic power to keep all the complex systems in the body working, even at the lowest possible level. Forcing the body to do more work when it is already not coping with the most basic level of functioning causes these problems to become even more severe as the quality of function achieved across various bodily systems is lowered even further, but even at rest these same problems can be quite severe because of course so many different bodily systems never can 'rest.'

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.

For me, even if I rest as much as I can my symptom severity level is still at around the 6/10 level (including cardiac problems, pain, seizure-like episodes, headaches and so on) and I still suffer with a whole host of different cognitive problems and am quite cognitively impaired in a lot of different ways as well. If I overexert myself I make these problems a lot worse of course, but they are still quite bad even when I am at rest unfortunately.

**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.'

Patients with M.E. must be allowed to determine for themselves a level of daily activity which is not needlessly restrictive, but which is also sustainable in the long term without causing a worsening of symptoms or disease progression (and which also holds back a small amount of ability to cope with occasional unplanned or unavoidable overexertions, to prevent these from causing significant setbacks). People with M.E. must also be allowed to determine for themselves how much rest they need. Giving people with M.E. the support they need to limit their activities in this way is actually the best way to ensure that we each get to be as active as possible in the long term (which benefits individual sufferers and their families, as well as our whole society).

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. Engaging in even low levels of physical and cognitive activity, sensory input and orthostatic stress beyond your limits can have catastrophic and very long-term consequences if you have M.E.

- Because of the waxing and waning nature of the severity of M.E., daily activity limits also need to be very flexible to accommodate those random (or overexertion related) worse than usual hours/days/weeks/months etc. It is essential to impose activity limits on yourself when you have M.E., but this is much easier said than done – as anyone who has M.E. will tell you. It is a constant battle between deciding how much you can do and how much you need and WANT to do, and having to constantly readjust your activity levels to suit the fluctuations of your illness, and so on.

Resting does NOT always come easy when you have M.E. either! Sometimes all you can do is rest (for hours or days or weeks at a time or more), you are just too ill for anything else. But at other times it's far easier to push yourself to do more than you should, at least in the short term, than to miss out on so many things. (This is especially true if you are very severely affected; you just have to do some things that are beyond your limits to make life worth living still in some way, very often. Even if speaking a few words does make you very ill afterwards, that is just what you have to put up with because not talking to your family for a month or a year is even worse, for example. When you have very severe M.E. it becomes about deciding what is worth relapsing for and what isn't, sadly, and how sick you are willing to make yourself to have some very basic comforts, or necessities.) Getting adequate rest with M.E. requires a lot of discipline and a lot of sacrifice too, certainly in the short term (and it must be remembered that the limits imposed by M.E. can last many years or decades, or the rest of your life.)

Resting is also really difficult because it stops you being able to have any distraction from the pain and other symptoms. I feel like I could cope with my illness so much more easily if I could just spend my day DOING things, anything, just to be able to have something else to focus on except the pain etc. like people with just about every other illness can (every day I think that same thought!) It is very unpleasant to just have to lie there in a dark quiet room having to really feel every bit of your pain with no distraction. (You even have to be very careful with how much you let yourself think!) The problem I have with low-level seizures, with feeling 'wired' also makes resting very difficult. It makes me feel extremely UN-fatigued and not at all calm and restful or sleepy. I very often wish I had some 'fatigue' I think it would make all the resting I have to do a lot easier. (Which is exactly what happens when I get the flu and get a lot of fatigue from it – it is quite nice, and a welcome change.)

- Setting activity limits in M.E. is a complex and intuitive task; it is ridiculous to suggest that these limits could ever be correctly set by any third party. (Especially one with a hidden agenda of gradually increasing activity levels because they've been taken in by the flawed 'science' involving fatigue patients who do not have M.E. improving with graded exercise programs.) Only the patient is capable of judging when activities can be increased or when they need to be further reduced. Patients with M.E. are universally very highly motivated to regain as much of their lives as possible, it is a far bigger problem that people with M.E. push themselves to do too much rather than not enough. I have never met or read about any person with M.E. who was not willing to do the things which they were well enough to do. It's just human nature not to want to be any more disabled, dependent and socially isolated than you need to be, trust me! (Not wanting to have severe M.E. any more is very highly motivating, to say the least; ask anyone who has it.)
- 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. there is still a desperate need for research to be done into actual treatments for the disease.) Whilst there is no cure as yet, or treatments which can dramatically influence the course of the illness, (due to the appalling lack of funding into research); intelligent nutritional, pharmaceutical and other interventions can make a significant difference to a patient's life. Appropriate biomedical diagnostic testing should be done as a matter of course (and repeated regularly) to ensure that the aspects of the illness which are able to be treated *can* be diagnosed, monitored and then treated as appropriate. Testing is also important so that dangerous deficiencies and dysfunctions (which may place the patient at significant risk) are not overlooked (eg. hypothyroidism and hypocortisolism). Thus while avoiding overexertion is essential for people with M.E., it is not appropriate for people with M.E. to just be told to rest and to not be offered any other medical care. It is also not appropriate that no money be put towards researching legitimate treatments for M.E. there is a desperate need for such research.
- As Dr Ramsay explains, 'Aggressive rest therapy' may also provide an even greater benefit in the acute stages of M.E. than simply avoiding overexertion. (It may also be helpful at later stages of the illness, depending on the severity level of the illness. For some chronic M.E. patients there is a real need for this type of rest and a real benefit to be had from it, it varies from patient to patient.)
- 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](#). (This paper also includes links to many different patient accounts of the effects of overexertion on people with

M.E.). If you have M.E. see [Treating Myalgic Encephalomyelitis - The Basics](#) and [Treating Myalgic Encephalomyelitis - Avoiding Overexertion](#) for more on the importance of avoiding overexertion.

**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.**

For very severely affected M.E. sufferers there is virtually no ‘safe’ level of physical or mental activity, orthostatic stress or sensory input; no level which does not produce a worsening of symptoms, and perhaps also contribute to disease progression.

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 such patients. It is not uncommon to hear of very severely affected sufferers who are unable to bathe themselves (or even be bathed by a carer) more often than once a week, or even once every few weeks, or even less. Some sufferers cannot chew or swallow food any longer and need to be tube fed. Many patients with severe M.E. are no longer able to toilet themselves, and so on. 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.’ It really can be 10/10 pain and just utterly unbearable. So when you are this severely affected you very often just have to lie there having to feel extreme illness and pain without any distraction from it at all, for hours, days or sometimes months on end with no let up, with not even a minute or a second of respite. Even the smallest movement, thought, touch, light, noise or period upright etc. can make your already very severe symptoms far, far worse.

Few illnesses demand such isolation and loss of quality of life as severe M.E. Severe M.E. can leave sufferers for months, years or even decades at a time; completely and utterly alone in a private agony – children, teenagers and adults alike. When you are at your worst, at your sickest, you are least able to physically tolerate getting basic personal care, medical care or even any type of emotional support from friends, family or fellow sufferers – very often people with very severe M.E. can barely communicate at all. This is what makes M.E. such a cruel disease and such an isolating disease, and such a ‘living death.’ 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 (50% of severe sufferers have no contact with the health system at all), 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 (with some notable exceptions) etc. The unethical involvement of vested interest groups in what should be a purely scientific discussion has caused an extreme level of suffering in many tens of thousands of already very disabled and vulnerable people all over the world for more than twenty years. 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. These appalling human rights abuses will continue to occur until our governments are forced to treat people with M.E. based on the existing scientific evidence, and not the false notion that M.E. is a psychological ‘fatigue state’ or is the same thing as ‘CFS.’ The disease category of CFS must be completely abandoned. The only groups which gain from this ‘CFS’ confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government. 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 don’t believe there is any such thing as a ‘perfect’ case study of M.E. (and I’m certainly not presenting myself as such) but everything I’ve read does tell me that I have a fairly typical and unremarkable, ‘textbook,’ case of M.E. – as do almost all of the other M.E. sufferers I’ve read about or met. (Although I may be somewhat more severely

affected than the average sufferer at present, and of course not every M.E. sufferer is able to put together a website like mine.) 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](#)

Additional clarifications and acknowledgments:

- 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](#), [Putting research and articles into context](#), [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.
- 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.
- 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.
- 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. Today patients with all sorts of different illnesses are commonly misdiagnosed as having 'CFS.' Under cover of the bogus disease category of CFS, this diverse mix of patients are treated as if they each suffered the exact same specific illness. This is clearly unscientific, and unethical. These patients must be given the opportunity to be diagnosed correctly if they are to have any chance of appropriate treatment or recovery, not given a meaningless 'CFS' misdiagnosis. Patients with M.E. need this same opportunity. Treating this diverse and heterogenous patient group as if their illnesses each shared the same symptoms, aetiology, pathology and response to treatment is inappropriate and highly unlikely to benefit the health and wellbeing of any of the patient groups involved. Physicians who diagnose 'CFS' in any patient experiencing new onset fatigue without looking and testing for the true cause of the symptoms do their patients – and themselves – a great disservice. Many of the conditions commonly

misdiagnosed as CFS are very well defined and well-known illnesses and very treatable – but only once they have been correctly diagnosed. Some conditions are also very serious or can even be fatal if not correctly diagnosed and managed, including Myalgic Encephalomyelitis. Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible. A correct diagnosis is half the battle won. 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) and why a diagnosis of CFS based on any of the definitions of CFS is always a misdiagnosis (and should never be accepted by a patient as the end point of the process of diagnosis), see: [Why the disease category of ‘CFS’ must be abandoned](#), [The misdiagnosis of CFS and Smoke and Mirrors](#)

- Lastly, a big thank you to all those fellow M.E. sufferers who offered me so much positive and insightful feedback (and enthusiasm) as I was writing this paper.

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**Disclaimer:** The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

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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Taken from [www.hfme.org](http://www.hfme.org)



- 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 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.