

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 day in the life of severe M.E.

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Taken from www.hfme.org



At the time of writing this, I was 28 and had had Myalgic Encephalomyelitis (M.E.) for 9 years. I based this account on an actual day I had at that time and although it's a notoriously unstable illness, not just from day to day but from hour to hour as well, it was an accurate snapshot of my life at this time, an average day in my life.

....I become conscious not all at once but gradually. Immediately though, I am aware of an immense burning pain in my throat, eyes, head and legs. For a long time there is very little of my consciousness that isn't just pain, it's all I am aware of. I try to move but nothing happens except I begin to feel sort of like the room is spinning around me. I feel my eyes roll back into my head and so I close them tight willing the spinning and rolling to stop so I can get out of bed. I become unconscious again.

This happens two or three more times.

I become conscious again some time later feeling much the same as before but a little more aware this time, able to think a tiny bit more. I try to move and find I can't. I can move only my eyes and only for very short periods and with extreme effort and they still keep intermittently rolling back into my head (nystagmus). I'm caught in alternating waves of vertigo and pain.

This paralysis, vertigo and pain lasts for about an hour and a half and I am conscious the whole time just lying there unable to do anything and feeling just horrible. As usual I've also woken up bathed in sweat and very hot and I am desperate to throw my blankets off, but I can't move at all even to do that. I just lie there getting hotter and hotter.

Very slowly the paralysis lessens, I become more alert mentally and my awareness of my body increases, bringing stronger, sharper, and more well defined pain with it, especially the glands in my throat - they feel like soccer balls about to explode. The urge to urinate that I've been trying to ignore for the last hour or so becomes impossible to ignore (any longer than I've been forced

to already) and so I move out of bed in one quick (but nevertheless painful) movement and feel the world roll backwards and sideways to meet me.

It takes a few moments to work out where my legs are and how to move them and then I shuffle stiffly to the toilet, eyes half closed against the painful sunlight that streams in through a nearby window, arms out slightly as I feel always on the verge of falling, touching the walls for balance, bumping into them as I go, sometimes quite painfully. I've lost that sense of where my body is in space and am always misjudging things, I always have bruises.

Trying hard not to pass out on the toilet, I lean right forward and breathe slowly trying to think of other things. My heart struggles to pump as I get up, it races and then beats very forcefully for a bit and then sort of starts beating in a deformed kind of slow motion. The beats are just all wrong. It feels like there's no blood or oxygen getting to my brain. I shuffle slowly to my permanently darkened day room where I lie down and pull the blanket closely around my body as I start suddenly to feel very cold. An hour passes, in room spinning, head-hurting pain with only the most simple of thinking processes going on. I'm conscious, but my body isn't working very well, which makes thinking physically impossible - the brain is merely another organ after all. I think thoughts like "hurts, cold, heart isn't working right, dizzy, stop, want to be sick, you will get through this just hang on". It takes about an hour to recover from the exertion of the toilet trip.

Slowly the urge to eat becomes larger than my nausea and I ask my mum (by intercom) if she'll make my usual eggs (which I hate with a passion but are one of the rare foods that I am not intolerant of in some way). The eggs are brought to me (with a concerned smile, which I return) and I look at them wishing that were all I had to do with them, they repulse me so much. I have no idea how I'm going to get them down let alone keep them there for long.... I lean over and grab a remote and turn the TV on to help me to mentally block out the taste of the eggs and to extend my attention span so I don't just eat a mouth-full and drift off into vague thoughts for half an hour. I barely look at my plate, instead I focus as hard as I can on the TV and usually I can sort of trick my body into eating in this way.

After eating I feel very, very ill. I lie still and immobile from the effort of eating, my jaw aches, as do my hands and arms and I try hard not to think about the eggs I've just eaten lest they come back up. The eggs do very little for my steadily increasing hypoglycaemia and after about a half hour the slow thinking, dizziness and feeling of falling that is low blood sugar becomes so strong that I know I must attempt lunch, so I press the intercom buzzer by my bed again.

Lunch arrives with a few nice words from mum; she always has something funny or interesting to say to keep me going. I have to put my hand over my eyes as she speaks as her movement makes the room spin and I feel unconsciousness pulling at me again. The stimulus is just too much for my eyes and brain this early in my day. My body craves complete immobility, silence and darkness. I smile in reply, grateful for the words but unable to speak at all myself. She leaves the room quietly. Before I can think about it too much I start to eat the already cut up steak and the mushy coleslaw. I eat lying down almost completely flat so that my heart can keep the blood pumping into my brain as I eat. (I have to lie completely flat very nearly all of the time actually for this reason). Again I turn the TV on to distract my body and brain from the food I'm eating and the pain that it's causing to eat it. I barely look at the food, instead concentrating as hard as I can on the screen, pushing though the pain and weakness I feel in my jaw, hands and stomach. With a sense of great relief I finish the last mouthful.

The edge has been taken off the hypoglycaemia by what I've eaten, but it will be hours before I feel the full effects (if at all), my body is so slow to raise my blood sugar. I feel completely mentally paralysed as well as physically, all the concentration, tricky strategies and positive thoughts needed to persuade my body to do the things I need it to do and to just keep going are difficult and make me even more ill in themselves.

I take that mornings scheduled medications and then I slowly sit up and stagger again, even more slowly this time, to the toilet and back. My heart beats strangely all over again as I gratefully lie back down flat in bed. It takes about an hour for it to return to anywhere near normal again. I feel pretty vague again during this recovery time, just completely ill in every way.

After a while, despite the blanket and the warm food I've just eaten I also start feeling steadily colder and colder. I pull my thick blanket tighter around my neck and turn my heater on from my bedside. I start to shiver slightly. The shivering intensifies and I start to really shake with the cold. The coldness feels like it is right in my bones, like they are made of ice. I start to feel sick to my stomach; my flesh feels starts to feel warm and feverish while my bones get colder and colder. It feels like my hot flesh is about to melt off my freezing cold bones - it's a really horrible feeling. I instinctively curl up in a rigid ball trying to reduce my surface area and warm up. I become unable to move at all, my body is so rigid and I am so cold, my thoughts become very slow and confused, I feel a feverish sort of delirium, my teeth chatter and then my eyes roll back into my head as I become unconscious.

A couple of hours later I wake up completely covered in sweat. After a few minutes spent working out how to move and where my arms are and stuff, I throw my blanket off and turn off the heater, then lie there completely still, unable to think or move, just lying there. A few moments later I feel my breathing become very shallow, like my lungs are not expanding as much as they should, or like my body isn't getting the oxygen into the bloodstream somehow. I sit bolt upright (painfully) in fright and the change of position seems to help thankfully. I lie down once more and it happens again until I eventually work out exactly how to lie in a way that (although very uncomfortable) lets me breathe enough, though it still doesn't feel (and indeed isn't) quite right.

After some time has passed I discover with some relief that I can breathe again without problems regardless of my position. I then put on some soft classical music by remote control, to give my brain and mind something nice to focus on. It does the trick, and slowly I am able to think a tiny bit, intermittently anyway. I try not to dwell on all the bad physical stuff, instead thinking of happier topics or finding small shreds of amusement in elements of my situation with some pretty black humour.

After an hour or so I feel like I have finally woken up for the day and I walk slowly back to my bedroom to change out of my sweaty nightwear and get dressed for the day and then I decide to search out mum or dad for a short chat; just about simple things, nothing I have to think about too much. If the chat is light and superficial enough (as it is today), I can fool myself for a bit that I'm okay, and have a fairly normal conversation for a short while. Today they are both in the kitchen and both more than happy to talk to me.

They are always really glad to see me up and talking, they worry about me so much I know, so this short chat probably does them almost as much good as it does me. It reassures us all that I am not as bad today as I could be. We always find something to laugh about too, which is something I really love about my family (especially my sister). After a few minutes though my brain stops working and I am unable to speak anymore, my body becomes wobbly and faint and I need to go back and lie down again by myself in my dark room. My heart races and the room spins for awhile until I recover from the talking and sitting up. It doesn't take too long thankfully. I make myself a protein shake and then I watch a bit of TV but I don't really take anything in. I decide I'll try to maybe read for a while, perhaps the fantastic book I started yesterday about...

....SUDDENLY A DEAFENINGLY LOUD NOISE ERUPTS INTO THE ROOM...

.... Instantly my thoughts dissolve into nothingness and the world drops away, no longer beneath me. I am surrounded by nothing but pain. A tidal wave of it crashes over me and I forget who I am. There isn't room for anything but this pain. There is no thought, no words, no sense of self at all. Time is suspended. This is just more pain than anybody should have to go through ever. It feels inhuman. I feel inhuman.

I can't remember anything I've said or seen that day or much of what I've said or done 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. I also forget how to walk, talk and also to understand speech. Every cell of my body and brain just screams. For a few minutes I am in this state, in unbelievable agony but unable to work out what it is, who I am and what is happening, my brain is completely overwhelmed. I think loud noise can cause me to have some kind of seizure.

Slowly two words fight their way through the swirling pain... "Make stop". It's primitive. I don't think them so much as feel them bubbling up primally 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 understanding the abstract concept of words at all.....I repeat them to myself until I realise that I must do something to make the pain stop. I lurch stiffly out of the room on legs that don't feel like my own, holding the walls for support, moving with jerky movements and much hesitation, running on pure animal determination and desperation, my eyes wide with terror, my heart beating erratically, all my thoughts going into each step forward. The noise becomes louder as I move further through the house and for a long moment I stop still, forgetting what I am doing altogether; the last thing I remember was watching TV, what happened I wonder?

I stare blankly for a few minutes trying to work it out then slowly a vague realisation comes back that I must keep moving and I lurch forward again, my task less clear now in my mind, but still urgent. Luckily my mum is home. I see her standing there in the kitchen and the first flicker of hope enters my mind fleetingly, she has her back to me. I'm aware as I get closer that my face is slack, my mouth open and my eyes are staring blankly but I can't move them at all. I try to speak and find my voice has gone, it's barely audible and unbelievably painful, but I push through it and manage to get out "noise...stop..... please!"

She turns around, looking frustrated, "your brother is just washing his truck with the high pressure cleaner" she says. My adrenaline rush has run out and I feel so ill I know I must lie down so I turn to go, feeling very confused. I can't

work out how this statement explains anything or is relevant to me in any way, but I accept it anyway and turn to leave.

I feel I will vomit so I stagger to the bathroom, on the way I catch sight of myself in the bathroom mirror, I'm white as a sheet, my eyes stare blankly ahead and my mouth is slack and slightly open. I don't recognise the reflection as me at all. I sit on the toilet lid feeling very ill but not quite ill enough to get the release of actually vomiting.... I lean forward and sit there uncontrollably shaking as I wonder what to do. I slowly 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. 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 solutions at all (except for this one unusable, unthinkable one) just more and more desperation and more and more unbelievable pain, with no way at all of stopping it....

Eventually the noise stops. I'm told later that it only went for 5 or 10 minutes, though to me it feels like about 3 days. I can't really remember much from before the noise either, or remember what it's like not to feel this way.

I can barely remember my own name, but worse than that, I struggle to remember *who* I am - what I like, what I think, things I've done, what's important to me, anything. Emptied by intense stimulus it can no longer cope with, my brain is completely unable to access all the happy thoughts I keep there, the memories that tell me who I am. The strong sense of humour that always keeps me going is lost, it's there but I can't work out how to find it, my brain is so confused. My mouth still gapes open and my eyes stare blankly, I can't make my face form normal expressions and I can't focus my eyes properly, it's all just slack muscles and the function of them is out of my control.

The noise has stopped but the awfulness doesn't go with it, my ears ring and my brain cavity feels hollowed out and empty but very shaky, still pulsing and vibrating horribly from the noise. My entire body is in shock. I feel catatonic, like I have just had the most enormous seizure that's irreparably damaged and completely reorganised my brain, changing who I am. I make myself lie down and put on a favourite comedy video, with the volume down very low. The only way to get over the shock is escapism. Immersing myself in a happy movie or favourite TV show on tape which I do for the next 3 hours or so, forcefully refilling my brain and mind with thoughts of happiness and normality and

trying to fill in the emptiness and the complete void that is my brain in extreme shock.

My mum comes in to see how I am and all I can hear is "waa waaa waaaa", I can't make out any words at all, it's like she's speaking Russian or something. I can understand the tone but that's all. It really scares me. I look at her face and am shocked to realise I don't recognise it either, but I gather from the tone and the clothes and things that it is indeed her. I try to look at her and convey thoughts of "I'll be ok eventually" (hoping to convince us both) but my face is still slack and as much as I try, I can't speak, all that comes out is "ughh". My lips won't form the words. I just look at her hoping she'll see from my eyes what I'm trying to say. She leaves the room.

After a few hours I start to get a sense of myself again and I am finally aware enough to realise what has happened. I feel hurt and then very angry that this has happened to me yet again. I feel stunned - all this for a clean truck, was it really worth it? Will the next 3 or more days of *extra* pain and suffering I have to endure be worth it? Don't I have enough unavoidable daily pain already? The truck will probably be dirty again within three days anyway. I don't understand how the people I love most in the world could think it was okay to let this happen to me, I feel an abyss open up before me, a profound sense of loss of hope, and a fear that I am without love, and that without that what is the point? I pull myself out of this feeling of hopelessness after a few minutes by remembering all the good things in life, the small happy things. I spend a few minutes thinking of as many good things as I can until I feel calmer and less hurt. I reassure and remind myself that my family *does* love me. I know for a fact they do, and that they are doing the best they can and also that I will always have myself to cheer me up when I need it and so I will always be okay, I will always be able to rely on myself.

I feel the inevitable hypoglycaemia return and so I manage to stagger to where my parents are to ask for dinner. They both immediately stop what they are doing and they each ask me if I am ok and I say "yes" but I know my eyes are kind of blank and my voice is weird so maybe they don't quite believe it but maybe it helps for me to say it anyway. I don't know but I hope so. Mum asks me if I need anything else or if there's anything else she can do, which is really nice but I can't think of anything really except for dinner so I shake my head (which makes me almost fall over) and then I turn to walk back to my room. Dinner arrives and I eat slowly and mechanically, lying down flat and with the TV on as always, then I take my second lot of tablets. I lie still for ages afterward recovering from the exertion of eating again.

I make another slow toilet trip, then spend an hour or so recovering from it. I put a pillow over my head to make the room extra dark and the weight of it on my head stops the vertigo a little bit too as well as blocking out some of the household and traffic noise. My heart pounds and my eyes feel like they're burned from all the TV (3 hours of it is way more than I can handle these days) and so I decide to have a late night bath. The heat makes my heart worse so I have to get out after only a few minutes. My eyes feel heaps better from it though. I get out feeling very wobbly and faint, it's really hard to lift myself out, but thankfully I manage it okay.

I lie down and the room spins and my heart beats really erratically. It feels like it's really struggling. I lie there for ages before I remember I have a tablet for that. I know getting up to get the tablet will make my heart worse but I decide to take the chance and so I get up to find the bottle, swallow one of the tablets with some water, and then go back to bed - my heart beating even more feebly than before.

I try to read for awhile but I can't really focus on the words. (Too much TV does strange things to my eyes). I have to keep changing the position I am lying in too or my muscles become stiff and painful but every time I turn over the room goes black for a few seconds and my eyes roll back in my head and I have extreme sensations of vertigo that make me want to hold on to the edges of the perfectly flat bed so that I won't fall off the edge. It's a really horrible feeling.

I keep on changing my position though. I roll over and the room spins and then I read a bit more, become stiff again and then I roll over again...completely forgetting each time that it makes me really, really ill and vertiginous. I do it again and again no matter how hard I try to remember to lie still, I just keep forgetting and the vertigo gets worse and worse each time. I feel like I have just about all the memory capabilities of your average glass of water and the thought depresses me almost as much as the vertigo attacks.

I sit up for a few minutes and rather dodgily put nail polish on my toes not so much for something to do but so that I'll have one positive thing to look at tomorrow, (holding my breath as I do it so the fumes don't give me a headache), something small to remind myself that the day wasn't a total waste and to keep myself going. I know I'll probably need it. I then make myself another protein shake.

I feel unbelievably ill but not at all sleepy, I haven't felt tired or sleepy for years.... Feeling ill is very different from being tired or sleepy. It's not the result of a busy day, and isn't helped by, or in itself, a healthy and relaxed state that signals the body to go to sleep so it can prepare for another day. What I'm

referring to when I use the word ill is a feeling like you have been poisoned, kept awake for three days and beaten up until you're black and blue all over - all at once. Lots of different bodily systems aren't working to the level they need to be for the body to function properly and that's just how it feels too, like the body is just not functioning properly. (*And it really isn't; serious problems have been discovered metabolically at the cellular level in those in Myalgic Encephalomyelitis, many other (in fact MOST other) bodily systems have also been found to be similarly severely affected*). M.E. is where you can't do anything but lie still because you are so very ill, but where the lying down and resting don't help at all. The body is not crying out for sleep or rest, but rather to be made healthy and whole again.

It's not that it is more severe than normal tiredness, (although it undoubtedly is), but it's more that it is something completely different to anything any healthy person has ever felt – ever. It is not actually fatigue or tiredness at all, despite the bad joke of a name sometimes wrongly used. It's anything but pleasant or relaxing and you just don't get that nice slow fuzzy sleepy feeling that's part of having a normally functioning body with it - ever. You just feel completely shockingly awful instead. Words can't describe it. It's a feeling I've had constantly, (to varying degrees) day and night, for years now....I'd give anything to be fatigued now and then in fact, I miss it.

I reach over and take some Melatonin. Half an hour later nothing has happened so I take some more. Again nothing happens so I put a meditation CD on by remote control, I can't focus long enough to really meditate deeply like I used to but it's soothing on some level anyway. I feel more relaxed mentally but my heart is still beating wrong and so I take another tablet. Then I lie there for 3 hours trying to sleep but it doesn't work, I'm still wide-awake as always. My joints have started to really ache too thanks to the stormy weather brewing outside (which always has this horrible effect on my joints since I became ill).

I'd love so much to be able to ring one of my friends right now, but even if it weren't 5am, I'm just not well enough to manage even short phone calls at all, it's one of the things I miss the most.

I decide to get up and go to the bathroom to wet my face and arms to cool myself down then go back to bed taking yet more Melatonin, but this time it works. I go from once more from completely alert to fast asleep instantly and sleep through what is left of the night....

.... Only to be woken by a loud noise early the next morning which starts the whole process off again... so much worse than before because this time I am

still very, very ill from the previous day and I also haven't slept anywhere near enough beforehand....

Severe Myalgic Encephalomyelitis is basically a living hell.

I am not the most severely affected by M.E. either. Far from it. One of my close friends has 5 times had to be resuscitated because she stopped breathing completely due to severe M.E., other friends are completely housebound and bedbound and need help with toileting and all personal care (they are unable to even brush their own teeth or feed themselves and often cannot speak or read or write or do almost anything except just lie there in a dark quiet room in agony) and others have died from the illness. M.E. is a neurological illness of extraordinarily incapacitating dimensions.

I'm also fortunate to have the support of most of my family; many people aren't so lucky due to the many myths and baseless propaganda that has been circulated about the illness (and accepted as uncritically as truth by many people unfortunately). I really have no idea how I'd cope without my parents, my sister, or the handful of amazing pre-illness friends I have that have stuck around or the great new (and also ill) ones I've met through my computer. I am very, very lucky in some ways.

This paper has taken me 8 months to write, on and off, bit by tiny bit. People need to know that those of us with M.E. desperately need so much more help, support, understanding and money for real research than we are currently receiving. (Government research funding into M.E. is currently 0\$ a year worldwide.)

I'd also like to add a quick but heartfelt THANK YOU to the wonderful people out there who helped me (and my illness damaged brain) so very much with the editing of this paper.

See the Case Studies page on the website to read many more personal accounts of life with M.E.

A note about Myalgic Encephalomyelitis: Myalgic Encephalomyelitis (M.E.) is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder with the code G.93.3.

M.E. can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. is similar in a number of significant ways to diseases such as multiple sclerosis, Lupus and Polio. M.E. can be very severe, or fatal.

It is very important to be aware that Myalgic Encephalomyelitis and 'Chronic Fatigue Syndrome' are not synonymous terms, and that 'fatigue' is not a defining feature of M.E. nor even an essential symptom of M.E. What defines M.E. is not mere 'fatigue' but a specific type of acute and acquired damage to the brain (the central nervous system) caused by a virus; an enterovirus.

'CFS' was created in the 1980s in the US in 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.* The fact that a person qualifies for a diagnosis of 'CFS' (a) does not mean that the patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' Every diagnosis of CFS – based on any of the CFS definitions – can only ever be a *misdiagnosis*.

The bogus disease category of 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various psychiatric fatigue states and various unrelated fatigue syndromes for the benefit of insurance companies and various other organisations which have a significant vested financial interest in how these patients are treated, including the government. This has meant that most people with M.E. are given no appropriate medical care at all. Many are simply left to die at home, alone. The decades of systemic abuse and neglect of the million or more people with M.E. worldwide has to stop. People with M.E. must again be treated ethically and based on the available scientific evidence. 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 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' 'CFIDS' and others) for the benefit of *all* patient groups involved. Knowledge is power. Please see: [What is Myalgic Encephalomyelitis?](#) for more information.

You may also like to read the new paper which lists the many medical similarities between M.E. and Multiple Sclerosis: [M.E. vs MS: Similarities and differences](#)

2006 update: It has been two years since I wrote this account and things have changed somewhat for me in that time. Many symptoms have stayed the same, a small number have improved and some have become much worse. Due to a less noisy living environment I suffer far less from the effects of sound sensitivity (which is fantastic!), but unfortunately my main symptoms now are cardiac and cardiovascular and are at least equally as terrible and scary in their own way. It seems my M.E. is continuing to become progressively worse and I am now completely housebound and much more bedbound than I was.

2008/2009 update: Finally, after thirteen years, it seems as if my illness is stabilising. I put this down to finally being able to rest as I need to due to finally knowing enough about M.E. to really appreciate how important this is, and

finally having the full support of my family. Certain medications I'm taking are also helping (see [Treating Myalgic Encephalomyelitis - The Basics](#) for more information on this). Having said that, I'm more housebound and bedbound than I have ever been right now, and as disabled in many ways as I have ever been. But at least EVERYTHING is not continually getting worse any longer.

I just hope so much I continue to improve way above the level I am at now so that life could become truly livable in the future; *at least* to 30% or so on my ability chart is the dream and to be able to live independently. I am much better than I was, but if I were to remain at this low level... I very much hope I don't have to remain at this low level forever.... It is just too much still to live with, with any real quality of life. My worst symptoms are still neurological, cognitive and cardiac/cardiovascular.

If only I could go back in time and undo all the damage I did to my heart and my body in the early stages of my illness. It seems to be permanent. You can pay for getting bad medical advice for the rest of your life when you have M.E. unfortunately. What is even worse is that every DAY more and more M.E. sufferers are still being given this same bad advice by ignorant doctors, and having their lives ruined just like mine was...or being killed outright. It is a human rights travesty. There just aren't words. *It's inhuman.*

(See the [About the author](#) page for more information on how I'm doing.)

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