

the **Fatigue** Cover-Up



- Since 2006 -

Stonebird

THE EXPERIENCE OF SEVERE MS

ME: the Fatigue Cover-Up

Greg Crowhurst

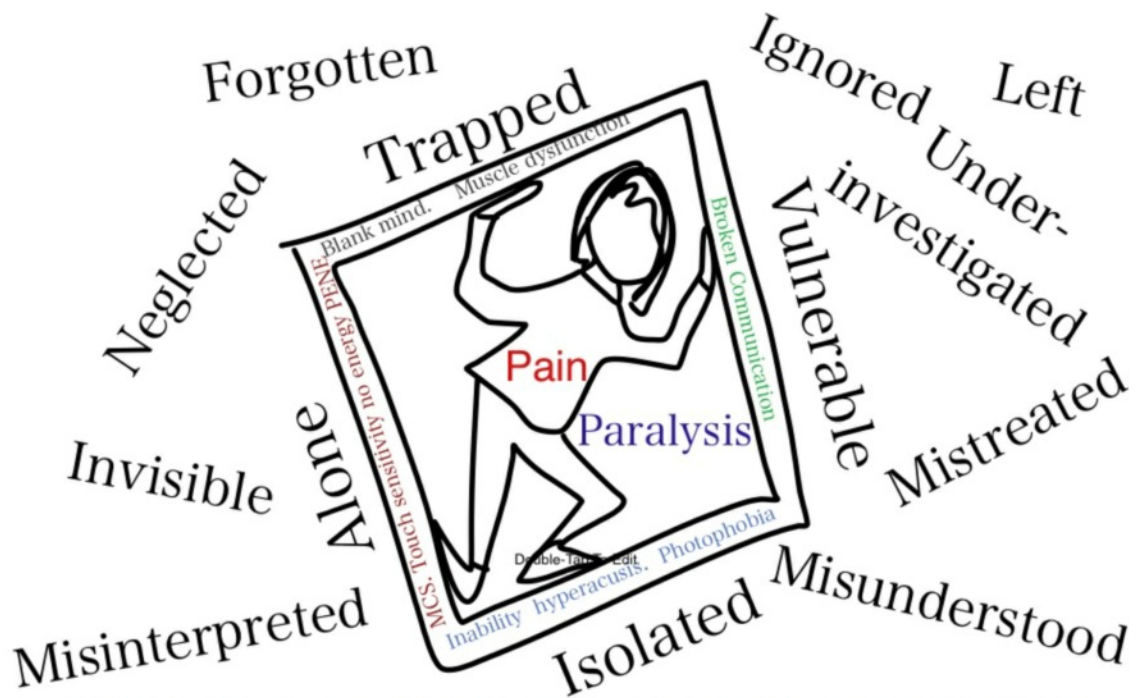
Disclaimer :

Please note that neither the author nor Stonebird
can be held accountable for any
damages or actions arising from this guide,
which is presented for informational purp-
oses only and is not intended as a substitute
for professional medical advice.

© Stonebird 2018



Thank you so much to everyone who responded to my question "What is ME?". This is dedicated with love, for your wonderful support and encouragement over so many years of struggle together.



With Severe/Very Severe ME, everything is cut off from possibility

The Fatigue Cover-Up

ME IS A MULTI-SYSTEM disease with many organ and bodily systems affected, producing a myriad of symptoms; it was the documented biochemical abnormalities in ME patients that led to the WHO classification of ME as a neurological illness.

Before the onset of ME many people enjoy a healthy lifestyle, however an infectious process caused by a virus, or a bacteria could trigger the disease especially if the person's neurological or immune *system has been compromised.* (Carruthers et al 2012)

The complex range of symptoms in ME include :

- Dysfunctional immune system. The illness starts with an acute, infectious-like episode in many people.
- Underlying intestine disorders– dysbiosis, gut permeability, reflux.
- Problems of oxidative stress leading to DNA impairment, impaired proteins and structures.
- Faulty mitochondria – shortage of oxygen and energy supply in body.
- Cardiac abnormalities, heart defects, heart not being filled completely, too little blood volume, poor blood circulation.
- Neurological abnormalities – with studies showing the grey substance or brain substance is reduced. Malfunctioning of short term memory, the recalling of words can be severely disturbed.
- Endocrine abnormalities leading to increased sensitivity to stress, from disturbance in the hypothalamic -pituitary-adrenal axis.
- Various muscle abnormalities, malfunction at the molecular level of the ionic channels.
- Central Nervous System involvement, suggesting immune dysregulation.
- Structural and functional brain abnormalities.
- Gene expression abnormalities.

- Sleep abnormalities.

(cf. De Meirleir 2013, Shepherd & Chaudhuri 2018)

Recently I asked on Social Media:

WHAT IS ME?

This is not as simple as it sounds. On Stonebird we are passionately committed to using the term Myalgic Encephalomyelitis or ME, however, the name, its system dysfunction and the symptoms that arise from having ME have all become confused, misrepresented and misinterpreted under the umbrella terms CFS/ME,/ ME/CFS, CFS and CF.

In 1956, Dr. A. Melvin Ramsay formally coined the name “benign myalgic encephalomyelitis”, to describe the 1955 Royal Free epidemic which affected 197 nurses, doctors and ancillary staff. (Parish J 1978, Acheson 1959)

At that time it was understood that ME, a “a paralytic illness of worldwide distribution ” (Acheson 1959):

- Follows a contagious epidemic and endemic infectious disease.
- Represents a diffuse Central Nervous and in some cases a Peripheral Nervous System
- Injury.
- Can be devastatingly painful.
- Is an illness that follows an infection, probably viral in nature.
- Is most commonly seen in (a) health care workers, (b) children and older students in residential schools, nurses residences and hospitals, (c) in military barracks.
- Has definite evidence of paralysis occurring in 50- 80 per cent of patients.

(cf. Hyde 2006, Acheson 1959)

A wide range of interpretations, however, is possible nowadays, even if you use the correct name, because a wide range of different criteria may be used to identify supposedly the same named illness and there is no specific test available to safely diagnose.

People with different illnesses poorly identified or missed, or deliberately included, may all be given the same name diagnostically, yet not necessarily have ME at all, including people with Lyme, people with uninvestigated rare diseases, people with allergies, people with unrecognised hypothyroidism and adrenal issues.

The situation is further confused by a call for subsets of ME with different symptom clusters, rather than different triggers, it seems. Originally ME was predominantly linked to an Enterovirus infection, now it appears to mean something much wider, hence the development of the Viral Protein 1 Test, now abandoned, under the influence of psychiatry. (Williams 2011)

Broadly speaking we suggest that there are at least three categories of “ME”, here in the UK:

- *The “ME Group”* who say that ME is Enteroviral.
- *The “ME/CFS Group”* who say ME encompasses a wide range of illnesses with the common denominator of fatigue, triggered by infectious agents or a toxic environment.
- *The “CFS/ME” Group* who say that ME is a psychiatric, somatoform disorder. This powerful group, unfortunately is still the dominant influencer.

Tragically this has created total confusion, resulting in a very wide pool of poorly diagnosed people, all with the understanding they have ME, but with very different conditions, needing very different responses and treatment pathways. This is further confused by the use of interchangeable names such as Chronic Fatigue Syndrome, Myalgic Encephalopathy, which gives people little hope of a way forward.

It begs the question:

Is ME a list of Symptoms or a list of System Dysfunctions, triggered by an infectious agent such as an Enterovirus or other viruses or wider still, does the trigger also include bacterial/parasite infection or wider still does it include Allergies or undiagnosed Thyroid or Adrenal issues or wider still, trauma including psychological trauma or mental health issues?

One thing is for sure, there is no biomedical treatment pathway for ME, here in the UK, but even if there was, until ME is better identified it would still be unsafe for some.

There is no cure. People ill for five years or more, have a poor prognosis for recovery. The most severely ill are left to cope as best they can. It concerns us how research, with notable exceptions, for example Chia (2005), tends to look at small aspects of the disease rather than studying the trigger subsets, at least that is our impression. It shows how even in the biomedical world there is a wide interpretation of what exactly “ME” is.

The NICE guidelines focus primarily on Fatigue, Pain and Sleep, as if they were manageable symptoms that represent the illness, with a recommendation for Cognitive Behavioural

Therapy (CBT) and Graded Exercise Therapy (GET) , for people with Mild or Moderate ME and Activity Management based on elements of CBT and GET for people with Severe ME, predicated upon the wrong premise that the illness is due to maladaptive thinking and deconditioning.

This travesty is due to the powerful influence of psychiatry in ME, despite patient outcry (Crowhurst 2018). The NICE guidelines are currently being rewritten. They will take 2 more years to come to fruition, yet NICE has still not withdrawn its unsafe guidance, known to make many people with genuine ME more ill. This is of huge concern.

It is in this context then, where the focus of the Scope for the new Guideline is likely to still predominantly be Fatigue, Sleep and Pain, that I looked for more information and recognition of the true symptoms of ME and people's actual experience of this illness, to see how far apart they are and how ME is misrepresented.

In particular I wanted to find out what in fact does the word "Fatigue" cover over, in terms of actual symptom experience?

My wife has had Severe, now Very Severe ME, for decades. She most certainly does not describe herself as fatigued or relate to "fatigue" as her primary symptom. We are concerned that the real symptoms are being covered up under the term 'fatigue' or simply ignored. We have found this to be true with my wife's most serious and debilitating repeated daily and nightly symptom: PARALYSIS.

So I googled "ME" initially on my internet search, but unless I entered the term 'ME/CFS', which NICE is going to use in its rewritten new Guidance, I could find little in respect of my question.

Then I asked on Social Media:

If you look up "ME/CFS" on the internet, just about every site lists the symptoms as "Fatigue, Pain and Sleep". I wonder is that YOUR truth?

There were many replies. First, here is a list of the symptoms that people say they are experiencing. They are a far cry from the diminishing term 'fatigue.'

Given the poor investigation, poor recognition of symptoms, the inadequate diagnosis, the different illnesses included under the umbrella term ME/CFS and the multiple criteria that may have been used, plus the poor testing and treatment of chronic Lyme disease and other

illnesses, the symptoms of which may overlap with ME, it is very likely that not every one who responded will have ME or they may have both.

Nevertheless my question is a valid one to ask, in an attempt to understand the wide separation between the term “fatigue” and the actual presentation of people who have ME.

These people are seriously physically ill, many house and or bed bound. The physiology of the disease has been poorly investigated, the symptoms go unexplained, as if they have no underlying physiological cause and this fans the flames of the misinterpretation of ME as psychological.

Meanwhile people suffer decades of torment and are exposed to medical ignorance if not outright harm.

These are the symptoms as described by those who responded.

Paralysis:

Total

Partial

Heavy limbs

Muscle weakness

Pain:

chronic nerve pain

Crushing pain

Global wide-spread pain

Muscle pain

Joint pain

Jolts of pain

Painful feet

Glandular pain

Sore throat

Hoarseness

Swollen glands

TMJ

Trigeminal neuralgia

Occipital neuralgia

Chest pain

Costrochondritis (inflamed chest wall)

Skin crawling sensations

Burning

Itching

Stabbing pain
Sharp pain
Aching
Skin pain
Vein pain
Inflammation
Severe Menstrual issues
Swelling
Inflammation
Severe Headaches
Migraine
Head pain
Neck pain
Tinnitus
Feeling of toxicity
Breathing difficulty
Respiratory depression
Air hunger
PENE / PEM
Cramps
Pins and needles
Tingling
Peripheral neuropathy
Tremor
Muscle spasms (shaking)
Twitching
Violent, uncontrollable 'tics' in limbs
Restless legs
Muscle wasting
Lack of strength
Hyperacusis (noise sensitivity)
Photophobia (light sensitivity)
Hypersensitivity to smells
Visual disturbance:
Staring
Inability to focus
Poor spatial recognition
Fuzzy/ blurred vision
Double letter vision

Tunnel vision
Eye pain
Dry eyes (do not hold tear film)
Itching eyes
Burning eyes
Flashing eyes (open or shut)
Seeing pinpoint of light in the dark
MCS
Drug sensitivity
Incontinence
Hyperesthesia (Touch sensitivity)
Movement Sensitivity
Motion Sensitivity
Nausea
Vomiting
Allergies (multiple)
Gastric issues
Swallowing difficulties
Choking
Acid reflux
Hypoglycaemia
Dental issues
Mercury intolerance (silver fillings)
Temperature control problems/ dysregulation (too hot or cold)
Sweating profusely
Temperature fluctuations
Heat intolerance
Cold Intolerance
IBS
Gut and bowel issues
Food allergy
Food sensitivity
Malabsorption issues
Weight loss
Oxygen depletion
Loss of sensation
Numbness
Loss of proprioception
Sinus problems

Extreme excess mucous
Severe anxiety
Sleep difficulties:
Lucid dreaming
Insomnia
Sleep disruption
Unrefreshing sleep
Sleep apnea
Nightmares
No restful sleep
Inability to stay awake
Hypnogogic jerks
Dizziness
Vertigo
Black outs
Lightheadedness
Low and/or high blood pressure
Heart issues:
Palpitations
Cardiomyopathy
Bradycardia (low heart rate)
Tachycardia (high heart rate)
Orthostatic intolerance
POTS
Dysautonomia
Loss of equilibrium
Loss of balance
Inability to stand
Inability to walk
Inability to sit
Poor/loss of co-ordination
Clumsiness
Raynaud's phenomenon (poor circulation in fingers and toes)
B12 deficiency
Endocrine dysfunction
Seizures
Unconsciousness
Cognitive dysfunction (brain fog):
An inability to follow conversation

Lack of ability to process information
Loss of ability to plan
Loss of ability to think
Loss of memory
Forgetfulness
Loss of speech
Slurring
Forgetting names
Not recognising faces
Word loss
Inability to understand
Inability to identify left from right
Switching letters round in words
Difficulty retaining information
Mental Confusion
Difficulty concentrating
Unable to hold two-way conversation
Not fully conscious
Unable to read
Unable to write
Inability to hold things
Inability to lift things
Sensory overload
Severe sensory issues
Loss of touch
Loss of taste
No energy
No strength
Lack of stamina
Disabling fatigue
Emotional lability
Compromised immune system
Repeated infections
Severe thirst
Dehydration
Excessive saliva
Mouth sores
Kidney infections
Flu-like symptoms

Crippling Exhaustion
Chronic infections
Slow recovery from colds/flu
Cysts
Skin rashes
Fevers
Shortness of breath
Malaise
Loose joints
Easily dislocated joints
Jumping at nothing
Hair Loss
Lichen planus
Vitamin D deficiency
Weight Gain
Weight Loss

The danger is that the long list of symptoms above can still, unintentionally, underplay their severity and seriousness, the totally disabling nature and the individual intensity of each one, which together add up to a *physical nightmare of indescribable proportion*.

Many of the people who contributed to the list are daily battered by a multiple, never-ending, overwhelming, symptom experience.

I therefore include below a fuller description of people's actual illness experience, in stark contrast to NICE's simplification of ME down to "Pain, Sleep and Fatigue". It gives a much fuller picture of the devastation of this illness.

These responses highlight two main areas of concern, one is how extreme people's symptoms are, the other is how they live in a world of medical denial:

1. ME is not fatigue, fatigue is just one of many, many symptoms and probably not even everyone's worst one. It's ridiculous that that's what's been latched onto by doctors about this illness, when time and time again I see posts like this and people respond with it lower down the list of their worst symptoms!! Clearly we are not being listened to.
2. Immune system dysfunction, flu symptoms, sore throats, swollen lymph glands, muscle malfunctions, activity exacerbating all my symptoms, temperature fluctuations,

cognitive issues.

3. ..being in this constant state of pain with no restful sleep.
4. I know the term muscle fatiguability was used by (I think) Ramsay in an early description of ME. That could also be interpreted as paralysis... muscle too fatigued to move. It's so much more than that though.
5. Pain, weakness, incapacitation in all areas including cognitive
6. Nightmares of being tortured because pain breaking into dreams.
7. Awakening Nightmare of pain.. almost 24/7.
8. Weakness, pain, shaking, noise & light sensitivity, soaring heart rate, cognitive difficulty, memory loss, exhaustion from the slightest activity like brushing teeth, walking to toilet, digesting a meal and even talking
9. Unreliability and inconstancy of muscles and all systems, insomnia, pain, brain fog and concentration/accuracy issues .. fatigued beyond belief but that I can handle.....what caused me the most issues was not being able to eat properly and being stuck in bed due to muscle tremors and failure of legs etc when trying to walk!
10. And you mention paralysis above... which I didn't know was common. I've had both sleep paralysis and episodes of inability to move at all whilst fully awake!
11. Constant pain, extreme digestive issues, weak immune system, numbness + sudden loss of limb movements, oversensitive senses, loosening of joint's that dislocate easily, burning skin, inability to control body temperature, low blood pressure attacks leading to blackout's, inflamed chest wall, shortness of breath, seizures, visual problem's, quick tolerance build up to medication's, struggle to maintain weight because of long episodes of vomiting + diarrhea, allergies to some foods, problem's with memory + retaining information, fatigue that is overwhelming that stops you where you are + knocks you out, you simply can't stay awake, problem period's, slurring word's so you appear drunk, no balance, I get up, I fall, can't go out without my wheelchair + someone with me because I am basically a zombie
12. Pain, dizziness and cognitive dysfunction.
13. Being incredibly weak which becomes rapidly worse on minor exertion, leaving no energy to even talk, or at best mumble a few words, until have rested enough to gain a tiny bit of energy back. I am too weak to be out of bed. Then severe sensory issues, lead like limbs, chronic head pain. Nerve and muscle pain low level rapidly increasing if I slightly exceed my limits which are very narrow. Severe orthostatic intolerance

preventing me sitting up in a wheelchair. Chronic head pain. Permanent chronic weakness in muscles in my left arm meaning I can't write. Sleep disturbance. Frequent flu like symptoms, feeling poisoned, sore throats, all which ratchet up if exceed activity limits. If my body was like a battery, it would have very little energy left in it and could never be recharged to full power.

14. I have had transient paralysis many years ago, including an arm that remained almost totally paralysed for 16 months
15. I feel constantly poisoned running through my veins
16. Cellular exhaustion.... I do have pain, severe sensory issues, cognitive issues, frequent flu like symptoms etc but I have to say for me it's the cellular exhaustion that keeps me bedridden and what I find so disabling.
17. Hypersensitivities, unable to regulate bodily functions (heat, blood pressure, breathing, heart rate, speech, vision etc), insomnia, sleep apnea. The body shutting down sometimes abruptly mid sentence, cognitive difficulties, dizziness temporary Paralysis, weakness, fatigue unable to coordinate movement, migraine, Occipital and Trigeminal Neuralgia nausea, sickness, IBS, unrelenting pain that seems to travel around the body - awful nerve, joint, muscle, skin and vein pain mixed with a trapped electric heat. Unable to lift your head and limbs, swollen glands, sore throat, dehydration, fever, tremors, inflammation, swelling, Costochondritis ... the list goes on but I can't think anymore sorry
18. Severe compromised immune system, unable to do simple household tasks, bed bound, PEM, extreme and chronic nerve pain, fatigue so severe you can no move or think, insomnia, restless leg syndrome, hand tremors, chronic viral infections, chronic skin rashes, infections, cognitive fatigue, word finding, and so much more. The worst watching or listening the world go by. Can not attend social events, outings, life.
19. All the nervous system dysfunction (including pain, temperature dysregulation, heart rate and blood pressure problems, dizziness, etc and also things like restless legs, spasms and twitching), muscle weakness and sleep dysfunction (despite being utterly knackered I find it hard to sleep most of the time, then there are the times when all I want to do is sleep). I think those three would be my top problems.
20. ...cognitive dysfunction, feeling like I'm in a fog and having a lack of concentration (stops me reading, watching tv and can interfere with conversation etc), and the sensory overload when noise, light, touch, smells, etc are just overwhelming.
21. varied types and intensities of pain, cognitive, dysfunction, endocrinal dysfunction,

different types of paralysis, environmental sensitivities, sleep dysfunction, etc. Yes, muscle weakness is an issue but not as big an issue as the results of muscular or cognitive overexertion. I think I could live with just fatigue or even exhaustion. But PENE is quite simply torture. People need to realise that those with Severe ME experience PENE 24/7.

22. Brain damage, no energy and fibromyalgia punishment for simple enjoyment
23. ME itself means I have little brain power to concentrate, a constant weight on my body making it hard to sit up and stand up, forgetfulness, and sensitivity to noises\ smells\ tastes and lights
24. ...there is a lot of fatigue but for me it's more about how even the smallest things can result in disabling fatigue.
25. just because I'm extremely fatigued it doesn't mean that I am able to sleep.
26. It's about previously incomprehensible levels of pain so bad that I can't focus and despite the unbelievable fatigue it keeps me awake until the fatigue outweighs the level of the pain.
27. Cognitive dysfunction, memory problems, loss of language, inability to explain anything, inability to make choices, sensory overload caused by just little things, inability to be with other people because all my symptoms are much worse when they are with me, they exhaust me so rapidly, concentration problems, inability to manage phone conversations, muscle and joint pain, PENE, clumsiness, eye problems,such eye problems.
28. Unbelievable pain that doesn't abate.
29. sleep ... non restorative and very heavy, plagued with pain.
30. fatigue, pain and sleep are my experience, but the words are not helpful if they are not understood.in the context of what they mean to me.
31. If fatigue just means a bit more tired than usual, then that is grossly inaccurate. If pain means just a bit hurty then it doesn't capture the shifting, sickening, nerve jangling reality of it and if sleep just means oh you have a bit of trouble getting to sleep then it doesn't cover the persistent insomnia... the deep dead.like sleeps interspersed with the adrenalin fueled constant waking.sleeps.
32. ...I also lumped cognitive.issues under fatigue and didn't realise hypersensitivity to sound, light and noise was unusual. Mine fluctuates a lot, so sometimes I can screen out the hypersensitivity and.other I end.up in bed curled up around the pain and cant

move or communicate clearly.

33. Pain - muscular, joint and glandular. Cramps, swollen glands, sore throats, heavy limbs which feel stiff and sore to move.
34. Fatigue - Exhaustion which stops me sleeping, keeps me awake and leads to emotional break downs, The inability to stay awake even when doing something important and knowing you need to stop NOW.
35. Cognitive - An inability to follow a conversation, finding out I've suddenly switched off half way though and don't remember it. Thinking you've done something to find out you haven't, being unsafe on own - leaving doors open, cookers on, left bank card in machine.
36. Sensory overload, hypersensitive, skin crawling
37. PEM, paralysis, global wide-spread pain, air hunger, cognitive dysfunction and feeling like my body is a tooth decay or toxic.
38. ... crushing pain, the heavy weights that are bearing down on me constantly, the feeling that I am as sleep deprived as someone who hasn't slept for five nights, the mental confusion that goes hand in hand with all that.
39. ...cardiomyopathy (also affecting lungs..); fatigue; tiredness; cognitive difficulty (with bad head sensations - makes everything else physically bad if push through), temp regulation difficulties with extreme heat intolerance; trapped, dysregulated heat-energy failure type sensations (excruciatingly intense and relentless in past, improved since); 'air hunger', (malaise, nausea now and then), feeling permanently 'out of it' like my brain can never reach full consciousness. Multiple other more background physiological 'situations' (endocrine, immune etc).
40. my body and my mind no longer functions in the same way. Sometimes it barely functions at all - a complete system breakdown!
41. When severe it was every symptom you could imagine, now I'm moderate it's mild orthostatic intolerance, shortness of breath , feeling of carrying someone on your back all the time , putting my foot on the accelerator calling for the fuel but it doesn't happen , then the engine floods and stops , lack of stamina , body temperature regulation is a problem now to
42. Raging permanent virus feeling, extreme sickness, inability to stand/walk, multiple allergies and respiratory difficulties, cannot see or speak on waking and eyes,nose and throat feel on fire. The list is endless.NOTHING like my GP's perception of what the

illness entails

43. Unreliable memory, lost memories from. the past, inability to think, loss of planning function of my mind, confusion, loss of focusing of my eyes, inability to process new surrounding and associated exertion, shaking limbs, loss if control of body temperature, sweats, issues with bright lighting, suddenly not knowing what I was doing, where I was going, inability to follow conversations.....post activity (any activity physical. or mental) malaise, added exhaustion, post activity energy deficient running from hours to days weeks or months, and more
44. One forgets that one ever had a life
45. like the virus is goin round in ur body hidin to pop up somewhere else, it's not fatigue like tiredness. It's weakness and lack of strength.For me it's about how quick it can change I can be relatively well and within seconds unable to put one foot In front of the other or hold a conversation- people say you were ok a minute ago and it makes me wanna scream because I can't explain how all of a sudden I'm very far away from ok. The worst is paralysis. The ones that define ME for me are all the neurological set: I lose equilibrium, coordination, proprioception, I drop things, lose the way, can't hear, don't see well, can't talk normally, etc...With it I have extra systole when I am resting after an effort.And I am so thirsty, if I don't drink all this worsen exponentially.I had paralysis only one year. When I worsen I have neurological symptoms always. And then other things.But the neurological set is always present.I also have fever, vomits, strong bowel pain (I found out that is because of my microbioma), high joints pain, headache, a wide set of infections, I am much dehydrated, I am sensitive to smells (a lot, to corporal bacteria most of all), to light, to sounds, I can't sit or stand straight, I need to sleep much more...etc...
46. paralysis.. the loss of all or some of my five senses.. (touch and taste regularly) with all the consequences that brings (once stabbing myself in my eye not realising I still had a knife in my hand) it can all be very scary and exhausting - when you need to think everything then think it again! .. along with fighting the persistant chronic pain. It's an awaking nightmare that never goes away.. for us and our carers.
47. Repeated daily and nightly periodic muscle paralysis, muscle spasms, tremor, muscle weakness, muscle wasting, profound hyperacusis, photophobia, hyperesthesia, visual disturbance including tunnel like vision, double letter images, muscles will not hold focus or stare, eyes itch, burn and are dry, not holding tear film, eye pain, fuzzy vision, eyelids paralyse shut, shifts in blood pressure, extreme head-pain and headache sometimes in 1/4 of head and eye, breathing difficulties, unrelieved, constant all over body pain - itching, burning, throbbing, stabbing, crawling sensations, cognitive

dysfunction including word loss, memory loss, saying words or letters the wrong way round, inability to understand or process, inability to think, unable to read or write or hold things, multiple chemical sensitivity, dizziness, tinnitus, gut issues, food and drug sensitivities, pins and needles, numbness, oxygen too low, overheating and sweating or freezing cold, emotional lability, lack of energy, loss of sensation and proprioception.

48. There are so many symptoms, so many different levels of severity and through a wide range of ages and backgrounds. It doesn't make sense to focus on one or two symptoms and especially fatigue which is a complete misnomer. Basically I would say that my body and my mind no longer functions in the same way. Sometimes it barely functions at all - a complete system breakdown!
49. We also need to consign the word "fatigue" to the trashcan cos everyone in the world thinks they know what fatigue is and what they feel is nothing like what we feel. Yes, tired, need a rest, need to put our feet up with a cup of tea for half an hour, need a good nights sleep, then everything will be fine. That's what the world thinks. What we suffer is a whole different dimension. I use the word "tired" cos I'm too exhausted to explain the crushing pain, the heavy weights that are bearing down on me constantly, the feeling that I am as sleep deprived as someone who hasn't slept for five nights, the mental confusion that goes hand in hand with all that, Throughout history people have died from exhaustion, from crippling, never ending overwork. The feeling/knowledge that your body can't take any more. That's what I mean when I say I'm tired, but I'm too tired to put it all into words, so uncaring listeners just assume tired means a bit sleepy - in my experience.
50. PEM, paralysis, global wide-spread pain, air hunger, cognitive dysfunction and feeling like my body is a tooth decay or toxic
51. Pain - muscular, joint and glandular. Cramps, swollen glands, sore throats, heavy limbs which feel stiff and sore to move.
52. Fatigue - Exhaustion which stops me sleeping, keeps me awake and leads to emotional break downs, The inability to stay awake even when doing something important and knowing you need to stop NOW.
53. Cognitive - An inability to follow a conversation, finding out I've suddenly switched off half way though and don't remember it. Thinking you've done something to find out you haven't, being unsafe on own - leaving doors open, cookers on, left bank card in machine.
54. Sensory overload, hypersensitive, skin crawling

55. Inflammation of the spinal cord And Brain Stem..
56. Unbelievable pain that doesn't abate.
57. chronic nerve pain peripheral neuropathy POTS tremors nausea multiple allergies and rashes, gastric and swallowing problems, light and noise sensitivity, temperature control problems resulting in constant overheating, IBS, headaches migraines sinus problems and many more as well as severe anxiety lucid dreaming which is very scary hypnogogic jerks dizziness high bp... as well as Raynauds and b12 deficiency.
58.terrible jolts pain, just about anywhere in his body; total paralysis, unconsciousness & seizures, often requiring paramedic assistance & hospitalisation; violent, uncontrollable "tics" in limbs; noise intolerance; exhaustion & a constant head pain.....multiple serious infections as a toddler, years before the main awfulness started.
59. extreme digestive issues, continuous vomiting, weak immune, severe bouts of constipation/diarrhea with stomach pain + vomited, loss of balance, vertigo, headaches that lasted month's on end, pins + needle's, numbness all over body in patches, weakness (which has gotten worse, particularly arm's + legs + face) difficulty swallowing, choking on food or excess saliva, TMJ, dental problems (intolerable to silver fillings) mouth sores, malabsorption issue's, allergies, sudden oversensitivity to smells, sound's + light, fast tolerance build up to medication's, tinnitus, slow recovery from colds/flu, terrible menstrual issues, loose joint's that dislocate easily, raynaud's, low blood pressure, blackout's, seizures, memory problems, slurring, not being able to retain new information + struggling to understand what people are saying to me though I understand what I'm saying, fatigue that quite literally knocks you out within minutes of feeling tired lasting hour's, costochondritis (inflamed chest wall pain) hoarseness, chest pain so bad upon standing I can only stand for a few minutes before I feel ill, acid reflux that doesn't respond to antacids, burning, freezing, tingling skin, stabbing, aching, sharp pain, heart palpitations, difficulty taking breath's, tight pain in chest, jumping at nothing, twitching, muscle spasms, bursting into sudden laughter or crying, incontinence issue's, depression that occurs for no reason, hair loss, cyst's occur in my breasts, ovaries + face, sudden sweating, inability to control body temperature, constantly painful feet, difficulty word finding, forgetting name's of thing's + people's faces, itching all over, bad kidney infections, difficulty focusing eye's, there's probably more.....
60. Main symptoms for me are crippling exhaustion, made worse by doing anything. Cognitive dysfunction that makes it impossible for me to watch tv, listen to radio or music, or exchange more than a few sentences.... though weirdly I can type for a little

while and manage the computer. I can also sit up sometimes and do a little art on my lap. But most of my time is spent in bed, and I have no strength, energy or stamina in my muscles. Housebound for the time being. Standing for more than a few moments is painful, can just about get to the bathroom and kitchen two or three times a day.....but otherwise walking is out. I get terrible neck pain, headaches, IBS, and am incredibly sensitive to noise, light, smells, foods, you name it. I use wax earplugs and shotgun ear defenders. Everything is exhausting - especially people! What else? Sleep is all over the place and rarely experience any kind of functioning before midday. Hand spasms, can't lift anything much, my husband cooks for me, bathes me, washes my hair, and those ablutions don't happen very often as it is such a ginormous effort.

61. Most have covered my list except maybe one symptom which is an auto immune condition called lichen planus. My GP thinks it's a direct result to having ME and coeliacs disease. It is a skin condition but I have it in my mouth and it constantly burns. It is extremely sore and you can see ridges down the both sides of my tongue. Never heard of it before. No cure - obviously!
62. Always thirsty and get dry eyes.
63. Main symptoms occur as a result of PENE due to walking or talking! I slur so badly I sound as though I'm drunk and all the same cognitive issues as mentioned.
64. I didn't think I'd experienced paralysis, but I do get severe leg pain and weakness / fatigue if I walk on my legs,
65. Complete body wide internal vibrating. A host of reactivating viruses; mycoplasma pneumoniae, klebsiella, cytomegalovirus, EBV, Parvovirus B19. Then low natural killer cells, adrenal insufficiency.

Conclusion

It is my hope that this document illustrates and illuminates the glaring discrepancy between the medical establishment's presentation of ME as ME/CFS etc and the reality of ME as a serious neurological disease with multi-system dysfunction and an intense disabling symptom experience.

It is important to recognise that the serious symptoms people endure, will have a physiological cause underlying them; even if it is being ignored, downplayed, not looked for or not presently understood.

Everyone with an ME diagnosis deserves better than they are currently receiving from the medical establishment at large, which seems quite happy to bury ME in a sea of fatigue misrepresentation and misinterpretation and psychological denial.

People with ME need:

- better recognition
- better diagnostic criteria -we currently prefer the ICC criteria with its recommendation to separate ME from CFS
- better management information
- further testing and investigation if tolerable.

This is going to require innovation alongside a much more aware way of approaching people with ME, understanding that the wrong approach, the wrong interaction, will cause harm either temporarily or permanently.

Of particular importance is the need to get across the fact that you cannot force anyone with ME to get better by demand, expectation, exercise or denial and lack of understanding of their physical reality.

They are seriously ill people, just not being taken seriously enough.

In order to meet need, a home bound service is a primary need - one that recognises that people are harmed by the ordinary environment and are too sick to engage with it in order to get help they desperately need and want. This not only includes medical input and clinician home visits, it means appropriate level of ongoing supportive care, provided with genuine knowledge of the difficulties people with ME face in coping with basic, ordinary, interaction, especially the more severely ill they are.

If help is to be provided, it must be the right help; a fundamental denial of the physical nature of their illness and their symptoms does nothing to help people with ME.

This list of symptoms and the vivid descriptions people have given of their experience illuminates why a fatigue focus is simply not the way forward.

Greg Crowhurst

August 2018

References :

Acheson E.D.(1959) **The Clinical Syndrome Variously Called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia**

<http://www.nameus.org/defintionspages/DefinitionsArticles/Acheson1959.pdf>

Carruthers B et al (2011) **Myalgic encephalomyelitis:International Consensus Criteria.** Journal of Internal Medicine Volume 270, Issue 4, pages 327–338, October 2011

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/full>

Chia J (2005). **"The role of enterovirus in chronic fatigue syndrome"**. Journal of Clinical Pathology.<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1770761/>

Crowhurst G (2018) **Straight-jacketed by Empty Air**

<http://stonebird.co.uk/emptyair/index.htm>

De Meirleir, K (2013) **Is it possible to diagnose ME/CFS?** ME/cvs Vereniging Nederland,

<https://www.youtube.com/watch?v=iHTV0lm5qMQ>

Hyde B (2006) **A new and simple definition of Myalgic Encephalomyelitis and a new simple definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis and an Irreverent History of Chronic Fatigue Syndrome**

http://www.imet.ie/imet_documents/BYRON_HYDE_little_red_book.pdf

Parish, J. (1978) **'Early outbreaks of 'epidemic neuromyasthenia,'** Postgrad, Medical Journal, 54: 711-717. A New Clinical Entity? Leading Article. Lancet 1956: 789-790 Pileki, B.C., Clegg, J.W., & McKay.

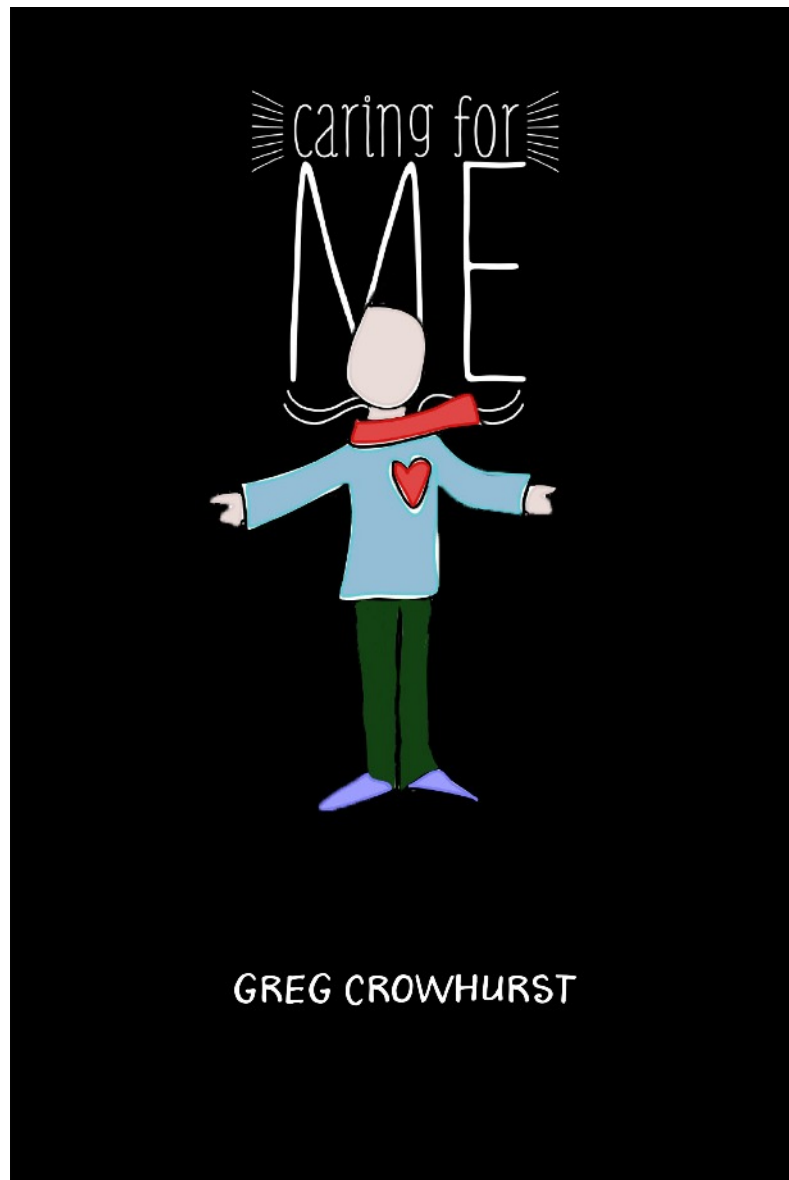
Shepherd C and Chaudhuri A (2018) **ME/CFS/PVFS: An Exploration of the Key Clinical Issues,** <https://www.meassociation.org.uk/shop/books/mecfspvfs-an-exploration-of-the-key-clinical-issues/>

Williams M(2011) **"Grey" Information about ME/CFS Compiled by Margaret Williams April 2011** <http://www.meactionuk.org.uk/Grey-Information-on-ME-CFS.htm>

Caring For ME, a Pocketbook Course for Carers.

We are sure this will be a great life saver to many carers out there ... This book offers a caring and helping hand coming from a person of such experience and knowledge in the field.

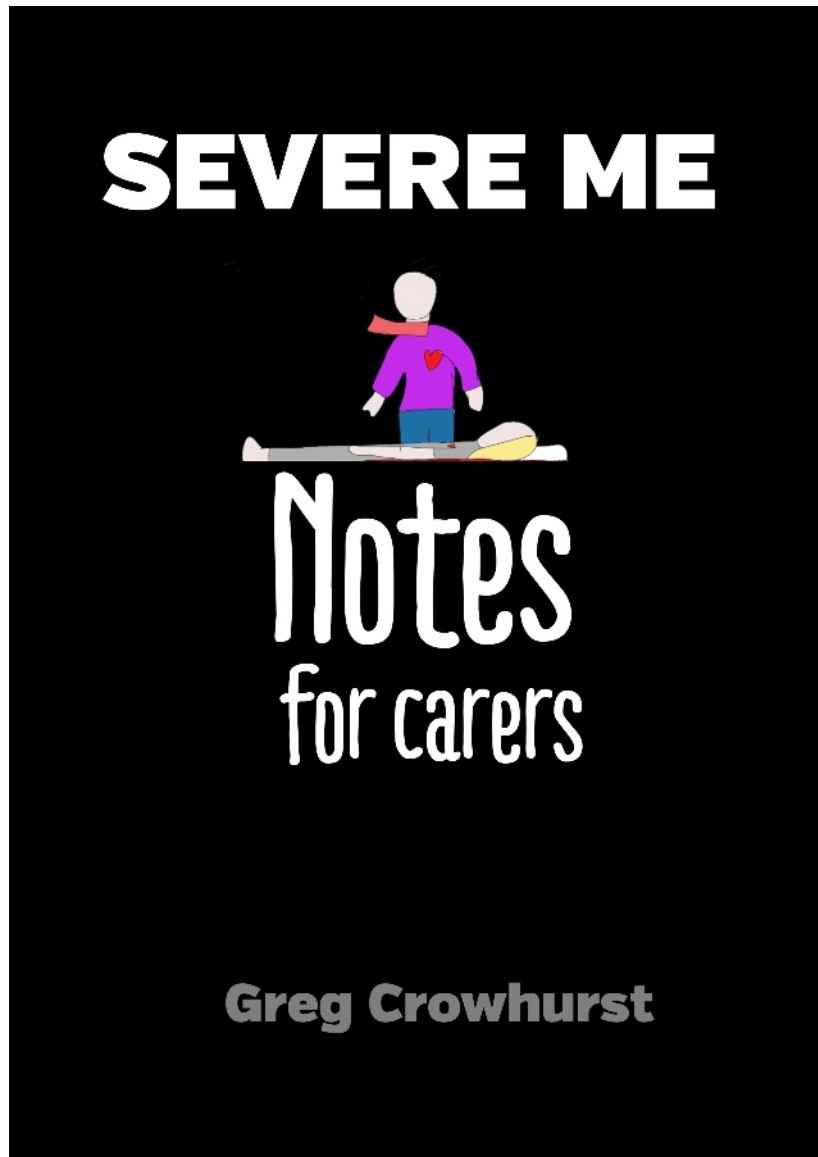
25% ME Group



<http://stonebird.co.uk/CARE/index.html>

Notes for Carers

An illustrated handbook packed full of practical tips, insights, guides and exercises.



<http://stonebird.co.uk/Notes/index.html>