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Severe ME : What You Don't Say, What You Don't See.

In Severe/Very Severe ME it is easy to say : *"I am too ill"* or *"Very/Severely ill"* or *"I can't do something"* but it is not so easy to identify WHY. Actually it is the WHY you can't do something, that illustrates the physical illness that you have, as opposed to a mental health misinterpretation, especially if you can say what physiological mechanisms underpin them.

If you have a known and accepted illnesses/disease, you would not need to explain why you cannot do something. For example, in Muscular Dystrophy or Motor Neuron Disease or Heart Disease, it is accepted, even if it is not necessarily visible, that you cannot do things.

But in ME, the invisibility of the most ill, because they are too ill to be visible and are only seen, if ever, in moments when it might be possible, inadvertently contributes to a prevailing psychiatric paradigm, which fills the gap with a FALSE WHY, for example :

- "You are deconditioned."
- "You are thinking the wrong thoughts."
- "You are doing it to yourself".

The newly ill, in particular, may experience real difficulty in identifying specifically what is happening in their bodies and articulating it, because so much is going on in the body and the symptoms can blend together so easily, into a horrendous feeling of terrible illness.

The word "fatigue" is often used as a cover-up term for serious and severe symptoms which are not investigated or even named or dismissed.

ME is a particularly terrible illness because of the way it hits you in multiple ways in multiple systems of the body, whilst the nature of the illness works against you articulating and working out what is wrong with you.

Either you are too cognitively blank to recognise, identify and articulate which symptoms are affecting you, in any one moment or you try to explain in detail everything that is going on, but that can be too much for people to follow or comprehend or the symptoms themselves all jumble together and you cannot tell why, in any one moment, you are as ill are you are, so instead, people may misinterpret you as having a mental health condition.

You also don't necessarily know if you are experiencing a post- exertional reaction, which can take hours or days to manifest - some call this Post- Exertional Neuroimmune Exhaustion (PENE) or if it is a longer more permanent deterioration or whether it is the normal fluctuation of your symptom severity or if there is an underlying other illness, often called a Co-morbid condition, that has been ignored or gone undiagnosed, that might be impacting as well as ME.

It is easy to say "I am house/bed bound" and to focus upon "fatigue", but this can minimise the full reality of severe symptoms, any of which could individually disable you, for example :

- Profound Noise Sensitivity
- Muscle Paralysis
- POTS/ Dysautonomia / Heart Rate/ Blood pressure Issues
- Muscle Weakness etc.

Any of these are completely disabling in their own right. In their severe forms they lead to isolation, invisibility and misunderstanding, especially when the physiological explanation is not sought for medically nor provided to you. Add several of these severely disabling symptoms together and you have an increasing nightmare reality.

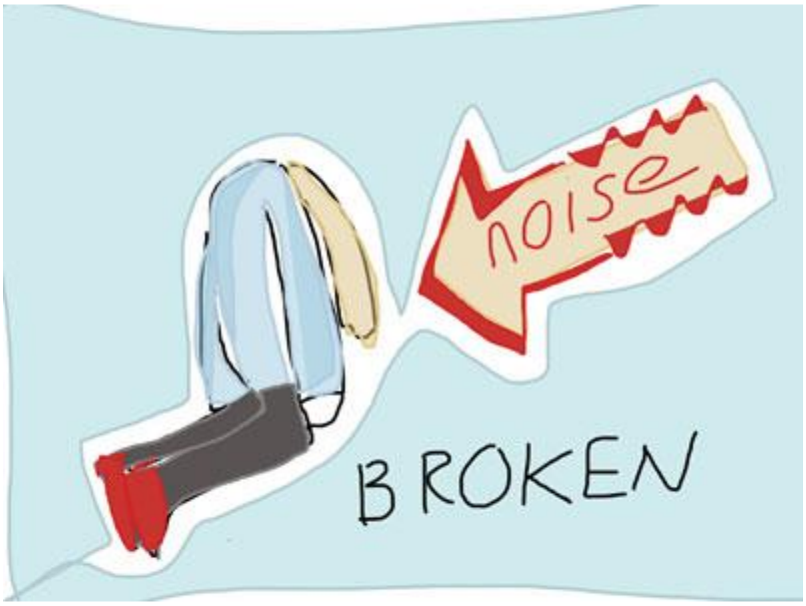
When you are as ill as you are and as severely disabled with Severe/Very Severe ME as you are, even the use of normal aids and equipment that might help other people with disabilities, becomes painful or impossible.

The usual assessment processes to get needs met become hard to go through, impossible to navigate or tolerate because of the very nature of the disease, that causes breaks to communication and makes tolerating the presence of anyone in the room with you virtually impossible or minimal. People with Severe ME will be housebound, may also be bed-bound or may even be unable to tolerate being in bed.

The level of suffering is under-described and unimagined. The term 'bed-bound', as a measure of severity, is one that we do not like or agree with, to describe Severe ME; it is behavioural in description and does not recognize the differences in symptom experience or symptom severity, nor help identify the reason why the person is in bed.

It can unfortunately be used to imply or at least encourage a fatigue focus and description. It is far more valid, we believe, to recognise the individual severity of the symptoms which lead to disability. They may be individually profound, yet vary significantly in impact between people. Many symptoms are ignored, denied or down-played . As a consequence, people are not provided with the recognition, advice or support , they need, to help deal with them . A Biopsychosocial attitude is irrelevant here; it undermines the physical suffering, the urgent need for physiological explanation, medical respect and a biomedical response.

For example, Noise Sensitivity, as mentioned earlier, may be totally disabling, requiring isolation from normality in order to cope. The person may not be in bed, but would still be severely disabled and isolated.



It dishonours people's experience, if generalised labels of 'bed-bound' or not, are ascribed as the only measure of severity of illness. Those with profound symptom experience, but not bed bound, yet housebound and unable to interact are completely overlooked by this simplistic behavioural terminology. Some people may not be bed-bound yet may still be amongst the most severely affected.

Below are some useful descriptions of why a person might be severely disabled with Severe ME and how that affects accessing help or even using basic disability aids. It is not necessarily a comprehensive list, just a few examples of what so often is omitted or unidentified and not necessarily understood by others or misinterpreted.

Difficulties posed by ordinary 'taken-for-granted' things, including the use of disability aids, for people with Severe ME.

Why do some people need/have to stay in bed?

- Orthostatic intolerance/dysautonomia.
- Blood Pressure variability.
- Muscle weakness.
- Extreme body and head pain.
- Paralysis.
- Shaking spasms/tremor.
- No energy.
- Muscle fatigue.
- Difficulty waking up and staying awake.
- Need for continued sleep.
- Difficulty feeling rested.
- Autonomic nervous system dysfunction.
- Altered Circadian rhythm cycle, delaying onset of sleep.
- A need to rest.
- Unrefreshing sleep.
- Profound exhaustion.
- Nausea/vomiting.
- Feeling extremely ill.
- Post-exertional deterioration.
- Dizziness.
- Breathlessness.
- Low oxygen.
- Difficulty processing environment.
- Heart rate variability - Bradychardia and Tachycardia.
- Loose joints.
- Inability to sit up/be upright.

Why do people need to stay in one room?

- Safety.
- Security.
- Need a perfume-free/ chemical free environment.
- Noise protection to limit exposure.
- Light sensitivity requires darkened space.
- Comfortably arranged to meet need.
- Level of pain incapacitating.
- Muscle weakness/stiffness.
- Temperature change intolerant.
- Decorated minimally to avoid over-stimulation.
- No energy to move.
- No energy to move about.
- Not able to tolerate interaction with others.
- Not able to tolerate motion.
- Not able to walk any distance or at all.
- Not able to physically tolerate sitting or lying in a wheelchair, even if needed.
- Intolerant to motion in a wheelchair.
- No energy to get dressed.
- Unable to use aids and equipment, such as walking sticks, walking frames, for supported movement.

- Severe Post-exertional deterioration.
- Need a noise -reducing environment.
- Need a simply decorated, uncluttered environment to avoid over-stimulation.
- Closest position to bathroom/toilet.
- Cannot travel.
- Intolerant to motion in a wheelchair.
- Everything is organised to be at hand.
- No energy to leave room.
- No ability to be upright or lie down in some cases.
- Best/only comfortable seating arrangements in home.
- Stuck upstairs unable to get down.
- Needs can only be met in a limited space.
- Controlled environment.
- Not generally able to be with other people in the home or tolerate background noise or interaction.
- Outdoor environment may be too bright, too noisy, too chemically/perfume contaminated, too overwhelming cognitively or visually or unsafe surfaces - steps, bumps, unsound ground etc.

Difficulties with stair lifts

- Expensive - may be unaffordable.
- Stairs may be too steep or an awkward shape.
- Noise of a motor may be too much to tolerate for people with severe noise sensitivity.
- Motion may be intolerable.
- May be unsafe due to muscle weakness to sit up or endure movement safely.
- Possible smell of oil for people with MCS endangers health.
- May not have a strong enough handgrip ability, due to muscle weakness/pain in hands.
- May be paralysed and unable to bear any contact or movement.
- Pain may be too severe to tolerate motion or movement.
- Seat may not offer enough back support or leg support.
- May not be strong enough to operate independently.
- Dizziness may make it unbearable.
- Nausea may make motion intolerable.
- May not be able to safely transfer onto seat and off again.

Difficulty with showers

- Difficulty getting out of bed or off seat to get to bathroom.
- Difficulty getting to the shower room due to muscle weakness, muscle fatigue, post- exertional neuro-immune reaction, paralysis.
- Not enough energy to undress, let alone wash.
- Difficulty transferring to a shower chair or bath-board over a bath.
- Difficulty with hardness of seat or bath-board causing pain or exacerbating existing levels of pain.
- Difficulty getting in and out of shower.
- Unable to turn shower on or off.
- Difficulty maintaining water heat at tolerable level.
- A shower over a bath may cause extra access problems.
- Inability to stand or safely sit - unsteady on feet even with support.
- Not enough energy to endure the whole process of getting in and out of shower and washing and drying oneself, even with help.
- Extreme pain may make physical contact of falling water an agony.
- Shock of water on skin may act as a shock to intensify symptoms.
- Head-pain may not tolerate contact of water.
- Getting too cold once shower stops.
- Hypersethesia making contact from water unbearable.
- Needing a dark room may make the environment not safe to shower in.
- Noise of water falling may be intolerable if sound sensitive.

- Noise of motor may be too loud and cause pain, headache, upset, intolerance, paralysis, muscle shaking or other symptom deterioration.

Difficulty with decorating

- Noise.
- Chemical exposure.
- Perfume exposure.
- Inability to tolerate people in the house or room.
- Difficulty of people wearing perfumed products contaminating environment further.
- Lack of energy or cognitive ability to arrange and cope with the process.
- Poverty: low -odour paints are extremely expensive.
- Inability to leave the room or the house that needs decorating.
- The length of time required to do the work may take too long even if someone can cope for a little time.
- Unpredictability and unreliability of people helping coming on time and sticking to agreed times.
- Finding helpers who understand your illness and who are willing to be flexible.
- Impossibility of cleaning up afterwards or coping with upheaval and changes to routine.
- Post-exertional deterioration.
- Risk of symptoms deterioration.
- Risk of new symptoms developing.

Difficulty with getting new things

- Inability to go to a shop to try something out to check it is comfortable or suits your need.
- Unpredictability of online buying, measuring, colour accuracy, inability to tell comfortability, texture of material, chemical or perfume smell of product or wrapping.
- Lack of physical ability or energy to send things back if unsuitable.
- Inability to deal with sales person online or on telephone or in person, due to severity of illness, headache, head pain, communication difficulties, no energy to speak or comprehend, noise sensitivity, cognitive difficulties, inability to speak or find words and phrases needed.
- Too ill to deal with delivery of product, especially if you live alone and are bed-bound or stuck on a chair unable to get off it.
- Cannot tolerate the door bell ringing.
- Cannot tell what time a parcel will be delivered to ensure someone is there to avoid noise, light, chemical, perfume exposure or other extra stresses that deteriorate symptoms.
- Difficulty unpacking purchase if weak hands, no strength, no ability to move it or put it where it needs to go.
- Vulnerability of chemical smells from new products which take many months to wear off and endanger health.
- Difficulty tolerating other people's presence in the room or house even if you have someone willing and able to help.
- Not enough energy to explain your need to someone else to help you.
- Someone else cannot tell how a product feels/smells, whether the colour / brightness of colour is okay for your eyes to tolerate, whether it has a noise, if mechanical - you need to do it yourself, but cannot.

Difficulty with using a wheelchair

- Not everyone will be able to sit upright or lean back at an angle in a wheelchair for different reasons: eg orthostatic intolerance/dysautonomia, muscle weakness or stiffness, extreme pain, loose joints, muscle spasms and tremor, periodic or permanent paralysis.

- Some may need to lie completely flat or have appropriate padding to get comfortable at the right angle; everyone will be the same.
- Some may not tolerate using a wheelchair even with very limited mobility, due to the nature and severity of symptoms.
- Motion, both forward and/or backward, may be intolerable to some.
- Being tipped backwards may be unbearable, especially with dysautonomia.
- A jolt to the chair or a bump may be excruciating, deteriorative, unbearable, trigger shock or paralysis, increase pain, cause irritation, confusion or upset, be too risky to attempt.
- It may be hard to get a seat that is soft enough or padded enough in the right places or with surfaces that are bearable with contact.
- New smells or chemicals and cushioning may be an issue for people with MCS.
- Cushions must be supportive yet soft enough for comfort and may not be possible to find anything suitable if extremely pressure sensitive, hypersensitive or in severe pain.
- Texture of fabric may also be an important barrier or chemicals and dyes.
- Professionals may not understand the need to use a wheelchair-especially if it is not always required or variably tolerated or possible to use and the Post-exertional impact or long term deterioration is not visible until it is too late.
- It is not easy to get a design that suits someone with severe pressure sensitivity, high pain or hyperesthesia.
- It is hard to get a wheelchair that does not have hard front wheels, but rather has pneumatic tyres to minimise bumps.
- Electric chairs may be impossible to control independently due to muscle weakness, lack of co-ordination or poor co-ordination, poor vision, post-exertional deterioration, lack of energy, muscle or nerve pain, lack of stamina, poor spatial awareness.
- There may be difficulty physically charging or safely charging batteries if there is limited space.
- Ramps and access are often issues to be considered.
- Wheelchair maintenance is impossibly difficult if you have severe ME and it may not be possible to cope with someone else doing it for you, if you can find someone, due to effort of communication, difficulty tolerating oil, cleaning products, noise, interaction, etc.

Difficulty engaging with people in person in order to get needs met

- People may be too ill to speak or move or convey need even.
- People may be too noise sensitive to tolerate another persons voice, both loudness and tone, their laughter or even a whisper, the sounds they make when moving their body, whilst making gestures or their footsteps in the room or on the stairs or the banging of doors, even if quietly shut or opened, may be too much to tolerate and risk deterioration.
- People may not know how to safely and effectively communicate especially if sign language or silence is required.
- A door bell can be incapacitating, painful, harmful, deteriorative to someone with severe sound sensitivity and the inability to answer or stop the sound can be disturbing or deteriorative.
- People may be too weak and limited in energy to move, think, talk, debate, answer questions, ask questions, find words, understand information, sit up, stand, explain, open windows to air rooms if perfume-exposed, unable to open curtains to let in needed light if needed, due to physical inability as well photophobia.
- Chemical and perfume sensitivity and allergy are real barriers to being with people or allowing them into the room or the home.
- Some people may be physically paralysed or near to paralysis, unable to communicate or tolerate anyone's presence, may appear asleep, when actually conscious and awake, yet unable to move or open their eyes.
- Clothing rustling, with another person's movement, can be a torment to a person with severe/profound noise sensitivity.
- People who gesticulate may cause pain, confusion, deterioration due to Movement sensitivity.
- People with Severe ME may sometimes suddenly, unpredictably and unexpectedly completely run out of energy, deteriorate, develop severe pain, headache, blank mind, nausea, vomiting, paralysis or

other symptom increase and no longer be able to engage in conversation or bear company in the room, may only have very limited time before this happens, if engagement is possible at all and will have strict regimes and specific needs, to cope in these circumstances, but not necessarily be able to convey them.

- A person with Severe ME may not be able to follow conversation if there is any background noise.
- It may not be possible to tolerate more than one person at a time in the room, if that, for a variety of different reasons, and may simply be too draining even to have someone in the room in apparent silence.
- Using phones or keyboards/ computers/ tablets, may be variable to impossible to use for communication purposes, depending on the ability to tolerate magnets, holding the implement, reading, typing, speaking a message, etc., even with the possible use of particular aids to help, such as voice activation programs, as these still may not be practicable to use, as they may take too much cognitive or physical effort or there may be problems with co-ordination, holding things or fine movement, making staying in touch with others or communicating vital needs very difficult indeed, especially if one to one time is not tolerable or possible or severely limited.
- Someone putting the slightest pressure, not just on the person, but on the bed or wheelchair or seat even, leaning on it, for example, can literally cause pain and weakening and should never be done without agreement, if at all, yet how easily this can be done by an unaware visitor, without any understanding of the dire impact.
- If speech is tolerated, it may need to be extremely slow, with no complex phrases, may need to use simple language, quietly spoken, may need long pauses between sentences to enable processing to occur, may, for some, need to be repeated, especially if spoken too fast the first time or it may be that only once is the limit, so comprehension is lost and conversation halted, especially if there is a lot of words to deal with.
- Questions may be impossible to answer for a variety of different reasons, such as difficulty comprehending the question, difficulty finding information to reply, difficulty articulating the response even if the information has been found. The effort of even thinking about the answer may cause further shutting down of the minds ability to think or communicate and may make physical symptoms worse or trigger symptoms unexpectedly, such as muscle spasms, severe headache etc.
- Visualisation or following description or information from someone else, may not be possible, making it hard to follow conversation and have two-way interaction.
- There is a post-exertional reaction not only to physical exertion but also to cognitive effort, which can result in an even blanker mind than the norm, for the person, making communication even more difficult to achieve and potentially jeopardising the possibility of essential communication in the near and/or long term future.
- Physical contact, even light contact, whether expected or unexpected, may cause shock, intense pain, paralysis, shaking muscle spasms, exacerbation of other symptoms and could be unintentionally catastrophic to the person affected in this way.
- The sudden exposure to noise, such as a sudden mobile phone ring or an object accidentally knocked over or dropped, a sneeze, a cough, even a head scratch, can negatively impact some, which brings an extra problem in interacting with anyone.
- There is an extra vulnerability to catching viruses from visitors, which brings an added risk and a particular additional issue to be aware of, in order to safe-guard health from worsening and may not always be fully thought through or understood, by people who live ordinarily in the busy outside world.
- A person in the room may not understand the specific and complex needs of the person and how their direct presence can create extra difficulties or deterioration from the subtlest thing, nor how to respond; they may not realise or recognise their cognitive impact, for example, that can limit language, memory, information understanding, nor comprehend the harm that ensues if the person's reality is ignored or not understood, is not known or accepted.

People with Severe ME are likely to have multiple breaks to communication and may struggle to engage with people at all.

They require an extremely aware, sensitive approach and an acute understanding of their genuine difficulties in getting even their most basic needs met.