

Paralysis, a qualitative study of people with Severe Myalgic Encephalomyelitis

GREG AND LINDA CROWHURST (AUGUST 8TH 2013).

Synopsis

Paralysis is a symptom that is rarely highlighted in the literature for ME, yet is found amongst the most severely ill ME population and even some of those not so severely affected. My wife has experienced it for almost 2 decades, without adequate exploration, alongside exposure to denial and dismissal, ignorance and neglect as well as harmful treatment.

We wanted to find out if there was anyone else with a similar experience to my wife's or if she was a rare and very severe case. We wanted to highlight the seriousness of this symptom and ask why it is being ignored and down played not only by the medical profession, with its inappropriate focus on fatigue and the psychosocial response, but also by the main charities, none of whom, flag it up as a main symptom.

This qualitative research study indicates that there are significant others experiencing apparently similar paralysis and that my wife is not unique. It begs the question why are they being neglected and why is there not urgent research into the understanding and alleviation of this devastating physical symptom? What is the mechanism, are there different mechanisms at play and are there any possible ways to treat it?

Objectives

We set out to establish how widespread paralysis is among a group of people who have Severe ME, whether anyone else, apart from my wife, experiences paralysis – awake, asleep, transient, partial or full, similar to my wife, or is it fundamentally different?

We wondered how many people with severe ME experience paralysis. Is it that rare? Is she only one of a few?

We were interested in people's experience of the medical profession, in response to paralysis, was it positive or negative?

Method

The preferred method would be a detailed survey, however this is not practical for anyone with Severe ME. Having to deal with a survey could be counter productive for the person

with Severe ME; the severity of paralysis, other complex symptoms, severe illness and cognitive dysfunction makes it extremely difficult to deal with questions, forms, external demands.

The method used was to highlight, in some depth, on Facebook, on my blog and on an ME Forum, my wife's experience of daily paralysis over 20 years, alongside the ongoing difficulties of obtaining respect, investigation, understanding and treatment and to ask if anyone else has had a similar experience?

Background

My wife has been daily paralysed for almost 20 years now. It is a great distress to her that what appears to be a cardinal symptom of Myalgic Encephalomyelitis is ignored and dismissed so readily by just about everyone, when it dominates her life and her disability so fundamentally. In that twenty years she has never known anyone personally who experiences it in the same way as she does.

It is easy to use the word paralysis, but does that mean the same experience and cause for each person? If we do not ask for more information, we do not get a clear picture.

In our experience of Severe ME no one seems to take much notice of paralysis, even the doctors and it tends to be rarely put on any list of symptoms, even though it is so serious and extreme. We have found that most neurological symptoms tend to be down played in ME, resulting in the cliché of the 'tired all the time' person whose fundamental symptom is fatigue.

The symptom lists, presented by the main charities, rarely take into account the most extreme symptoms. Paralysis is missing altogether it seems.

We are shocked at how my wife's paralysis has been dismissed, ignored, downgraded, neglected, patronised, misrepresented and overlooked down the years. It is hard to reconcile the focus on fatigue and the psychosocial treatment regimes that are currently on offer, whilst seeing first hand the physically tormented suffering of Very Severe ME on a daily basis for 2 decades.

A serious medical study of paralysis in ME needs to happen, however this is very difficult to achieve given that the most ill are ignored and left out of studies and physical research, possibly because they are too socially and medically isolated, too difficult to accommodate or deal with and because their needs are so complicated, their symptoms so complex and their health so fragile and at risk of harm and deterioration.

My wife's experience:

" I waken into consciousness with a start, but my body will not move. My breathing is regular and automatic as if still asleep. Eventually, after a period of hours I may be able to move a toe. I begin by trying to wiggle the toes of one foot then the other. It is always my toes that

respond first. My eyes are always last to be able to open, so I have had to get used to moving about with them shut. I cannot open my mouth or speak or swallow or chew. I am completely unable to indicate that even though I may appear asleep, I am actually awake and in physical distress, needing help. I cannot bear physical contact as I am in extreme pain. The gentlest touch feels like a massive physical assault.

The paralysis I experience in sleep is always total, all of my body. Intense numbness accompanies it too, along with shaking spasms as I finally try to escape from its clutches. Pain too is intensified, along with severe headache. I am gaspingly thirsty. My breathing is even and automatic like in sleep, often through my nose, as I was trained to breathe this way. It is as if my body is still asleep, but I am awake. I have started every day like this for almost two decades now and it is often afternoon before I can finally move enough to sit up, walk a few steps with help and get to a chair. Yet I cannot support my back upright and have to lean forward away from upright, as I cannot lean against a chair for physical support, due to severe pain and pressure sensitivity. I cannot tolerate contact with my head and neck against any surface.

Still I cannot bear conversation. I stare unable to focus, my eye muscles still paralysed. My eyes remain painful and struggle with focussing all day. My sight is blurred. I have double vision. My noise sensitivity is increased and the paralysis, although it has shifted in some groups of muscles, enough for me to get to the next room, has not left me, it never does. I remain very close, to near complete inability to function and can return at any moment to paralysis. Even my thoughts seem paralysed as if everything, mind and body are in a complete empty fog.

This is not the only sort of paralysis I experience though.

Once up and with limited movement, I can suddenly feel my hands, feet and limbs becoming cold, numb and lifeless. I often lose feeling, sensation, proprioception (bodily awareness of the limbs) and my hands, arms and feet lie lifeless, useless, unable to feel or move. They have no use. This may be accompanied by my body overheating, despite cold extremities and feeling more intensely ill. This may be for an hour or several, it may be for days or weeks, months even. It may be more predominantly one sided, it can be left or right and it also creeps into my face so that I am palsied, my mouth will not smile on one side. My eyeballs swell and feel numb and I stare like a fish. I have no control over this. It comes and goes as it will. It can affect my speech.

If I sit too long in one position my body moves closer to paralysis and inability. If I lie down I get paralysed a lot quicker than upright. The nearer I am to sleep, the nearer I am to full paralysis, but it will come on totally when lying down, just by trying to relax or rest, without sleep. It appears to be rest and relaxation of muscles that trigger the whole body paralysis. But I have become aware that there are other triggers of the limb paralysis: being too cold, being exposed to loud or repeated noise or any noise that I experience as too loud, doing too much, sitting too long, overuse of a muscle.

Paralysis then is central to my existence and dominates every single moment of my life. I am in a constant continuum with paralysis, either moving towards it inadvertently or trying to move away from it, till it hijacks me again."

History

Paralysed for nearly two decades following a course of amitriptyline, from the beginning my wife experienced negativity, denial and downplaying of severe illness and symptom experience.

The medical profession were often unhelpful and dismissive. They certainly did nothing effective to alleviate it or investigate her illness after the initial MRI and nerve conductivity test showed nothing obvious, alongside the standard tests that are not subtle enough to show up the cellular dysfunction in ME.

Her paralysis was not considered for over a decade and then was dismissed as not true paralysis by the neurologist she saw, without conducting any in depth physical tests or further investigation, saying only that she only needed reassurance. Some of the information and superficial tests were ignored, mis-recorded or omitted. Where we expected help, support, investigation, explanation, that was not forthcoming.

Following a six month period when she completely lost the use of her right hand and arm, she had a nerve conductivity test. The consultant doing the test mentioned that the paralysis might be linked to how cold she was. Her hand and arm were freezing cold like a block of ice. We now think that this could have been an indication for a form of Periodic Paralysis, linked to a rare channelopathy, which could have been further investigated. However we did not associate this at the time. There was no follow up as the test showed no problem with conductivity. The problem it seemed stems from elsewhere.

Unfortunately once you have an ME or the more vague CFS diagnosis, which is being mis-applied to people with neurological ME, it will be difficult to get further investigations. Tests that others might have access to are strangely denied you. So you cannot easily discover if you have treatable symptoms, nor can you find out if you have a rare disease or have been wrongly diagnosed. You are stuck in a fatigue wilderness.

A bad experience

Her next attempt to gain help led her down a very damaging pathway. She was advised that the paralysis was purely due to hypocapnia (low CO₂), caused by hyperventilation. It is true that hypocapnia can result in paralysis in rare cases, but the underlying cause needs addressing.

An aggressive treatment protocol, breathing into a Philipps mask for 4 hours a day was recommended. It was a traumatic and harmful experience from which she has not totally recovered. It was unachievable and painful attempting it.

We have since discovered that there are other reasons for low CO₂ in the body, not just breathing, for example a poor methylation pathway, mitochondrial damage, environmental poisoning, even hypothyroidism. There may be others.

There are other possible reasons than nerve damage, for the paralysis in Very Severe ME; it may be linked in some way to Polio, given that ME was initially called Atypical Polio and has been linked to enteroviruses or it could be linked to the dysfunction of the autonomic nervous system, mitochondrial dysfunction, environmental poisoning or channelopathy.

Paralysis is also associated with Lyme Disease, another disease with similar symptoms to ME, which is not been adequately tested or treated currently.

A possible mechanism: Potassium imbalance

Since then, we have also discovered a rare potassium imbalance, which manifests in several forms: Hypokalemic periodic paralysis characterized by muscle weakness or paralysis with a matching fall in potassium levels in the blood, primarily due to a defect in a voltage-gated calcium channel.(1)

And Hyperkalemia, where the potassium in the blood is elevated.

Periodic paralysis is triggered by a variety of things including cold, noise and overexertion, sleep and resting, too much or too little carbohydrate, exactly the triggers that my wife has. The mechanism is a rare channelopathy. There is not too much potassium or too little. It is just in the wrong place at the wrong time.

Severe attacks usually begin in the morning. People awake with marked symmetrical weakness, often with truncal involvement: mild attacks can be frequent and involve only a limited group of muscle and may be unilateral, partial or affecting just one muscle.(1)

Surely in this context the neurologist was wrong to dismiss my wife's paralysis as not true paralysis, with so many possibilities unexplored? Perhaps Potassium imbalance in the muscles could have been investigated, rather than dismissed?

Potassium imbalance may not be the mechanism for paralysis in ME or my wife's paralysis, though we have since discovered two studies exploring the possibility of channelopathy involvement in ME, (2)(3) but why is it that we, a carer and patient, can see possible links to how she might be becoming paralysed, that no one else seems willing to make or further investigate ?

She does not understand how she can have been left like this for two decades without it being adequately, safely and sensibly investigated or without anyone listening to her or asking her the right questions to find out what triggers it or even to observe her, when paralysed.

Ultimately the responsibility must lie with the psychiatric misrepresentation of a genuine neurological disease and the wrong focus on fatigue that has got in the way of biomedical

investigation and research and influenced so many practitioners, giving them a choice as to whether they even believe that ME is a physical disease or not.

This is the first time that we have ever found a pathway for her paralysis that makes sense to us, even if it is not the whole or the correct picture.

Research

This understanding and frustration led us to ask others for their experiences. In all we received 46 responses, which all confirmed varying degrees of transient awake or sleep paralysis. Unfortunately only 23 were able to confirm their agreement for publication.

These are their comments, giving a true glimpse into the real illness, Myalgic encephalomyelitis, a WHO acknowledged neurological disease and their experience of paralysis.

1 I had paralysis 16 years ago of both legs, really frightening and I had at the time been doing more (not over-doing though i should stress) so it was in no way deconditioning. I really thought I definitely had MS as what had been thought at the beginning when I got ill. All I did was total bed-rest and hope I would get walking again. My GP visited me at home and said she definitely thought it was my M.E and not MS. eventually I managed to start crawling to the toilet and then going downstairs on my bottom step by step. My legs have never been the same since then but I did get walking again and I know I am lucky that I didn't remain in that state. I have been ill 18yrs. My leg muscles have always been affected the most.

2 I have had different types of paralysis...partial paralysis of certain muscles-lungs, diaphragm and I'm sure heart-my legs and arms were just extremely extremely weak and therefore I was unable to do anything with them. My doctor said I had a form of Polio. I also suffered ,which is the worst symptom I have ever had, total paralysis,where I was conscious in my mind but unable to even move my eyelids. I couldn't speak at the time and couldn't tell anyone what was happening after the episodes passed. I couldn't even gesture with my arms. Truly horrifying.

3 I get Parkinson-like freezing where I have difficulty initiating movement. I get 'stuck'. This is worse if I've over done things.

I get a lot of neurological symptoms, such as what I can only describe as explosive involuntary movements - looks like I've been badly startled when I haven't been. I'm not even what I would call severely affected.

It took me a long time to accept I have M.E because of my neurological symptoms, few of which were mentioned in any modern descriptions of the illness.

4 Would you say that the complete loss of the use of one of your legs and partial loss in the other, is indicative of the paralysis you mentioned above?

(My wife) has suffered that paralysis since going through a Cancer operation and a course of radiotherapy. Neither the Cancer Dr's nor physiotherapists can explain it so it must be due to her underlying Severe ME, that has deprived her of the ability to recover nearly 12 months after the operation.

5 I have experienced it mildly, usually when waking, I just lie there and wait for it to pass. It's not comparable to what you are describing.

I get "stuck" too, have never mentioned any of these symptoms to GPs as I usually get a blank stare in return.

6 I experience sleep paralysis (whole body paralysis before or just after sleep) frequently, often several times a week. I knew what it was because I'd previously experienced it as a side affect of a medication years before I got ME. Getting movement back can take minutes or hours. Sometimes I can change my breathing though, which helps as my husband then knows I'm awake.

When very ill I also lose the ability to move various limbs, though whether I lose sensation with it or not varies (and I've not figured out why). It happened a lot more when I was over-doing it while still able to get out, and less so now I'm resting more (as I'm completely bed bound).

7 I had full body paralysis to the point of not being able to open my eyes, for most of every day for six and a half years. Terrible symptom. I was always scared I won't have a time each day when I could move, because I needed to eat. But most days I had a few minutes I could manage to!

8 I'll add that I have woken up and been unable to move. I want to move my arm, for example, and it won't budge. To me, that is paralysis. Luckily for me, it does go away, but it certainly is frightening.

9 That paralysis is both painful and alarming. I get it if I have had too many visitors or have been stressed. I just hope my vitals don't stop and rest quietly and it goes with a few hours.

10 I have total lower limb paralysis for most of the time and left side paralysis for a lot of the time. Its totally numb with like electric shocks darting through. On occasion I get total body paralysis and this can last for days. Most days for some time I will lose the ability to move my arms for some of the day, during these periods I now tend to try and sleep off the symptom. I find the paralysis is difficult my GP is supportive about it but I have been met with disbelief and even anger from others in the medical professions. My district nurses didn't believe I couldn't make it to the commode next to the bed because I physically couldn't move and I don't feel the need for the toilet, its taken me three years to get the continence support I need.

11 You know it's odd..... I didn't realise that I too had it... Not for long periods... But the inability to move for a brief time yes... The swallowing has been bad since the onset... Funny how you just accept it as part of what is happening...

12 I have had varying degrees of paralysis - often due to seizure or infection. It lasts anywhere between 3 hours and 3 weeks I have lost count the number of times I have been in hospital with this. Definitely in double figures My last stint was in Feb of this year was 11 nights. There's varying degrees of 'believing' this paralysis by NHS staff/ However this last time the doctor had seen it before and was good. I heard one nurse telling another nurse that M.E can paralyse from neck down wards.

13 I get the paralysis too, but not to the extremes of daily like you do. Usually it's both legs or combined with limbs. I get the tremors too & have tongue biting seizures. If highly stressed I get the sleep paralysis which is total body. I'm alone, so when it happens there is no one to notice or help. I just wait the hours out in bed because that's where I live now, cannot sit in a chair or be upright too long. If I pee the bed so be it (have plastic air topper under the sheet because of many pressure sores) or wear incontinence pads if I'm especially bad. Docs don't seem very interested & I have never been offered further investigation or treatments.

14 I'm in Canada I was totally paralysed for about 8 months. it started when standing up for the commode was too much after my blood sugar plunged and I had a huge crash. at first it only affected me from my waist down, but within weeks my upper body followed suit. It seemed like an energy-conservation mechanism. my specialist dr.....had never seen this before, so I was checked for MS which I didn't have.

The other week my legs were transiently paralysed again after the carer dumped them off the edge of the bed when she was trying to roll me over....

15 Your description of what you go through every day with paralysis breaks my heart. I have been suffering with M.E. for nearly thirty years, and I suffer from transient periods of paralysis, which are scary--and quite painful, but these do not happen every day.

16 I experienced about 6 months in 2006 when my right leg would collapse under me without warning and I could not move it - had to drag it behind me. Then it went away. I've had the odd occasion when I've been unable to lift an arm (including once in my GP's surgery so it's in my medical records), but nothing approaching Linda's experience.

When I was at primary school I often went to my friend's house while her mother was in an iron lung in the back room with polio. Until my parents realised the situation and stopped me going, that is. I sometimes wonder if this was a coincidence (the vaccine was introduced several years later).

17 I've never had the type of paralysis that Linda experiences, though I have had transient paralysis.

I had a diagnosis of M.E. in 1994, which was later changed (despite my protests) to CFS/ME after the 1996 Royal Colleges Report was published. Despite my illness becoming severe after catching viral meningitis, which can leave even healthy people with chronic neurological problems, my symptoms have never been taken seriously. Neurologists are the absolute worst people to see when you have ME. At one stage I was having A-typical seizures, which included paralysis of my arms. I was referred to a neurologist, who called the seizures 'dos' and then wrote in my notes they were panic attacks. This despite the fact my head tilted backwards, my tongue protruded, I could hear but not speak, I had a staring gaze, and afterwards I developed a speech impediment for days, paralysis in both arms which lasted for several hours, and slept for hours after an attack. Panic never was a symptom, as I was barely conscious. Nothing showed up on EEG or MRI scan though, ergo there was nothing wrong with me – being as though I already had a diagnosis of ME they'd decided before I even got to the hospital that I was mentally, not physically, ill.

18 Last year I suffered total sudden paralysis. That day I was experiencing all my general symptoms, distressed at what was happening to me and being ignored or told it was psychological by my then GP. Suddenly I felt the weird sensation I was often getting but much, much worse. Within 5 minutes I had total paralysis. Laying on the bed, unable to move any part of me more than 1% of normal. I remember a profound effect on my bladder (very full but would not work for hours). The phone had to be held for me and then I had trouble speaking. I was admitted to hospital. Tests MRI's (yep standard ones) and other tests came back clear, no brain lesions etc.. I was kept in for four days in a Neurology Ward for observation. Please note that by the time a Consultant Neurologist came to see me in hospital my paralysis was significantly eased, but feeling extremely unwell and with poor mobility.

The observation was a joke looking back. Blood pressure, was I eating, student poking me around but they didn't listen to me let alone seem to believe me. I was discharged and the discharge note didn't even describe that I was admitted with full paralysis. Things went from bad to worse with the NHS from then on.

A Neurologist Consultant follow up appointment revealed they thought it was all somatic (hysteria!!!). I couldn't believe it as I had so many physical symptoms also like severe gland problems, weird rashing, low blood pressure and other stuff. To cut a long story short I ended up with the Neurologists colleague seeing me (didn't ask for that but made it clear that I 100% disagreed with their Somatic view and it didn't go down well)....I was referred to psycho neuro not that I have heard from them. The also said 'do not go to A&E if this happens again and there will be no more test'. I was distraught to say the least.

... my total paralysis events (usually subsiding within a round 6 - 8 hours) have happened on and off but the first was the most extreme. Like you, a higher degree of paralysis seems to start or progress when sat or lying down. There are many more symptoms I suffer. My life is horrid with it all.

I find it unbelievable how the NHS Consultants are allowed to treat me. They told me there is no condition with total paralysis as always right or left side....lost count of the lies they told me. There is a sheer arrogance about how I was treated and dread the day I ever have to see one of them again....would avoid at all costs. Incidentally they were keen initially when they

thought I had some rare condition. Their disappointment when found I didn't was very obvious. The stress caused I believe escalated my suffering.

Just for the record I would consider myself to be an intelligent, up front honest person. I used to very active, always on the go, bubbly, trying to achieve, happy person.

I question why we are left to it. My weakness and poor mobility, on /off paralysis seems to be getting worse and more frequent. Also suffer with noise, vision, pain, severe head crawling, chronic gland pain and swelling, and cognitive problems.

19 Had hundreds episodes ability to control /or start or stop movement but as far as complete loss of ability to move these some ones off top of head-

- various episodes complete paralysis of various parts or whole of body
- sudden inability open mouth..move tongue or lips or utter sound
- sudden inability to speak can open mouth but not form words or produce sound just breath sound
- sleep paralysis
- sudden loss all muscle tone drop to floor fully conscious but completely unable move or speak-lasts minutes then ok then happens again and again
- repeated sudden cessation of breathing
- sudden inability to breathe voluntarily
- going to take step and unable to lift foot off floor try nothing happens
- sitting and sudden complete inability to move or communicate
- bout sudden eyes shutting repeatedly- wide awake but not able to control eyelids
- sudden inability to move tongue
- sudden inability to swallow-happens repeatedly
- sudden inability to cough-choke
- movement that should happen either voluntarily or involuntarily just doesn't happen- there's sudden complete loss of communication between brain and certain muscles that can't be overridden by conscious effort or will
- paralysis of thought! Literally unable to think

20 I had paralysis in a very bad way. Now I only have it sometimes and only locally at the spots where the infection/immune response is active.

I think it is a nicotine acetylcholine receptor problem caused by the infection and/or the response to the infection.

Nicotine together with an $\alpha 7nACh$ receptor modulator have helped me a lot.

21 "It was a global disablement comparable to paralysis"
-Dr Daniel Peterson, described the Tahoe mystery-malady.
Yes, it was!

It was not like fatigue. Not on any scale of fatigue.

And that paralysis is EASILY the most salient aspect of the illness that was eventually called "Chronic Fatigue Syndrome"

22 I have and had several different types of paralysis happening (now almost daily since xmas eve 2010), for various reasons thou I don't have all the answers. ppl with M.E. can have partial or temporary or permanent paralysis which is mostly ignored by doctors. I had partial paralysis with the full, upper respiratory & contagious that started M.E. March 16, 1991, I thought I was polio or a strain of it when it happened as it was the ribcage around my lungs, spine.

I have also had paralysis from medications repeatedly January-March 2003 that damaged me for life, Also paralysis left side of body, stroke,which remains weak and a movement disorder. I also have paralysis and cramping from dystonia. Also from low blood volume, hours of saline in hospital (5-7 hours) would stop the paralysis but only temporary. as she mentions on the blog, electrolytes can be out of whack especially potassium and can cause paralysis. however, your electrolyse can be fine, they often are in people with m.e., that doesn't show dehydration but they are dehydrated to some degree, also electrolytes can be fine in a blood test but the ions are not charged or charging which can cause paralysis. If I get too much pressure on brain, I start getting same reaction as Jan/2003. Also low blood volume regular doctors think a RBC count tells if you have low blood volume which it usually doesn't, it's a neluar test, many with m.e. are helped by saline infusions some are not. also we are low on oxygen which can also cause paralysis (and m.e. itself which is also ignored. In a study by student here in the 90's her fathers patients were missing an enzyme or low in it and we need to drop the oxygen from the blood to the organs etc. DH_23, have still ignored. I have had many explainable causes of paralysis , however, the doctors involved hide them, as in not on med files.

23 I am absolutely thrilled that someone is flagging this up!

My whole journey began when I started having episodes where I could neither move nor speak. I was initially put on a stroke ward because of this.

I was having several episodes a day but all scans and tests coming back 'normal'

Everyone was working hard to find out why these attacks or episodes were leaving me in so much pain and so exhausted and unable to speak or walk properly afterwards.

One day out of sheer exasperation I googled exhausted and painful legs. This took me to an m.e. website where I was stunned to see a perfect list of all my symptoms, including...stroke like seizures. It was The Hummingbirds Foundation. I took this to my GP.

My GP said....we've been looking at this back to front. The attacks aren't causing the exhaustion, if you have m.e. the exhaustion is causing your body to shut down.

This is how it feels for me. Almost like my bodies defence mechanism. Once I had this information, I rested. I did not have an episode of paralysis for 10 days.

If I do not rest or if I have too much stimulus...noise, talking or I do too much...my head goes cold and numb, my speech becomes slow and slurred and I stutter. My actions slow down until I can no longer move or speak at all. But I can still hear everything around me.

When I can move again, it takes my legs a long time to remember how to walk again and my speech can be slowed for some time.

For me, I definitely feel like my body is saying, 'right, if you won't stop to rest, I'm gonna do it for you' and then I just shut down from head to toe.

My last hospital admission was due to me drifting in and out of these episodes for 5 hrs being only able to mutter a few words before I lost speech again and unable to move the whole time.

Sometimes when I wake I cannot move. My husband or mom have to move my arms and then they pull me up to prop me up a little as they know I feel very out of control if I'm awake and laid flat. I feel 'safer' and more in control if I'm in more of a sitting position.

I also suffer with sleep paralysis, and very much like your wife my husband has to move my arms off the pillow for me in a morning.

Summary

The responses were painfully familiar and shocking in the discovery that there are considerable others with very similar experience being ignored and neglected medically. Or not receiving adequate explanation.

These responses highlight that the most severely affected can experience regular total body paralysis, partial muscle, limb and body paralysis, transiently during the day and /or totally, following sleep. Paralysis can be occasional, repeated daily or weekly, is erratic and unpredictable, may be accompanied by severe to extreme pain, cannot be broken out of at will, is completely incapacitating and interestingly even some of those less severely affected, nevertheless experience some paralysis or 'get stuck'.

Further, the paralysis, whilst apparently transient, can remain for whole blocks of time, ranging from a few minutes, hours, days, weeks to months and in one instance for nearly a year to date.

Furthermore the paralysis can impact breathing, swallowing and speech. For anyone in these circumstances, daily living becomes immensely complex especially as movement and communication are affected. This survey highlights that paralysis is a recurring experience in ME, with many common elements involved, although impacting erratically and variably. There is no excuse not to use it as a key symptom in definitions that are used to identify ME and would easily help to separate ME from chronic fatigue.

This surely indicates that there is a common theme of paralysis amongst the severely affected. They are not isolated instances. There is currently not enough examination, biomedical

investigation and comprehension about what people are going through, nor adequate medical explanation, only varying hypotheses. There is no real language, even amongst people with the disease, to help them to identify this key symptom clearly, or articulate their complex symptom experience, because the medical focus is not upon neurological symptoms, as one might expect for a neurological disease, but on fatigue.

Neither is there adequate explanation for these profoundly disabling and disturbing physical-complex symptoms. The reality of paralysis is simply not being adequately represented, nor medically acknowledged or supported. Over a third stated that they had experienced denial, negation or ignorance regarding paralysis, although in reality, it is likely to be a higher proportion, as it was left for people to share what they wanted, so not everyone commented on this. It indicates that a more specific questionnaire would provide greater quantifiable data and would be invaluable, though would be difficult practically for people with such severe disability and complex symptom interaction.

Many were only too pleased to share their experience of paralysis to raise greater awareness of the true physical nature of ME. It is not commonly identified as a main symptom. It needs to be.

Thanks

With many thanks to all those who made such effort to contribute in order to highlight this dramatically disabling, recurrent experience. It is unacceptable neglect to ignore this or dismiss it. If only it were taken seriously, we might all have some answers. By highlighting this is not just an isolated experience, but seems to be a common reality, particularly of the most severely affected, we are hopefully making a small step in the right direction.

Conclusion

Clearly there is some similarity between most people's experience in this research sample, something is occurring which is causing people either to be totally and/or partially unable to move or function. This is such a serious physical symptom. It deserves more attention and medical investigation. It requires specialist input from medically knowledgeable consultants.

What is also needed, however, is serious physical research in this area and a change of direction and attitude, not least from the charities, who unbelievably, do not even identify paralysis as a symptom on their main symptom lists. They need to start speaking up about the true physical dysfunction and symptoms of genuine ME.

Paralysis is not just tiredness. Paralysis in ME is frightening and regularly incapacitating for people and very real. It is long over due for respect and biomedical investigation.

It leaves us still asking how can such a serious, severely disabling symptom be so dismissed, neglected or misinterpreted? How can people be left to cope for decades in this state, often

without adequate health or care support? We do not understand and can find no justification for it.

Unfortunately the new UK ME Research Collaborative, supported by mainstream charities, seems to be a step in the wrong direction for people with ME, giving more apparent acceptance and power to the psychiatric paradigm and not clearly separating ME research from psychiatric fatigue research. This is a huge mistake, which will potentially leave the most severely affected people with Myalgic encephalomyelitis still without the much needed validation of a clear, separate definition from fatigue, that is essential in order to honour and thereby accurately and fairly investigate their serious physical illness, particularly the more serious symptom of paralysis.

What is required is a politically effective voice, across the board to represent the most severely affected, to ensure that people with Very Severe ME have a genuine voice and fair treatment. It is hoped that the newly created Severe Myalgic Encephalomyelitis Understanding and Remembrance Day on August 8th, each year, will be a focus for this much needed voice and have a powerful impact.

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