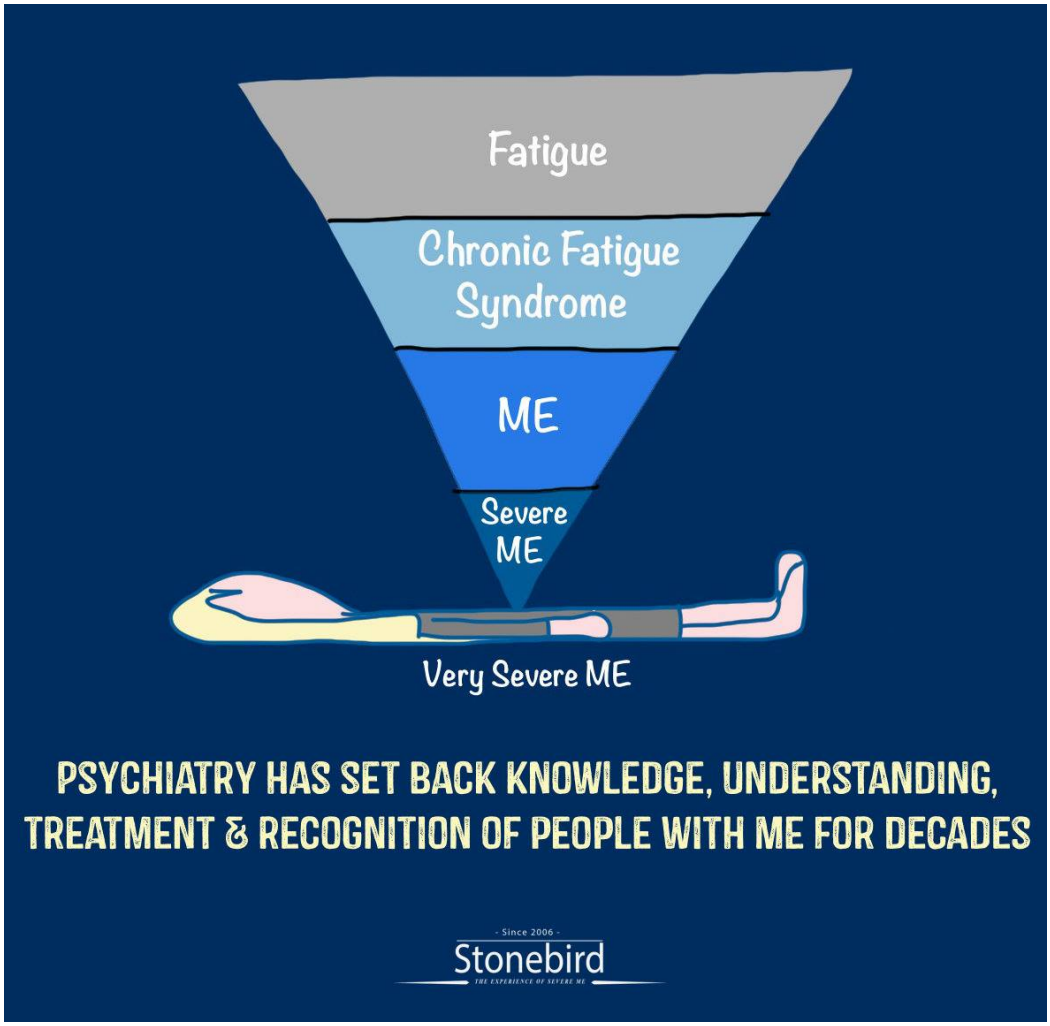
Severe/Very Severe ME : The need for proper symptom identification.



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Stonebird

THE EXPERIENCE OF SEVERE ME

Severe/Very Severe ME : The need for proper symptom identification.

Greg and Linda Crowhurst August 2019

Living tortured, isolated, invisible lives of silent agony, on the furthest edges of existence, people with a Severe/Very Severe ME diagnosis are some of the most tormented and isolated, neglected people in the UK.

Their illness is a trauma and a tragedy. Deterioration can be instant, unpredictable and severe, following even the slightest interaction or intervention. The disease goes on for decades and decades, without resolution or proper recognition.

Unfortunately an incredibly powerful psychiatric lobby has dominated social, health and welfare policy in the UK, for decades on end, perpetuating the untruth that Myalgic Encephalomyelitis (ME), a WHO G93.10.3 classified neurological disease, is a mental health disorder.

Things have only got worse in recent years with the promotion, incorrectly, of ME as MUS, a mental health condition treatable through IAPT psychological therapies.(NHS 2019)

If someone has any other physical disease, most likely their symptoms will be correctly identified and recognised, the physiological cause will investigated and there will be an understanding of what to do, to treat the person, once diagnosed.

Unlike people with ME, patients with other common diseases like Diabetes or Cancer, do not have to contend with:

- interchangeable names with totally different interpretations
- unsafe treatment protocols
- invisibility of suffering
- no appropriate tests or thorough investigation
- neglect of symptoms
- specialists choosing whether or not to believe the patient is physically ill
- no recognition of the specific cause of the disease, leaving it open to misinterpretation

- no long term specialist support

Cancer and Diabetes, however, both have a clinical pathway, monitoring, support and respect.

What a different world to ME!

Abandonment and Neglect

Unimaginable and intense neglect and dismissal, that is what my wife suffered, once she was diagnosed over a quarter of a century ago with Severe ME; professionals were far too quick to imply there was no physical basis for her extreme, off the scale, suffering. No one knew how to help her.

That is an incredibly long time to have no proper answers or understanding of what is fundamentally wrong.

Hope of getting real medical respect and investigations and any safe, appropriate treatments has been impossibly hard.

The prevailing biopsychosocial paradigm has heavily influenced other specialisms, particularly neurology, into believing that ME , fundamentally, is not a disease, but a mental health condition and should not be thoroughly investigated.

Our own experience has shown us just how much nurses, nursing assistants, doctors, neurologists, other specialists and occupational therapists, under the influence of the biopsychosocial model, do not see the person or their symptoms in its true context, that of a neurological disease with multiple systems affected.

Tests that could have and should have been done, in the past, have not been done thoroughly or at all. Symptoms have been ignored or gone under-investigated.

Having an ME diagnosis, misinterpreted as Chronic Fatigue, makes it incredibly hard to be taken seriously or treated properly or safely within the health care system.

Psychosocial misinformation has wreaked absolute havoc in our lives. I fought once for seven long years, at the highest level, to get a biomedical service here in

Norfolk, only to find out I had been wasting my time.

The suffering caused by the psychiatric misinterpretation of ME, is terrible and unquantifiable. It reaches across all medical specialities, it leads to a dearth of safe treatment protocols, it results in the abandonment of the most ill, to, somehow, just "*get on with it"*, without investigation, treatment, hope or the provision of adequate, long term, aware care.

You Cannot Sit On The Fence!

Services are still compromising people's lives away.

There has to be a complete paradigm shift and break with the failed psychosocial fatigue pathway, that has come to represent health care for ME in the UK, for there to be any real hope for people.

It is our hope that recognition, validation and a proper medical pathway, based upon much better criteria than those in use today, will become the norm for people with ME, in the absence of a specific test.

A much tighter definition of ME is required, alongside a more accurate picture of the disease, especially for the more severely affected, which aims to explain, medically, their wide range of serious physical and cognitive symptoms.

You cannot sit on the fence, looking both ways, playing both positions. You should not be able to choose whether to believe ME is a physical disease or not, depending on whose viewpoint you decide to endorse; clearly, that is a nonsense.

Either you accept that ME is a neurological disease, as classified by the WHO, with pathology underlying each symptom or ignorantly, you consider it to be idiopathic fatigue, with no pathology; which is the terrifying biopsychosocial view.

To pretend there is a middle way in ME, where you compromise with the psychosocial pathway, is inconceivable and unrealistic. ME cannot be both a disease with pathology and a condition without it.

Even so, even if you recognise that ME is a physical disease and apply a better,

more specific definition, still much of the necessary medical information to confirm it as a disease is missing. Without any test, those identified as having ME are still likely to be ill for different reasons and may have comorbid unidentified diseases or even be misdiagnosed.

There is a danger that “ME” will still remain an umbrella term, albeit a tighter one.

No one, for example, can say for certain if ‘their ME’ and their range of symptoms is caused by exactly the same thing, with exactly the same physical processes; whether they indeed do have the same illness as someone else.

A clinical judgment, without tests, at best, is only a very good guess.

The issue, it seems to us, is that the central concept of the disease, Myalgic Encephalomyelitis, as enteroviral in origin, initially defined back in the 1950’s, has become removed from the definition of “ME”.

Nowadays, unfortunately, “ME” is represented as little more than a limited list of signs and symptoms, primarily focussing on fatigue, with an unclear range of triggers, without proven, specific physiological explanation or with an understanding of the disease process. ‘ME’ really means what anyone decides it means, which is a terrible state of affairs.

The possible association with Polio (Dowsett 2001) seems to have got lost too, in its representation as primarily a Fatigue illness of unknown origin.

All the time the central core issue - what caused it- is ignored and a vague fatigue focus is sustained, different conditions and diseases are likely to be included under the term “ME”.

At the end of the day, unless you identify the physiological causes for the symptoms, especially the most severe symptoms that people identify as having (the ‘why’ they have them), for example:

- why there is head pain
- why there is a lack of energy
- why there is body pain
- why there is cognitive dysfunction

- why there are muscle spasms
- why there is muscle paralysis
- why there is parasthesia
- why there is difficulty swallowing
- why there is hyperacusis
- why there is photophobia

...there is room for misinterpretation.

Better testing is required. These symptoms do not come out of thin air and would surely be taken so much more seriously when individually presented. There are many causes that could be explored. Each is disabling in its own right. Add them together, however, and it is 'just ME'.

All people can rely on is the safety and accuracy of their diagnosis, if it is reliable.

This has implications not only for safe health care experiences, but also for claiming benefits and gaining correct level of care provision; especially given the current focus on managing symptoms- as if those with Very Severe ME can ever have enough energy or ability to "manage" their symptoms, which are extreme and never-ending.

When practitioners do not believe the person is physically ill or do not know what is really going on in the person's body, recommending treatments, either for ME or for other conditions, is a dangerous hazard.

Management strategies that are rigid and incremental are unrealistic and endangering within this context.

People with ME hope that there will be reliable research to shine new light on their disease. Research though, still has a long way to go in order to be able to provide the specific information required to enable safe health care and treatments.

When you look at the current state of ME medical research it is not clear who is being researched or whether they even have the same illness, even though they may fall into some kind of generalised "ME" umbrella cohort.

Those most severely ill are mostly overlooked or too ill to participate or too long

term ill to be considered for inclusion.

Not Enough Is Known Yet

Who can even say they have got “ME” ?

Without physiological confirmation and with varying definitions used, no one can safely say what they have got. A diagnosis of exclusion is not really that reliable it seems to us.

For many years we have fought and argued for a biomedical pathway here in the UK, to stop the widespread psychiatric misrepresentation, mistreatment and negation of ME. It would certainly be a step in the right direction.

However, who can say that if a biomedical “ME” service was created tomorrow, it would have the right agenda or correctly trained practitioners and specialists?

Who can say it would be looking in the right places or focusing upon the right physiological issues?

Who can say it would be sufficiently aware of the great risk of inflicting harm, especially in Severe/Very Severe ME?

Who can say it would know how to genuinely help, not risk deterioration?

Would it even have the required clinical excellence and state of the art testing that might be required?

Would a standard risk assessment protocol be put in place before interacting?

Not enough is known yet.

The most severely ill are at great risk, all the time the ‘how’ of interaction is not understood.

Their health is at great risk all the time there is no flexible, aware, medical, home bound service available for those too ill to attend clinics. Hospital settings are

rarely ME friendly for those who struggle to attend.

Let us not forget that the most ill are likely to be invisible, off the radar, not provided for, not necessarily seen or their severity and needs understood.

A completely different approach, based on an honest prognosis, acknowledging how vulnerable, frail and potentially easily harmed people with Very Severe ME can be, by even the slightest inappropriate interaction, expectation, demand or contact, is required.

Let us not forget that ME is an incurable, long term chronic illness.

Who, then, can deny that being told you have "ME" is, still, to have your life ruined?

The point is this, in ME, proper symptom identification and understanding, must be the starting point.

Recognising Differences in Severity

There must be a clear focus on the disabling nature and severity of each symptom alongside a recognition of physiological processes that might be causing them.

There is a quantum leap, we suggest, in experience and needs between each severity level. Without this recognition, the most ill will not be seen or represented adequately, their differences will be ignored.

That is how you protect people from harmful expectations, environments, demands, misinterpretation, endangering treatment or management protocols.

Unfortunately for people with Severe/Very Severe ME, many of the investigations that could shed light on their symptoms or diagnose comorbid or alternative diagnoses, may be too invasive or endangering to health.

It is important to recognise that even if those investigations are not possible, it does not mean that there are no comorbid, alternative diagnoses or that there is no underlying ME pathology.

ME, for example, was originally described as : a "*paralytic illness of worldwide distribution*" (Acheson 1959).

We, however, are extremely concerned that paralysis is not treated as if it is part of ME today. Paralysis, like many of the other symptoms, in Myalgic Encephalomyelitis is generally ignored, down played, disrespected or treated as not real.

Who is treating or researching or taking paralysis seriously as a fundamental symptom especially in Severe/Very Severe ME? Who can help and advise and support the detailed investigation needed for this particularly devastating symptom?

In our experience, it requires going outside of ME health provision to gain anything like the medical respect required.

We conducted our own study (Crowhurst & Crowhurst 2013), it shocked us when we discovered how many others suffer from paralysis. The study (n=46) showed that the most severely affected may experience regular total body paralysis, partial muscle, limb and body paralysis, transiently during the day and /or totally, following sleep.

A recent study by Holtzman et al (2019), found 29.45 % of respondents experienced paralysis as a symptom of PEM (Post Exertional Malaise), however ME patients are in great danger of being told their paralysis is a form of hysteria, to be treated with psychotherapy.(Geraghty 2016)

Yet, as the chart below shows, there are a whole range of possible testing and diagnoses available for Paralysis that, in our experience, are really difficult to get done.

With no one else to advise us, we have struggled over decades, to work all this out for ourselves.

The chart shows how symptoms do have underlying pathology. They are not imagined or disconnected from physiological pathways.

Paralysis:	**Alternative possible diagnoses:**	**Some possible tests that might indicate underlying physiology of symptom, whether part of ME or alternative diagnosis :**	**Considered to be part of ME:**
Underlying physiology needs identifying: may be brain damage, spinal chord damage, muscle paralysis, nerve damage.	Periodic Paralysis, Channelopathies, Hemiplegic Migraine, Adrenal or Aldosterone insufficiency, Electrolyte imbalance, Tumor, Nerve damage, Kidney Disease, Hyperthyroidism, Cataplexy and Narcolepsy, Bells Palsy, Gastoparesis, Stroke, Mitochondrial Disorder, MELAS	Electrolytes, Genetic Testing, ECG, EMG, Muscle Biopsy, Kidney function, Thyroid auto-antibodies, T4, TSH, MRI, Lactic Acid test, Lactate Dehydrogenase Test, ACTH test, Aldosterone/renin, Cortisol, Nerve Conductivity Test	Historically so, recognised by Ramsay, Dowsett, Richardson, Bruno, but not recognised in current diagnostic criteria, leaving people experiencing paralysis open to denial or misinterpretation as MUS or FND

All the time you have a group of people identified by limited symptoms, without recognition of the underlying disease pathology, the label “ME” is rendered relatively meaningless, especially in a psychosocially biased health service, offering inappropriate therapies as treatments.

In all honesty, no one is currently safe because:

- they truly do not know what is physically wrong with them
- they do not know why they are so very ill
- they do not know why they are still denied proper recognition.

Saying you have ME, sadly, is still not enough to guarantee safe treatment or understanding.

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