IOM Committee - Cognitive, Sleep, and Diagnostic Issues Patient Survey

#1

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 10, 2014 9:32:09 PM
Last Modified: Thursday, April 10, 2014 10:31:28 PM
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PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

FIRST IN IMPORTANCE TO ME IS THAT THE DR'S GET EDUCATED THAT CFS IS A REAL ILLNESS.
OVER THE LAST 10 YEARS , I HAVE NEEDED TO SEE A VARIETY OF SPECIALIST .
EACH IN THEIR ON WAY WAS COMPLETELY "IGNORANT" ABOUT THE ILLNESS .
EVEN THOUGH I HAD A DRUG REACTION TO A DENTAL ANESTHESIA DURING A ROOT CANAL .....NO ONE WAS WILLING TO CONSIDER MY UNDERLYING CHRONIC HEALTH PROBLEMS (ie CFS) AS THE REASON FOR THE REACTION.
THEIR RESPONSE TO MY HEART RACING OUT OF MY CHEST AND PANIC ATTAC WAS THAT " NEXT TIME I JUST NEED TO TAKE A XANAX BEFORE & HAVE SOMEONE DRIVE ME ! "
.
I HAVE HAD PROBLEMS "EDUCATING " A
CARDIOLOGIST, ANAESTHESOLOGIST ,
ORTHOPEDIC SURGEON, GYNECOLOGIST. DENTISTS.
NONE ACCEPTED MY DIAGNOSIS AS REAL AND ARROGANTLY DEBATED IT'S EXISTENCE WITH ME.
IT'S PRETTY SCARY WHEN YOU ARE NEEDING TO GO "UNDER THE KNIFE" ...
AND NO ONE IS WILLING TO ACCEPT YOUR ILLNESS AS "REAL" NOR TAKE INTO CONSIDERATION THE MANY NEURO-ENDOCRINE-IMMUNE SYSTEM DYSFUNCTIONS YOUR BODY HAS.
SOME TYPE OF GUIDELINES OF THE BASIC
PRE-SURG TESTS THAT NEED TO BE DONE TO ASSAY THIS NEURO-ENDOCRINE-IMMUNE SYSTEM DYSFUNCTIONS NEEDS TO BE DEVELOPED .
UNLESS THERE IS A QUANTITATIVE DIAGNOSTIC MARKER PRESENT ...
THEY WILL NOT BELIEVE THAT THE ILLNESS IS "REAL "
SO, RESEARCH ABOUT THE MANY DYSFUNCTIONS CFS PTS HAVE NEED TO BE "VERIFIED " AND PUBLISHED IN MEDICAL JOURNALS THAT THE SPECIALISTS WILL READ .

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

IS THE TERM "MYALGIC ENCEPHALOMYELITIS " A TERM THE DR'S IN USA ARE WILLING TO UNDERSTAND & ACCEPT ?

CFS IS A LOUSY NAME ....BUT I WOULD RATHER HAVE $$$ PUT INTO RESEARCH THAT WOULD DEVELOP BIO-MARKERS AND FROM THERE A "REAL" NAME BE GIVEN TO THE ILLNESS THAT IS CAN NOT BE REFUTED.
WILL THE "M E " NAME CLEARLY IDENTIFY THIS ILLNESS WITH ALL IT'S MANY SUBTLE DIFFERENCES . ?
ONE DAY I AM FIGHTING THE "IMMUNE SYSTEM " ......
THE NEXT IT'S THE MUSCLE PAIN, ...
THE NEXT'S IT'S THE GI SYMPTOMS, ...
THEN THE STRANGE RAPID HEART BEAT, WOOSY, WASHED OUT , RINGING IN THE EARS , , ...
THE BRAIN FOG & OTHER COGNITIVE IMPAIRMENTS ....
AN ACUTE VIRAL ONSET ....VS .NON ACUTE ,,,
FATIQUE VS ABSOLUTE EXHAUSTION ,,,,,,,,,,
OH, YEA I'M LEAVING OUT THE SLEEP DISORDERS ....
SORRY, BUT I AM UNABLE TO PROPERLY WRITE AN "INTELLIGENT " RESPONSE TO THESE QUESTIONS.
I HAVE MORE QUESTIONS ABOUT THIS WHOLE PROCESS AND WHAT IT IS GOING TO ACCOMPLISH THAN ANSWERS.

A HUMBLING EXPERIENCE FOR A FORMER
MEDICAL TECHNOLOGIST, B.S. , WITH A
MT (ASCP) CERTIFICATION AND 12
YEARS OF MICROBIOLOGY EXPERIENCE.
BUT THAT WAS IN "ANOTHER LIFE " ...>.25 YEARS AGO,

#2

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 2:29:31 PM
Last Modified: Friday, April 11, 2014 2:31:06 PM
Time Spent: 00:01:35
IP Address: 217.28.0.157

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Importance of pacing and early diagnosis and specialist care

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Cfs devalues our illness and is widely misunderstood. Me works better

#3

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 3:03:54 PM
Last Modified: Friday, April 11, 2014 3:04:43 PM
Time Spent: 00:00:49
IP Address: 146.90.34.75

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

It's not FATIGUE.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis or Ramsay's Disease

#4

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 3:14:06 PM
Last Modified: Friday, April 11, 2014 3:17:21 PM
Time Spent: 00:03:15
IP Address: 72.93.165.82

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That the illness is not psychiatric and that many new problems can crop up in a patient (such as cancer), so all symptoms should not just be lumped under CFS/ME and ignores.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think we should stick with the myalgic encephalomyelitis terminology. It has a long history and there is strong research support for its accuracy.

#5

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 3:25:39 PM
Last Modified: Friday, April 11, 2014 3:27:27 PM
Time Spent: 00:01:48
IP Address: 174.144.253.174

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it's REAL
That it's NOT depression
How to diagnose it correctly
That patients should NOT be told to exercise their way back to health, and WHY this is detrimental.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME sounds like a real disease.
CFS sounds like the BS it was intended to be.

#6

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 4:30:26 PM
Last Modified: Friday, April 11, 2014 4:36:12 PM
Time Spent: 00:05:46
IP Address: 67.174.113.35

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1) Mitochondrial dysfunction and correct supplements to help with.
2) Testing for active viruses or antibodies to said viruses
3) Intestinal health/Leaky gut syndrome and it's connection to undiagnosed candida overgrowth that cannot be accurately tested with blood test, must be a cultured stool sample.
4) The heart-brain connection, and how sleep apnea is key!! Sleep apnea helps cause the seizures!
5) post exertional malaise and understanding how stress and exercise affects the body.
6) Be aware of adrenal fatigue and do not rely on a blood test to diagnose it. Use saliva tests.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Get RID of CFS!! neuro-endocrine-immune disorder is more appropriate.

#7

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 8:02:44 PM
Last Modified: Friday, April 11, 2014 8:21:26 PM
Time Spent: 00:18:42
IP Address: 72.188.32.110

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1. Check for microbes - viral, bacterial, fungal and parasites in the blood, in the stool, in the saliva, in the tears, in the tissue.
2. If someone has little or no stage 3 and 4 sleep they aren't releasing HGH so cell repair isn't happening.
3. There are many KINDS of pain: joints, muscles, nerve, skin that are not explainable but they are just as bad or worse than pain caused by a specific injury. Pay attention to the pain level for these unexplainable kinds of pain. Lack of treatment for this can cause severe bouts of hopelessness.
4.Fatigue - that my vagus nerve has been telling my brain for 18 years to get me to lie down is significant. My sleep is disordered but that is different from neuro immune behaviors. And Fibro Fog is real.
5. I have never met one of us who wouldn't go to any lengths to get better. We are not psychosomatic and this is most definstely not a mental illness. I have the labs to prove it now. Stop f#%|ing around about that.
7. Kids of parents with this illness have no support or way to cope because of the govt smoke and mirrors. This is an assault on innocent lives that needs to stop now.

There are tests you can do right now that can be used to diagnose. Dr Klimas, Dr Lipken, Dr Cheney, they know what they are. Ask them!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I'm fine with ME. We just need to get the name and what it means into the mainstream so there is a shorthand for it.

Or maybe NeuroImmune Microbe Imbalance ~
Yes that's it: NMI. If you choose this I want credit;)

#8

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 11, 2014 7:59:37 PM
Last Modified: Friday, April 11, 2014 9:41:04 PM
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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The most recent published research on immunological, and neurological abnormalities including intestinal and brain dysfunction in ME. To teach the Canadian Consensus Criteria or one that is modeled on the CCC

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis (ME), is an organic disease.
Myalgic Encephalomyelitis (ME) was identified as a new
clinical entity in 1959 and has been acknowledged as a disease of the central nervous system/ neurological disease by the World Health Organization since 1969.
Cognitive impairment, (muscle) weakness, circulatory disturbances, marked variability of symptoms, and above
all, post-exertional malaise: a long-lasting increase of symptoms after minor exertion,are distinctive symptoms of ME. Post-exertional malaise and cognitive
deficits e.g. are not mandatory for the diagnosis CFS,
which has has caused much confusion and impeded progress in research over decades. I would strongly recommend the name Myalgic Encephalomyelitis.

#9

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:52:03 AM
Last Modified: Saturday, April 12, 2014 1:24:58 AM
Time Spent: 00:32:55
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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is difficult to diagnose, but important to put the work into it. It is not impossible to treat. While we lack a proven central pathology, there are many symptoms and associated diseases which are treatable. Tests which might be useful can be found in the 2003 Carruthers et al. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols" and updates such as the 2011 "Myalgic Encephalomyelits: International Consensus Criteria", and from specialists such as Nancy Klimas, A. Martin Lerner, Jose Montoya, John Chia, Derek Enlander, Sonya Marshall-Gradisnik, Kieren Hollingsworth, Frank Duffy, and so forth.
As many of our specialists have requested, it's essential to let the specialists define the disease as is typically done in other diseases. They have said that Carruthers et al.,
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols should be the jumping-off point, with updates as new research comes in. There has been little funding, and a lot of the research is conducted on cohorts with many patients having other diagnosable conditions (e.g. http://www.ncbi.nlm.nih.gov/pubmed/21132135), so it's a bit tricky to simply survey the extant literature.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS should not be used alone because it is confusing. Other diseases are not typically named for a single symptom (do we call COPD "chronic coughing disease"? or diabetes "chronic peeing disease"? Of course not. That would be silly and confusing, and many of the patients--and physicians--would doubtless find it trivializing.) We tend meet lots of people who say, "I hiked/stayed up late a few nights this week/work too much... I feel tired... I think I have CFS, too!" Many of them do not appear to be joking.

Our muscles hurt, we do appear to have brain inflammation, and lots of us have neuropathy, so I do not think myalgic encephalomyelitis is inaccurate. However it shouldn't really matter, as Lupus and malaria are not accurate. Myalgic Encephalomyelitis is already coded in ICD. A lot of work has been done to make it SSA-ready in the US. It sounds like an actual disease, which is kind of essential when one is in ER and needs to be taken seriously (too often we are not, and we would actually be dismissed from ER with our asthma or complications of ME/CFS or kidney stone or whatever brought us there, completely unaddressed).

Since ME has been maligned in UK, we might eventually need another name, after we have more research. There is really no point in changing it from ME now. Thinking about a recent example, "chronic multisymptom illness" is no better than "chronic fatigue syndrome".

#10

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 6:25:51 AM
Last Modified: Saturday, April 12, 2014 6:52:39 AM
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IP Address: 70.131.112.103

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1. doctors ignorant of the condition and unwilling to make a proper diagnosis: most important issue facing a patient, and all future patients with this disease
2. doctors scorning patients who have been diagnosed, using it as a reason not to treat them for other conditions; the doctor needs to understand the danger of shunning patients
3. What the disease is, how serious it is, how early intervention might change the prognosis for an individual patient, and then learn the tests that will help the doctor to find treatments to try.
4. How to read the medical literature for the ideas that are finding success, and try them, as is their profession

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis is a reasonable name.
The post exertional response, cognitive problems, sleep problems and interference in other physical systems of the body mark the disease.
Other names, like Neuro Endocrine Immune Disease (NEID), are feasible, if doctors will accept them to identify a disease of the body.
The mind-body school of medical thought is not very useful in the process of naming this disease, as the cure and treatments will not arise from that line of talk.

The name invented in the 1980s by the CDC is a pure and simple insult, and not descriptive of the main aspects of the disease. It should be dropped from use anywhere and everywhere.
Fatigue is something that goes away after rest and sleep, like hiking all day then sleeping all night, and hiking again the next day. It never was the correct word; it was selected by psych doctors, shrinks, who then proceed to ignore patients, having made us pariahs to doctors who treat physiological diseases. The worst shrinks prescribe treatments that make patients sicker, lifelong disabled, and of course there is no liability on the shrink who caused this damage, while certainly being no help. It is hard to call it a treatment when it is a near certainty that the program of forced exercise will make the patient worse for life.

#11

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 11:54:02 AM
Last Modified: Saturday, April 12, 2014 11:58:21 AM
Time Spent: 00:04:19
IP Address: 81.101.68.23

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How serious the illness actually is and that it affects all bodily functions.
Also they must understand the devastating effect that exercise (even basic daily tasks) have on the body of an ME person.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

As research has now found inflamation in the brain and the main cause of the fatigue is that the muscles are not receiving/making enough energy to power them Myalgic Encephalomyelitis seems the appropriate terminology.

#12

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 11:58:36 AM
Last Modified: Saturday, April 12, 2014 12:02:43 PM
Time Spent: 00:04:07
IP Address: 108.56.197.148

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That no medical test can diagnose CFS, that doctors should be aware of the symptoms of CFS, that doctors should understand the disability that accompanies the illness, and that doctors should know that CFS is not a psychiatric illness!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think the terminology is fine

#13

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 11:58:40 AM
Last Modified: Saturday, April 12, 2014 12:05:03 PM
Time Spent: 00:06:23
IP Address: 80.229.113.111

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

More information about symPtoms such as heart palpitations, sleep issues, foggy brain, joint pain as doctors don't seem to relate these to ME

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ChrOnic Fatigue makes it seem less serious than it is. I am happy with Myalgic Encephalomylitis

#14

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 11:59:33 AM
Last Modified: Saturday, April 12, 2014 12:16:55 PM
Time Spent: 00:17:22
IP Address: 68.63.50.37

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Healthcare providers need to understand that ME/CFS is more than just one problem. It is a syndrome. They need to understand the fluidity of symptoms and how they manifest. Even if pain is well controlled, fatigue and/or cognitive function may still exist to such a degree to cause a high state of impairment. Healthcare providers also MUST understand that a flair or exacerbation of symptoms can be caused by a multitude of factors, including a change in medication. Even a minor change in a prescription regimen can cause issues that have to be worked out. A diagnosis of this disease is not the end of the journey but the beginning. Healthcare providers need to understand that. They need to understand the deep impact this has on their patients' lives. It prevents patients from working, maintaining relationships, and can even cause problems with personal hygiene and care. This is also a diagnosis of exclusions, meaning that they must have patience with their patients! A patient, like myself, may have been to nearly every -ologist out there and still not have correct answers. My journey took me through family practice to gynecology, urology, otolaryngology, psychiatry, sleep labs, cardiology, and finally infectious diseases before a diagnosis was made. (I turned down offers of referrals to nephrology and pulmonary because I thought there were no answers to be had there.) And there was no real relief in the diagnosis. The one positive about that whole process was that I could be certain I did not have a variety of other illnesses including lupus, MS, muscular dystrophy, AIDS, cancer, and several others that I cannot recall. So understand that this is a syndrome. Understand that your patient may be fully compliant with your treatment plan and still have serious flairs. Understand that the long road to diagnosis leaves many people distrustful, broke, and sicker than they were in the beginning. Understand the diagnosis is only a relief insofar as it rules out other problems. There is no real relief in CFS.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis is just ridiculous. That needs to be dropped altogether. Chronic Fatigue Syndrome is better in terms of being understandable. However, it captures only one part of the problem. I like the Chronic and Syndrome parts of the name. Maybe the word in the middle needs a little tweaking.

#15

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:14:51 PM
Last Modified: Saturday, April 12, 2014 12:21:09 PM
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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Our opinions do not matter, why are you asking?

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

You know our thoughts, this is a 20 year old question.

#16

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:19:08 PM
Last Modified: Saturday, April 12, 2014 12:22:07 PM
Time Spent: 00:02:59
IP Address: 50.188.111.35

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a real disease that requires help, whether or not conventional medical testing shows anything medically remarkable.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS is not a good term. That is for certain.

#17

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:17:59 PM
Last Modified: Saturday, April 12, 2014 12:23:07 PM
Time Spent: 00:05:08
IP Address: 81.157.207.61

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it not phycological and multiple systems of body affected that need monitoring and help with managing the multiple symptoms that arise .

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Should not be called cfs . Or any adjoined acronym to cfs . Name needs to reflex inflammation and neuro immune dysfunction and metabolic (mitochondria) impairment

#18

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:17:36 PM
Last Modified: Saturday, April 12, 2014 12:28:34 PM
Time Spent: 00:10:58
IP Address: 216.67.32.203

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it exists and is not normal fatigue and that exercising more is not helpful.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I'm not sure what I would recommend switching terminology to, but I think it is time to get rid of the term CFS. The name is associated with old, outdated ideas, including malingering and psychological problems. It is not taken seriously. A "rebranding" would help.

#19

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:27:22 PM
Last Modified: Saturday, April 12, 2014 12:32:28 PM
Time Spent: 00:05:06
IP Address: 50.170.7.144

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Specific criteria to look for when examining the patient. Even though i was diagnosed in 2005, every doctor I have seen since, doesn't even acknowledge it as an ongoing issue. I

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

get rid of the word SYNDROME other then that, it's fine.

#20

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:36:54 PM
Last Modified: Saturday, April 12, 2014 12:43:52 PM
Time Spent: 00:06:58
IP Address: 173.79.117.106

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Healthcare providers should be aware of the cognitive and other neurological impacts. They should know enough about the symptoms to correctly diagnose the syndrome. They also should be aware of what approaches to treatment have actually been successful for some patients.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I do not care much about terminology. In my area, most practitioners have heard of CFS and understand that it is something real, and I see this as a plus for using CFS. ME is not a term that medical practitioners seem to use. I would focus on increasing practitioners' understanding of the illness and less on changing a name. When the illness is more fully understood, maybe then a new name or names will be more appropriate.

#21

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:26:25 PM
Last Modified: Saturday, April 12, 2014 1:13:46 PM
Time Spent: 00:47:21
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PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Understanding the complete nervous system collapse and how other body systems are affected as well. Rather than thinking of it as "tiredness". A question such as "Why do you think you are so tired?" can be quite patronising and leads to despair. It demonstrates a lack of awareness/understanding of this illness. Focus on the fact that abilities/mobility are severely impacted. I needed help to get up out of bed and stand up - that was not because of tiredness but rather no "oomph" in my body and I was overwhelmingly weak. I had no "get up and go" at my worst. Yet my motivation and determination was always strong my body couldn't follow through. When patients are in a severe crash state exercise is not an option and pushing it can be very damaging (though moving body and muscles is still important). Exercise needs to be gentle to enable improvement as opposed to further collapse. Overdoing it in my case leads to severe nausea and headaches/migraines and "brain fog" to the extent I can't make a coherent sentence. On a bad day simple things such as having a shower is overdoing it and even having a bowel motion is debilitating. When you are "crashing" this means needing to lie on the bed very still not moving for sometimes hours with your eyes shut. An understanding of the deeper issues which make daily life severely limiting - e.g. not being able to walk, drive, stand for more than a minute or two, conversation is exhausting, poor concentration, etc. All of this increases isolation. They need to "get this" despite the fact that the person they are seeing might look "normal" or even well and have "normal" test results.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Severe Systematic Collapse. Energy Collapse Syndrome or Complex Energy Collapse Syndrome or Complex Energy Drain Syndrome. Body Breakdown Syndrome.

#22

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 1:27:45 PM
Last Modified: Saturday, April 12, 2014 1:35:22 PM
Time Spent: 00:07:37
IP Address: 75.87.127.237

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

It is very real. If I make it to an appointment in your office, it is one of my better days. Fatigue is not the same as sleepy. Exercise or over doing it will cause much worse symptoms in the coming days.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

OK, better than just Chronic Fatigue Syndrome. I would prefer something that didn't include the word Fatigue.

#23

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 1:39:51 PM
Last Modified: Saturday, April 12, 2014 1:46:03 PM
Time Spent: 00:06:12
IP Address: 24.183.138.249

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Post exertional relapse, pain, orthostatic intolerance, HPA axis abnormalities.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS should be dropped altogether because everyone is chronically fatigued for w hatever reason. This illness is something totally different that just happens to be fatiguing like everything else.

#24

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 1:54:29 PM
Last Modified: Saturday, April 12, 2014 1:56:40 PM
Time Spent: 00:02:11
IP Address: 66.203.229.16

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That is is NOT a psychiatric disease and that we cannot exercise. It would be nice if they even knew what it was.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Chronic Fatigue belittles those who suffer with the disease. There is so much more to it. As one doctor said to me recently, "everyone gets tired, get over it" then proceeded to tell me to go to a gym. At least myalgic encephalitis encompassed the pain the brain dysfunction.

#25

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 1:48:41 PM
Last Modified: Saturday, April 12, 2014 1:57:53 PM
Time Spent: 00:09:12
IP Address: 98.77.47.240

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Listen to the patient and not discount them. Each is different and treatment and management must be customized. After over 20 years I still have to direct my condition.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Having the ME attached makes it sound a little more legitimate. The comments when you said you had CFS was oh I am tired too. That was so upsetting as you had to explain everything.

#26

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 2:00:52 PM
Last Modified: Saturday, April 12, 2014 2:09:26 PM
Time Spent: 00:08:34
IP Address: 83.251.227.239

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

It's a serious, physical disease.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Latin terms, nothing with fatigue, disease rather than syndrome. Notting w/ Flo Nightingale since she is famous for accomplishing, not for being sick.

#27

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 2:09:41 PM
Last Modified: Saturday, April 12, 2014 2:13:12 PM
Time Spent: 00:03:31
IP Address: 71.236.253.191

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Understanding & believing there is such a thing as ME/CFS and post exertional malaise is debilitating. How to treat sleep issues effectively and help manage patients expectations.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS should be stricken from the language as it is misleading and easy to dismiss as "just being tired".

#28

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 2:03:18 PM
Last Modified: Saturday, April 12, 2014 2:13:19 PM
Time Spent: 00:10:01
IP Address: 216.246.154.211

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Once the diagnosis is made, leave it be. Don't try to fix it, it can't be fixed. Please treat our symptoms even if it frustrates you that you cannot heal us. Oh and, it has NOTHING to do with being overweight so stop torturing us by saying if we just lost weight we'd feel better. I am living proof that is not true. Weight loss surgery demanded by my docs left me more ill than ever and at 118 lbs less weight all I am is a smaller sized woman with new medical issues from the surgery.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Of the two, I prefer ME but neither is perfect. I actually liked the phrase Post Viral Fatigue Syndrome back in the 80s when I was diagnosed. At least it made it seem like it stemmed from somewhere! But that's gone so I'd go with something that references the neuro-inflammation thought to be the cause of this illness, but separate from ME, my fear is if we lump it all into ME and there is a test for ME and we with CFS fail that test.... it's a slippery slope. Whatever you call it, just leave out the word fatigue and we'll be happier about it. That word just makes us look lazy....

#29

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 11:06:11 AM
Last Modified: Saturday, April 12, 2014 2:23:34 PM
Time Spent: 03:17:23
IP Address: 69.228.80.201

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

If the person cannot exercise or be active without feeling worse (either immediately or a day or two following) they probably have ME/CFS. This could be as little as washing a few dishes or taking a shower for some people. Sensitivity and symptoms in response to the environment is another hallmark of the illness, this can be molds, perfumes, foods, light, sound, virtually any environmental stimulus. Be innovative in testing (CBC, metabolic panel, and such rarely turn up values out of range, so if these are normal for goodness sake don't tell the patient there is nothing wrong with them). Check things like thyroid, cortisol/ATCH, amino acids, and hormones like pregnenolone/DHEA, these were all abnormal, some very much so, in my case. If the patient presents with psychiatric symptoms assume these are secondary if the patient has problems with exercise such as post-exertional malaise. Finally the experience of having ME/CFS and it's treatment can be very counter-intuitive (for example there is no "exercising to get in shape" in the conventional sense), so practice with a lot of humility.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I used CFS for a long time since people knew what it was. If the medical profession and the government had taken it seriously it might have worked but I think CFS as a term is permanently tainted now. CFIDS (chronic fatigue and immune dysfunction syndrome) is pretty good but leaves out endocrine and other abnormalities. I understand the problems with using ME as it is too specific for many cases of the illness. One suggestion would be finding a name that sounds medical (like ME) but is broader to encompass more possible causes of the illness. I think a lot of the difficulty is medicine is reductionist so the names of most disease become more and more specific and ME/CFS is a whole body illness caused by a variety of things. So perhaps the best choice would be a person's name like "Sophia Mirza Disease" (given her case was a particularly sad and devastating example of medical neglect that led to her death) or some researcher like "Peterson's disease". After all if you mention Lou Gehrig's disease or Alzheimer's disease everyone knows how serious it is.

#30

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 2:34:45 PM
Last Modified: Saturday, April 12, 2014 2:39:18 PM
Time Spent: 00:04:33
IP Address: 98.206.172.46

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

We are always fighting viruses and fungus. We all react differently to meds. We are not looking to take more meds we just want to get well enough to have at least 1/2 of a life.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Anything but Chronic Fatigue Syndrome, when I say it to people they dismiss it. It does not convey the severity the lose of ones normal life, confined to bed.

#31

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 2:54:07 PM
Last Modified: Saturday, April 12, 2014 2:56:48 PM
Time Spent: 00:02:41
IP Address: 72.239.132.143

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Memory problems; fatigue

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Combining two medical terminologies is confusing.

#32

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:10:34 PM
Last Modified: Saturday, April 12, 2014 3:19:27 PM
Time Spent: 00:08:53
IP Address: 92.16.67.81

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That ME is not a psychosomatic condition. That CFS was a corrupt act to submerge ME under a psychosomatic disorder with no medical evidence.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS is a fantasy creation of the CDC. ME is NOT just fatigue. Give ME the sort of research funding and media respect that is given to MS & MDN and they will find real treatments for the disease. 30 years have been wasted, how much longer must we wait.

#33

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:04:32 PM
Last Modified: Saturday, April 12, 2014 3:19:54 PM
Time Spent: 00:15:22
IP Address: 207.102.133.154

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That we don't feel as well as we look. We are afraid that we have something terminal. Please tell us if you suspect ME and that it is quite a long process of elimination to diagnose so we don't get discouraged.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS brings insulting responses from those we tell (oh I must have that too cuz I'm always tired) Myalgic Encephalomyelitis is hard to remember. ME sounds egotistical (lol) I would suggest : Multi Symptom Cognitive & Energy Challenge Syndrome or MSCECS...that's almost as long as myalgic encephalomyelitis but easier to interpret to the multitudes

#34

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:07:46 PM
Last Modified: Saturday, April 12, 2014 3:20:09 PM
Time Spent: 00:12:23
IP Address: 212.159.22.217

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The complete disability and impact on families this has is devastating and still the stigma and disbelief in the medical community is sickening. This illness destroys the immune system and ruins lives. Just because Drs dont understand something they should tell patients its all in their heads. Trust me - Nobody would make up having this illness. It has ruined my career, social life and my marriage. More research is required, people are dying and its being ignored and covered up.....time for change.
Drs need to testing immune markers to diagnose and be researching the causes to create a cure.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME is ok CFS belittles this serious condition.
A new name could wipe away the stigma, viral immune defienciency syndrome.

#35

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 12:37:02 PM
Last Modified: Saturday, April 12, 2014 3:29:30 PM
Time Spent: 02:52:28
IP Address: 123.231.101.148

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That ME/CFS is a real, biological illness and definitely not "all in your head". That ME/CFS is a complex illness that is best evaluated by a knowledgeable specialist / CFS/ME expert. That anti-depressants, positive thinking, exercise and "pushing yourself" to be more active are not appropriate treatment strategies for ME/CFS.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The name Chronic Fatigue Syndrome is harmful to patients as it does not convey the true gravity of the illness. Many people, including doctors have mistaken conceptions that CFS = yuppie flu, simple fatigue, depression or even hypochondria and do not take the illness seriously. Myalgic Encephalomyelitis has the unfortunate acronym ME and is hard for lay people to pronounce or understand.

I would like to see terminology used that is truly descriptive of our situation such as Catastrophic Multisystem Dysfunction. Even though we don't yet know the cause (or causes) this name covers the fact that ME/CFS certainly involves multisystem dysfunction (such as Immune, Endocrine, ANS and more) and the term catastrophic evokes the true gravity and magnitude of this illness. A name like this would give our illness and our patient community the serious consideration, respect and credibility it deserves. This name would be easy for laypeople (and the media etc) to understand and is still an accurate reflection of the medical condition itself.

#36

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:27:32 PM
Last Modified: Saturday, April 12, 2014 3:33:10 PM
Time Spent: 00:05:38
IP Address: 162.224.189.160

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

First, clinicians should be aware that the CCC is the preferred case definition. It was created by experts, and has been used by researchers for over a decade. Leonard Jason has a simplified method that clinicians can use to quickly identify potential ME patients before moving on to the CCC. Every clinician needs to ask this question of patients who may have ME: "How do you feel after you exercise?"

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I would suggest using ME. It's been in use since the 1950s. I see no reason to invent another name for the illness. CFS was a mistake, and the only way to rectify that error is to eliminate it as a diagnosis. It is not only meaningless, it has created a great deal of confusion in the medical community,

#37

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:14:39 PM
Last Modified: Saturday, April 12, 2014 3:40:22 PM
Time Spent: 00:25:43
IP Address: 76.27.200.83

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That, so far, there are no tests for ME/CFS so don't rely on test results. That ME/CFS is a physical not a psychological disease that is so debilitating that the patient may have resulting psychological symptoms like reactive depression. That research has not yet revealed the cause or cure of ME/CFS, so only symptoms can be treated. That unlike with clinical depression and many other diseases, exercise exacerbates symptoms and should be approached with extreme caution. That patients are not malingering and actually detest being sick.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The term CFS is meaningless as a medical term and gives the medical community and the world at large an erroneous interpretation of the seriousness of the disease. It implies that fatigue is a major symptom whereas the "fatigue" referred to is actually a profound lack of energy to the point of being unable to get messages from the brain to the muscles to tell them to move. Myalgic Encephalomyelitis is fine until/if research finds a cause and cure that recommends another more accurate name.

#38

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 3:31:40 PM
Last Modified: Saturday, April 12, 2014 3:47:32 PM
Time Spent: 00:15:52
IP Address: 75.67.189.93

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Please convince doctors that Chronic Fatigue is not "in our heads" and throwing anti-depressants at it won't cure anything and may make things worse. Educate yourselves, doctors! Handing out random anti-depressants to patients without a diagnosis of clinical depression can negatively effect brain chemistry and cause irreparable damage. It makes me angry that many/most doctors' first (and sometimes ONLY) response to treat CFS/ME is to give patients anti-depressants. My doctor told me the only thing that would work is TALK THERAPY with a psychiatrist because she couldn't find anything "REALLY" wrong with me. It's offensive for doctors to behave this way and negate our symptoms because they can't be diagnosed with one simple test. Medical schools should include CFS/ME as an area of specialization, perhaps along with RA and Fibromyalgia, so more doctors would study it and be able to effectively treat it. There are way too many people affected and suffering with CFS/ME for this to continue to get zero attention.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Call it pretty much anything BUT "Chronic Fatigue Syndrome"! That name suggests I take a nap and I'll feel better in a day or two. It's insulting and cruel for us long-time sufferers. ME is a much better name and makes people think what you have is truly as serious as it feels.

#39

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 4:03:02 PM
Last Modified: Saturday, April 12, 2014 4:09:31 PM
Time Spent: 00:06:29
IP Address: 69.14.250.36

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is not psychosomatic. That it is REAL. And the importance of compassion and not pity. I am BLESSED to have a team of healthcare professionals (a nurse practitioner and a physiatrist) who are extremely compassionate and do their very best for me. Not everyone is so blessed. (I had a dr. 15 years ago, after I had my "CFS" diagnosed at the the UM Chronic Fatigue Center insist that there was no such thing as fibromyalgia or chronic fatigue syndrome and I just needed to have a better attitude.)

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I prefer ME over CFS. and prefer CFIDS over CFS. The CFS term gives the appearance of "oh, you're just tired all the time, get some sleep." The ME at least relays that this is something that is going on with inflammation and the nervous symptom.

#40

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 4:39:07 PM
Last Modified: Saturday, April 12, 2014 4:41:41 PM
Time Spent: 00:02:34
IP Address: 108.84.86.21

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

This disease is a WHOLE BODY DISEASE, not just my head, arm, leg, heart, etc.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I really don't care what they call it; just give me something to deal with it on a daily basis.

#41

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 4:54:56 PM
Last Modified: Saturday, April 12, 2014 5:03:31 PM
Time Spent: 00:08:35
IP Address: 99.59.224.106

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That CFS(stupid name) is REAL.No exercise will make me better.I look "normal" ,but i'm not.--I have been sick for over 44 years,it is 2014 and still nothing has been done to promote this illness.Every health care provider should be educated on this horrible long lasting flu.There is no cure on the horizon.I feel like the health system doesn't care .It's all a joke,started with the stupid name diagnosis.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Anything is better than CFS.I have stopped telling Dr's (new ones that i see) that i have CFS.ME is good,for lack of better terminology.

#42

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 5:03:49 PM
Last Modified: Saturday, April 12, 2014 5:09:48 PM
Time Spent: 00:05:59
IP Address: 66.58.147.162

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Symptoms involve most body systems and are often changing. Prone to infection - pay attention - I haven't had a fever over 99 in 18 years despite MRSA twice, kidney infections, bronchitis, endless bladder infections.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I prefer ME. Many doctors have told me they don't believe in Chronic Fatigue Syndrome and I have been sent home twice from Emergency Room with no treatment because I didn't have fever (got cultured by regular doctor the next day - MRSA in digestive system and pneumonia type germ in bladder.)

#43

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 4:52:39 PM
Last Modified: Saturday, April 12, 2014 5:15:45 PM
Time Spent: 00:23:06
IP Address: 50.132.124.70

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That is a serious condition that is extremely debilitating. They need to be educated on the latest methods for diagnosis and treatments for quality of life for patients.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Neuroimmune disease or disorder. It seems to fit better than just fatigue and ME is tough to pronounce.

#44

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 5:17:47 PM
Last Modified: Saturday, April 12, 2014 5:24:18 PM
Time Spent: 00:06:31
IP Address: 173.246.2.33

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That there are many effects all related to this illness and that symptomatic treatment, while not a cure, can put a floor under a patients' decline and enlist more co-operation from them in reporting and overcoming remaining symptoms.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Name change will require an immediate re-orientation but remove an immediate stigma. How about neuro-immune spectrum disorder or NIS-D?

#45

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 5:33:26 PM
Last Modified: Saturday, April 12, 2014 5:35:50 PM
Time Spent: 00:02:24
IP Address: 166.137.84.69

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That this is a physical disease not a mental illness. And that it's often highly debilitating.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS is inappropriate. Fatigue is just one of the many symptoms & it suggests that this disease just means feeling tired regularly.

#46

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 5:53:15 PM
Last Modified: Saturday, April 12, 2014 6:00:59 PM
Time Spent: 00:07:44
IP Address: 75.1.166.0

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

that rest is not restorative, exercise causes post-exertional relapse, and I have knowledge of excellent nutrition but do not have the energy to prepare it alone. Life is lived in slow motion.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

E/CFS for those of us who do not experience myalgia.

#47

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 6:52:44 PM
Last Modified: Saturday, April 12, 2014 6:54:26 PM
Time Spent: 00:01:42
IP Address: 64.203.30.60

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How sick the people are.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Prefer ME

#48

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 6:51:57 PM
Last Modified: Saturday, April 12, 2014 6:55:22 PM
Time Spent: 00:03:25
IP Address: 71.71.80.34

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Fatigue,pain,and nuerological problems

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

MEis ok. Chronic fatigue Syndrome terrible

#49

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 7:22:21 PM
Last Modified: Saturday, April 12, 2014 7:26:17 PM
Time Spent: 00:03:56
IP Address: 174.240.0.240

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?

It is more than "I have no energy" or "I am always tired."

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?	*Respondent skipped this question*

#50

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 7:23:39 PM
Last Modified: Saturday, April 12, 2014 7:31:45 PM
Time Spent: 00:08:06
IP Address: 50.92.62.172

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The severity.
That we are too sick to have to convince them to help. They are there to help, not judge. Learn how to.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Neural-endocrine exhaustive dysfunction - NEED

#51

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 7:43:24 PM
Last Modified: Saturday, April 12, 2014 7:52:05 PM
Time Spent: 00:08:41
IP Address: 72.51.153.158

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

First of all, I think they should be taught to actually consider it as a possibility when someone comes in complaining of fatigue, flu-like symptoms, depression, etc. and not just write it off as depression or hormones. They should recognize that depression does not cause ME/CFS but is caused by it. They should understand that by the time a patient comes to them they have done some research on their own and probably suspect this diagnosis. They should know that it is a syndrome that needs a multi-faceted approach and possibly a team of doctors to treat it and not be offended when the patient asks to be referred to other specialists. In fact, they should refer without being asked.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think the terminology is fine.

#52

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 7:42:30 PM
Last Modified: Saturday, April 12, 2014 8:13:52 PM
Time Spent: 00:31:22
IP Address: 67.45.96.240

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a very real disease and causes many symptoms. Most of my health care providers have just looked at symptoms and ignore the underlying disease. An uneducated health care provider does not understand the huge impact this disease has on one's life. They don't understand how it comes an goes - on a daily, weekly, monthly and even yearly basis.
I want everyone - including health care providers to understand how disabling the disease it and how it affects every aspect of my life. My relationships, self image/esteem, my career (or lack of one), stress levels as well as day to day living.
I am a very smart person who loses my ability to think on bad days. A very active person who can't be active. I want to sleep but can't. I want to do things but often can't. I have to constantly balance my level of activity and stress to be able to function at even a pretty low level.
I wish it were easier to get disability since there are very few jobs that would hire someone who can make it to work maybe half the time - and I'm one of the lucky ones!
One of the most important thing my doctor has done for me is to make sure I'm getting the best sleep possible, I'm on low dose tranquilizers to minimize stress and I have access to pain meds for the days when the pain is bad. Those things make it so much easier for me to keep my spirits up so I can make the best of my situation.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Anything but CFS - Chronic Fatigue Syndrome. When I say that people don't get it, it doesn't sound like a serious disease. Prefer CFIDS or ME.

#53

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 8:15:17 PM
Last Modified: Saturday, April 12, 2014 8:17:51 PM
Time Spent: 00:02:34
IP Address: 173.35.64.6

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Post exertion all malaise is often an important clue that gets overlooked with someone is trying to get diagnosed and get help!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Chronic immune defencency.

#54

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 9:01:19 PM
Last Modified: Saturday, April 12, 2014 9:03:30 PM
Time Spent: 00:02:11
IP Address: 24.105.245.49

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Listen to all the patient says. Run proper tests. Follow up with referrals stbspecialists

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Dosnt matter what they call it. Just find cause and cite

#55

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 9:57:17 PM
Last Modified: Saturday, April 12, 2014 10:05:35 PM
Time Spent: 00:08:18
IP Address: 184.34.9.208

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That a diagnosis of ME/CFS does not mean a patient is no longer worthy of medical care and treatment.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I would prefer an honest attempt to describe what patients appear to be suffering, an honest attempt to collect data on sufferers and less insulting press releases that imply patients are just pleasantly bored yuppies. The muscle fatigue at the point of failure is very painful and specific.

#56

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 10:01:13 PM
Last Modified: Saturday, April 12, 2014 10:07:24 PM
Time Spent: 00:06:11
IP Address: 76.186.177.20

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

LISTEN to the patient and keep an open mind. Just because you can't see it doesn't mean it isn't there.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

This is the first I've heard of ME. CFS covers it, but people don't understand the intensity of the fatigue from this.

#57

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 10:14:00 PM
Last Modified: Saturday, April 12, 2014 10:21:46 PM
Time Spent: 00:07:46
IP Address: 174.29.136.241

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That primary care physicians are taught about the illness and take it seriously. I also think it is important to educate cardiologists as well, it seems like they might be overdosing their ME patients that have heart issues like mitral valve prolapse. There is a real danger of conflict between heart meds and the use of antidepressants. People being treated for fatigue because of heart disease might also be dealing with ME and it isn't diagnosed.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I would use Myalgic Encephalomyelitis and drop the Chronic Fatigue Syndrome. To define this illness by one symptom isn't accurate.

#58

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 12:25:23 AM
Last Modified: Sunday, April 13, 2014 12:29:33 AM
Time Spent: 00:04:10
IP Address: 74.209.14.224

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Fatique, pain, w eight, saying its all in our head, oh you're just depressed take another pill, insomnia, somulance

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I like the ME title better, chronic fatigue doesn't even begin to encompass the w hole disease. When I tell people I have chronic they just think I am tired.

#59

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 1:32:47 AM
Last Modified: Sunday, April 13, 2014 1:51:29 AM
Time Spent: 00:18:42
IP Address: 86.186.184.130

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

They need to listen to the patient and do more and see the patient regularly. Early diagnosis is key. It took 28 months for me to get my diagnosis of m.e and by that time I was a shell of my former self ... It's debilitating and soul destroying ... benefits agencies don't understand,government and medical agencies don't understand. Pure ignorance is what surrounds our illness. It's not a mental health disease it's very physical I have had it for 6 yrs my brain is broken and I can literally feel it malfunction and the affects and symptoms that has on my body!! Cfs is more fatigue m.e is the illness. I think there 2 different illnesses. I'd love to come and do trial research for this illness . But only with intelligent..open minded... caring.. health care professionals. And I also believe it's possibly genetic because my 8 yr old daughter has cfs... which is why I know cfs is different to m.e. x

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I don't think chronic fatigue is what our illness is... chronic fatigue is a symptom it gives people the wrong idea about us. I think it should be called "mefs" (myalgic encephalomyelitis fatigue syndrome) this explains in a name our illness .

#60

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 2:47:14 AM
Last Modified: Sunday, April 13, 2014 2:54:09 AM
Time Spent: 00:06:55
IP Address: 86.133.148.223

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

their opinion of what is real and what is not real in invalid. they should be educated that only the scientific facts count and not their personal opinion!!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

i feel the name CFS undermines the illness and leads to the opinion that the patient is just tired.

#61

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 5:20:07 AM
Last Modified: Sunday, April 13, 2014 5:24:42 AM
Time Spent: 00:04:35
IP Address: 98.30.108.146

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

First they should listen to what the patient has to say. I have been stuck with the same MD for 10 yrs and doesn't say anything about CFS/ME. I giver her symptoms and she thinks I am drug seeking. I can't get a new MD due to the meds I am on from previous docs that did understand the process. But if you are not healed or better within 5 yrs, time to find a new doc. I have had this for 23 yrs. Very frustrating. Also on SSD, I have limited resources for medical, even on my spouses insurance. Making payements on my last lab bill of over $500.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I believe ME would be taken more seriously than CFS. If a lay person hears CFS, "Oh, I have been so tired too." No one seems to understand and don't believe the majority of MD's do either.

#62

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 5:37:28 AM
Last Modified: Sunday, April 13, 2014 5:41:44 AM
Time Spent: 00:04:16
IP Address: 98.196.79.188

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1. This is a REAL disease 2. Make them aw are of the disabling symptoms 3. Give them a list of tests that SHOULD be performed to rule in/rule out other conditions 4. Give them current updates on research 5.Encourage them to STOP treating this as 'depression' or self-created!!!!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelis is INFINITELY better than CFS, w hich trivializes this disease, but it w ould help if some easier w ould be used, that w ould 'roll off the tongue' better, so to speak.

#63

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 6:22:34 AM
Last Modified: Sunday, April 13, 2014 6:31:04 AM
Time Spent: 00:08:30
IP Address: 68.84.66.41

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

It's severity. Multiple symptoms. Not just Fatigue, risks when facing an operation, understanding pacing and how too much exercise makes it worse. The benefit of some vitamins, propioticsabd the latest experimental trials.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Drop the Chrini fatigue syndrome and add name after a famous person who had it "Nightengales disease . Make sure it is a disease!

#64

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 7:25:28 AM
Last Modified: Sunday, April 13, 2014 7:36:51 AM
Time Spent: 00:11:23
IP Address: 24.218.32.4

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

M.E is a serious & debilitating disease. It is an inflammation of the central nervous system that destroys patients chances of living life fully, participate in a career, hanging out with friends,and traveling. We only exist.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

myalgic encephalomyelitis It describes what is going on in our bodies.

#65

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 7:47:33 AM
Last Modified: Sunday, April 13, 2014 7:48:22 AM
Time Spent: 00:00:49
IP Address: 173.175.241.113

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The gravity of the illness.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Keep until the science gives us something clear.

#66

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 7:45:17 AM
Last Modified: Sunday, April 13, 2014 7:50:34 AM
Time Spent: 00:05:17
IP Address: 67.81.22.99

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Exacerbation of symptoms with activity, sometimes very little activity. Also known as PEM or PENE. They need to know what it is, how to assess it and to warn patients not to push through it or they can make themselves significantly worse. They should also be aware of and test for immune system problems.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I'm not as concerned with the name. I'm more concerned with identifying the ideology and treatment.

#67

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 7:42:53 AM
Last Modified: Sunday, April 13, 2014 7:53:56 AM
Time Spent: 00:11:03
IP Address: 24.205.43.122

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

First and foremost, that ME/CFS is real, it is a medical condition, and it needs to be taken seriously. Second, there are things that can be done to manage symptoms and help patients deal with this disease.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I have taken to telling people I have ME rather than CFS, simply because they take it more seriously.

#68

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 8:15:20 AM
Last Modified: Sunday, April 13, 2014 8:34:46 AM
Time Spent: 00:19:26
IP Address: 76.126.124.138

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a neurological illness as defined by the WHO in 1969. It has severe symtoms which cause disability. The CCC and the ICC should be used to check off the patients symptoms for a diagnosis. Post exertional malaise is one of THE symptoms which should be present for a diagnosis of ME. They should be educated that ME is not just fatigue but has neurological symtoms too, as listed in the CCC and ICC.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myagic Encephalomyelitis is the name that should be used because this was the orginal name given to this illness in the 1950's and the one used by the WHO in 1969. Recent research has been shown to find swelling in the brain and spinal cord of sufferers, validating the use of the word encephalomyelitis. Chronic fatigue syndrome is too vague a name for the neurological illness ME and includes other illnesses which do not have all the symptoms listed in the CCC and the ICC defintion of ME. This has caused confusion and some research has been done on patients who do not not have true neurological ME and has muddied the water when coming to diagnosis and treatment of the illness.

#69

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 12, 2014 6:32:40 PM
Last Modified: Sunday, April 13, 2014 9:05:26 AM
Time Spent: 14:32:46
IP Address: 76.99.207.124

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That ME/CFS is an immune disorder, that it is a serious illness that causes widespread problems in the immune, endocrine, and nervous systems. That there are treatments available that can help: correcting sleep dysfunction, treating orthostatic intolerance, testing for and treating underlying infections, and treating immune dysfunction.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

It's a tough question. All patients (and most medical CFS experts) HATE the term CFS because it is so misleading and trivializing, focusing on one symptom of a complex, multi-systemic illness. ME is much better - more scientific, more accurate, and already well-known in other parts of the world. However, the name CFS HAS gained some recognition in the medical community and general public (though not all of it positive), so for now, I believe a combination name is best: ME/CFS, at least until ME is better known in the US, as it is in other parts of the world.

#70

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 8:58:30 AM
Last Modified: Sunday, April 13, 2014 9:21:33 AM
Time Spent: 00:23:03
IP Address: 2.223.36.237

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

To be educated about bio physiology of
M.E and up to date with biomedical research studies, and to use the ICC or CCC criteria for diagnosis. Understanding that this is an organic chronic systemic illness that can have very serious and even life threatening consequences if neglected and ignored. Treat psychological issues that arise, know that they are secondary to an organic illness, not the cause of illness. Don't dismiss concerns. Treat patients respectfully, don't dismiss all symptoms as psychosomatic, listen to patients, investigate why certain symptoms are happening.
ME patients are known (recorded widely in studies) to have cardiac abnormalities, immune abnormalities, mitochondrial abnormalities, neuro endocrine abnormalities and more. Be aware that those abnormalities can occur. It's all about education on biomedical studies and explanations and being a support for the patient, not a person they have to fight against to get what they need.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think the terminology Chronic Fatigue Syndrome is terrible and very destructive. It completely trivialises the illness and has psychosomatic connotations meaning medics are already prone to disbelief. It is misleading. I think bodily distress disorder is even worse. I think that can be manipulated and again is completely misleading and also has connotations to psychosomatic disorder and ignores all organic and biomedical research material. It's very important to take all the organic and biomedical research material into account which 9 times out of 10 is completely ignored. I think that should be the focus. I am aware of the debate about the 'itis' is Myalgic Encephalomyelitis, if that is a cause for concern, I propose the term Myalgic Encephalopathy which is more widely accepted within the patient community and within the medical community because it eliminates the 'itis' which is the part most debated and controversial among the medical world, which retaining the terminology of biology. This then implies that this is a clinical syndrome with biomedical roots and it alludes to the range of symptoms. I think this should be the main term for consideration if the medical world feels the current term has to change. I think the abolishment of the term CFS would benefit everyone, including Drs, patients, researchers, professionals, media, social services etc etc etc. I think everyone wins with myalgic encephalopathy and that it should be the only thing in consideration at this time.

#71

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 9:33:04 AM
Last Modified: Sunday, April 13, 2014 9:34:56 AM
Time Spent: 00:01:52
IP Address: 84.82.79.68

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

IT IS NOT IN THE MIND

it is a rather uncommon illness, not everyone who feels exhausted all the time should be diagnosed with it, but it is a real disease, with symptoms

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

another name indicating the neurological and inflammatory roots of ME would be nice

#72

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 9:16:05 AM
Last Modified: Sunday, April 13, 2014 9:37:34 AM
Time Spent: 00:21:29
IP Address: 108.86.106.108

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How to listen carefully without assumptions/judgements to patients symptoms/complaints asking detailed questions for better understanding (avoids mis-diagnoises). Its very difficult for patients to find "words to describe symptoms. Our vocabulary do not have words to adaquetly describe them.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

This is the term I use b/c I most relate to meaning. I hope we all adapt it, its also helpful (unfortuntely), b/c some doctors/people respond better to medical-sounding-terms.

#73

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 9:58:15 AM
Last Modified: Sunday, April 13, 2014 10:04:42 AM
Time Spent: 00:06:27
IP Address: 87.113.43.204

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The massive impact that not getting refreshing sleep has on all other symptoms. The resulting frustration and derpession caused by remaining undiagnosed for long periods of time and how it negatively impacts on sufferer's ability to cope with diagnosis and acceptance , thereby impeding their ability to adjust and begin to make steps towards getting better.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I prefer ME to CFS as when the latter is used, unaware people just assume you're tired. At least the ME offers the opportunity for them to ask what it is and sufferers to explain, rather than to be immediately written off.

#74

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 10:12:18 AM
Last Modified: Sunday, April 13, 2014 10:24:03 AM
Time Spent: 00:11:45
IP Address: 74.37.248.60

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

A person might not be able to answer questions about symptoms due to brain fog.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME Because you normally have muscle pain each time you over exert. Disease affects multiple organs where actions are occurring at cell levels in the brain and through out the body.

#75

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 11:22:37 AM
Last Modified: Sunday, April 13, 2014 11:24:59 AM
Time Spent: 00:02:22
IP Address: 208.100.161.220

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a very serious & real illness, not a mental health issue.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

We have to change the name & get rid of CFS- it trivializes the illness. I support the name ME.

#76

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 11:45:31 AM
Last Modified: Sunday, April 13, 2014 11:52:00 AM
Time Spent: 00:06:29
IP Address: 98.208.6.162

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That this is a serious/broad spectrum illness & to be able to recognize symptoms & refer patients to an ME/CFS specialist. (which the world needs more of!)

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I believe the use of ME/CFS in that order is important. It will help with the connection as we transition away from the term Chronic Fatigue Syndrome.

#77

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 11:33:29 AM
Last Modified: Sunday, April 13, 2014 11:52:01 AM
Time Spent: 00:18:32
IP Address: 89.242.196.211

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

(1) While post exertional malaise is real, people with mild cases may not have caught on that they are experiencing post exertional malaise when they push so much. They may be pacing without being aware of it. This does not mean that the person is not getting worse or managing well and not in need of a diagnosis. So despite the idea that PEM is essential to ME/CFS, physicians need to be aware that people may adapt over time with mild cases and be unaware of their adaptation. These folk still need a diagnosis to protect their future state of health and quality of life. Ask questions, ask patients to pay attention. Don't be so afraid of putting ideas into patients heads.

(2) Most people with ME/CFS, particularly in the early stages, including total disability, will have unremarkable standard lab results (CBC and CMP).

(3) If a standard lab test is unremarkable (e.g., for thyroid), do more sophisticated tests. It could be that someone does not have ME/CFS; it could be that they simply need more testing.

4) The illness is not in people's heads. It's a real illness and they need to be educated regarding the research that demonstrates this. It's time to start educating doctors in med school and to stop avoiding ME/CFS.

5) Many sufferers cannot take drugs or have found that they are super sensitive to drugs. Do not doubt your patients and write them off as being non-compliant or worse, crazy. Also, many are sensitive to other chemicals, but not all. They too are not crazy or unreliable.

6) Patients often find that their illness is dismissed in all aspects of their lives; they do not need you or your staff to be dismissive as well.

7) Pay attention to issues regarding the ability to function. What most patients want is to be able to function not a doctor to zero in on the one thing s/he thinks she can help the patient with. If you do that, at least admit that you are doing that because you lack knowledge/expertise. Patients appreciate a doctor who says, "I don't know."

8) Be willing to work with your patients. They may be more up to date on the research than you. If they offer you a paper to read that speaks to a treatment that they think might help them, read it.

This seems like a pointless exercise to me since most people are in agreement that the Canadian Consensus Criteria pretty much covers the "important issues." I'm not even certain what that means. Are we being asked what we think the diagnostic criteria ought to include? If so, the Canadian Consensus Criteria pretty much covers it.

However, I do want to mention that there are plenty of people with long-term onset. These people have generally had a lot of allergies, sinus infections, pharyngitis, etc. Because they don't have a "I remember this one virus" story, doesn't mean that they don't have all the other symptoms that people with ME/CFS typically have.

I guess I answered more than the question asked.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I very much dislike Chronic Fatigue Syndrome and feel like the name has trivialized the illness. "I get tired too" is a common response to telling someone you have CFS. I don't know that ME covers the full range of the disorder but it does a far better job of describing what is going on than CFS does.

#78

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 12:05:03 PM
Last Modified: Sunday, April 13, 2014 12:07:47 PM
Time Spent: 00:02:44
IP Address: 75.169.19.51

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How disabling it is, vs. how the person appears.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic encephalomyelitis is a better descriptor, not reminiscent of the "yuppie flu".

#79

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 1:11:26 PM
Last Modified: Sunday, April 13, 2014 1:35:05 PM
Time Spent: 00:23:39
IP Address: 76.191.146.197

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The impact on quality of life and functional level. Most physicians weigh the seriousness of patient complaints by the degree of abnormalities seen in lab tests / physical exam. If their lab tests / physical observations cannot measure an illness process they do not take patient complaints about low quality of life and low functional level seriously. Of course from the patients point of view the seriousness of their illness is primarily a function of their quality of life - even if widely available medical technology cannot easily measure the underlying biological parameters of that illness process . A patient with a low functional level must spend most of their physical / mental energy on self care - they need the economic resources to do so. If physicians do not support them in disability matters, they may not be able to survive. I think there are many folks out there that simply fall off the governments / health care systems radar screens. Presumably some people should care about that (they get paid to do so after all).

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Respondent skipped this question

#80

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 2:59:05 PM
Last Modified: Sunday, April 13, 2014 3:12:45 PM
Time Spent: 00:13:40
IP Address: 203.219.140.140

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

- use of Canadian criteria or International Consensus criteria for proper diagnosis
- education abt the most up-to-date findings & recommendations of expert practitioners & researchers who have made the illness their life's work
- the possible severity of the illness
- the importance of proper management & the positive impact that has on prognosis
- first do no harm: at best there are serious doubts abt safety of GET. It is therefore imprudent to be risking patient's health by prescribing GET at this stage

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis
or possibly NEID - neuro-endocrine-immune disorder but this is just a category rather than a specifific illness
CFS must go! Preferably with an apology from the CDC for the harm the terminology has caused patients, and progress in researching, diagnosing and managing the illness.

#81

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 3:26:39 PM
Last Modified: Sunday, April 13, 2014 3:30:29 PM
Time Spent: 00:03:50
IP Address: 76.172.50.253

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That is exists, that it's serious, and how to diagnose it properly. And what it looks like in its severe form, since we are underrepresented in research, etc.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME/CFS is OK--better than CFS. It's be nice to come up with a new name that is simpler and without baggage, but that's hard to do and then requires a whole reeducation campaign.

#82

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 5:39:58 PM
Last Modified: Sunday, April 13, 2014 5:45:07 PM
Time Spent: 00:05:09
IP Address: 208.58.5.162

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The patient does not present the same after 25 years of living with CFS, why would the diagnostic criteria be the same?

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Keep the current name for now until there is sufficient diagnostic info to split the patient population into smaller less diverse groups. Much research is currently ongoing that will shed new light to help propel us forward in the understanding of the mechanics of at least some segments of this illness. Lets not split hairs until we have something definitive to move towards.

#83

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 13, 2014 6:58:17 PM
Last Modified: Sunday, April 13, 2014 6:59:51 PM
Time Spent: 00:01:34
IP Address: 66.87.152.93

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?	*Respondent skipped this question*

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?

I hate to tell people I have Chroniv Fatigue Syndrome, it's a huge deal in my life and it sounds line I'm just always tired sickness! It should be ME!!

#84

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 1:16:05 AM
Last Modified: Monday, April 14, 2014 1:20:27 AM
Time Spent: 00:04:22
IP Address: 76.102.92.18

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Current research

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

something based on future research that is not yet strong enough to make any conclusions

#85

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 10:22:33 AM
Last Modified: Monday, April 14, 2014 10:26:56 AM
Time Spent: 00:04:23
IP Address: 50.150.97.153

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The fact that it's not in our heads. What we are feeling is real. Treat CFS WITH concern for other things we might have. Not ignore the effects of it.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Fatigue does not convey the difficulty we have. We have the fatigue but it how to say it means nearly falling down or not being able to walk 100 meters. Stop telling up to "exercise more" or "just lose weight"

#86

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 10:43:54 AM
Last Modified: Monday, April 14, 2014 10:58:34 AM
Time Spent: 00:14:40
IP Address: 74.4.247.101

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?

I wish the definition focused on what was unique about our disease.

--the fatigue is post exertional, with a rise in symptoms 24-48 hrs after exertion or exercise.

--orthostatic intolerance is so common, and it is my most disabling symptom. I cannot hold a job due to this symptom. I believe it should be emphasized.

--flu-like symptoms (these may be systemic inflammation, so I wouldn't word them as viral, but they are what differentiates this illness). What makes these symptoms unique is that they are more severe after exertion.

Please don't place sleep dysfunction and numerous, very variable, neurological symptoms foremost. Neurological symptoms are most variable among different patients (some sleep more, some less), and are non-distinct. They need to be placed in a category and emphasized that they may differ greatly.

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?

The name CFS has become a human tragedy, and it is very misleading for clinicians who see large numbers of fatigued patients of all types in their offices. The name has little justificiation -- clinically and scientifically.

Myalgic Encephalomeylitis is esoteric, but it really seems to point toward fibromyalgia pathology and symptoms, which concerns me.

If I had to pick a name it would be neuro-immune dysfunction syndrome. NDS. NDS is based on what we know, without isolating or enforcing specifics. It allows for continued work on understanding immune, inflammation, and brain pathology. NDS doesn't choose sides, and it allows for this illness to get a "start", without choosing where that start will be.

I do not support the name neuroendocrineimmune dysfunction syndrome. I believe the simpler nuero allows for neuroendocrine research, and the name is too complex and may continue some of the problems we have today.

#87

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 12:21:38 PM
Last Modified: Monday, April 14, 2014 1:11:44 PM
Time Spent: 00:50:06
IP Address: 74.44.142.213

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?

1. I am sicker than I look. (Even renowned physician Dr. David Bell said I was sicker than HE had thought after sending me to the Pacific Fatigue Lab for exercise testing.)

2. My symptoms are numerous and confusing, even to me. (The most helpful diagnostic tool was a sheet listing a myriad of symptoms I could check-off from an endocrinologist.)

3. The most debilitating symptom is intolerance to physical activity. If you can define and understand that symptom, you can understand my limitations. I liken myself to an 80-year-old woman with CHF or COPD in need of 24/7 oxygen.

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?

The use of the name Chronic Fatigue Syndrome (CFS) does not reflect the severity of this disease. I do not think such a complex disease, or any disease, should be categorized by a broad category like "chronic fatigue."

The name Myalgic Encephalomyelitis (ME) is a much more compelling, specific name. It creates a sense that we are dealing with a serious, specific disease; which we are. Also, ME is used throughout the world, creating a sense of uniformity and global recognition. Researching a new name other than ME would be confusing and a waste of resources.

#88

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 1:59:04 PM
Last Modified: Monday, April 14, 2014 2:03:45 PM
Time Spent: 00:04:41
IP Address: 99.93.68.160

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That this is not a mental Illness, Neuro-Psych testing is not part of the diagnostic criteria for ME/CFS !!!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The ME part of the name is fine, but they most definitely need something more descriptive than CFS as most Physicians think of people with this disease as being tired and run down - which is not all there is to this illness

#89

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 2:25:11 PM
Last Modified: Monday, April 14, 2014 2:50:37 PM
Time Spent: 00:25:26
IP Address: 174.140.118.63

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Since their is still no bio marker, 1. They need to have a good understanding of the multitude of symptoms, with an emphasis on maybe the top 10 or so; 2. An understanding that the typical tests almost all doctors rely on, will show almost nothing wrong, but this does not mean that there is nothing wrong. 3. They need to be able to distinguish between this illness and depression. When doctors have no idea what is going on or what to do - it becomes "depression" or blame the patient. It is devastating to not be believed by your doctor when you are so sick and barely functioning.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I don't have a good suggestion, but Chronic Fatigue Syndrome needs dropped, it is demeaning and trivializing to an illness that is debilitating and devastating. When others ask me what I have, I have no idea what to tell them. To tell them I have Chronic Fatigue Syndrome is pathetic, and they have no idea how life destroying this illness is or the limitations it places in doing almost anything; And it ignores all the other devastating symptoms that noone seems to be able to treat or help. These other symptoms are every bit as disabling as the "fatigue". Plus the fact that the term "fatigue" doesn't even come close to describing how it feels.

#90

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 4:04:37 PM
Last Modified: Monday, April 14, 2014 4:08:47 PM
Time Spent: 00:04:10
IP Address: 98.216.98.162

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

They need to know more about the science of the disease(evidence of biological abnormalities). And they should recognize autonomic nervous system disorders more too

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I don't know if I have encephalomyelitis so I don't know if that correctly describes my disease or not.

#91

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 4:18:01 PM
Last Modified: Monday, April 14, 2014 4:28:59 PM
Time Spent: 00:10:58
IP Address: 82.16.168.242

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Ratchet effect of cognitive and somatic symptoms combining to impair physical capacity and ability to communicate.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Chronic Myalgic Encephalopathy Syndrome - descriptive and medically uncontroversial. The condition is marked by chronicity, myalgia is almost always present, encephalopathy is descriptive of a broad neurological involvement, syndrome acknowledges definition by symptom list in the absence of biomarker or other repeatable tests.

#92

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 5:39:29 PM
Last Modified: Monday, April 14, 2014 5:49:18 PM
Time Spent: 00:09:49
IP Address: 98.207.66.10

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

they should do thorough testing for Lyme and coinfections such as babesiosis. Most of them do no Lyme testing or the useless ELISA.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

People laugh when I say chronic fatigue syndrome, compounding the physical pain with emotional pain. I think they should figure out what causes it (usually Lyme) and call it that--Lyme complex, ciguetera etc. or if they must name the syndrome, call it Multisystemic Dysregulation or something.

#93

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 7:29:53 PM
Last Modified: Monday, April 14, 2014 7:32:55 PM
Time Spent: 00:03:02
IP Address: 24.12.191.39

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

severity and physiological basis of illness and existence of many sub-groups

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

In the absence of research which better specifies illness physiology, I prefer myalgic encephalonyelitis. Certainly not "chronic fatigue syndrome" which has served only to relegate us to the bottom of every heap.

#94

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 14, 2014 7:43:16 PM
Last Modified: Monday, April 14, 2014 7:53:10 PM
Time Spent: 00:09:54
IP Address: 174.92.34.80

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1.its a real physical illness
2. Details of the Canadian Consensus Criteria - it should be their guide and adopted worldwide
3.exercise is not tolerated - 2 day testing by Staci Stevens - GET is bad for ME patients
4. Summary of iacfsme conference - state of current research

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME as it is used world wide and when broken down into its parts it fairly describes the condition

#95

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Tuesday, April 15, 2014 8:55:57 AM
Last Modified: Tuesday, April 15, 2014 9:06:04 AM
Time Spent: 00:10:07
IP Address: 24.93.170.49

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

We ALL seem to experience some type of PENE (PEM). Exercise intolerance. I would urge anyone making a diagnosis to keep that in mind. Since the typical recommendation "exercise will make you feel better" sent me into a huge pain-filled crash from which it took me years to recover, I would have to say, PLEASE educate the medical field about this and use PENE as part of the recommended diagnostic criteria!! Even trying to do the one time recommended GET sent me into another crash. I recovered, but it took months. Some do not ever fully recover!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis

#96

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Tuesday, April 15, 2014 1:33:04 PM
Last Modified: Tuesday, April 15, 2014 1:46:20 PM
Time Spent: 00:13:16
IP Address: 174.26.43.206

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That this is a real condition & that the symptoms can be so varied from patient to patient. Sometimes symptoms can appear not to connect to one condition as they are so varied. Healthcare providers I have been too look at me as if I am making it up, I am an RN and sometimes the symptoms didn't make sense to me, it's only after I have learned more about the condition that the symptoms make sense. It took 3 1/2 years to get my diagnosis, and then I was told by my PCP and neurologist at Mayo Clinic that it's just something I have to put up with, as if they don't know or understand how ill you feel, they treat it as something minor, they both made me feel as though I was being neurotic! So I think they should be taught that if they have a patient with multiple different symptoms to bear this diagnosis in mind when doing testing

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

When I say I have CFS, people, just assume that I just feel tired all the time, that name only pertains to one of the many symptoms.

#97

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 7:33:24 AM
Last Modified: Wednesday, April 16, 2014 7:48:39 AM
Time Spent: 00:15:15
IP Address: 72.161.214.190

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That ME/CFS is, in fact, a real condition. That "mild exercise" does NOT make us healthier; it's damaging to the vast majority of us. When a medical professional recommend that for us, it's immediately clear to us that this medical professional knows virtually nothing about CFS.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I believe the ME definition is much closer to our condition, and the CDC must add it to their diagnosis list. CFS is an old name for a condition that is much better understood today (we don't call it yuppie flu anymore - right?).

#98

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 7:04:24 AM
Last Modified: Wednesday, April 16, 2014 8:03:26 AM
Time Spent: 00:59:02
IP Address: 67.189.226.220

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

that it is an elusive condition impacting each patient differently. There is an Autoimmune factor being overlooked either metabolic/systemic and it can no longer be ignored.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Obviously CFS/CFIDS or ME has not been taken seriously by the medical profession or insurance companies...The name/label is NOT the problem; for years we've been told its all in our heads...so then how about Brain Dysfunction Induced ME/CFS???

#99

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 1:40:37 PM
Last Modified: Wednesday, April 16, 2014 1:46:46 PM
Time Spent: 00:06:09
IP Address: 104.3.184.142

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Pain relief from residual and progressive nerve damage, memory loss, pacing to receive the most quality of life

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Most people are unaware that M.E. is an inflammation of the brain. Chronic Fatigue Syndrome sounds like it is a psychological based problem. There are many more symptoms than just chronic fatigue.

#100

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 1:48:37 PM
Last Modified: Wednesday, April 16, 2014 1:52:39 PM
Time Spent: 00:04:02
IP Address: 71.202.218.120

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Deciding what criteria goes should be used to diagnose CFS

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Hard to decide. Current names are ok with me.

Why don" t researchers look into how CFS started in patients.

#101

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 2:04:21 PM
Last Modified: Wednesday, April 16, 2014 2:20:29 PM
Time Spent: 00:16:08
IP Address: 50.192.73.249

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Multi-system organ and bodily function involvement, and the terrible effects the illness causes, physically, and emotionally. They need to know how desperately ill we can be, and how much we need their help and attention.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

To be honest, the ME part is fine with me. It sounds almost as horrible as this disease really is. The CFS part is unfortunate. Chronic fatigue, while one of many issues involved in this disease, it is certainly, by far, not the worst issue, nor are the words "chronic fatigue" sufficient to describe the fatigue the patient feels. Maybe it should be named after the worst of the symptoms and effects, but that would be a very long name. I think a name that would or could suggest the neurological aspects, the multi-system/ organ involvement, and the immunosuppressive aspects, that might be good. I do not believe I am qualified to know what that specific name would be, but if it could include or suggest those symptoms I mentioned, it would be a better name. Thank you.

#102

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 2:34:39 PM
Last Modified: Wednesday, April 16, 2014 2:37:34 PM
Time Spent: 00:02:55
IP Address: 71.8.115.254

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it actually exists. People are not just "lazy", there is really something wrong.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I would include the immune dysfunction in the name.

#103

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 2:37:42 PM
Last Modified: Wednesday, April 16, 2014 2:41:54 PM
Time Spent: 00:04:12
IP Address: 98.83.121.125

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Health care providers should be made aware their is not specific test and they need to rule out all other possibilities before making a diagnosis and they should also stay current on any new information concerning this illness.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think "Syndrome" gives the mistake impression that CFS is not a REAL disease. I'm not sure what name I would use but it definitely wouldn't have "syndrome" as part of the name.

#104

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 2:33:50 PM
Last Modified: Wednesday, April 16, 2014 2:42:03 PM
Time Spent: 00:08:13
IP Address: 69.112.27.16

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Performance Status scores similar to oncology might be useful. Number of hours per day in bed or on the couch. Objective measurement is important especially in the beginning when patient "looks so good".

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

CFS trivializes the disease. Fatigue is a symptom, albeit a predominant symptom. The immune system is diseased; the diagnostic term should reflect this. In my case I wasn't just "fatigued", I was debilitated and bedridden.

#105

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 3:08:19 PM
Last Modified: Wednesday, April 16, 2014 3:17:30 PM
Time Spent: 00:09:11
IP Address: 68.103.82.228

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Most often they simply do not know about it, that it is a biological illness and not a psychosomatic illness that is all in the persons head. It seems that there are few primary care doctors who are educated about it at all even minimally. It needs to be talked about in medical communities, schools and conferences. Awareness is huge and educating the medical practitioner that it ME is a multiple organ system disorder.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

People take my illness seriously when I say I have Myalgic Encephalomyelitis, but I get negative reaction when I say I have Chronic Fatigue Syndrome because they misunderstand that it is just chronic fatigue thinking that my problem is just being tired all the time when it is so much more complex than only the fatigue. I would like the scientific name to be used more.

#106

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 3:37:53 PM
Last Modified: Wednesday, April 16, 2014 3:40:17 PM
Time Spent: 00:02:24
IP Address: 67.81.22.99

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

PEM/PENE, impact on multiple systems

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I'd prefer that ME/CFS efforts be directed to diagnositic markers and treatments. The name issue does not concern me.

#107

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 3:44:59 PM
Last Modified: Wednesday, April 16, 2014 3:51:24 PM
Time Spent: 00:06:25
IP Address: 96.61.84.217

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

the impact of no known cause & therefore no known cure is devastating. Understanding how important it is to come up with alternatives to provide for as much quality of life as possible is critical- tests of all kinds & the willingness to experiment with various drugs is needed. Learn how to support the patient in his/her quest for disability funding. Empathy!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Not chronic fatigue- seems to highlight only one primary symptom; "Brain Stem Infection" seems more apt in describing what happened & is still possibly occurring & doesn't delineate symptoms. "Common" people can better understand that description.

#108

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 3:51:33 PM
Last Modified: Wednesday, April 16, 2014 3:59:54 PM
Time Spent: 00:08:21
IP Address: 98.252.68.141

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The physical characteristics of the disease. For instance the proper blood testing, specific to ME/CFS rather than standard CBC panel. Many facts live in these results.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis better describes the state of the dies was more accurately. Specifically the altered brain function due to some disease of the brain. CFS implies that we are simply tired. Nothing more. It would help public perception and acceptance.

#109

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 4:08:24 PM
Last Modified: Wednesday, April 16, 2014 4:28:10 PM
Time Spent: 00:19:46
IP Address: 71.237.3.1

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That this is an extremely debilitating illness even if the patient looks "well" and seems functional. That this illness is a complex one with a physiological basis, not a psychological one. And that post-exertion malaise, although hard for a well person or unfamiliar treating doctor to comprehend, is an extremely significant factor in this condition.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I hate the term CFS and am hesitant to use it when trying to describe my illness to non-medical people because it serves to trivialize the condition (and does the same to some uneducated medical professionals too). But at the same time I don't know how the condition can be renamed until there is more understanding of its cause. But until then, I will continue to describe my condition to others (when necessary) as a poorly-understood dysfunction of my autonomic nervous system and immune system in general with auto-immune conditions thrown in. I've never used the term ME before, as that wouldn't begin to explain anything to a lay person anyway.

#110

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 4:38:43 PM
Last Modified: Wednesday, April 16, 2014 5:13:36 PM
Time Spent: 00:34:53
IP Address: 69.250.84.68

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Multisystem infectious disease syndromeImmune dysfunction causes inability to fight normal yeast, fungus in the gut. Leaky gut is real and must be treated. immune dysfunction causes food allergies. Loss of muscle mass occurs, cardio issues - post exertion malaise, damaging to push/crash. Flu shots, vaccines trigger CFS, allergy shots diminish functioning of immune system, EBV can be treated with anti-viral drugs, epididymitis can be treated, skin rashes & acne of unknown origin, high viral titers are not normal & viruses are retriggered with immune dysfunction, looks like AIDS patient, ***CFS patients can't digest milk protein & allergy tests for milk allergy always return negative*** Have trouble with sugar & wheat also, have orthostatic intolerance
Brain fog & inability to deal with mental or physical stress. Most docs don't know where to begin and prefer to offer no treatment for fear anything will do harm

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

NOT CFS! Neuro-immune Disorder, or something related to the debilitating symptoms that are neuro- immune related and not just fatigue related

#111

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 6:43:48 PM
Last Modified: Wednesday, April 16, 2014 6:48:35 PM
Time Spent: 00:04:47
IP Address: 24.228.146.124

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

It's a real life-shattering disease. It's worth investing time and money to find the cause and cure. If aids could be made livable , money could enable the same for CFS/ME.   Fatigue is the major issue, l hitting/preventing a real life.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Anything but chronic fatigue. This is illness, not a joke.

#112

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 6:43:58 PM
Last Modified: Wednesday, April 16, 2014 6:49:51 PM
Time Spent: 00:05:53
IP Address: 108.32.180.120

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Exercise Intolerance (PEM). They need to understand that we cannot do aerobic exercise the way healthy people can.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Chronic fatigue syndrome is terrible, because it implies we are just tired. We are ill. ME is a better name.

#113

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Wednesday, April 16, 2014 9:34:38 PM
Last Modified: Wednesday, April 16, 2014 9:44:28 PM
Time Spent: 00:09:50
IP Address: 76.179.44.237

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a very real disabling medical condition. That the fibromyalgia presentation is painful, not just fatiguing.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The term CFS trivializes the severity of the condition, making it sound like people are just tired. When I lost my career at age 59, I slept 15 hours a day for the next two years.

#114

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 12:03:19 AM
Last Modified: Thursday, April 17, 2014 12:04:30 AM
Time Spent: 00:01:11
IP Address: 108.244.31.97

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That disabling fatigue is a serious physical problem and not just a "psychological" problem

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Chronic fatigue syndrome makes the disease sound like a joke

#115

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 3:59:02 AM
Last Modified: Thursday, April 17, 2014 4:01:53 AM
Time Spent: 00:02:51
IP Address: 97.127.241.8

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That affects the entire body and that it does progress.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Not crazy about either name, but ME is much better than CFS.

#116

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 7:44:38 AM
Last Modified: Thursday, April 17, 2014 7:48:34 AM
Time Spent: 00:03:56
IP Address: 155.98.164.38

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How to do a thorough history and work-up of symptoms that can appear in many diseases (fatigue, pain, vertigo, etc.). How to rule out the many causes in a systemic way that leads to an accurate diagnosis of ME.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I would urge retiring the name chronic fatigue syndrome. It isn't a good description of what is happening to me medically and it is too easy for friends, family, and even providers to dismiss... "I must have that too, I am tired all the time." I plead with you to adopt ME as the accepted name.

#117

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 12:13:05 PM
Last Modified: Thursday, April 17, 2014 12:17:16 PM
Time Spent: 00:04:11
IP Address: 24.62.148.102

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

I would hope that healthcare providers would recognize how incredibly debilitating this disease is, and not write it off to stress, anxiety or possible mental illness, and not treat the patient like a hypochondriac.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Anything that mentions "chronic fatigue" as a description of this disease is unacceptable. That would be like calling diabetes "sugar intolerance." Not only is it misleading, it downplays all the other issue patients suffer with this disease. I generally use the ME terminology.

#118

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 1:15:46 PM
Last Modified: Thursday, April 17, 2014 1:26:30 PM
Time Spent: 00:10:44
IP Address: 108.210.202.36

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

that me/cfs is real. that a treatement that works for one patient may not work with another.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

i prefer "myalgic encephalomyelitis" to "chronic fatigue syndrome" it's the difference between saying someone has "multiple sclerosis" vs. ""hysterical paralysis." .

#119

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 2:23:24 PM
Last Modified: Thursday, April 17, 2014 2:35:30 PM
Time Spent: 00:12:06
IP Address: 71.235.61.117

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The severity of impact of the symptoms on patients' lives. The fact that CFS insomnia is not "just" insomnia and is not caused by depression. That there is recognizable constellation of symptoms shared by most patients (with some differences of course as with other illnesses).

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The current terminology contributes to dismissive attitudes toward patients' symptoms. But I am unable to come up with an alternative.

#120

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 5:24:32 PM
Last Modified: Thursday, April 17, 2014 5:35:56 PM
Time Spent: 00:11:24
IP Address: 66.245.20.176

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

need to spend time with us going over what is working/not working and what new drug or protocol can be tried. Willingness to venture prescribing drugs off-label. Willingness to keep following up with us to find other treatments that might help.
My physician at UCSF is wonderful primary care provider but no one at UCSF will talk about ME/CFS - its like there is a policy of not dealing with it, its too controversial and complex. Very strange from world class research facility.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

use Myalgic Encephalomyelitis by itself. I was diagnosed in Canada with ME, just plain ME. In US "fatigue" has connotation of malingering or laziness. Do away with it. "Fatigue" doesn't capture the malaise anyway. "Chronic Influenza Syndrome" o.k. I do always feel fluish and I began with flu, Cytomeglavirus

#121

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 7:21:20 PM
Last Modified: Thursday, April 17, 2014 7:24:10 PM
Time Spent: 00:02:50
IP Address: 4.31.115.122

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?	*Respondent skipped this question*

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think it's a good idea to stop using CFS since it trivializes a devastating illness

#122

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 8:08:29 PM
Last Modified: Thursday, April 17, 2014 8:16:48 PM
Time Spent: 00:08:19
IP Address: 71.162.228.102

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Don't first assume it is all in the patient's head. It is real, and for some of us, it never goes away.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME and Chronic Fatigue do have the connotation of whining. Another label would be helpful, I'm sure.

#123

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Thursday, April 17, 2014 11:21:27 PM
Last Modified: Thursday, April 17, 2014 11:35:24 PM
Time Spent: 00:13:57
IP Address: 65.13.173.36

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

ME/CFS is real. ME/CFS is more than muscle pain and fatigue. ME/CFS is not fibromyalgia. ME/CFS is not depression. ME/CFS is not General Anxiety Disorder. ME/CFS is not a psychiatric disorder. This is only the tip of the iceberg.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephalomyelitis describes perfectly every symptom I have experienced for over twenty-five years. Call this disease anything except Chronic Fatigue Syndrome.

#124

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 18, 2014 12:37:39 AM
Last Modified: Friday, April 18, 2014 12:46:59 AM
Time Spent: 00:09:20
IP Address: 74.64.83.189

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Chronic pain, all over, not only FM triggers points. Post exercise or exertional fatigue. Not just immediately after exercise but 1-2 days later, relapse conditions. Sleep disorder with no medication relief that is consistent . Cognitive decline, especially when in a relapse. Inability to plan life. One never knows when symptoms will get in the way of life.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

The currently in use is horrible. There is no good term. I still used CFS due to the fact that most medical professionals know what they think that means. I also use FM to gain some credibility for my symptoms. I have no Idea what to call this life sentence.

#125

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 18, 2014 7:36:21 AM
Last Modified: Friday, April 18, 2014 7:42:38 AM
Time Spent: 00:06:17
IP Address: 168.177.140.49

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

that this is real! We are not depressed or having anxiety issues. that physicians should read the patients history charts before dismissing the possibility that they have ME/CFS.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

well, the word "fatigue" is misleading. people think that all we have to do is sleep or get some rest to make this go away. While quality of rest is very important in this illness, "fatigue" is not the only problem. LOL, how about Chronic Influenza Syndrome?

#126

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 18, 2014 8:57:21 AM
Last Modified: Friday, April 18, 2014 9:00:48 AM
Time Spent: 00:03:27
IP Address: 74.105.169.205

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The serious nature of ME/CFS, diagnostic tools, where they can find reliable information and treating physicians

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I think ME/CFS is a good transition name. If ME is used widely, it will replace CFS.

#127

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Friday, April 18, 2014 6:01:56 PM
Last Modified: Friday, April 18, 2014 6:11:32 PM
Time Spent: 00:09:36
IP Address: 71.236.182.100

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

1. Patients with ME/CFS are not just depressed.
2. Exercise is, for most people, a good and healthy thing. But for patients with ME/CFS it can be very tricky and must be approached carefully.
3. Patients desire to get better, but ME/CFS is a very complex disease.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I dislike the name Chronic Fatigue Syndrome. I have always felt it does not appropriately convey the severity of the illness. It is almost an embarrassing name to have to tell others. I would much prefer Myalgic Encephalomyelitis or something else entirely new.

#128

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 19, 2014 2:39:57 AM
Last Modified: Saturday, April 19, 2014 2:46:08 AM
Time Spent: 00:06:11
IP Address: 70.36.134.103

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Give it a better name and explain to doctors how it affects patients and not to judge us by how we look or sound one day. Relate to us based on our BAD days! Know that we make a huge effort just to see a doctor/nurse and what the doc sees is not a normal day for us. They should know that ME affects many systems and organs and not to focus too much on one...

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

M...E.... is better. Anything that doesn't have "fatigue" or just a symptom in it. Please, something that conveys that our brains are damaged, like "neuroimmune disease." Really, even the name of someone, like "Jones' Disease" would be better than "fatigue." "Fatigue" is insulting and I refuse to use it!!!!!!

#129

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 19, 2014 11:00:56 AM
Last Modified: Saturday, April 19, 2014 11:08:49 AM
Time Spent: 00:07:53
IP Address: 86.142.93.120

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

How ME affects every aspect of life, from simple things like getting dressed to huge gaps in memory and how individuals have such extremes in intolerances, energy levels, nausea, body and mind weaknesses and pain.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

M.E. is fine if used in the correct way. I hate the blanket ME/fibro/CFS wooliness. It says nothing about the condition only highlights it's name that says even the medics are unsure what to call it and what to believe.

#130

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 19, 2014 12:34:49 PM
Last Modified: Saturday, April 19, 2014 12:46:34 PM
Time Spent: 00:11:45
IP Address: 74.101.157.142

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The complexity of the disease. The multi-system nature of the disease. Crashing phenomena. The unique and eccentric symptom patterns (well described by in Carruthers 2003 and 2011). The need for patients to guide their own treatment (to accord with their individually most problematic symptoms and their own life priorities).

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME seems like a great term. It eliminates the imprecision of Myalgic Encephalomyelitis (and is so much shorter!). Chronic Fatigue Syndrome and CFS need to go. (Burry them in a landfill!)

#131

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 19, 2014 3:41:32 PM
Last Modified: Saturday, April 19, 2014 6:04:59 PM
Time Spent: 02:23:27
IP Address: 68.185.95.107

PAGE 1

Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?

First of all, their denial of the illness means people are not getting the care they need - with the likelihood of getting much, much worse. Next, when providers don't understand the illness and insist on a (primary) psychiatric diagnoses (rather than a possible -secondary- diagnosis resultant of the primary -physical- illness)-- patients, again, don't get the interventions and education they need; and even worse-- they are stigmatized, making future attempts to receive the correct treatment, all the more difficult - if not impossible. For those who do accept the diagnosis, they need to know their clients have (minimally!) cognitive, hormonal, and systemic interference - limiting their ability to fully (or even accurately) describe symptoms or symptom fluctuation (in days, weeks, months, and years). Providers must know of the REAL DANGER in exercise and the REALITY of Post Exertional Malaise (physical AND emotional), since most of us have been raised to believe increasing exercise is curative. In this, they need to support & encourage patients to learn the skill: Pacing. It is the single most empowering tool a patient can utilize daily. And, finally-- they should refer their patient to a CFS/ME specialist. They should not believe they are -sufficient- to help the patient, except as in a -supportive- role to a primary care CFS/ME specialist. Problem here: there are so very few CFS/ME specialists and these few are too often denigrated by their majority colleagues. In fact, if we can't even come up with a NAME for the illness, how can we expect the medical community to coalesce to support either CFS/ME specialists or the hundreds of thousands afflicted? The medical community simply needs to know THE ILLNESS IS REAL. And, in admitting they don't understand, lobby for research funding.

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?

If the rest of the world is using Myalgic Encephalomyelitis, then it makes sense, to me, for us to join-in, ...rather than think ourselves "exceptional", when we're really only being renegade.

However, if not that, then-- there should be NO word like "fatigue", since that is merely a pop symptom - and not scientifically defined (that I know of). In essence, fatigue is meaningless and -too- easily misconstrued as laziness or being weak willed.

I'm not actually sure whether "myalgic" is appropriate, across the board! Whereas, in fibromyalgia, myalgia is front and center.

I do believe "encephalo" -and- "myelitis" are accurate.

Possibly the mention of "cytokines" as a cytokine: "cascade", "inflammatory (process)", or "syndrome"--

"Encephalomyelitic Immune Syndrome"
"Encephalomyelitic Immune Inflammatory Cascade"
"Encephalomyelitic Cytokine Syndrome"
"Enephalomyelitic Cytokine Inflammatory Cascade"

Words like "Diffuse" or "Systemic" may be appropriate add-ons--

"Diffuse Encephalomyelitic Immune Inflammatory Syndrome"

Obviously, I am no scientist. I am just an average Joe, thinking of my disease expression over time.

#132

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Saturday, April 19, 2014 6:54:51 PM
Last Modified: Saturday, April 19, 2014 6:58:09 PM
Time Spent: 00:03:18
IP Address: 75.6.2.23

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The possibility of either infectious agents (Lyme or mold) affecting me/CFS and getting insurance to cover all types of treatment and natural herbs and supplements

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Something if possible that wasn't so difficult for layperson to,recognize, I wish my brain was working better to suggest somtething

#133

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 20, 2014 10:58:25 AM
Last Modified: Sunday, April 20, 2014 11:03:35 AM
Time Spent: 00:05:10
IP Address: 99.163.250.222

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

To take the time to determine how fatigued a patient is when they say they are tired all the time. How tired? Too tired to take care of themselves properly? Falling asleep sitting up during dinner?...

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I am not sure what is the best terminology but it is important that people realize that we are not just tired and that there are many other related symptoms.

#134

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 20, 2014 12:52:13 PM
Last Modified: Sunday, April 20, 2014 1:16:32 PM
Time Spent: 00:24:19
IP Address: 174.26.105.204

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

PWCs may be suffering from clinical depression which makes their situation seem dire and hopeless. You have to treat the depression.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Immune Dysfunction Syndrome

#135

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Sunday, April 20, 2014 10:57:31 PM
Last Modified: Sunday, April 20, 2014 11:04:42 PM
Time Spent: 00:07:11
IP Address: 162.196.88.116

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Q1: In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?

The IA/CFSME physician's primer does a good job at educating physicians about the condition, imo.

Generally, I hope that healthcare providers know where to send patients for further information on the illness. I recommend Health Rising's, or the CFSKnowledgecenter's website.

Q2: What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?

I believe that the term Chronic Fatigue Syndrome is horribly minimizing the condition.

ME is not minimizing, but since the exact pathophysiology of ME/CFS is unclear, it might also not be correct.

Therefore I suggest that the illness will be named not connected to a particular symptom or abnormality, but a neutral name that is not minimizing.

I suggest we name it after a doctor who did well to diagnose it at first and who has a good reputation. I suggest we call it "Peterson Syndrome."

#136

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 21, 2014 8:10:22 AM
Last Modified: Monday, April 21, 2014 8:58:04 AM
Time Spent: 00:47:42
IP Address: 65.87.156.82

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it is a real disease and the test to confirm it will be discovered.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I like Myalgic Encephalomyelitis.

#137

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 21, 2014 9:04:18 AM
Last Modified: Monday, April 21, 2014 9:09:34 AM
Time Spent: 00:05:16
IP Address: 76.212.14.188

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

All potential CFS patients should be rigorously screened for Lyme disease, including a western blot even if the ELISA is negative. In addition: cognitive dysfunction, dysautonomia, post-exertional malaise, adrenal insuffiency, insomnia, pain, immune dysfunction. And fatigue, obviously.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

ME is fine with me if it is widely considered accurate terminology, ie consistent with scientific findings. CFS is problematic.

#138

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 21, 2014 12:39:21 PM
Last Modified: Monday, April 21, 2014 12:51:03 PM
Time Spent: 00:11:42
IP Address: 84.198.76.62

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

that it is a multi system illness, that medication is often not tolerated or just does not work for sleep for example, that there is yet no diagnostic tool or treatment, that it is not psychological, that they must keep updated on research because it goes fast, that the subgroups have got to be made still, that there are degreas in severity and that it can fluctuate over time and symptoms change... so many things in fact

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

neuro immune endocrine muscular desease or just multi system desease. The reason why I would call it so is that those areas are problematic and that not everyone has an infection in the brain. I would also make subgroups for example multi system desease 1, multi system desease2 , multi system desease/ME, multisystem desease POTS... I would give it just a name for now and later when the cause(s) are known give it a real name

#139

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 21, 2014 3:12:57 PM
Last Modified: Monday, April 21, 2014 3:15:54 PM
Time Spent: 00:02:57
IP Address: 81.48.150.24

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The multi systemic nature of the illness and different patient subsets.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Cfs must be scrapped for preferably Ramseys Syndrome or myalgic encephomyelitis.

#140

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Monday, April 21, 2014 4:10:52 PM
Last Modified: Monday, April 21, 2014 4:12:51 PM
Time Spent: 00:01:59
IP Address: 50.129.98.6

PAGE 1

Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

That it exists!

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

I'm glad myalgic encephalomyelitis was added to CFS. It's much more than just feeling tired.

#141

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Tuesday, April 22, 2014 4:15:36 AM
Last Modified: Tuesday, April 22, 2014 4:19:59 AM
Time Spent: 00:04:23
IP Address: 68.100.166.82

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

Innate immune disease. Stop sending us to shrinks. Start understanding innate immunity.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

None of the name are any good; we should stop arguing about them until we find the innate immune mechanism after which we can name the illness.

#142

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Tuesday, April 22, 2014 6:58:05 AM
Last Modified: Tuesday, April 22, 2014 7:08:11 AM
Time Spent: 00:10:06
IP Address: 72.200.170.40

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The illness causes many symptoms, primarily based on immune, neurological and endocrine dysfunction; PEM is a mandatory symptom and can be extremely disabling; the CCC and/or the IACFSME Primer should consulted when diagnosing a patient

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Myalgic Encephaloymyelitis (ME) should be adopted - without the CFS add-on. The name ME was accepted by the WHO in the 1960's and is used in many countries around the globe. If research leads us to believe that the term "ME" is inappropriate, let it be changed all over the world. But we shouldn't separate ourselves with yet another name now.

#143

COMPLETE

Collector: IOM - Cognitiv...nostic Issues (Web Link)
Started: Tuesday, April 22, 2014 2:40:23 PM
Last Modified: Tuesday, April 22, 2014 2:53:46 PM
Time Spent: 00:13:23
IP Address: 12.130.116.3

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Q1: **In your opinion, what are the most important issues that healthcare providers should be educated about when it comes to diagnosis of ME/CFS?**

The fact that for most ME/CFS stricken individuals, almost everything is an effort, and often one has to prioritize, even when seeking MD attention, actions according to the days "energy budget". That the chronicity of this, including pain and the "drama" that is the process of attempting to get sleep is itself an inordinate mental challenge with life altering consequences quite separate from the physical symptoms themselves.

Q2: **What are your thoughts on the current terminology used to describe this disease: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If you could suggest new terminology, what would you suggest and why?**

Among the best events that can happen in near term is a conclusive diagnostic toolbox. Until such time, ME/CFS is a syndrome that risks lumping together individuals with illnesses of different etiologies. CFS is a misleading term that due to the history of it risks adding ridicule to a person's already difficult life situation and therefore needs to be retired. ME has the advantage of "sounding" serious, but it leaves the patient the burden of explaining what it is. For the years I've had symptoms of ME/CFS, I've mostly learned not to name the illness or say, "it is real, but unknown and some call it ME/CFS, but what that means is unclear." A name should provide the patient the aid of being able to explain him/herself, but be accurate to greatest extend possible (neither ME nor CFS fulfill either criteria). Credibility may not arrive before and until objective diagnosis arrives. In the meantime, I'd advocate "Illness X" (joke), staying with the "phrase" ME/CFS because anything new will just invite yet more confusion without solving many patients problems.