

**DIVISION OF RHEUMATOLOGY, IMMUNOLOGY AND ALLERGY
GEORGETOWN UNIVERSITY MEDICAL CENTER
DEPARTMENT OF MEDICINE
ROOM 3004 F, 3RD FLOOR, PHC BUILDING
3800 RESERVOIR ROAD, N.W.
WASHINGTON, D.C. 20007-2197**

JAMES N. BARANIUK, M.D.
GEORGETOWN UNIVERSITY PROTEOMICS LABORATORY
GEORGETOWN UNIVERSITY CHRONIC PAIN & FATIGUE CENTER

LAB 202-687-8231
FAX 202-687-9886
PAGE 202-405-2396
E-MAIL baraniuj@georgetown.edu

February 19, 2016

RE: VA CFS Disability Benefits Questionnaire

Friends,

Filling out VA FORM 21-0960Q-1, OCT 2012, the Department of Veterans Affairs Chronic Fatigue Syndrome Disability Benefits Questionnaire has a "Respondent Burden" of 15 minutes if I complete the form with you in the office. However, there are open ended questions that require specific examples from your life. These need to be included on the form in order for you to make the best disability case for yourself.

The new form from October 2012 supersedes the old form VA FORM 21-0960Q-1, MAR 2-11 which will not be used. As a result, there are new boxes to check off that I do not have information about.

In order to do the best job in completing this form and the disability claims process, I have prepared a form of my own to use as a template. Please type in your personal responses for each of the questions on the template. The outline is from the VA Disability Form. Notice that this form is very redundant, so you may have to put the same information in two or more places.

I recommend that you also prepare a 1 page summary of key events about your medical history with a focus on the symptoms of Gulf War Illness (next page). That short summary can also be used for doctor visits and other medical information.

Please fill out the attached Disability Form using the instructions I prepared. Send it back to me by email in WORD format with your summary. Also send back the forms where you score your symptom severities for Gulf War Illness and Chronic Fatigue Syndrome. I will need your responses to prepare the final form.

baraniuklab@georgetown.edu

Best regards,

Jim Baraniuk

Medical Problem List and Summary for VA and Other Doctors

Please fill out this form to list your major health issues. Add more lines if necessary. A similar list may be available to you in your VA Medical Record as the “VA Problem List”. The VA Problem List looks like this:

Chronic pain syndrome (SCT number) Date/Time Entered: 10 Mar 2016 @ 12:00 Provider: Trump, Donald Location: Atlantic City NJ VAMC Status: Active Comments:_____

Painful joint (SCT number) Date/Time Entered: 10 Mar 2016 @ 12:00 Provider: Clinton, Hillary Location: Washington DC VAMC Status: Active Comments:_____

This form will help Dr. Baraniuk determine if you can take part in the study.

You will be able to give this list to your VA and other doctors at your clinic visits so they can catch up on your important health issues. You will be able to direct the clinic visit by saying, “This is my complete medical problem list, but today I am here for help with my painful joint.” This will give you a more active role in your health care, and will allow the doctor to work more efficiently with you, rather than wasting time by trying to figure out why you came for your appointment.

In addition, this list becomes the starting point for completing disability forms.

Major Health Problems or Hospitalizations	Diagnosis Codes from Medical Bills or Insurance (if available)	Year	Symptoms	Are you taking medicine for this?
e.g. Gulf War Illness	None	1991 to present	Fatigue pain thinking problems	<input type="checkbox"/> YES <input checked="" type="checkbox"/> NO
e.g. Type II diabetes	250.12, E11.69, E11.65	2006	Good control of sugar	<input checked="" type="checkbox"/> YES <input type="checkbox"/> NO
Health Issues Discussed in the Screening Telephone Call				
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
Additional Health Problems and Issues				
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO

Also fill out the Medication List with all the drugs, over-the-counter medications, vitamins and other supplements that you take.

MEDICATION LIST

Name:

Date:

Please list all of your drug allergies and adverse reactions.

Write in the medications that you are currently taking, the dose of the drug, how many times a day you take it, the doctor that wrote the prescription, and reason you are using the drug. You do not have to fill in every box if you are not on that many medications. Add more lines if you need to. Email baraniuklab@georgetown.edu if you have any questions.

Drug Allergies:

Medication:	Dosage:	Frequency Taken:
Prescribing Doctor:	Reason for Use:	
Medication:	Dosage:	Frequency Taken:
Prescribing Doctor:	Reason for Use:	
Medication:	Dosage:	Frequency Taken:
Prescribing Doctor:	Reason for Use:	
Medication:	Dosage:	Frequency Taken:
Prescribing Doctor:	Reason for Use:	
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Prescribing Doctor:	Reason for Use:	
Medication:	Dosage:	Frequency Taken:
Prescribing Doctor:	Reason for Use:	

**Filling out VA FORM 21-0960Q-1, OCT 2012,
the Department of Veterans Affairs Chronic Fatigue Syndrome Disability Benefits Questionnaire**

Please fill out this long document using WORD to type your personal responses into or below the boxes. You can make the boxes larger if you need to enter more information. I may cut and paste some of your words into my letter.

For the questionnaires on the final pages, you can color or mark the word that best describes the severity of each symptom over the past 6 months.

Then, fill out as many of the sections on the VA Disability Form as you can based on your answers below.

When you are finished, send the VA Disability Form for me to sign, your personal one page CFS & Medical Summary, Medication List, and this whole document back by email in WORD format so I can compose a letter. You can send it to:

baraniuklab@georgetown.edu

SECTION I - DIAGNOSIS

1A. Name (print clearly or type):	Social Security Number:
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Ordinarily I do not want your social security number because of security and identify theft. However, the VA wants me to FAX this to your regional office. See if you can hand deliver or FEDERAL EXPRESS this paper instead.

1B. Condition:	<input type="checkbox"/> Chronic Fatigue Syndrome	ICD-10 G93.3.
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This International Classification of Disease Version 10 (ICD-10) number is for “Postviral fatigue syndrome” and “benign myalgic encephalomyelitis.” There is no diagnosis code for CFS or GWI. The VA has the same situation with their coding system. As long as they deny that GWI is real, there be no code number for GWI.

I have attached the forms that we fill out together during your Clinical Research visit. The forms have evolved a long way since these studies started. They cover the Fukuda 1998 Chronic Multisymptom Illness (CMI), Steele “Kansas” 2000 GWI, Fukuda 1994 Chronic Fatigue Syndrome, 2003 Carruthers Canadian Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME), 2011 “International CFS/ME, and Institute of Medicine 2015 Systemic Exertion Intolerance Disease (SEID) criteria. The references for each paper are on the forms. Review these forms so you can include as many problems and complaints as apply to you in your disability request.

An important part of this process is to think about HOW SEVERE your symptoms are, and HOW MUCH of the time they are present. Severe symptoms should be included and described on the form. “How much?” can be boiled down to whether you have the symptom for more than 50% of the time. This can be per day, per week, or over the last 6 months. You will need to give examples of your severe problems that affect you more than half of the time.

<input type="checkbox"/> OTHER Other diagnosis #1 _____
--

1C. If there are additional diagnoses...
--

Leave these blank.

I used to include many other diagnoses like migraine, irritable bowel syndrome, fibromyalgia and sleep apnea. Some of these are competing diagnoses that may be used by the VA instead of CFS. For example, fibromyalgia has only a 10% rating, and some claim that you cannot have CFS if you have sleep apnea. Why give them a chance to deny your application or give you a lower rating than is appropriate? Some illnesses have their own separate forms. Therefore, I recommend we keep this form focused on CFS and the many conditions that are part of CFS.

Check all of the following that apply and type out examples to strengthen your case.

Note – For VA purposes, the diagnosis of chronic fatigue syndrome requires:

- (A) New onset of debilitating fatigue severe enough to reduce daily activity to less than 50 percent of the usual level for at least 6 months, and
- (B) The exclusion, by history, physical examination, and laboratory tests, of all other clinical conditions that may produce similar symptoms, and
- (C) Six or more of the following:

1. Acute onset of the condition

Did CFS start with a sudden flu-like illness? Did you get sick Friday October 13, 2000 at 5 pm and have never been the same since. Did the fatigue and other problems get worse over a 30 day period? This is also considered acute or sudden. Was it a slow, gradual process over weeks to months to years?

2. Low grade fever

Fever that you measure as an increase in body temperature with a thermometer is not a part of actual CFS or GWI. The sense of being hot or feverish is part of the diagnosis.

3. Non-exudative pharyngitis.

Sore throat

4. Palpable or tender cervical or axillary lymph nodes

Sore nodes in your neck or arm pit that you can feel and that are sore more than half of the time.

5. Generalized muscle aches or weakness

Do you have severe total body pain more than half of the time? This should be on the left and right sides of your body, above and below the waist, and in your neck, spine (back) or ribs.

6. Fatigue lasting 24 hours or longer after exercise

This is the post-exertional malaise or exertional exhaustion that is critical for CFS in the Canadian criteria. Have you stopped exercising because you would develop fatigue, pain, or brain fog? Emotional, cognitive, computer, other work and stresses can also bring on the fatigue, pain and problems thinking.

7. Headaches (of a type, severity or pattern that is different from headaches in the pre-morbid state)

Severe headaches and migraines count here. People who had migraines as a child or with periods should be able to show they have a different pattern to the pain since the fatigue began.

8. Migratory joint pain

The pain should move throughout your body, generally with the muscle aches in #6. "Arthritis" is when you have red, hot, swollen joints that you cannot move, or hurt to move. Arthritis is not part of CFS.

9. Neuropsychological symptoms

This includes problems thinking, doing arithmetic, anxiety, sadness, anger, irritability, numbness, tingling or other sensations in your face, body or limbs. Are they severe and do they occur more than half of the time?

10. Sleep disturbance

This may be a trick question because they may say that if you have sleep apnea you cannot have CFS. The most important issue is whether you wake up refreshed after a good sleep most nights, or if you are unrefreshed most mornings. Other problems include inability to fall asleep, stay asleep, waking up very early, napping frequently during the day.

SECTION III – MEDICAL RECORD REVIEW

This is for the doctor.

SECTION III – MEDICAL HISTORY

3A. DESCRIBE THE HISTORY.

Type up a short, point form summary that begins with your health before the 1st Persian Gulf War (“I was previously healthy.”) and exposures such as Khamisiyah, pyridostigmine bromide pills, personal pesticides, and oil well fires. Give the date when you first began to have symptoms of GWI (see the Steele Kansas criteria). Was it sudden or gradual? Did all the symptoms come as a single illness, or did different parts start at different times?

Are you getting better, worse, or staying the same?

Are your symptoms severe? Are they present over half of the time?

3B. Is continuous medication required for control of chronic fatigue syndrome?

YES NO

What medicines, vitamins, supplements, yoga, cognitive behavioral therapy, and other treatments have you used? Did they work? What symptom did they help? Did you have adverse affects? This information helps the doctor so you do not get the same medicine over again, and so you can get a better treatment plan.

There are no medicines for GWI or CFS proven by randomized, double blind placebo controlled studies and approved by the Food and Drug Administration (FDA).

3C. Have other clinical conditions that may produce similar symptoms been excluded by history, physical examination and/or laboratory tests to the extent possible?

YES NO

This will certainly be yes. Untreated diabetes, hypothyroidism or other chronic diseases are what they are looking for.

3D. Did the veteran have an acute onset of chronic fatigue syndrome?

Did you get sick in the Gulf in 1991? Were you around Khamisiyah? Did you get sick when you returned to the U.S. in 1991? Did all the GWI symptoms begin suddenly one day, or one month, and have been present ever since? Did each symptom begin slowly and separately from the others? Did they get worse over the course of days, weeks, years?

3E. Has the debilitating fatigue reduced daily activity level to less than 50% of pre-illness level?

YES NO

If yes: Less than 6 months

6 months or longer

This must be more than 6 months to be CFS or GWI.

SECTION IV - FINDINGS, SIGNS AND SYMPTOMS

4A. Does the veteran now have or has the veteran had any findings, signs and symptoms attributable to chronic fatigue syndrome?

YES NO

Debilitating fatigue (Severe and more than half of the time for more than 6 months. Try to give examples.)

Low grade fever

Fever that you measure as an increase in body temperature with a thermometer. If you have a chronic fever there is likely another cause and not CFS or GWI.

Non-exudative pharyngitis.

Say how often do you get a sore throat.

Palpable or tender cervical or axillary lymph nodes

Tell how often you have sore lymph nodes in your neck or arm pit.

Generalized muscle aches or weakness

Do you have severe total body pain more than half of the time? This should be on the left and

right sides of your body, above and below the waist, and in your neck, spine (back) or ribs.

Give examples of the ache. What muscle groups or parts of your body get weak?

Fatigue lasting 24 hours or longer after exercise

What types of exercise do you do now? What could you do in the past, such as 6 months ago? How far can you walk before you feel pain, fatigue or out of breath? Do you have heart disease or another reason to get tired with exercise?

Headaches (of a type, severity or pattern that is different from headaches in the pre-morbid state)

Severe headaches and migraines count here. People who had migraines as a child or with periods should be able to show they have a different pattern to the pain since the fatigue began. Where are your headaches? Behind your eyes? Do you get an aura? Is it a steady pain or throbbing? How often do you get headaches? Daily? Once a week? Once a year?

Migratory joint pain

What joints have severe pain more than half of the days? Make clear that you do not have arthritis (red, hot, swollen joints that you cannot move, or hurt to move.)

Neuropsychological symptoms

This includes problems thinking, doing arithmetic, anxiety, sadness, anger, irritability, numbness, tingling or other sensations in your face, body or limbs. Are they severe and do they occur more than half of the time? Have you been treated for depression? This is a trick question since 40% of people with any chronic illness like diabetes will meet the diagnostic criteria for depression. However, it may Inflammatory Dysaffective Disorder (IDD) with sadness about being sick, anxiety about getting better, anger about getting sick, and irritability from the discomfort.

Are you suicidal? If so, get help immediately. The VA is there to help swiftly.

Sleep disturbance

Try to be precise about the type of problem you have. The key is whether you wake up refreshed or not. Give a few other details such as inability to fall asleep, stay asleep, waking up very early, napping frequently during the day.

Remember that sleep apnea may make this a trick question because they may say that if you have sleep apnea you cannot have CFS.

4B. Provide a description of the conditions.

This small space is where all of these details are supposed to go. HaHaHa! That is why I make a longer version as a letter.

I usually like to fill this form out in brief, and then include your words in a letter that will go with the form.

4C. Does the veteran now have or has the veteran had any cognitive impairment attributable to chronic fatigue syndrome?

- YES NO
- Poor attention
- Inability to concentrate
- Forgetfulness
- Confusion
- Other cognitive impairments

This is a very important issue. In your 50's and 60's it will become harder to remember and think about things. Are you having more problems than "average"? If you think so, then see if you can get neuropsychological testing done at a VA. These tests are expensive if done on your own. They take all day.

4D. Provide a description of the conditions

These symptoms are common in GWI, but give specific examples of how you are affected. One of the concerns I have had is that the VA will begin to say that people with these symptoms have "mild cognitive impairment" and not GWI. Mild cognitive impairment is an early form of Alzheimer's disease. I do not think that GWI will lead to Alzheimer's disease.

4E. Specific the frequency of symptoms

- Symptoms wax and wane
- Symptoms are nearly constant
- Other

Check the pattern than fits for you and your worst problem(s).

4F. Provide a description of the frequency

If pain, fatigue, brain fog, diarrhea or other issues have different patterns, then give the pattern for each.

4G. Do the veteran's symptoms due to chronic fatigue syndrome restrict routine daily activities as compared to the pre-illness level?

- YES NO
- Symptoms restrict routine daily activities by less than 25% of the pre-illness level (more than 75% of the pre-illness level of activities are not restricted)
- Symptoms restrict routine daily activities to 50% to 75% of the pre-illness level

- Symptoms restrict routine daily activities to less than 50% of the pre-illness level
- Symptoms are so severe as to restrict routine daily activities almost completely
- Symptoms are so severe as to occasionally preclude self-care. (If checked, describe the frequency with which this occurs)
- Other

NOTE: For VA purposes, chronic fatigue syndrome is considered incapacitating only while it requires bed rest and treatment by a physician.

4H. Do the veteran's symptoms due to chronic fatigue syndrome result in periods of incapacitation?

YES NO

(duration in the past 12 months)

- Less than 1 week
- At least 1 but less than 2 weeks
- At least 2 but less than 4 weeks
- At least 4 but less than 6 weeks
- At least 6 weeks total duration per year

NOTE: The VA is applying its own interpretation of severity for CFS.

The standard CFS criteria would be more than 50% reduction in ability to do work or other activities as described in #4G. It is important to describe your life before you were sick and what it is like now. "Working 9 to 5 at the stone quarry and Scout Troop leader" would be fine rather than a long paragraph.

My interpretation of "Symptoms [of CFS that] are so severe as to occasionally preclude self-care" and "Incapacitation" suggests that you would need to be in a nursing home or assisted living facility for supervised help getting in and out of bed, going to the bathroom, getting dressed and feeding yourself. This is beginning to sound like treatment for Alzheimer's disease or some other severe crippling or end-of-life situation. A more reasonable level would be where the pain, fatigue, brain fog and other problems combine to the point where you cannot perform your usual duties and activities. This is why it is important to describe how you are affected by GWI, and to give examples:

"Total body pain, clouded thoughts, unable to plan, exhausted, can't get to the car, diarrhea so bad that I can't leave my room."

How restricted are you when symptoms are severe? Are you limited to lying in bed, sitting in a chair, and resting all day and night? Can you prepare your own meals? Walk the dog? Go outside? Watch TV or work on the computer? Read? How does this level of activity compare to your previous level, or when things were "normal?"

How long are you affected like this? Six weeks per year is about 1 day per week, every week. Do the math. If you can't, it may be the brain fog.

SECTION V – OTHER PERTINENT PHYSICAL FINDINGS, SCARS, COMPLICATIONS, CONDITIONS, SIGNS AND/OR SYMPTOMS

5a. Does the veteran have any scars.... related to chronic fatigue syndrome?

YES NO

Are the scars painful and unstable....

YES NO

This is very interesting. Have you heard of GWI veterans with chronic ulcers, skin breakdown or scarring like this? I wonder what the VA knows but is not telling?

5B. Does the veteran have any other pertinent physical findings.....

YES NO

This is to describe specific problems like tenderness to pressure over the muscles and bones, regions of muscles that are weak out of proportion to the rest of the body, loss of reflexes, trouble standing up, fast heart rate when going from lying down to standing up, tremor, problems walking, tumors and anything else that may be a problem for GWI. This includes other medical problems that may not be part of GWI but are still important. This is also the place to say that the physical examination was normal because that is usually the case in GWI.

SECTION VI – DIAGNOSTIC TESTING

NOTE: If testing has been performed and reflects that veteran's current conditions, repeat testing is not required.

6. Are there any significant diagnostic test findings and/or results?

YES NO

Most of you have had all the standard tests done at your doctor's office. I discuss the lab work done in our study with you, and send you home with a copy of the results. If I find abnormalities, then you and I would have discussed the issue and made a plan of what to do next. There is no test for GWI (yet). Sometimes we find abnormal test results that you have to get double-checked with your local doctor.

SECTION VI - FUNCTIONAL IMPACT

7. Does the veteran's CFS impact his or her ability to work?

YES NO

Almost certainly you will be unable to work if you applying for disability. This is a chance for you to say what you were able to do before getting GWI, and what your activities are like now that you have GWI. Be clear about what you can and cannot do when you are at your best and at worst. This shows the variability of the disease. Don't write a book about yourself, but do give a few short, pithy statements about what you can do.

SECTION VIII – REMARKS

8. Remarks

This will be a short summary and conclusion. "GWI sucks" is succinct but does not make clear to the reader the ways that you are limited by GWI.

SECTION IX – PHYSICIAN'S CERTIFICATION AND SIGNATURE

I fill out these boxes.

IMPORTANT – Physician please fax the completed form to: _____ (VA regional Office FAX number)

I need to have your name on the form before I will sign it. Otherwise it is theoretically possible for someone to take the form, put another name on it, and submit it. Then we have a fraud and forgery issue to deal with. I do not want to go to prison.

The VA wants me to FAX this to your regional office. If this is true, then you will have to give me the number, and the name of the person that it is going to. Check in case you can hand deliver or FEDERAL EXPRESS this paper instead.

I cannot make things up or exclude details that may be inconvenient. That would be fraud and I do not want to go to jail. Read over the report I prepare, and make sure that I have described your case fairly and correctly.

KANSAS CRITERIA for GWI – Select your level of severity for the past 6 months

Systems and Symptoms (Odds ratio)	None	Trivial	Mild	Moderate	Severe	Year
Fatigue/sleep problems						
-Feeling unwell after exercise or exertion (4.28)	None	Trivial	Mild	Moderate	Severe	
-Fatigue (4.10)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple fatigue symptoms (3.32)	None	Trivial	Mild	Moderate	Severe	
-Problems falling or staying asleep (2.98)	None	Trivial	Mild	Moderate	Severe	
-Not feeling rested after sleep (2.69)	None	Trivial	Mild	Moderate	Severe	
Pain symptoms						
-Pain in muscles (4.57)	None	Trivial	Mild	Moderate	Severe	
-Body pain. Hurt all over (3.93)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple pain symptoms (3.57)	None	Trivial	Mild	Moderate	Severe	
-Pain in joints (3.27)	None	Trivial	Mild	Moderate	Severe	
Neurologic/cognitive/mood symptoms						
-Night sweats (5.33)	None	Trivial	Mild	Moderate	Severe	
-Feeling irritable or angry outbursts (5.18)	None	Trivial	Mild	Moderate	Severe	
-Problems remembering recent information (4.92)	None	Trivial	Mild	Moderate	Severe	
-Symptomatic response to chemicals, odors (4.62)	None	Trivial	Mild	Moderate	Severe	
-Difficulty concentrating (4.60)	None	Trivial	Mild	Moderate	Severe	
-Trouble finding words when speaking (4.20)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple neurologic symptoms (3.94)	None	Trivial	Mild	Moderate	Severe	
-Low tolerance for heat or cold (3.67)	None	Trivial	Mild	Moderate	Severe	
-Feeling dizzy, lightheaded, or faint (3.35)	None	Trivial	Mild	Moderate	Severe	
-Feeling down or depressed (2.99)	None	Trivial	Mild	Moderate	Severe	
-Headaches (2.96)	None	Trivial	Mild	Moderate	Severe	
-Eyes very sensitive to light (2.62)	None	Trivial	Mild	Moderate	Severe	
-Blurred or double vision (2.49)	None	Trivial	Mild	Moderate	Severe	
-Numbness or tingling in extremities (2.33)	None	Trivial	Mild	Moderate	Severe	
-Tremors or shaking (1.95)	None	Trivial	Mild	Moderate	Severe	
Gastrointestinal symptoms						
-Nausea or upset stomach (4.25)	None	Trivial	Mild	Moderate	Severe	
-Abdominal pain or cramping (4.23)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple gastrointestinal symptoms (3.63)	None	Trivial	Mild	Moderate	Severe	
-Diarrhea (3.38)	None	Trivial	Mild	Moderate	Severe	
Respiratory symptoms						
-Difficulty breathing or catching breath (4.09)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple respiratory symptoms (3.37)	None	Trivial	Mild	Moderate	Severe	
-Wheezing in chest (2.51)	None	Trivial	Mild	Moderate	Severe	
-Persistent cough when don't have cold (2.20)	None	Trivial	Mild	Moderate	Severe	
Skin symptoms						
-Rashes (5.73)	None	Trivial	Mild	Moderate	Severe	
-Moderate or multiple skin symptoms (4.09)	None	Trivial	Mild	Moderate	Severe	
Other symptoms						
-Mouth sores (6.63)	None	Trivial	Mild	Moderate	Severe	
-Unusual hair loss (5.79)	None	Trivial	Mild	Moderate	Severe	
-Ringing in ears (4.06)	None	Trivial	Mild	Moderate	Severe	
-Self or partner has burning sensation after sex (3.75)	None	Trivial	Mild	Moderate	Severe	
-Hearing loss (3.34)	None	Trivial	Mild	Moderate	Severe	
-Sore or swollen glands in neck (2.94)	None	Trivial	Mild	Moderate	Severe	
-Sinus congestion (2.64)	None	Trivial	Mild	Moderate	Severe	
-Sore throat (2.39)	None	Trivial	Mild	Moderate	Severe	
-Problems with teeth or gums (2.04)	None	Trivial	Mild	Moderate	Severe	

Gulf War Illness by "Kansas" GWI criteria = moderate or multiple symptoms in at least 3 of 6 groups

Not GWI

Steele L. Prevalence and patterns of Gulf War illness in Kansas veterans: association of symptoms with characteristics of person, place, and time of military service. Am J Epidemiol. 2000 Nov 15;152(10):992-1002. PubMed PMID: 11092441.

Chronic Multisystem Illness (CMI) – Select your level of severity for the past 6 months

<input type="checkbox"/> Fatigue → If the symptom is present, score its severity →	None	Trivial	Mild	Moderate	Severe	
<input type="checkbox"/> Mood and cognition	<input type="checkbox"/> symptoms of feeling depressed →	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> difficulty remembering or concentrating	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> feeling moody	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> feeling anxious	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> trouble finding words	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> difficulty sleeping	None	Trivial	Mild	Moderate	Severe
<input type="checkbox"/> Musculoskeletal	<input type="checkbox"/> joint pain	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> joint stiffness	None	Trivial	Mild	Moderate	Severe
	<input type="checkbox"/> muscle pain	None	Trivial	Mild	Moderate	Severe

Chronic Multisystem Illness (CMI) if 2 categories with at least 1 symptom for ≥6 months

Severe if all case-defining symptoms were severe. Mild-to-moderate if not severe for all responses.

Fukuda K, Nisenbaum R, Stewart G, Thompson WW, Robin L, Washko RM, Noah DL, Barrett DH, Randall B, Herwaldt BL, Mawle AC, Reeves WC. Chronic multisymptom illness affecting Air Force veterans of the Gulf War. JAMA. 280:981-988, 1998. PubMed PMID: 9749480.

Systemic Exertion Intolerance Disease, Institute of Medicine (IOM) 2015

Symptom	At least half of the time	Moderate, substantial or severe intensity
<input type="checkbox"/> 1. A substantial reduction or impairment in the ability to engage in pre-illness levels of: <input type="checkbox"/> occupational, educational, social, or personal activities, <input type="checkbox"/> that persists for more than 6 months and is <input type="checkbox"/> accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertions, and <input type="checkbox"/> is not substantially alleviated by rest.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> 2. Post-exertional malaise	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> 3. Unrefreshing sleep	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
At least one of the two following manifestations is also required:		
<input type="checkbox"/> 1. Cognitive impairment or	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> 2. Orthostatic intolerance	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Diagnosis of Systemic Exertional Intolerance Disease	SEID?	<input type="checkbox"/> Yes <input type="checkbox"/> No

(Box S-1 Proposed Diagnostic Criteria for ME/CFS) Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Board on the Health of Select Populations, Institute of Medicine. Beyond Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015 Feb 10. PMID:25695122.

CHRONIC FATIGUE SYNDROME CRITERIA

<input type="checkbox"/> Clinically evaluated, unexplained, persistent, or relapsing fatigue lasting more than 6 months <input type="checkbox"/> Of new or definite onset (more than 6 months ago) <input type="checkbox"/> No relief by rest <input type="checkbox"/> Results in a substantial reduction in previous levels of occupational, social, or personal activity
AND four or more of the following symptoms that persist or recur during 6 or more consecutive months that do not predate the fatigue <input type="checkbox"/> Self-reported impairment of short-term memory or concentration <input type="checkbox"/> Sore throat <input type="checkbox"/> Tender lymph nodes <input type="checkbox"/> Muscle pain <input type="checkbox"/> Multijoint pain without swelling or redness <input type="checkbox"/> Headaches of a new type, pattern or severity <input type="checkbox"/> Unrefreshing and/or interrupted sleep

Postexertional malaise (a feeling of general discomfort or uneasiness) lasting more than 24 hours

Meets 1994 Center for Disease Control (CDC) Chronic Fatigue Syndrome (CFS) Criteria
(ICD-10 Postviral fatigue syndrome G93.3; also for benign myalgic encephalomyelitis)

- Chronic Idiopathic Fatigue syndrome (chronic fatigue syndrome NOS) R53.82
- CFS-like with Insufficient Fatigue Syndrome (CFSLWIFS; code by symptoms)

Fukuda et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. Ann Intern Med. 1994 Dec 15;121(12):953-9. PubMed PMID: 7978722.

Reeves et al. Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution. BMC Health Serv Res. 2003 Dec 31;3(1):25. PMID: 14702202; PMCID: PMC317472.

Baraniuk JN, et al. A Chronic Fatigue Syndrome (CFS) severity score based on case designation criteria. Am J Transl Res. 2013;5(1):53-68. PubMed PMID: 23390566; PubMed Central PMCID: PMC3560481.

Carruthers Canadian Criteria for Myalgic Encephalomyelitis (ME/CFS)

Persistent or recurring chronic fatigue lasting for over 6 months that is not lifelong. Substantial reductions in occupational, educational, social and personal activities compared to before the fatigue started. The concurrent occurrence of the following classic ME/CFS symptoms must have persisted or recurred during the past six months of illness. Symptoms may predate the reported onset of fatigue.

Post-exertional malaise, fatigue, or exhaustion. The activity or exertion causing problems may be relatively mild such as walking up a flight of stairs, using a computer, or reading a book. It does not have to be strenuous exercise. There must be a loss of physical stamina, loss of mental stamina, rapid/sudden muscle fatigue, cognitive fatigue, postexertional malaise and/or fatigue, and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. The recovery is slow, often taking 2-24 hours or longer.

Unrefreshing sleep or disturbance of sleep quantity or rhythm disturbance. Sleep problems may include unrefreshing sleep, prolonged sleep, inability to fall asleep, early awakening, day/night reversal or frequent naps.

Pain (or discomfort) that is often widespread and migratory in nature. At least one symptom from any of the following: Myofascial pain. Achy and sore muscles. Pain, stiffness, or tenderness may occur in any joint but must be present in more than one joint and lacking edema or other signs of inflammation.

Noncardiac chest pain. Abdominal / stomach pain. Pelvic pain.

Headaches often localized behind the eyes or in the back of the head. Headaches are more frequent, severe, and have a new location or quality of pain compared to headaches experienced previously. Migraine

Two or more neurological/cognitive manifestations:

Impaired short-term memory (self-reported or observed difficulty recalling information or events)

Difficulty maintaining focused attention. Disturbed concentration may impair ability to remain on task or to screen out extraneous/excessive stimuli.

Loss of depth perception in vision

Difficulty finding the right word

Frequently forget what wanted to say

Absent mindedness

Slowness of thought

Difficulty recalling information

Need to focus on one thing at a time

Trouble expressing thought

Difficulty comprehending information

Frequent loss of train of thought

Sensitivity to bright lights or noise

Muscle weakness/muscle twitches

At least one symptom from two of the following three categories:

Autonomic manifestations: Positive tilt table test for postural orthostatic tachycardia,

<input type="checkbox"/> neurally mediated hypotension, <input type="checkbox"/> delayed postural hypotension. Complaints of <input type="checkbox"/> dizziness or fainting, <input type="checkbox"/> feeling unsteady when standing up, <input type="checkbox"/> disturbed balance, <input type="checkbox"/> palpitations with or without cardiac arrhythmias, <input type="checkbox"/> shortness of breath, <input type="checkbox"/> nausea, <input type="checkbox"/> irritable bowel syndrome, <input type="checkbox"/> bladder pain
<input type="checkbox"/> Neuroendocrine manifestations. Recurrent feelings of <input type="checkbox"/> feverishness and <input type="checkbox"/> cold extremities, <input type="checkbox"/> subnormal body temperature and <input type="checkbox"/> marked diurnal fluctuations, <input type="checkbox"/> sweating episodes, intolerance of extremes of <input type="checkbox"/> heat and <input type="checkbox"/> cold, <input type="checkbox"/> marked weight change, <input type="checkbox"/> loss of appetite, <input type="checkbox"/> abnormal appetite.
<input type="checkbox"/> Immune manifestations: <input type="checkbox"/> Recurrent flu-like illness, <input type="checkbox"/> non-exudative sore or scratchy throat, <input type="checkbox"/> repeated fevers and sweats, <input type="checkbox"/> lymph nodes tender to palpitation with minimal or no swelling, new sensitivities to <input type="checkbox"/> food, <input type="checkbox"/> odors, or <input type="checkbox"/> chemicals.
VII. Exclusionary versus Non-Exclusionary conditions:
A. Exclusionary conditions:
<input type="checkbox"/> Medical: Any active medical condition that may explain chronic fatigue, such as:
<input type="checkbox"/> Untreated hypothyroidism
<input type="checkbox"/> Sleep apnea
<input type="checkbox"/> Narcolepsy
<input type="checkbox"/> Malignancies
<input type="checkbox"/> Leukemia
<input type="checkbox"/> Unresolved hepatitis
<input type="checkbox"/> Multiple Sclerosis
<input type="checkbox"/> Juvenile rheumatoid arthritis
<input type="checkbox"/> Lupus erythematosus
<input type="checkbox"/> HIV/AIDS
<input type="checkbox"/> Severe obesity (BMI greater than 40; but if weight gain follows onset of ME/CFS, the patient could meet the Clinical Criteria)
<input type="checkbox"/> Celiac disease
<input type="checkbox"/> Lyme disease
<input type="checkbox"/> Psychiatric: <input type="checkbox"/> Active or <input type="checkbox"/> treated in the past 5 years that may explain chronic fatigue:
<input type="checkbox"/> Schizophrenia or psychotic disorders
<input type="checkbox"/> Bipolar disorder
<input type="checkbox"/> Active alcohol or substance abuse for the past 6 months ○ Alcohol or substance abuse that has been successfully treated and resolved should not be considered exclusionary.
<input type="checkbox"/> Active anorexia nervosa or bulimia nervosa ○ Eating disorders that have been treated and resolved are not exclusionary.
<input type="checkbox"/> Depressive disorders with melancholic or psychotic features
B. Not necessarily exclusionary as do not adequately explain fatigue.
<input type="checkbox"/> Psychiatric diagnoses such as:
<input type="checkbox"/> Anxiety disorders
<input type="checkbox"/> Somatoform disorders
<input type="checkbox"/> Depressive disorders
<input type="checkbox"/> Other conditions defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, such as:
<input type="checkbox"/> Multiple food and/or chemical sensitivity
<input type="checkbox"/> Fibromyalgia
<input type="checkbox"/> Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented.
<input type="checkbox"/> Any condition that was treated with definitive therapy before development of chronic symptomatic sequelae.

Any isolated and unexplained physical examination, laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition.

Definition of Research ME/CFS criteria YES NO

Carruthers BM. Definitions and aetiology of myalgic encephalomyelitis: how the Canadian consensus clinical definition of myalgic encephalomyelitis works. J Clin Pathol. 2007 Feb;60(2):117-9. Epub 2006 Aug 25. Review. PubMed PMID: 16935963; PubMed Central PMCID: PMC1860613.

Myalgic Encephalomyelitis (ICD G93.3): International Consensus Criteria.

Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T, Staines D, Powles AC, Speight N, Vallings R, Bateman L, Baumgarten-Austrheim B, Bell DS, Carlo-Stella N, Chia J, Darragh A, Jo D, Lewis D, Light AR, Marshall-Gradisbik S, Mena I, Mikovits JA, Miwa K, Murovska M, Pall ML, Stevens S. Myalgic encephalomyelitis: International Consensus Criteria. J Intern Med. 2011 Oct;270(4):327-38. doi: 10.1111/j.1365-2796.2011.02428.x. Epub 2011 Aug 22. Review. PubMed PMID: 21777306; PubMed Central PMCID: PMC3427890.

1. Post-exertional neuroimmune exhaustion (PENE): All five characteristics.

<input type="checkbox"/> 1.	Marked, rapid physical and/or cognitive fatigability in response to exertion, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse.
<input type="checkbox"/> 2.	Post-exertional symptom exacerbation: e.g. acute flu-like symptoms, pain and worsening of other symptoms.
<input type="checkbox"/> 3.	Post-exertional exhaustion may occur immediately after activity or be delayed by hours or days.
<input type="checkbox"/> 4.	Recovery period is prolonged, usually taking 24 hours or longer. A relapse can last days, weeks or longer.
<input type="checkbox"/> 5.	Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level.

2. Neurological impairment: Three of four categories.

<input type="checkbox"/> 1.	Neurocognitive impairment with either: <input type="checkbox"/> a. Difficulty processing information: slowed thought, impaired concentration, OR <input type="checkbox"/> b. Short-term memory loss
<input type="checkbox"/> 2.	Pain with either: <input type="checkbox"/> a. Headaches, OR <input type="checkbox"/> b. Significant pain can be experienced in muscles, muscle-tendon junctions, joints, abdomen or chest. It is non-inflammatory in nature and often migrates.
<input type="checkbox"/> 3.	Sleep disturbance
<input type="checkbox"/> 4.	<input type="checkbox"/> a. Neurosensory and perceptual disturbances, OR <input type="checkbox"/> b. Motor disturbances

3. Immunological impairment: Three of five categories.

<input type="checkbox"/> 1.	Flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion
<input type="checkbox"/> 2.	Susceptibility to viral infections with prolonged recovery periods
<input type="checkbox"/> 3.	Gastrointestinal tract
<input type="checkbox"/> 4.	Genitoruinary
<input type="checkbox"/> 5.	Sensitivities to food, medications, odours or chemicals

4. Energy production/transport impairment: One of four categories.

<input type="checkbox"/> 1.	Cardiovascular
<input type="checkbox"/> 2.	Respiratory
<input type="checkbox"/> 3.	Loss of thermostatic stability
<input type="checkbox"/> 4.	Intolerance of extremes of temperature

Myalgic Encephalomyelitis (ICD-10 G93.3): YES NO

I find the "Immunological impairment" and "Energy production/transport impairment" to be inscrutable and lumped together without any thought about potential mechanisms. I do not like what this committee cobbled together.