

Documenting disability in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

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Abstract.

BACKGROUND: According to the 2015 National Academy of Medicine report, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) “is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients.” ME/CFS affects between 1 and 2.5 million Americans, leaving as many as 75% unable to work due to physical, cognitive and functional impairment. Unfortunately, many doctors and lawyers lack the knowledge of how to properly document an ME/CFS disability claim, leaving patients unable to access disability benefits.

OBJECTIVE: The goal of this article is to summarize the approaches used by experienced clinicians and lawyers in successful ME/CFS disability claims.

METHODS: The authors reviewed the types of US disability insurance programs and the evidence commonly required by these programs to demonstrate ME/CFS disability.

RESULTS: This article summarizes the range of methods used in successful US disability claims, which include documentation of the functional impact of post-exertional malaise and the use of methods that provide objective evidence of impairment.

CONCLUSIONS: Medical providers and lawyers can use these tested methods to obtain disability benefits for people with ME/CFS. Physical therapists, occupational therapists, and other specialists play an important role in providing objective evidence for ME/CFS disability claims.

Keywords: Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, ME/CFS, disability, functional impairment

1. Introduction

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS, previously called Chronic Fatigue Syndrome) has been a poorly understood disease,

often thought to be a form of depression, malingering, or perhaps not even real. But a groundbreaking report in 2015 by the National Academy of Medicine (previously called the Institute of Medicine) has begun to change this. It concluded that “ME/CFS is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those it afflicts” [1]. ME/CFS

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is associated with neurological, immunological, autonomic, and energy metabolism impairment [1, 2] and causes a range of symptoms, such as orthostatic intolerance, cognitive impairment, sleep dysfunction, pain, gastrointestinal disturbances, flu-like symptoms, an intolerance of exertion called post-exertional malaise, and a substantial impairment in function associated with fatigue [3].

The hallmark of the disease is post-exertional malaise (PEM) in which even small amounts of previously tolerated physical, mental, or emotional exertion or an orthostatic stressor can cause a delayed exacerbation of all other symptoms and a further impairment in functioning [1]. It can take days, weeks, or longer to recover from an episode of PEM [1]. As a result of PEM and the waxing and waning of the disease, patients can often experience significant and unpredictable fluctuations in symptoms and functioning from day to day, referred to as “good days” and “bad days”. For a person with ME/CFS, a good day may be one when they can perform one or two activities with rest intervals, hardly a good day to most people. On a bad day, the level of function can plummet to little more than eating, drinking and going to the bathroom. Even on a good day, the most severely ill may be unable to do the most basic activities of daily living, such as showering, dressing, or eating [4].

The National Academy of Medicine estimates that ME/CFS affects 1 to 2.5 million Americans and that as many as 84 to 91 percent are undiagnosed [1, 5]. The average age of onset is 33 years [1, 6]. The National Academy of Medicine also reported that patients with ME/CFS can be more functionally impaired than patients with type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease [1, 7]. An estimated 25% are bedbound or housebound [1, 6] and the Centers for Disease Control and Prevention (CDC) reported that an estimated 75% are unable to work [8]. Recovery rates are low, estimated to be about 5% [9] and as a result, patients can be ill for decades. This level of impairment led the National Academy of Medicine to establish new clinical diagnostic criteria in 2015 that require “A substantial reduction or impairment of the ability to engage in pre-illness levels of occupational, educational, social or personal activities.”

Yet, in spite of this level of impairment, people with ME/CFS often struggle to obtain disability benefits. In fact, in 2017, the US Social Security Administration (SSA) reported that only about 13,000

individuals were receiving Social Security disability for a diagnosis of ME/CFS at that time [10]. Given the prevalence and level of debility, this is a surprisingly low number and likely reflects the lack of understanding of the disease and its functional impact. This low number of recipients also reflects the high standards of proof required to qualify for ME/CFS disability and the need to use evaluation methods that do not come naturally to most clinicians or even to attorneys who have experience with disability claims for other diseases.

One critical difference about ME/CFS is that even when a patient has profound physical or cognitive limitations made worse by post-exertional malaise (PEM), documenting these effects requires following the patient over hours or days. Poor stamina and PEM, by definition, cannot be measured during a standard medical office physical exam.

This paper summarizes the approaches that can be used by physicians caring for people with ME/CFS and also by attorneys and the patients themselves to document ME/CFS and its functional impairment for Social Security and private disability claims. Physical therapists and occupational therapists are likely seeing people with ME/CFS in their practices and may be the first to recognize the disease. Further, physical therapists and occupational therapists, along with neuropsychologists, cardiologists, and other specialists, play an important role in providing the objective evidence of functional impairment that is so essential in an ME/CFS disability case.

2. Standard for disability claims in the United States

In the United States, there are multiple types of disability programs. One type is a government program administered through the Social Security Administration (SSA) [11]. The private sector also provides various types of Long-Term Disability (LTD) insurance benefit plans and policies, including plans provided through employers or purchased by individuals.

Regardless of the type of program, most disability claims require both 1) proof that an individual has one or more medically documented disabling impairments and 2) proof that the resulting functional limitations prevent that individual from performing the physical and/or cognitive functions required by his or her job, and/or of any job in the national

economy in light of that individual's age, education and work experience.

For Social Security Administration disability claims, the level of functional impairment must be so great that an individual cannot perform any job that is reasonably available in the U.S. economy, in light of that person's age, education and work experience.

With respect to a finding of disability in the case of a 25 year old with a high school degree or more but with limited work experience, the regulations assume broad vocational adaptability as a result of the claimant's age (since under the SS regulations, a 25 year old claimant is categorized as a younger individual) and education (since a high school degree or more is considered a higher degree of education). As a result, such a claimant would have to document significant non-exertional functional limitations [12], which would preclude him from performing the full range of sedentary work activities, which is the lowest work category. And since ME/CFS claimants are substantially impacted as a result of non-exertional symptoms (such as fatigue, pain and cognitive deficits which result in unpredictable good days and bad days and sustained activities of any kind), the 25 year old would need to present proof of those symptoms and limitations.

In determining whether an individual is disabled, SSA claims adjudicators examine that individual's medical records for severity of symptoms, and most importantly, whether the functional limitations caused by the illness prevent that individual from performing the work-related tasks used in the last fifteen years of employment. If the individual is unable to perform these tasks, SSA then evaluates whether the individual can perform the work demands of any job in the national economy given the claimant's age, education and work experience.

In the private sector, one type of program is an ERISA (Employee Retirement Income Security Act) LTD Plan, a group plan obtained through employment or a professional association. Individuals can also purchase an individual disability insurance policy through a disability insurance broker. For both ERISA and individual plans, the definition of disability varies; the LTD insurance claims reviewers are guided by the specific terms and provisions of the LTD plan or policy. Thus, the claimant and/or lawyer must always review the plan and/or policy provisions to determine what is required by that specific plan and policy to establish disability.

Generally, the level of functional impairment must be so great that it prevents the individual from per-

forming the duties of their own occupation, any similar job, or any other job in the national economy given the individual's age, education and work experience. Some require proof that due to the disabling impairment(s), the claimant cannot perform the "material and substantial" duties of his or her own occupation. Terms such as "material and substantial" have specific meanings defined by the specific LTD Plan or policy. Other LTD plans and policies require proof that as a result of the disabling impairment(s), the claimant cannot perform the work demands of any job in the national economy in light of the claimant's age, education and work experience. Some plans and policies will require proof of both.

Plans and policies may also specify certain limitations. For example, some private disability policies have added a provision that limits the duration of a disability award if a substantial proportion of the evidence is dependent on the claimant's "self-report". Other disability plans state that the payment period will be limited, sometimes to just two years, if psychological factors have caused and/or contributed to the state of disability.

Therefore, the claimant must always look to the LTD plan or policy glossary to determine how specific terms are defined, what limitations are specified, and what proofs of disabling impairments are necessary to support the disability claim. The starting point for all disability claims is the medical proof that the applicant is medically impaired and cannot perform the functions of their past work and/or any other work in the national economy. The disability claim must also include any needed vocational proofs, such as job descriptions and performance evaluations, or factual proofs, such as a certification of functional impairment provided by a long-term family friend or clergy.

ERISA LTD claims are unlike private disability insurance claims in that claimants must include all medical, vocational and factual proofs before the administrative record is closed for that evidence to be considered either by the ERISA LTD insurer or ultimately a court if litigation becomes necessary. In many ERISA LTD actions, the courts are limited to determining whether the insurance claims reviewer abused his or her discretion in denying the claim. In that context, the courts will only review the insurer's conduct during the administrative appeal process to determine whether the actions taken were arbitrary and capricious. The court will consider factors such as whether the reviewer ignored substantial evidence in the medical record, cherry-picked only unfavorable

evidence to support their adverse decision, or did not conduct a full and fair review to determine whether it abused its discretion and acted in an arbitrary and capricious manner.

In *Bergman v. Federal Express Corp.* Long Term Disability Plan, 2017 WL 4310751 (S.D>Cal. September 27, 2017), the Court found an abuse of discretion after identifying three reasons to review the LTD claim decision: “the failure to follow proper procedures in denying the claim, including failing to provide a reasonably clear reason for denial and communicate fully with Bergman, the absence of an in-person (medical) examination of Bergman; and the quality and quantity of the medical evidence [13]. And while the Court noted that the LTD plan specifically provided that pain alone cannot prove disability, the court found that that provision did not give Aetna the right to disregard pain altogether and that it must be taken into consideration “if other objective findings are present.” Equally important, the court noted that Bergman’s complaints of pain were not merely self-reported: Bergman submitted clinical exam findings and other diagnostic test results from multiple treating specialists.

Therefore, it is crucial that the medical evidence supporting disability and the claimant’s complaints and functional limitations are included in the medical record and furnished to the ERISA LTD insurance company before it renders its final administrative decision. Wherever possible, the claimant’s complaints should be objectively documented to provide the court with an accurate picture of the overall disabling nature of the claimant’s ME/CFS.

In the context of a private disability insurance claim that is not ERISA, it is equally important to medically document disability for the claim to be paid. However, in the event a disputed disability claim must be litigated, the claimant can generally provide additional evidence of disability after the lawsuit is filed.

Given the debilitating nature of PEM in ME/CFS cases, of particular importance is the well-established legal treatise definition of disability which states that “[t]he insured is considered to be permanently and totally disabled when it is impossible to work without hazarding his or her health or risking his or her life” (see *Appleman, JA. Appleman on Insurance* §187.05[A] at 214 (2d ed.2007) [14–16].

Additional general information about the disability process is available online [17]. The remainder of this paper discusses the approaches used to document an ME/CFS disability claim.

3. Overview of documenting an ME/CFS disability claim

The Social Security Administration’s 2014 ruling for ME/CFS (SSR 14-1p) and its 2018 guidance for health professionals require submission of medical records that include a thorough medical history including diagnosis, onset, duration, and prognosis of the individual’s ME/CFS and any comorbidities [18, 19]. These also require submission of physical exam findings, mental status exams, laboratory tests, and longitudinal clinical records describing the course of ME/CFS, including any treatment and the patients’ response to that treatment. The 2014 ruling specifies that only a licensed physician can provide evidence of a diagnosis of ME/CFS. Finally, SSA requires documentation of functional limitations and whether those limitations prevent the claimant from engaging in substantial gainful activity. The claimant and/or lawyer will need to review the specific requirements.

The 2014 SSA ruling adapted the 1994 CDC case definition for CFS and to some extent the 2003 Canadian Consensus Criteria and the 2011 International Consensus Criteria [18]. But since the inception of the SSR 14-1p ruling, the CDC has replaced the 1994 case definition with the 2015 clinical diagnostic criteria established by the National Academy of Medicine [3, 20].

In either SSA or LTD disability claims, if the doctor’s physical exam confirms that the claimant’s muscles are very weak or that the joints are very stiff, it is crucial to clinically document those complaints in the medical record. But despite the clinical documentation, those complaints may or may not be accepted as medically documented in the context of an adversarial disability claim. This emphasizes the importance of objective testing, such as that discussed in Section 5 below.

In ME/CFS, many disability reviewers may incorrectly assume the claimant’s inability to function as a result of the illness has not been medically documented because the ME/CFS claimant’s functional limitations and symptoms, such as fatigue, poor stamina, cognitive impairment, inability to tolerate prolonged periods of standing, severe pain, and post-exertional malaise, cannot usually be tested during a standard medical exam. Therefore, the treating physician must document the specific complaints and functional limitations with objective testing, wherever possible.

This can be done by conducting in-office tests such as the typing test to document functional

capacity [21], and/or sending the claimant for neurocognitive testing to document cognitive deficits, cardio-pulmonary exercise testing to document PEM, tilt-table or standing test [22] to document orthostatic symptoms, and other objective tests as documented below.

It is also critically important that the medical record documents the patient complaints of post exertional malaise, severe pain, fatigue, orthostatic intolerance (OI), poor stamina, cognitive problems, and other symptoms. The medical record should also document the specific functional limitations caused by ME/CFS that adversely affect the patient's ability to work. This is especially true if the physical exam is normal or if the patient is so severely ill that he/she is unable to participate in some of the evaluation methods described below.

4. Patient documentation of symptoms and functional limitations

For most patients with ME/CFS, with or without comorbidities, the most important factor limiting function is what medical specialists call post exertional malaise or PEM. As described above, PEM is the severe and long-lasting flare-up of symptoms and decrease of function that often results from even modest degrees of physical or cognitive exertion. When the ME/CFS patient is severely ill, PEM flare-ups tend to be both more frequent and more severe, and can often reduce function for many hours, days, weeks, or longer.

To ensure that symptoms and functional limitations are well documented in the medical record, disease experts recommend that patients keep a daily journal of their complaints and functional limitations to give to their physician at every medical provider visit. This will provide real-life examples of what happened when the patient pushed too hard and encountered PEM. This journal should be maintained even by patients already receiving disability benefits as the claim may be subject to later review. The journal should include both "good day" and "bad day" examples to reflect the range of symptoms and functional impairment caused by the claimant's ME/CFS and other important comorbidities (Supplementary Material A).

If the patient is unable to keep a daily journal, then the patient should give his or her physician three or four recent real-life examples of what happened as a result of overexertion. For each "anecdote," the

patient should provide two or three brief paragraphs that describe how he or she felt before exerting themselves, the physical or cognitive activity that turned out to be too much, the resultant increase in symptoms and decline in functioning if any, and how long it took for symptoms and functions to return to baseline. Very often, it takes a few days or more to recover from an episode of PEM.

The patient journal and/or the documentation of recent anecdotes should be filed in the medical record and submitted for disability. Doing so will help both the medical provider and SSA and/or the LTD insurance company better understand how PEM and other symptoms limit the patient's ability to function over time. For the most severely ill patients with ME/CFS, the caretaker may need to provide this documentation.

These records may also be important in the event the disability benefits insurer or the Government Accounting Office (GAO, on behalf of SSA) conducts video surveillance to demonstrate that the claimant can leave the house and engage in activities of daily living. Most often, the surveillance footage documents that the ME/CFS claimant is engaging in limited and simple activities of daily living. The LTD insurer or the GAO may then extrapolate from that footage that the claimant has broad functional abilities and conclude the claimant is thus able to work. However, the surveillance does not capture the unpredictability of symptoms and the impact of PEM after even modest activities. The patient record of PEM symptoms and functional limitations following activity will provide important context to accurately interpret such surveillance.

5. Medical provider methods for documenting impairment and disability

The medical record submitted for a disability claim must also include other more formal methods of documenting the medical impairment and the functional impact of ME/CFS and any comorbidities. This is best done with the help and advice of clinicians who have significant experience with ME/CFS and/or other commonly co-occurring comorbidities such as fibromyalgia or postural orthostatic tachycardia syndrome. When these evaluations are done, it is important to ensure that each of these is included in the medical record submitted for disability. Attorneys with substantial experience representing ME/CFS disability clients are well aware of the clinicians with

such expertise and the need to be tested by them. Local ME/CFS patient support groups may be able to help identify experienced clinicians.

In documenting disability in ME/CFS cases, the following methods must be followed.

5.1. Documentation of medical signs

The 2018 Social Security Administration Guidance for ME/CFS for Health Professionals recommends recording specific medical signs to document a diagnosis of ME/CFS [19]. While these signs may not be present in all patients, they should be documented in the medical record when they are present. The SSA guidance lists the following signs:

- “Orthostatic intolerance (symptoms worsen on maintaining upright posture and improve by lying down).” Note that changes in heart rate and blood pressure upon standing can be objectively documented with orthostatic testing such as tilt table testing [23];
- “Palpably swollen or tender axillary or cervical lymph nodes;”
- “Persistent, reproducible muscle tenderness on examinations;”
- “Abnormal immune function, including frequent viral infections with prolonged recovery; or”
- “Non-exudative pharyngitis”

The 2014 Social Security Administration ruling for ME/CFS (SSR 14-1p) also recommends recording “any other medical signs that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record,” including sinusitis; ataxia (often manifested as difficulty with balance); extreme pallor; and pronounced weight change.

These findings should also be documented for private LTD insurance. In addition, the claimant and/or lawyer should review the LTD plan or policy to determine if additional documentation is required.

5.2. Documentation of symptoms

The Social Security Administration’s 2018 Guidance for ME/CFS for Health Professionals [19] also recommends documenting the following ME/CFS symptoms when present:

- “Persistent or relapsing fatigue resulting in reduction or impairment in ability to carry out daily or work-related activities;”

- “Post-exertional malaise (worsening of symptoms after physical, cognitive, or emotional effort);”
- “Waking unrefreshed (individual is still fatigued after sleep);”
- “Disturbed sleep patterns, such as insomnia or prolonged sleeping;”
- “Cognitive impairment(s) such as having difficulty with information processing, short-term memory, reduced concentration and attention;”
- “Persistent muscle pain, tenderness, stiffness, or weakness;”
- “Multi-joint pain without swelling or redness;”
- “Headaches of a new type, pattern or severity;”
- “Sore throat that is frequent or that reoccurs;”
- “Cardiovascular abnormalities, such as palpitations;”
- “Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain);”
- “Respiratory difficulties, such as labored breathing or sudden breathlessness;”
- “Urinary or bladder problems, such as urinary frequency, nocturia, dysuria, or pain in the bladder region); or”
- “Visual difficulties, such as difficulty with visual focus, impaired depth perception, or severe photosensitivity.”

As with the signs of ME/CFS above, these symptoms may not all be present in every patient. But they should be documented for both SSA and private disability cases when they are present. For private insurance, the claimant and/or lawyer should review the LTD plan or policy as it may require additional documentation.

5.3. Social Security Administration recognized tests

The 2014 Social Security Administration ruling (SSR 14-1p) for ME/CFS acknowledges that standard laboratory tests are often normal and abnormal tests are not required to establish an ME/CFS diagnosis [18]. However, the ruling also states that the following laboratory findings establish the existence of a medically determined impairment due to ME/CFS. If they are present, they should be documented because establishing the existence of a medically determined impairment is a key step in the disability process.

- “An elevated antibody titer to Epstein-Barr virus (EBV) capsid antigen equal to or greater than

Table 1
Severity of Symptoms Following 60-minute Typing Test²

Symptom	Severity at Specified Time for a Patient with Widespread Pain ³ (Severity scale 0–10 with 10 the most severe)					
	Before test	At end of test	1 hr. post-test	8-12 hrs. post-test	24 hrs. post-test	48 hrs. post-test
Fatigue	4	6	6	8	8	6
Cognitive Difficulties (“brain fog”)	5	5	5	7	7	5
Pain in Forearms	3	5	6	8	9	5
Pain in Wrist	2	4	6	8	9	5
Pain in Hands/Fingers	2	3	5	8	9	6
Pain in Upper Arms	2	4	6	7	8	6
Pain in Shoulders	2	3	4	5	6	4
Pain in Chest	3	4	4	4	6	3
Pain in Neck	0	1	2	3	4	4
Pain in Face	2	2	2	3	5	3
Pain in Head	0	0	1	1	2	1
Pain in Low Back	3	4	5	6	6	3
Pain in Upper Back	3	4	5	5	5	3
Pain in Legs	5	5	5	6	6	5

²Test on ME/CFS claimant with fibromyalgia comorbidity. ³The specific symptoms evaluated should reflect those that most impact the patient.

1:5120, or early antigen equal to or greater than 1:640;”

- “An abnormal magnetic resonance imaging (MRI) brain scan;
- “Neurally mediated hypotension as shown by tilt table testing or another clinically accepted form of testing;”
- “Any other laboratory findings that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record (for example, an abnormal exercise stress test or abnormal sleep studies, appropriately evaluated and consistent with the other evidence in the case record).”

SSA’s 2014 ruling for ME/CFS notes that this list is not exhaustive and that as a result of research advances, additional laboratory tests and signs may be found that are useful to document disability in ME/CFS. In addition to the above tests, clinicians and attorneys familiar with ME/CFS should also include additional objective documentation [24], such as EEGs [25], QEEGs [26], SPECT scans [27], PET scans [28], CPET [29], and MRIs [30, 31] to support successful disability cases [32, 33].

Documenting objective findings such as these is important for any LTD claim as well. The claimant and/or lawyer should review the LTD plan or policy to understand any additional requirements.

5.4. Tests of functional capacity for workplace-related activities

One way to document the level of functional impairment is with direct functional tests that assess some of the physical and/or cognitive functions used on the job such as typing, putting books on and off a shelf, standing for long periods, walking up stairs, or reading and understanding the technical articles required for the patient’s field. The physician should select the functional test most appropriate to the patient’s job and track the specific symptoms that are most problematic for the patient, particularly when he or she experiences PEM. These physician-administered limited tests obviously cannot capture the daily and sustained functional demands of a job. However, they can serve to document the often-debilitating results of even modest work demands on an ME/CFS patient.

One example of the physician-administered direct functional test is a typing test in which the patient types for one hour straight. As a part of this test, the patient scores his or her symptoms, such as pain, fatigue, and cognition. This scoring is done on a zero to ten scale before the test starts, at the end of the test, and then at 1 hour, 8–12 hours, 24 hours, and 48 hours after the end of the test. As seen in Table 1, the patient with ME/CFS may feel more tired, achy, and cognitively impaired right after the exertion. But because of post-exertional malaise, the greatest onset

of increased fatigue, pain, and other symptoms is often delayed and may not peak for 1 to 2 days after the exertion before then receding back toward the former baseline. This worsening of symptoms and decrease of function due to PEM is the most important limitation that prevents persons with ME/CFS from being able to work.

Even a simple typing test involves multiple PEM-contributing stressors such as the physical demands of typing, the cognitive demands from concentrating on the text being typed, sensitivity to the brightness of the testing environment, and the orthostatic demands from sitting upright and with feet on the floor. Each of these can contribute to the degree of exacerbation of symptoms that the patient experiences.

5.4.1. *Warning regarding the Functional Capacity Evaluation (FCE) test*

Disability insurance companies often ask applicants to perform a different form of functional testing called the Functional Capacity Evaluation or FCE. The FCE test is not recommended for patients with ME/CFS because it overestimates a patient's functional capacity.

For the FCE, the insurance company contracts with an examiner to observe the claimant perform a fairly long series of medium intensity exercises such as lifting, pulling and pushing a weight, climbing stairs, skipping, hopping, crawling, etc. These sessions often last approximately 3 hours. Then, based on these limited hours of observation, the examiner will judge whether or not the claimant can work effectively at their job—not for just a few hours but for a full 8 hours a day and 5 days a week.

But under the most usual FCE rules, the examiner does not seek out any information on how the claimant felt and functioned during the hours and days after their FCE exertions. This deprives the examiner and the insurance company of any information about whether the level of exertion during the FCE resulted in a significant or prolonged PEM episode in the hours and days following the FCE. Also, remember that the FCE is a physical test that does not take into account the cognitive demands of the job.

Further, when LTD insurers request that ME/CFS claimants undergo standard functional capacity evaluations, those administering the tests often note “self-limiting behavior” on the part of the ME/CFS claimant and either require the claimant to continue with testing beyond his or her ability, or else report to the insurer that the claimant failed to

cooperate if the claimant insists on stopping the test.

For these and other reasons, the ME/CFS claimant should not undergo standard FCE testing. The attorney representing the claimant should obtain a letter from the treating ME/CFS physician explaining that the standard FCE test will not accurately assess the ME/CFS individual's ability to perform a job but will likely exacerbate the claimant's ME/CFS complaints and symptoms and cause PEM [34]. Thus, taking an FCE is medically contraindicated.

The attorney can then submit the physician letter to the insurance company with a demand that the FCE not be done. Once the testing is documented to be medically contraindicated, it is unlikely that the LTD insurer, aware of Appleman's legal treatise definition of disability (see Section 2), will continue to demand FCE testing. In the unlikely event it does, an experienced ME/CFS LTD attorney will use that decision to document either an abuse of discretion (in an ERISA LTD case) or bad faith in a private disability insurance claim.

For a summary of the concerns with the FCE, see Table 2.

5.5. *Two-day cardiopulmonary exercise testing*

As noted above, people with ME/CFS have an impairment in their ability to produce energy aerobically. As a result, they switch to anaerobic metabolism at a lower threshold and corresponding workload than expected, often causing many daily household activities to be above this limit. This effect, which can be objectively documented with the two-day cardiopulmonary exercise test (CPET), is especially pronounced on the second day of the test compared to the first day [1, 29]. This second day decline in the anaerobic threshold is an objective measure that corresponds with and validates the symptom of PEM. This decline, which can be significant, is not seen in healthy people, in those merely suffering from deconditioning, or in a number of other chronic diseases where it has been evaluated, such as cardiovascular disease, lung disease, end-stage renal disease, cystic fibrosis, and pulmonary arterial hypertension [29]. When done correctly, the 2-day CPET test is a gold standard for objectively demonstrating PEM and functional impairment in ME/CFS.

Patients and attorneys who specialize in ME/CFS have reported that the objective findings of the two-day CPET have been instrumental in gaining approval for disability [32, 33].

Table 2
Concerns with the Functional Capacity Evaluation in ME/CFS

The Functional Capacity Evaluation (FCE), as most often practiced, has at least four major problems when applied to ME/CFS [34]. By overestimating the claimant's capacity to work, these negatively impact the ability of the claimant with ME/CFS to gain recognition that they are disabled. These problems include:

1. The standard FCE is not a valid predictor of the ability of the claimant with ME/CFS to work because it only observes the claimant doing modest degrees of exercise. There is no evidence in peer reviewed medical journals that the standard FCE can accurately predict whether a person with ME/CFS can function effectively at a full-time job.
2. The currently used method of scoring an FCE is strongly biased to under-estimate the functional limitations that affect most persons with ME/CFS. This is because the current FCE rules forbid any gathering of information that occurred after the test and thus fails to account for the impact of post-exertional malaise on a claimant's level of day-to-day functioning.
3. The examiner may wrongly attribute the claimant's failure to continue an assigned exercise to willful choice, not an inability to do so. For instance, if the claimant is unable to continue the test because of pain, fatigue, orthostatic intolerance or other issues, examiners may dismiss these issues and conclude the patient is deliberately "self-limiting" their behavior. This could serve as an excuse to deny or terminate benefits.
4. The exertions during the FCE will often trigger an exceptionally severe and prolonged increase of symptoms. Given that FCE protocols do not include active surveillance of PEM, it doesn't make sense to risk having a severe episode of PEM.

There are only a few centers familiar with CPET testing in the context of an ME/CFS case.¹ The testing, like most diagnostics, is often expensive. But the physician treating the ME/CFS patient may order the CPET test because it objectively documents the severity of the claimant's PEM. While the CPET test is likely to provoke PEM, if it is conducted at a center familiar with ME/CFS, unlike the standard FCE examiner hired by the insurer, there will be no charge of self-limiting behavior and care will be taken to ensure that the claimant is not abused in the process.

If the patient with ME/CFS decides to obtain a two-day CPET, it is important that the testing site follow the correct testing methodology to account for the unique considerations in ME/CFS [35] followed by appropriate interpretation [29], ideally by a provider experienced in ME/CFS. Failure to do so may produce misleading findings and conclusions.

It is also important that the treating physician documents the CPET findings in his or her medical records and reports his or her own medical opinion on whether the findings a) document the presence of a substantial functional impairment, and b) support the determination that the patient is functionally impaired due to ME/CFS. It is especially important that the treating physician provides his or her medical opinion when the CPET tester is not a physician. The patient should also provide a diary of changes in symptoms and the

ability to function that occurred the next day and week or longer following the CPET test to document worsening of symptoms and decline in function due to PEM.

5.6. Formal neuropsychological testing

Cognitive dysfunction is one of the most common symptoms for patients with ME/CFS and is often referred to as "brain fog." Research has shown that the primary areas of cognitive problems in ME/CFS include attention problems, a slowed ability to process new or complex information, and decreased working memory, an inability to keep even simple information online" for immediate use [1]. Learning new information and the ability to recall information are also impacted by poor attention, processing speed, and working memory. Individuals with ME/CFS are often not able to sustain attentional control, absorb information fast enough, and keep it "online" to encode all new verbal and/or visual information transmitted. Therefore, they may only be able to recall partial information resulting in perceived short or long-term memory problems. However, memory storage problems or significant overall intellectual decline, as seen in dementing conditions, are rare. Research has also demonstrated that exertion can worsen cognitive impairment and impact brain function [36].

Neuropsychological testing can document the patient's cognitive limitations. Generally, testing will take one day, during which the neuropsychologist evaluates overall intellectual function in terms of

¹Two centers that have been used include Dr. Betsy Keller at Ithaca College in Ithaca, New York and Stacie Sevens at the Workwell Foundation in Stockton, California (<https://www.workwellfoundation.org/>).

what is preserved and the state of cognition on the day of assessment. The neuropsychologist will also assess the patient's ability to pay attention, speed of processing, working memory, mental flexibility, ability to reason and make decisions (also called executive function), learning and memory, language, and visuospatial, motor and emotional function [37]. Prior to the actual assessment, the neuropsychologist should get detailed medical, psychiatric, family, and social histories from the patient and should obtain a copy of the pertinent medical records for review. The neuropsychologist uses all this information, in addition to information gleaned from a clinical interview, observations during testing, and documentation of pain and fatigue severity throughout the evaluation, to render an opinion about how the patient's illness affects his or her ability to work.

The concept of hypothesis testing and pattern analysis is a useful one when evaluating cognitive function in individuals with ME/CFS as subtle deficits in attention, processing speed, and working memory - the hallmarks of cognitive dysfunction in this disorder - have to be uncovered. It is useful to first administer the well-standardized and normed WAIS IV core battery to evaluate discrepancies across the four aspects of overall cognitive function as conceptualized by Wechsler [38]. It is not uncommon that those domains of an ME/CFS patient's cognitive profile that are reliant on academically acquired information are preserved and fall within the high average or higher range of functioning while speed of processing or working memory may be at average or even lower levels. A thorough statistical analysis needs to be undertaken to evaluate whether 1) the differences between WAIS IV index scores in different domains are at the statistically significant level of $p = 0.05$, and thus do not just constitute a random fluctuation or measurement error and 2) whether the discrepancy between index scores is rare (below a base rate of 15% as recommended by Wechsler) in the normative population. If both conditions are met, an "average" score on, for example, processing speed may be a "true" decrement in function at statistical and clinical levels and should be considered an impairment, as it will significantly affect that individual's cognitive efficiency and smoothness of operation [37, 39].

During testing, neuropsychologists familiar with ME/CFS cases often provide whatever time is necessary for the claimant to complete testing. This is because patients may experience PEM and crash mid-exam and thus may require a rest break or need to reschedule. As a result, testing may last much

longer than is usually necessary. However, another paradigm has also been employed called an "exertion paradigm" in which the patient is tested in one day to simulate a "working day." If this paradigm is used, the patient needs to be thoroughly briefed about the possibility that he or she may experience an extended period of PEM after the cognitive testing. As with cardiopulmonary testing, neuropsychological testing, even when administered over several sessions, may cause post-exertional malaise. Finally, the patient should keep a health diary for several days after testing and send it to the neuropsychologist so it may be included in his or her report.

Neuropsychological testing is lengthy, and like all diagnostic testing, may be costly and not reimbursed by health insurance. If such testing is to be done, it is important to select a practitioner who is familiar with ME/CFS and the research on cognition in this disorder so that appropriate tests are selected to show cognitive strengths and weaknesses and the relationship between them.

5.7. *The Fibromyalgia Impact Questionnaire (FIQR)*

This pencil and paper test is most useful for the very large proportion of persons with ME/CFS who also suffer from pain due to severe fibromyalgia. The FIQR has been validated in the medical literature as a measure of how much fibromyalgia impacts a person's ability to function [40]. People with mild to moderate fibromyalgia typically score in the 30 s and 40's. People who score in the 60 s or higher are very often too ill to work.

If pain is not an important problem, then the FIQR might not be useful. But note that many people with ME/CFS and fibromyalgia may under-estimate how much their conditions affects them. This is often because they have already learned to limit their activities. For example, if a patient had to cut their hair short because it was too painful to brush it when long, the impact of their condition on this function should be ranked as a level 8 or 9 out of 10, even if brushing their currently short hair once or twice isn't a problem.

5.8. *Tender points*

Tender points are areas of muscle that are painful upon palpitation. They are key findings in the formal diagnosis of fibromyalgia using the 1990 criteria of the American College of Rheumatology [41]. If chronic pain is an important issue, the provider

should do a formal fibromyalgia diagnostic tender points examination at each (or every other) visit and document that in the patient's medical record. In several cases where the doctor failed to document the fibromyalgia tender point exam for a year or more, the insurance company and/or Social Security Administration took that as evidence that fibromyalgia was no longer present [42]. Documenting the tender points diagnostic exam is especially important for the visits near the time of the disability application.

5.9. Trigger point evaluation

Trigger points are small points of intense muscle spasm, which if pressed forcefully for 30 seconds or more will typically cause pain to radiate out from the trigger point in predictable directions. Having many trigger points predicts a high degree of functional limitation. Trigger point evaluation is most useful for patients with ME/CFS who have abnormalities of the muscle and/or widespread chronic pain with or without a fibromyalgia comorbidity. Trigger point evaluation should be done by the method of Travell and Simons [43]. Note that many insurance companies incorrectly refer to fibromyalgia's diagnostic tender points as trigger points. These are not the same thing.

6. Letters from family, friends, employers, and clergy

Letters from those who have known the patient both before and after the patient became ill can provide valuable insight into the symptoms and limitations the patient is experiencing as a result of ME/CFS. Contrary to popular belief, many disabled individuals underplay their symptoms and limitations, sometimes as a result of denial or embarrassment or because it can be difficult to remember specifics of what the patient was able to do prior to becoming ill. As a result, people who know the patient well – e.g. spouses, adult children, close friends and family members, employers, and clergy - may be able to more accurately report the symptoms and functional limitations that the patient is experiencing. This includes the patient's work history and overall changes in the patient's level of activity. Attorneys experienced with ME/CFS disability cases recommend including in the file letters from a few selected individuals who have known the patient since before he or she became ill.

7. The importance of a competent and experienced disability lawyer

For disability claims filed with either the Social Security Administration or with a disability insurance company, it is important to work with an attorney who has substantial experience with disability cases in general and also specifically with the particular issues affecting ME/CFS and any comorbidities. ME/CFS patient support groups and forums may be able to help find lawyers in the local area.

8. Keeping medical records up-to-date

It is a good idea for the patient to periodically ask for a copy of their medical records from each medical provider to ensure the records accurately reflect the chronic symptoms and functional limitations they experience. By reviewing these records at the time of a disability claim and also on an ongoing basis, the patient can ensure the records are complete and best reflect how ME/CFS has affected them. The patient will also want to review the medical records submitted to disability to ensure that all the relevant medical records were submitted.

9. Conclusion

For disability cases involving ME/CFS claimants, complete, detailed documentation, particularly of the impact of PEM on functioning, is essential. The medical record submitted for the disability claim must include the doctor's medical records, the claimant's journal of complaints and functional limitations, and the objective documentation that supports those limitations. The treating physician must provide this documentation, even when other specialists, such as neuropsychologists, cardiologists, physical therapists, and occupational therapists, are also called upon to conduct specific tests such as the cardiopulmonary exercise test or the neuropsychological evaluation.

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RP conceptualized the article and wrote the first draft. BC wrote the sections on legal standards and issues and provided input on the rest. MD provided input, collation, and overall editing. No author received financial compensation for this article.

Attorneys wishing to discuss disability issues and reach Dr. Podell by email at podell2@gmail.com and Ms. Comerford at bcomerford@barbaracomerfordlaw.com. If you are a clinician and want more information, please contact us at <https://forms.gle/PQ5LWCZjiwCPppfQA> and we will make our best effort to respond. Dr. Podell is not permitted to offer medical advice to persons who are not his active patients.

Conflict of interest

None to report.

Supplementary material

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