Major 2014 Social Security Ruling Establishes New Standards for Documenting ME/CFS Social Security Disability Claims/Reviews

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The following is a comprehensive review and evaluation of the April 3, 2014 Social Security Ruling for the evaluation of medical evidence and work capacity in ME/CFS disability claims. Understanding and use of this Ruling is essential for anyone pursuing a ME/CFS Social Security Disability Claim or Review—including those assisting them, such as health care practitioners and attorneys/advocates.

This review and evaluation is extensive because its importance is in the detail, and in understanding the detail and its application. We urge patients and their families needing Social Security benefits to read and digest the following review. For a short overview, see Medically Documenting Disability in ME/CFS Cases (https://www.frontiersin.org/articles/10.3389/fped.2019.00231/full), by Barbara Comerford, Esq. and Richard Podell, MD (Frontiers in Pediatrics, 2019).

Disclaimer: This review and evaluation of the Ruling contains the opinions of the author as to how claimants, physicians, attorneys and others might utilize the policies and language in the Ruling in the effort to document CFS disability claims.

While these opinions are based on the language of the Ruling, as well as extensive experience with the Social Security disability process, there is no way to accurately know in what manner the Social Security Administration and associated agencies will, in practice, implement the Ruling. The Ruling will likely not be applied or interpreted uniformly at all administrative levels or geographic areas of evaluation. Some elements of the Ruling are likely to be given more emphasis than others; nor is the Ruling expected to remain static in its application over time.

In regard to the documentation of medical signs, symptoms, medical tests and functional evaluation, it is only possible, at this time, to make reasonable inferences from the Ruling's language as to how CFS claims might be evaluated; however, these inferences cannot be expected to predict how the different signs, symptoms and tests will actually be evaluated.

Therefore, Kenneth Casanova, other authors/contributors to this article, and the Massachusetts ME/CFS & FM Association assume no responsibility for any use of this document by its readers, or for any results or consequences of such usage or further, for any other activity which occurs from the reading of the document or the application of its content. This document is not intended to be a substitute of the advice of a competent attorney who is well-versed on the Ruling and the disability evaluation process. For legal advice it is imperative to consult with such an attorney or qualified legal advocate of the reader's own choosing.

The Ruling

On April 3, 2014, the Social Security Administration issued a critical new Ruling: **SSR 14-1p "Titles II and XVI: Social Security Rulings: Evaluating Claims Involving Chronic Fatigue Syndrome**." (/component/weblinks/weblink/45-disability-web-links/30-2014-me-cfs-social-security-ruling?Itemid=267&task=weblink.go) This Ruling now establishes the guidance by which Social Security evaluates CFS/ME disability claims, and reviews, for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). (See below for a note on the relevance of disease names to this Ruling.)

The Ruling is "…binding on all components of the Social Security Administration."

This new Ruling replaces the former CFS evaluation Ruling issued in 1999 (**SSR-99-2p (/component/weblinks/weblink/45-disability-web-links/31-1999-me-cfs-social-security-ruling?Itemid=267&task=weblink.go)**).

The new SSR provides guidance on how evidence is properly developed to establish that a person has a medically-determinable impairment (MDI) of Chronic Fatigue Syndrome and how the impairment is evaluated in determining whether the claimant is sufficiently disabled to qualify for benefits.

The Ruling requires that for a person to be found disabled "… he or she must be unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) (MDI) which…has lasted or can be expected to last for a continuous period of not less than 12 months."

The medical impairment must be established "by medical evidence that consists of signs, symptoms, and laboratory findings"… Therefore, "a claimant may not be found disabled on the basis of a person's statement of symptoms alone." Hence, the Ruling sets forth the medical signs and laboratory findings by which a case of CFS may be determined.

In the 1999 Ruling, the SSA used only the 1994 Centers for Disease Control (CDC) case definition as the basis for determining a case of CFS and for establishing its medically determinable signs, symptoms and laboratory findings.

The new Ruling primarily adapts the 1994 CDC definition, but also uses "to some extent" the newer 2003 Canadian ME/CFS Criteria as well as the 2011 ME International Consensus Criteria (Adult and Pediatric). As a result of recognizing the two more recent diagnostic Criteria, the Ruling includes a broader and more characteristic listing of signs, symptoms, and laboratory tests for CFS—thereby allowing claimants and their physicians to better, and with less difficulty, document and validate the illness.

(Interestingly, the Ruling states: "As mentioned we include ME as a subtype of CFS. When we refer to CFS in this SSR, we include ME." *Note: Because the Ruling primarily adopts the 1994 CFS Case Definition, claimants and their doctors would be wise to include CFS as a diagnosis, in addition to a diagnosis of ME, if applicable.*)

Summary and evaluation of Ruling

The following will be a summary of the Ruling. We suggest that the applicant, or anyone assisting the applicant, thoroughly review the Ruling itself at **https://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html** (/component/weblinks/weblink/45-disability-web-links/30-2014-me-cfs-social-security-ruling?Itemid=267&task=weblink.go)

The Ruling is divided into six major sections:
I. What is CFS?
II. How does a person establish an MDI of CFS?
III. How do we document CFS?
IV. How do we evaluate a person's statements about his or her symptoms and functional limitations?
V. How do we find a person disabled on an MDI of CFS?
VI. How do we consider CFS in the sequential evaluation process?

I. What is CFS?

In determining a case of CFS, the first portions of this section (A. and B1.) largely follow the 1994 CDC definition, the text of which can be found on page 3 of the Ruling.

"The CDC and other medical experts characterize CFS, in part, as a syndrome that causes prolonged fatigue lasting 6 months or more, resulting in a substantial reduction in previous levels of occupational, educational, social or personal activities."

Using the CDC definition, the Ruling makes clear that a "physician should make a diagnosis of CFS only after alternative medical and psychiatric causes of chronic fatiguing illness have been excluded."

Major hallmark symptom

"...clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; cannot be explained by another physical or mental disorder; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities;"

Additional symptoms of CFS

Diagnostic symptoms: "the concurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue:

- post-exertional malaise lasting more than 24 hours;
- self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities;
- sore throat;
- tender cervical or axially lymph nodes;
- muscle pain;
- multi-joint pain without joint swelling or redness;
- headaches of a new type, pattern, or severity;
- waking unrefreshed"

An applicant's physician must document and validate the ME/CFS diagnosis by using the CDC definition and when able, also by the CCC and ICC definitions. Diagnosis is made by symptoms, medical signs and medical/laboratory tests. Hence, any of the above diagnosis symptoms should be included.

Other symptoms

However, in section B2., "Other Symptoms", the Ruling expands the list of CFS diagnostic symptoms as more recently outlined in the Canadian Criteria and the International Consensus Criteria:

"Other Symptoms. Within these parameters, the CDC case definition, CCC, and ICC describe a wide range of other symptoms a person with CFS may exhibit, in addition to the CDC symptoms.

- Muscle weakness;
- Disturbed sleep patterns (for example, insomnia, prolonged sleeping, frequent awakenings, or vivid dreams or nightmares);
- Visual difficulties (for example, trouble focusing, impaired depth perception, severe photosensitivity, or eye pain);
- Orthostatic intolerance (for example, lightheadedness, fainting, dizziness, or increased fatigue with prolonged standing);
- Respiratory difficulties (for example, labored breathing or sudden breathlessness);
- Cardiovascular abnormalities (for example, palpitations with or without cardiac arrhythmias);
- Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain); and
- Urinary or bladder problems (for example, urinary frequency, nocturia, dysuria, or pain in the bladder region)."

As will be seen later, the inclusion of these common elements of CFS allows for an increased ability to provide medical evidence of the illness in terms of the necessary documentation of medical signs and laboratory testing.

Co-occurring conditions

In the last subsection 3 is the following text:
"Co-occurring Conditions. People with CFS may have co-occurring conditions, such as fibromyalgia (FM), myofascial pain syndrome, temporomandibular joint syndrome, irritable bowel syndrome, interstitial cystitis, Raynaud's phenomenon, migraines, chronic lymphocytic thyroiditis, or Sjögren's syndrome. Co-occurring conditions may also include new allergies or sensitivities to foods, odors, chemicals, medications, noise, vibrations, or touch, or the loss of thermostatic stability (for example, chills, night sweats, or intolerance of extreme temperatures)."

Here, again, the new Ruling (based on the more recent CFS/ME and ME definitions) includes many more of the essential elements of the illness that increase the physician's ability to provide medical documentation. Many of these "co-occuring conditions" are essential symptoms of CFS and their documentation add to diagnostic clarity. Notably, multiple sensitivities and loss of thermostatic stability have for years been known to patients and educated clinicians, but are now just being fully recognized.

Other conditions that may explain symptoms similar to CFS

The Ruling reads: “Additionally, several other disorders (including, but not limited to FM, multiple chemical sensitivity, and Gulf War Syndrome, as well as various forms of depression, and some neurological and psychological disorders) may share characteristics similar to those of CFS. When there is evidence of the potential presence of another disorder that may adequately explain the person's symptoms, it may be necessary to pursue additional medical or other development. As mentioned, if we cannot find that the person has an MDI of CFS but there is evidence of another MDI, we will not evaluate the impairment under this SSR. Instead, we will evaluate it under the rules that apply for that impairment.”

Therefore, in documenting a diagnosed case of CFS, the treating physician(s) should not only document any co-occurring conditions, but also should be sure to, if possible, clearly differentiate CFS from other conditions that may share over-lapping symptoms.

II. How does a person establish CFS as a medical impairment?

The person making a Social Security claim through medical evidence provided by a physician must document they have a medically-determinable impairment – that is a medically recognized, properly diagnosed illness – in this case: ME/CFS.“

“***A licensed physician (a medical or osteopathic doctor) is the only acceptable medical source who can provide such evidence.***” (Emphasis added.)

Additional supporting evidence can be provided by other health care practitioners and other lay people, but without the primary medical evidence provided by a physician, the case will fail.

The Ruling goes on to note:
“We cannot rely upon the physician's diagnosis alone. The evidence must document that the physician reviewed the person's medical history and conducted a physical exam. We will review the physician's treatment notes to see if they are consistent with the diagnosis of CFS; determine whether the person's symptoms have improved, worsened, or remained stable; and establish the physician's assessment of the person's physical strength and functional abilities.”

Despite the fact that the CDC definition allows for physician diagnosis based on symptoms and exclusion of other illnesses and conditions, the Ruling requires that for the purposes of establishing disability “***there must also be required medical signs or laboratory findings.***” (Emphasis added.)

What are the medical signs?

“For the purposes of Social Security disability evaluation, one or more of the following medical signs clinically documented over a period of at least 6 consecutive months help establish the existence of an MDI of CFS:

- Palpably swollen or tender lymph nodes on physical examination;
- Non-exudative pharyngitis;
- Persistent, reproducible muscle tenderness on repeated examinations, including the presence of positive tender points; or
- Any other medical signs that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record. For example, the CCC and ICC explain that an acute infectious inflammatory event may precede the onset of CFS, and that other medical signs may be present, including the following:
    - Frequent viral infections with prolonged recovery;
    - Sinusitis;
    - Ataxia;
    - Extreme pallor; and
    - Pronounced weight change.”

This short list is not strictly limited: note the reference, “Any other medical signs that are consistent with medically accepted clinical practice and consistent with the other evidence in the record.” Hence, a physician well-educated and experienced in CFS practice may be able to provide additional signs consistent with CFS depending on the individual case. It should be clearly

understood that CFS disability documentation is not necessarily limited to the signs specifically listed. Many patients may not have one or more of the listed signs, but will have others known to be consistent with CFS.

The inclusion in the signs of frequent viral infections with prolonged recovery is a new recognition of another hallmark of the illness; so also is the new inclusion of an “acute infectious inflammatory event [that] may precede the onset of CFS”.

The new acceptance of these signs is a very distinct improvement in Social Security’s criteria and recognition of the illness.

Again, one or more physicians must fully document the medical signs, and this should be done over sequential office visits.

All of these signs, including their severity and chronicity, should be carefully documented in the doctor(s)’ notes and medical reports.

Laboratory findings

Subsection C outlines acceptable laboratory findings as follows:

“At this time, we cannot identify specific laboratory findings that are widely accepted as being associated with CFS. However, the absence of a definitive test does not preclude our reliance upon certain laboratory findings to establish the existence of an MDI in people with CFS. While standard laboratory test results in the normal range are characteristic for many people with CFS, and they should not be relied upon to the exclusion of all other clinical evidence in decisions regarding the presence and severity of an MDI, the following laboratory findings establish the existence of an MDI in people with CFS:

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

Essentially, these tests are the same as those stated in the 1999 Ruling.

Comments on these laboratory tests:
The EBV titer threshold numbers are so high as to have only occasional diagnostic purpose for selecting cases of CFS. Most patients may have above average titers, but not in the stated range. Above average numbers for EBV or other herpes viruses should be included as indicative of ME/CFS, especially if tests show a viral reactivation.

Only in a small percentage of CFS patients will MRI brain scans show abnormalities as punctate white spots. However, a patient showing abnormalities on one scan will often on a second scan show perfectly normal results. Therefore, such scans are likely diagnostic only in a minority of cases. Many patients, however, not showing diagnostic results on other tests may feel compelled to obtain an MRI in an effort to document their illness. MRIs are costly, and without insurance, beyond the reach of many patients. Moreover, only a neurologist familiar with the relation of punctate white spots to CFS would usually be to provide the likely diagnostic connection to CFS.

A proportion of CFS patients have neurally-mediated hypotension. Tilt-table tests are expensive and may not be reimbursable. Patients seeking the test would have to receive the test from a physician following protocols known to be diagnostic for CFS patients. A tilt-table test performed by a tester unfamiliar with CFS may or may not be of value.

The Ruling appears to allow for an alternative test (“or other clinically accepted form of testing”) which might include the "poor man's tilt-table": the taking of blood pressure sequentially—lying down, then immediately after standing, and then 3 minutes later, standing again. Such a test performed by a CFS-informed physician could be of value if a standard tilt-table test is not available.

Sleep studies certainly may show abnormalities in CFS patients. However, the CFS diagnostic value of the sleep testing for Social Security will depend on the tester’s knowledge of abnormal sleep architecture in the illness.

Exercise stress tests performed on CFS patients often appear normal during and immediately after the test itself—but abnormal effects may only appear as severe insufficiency of recovery in the days following the testing. Therefore, a tester familiar with CFS will document the "recovery period" (or lack of it) as an integral part of the test.

Hence, some of these lab tests listed will be difficult for most CFS patients to obtain and if not knowledgeably performed may not be diagnostic in a substantial percentage of cases.

Additional signs and laboratory findings

However, the current Ruling includes additional important text relating to:

"Additional signs and laboratory findings:
Because of the ongoing research into the etiology and manifestations of CFS, the medical criteria discussed above are only examples of physical and mental signs and laboratory findings that can help us establish the existence of an MDI; they are not all-inclusive. As medical research advances regarding CFS, we may discover additional signs and laboratory findings to establish that people have an MDI of CFS. For example, scientific studies now suggest there may be subsets of CFS with different causes, including viruses such as Human Herpesvirus 6. *Thus, we may document the existence of CFS with medical signs and laboratory findings other than those listed above provided such evidence is consistent with medically accepted clinical practice, and is consistent with the other evidence in the case record*." (Emphasis added.)

Therefore, physicians and patients should not be limited by the specific laboratory findings outlined. Abnormal antibody findings or the continuing presence of other infectious agents should be documented.

Furthermore, it is well-established among ME/CFS knowledgeable clinicians that certain abnormalities in blood work can help in the confirmation of CFS.

Dr. Anthony Komaroff, a leading specialist in CFS, cites the following laboratory abnormalities as supportive of a CFS diagnosis (while these are not listed in the Ruling, they should be documented):

Laboratory Abnormalities and Chronic Viral Fatigue Syndrome (CFS)

- Mild leukopenia (3000-5000/mm)
- Moderate monocytosis (7%-15%)
- Relative lymphocytosis (>40%)
- Atypical lymphocytosis (1%-20%)
- Slight elevation in SGOT and SGPT
- Erythrocyte sedimentation rate unusually low (0-4mm)
- Partial reduction in immunoglobulins
- Circulating immune complexes (low levels)
- Increased CD4/CD8 ratio

Also, very important: In Section I, "What is CFS", B2, "Other Symptoms", discussed above, the Ruling introduces new elements of the illness identified in the Canadian and International Consensus Criteria. Many of these symptoms can be identified objectively as medical signs or in laboratory testing. If the diagnosing physician identifies such symptoms and conditions, and s/he can document their signs and obtain identifying lab or other testing, then such positive documentation should be provided to Social Security.

Such conditions, cited in the Ruling, include:
"Muscle weakness; Visual difficulties (for example, trouble focusing, impaired depth perception, severe photosensitivity, or eye pain); Respiratory difficulties (for example, labored breathing or sudden breathlessness); Cardiovascular abnormalities (for example, palpitations with or without cardiac arrhythmias); Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain); and Urinary or bladder problems (for example, urinary frequency, nocturia, dysuria, or pain in the bladder region)."

Mental limitations

"E. Mental limitations" is the next subsection, and reads as follows:

“Some people with CFS report ongoing problems with short-term memory, information processing, visual-spatial difficulties, comprehension, concentration, speech, word-finding, calculation, and other symptoms suggesting persistent neurocognitive impairment. When ongoing deficits in these areas have been documented by mental status examination or psychological testing, such findings may constitute medical signs or (in the case of psychological testing) laboratory findings that establish the presence of an MDI. When medical signs or laboratory findings suggest a persistent neurological impairment or other mental problems, and these signs or findings are appropriately documented in the medical record, we may find that the person has an MDI.”

CFS patients and their physicians must understand both the assistance provided by this section, but also be acutely aware of its pitfalls—so as not to be misguided into undermining CFS illness diagnosis. The above findings fall into two different diagnostic categories: “neurocognitive impairments” and “mental problems”.

Neurocognitive impairments, as listed, are a hallmark of the biological aspects of CFS and are suffered by a high proportion of patients. When they are documented by proper testing, the impairments provide important laboratory documentation of the illness. *However, despite the text of the Ruling, neurocognitive impairments in CFS are best determined by “neuropsychological testing” not “psychological testing.”*

Very important: Neuropsycholgical testing will only be diagnostically helpful in the hands of an experienced tester familiar with CFS. In the wrong and inexperienced hands such testing may falsely indicate a psychological disorder. Neuropsychological testing from an experienced CFS tester is probably not easily available in many parts of the U.S. Such testing is also relatively expensive. Yet obtaining the proper neuropsychological testing may be one of the best ways, under these guidelines, to provide a positive laboratory finding.

Despite some prevailing opinion that CFS claimants must obtain neuropsychological testing in order to have a chance at obtaining Social Security benefits, the fact is that such opinion is both incorrect and may lead to harmful results if the testing is done by an tester inexperienced with CFS.

Many, many CFS patients (likely in the thousands) have been approved for benefits without having had neuropsychological testing. A CFS patient who receives testing from an unreliable tester may receive an opinion that the neurocognitive deficits are based on a psychological disorder—thereby undermining the CFS diagnosis. If a patient does not know of an experienced tester familiar with CFS, it would be more prudent not to be tested.

Mental status examination

The text of the Ruling mentions a “mental status examination” along with psychological testing as a method of documenting the types of neurocognitive deficits listed in the text, e.g. short-term memory, information processing, word-finding, calculation, etc.

The 1994 CDC case definition describes a mental status examination in the following terms:

“A mental status examination to identify abnormalities in mood, intellectual function, memory, and personality. Particular attention should be directed toward current symptoms of depression or anxiety, self-destructive thoughts, and observable signs such as psychomotor retardation. Evidence of a psychiatric or neurological disorder requires that an appropriate psychiatric, psychological, or neurological evaluation be done.”

However, the CDC diagnostic criteria states that the mental status examination is performed by the diagnosing physician—and therefore does not necessarily require examination by a psychiatrist or other mental health professional.

The term, "mental status examination”, does not refer to any standardized or formal test or procedure of evaluation; instead, the term refers to a fairly informal and basic assessment of the presence of any disorders or symptoms listed just above; certainly what constitutes a "mental status examination" will vary among examining physicians. The CDC definition indicates that if evidence of a psychiatric or neurological disorder is found, then a further psychiatric, psychological, or neurological evaluation would be required.

Here CFS patients and the physicians assisting in documentation of their CFS disability must be knowledgeable. Physicians who note symptoms of depression or anxiety must determine initially if such symptoms/conditions are largely determined by the patient’s natural reaction to a serious chronic physical illness. Such depressive symptoms are known as secondary or reactive

depression. In documenting these symptoms, the physician should carefully and explicitly note their secondary nature and the CFS itself as their causative factor. By so doing, the physician will not undermine a diagnostic finding of CFS.

In some cases it is quite possible for a person to suffer both from ME/CFS and additionally a primary – not secondary – psychiatric illness. For instance a person with primary depression could also have MS. In such a case, the physician or psychiatrist must absolutely document that the person has ME/CFS independently from the psychiatric illness.

Long-term disability policies and mental impairments

****Important Caution: If a patient is also on, or applying for, long-term disability insurance, he or she should carefully examine their disability policy. Different policies use different language relating to the effect of depression, anxiety, or other mental impairments on long-term disability eligibility.*

Some policies state that if a mental impairment simply "contributes to" the physically-based CFS disability, then the patient will be ineligible for LTD or the benefits will be limited to a relatively short time period.

If this language is in the disability policy, then the physician documenting CFS for Social Security should clearly note that the depression, anxiety, etc. does not, in any way, contribute to the disability—that the disability and the inability to work is entirely the result of the CFS.

For the patient who is applying for, or already receiving, both LTD and Social Security benefits, it is critical to utilize a single knowledgeable attorney who is familiar with CFS, as well as being competent in representation for both Social Security and LTD benefits. As just discussed, how the person is represented for Social Security can have profound effects on their LTD eligibility. Having one attorney make sure the representation for both is coordinated is essential. *The patient should not accept an insurance company's offer to provide an attorney to represent them before Social Security. Such representation can provide the insurance company with information that could affect eligibility for LTD benefits.*

If the physician feels s/he is not qualified to make a proper diagnosis of CFS in the light of the patient's mental/emotional symptoms, then a referral should be made to a mental health professional familiar with CFS—so that a possible misdiagnosis of a psychiatric illness to the exclusion of CFS will not be made. Also, if a treating physician judges that depression or anxiety secondary to CFS is sufficiently serious in itself and requires treatment, then referral should be made to a mental health professional who can correlate mental health treatment to CFS.

III. How do we document CFS?

What type and form of medical documentation is required by Social Security in the new Ruling?

The Ruling states:
"In cases in which CFS is alleged, we generally need longitudinal evidence because medical signs, symptoms, and laboratory findings of CFS fluctuate in frequency and severity and often continue over a period of many months or years. ["Longitudinal evidence" means that which is collected and documented over multiple office visits over a reasonably substantial period of time.]

Longitudinal clinical records reflecting ongoing medical evaluation and treatment from the person's medical sources, especially treating sources, are extremely helpful in documenting the presence of any medical signs or laboratory findings, as well as the person's functional status over time. ***The longitudinal record should contain detailed medical observations, information about treatment, the person's response to treatment, and a detailed description of how the impairment limits the person's ability to function***." (Emphasis added.)

If the person has been ill for more than 12 months prior to application, the Ruling states:
"…Generally we will request evidence from your medical sources for the 12 month period preceding the month of application unless there is reason to believe that development of an earlier period is necessary…"

Also: "When the alleged onset of disability secondary to CFS occurred less than 12 months before adjudication, we must evaluate the medical evidence and project the degree of impairment severity that is likely to exist at the end of 12 months. Information about the person's treatment and response to treatment, as well as any medical source opinions about the person's prognosis at the end of 12 months, helps us decide whether to expect the MDI to be of disabling severity for at least 12 consecutive months."

Building the medical record over time

Comments: It is the patient's responsibility to work with his/her physician(s) to develop and maintain a detailed and complete record in which entries are made at sufficiently frequent periodic intervals.

The Ruling requires documentation of medical signs, symptoms, laboratory findings and observations as to how the patient's illness over time has limited and will limit his/her ability to function over time. The Ruling is clear that the doctors' office notes, record, and charts are primary evidence.

Most of us when we first become ill never imagine that at some point we may need to apply for disability, whether it be Social Security or through our employer.

Nevertheless many ME/CFS patients, at some point, find that they must seek disability benefits. Therefore, especially if a patient is considering applying, and also if a patient is already receiving benefits (anticipating a review), he or she must alert and actively work with his/her physicians to build a comprehensive clinical record that records each and every medical sign, symptom and laboratory result during or following each office visit.

The Ruling makes clear that prior to or during an application or review period, a 12 month consecutive clinical record is needed. Therefore, anticipating or during such periods, patients must make efforts to visit their doctors frequently (6-8 weeks) in order to build the necessary record and be in the best position to document their illness. During this period, patients should discuss with their physicians which lab tests would be appropriate for the documentation of their CFS.

After a successful application or review, patients should maintain ongoing examinations/follow-up with their physicians (every 4-6 months) in order to maintain a current and ongoing record in anticipation of reviews. Too many CFS patients receiving disability do not see their physicians for long periods of time, often because no new or specific treatments are offered. Then when a review occurs there is no current medical documentation.

Also, very important: While the Ruling emphasizes the 12-month period prior to application or review, the illness in many CFS patients has lasted at least several years prior to application, if not longer. In these cases, it is crucial to provide as a full medical record as possible to Social Security including: the nature of onset, the development and progression of the illness and its symptoms (which may change over time), including their severity. Also, there should be documentation of various treatments and treatment outcomes. The full picture of an illness like CFS can best be documented over its full course. Such documentation adds weight and authenticity to the disability application.

Evidence from medical sources other than physicians, and from non-medical sources

"In addition to obtaining evidence from a physician, we may request evidence from other acceptable medical sources, such as psychologists, both to determine whether the person has another MDI(s) and to evaluate the severity and functional effects of CFS or any of the person's other impairments. Also, "Under our regulations…we may also consider evidence from medical sources we do not consider 'acceptable medical sources' to help evaluate the severity and functional effects of the impairment." This might include an ongoing relationship with a chiropractor, naturopath, etc.

We may also consider information from non-medical sources. This information may also help us assess the person's ability to function day-to-day and over time. It may also assist us in assessing the person's allegations about symptoms and their effects (see section IV below). Examples of non-medical sources include:

- Spouses, parents, siblings, other relatives, neighbors, friends, and clergy;
- Past employers, rehabilitation counselors, and teachers; and
- Statements from SSA personnel who interviewed the person."

IV. How does Social Security evaluate various treating physicians' medical documentation of the patient's impairments?

The Ruling reads: "We consider the nature of the treatment relationship between the medical source and the claimant…If we find that a treating source's medical opinion regarding the nature and severity of a person's impairment(s) is well-supported by medically acceptable clinical and laboratory diagnostic techniques, and the opinion is not inconsistent with other substantial evidence in the case record, we will give it controlling weight."

If there is conflicting medical evidence in the claimant's record, Social Security "may seek clarification of any such conflicts in the medical evidence first from the person's treating or other medical sources…"

If there is insufficient medical evidence to determine disability, Social Security may seek further evidence from treating or other sources; additional existing records may be asked for; more information may be requested from the claimant or others; Social Security may request the claimant undergo a consultative examination by an independent examiner of their own choosing.

(Note: The claimant must accept and attend such an examination or Social Security may deny benefits. Hence it is important to provide sufficient evidence from physicians, when possible, to avoid a consultative examination.)

V. How do we find a person disabled on an MDI of CFS?

There is a sequential process in making a finding on whether a person with ME/CFS is disabled. "In this process, once we establish a medically-determinable impairment of CFS, we must establish the severity of the impairment(s). We determine the severity of the impairment(s) based on the totality of medical signs, symptoms, and laboratory findings, and the effects of the impairments, including any related symptoms, on the person's ability to function."

The five-step sequential evaluation process

Here is a summary of the five-step sequential evaluation process:

Step 1: "We consider the person's work activity. If a person with CFS is doing substantial gainful activity, we find that he or she is not disabled."

Comment: "Substantial gainful activity" in relation to CFS is ill-defined. Based on our experience with scores of CFS claims, and advice from a number of experienced attorneys, any patient working for an even limited number of hours at the time of application risks a finding of performing substantial gainful activity. Limited part-time hours, say 8-10 hours a week may or may not be considered substantial gainful activity depending on the type of work and, to an extent, the claimant's past work experience. Therefore, while applying, it is generally best not to be employed, based on our experience. If a person must work, it should be generally less than 8 hours per week, and at a job that requires very little effort. Still, to do so, may jeopardize a disability application. After an application is approved, there is some greater allowance for work.

Step 2: There must be a finding that the person has CFS (as well as any other conditions) as a medically-determinable impairment (MDI) which would reasonable cause a person's symptoms. Moreover, This step also involves determining whether the person's impairment is "severe".

In this step there is an evaluation of the intensity and persistence of the person's symptoms in order to determine the "extent to which they limit the person's capacity for work… Once a finding is made that the individual's CFS meets the duration requirement [see above], a determination is made whether the fatigue, pain, neurocognitive symptoms, or other symptoms cause a limitation or restriction, and they have more than a minimal effect on a person's ability to perform basic work activities, we must find that the person has a 'severe' impairment."

Step 3: There is a Social Security listing of medical impairments that are considered necessarily severe. ME/CFS in itself is not considered necessarily severe and is not on the Listing of Impairments. However in each ME/CFS case the impairment may be compared to a Listing to determine if there is an equivalency of severity. "Further in cases in which a person has psychological manifestations related to CFS, we must consider whether the person's impairment meets or equals the severity of any impairment in the mental disorders listing."

This regulation has in the past often been used by attorneys to take the patient "off the grid" (see below) in order to make acceptance of the ME/CFS claim less difficult – in order to create an "equivalency". This approach can avoid having to go to steps 4 and 5 of an evaluation of the person's residual functional capacity (RFC). However, a finding of equivalency in cases of ME/CFS is infrequent and most claims "advance" to steps 4 and 5 to determine individual functional capacity.

Steps 4 and 5: When CFS does demonstrate a Listing equivalence there must be an assessment of the person's residual functional capacity – that is their ability to work. Ability to work means the person is unable to do any work, even part-time sedentary work on a predictable basis. In other words, if a person could do 4 hours today and 4 hours tomorrow of light work, but then would be sick for a week or more, then they could not work on a predictable basis and would be considered disabled.

"In assessing RFC, we must consider all the person's impairment related symptoms and how such symptoms may affect functional capacities…we must determine that the person's impairment(s) precludes the performance of past relevant work (or if there was no past relevant work). If we determine that the person's impairment precludes performance of past relevant work, we must make a finding about the person's ability to perform other work. We must apply the usual vocational considerations in determining the person's ability to perform other work."

Also, in attempting to evaluate the functionally limiting effects of symptoms: "…we consider all the evidence in the case record, including the person's daily activities; medications or other treatments the person uses, or has used, to alleviate symptoms; the nature and frequency of the person's attempts to obtain medical treatment for symptoms…" Hence the patient and treating physician(s) should document these types of evidence in the continuing medical record.

The Ruling also notes: That "statements by other people about the person's symptoms…" may be used. These could be statements by other types of professionals or work supervisors, etc.

Therefore, in preparing medical documentation, the person's treating physician(s) must enter into their treatment notes and disability reports, the chronicity and severity of the patient's symptoms over time, as well as how the symptoms may objectively limit the person's functionality and ability to work.

The documentation of a person's residual functional capacity is just as critical as the documentation of ME/CFS diagnosis and severity. It is recommended that the physician or other professional assess and document the person's lack of capacity to carry-out activities of daily living (ADL), their lack of ability to carry-out basic work functions: deficits of concentration, memory, sustaining physical and cognitive activity, carrying out basic physical activities: such as walking, standing, carrying more than a very light weight object, etc.

Continuing Disability Reviews

"In those cases in which we find that a person is disabled based on CFS, we will schedule an appropriate continuing disability review. For this review, we take into account relevant individual case facts, such as the combined severity of other chronic or static impairments and the person's vocational factors."

In our experience, Disability Reviews should entail complete documentation of the illness, especially for the 12 months preceding the Review, but also for the period since benefit approval or a preceding review. Please see the Appendix VI Disability Reviews (/images/pdf/handbook/Disability%20Handbook-Appendix%20VI.pdf) in the Massachusetts CFIDS/ME & FM Association Disability booklet.

This ends the review and explanation of the new Ruling.

Footnotes in the Ruling

The extensive footnotes to the Ruling should be important, over time, to the further recognition of ME/CFS, to a broadening of the acceptable medical signs and laboratory tests, and for attorneys adjudicating cases before Administrative Law Judges. Attorneys should review these footnotes.

Of interest to patients and their doctors, here is a quick summary of important footnotes:

(1) The policies of the Ruling apply to claims of children (under 18).

(12) “In children, symptoms may progress more gradually than in adolescents or adults.”

(16) “In addition, generalized pain and neurological symptoms (for example, headaches, cognitive impairments, sleep disturbance, and dyslexia evident when fatigued) may be common in children and adolescents. Episodes of intense postexertional malaise may occur, eventually causing a previously active child to reduce or avoid physical activity.”

(5) “Although the panel that developed the ICC considers its criteria appropriate for diagnosing only ME, we consider the ICC helpful in establishing an MDI of CFS because of the similarities between CFS and ME. For example, ME also is a systemic disorder that manifests many of the same symptoms as CFS, including prolonged fatigue. Medical experts who consider ME to be a subtype of CFS may use hybrid terms to describe the syndrome, such as CFS/ME and ME/CFS. We adapted the CDC criteria, CCC, and ICC because the Act and our regulations require a claimant to establish by objective medical evidence that he or she has a medically determinable impairment.”

(7) This last footnote indicates that medical findings and tests outlined in both the Canadian Criteria and the Consensus Criteria may be used in documenting a case of CFS. Again, this statement is a major step forward in ME/CFS recognition and advocacy, though undoubtedly full use of the two newer definitions will take time to be implemented. However, physicians and attorneys should make full use of the definitions when necessary and appropriate, in conjunction with the CDC definition.

Application of 2016 SSR 16-3p Social Security Ruling “Evaluation of Symptoms in Disability Claims” to ME-CFS Disability Claims.

SSR 16-3p was issued to instruct examiners and adjudicators on how a claimant’s symptoms should be evaluated in light of both objective medical evidence (medical signs and lab tests), and the entire record, including non-medical evidence. As ME-CFS symptoms are important in both diagnosis and their effect on a person’s ability to work, the Ruling would be applied to ME-CFS disability evaluation.

The Ruling and its application to the ME-CFS disability evaluation will be summarized here. The Ruling states: “We define a symptom as the individual’s own description of his or her physical or mental impairments… In determining disability all of the patient’s individual symptoms, including pain, and the extent to which the symptoms can reasonably be accepted as consistent with the objective medical and other evidence in the individual’s record.”

The Ruling requires that a person’s symptoms and their severity, persistence and disabling effects on the ability to work should be reasonably consistent with objective medical evidence – however: there are times when the person’s the intensity or nature of the person’s symptoms may not be entirely reflected in the objective medical evidence in the record. For instance, post-exertional malaise a person experiences may be greater than indicated by medical signs or lab tests.

When such an “inconsistency” occurs, examiners must seek to clarify medical evidence, but also must take into account evidence in the record from other sources which may help to verify or detract from the level of symptoms. Other sources of evidence include medical sources, non-medical sources, and other factors. Important information about symptoms recorded by medical sources and reported in the medical evidence may include, but is not limited to, the following:

- “Onset, description of the character and location of the symptoms, precipitating and aggravating factors, frequency and duration, change over a period of time (e.g., whether worsening, improving, or static), and daily activities. Very often, the individual has provided this information to the medical source, and the information may be compared with the individual's other statements in the case record. In addition, the evidence provided by a medical source may contain medical opinions about the individual's symptoms and their effects. Our adjudicators will consider such opinions by applying the factors in 20 CFR 404.1520c and 416.920c.[15]
- A longitudinal record of any treatment and its success or failure, including any side effects of medication.

- Other sources may provide information from which we may draw inferences and conclusions about an individual's statements that would be helpful to us in assessing the intensity, persistence, and limiting effects of symptoms. Examples of such sources include public and private agencies, other practitioners, educational personnel, non-medical sources such as family and friends, and agency personnel. We will consider any statements in the record noted by agency personnel who previously interviewed the individual, whether in person or by telephone. The adjudicator will consider any personal observations of the individual in terms of how consistent those observations are with the individual's statements about his or her symptoms as well as with all of the evidence in the file."

"d. Factors to Consider in Evaluating the Intensity, Persistence, and Limiting Effects of an Individual's Symptoms: In addition to using all of the evidence to evaluate the intensity, persistence, and limiting effects of an individual's symptoms, we will also use the factors set forth in 20 CFR 404.1529(c)(3) and 416.929(c)(3). These factors include:

- 1. Daily activities;
- 2. The location, duration, frequency, and intensity of pain or other symptoms;
- 3. Factors that precipitate and aggravate the symptoms;
- 4. The type, dosage, effectiveness, and side effects of any medication an individual takes or has taken to alleviate pain or other symptoms;
- 5. Treatment, other than medication, an individual receives or has received for relief of pain or other symptoms;
- 6. Any measures other than treatment an individual uses or has used to relieve pain or other symptoms (e.g., lying flat on his or her back, standing for 15 to 20 minutes every hour, or sleeping on a board); and
- 7. Any other factors concerning an individual's functional limitations and restrictions due to pain or other symptoms."

The Symptom Ruling also states that Social Security examiners may evaluate a claimant's behavior in attempting to treat their symptoms: "We will consider an individual's attempts to seek medical treatment for symptoms and to follow treatment once it is prescribed when evaluating whether symptom intensity and persistence affect the ability to perform work-related activities for an adult or the ability to function independently, appropriately, and effectively in an age- appropriate manner for a child with a title XVI disability claim. Persistent attempts to obtain relief of symptoms, such as increasing dosages and changing medications, trying a variety of treatments, referrals to specialists, or changing treatment sources may be an indication that an individual's symptoms are a source of distress and may show that they are intense and persistent.[18]"

Lack of such "treatment behavior" may or may not affect Social Security's evaluation of the presence and intensity of symptoms. For instance, failure to follow treatment programs or take medications may reflect negatively on a patient's symptom report. On the other hand, the Ruling requires that possible reasons for such failure must be taken into account:

- An individual may have structured his or her activities to minimize symptoms to a tolerable level by avoiding physical activities or mental stressors that aggravate his or her symptoms.
- An individual may receive periodic treatment or evaluation for refills of medications because his or her symptoms have reached a plateau.
- An individual may not agree to take prescription medications because the side effects are less tolerable than the symptoms.
- An individual may not be able to afford treatment and may not have access to free or low-cost medical services.
- A medical source may have advised the individual that there is no further effective treatment to prescribe or recommend that would benefit the individual.
- An individual's symptoms may not be severe enough to prompt him or her to seek treatment, or the symptoms may be relieved with over the counter medications.
- An individual's religious beliefs may prohibit prescribed treatment.
- Due to various limitations (such as language or mental limitations), an individual may not understand the appropriate treatment for or the need for consistent treatment of his or her impairment.
- Due to a mental impairment (for example, individuals with mental impairments that affect judgment, reality testing, or orientation), an individual may not be aware that he or she has a disorder that requires treatment.

There are a number of important "take-aways" from the Symptom Ruling as it applies to ME-CFS. First an applicant, after MDI ME-CFS diagnosis, should gather as much objective medical evidence as possible to validate their symptoms and the severity, intensity and persistence of their symptoms. Besides any lab or other tests, medical signs might include: "The intensity, persistence,

and limiting effects of many symptoms can be clinically observed and recorded in the medical evidence." Examples would be low grade fevers, any breathing difficulties, rapid heartbeat, low grade fevers, difficulty in walking and abnormal tiredness, cognitive difficulties, and many other symptoms.

Second, the person should gather as much other evidence from medical and non-medical sources to corroborate their symptoms and the limitations caused by them.

All of this information should be communicated to one's treating physicians who may be able to evaluate it for his or her disability medical report. All of the documentation should also be submitted to Social Security by the various non-medical sources. The claimant should also, as much as possible be consistent in their report of symptoms, even if they vary. If the claimant must appeal, his or her attorney should be aware of the symptom Ruling. ME-CFS is an MDI that requires a greater evaluation of symptoms than many other illnesses.