

How to Navigate Disability Insurance with ME/CFS

a focus on Social Security



Solve M.E.





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Sharon Stevenson , DVM, PhD, Board Certified Patient Advocate

Moderator

Sharon is President of Bellwether Care, Inc., a patient advocacy company that empowers patients, caregivers, and families to participate fully in shared decision making during serious illness, which she founded in 2016. The company provides clients with the necessary tools to reach careful, information-based decisions that are integrated with their value systems. Sharon is also a Managing Director of Okapi Venture Capital, which she co-founded in 2005 and is responsible for the firm's life sciences investments.

Prior to moving to the private sector, Sharon was a tenured Associate Professor in the Department of Orthopedics at the Case Western Reserve University School of Medicine. Her clinical training was in veterinary surgery and she is a Diplomate of the American College of Veterinary Surgeons (ACVS). Sharon received a Certificate in Patient Advocacy from UCLA Extension, an MBA from the UCLA Anderson Graduate School of Management, a PhD in Comparative Pathology from UC Davis, and a Master of Science in Veterinary Pathology and Doctor of Veterinary Medicine from The Ohio State University.



Lucinda Bateman MD

Dr. Bateman graduated with honors from the Johns Hopkins School of Medicine, completed her internal medicine residency at the University of Utah, and was a general internist in Salt Lake City for 10 years. During that period, she recognized the need for advances in diagnosis and treatment of multi-symptom chronic illnesses like Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM). She left general practice and formed the Fatigue Consultation Clinic in 2000 to learn more about these illnesses. In 2015 she left private practice and formed the Bateman Horne Center, a 501(c)3 non-profit organization with a mission to improve the lives of people with FM and ME/CFS through clinical care, education and research.

Since 2002 she has participated in more than 40 clinical trials, including collaborations with researchers from the University of Utah, Columbia, Harvard, Nova Southeastern, Stanford, Jackson Laboratory, the National Institutes of Health and the Centers for Disease Control and Prevention. She was part of the FibroCollaborative that created expert treatment guidelines for fibromyalgia. She has served on the board of the IACFSME, and was an author of the "Primer" for ME/CFS. She was invited to participate as a clinical expert on a committee of the Institute of Medicine (IOM) to review the literature and recommend new clinical diagnostic criteria for ME/CFS. This report was published in 2015. She has a passion for advancing the knowledge and skill of medical providers in order to improve the lives of underserved patients.



Christopher R. Snell, Ph.D.

Dr. Christopher Snell has over 25 years' experience studying ME/CFS, particularly the post-exertional fatigue and malaise that typifies this illness. He is part of a group that was among the first to advocate for use of cardiopulmonary exercise testing to measure fatigue in ME/CFS research. Together they have probably conducted more exercise tests with patients than anyone. Their two-day exercise testing protocol has potential to be a biomarker for both pathology and function in ME/CFS. Dr. Snell is a former chair of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) to the U.S. Secretary for Health. He has published extensively on ME/CFS and lectured in the USA and abroad, including invited presentations for the National Institutes of Health and the Food and Drug Administration.



Moselle C. Leland

is an attorney with the Law Offices of Judith S. Leland. She graduated *Magna Cum Laude* from the University of California, Los Angeles with a bachelor's degree in psychology. She completed her legal studies at Southwestern University School of Law in Los Angeles. Ms. Leland's passion fighting for the disabled started at an early age watching her mother helping individuals obtain Social Security benefits. While in college, Ms. Leland worked for a disability attorney and volunteered at the Braille Institute as a teaching assistant. During law school, Ms. Leland studied disability rights.

Ms. Leland is admitted to the bar of California and has been in private practice in California since 2009, emphasizing Social Security disability law. She is an active member of the National Organization of Social Security Claimants' Representatives [NOSSCR], and has served as co-president of the Social Security Section of the Orange County Bar Association and has spoken at a multiple sclerosis informational event. Ms. Leland has pursued cases at all adjudicatory levels, including the US 9th Circuit Court of Appeals.





You are sick, unable to function, financially struggling, frightened and misunderstood. Getting disability support can be a lifeline.

The first big challenge is building a medical record that provides adequate information for disability adjudicators; This is not easy in today's rushed, electronic, and generally uninformed medical system.



Develop a doctor-patient relationship

- Be sure at least **one physician, usually PCP**, follows your illness and is aware of all specialty consultations and all test results.
- See PCP at regular intervals to develop a clear medical record. I usually see patients at least **every 3 months** until the disability has been approved, then every 3-6 months to maintain disability forms.
- Do your best to **educate your PCP about ME/CFS** and engage them in ME/CFS management.
 - “Diagnosing and Treating ME/CFS.” US ME/CFS Clinician Coalition. Aug 2019.
 - The Clinician Coalition is developing a website with medical resources for doctors



Be sure your doctor is aware of the 2015 IOM/NAM clinical diagnostic criteria for ME/CFS. They are more likely to respect an “evidence-based” publication.

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.

Editors: Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb

<https://www.ncbi.nlm.nih.gov/books/NBK274235/>



Communicate clearly with medical providers

- Describe how **activity can appear almost normal when rested** but is **not sustainable day after day** due to development of PEM
- Describe specifically why the daily demands of a work environment are not tolerable without **illness worsening** and **workplace absences**
 - Why can't you work 5 days/week, 8 hours/day?
 - Give **specific examples** of you doing an activity and then developing PEM
- Describe clearly **how illness symptoms impair ability to function**
- Write down your observations and give it to medical providers.
- Keep a clear and organized record of all tests, consults, timeline of events.



Communicate clearly with medical providers

- Be specific about **symptoms** in terms of **frequency** and **severity**
 - Instead of “tired all the time” describe your level of fatigue upon awakening, how it progresses through the day, when it peaks, what makes it improve or worsen, how it impacts ability to function, etc.
- Do not exaggerate or only describe the worst symptoms to make a point.
- **Point out physical findings** for the provider to assess and record.
 - Pale or splotchy skin. Cold hands and feet. Red throat. Tender lymph nodes.
 - Imbalance. Tremor. Thinning hair. Muscle or joint tenderness. Tender Points.



Good Day

Average number of GOOD days per MONTH: "5-10 days"

Average hours of UPRIGHT activity (HUA) on a GOOD day (sitting, standing, walking --- activities with FEET ON FLOOR): "2-3 hours"

Average hours of non-upright activity on a GOOD day (reclining, elevating feet, lying in bed): "21-22 hours"

Give specific examples of activities/tasks you CAN do on a good day: "Drive, go on a short walk, stretch, run an errand with help"

Give specific examples of activities/tasks you CAN NOT do even on a good day: "Clean, make my own meals, go to work"

Bad Day

Average number of bad days per MONTH: "20-25 days"

Average hours of UPRIGHT activity (HUA) on a BAD day (sitting, standing, walking --- activities with FEET ON FLOOR): "30 min- maybe"

Average hours of non-upright activity on a BAD day (reclining, elevating feet, lying in bed): "All day"

Give specific examples of activities/tasks you CAN still do on a BAD day: "Sit up, read, watch tv, eat.."

Give specific examples of activities/tasks you CAN NOT do when it's a BAD day: "Walk, have conversations"



Identify and include co-morbid conditions that have objective markers

- **Dysautonomia, POTS, orthostatic hypotension, neurally mediated hypotension (NMH).**
 - Tilt Table testing
 - 10 min NASA Lean test
- **Mast Cell Activation Syndrome (MCAS), allergies, sensitivities**
 - Blood tests
 - Stain of biopsy specimens
- **Small Fiber Neuropathy (SFN)**
 - skin biopsy
- **Autoimmune Conditions**
 - Autoimmune thyroid disease
 - Antibody tests
 - Celiac disease
 - Antibody tests, gastric biopsy
 - Sjogrens syndrome
- **Primary sleep disorders**
 - Polysomnography
- **Raynaud's Syndrome**



Objective evidence is imperative

- **CPET**, 2-day testing
- Head Up **Tilt Table** Testing or
- 10 min NASA Lean testing
- **Neurocognitive testing** aka neuropsychometric testing
- **Brain MRI** with any abnormalities
- Abnormal **sleep studies**
- **Self monitoring** reports using FitBit, Apple Watch, Ouraring...
 - Heart rate data
 - Heart Rate Variability during sleep
 - Sleep records
- **Lab abnormalities**, even if nonspecific.



ME/CFS Evidence-Based Clinical Diagnostic Criteria 2015:

Myalgic encephalomyelitis/Chronic Fatigue Syndrome

The **CORE** criteria (are required for diagnosis)

- 1) *Impaired function in association with exhaustion/fatigue/low stamina > 6 mo
- 2) *PEM: post exertional malaise (illness relapse after physical or cognitive activity)
- 3) *Unrefreshing sleep (disordered sleep not explained by another disorder)
- 4) A. *Cognitive impairment and/or
B. Orthostatic intolerance

Other common features of illness, not considered "core" or required for diagnosis

---Pain of all types

---Immune impairment (allergy, inflammation, sensitivities)

---Infection symptoms, onset with infection, relapse after an infection

These highlighted core features of illness can ALL BE OBJECTIVELY MEASURED

*Must be moderate-severe, present >50% of the time



What is Orthostatic Intolerance?



Orthostatic intolerance (OI) is the development of symptoms while **standing upright** that are relieved by **reclining**



philipmartin.info



Measuring orthostatic intolerance (OI)

- **Tilt Table test** (not readily available or standardized)
- Bedside orthostatic vital signs---**Sit to Stand Test** (1, 3, 5 minute measures of BP and HR. (inadequate).
- FitBit or other **HR tracking devices** can track heart rate as an indicator of exercise effort, but also an indirect measure of orthostatic intolerance
- **10 min NASA Lean Test**



10 minute NASA Lean Test upright position





Orthostatic Intolerance/OI

- **Orthostatic hypotension:** a drop in BP of at least 20 mm Hg systolic or 10 mm Hg diastolic within the first 3 min standing
- **Postural Orthostatic Tachycardia Syndrome (PoTS):** the reproduction of orthostatic symptoms together with a **+30 bpm** increase in HR standing, or a HR of **≥120** . Ages 12-19 HR increase must be 40 bpm
- **Neurally Mediated Hypotension (NMH):** also called vasovagal syncope (syncope=fainting), neurocardiogenic syncope . A delayed development of hypotension/syncope. (may need more than 10 minutes of testing to detect)



10 min NASA lean test: NMH

58 year old woman with CFS. BMI 17. Unaware of her OI

Lying down on bed at rest:

Supine 1 minute BP: 114/76 Pulse: 75 Pulse Ox 98%

Supine 2 minute BP: **112/78** Pulse: **75**

Standing leaning shoulder blades against the wall:

Standing 0 minute BP: 111/86 Pulse: 89

Standing 1 minute BP: 118/80 Pulse: 90 Pulse oximeter 95% "Lightheaded"

Standing 2 minute BP: 120/92 Pulse: 92

Standing 3 minute BP: 120/98 Pulse: 93 "Tired"

Standing 4 minute BP: 121/98 Pulse: 94 "Trying to catch breath"

Standing 5 minute BP: 123/100 Pulse: 95 "Heavier breathing and need to sit"

Standing 6 minute BP: 124/90 Pulse: 97 Pulse ox 94%

Standing 7 minute BP: 116/52 Pulse: 98. "Feels very different"

Standing 8 minute BP: 108/50 Pulse: 99 Pulse ox 92%.

Standing 9 minute BP: 108/60 Pulse: 100 "Feeling hot, thirsty, blurry vision"

Standing 10 minute BP: **95/50** Pulse: **100** "Need to lie down"



Orthostatic Vital Signs/The NASA LEAN Test (ON midodrine, propranolol, fluids, compression socks)

Supine measurements:

Patient has been resting supine for 15 minutes.

1 min BP: 126/80 PP Score: 46 HR (bpm): 53 SpO2: 98%

2 min BP: **130/86** PP Score: 44 HR (bpm): **52** SpO2: 98%

Standing measurements:

Standing straight with shoulder blades against the wall and feet 6" from the wall

1 min BP: 94/78 PP Score: 16 HR (bpm): 107

2 min BP: 92/80 PP Score: 12 HR (bpm): 111 "Dizzy"

3 min BP: 92/76 PP Score: 16 HR (bpm): 108

4 min BP: 98/84 PP Score: 14 HR (bpm): 107

5 min BP: **90/84** PP Score: 6 HR (bpm): **109** SpO2: % Patient asked to stop test.

SBP decreased from 130 mmHg supine to 90 mmHg at 5 minutes standing. (Score: **-40**) **OH**

PP decreased from 44 mmHg supine to 6 mmHg at 5 minutes standing. (Score: 85% drop)

HR increased from 52 bpm supine to 109 bpm at 5 minutes standing. (Score: **+57**) **POTS**



WORK: A Journal of Prevention, Assessment & Rehabilitation

A special themed issue on ME/CFS will be published this year.

Among many other interesting papers, there will be an excellent article entitled:

**DOCUMENTING DISABILITY IN MYALGIC
ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME
(ME/CFS).** Richard Podell ,* Mary E. Dimmock, and Barbara B.
Comerford. *(publication pending)*



Disability resources for ME/CFS

Medically Documenting Disability in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Cases. Barbara B. Comerford^{1*} and Richard Podell². Front. Pediatr., 02 July 2019. <https://doi.org/10.3389/fped.2019.00231>

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.
Appendix C : Disability in ME/CFS <https://www.ncbi.nlm.nih.gov/books/NBK284900/>

CDC: Disability and ME-CFS <https://www.cdc.gov/mecfs/resources/disability.html>

SSA Information for Healthcare Professionals: Fact Sheet "Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)" <https://www.ssa.gov/disability/professionals/documents/64-063.pdf>



SMCI and BHC have links to:

- PDF: Instructions for the 10 min NASA Lean test
- PDF: Diagnosing and Treating ME/CFS. US Clinician Coalition. August 2019



How to Support Your Claim: Proving Fatigue with 2-Day CPET

Cardiopulmonary Exercise Testing (CPET): Two day test, 7 minutes of physical activity (bike) per day, external sensors placed on, rather than in, body.

- **Designed to detect limiting fatigue by measuring:**
 - How much oxygen the body is using;
 - How much carbon dioxide the body is using;
 - Breathing patterns and heart rate in conjunction with the aforementioned two measures.
- **The report provides three key measures:**
 - **Peak oxygen consumption (VO₂)**
 - Designed to measure someone's maximum performance
 - **Oxygen consumption at the ventilatory/anaerobic threshold (V/AT)**
 - Provides information about a person's ability to perform sustained daily activities
 - **Respiratory exchange ratio. (RER)**
 - Validates the VO₂ measure by assessing whether VO₂ was artificially limited by poor effort (malingering).
- **Measures disabling chronic fatigue, regardless of the source.**
 - One popular misconception is that CPET only measures fatigue *caused by chronic fatigue syndrome*. This is not the case. CPET measures fatigue regardless of source.



Notes about 2-Day CPET: Know Your Results

- Supportive Conclusions come in two types; impaired, and totally disabled.
 - Impaired
 - Ms. X demonstrates cardiopulmonary anomalies, low function and delayed recovery with severe symptom exacerbation post-exertion. This will limit her ability to engage in normal activities of daily living **and places restrictions on her capacity for full-time employment.**
 - Totally Disabled
 - Ms. X demonstrates cardiopulmonary anomalies, low function and delayed recovery with severe symptom exacerbation post-exertion. This will severely limit her ability to engage in normal activities of daily living and **precludes employment of even a sedentary/stationary nature.**



Notes about CPET: Support From Provider

- **Don't be afraid to ask for a rebuttal letter.**
 - You'll need someone around to rebut Insurers' creative and fun medical justifications used to discredit and discount the CPET:
 - Patient is **too fat**, so result are invalid. (MetLife)
 - Patient is **too skinny/fit**, so results are invalid. (MetLife, Prudential and Cigna)
 - Patient's CPET results are **inconsistent with her negative stress echo** (which is equivalent to saying her X-ray showing a leg break is inconsistent with a nerve conduction test performed on the same leg- they are entirely different tests designed to identify entirely different things.) (Aetna)
 - **The patient was malingering.** (In other words, the client somehow faked their VO2 and blood pressure. The insurer didn't bother going into much detail with that explanation). (Cigna)
 - **"A physician was not on site to supervise the results, and thus the results cannot be relied upon"** – Some insurance company doctor who never examined the patient in person. The irony was lost on the insurance company defense counsel....as it so often is.



CPET and the SSA

- When we make a determination or decision of disability, we will consider all of the available evidence in the individual's case record. This includes, but is not limited to, objective medical evidence; other evidence from medical sources, including their opinions; statements by the individual and others about the impairment(s) and how it affects the individual's functioning;
[<https://www.ssa.gov/disability/professionals/cfs-pub063.htm>].



CPET and the SSA (cont.)

- the Social Security law requires that a disabling impairment be documented by medically acceptable clinical and laboratory findings. (....).Thus, it is essential that you submit all objective findings available concerning your patient's condition, even if they relate to another disorder or establish that the person has a different condition. [<https://secure.ssa.gov/poms.nsf/lnx/0424515008>.]
- if you have a severe medically determinable impairment(s) that does not meet a listing, we will determine whether your impairment(s) medically equals a listing.[14.00.J.3]



CPET and the SSA (cont.)

- SSR 14-1p includes “an abnormal exercise stress test” among laboratory findings that “establish the existence of an MDI in people with CFS”. [IIC]
- Occasionally, medical evidence will include the results of an ETT with VO₂. While ETTs without measurement of VO₂ provide only an estimate of aerobic capacity, measured maximal or peak oxygen uptake provides an accurate measurement of aerobic capacity[4.00.C5]

CPET Applied





CPET Applied (cont.)

- **It is not unusual for the veracity, morality, and accuracy of patients' self-reported symptoms to be questioned [9].** This is despite a recommendation from the IOM that “listening to patients and taking careful history” is paramount with respect to diagnosing ME/CFS [6, p.213].
- **The patient's reaction to the physical stress of CPET matches closely descriptions of the post-exertional malaise (PEM) that is a primary feature of ME/CFS.** On the topic of “objective indicators that may help us understand the presentation of PEM in in ME/CFS patients”, the IOM report states:
 - One common characteristic of PEM is delayed ability to return to prior levels of physical capacity after physical exertion. One way to have them demonstrate this delayed lack of recovery in patients with ME/CFS is to have them perform two cardiopulmonary exercise tests (CPETs) separated by 24 hours—the first to assess current level of function and elicit illness relapse (CPET 1) and the second to measure changes in exercise capacity due to the challenge (CPET 2) [6, p.83].



CPET Applied (cont.)

- Psychiatric problems are not uncommon in chronic illness including heart disease, stroke, diabetes mellitus, asthma, cancer, arthritis and osteoporosis [10].
- The IOM include **psychiatric disorders** among a group of conditions with overlapping symptoms that “may develop as part of the spectrum of ME/CFS or in response to the burdens of this disorder”. **They found no scientific evidence to suggest “that being affected by such disorders precludes having ME/CFS” [6. p.224].**
- Depression or mood disturbances are among the symptoms of ME/CFS that may be exacerbated following physical or cognitive exertion. Depression does not explain exercise test results. Indeed, the preponderance of research shows patients with a primary diagnosis of depression as more likely to cope with their illness by increasing, rather than avoiding, physical activity. Compared with ME/CFS, in depression exercise results in improved mood, increased strength and less pain [12].



CPET Applied (cont.)

- Deconditioning is often associated with chronic illness and should not be dismissed as trivial when considering symptoms of exercise intolerance and reduced work capacity.
 - Cardiopulmonary exercise testing can differentiate low oxygen consumption from deconditioning versus circulatory impairment versus pulmonary impairment [5]. The CPET data indicate reduced peak oxygen consumption relative to other same age males and lower than one would expect due to deconditioning, i.e., at the 10th percentile with well-below average functional capacity [13]. Motivation is not an issue. Effort on both tests was excellent, as evidenced by RER's greater than 1.1. The patient cannot manipulate RER. V/AT is low but in the normal range as a percentage of peak oxygen consumption, i.e., 40%–60% peak VO_2 . VAT < 30% peak VO_2 is considered an indication for deconditioning. Despite their low functioning, deconditioned individuals can repeat CPET results on consecutive days.



CPET Applied (cont.)

- Sleep problems feature prominently in the medical record and MCN's reviewers argue that these can also explain his symptoms.
- The IOM found complaints of unrefreshing sleep to be universal in patients with ME/CFS. However, there is scant evidence to show that treatment of primary sleep disorders improves ME/CFS symptoms. Contrary to the view "that a diagnosis of chronic fatigue syndrome or myalgic encephalitis [sic] cannot be made without ruling out other conditions", the IOM recommend that primary sleep disorders be considered "important comorbid conditions" in the diagnosis of ME/CFS. Treatment should focus on reducing symptoms of the comorbid sleep disorder without expectations that ME/CFS symptoms will necessarily resolve. Diagnosis of a primary sleep disorder does not preclude an ME/CFS diagnosis [6, p.96].



CPET Applied (cont.)

- **Orthostatic hypocapnia is associated with symptoms of OI in ME/CFS patients [15].**
- Hypocapnia causes blood vessels in the brain to narrow, impeding blood flow and causing dizziness, anxiety and alkalosis, i.e., confusion, hand tremors, lightheadedness, muscle twitching, nausea, numbness or tingling in the face, hands, or feet. Following testing, the patient reported significant “lightheadedness”, “trouble communicating”, feeling “winded”, “slight hand tremors”, “a tingly feeling in the hands”, and “temperature tolerance symptoms”, including feeling “sweaty”. MCN dismiss these self-reported symptoms as “subjective” and “not particularly convincing”. I would argue that they represent important clinical data consistent with the CPET results and supporting autonomic dysfunction and ME/CFS diagnoses.



CPET Applied (cont.)

- V/AT is the point where lactic acid is produced faster than it can be removed from the muscles; activity rapidly becomes much more difficult and unpleasant; muscles ache, burn, and become fatigued; the heart pounds; and you feel starved for air. Symptoms worsen with continued exertion and in a very short time sustaining activity will be impossible.
 - A primary physiological finding of CPET was an early onset of ventilatory/anaerobic threshold (V/AT).



CPET Applied (cont.)

- In most instances exceeding V/AT for a short time has no adverse effects. An increase in the supply of oxygen at rest would remove the excess lactic acid and allow recuperation. However, this does not account for the prolonged recovery and reduced functional ability due to the phenomenon of PEM which may be unique to ME/CFS. In ME/CFS the physiologic stress associated with exceeding V/AT is likely to elicit exacerbation of symptoms.
 - V/AT is a valuable measure because it gives an estimation of the types of activities that a person can perform for a prolonged period.



CPET & Coronavirus

- Cort Johnson recently suggested that the “dark cloud” of COVID-19 might hold a silver lining for understanding other postviral immune mediated diseases such as ME/CFS.
- A vigorous research effort to understand the plight of those recovering from COVID-19 should also hold clues to what is happening with ME/CFS.



CPET & Coronavirus: It's an Ill Wind

- The clinical and sleep features of chronic post-SARS form a syndrome of chronic fatigue, pain, weakness, depression and sleep disturbance, which overlaps with the clinical and sleep features of FMS and chronic fatigue syndrome. [BMC Neurology 2011,11:37]
- Significant exercise limitation is evident in patients who have had critical illness.
- Early CPET appears a practical method of assessing exercise capacity in ICU survivors.[Journal of Critical Care 2012, 27, 89–94]



CPET Caution

- Currently only available in CA and NY, but attempting to move to additional locations.
- Cost is \$2200 out of pocket, insurance isn't reimbursing claims.
 - LTD lawyer who advances costs will almost always advance cost of CPET.
 - Depending on value of benefits, often an extremely worthy investment.
- Without a lawyer who understands 2-day CPET, hard to respond to attacks against CPET or properly utilize it to create complete vocational assessments with vocational experts.
 - Utilize the evidence provided here and by Workwell- make sure when you hire an attorney they understand the nuances of SSDI, SSI or LTD in the context of ME/CFS claims.
- Can be physically taxing.



Social Security 101: The Two Distinct Programs

- Must have worked 5 of the past 10 years before onset of disability.
- Benefits paid 6 months after onset date or 1 year prior to date of application, whichever is later.
- Medicare entitlement – 24 months after onset date.
- May be entitled to benefits for dependents.
- Income and resource limits:
 - Individual: Max income \$783/mo.
 - No more than \$2000 in resources.
 - Couple: Max income \$1175/mo.
 - no more than \$3000 in resources.
- Benefits paid from date of application forward.
- Medi-Cal entitlement – 1 month after application.
- Generally available only to US citizens.
- No benefits for dependents.



Objective evidence is imperative

- **CPET**, 2-day testing
- Head Up **Tilt Table** Testing or
- 10 min NASA Lean testing
- **Neurocognitive testing** aka neuropsychometric testing
- **Brain MRI** with any abnormalities
- Abnormal **sleep studies**
- **Self monitoring** reports using FitBit, Apple Watch, Ouraring...
 - Heart rate data
 - Heart Rate Variability during sleep
 - Sleep records
- **Lab abnormalities**, even if nonspecific.



Social Security Programs

Social Security Disability Insurance (Title II)

- Must have worked 5 of the past 10 years before onset of disability.
- Benefits paid 6 months after onset date or 1 year prior to date of application, whichever is later.
- Medicare entitlement – 24 months after onset date.
- May be entitled to benefits for dependents.

Supplemental Security Income (SSI) (Title XVI)

- Income and resource limits:
 - Individual: Max income \$783/mo.
 - No more than \$2000 in resources.
 - Couple: Max income \$1175/mo.
 - no more than \$3000 in resources.
- Benefits paid from date of application forward.
- Medi-Cal entitlement – 1 month after application.
- Generally available only to US citizens.
- No benefits for dependents.



Social Security Timeline

- Initial application: 3-6 months for a decision.
- If denied, you must appeal and ask for “Reconsideration.” 3-6 months for a decision at this level.
- If denied, you must request a hearing before an Administrative Law Judge(ALJ).
- Wait times for hearings are between 18 and 22 months currently.
- If denied by ALJ, must appeal to the Appeals Council. Anywhere from 12-18 months for a response.
- If denied by Appeals Council, must file a civil suit in federal court. At this point, a new application may be submitted.
- If denied by District Court, you may file an appeal to the Court of Appeals.



Definition of Disability

Inability to engage in any substantial gainful activity due to a physical or mental impairment that is expected to either result in death OR last for a continuous period of at least 12 months.

- Condition meets a SSA Medical Listing or
OR
- Unable to do Past Relevant Work and
unable to adjust to other work because of
age, education, and/or medical condition



What is Substantial Gainful Activity

Substantial Gainful Activity – paid work with earnings above \$1260/month, \$2110 if blind

Substantial – requiring significant mental and/or physical activity

Gainful – generally, paid work. However, if not paid but engaging in activities that are usually paid, it may be considered gainful



Five-Step Evaluation: Step One

Step One: Are you working?

less than \$1,170/month

- ▶ If no, go on to step two.
- ▶ If yes, not disabled.

- ▶ Different rules apply for self employed
 - ▶ Look at value of services you provide to business and your income.



Five-Step Evaluation: Step Two

Step Two: Do you have a severe impairment?

Anything more than a minimal impairment will be considered severe.

A severe impairment or combination of impairments that significantly limits physical or mental abilities to do basic work activities.

E.g., lifting, carrying, walking, concentrating

Do you have a severe impairment?

IF YES, GO TO STEP FOUR.

IF NO, NOT DISABLED.



Five-Step Evaluation: Step Three

Step Three: Do you meet a listed impairment?

Security has a list of medical conditions with specific limitations/symptoms you must have in order to be considered disabled.

If you don't meet the criteria for a listed impairment, you may "equal" a listing if your condition is found to be equal in severity and duration to a listed impairment.

Do you meet or equal a listing?

- IF YES....YOU ARE FOUND DISABLED
- IF NO...Social Security must determine your Residual Functional Capacity (RFC)



Five-Step Evaluation: Step Three (cont.)

RESIDUAL FUNCTIONAL CAPACITY – The most you can still do despite medical limitations

◦Physical: lifting, carrying, sitting, standing, walking, pushing, pulling

◦Mental:

- understanding, remembering, carrying out instructions
- Responding appropriately to supervision, coworkers and work pressures

• Other Limitations:

- Environmental restrictions, vision impairments, fatigue



Five-Step Evaluation: Step Four

- Step-Four: Can you do past relevant work?
- An individual's RFC is compared to past relevant work. If the person retains the physical and mental capacity to do any past relevant work, he/she is found not disabled.
 - Only considered PRW if performed in the past 15 years, performed long enough to learn it and performed at SGA
- If you cannot do past relevant work or have no past relevant work, go to Step Five.



Five-Step Evaluation: Step Five

- ▶ Step Five: Can the individual make an adjustment to any other work that exists in the national economy?
- ▶ An individual's RFC, age, education, and work experience are considered.
 - IF YOU CAN'T DO OTHER WORK...YOU ARE DISABLED
 - IF YOU CAN...YOU ARE NOT DISABLED



Unsuccessful Work Attempt

- For earnings above the SGA level (\$1260) not to count, you must have stopped working for at least 30 days because of your impairments.
- If you worked for less than 6 months and then stopped working or reduced your work below SGA due to your medical impairment, this work effort can be treated as an unsuccessful work attempt.



How to Build Your Case

- Establish a good relationship with your doctor.
- You must show that you have impairment-related limitations
- A doctor's diagnosis by itself is not enough to prove disability.
- Must have objective test results.
 - MRIs, spinal tap results, etc.
- Treatment notes must document clinical findings.
 - Make sure your doctor documents symptoms such as fatigue and weakness. Get a copy of your records.



Evaluating ME/CFS Under SSA 14-1p

- A doctor's diagnosis based on reported symptoms alone is not enough for SSA.
- Doctor must document medical signs, laboratory findings, subjective symptoms and other findings.
 - Swollen or tender lymph nodes, positive tender points
 - Inflammation of the throat
 - Frequent viral infections with prolonged recovery, sinusitis
 - Ataxia (loss of full control of body movements)
 - Extreme pallor, pronounced weight change
 - Elevated Epstein-bar virus antibody titer
 - Abnormal brain MRI scan
 - Abnormal exercise stress test, abnormal sleep study, or other findings
 - **Other findings:** neurocognitive impairment (mental status exam or psychological testing)



Evaluating ME/CFS Under SSA 14-1p

- SSA will look at how often you go to the doctor, medication/treatment compliance, all treatment attempted, and your daily activities.
- Self-reported impairments documented in doctor's notes and in forms you complete for SSA.
 - Keep a journal. This is evidence! Keep track of good and bad days.
- To determine severity, SSA will also look at evidence from:
 - Spouses, parents, siblings.
 - Past employers, rehabilitation counselors, and teachers.
 - **Medical Source Statement/opinions: opinion cannot merely state "disabled" or "unable to work." Must give specific limitations called a residual functional capacity (RFC).**



“Private” Disability Insurance

- Short Term Disability (STD) v. Long Term Disability (LTD)
 - STD usually pays 6 months but can pay up to 2 years. LTD generally pays up to age 65.
 - Both pay a percentage of her salary, usually 60%, depending on policy.
 - LTD will often be reduced by other income such as SSDI.
 - LTD is sometimes taxed.
- Disability defined:
 - Generally, first 2 years found disabled if you cannot do your own occupation.
 - After 2 years, must show you cannot do any occupation. Similar to the Social Security.



Private Disability Insurance v. SSDI/SSI

- LTD and STD are funded by insurance companies or an employer
- SSDI & SSI are funded by taxes and administered by the Social Security Administration.
- When applying for both LTD and SSDI, the LTD policy will require a coordination of benefits. Any SSDI received will reduce the LTD amount ("offset").
- Retroactive SSDI benefits ("backpay") must be reimbursed to LTD carrier.
- LTD benefits usually pay 60% of salaried earnings prior to disability up to a maximum specified in the policy.
- SSDI pays a maximum of \$2857 a month until age 66, depending on income earned. Medicare eligibility starts 2 years after SSDI benefits start.



Private Disability Insurance v. SSDI/SSI

- SSDI is generally considered a more stringent standard.
- SSDI doesn't have limitations, unlike many LTD policies.
 - E.g., pre-existing condition limitations in LTD policies.
- SSDI approval helps support and LTD claim, but LTD approvals are not considered persuasive in SSDI claims on their own.
- However, the evidence obtained for one claim can be used to support the other claim.



How to Build Your Case

- Keep a journal. This is evidence!
 - Keep track of good and bad days. If working, keep track of your sick days.
- Ask your doctor to complete a form documenting your objective findings, clinical symptoms, and physical or mental limitations.
- Employers, co-workers, friends, family and caretakers can provide statements to support your claim.



How to Build Your Case

- Establish a good relationship with your doctor.
- You must show that you have impairment-related limitations
- A doctor's diagnosis by itself is not enough to prove disability.
- Must have objective test results.
- Treatment notes must document clinical findings.
 - Make sure your doctor documents symptoms such as fatigue, unrefreshed sleep, post exertional malaise, tender points. Get a copy of your records.



How to Build Your Case

- When filling out questionnaires from Social Security such as functional questionnaire and disability report, think about how you feel on a bad day.
- Make sure you let Social Security know about any help you get from family or friends.
 - Help with making meals
 - Doing household chores
 - Help taking care of kids or pets



Break





Q&A





Thank you to our sponsor!



**Thank you for
joining!**



Solve M.E.

