



January 31, 2020

Office of Regulations and Reports Clearance
Social Security Administration
3100 West High Rise Building
6401 Security Boulevard
Baltimore, Maryland 21235-6401
ATTN: Cheryl A. Williams, Office of Disability Policy

Public Comments – Docket No. SSA-2018-0026: Rules Regarding the
Frequency and Notice of Continuing Disability Reviews

Dear Social Security Administration,

On behalf of the Solve ME/CFS Initiative (Solve M.E.) and as a caregiver for a person with myalgic encephalomyelitis (ME), I am writing to share the experience of patients and their loved ones disabled by ME, previously called Chronic Fatigue Syndrome (CFS), and **encourage you to reject the proposed rule described in Docket No. SSA-2018-0026**, Rules Regarding the Frequency and Notice of Continuing Disability Reviews.

It is essential for the reviewers to understand the facts about of myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS). ME/CFS is a complex disease with an array of debilitating symptoms including cellular energy disruption, orthostatic intolerance, unrefreshing sleep, memory loss, joint pain, inflamed lymph nodes, severe headache, sore throat, neurological abnormalities, and even complete organ system shutdown. The cause of ME/CFS is unknown, and there is no existing cure nor FDA-approved treatment for the disease. Here's a few facts about this prominent and often misunderstood condition from the 2015 Institute of Medicine Report "[Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.](#)"

- An estimated 836,000 to 2.5 million Americans have ME/CFS
- ME/CFS affects four times more women than men
- One quarter of ME/CFS patients will become house- or bedbound in their lifetime
- ME/CFS can strike anyone at any time; onset has been reported from ages 8 to 80
- Recovery from ME/CFS is rare and symptoms often persist for life
- Many with ME/CFS have comorbid disorders, such as irritable bowel syndrome, dysautonomia, and fibromyalgia
- Patients with ME/CFS have the lowest median and mean quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke

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In short, ***ME/CFS is often a life-long disease*** resulting in an extreme reduction of every-day function and ***long term disability***. 54% of patients report being unemployed and 89%ⁱ report job loss as a result of their illness. For many with ME/CFS, Social Security disability benefits are the difference between life and death.

The proposed rule in Docket [SSA-2018-0026](#) **will cause harm to disability beneficiaries with ME/CFS** while increasing SSA expenditures and abandoning our most vulnerable citizens to poverty. The proposed increase in continuing disability reviews (CDRs) will result in an estimated “2.6 million additional eligibility reviews of adults and children currently receiving Social Security disability benefits in the next decade.”ⁱⁱⁱ This increase creates additional and unnecessary expenses in review and oversight that will not be offset by savings from purging vulnerable people from the program. Similar policies were implemented during the Reagan administration and they resulted in an increase in program expensesⁱⁱⁱ, rather than a reduction. Yet, beyond the financial cost – these rules will exact a far more significant toll in the pain and suffering of thousands of Americans.

It is important to note that ME/CFS is a disabling life-long disease with estimated recovery rates lower than 5%. It would be wildly inappropriate to place disability beneficiaries with ME/CFS into the proposed “Medical Improvement Likely” category. While each case is unique, SSA should issue guidance to application reviewers that ME/CFS should be included in the “Medical Improvement Not Expected” category.

Applicants with ME/CFS face some of the lowest initial approval rates for disability than any other condition. According to the SSA, over 79% of initial applications denied. Appeals processes, medical documentation, and hearings can take years. The process for being awarded a disability allowance is so difficult and rare that many patients give up before reaching the end. Increasing CDRs for this vulnerable population means that social security beneficiaries with ME/CFS will be forced to relive this painful process excessively, especially if placed in the “Medical Improvement Likely” category.

ME/CFS patients are unique in the “invisible” illness category because of a symptom commonly called “post-exertional malaise (PEM).” PEM is the hallmark symptom of ME/CFS. Dr. Anthony Komaroff of Harvard University described PEM as “***an illness within an illness***.” PEM is a debilitating onslaught of fatigue, pain, cognitive difficulties, sore throat, and/or swollen lymph nodes after a physical or mental activity. These symptoms can present as late as 48 hours after the activity which triggered them. ME/CFS patients will likely be forced to exertion by additional CDRs and subsequently suffer for weeks, months, or even years as a result. Increased CDRs will trigger PEM and “crashes” unnecessarily in thousands of disability beneficiaries with ME/CFS resulting in pain, suffering, economic loss, and perhaps even a worsening of the condition permanently. SSA must acknowledge the potential for harm as a result of the proposed regulations and reject their adoption.

Additionally, the unpredictability and variability of symptoms for ME/CFS can create a false sense of “health” or “improvement” for those who only briefly interact with an ME/CFS patient, thus making many disability protections and accommodations extremely difficult to secure. As patients with an “invisible” illness, people with ME/CFS are often punished for temporary improvements in their health. CDRs are disproportionately difficult for people with ME/CFS because of the poor medical understanding and stigma. Increased CDRs for disability beneficiaries with ME/CFS create unnecessary risk of significant harm. It is all too common for patients to risk losing disability insurance, workplace/education accommodations, or public support just because they had a “good” day.



I hope this information and insight into the lives of those with ME/CFS has been helpful and that the SSA will focus on improving service delivery and outreach to Americans disabled by ME/CFS. These proposed regulatory changes regarding CDRs will cause financial harm to the program and pain and suffering to Americans. **Our organization strongly urges SSA to reject these proposed changes.** Please don't hesitate to contact me or my organization if there is any way we can assist.

Sincerely,

Emily Taylor
Director of Advocacy and Community Relations
Solve ME/CFS Initiative

Additional comments regarding SSA-2018-0026 from members of the ME/CFS Community:

Comment #1

I've been unable to work for sixteen years, but waited to apply for Disability benefits because I kept thinking that my excellent self care and efforts by my doctors to treat whatever symptoms they could would do the trick. Six years later it was finally my GP who suggested I should apply. The effort of doing so was tremendous over the next eighteen or twenty months. I've already applied, worked through a denial, hired two different attorneys, sat through a hearing with a judge. My health was made worse through that process; must I go through it again and again?

Despite my diligence with daily medicines, doctor-recommended supplements, weekly infusions for a concomitant condition, my underlying immune condition has not improved since then and has in fact worsened. I have developed several additional commonly co-morbid chronic conditions as well. As we age with ME/CFS, getting worse is more common than improving.

The clinicians who are knowledgeable about this illness are few and far between, many of them also researchers. I want them to be able to focus on helping patients and doing their research which may actually lead to some real treatments rather than being stuck in the paperwork of frequent reviews.

The cost to Social Security to staff up for the increase in frequency of reviews would be way better spent on beefing up the CDC budget to disseminate the information they finally updated on their website about ME/CFS to reflect current scientific thinking, to train medical professionals in at least that much, which might help end the now well refuted stigma about this illness having psychological roots. I question if that outdated and unscientific thinking is partly what has created this idea at Social Security. Instead, I would hope that our federal resources would be put to funding more studies into its bio-organic causes that might lead to treatments that would give us patients back our lives and career—and allow us to gladly step back from this help we so sorely need.

Comment #2

Dear Social Security Commissioner Saul:

I am writing about the proposed Social Security rule that would make many people getting disability benefits prove that they have disabilities every two years.

I am very worried about the additional burden of the rule change on the many disable individuals that will be impacted.



I do not agree there is an overall benefit in a review period rule change for these reasons:

1) Increased CDR (Continuing Disability Review) audits are an invisible tax on caregivers.

- (AARP, October 1, 2019) "Costs for Caregivers" cites: "The strain can be enormous and may put [caregivers'] own financial and retirement security at risk." Their costs include out-of-pocket costs (e.g., household expenses, personal costs/cutbacks, medical needs, personal care expenses, education, travel and legal fees).
- More than half of family caregivers have to take time off from their main job, reduce hours at work or quit their jobs altogether to accommodate their responsibilities, AARP researchers found. This can mean diminished chances for promotions, less job security, fewer employment benefits, reduced amounts paid for social security tax due to reduced caregiver incomes, reduced money set aside for their own retirements and lower Social Security benefits for themselves when the time comes.
- In many disability situations, it is the caregivers that will be burdened with providing and/or helping the disabled individual provide the necessary support and documentation for the review. Shortening the timeframe increases the frequency and number of reviews over the years, further burdening this group.

2) Increased CDR audits are likely a false savings (cost to implement vs. proposed savings)

- The cost & health burden to caregivers is not included in the proposal assessment.
- The cost & health burden to truly impaired individuals is understated, particularly in those illnesses where the audit itself creates a worsened impairment as a result of the energy spent on the preparation.

3) Increased CDR audits are an invisible tax on each disabled person's health, having a negative health impact on the disabled – an already burdened group.

- The proposed CDR change is further insult to injury.
- What does my level of impairment look like?
 - Prior to 2013 I was working full time as a Sr. Project Manager for a major engineering company, overseeing 6-8 people. Now, on a good day, I have trouble writing / responding to 6-8 (simple!) emails, due to brain fog and pain from sitting in one place / position.
 - I'm not looking forward to my next CDR no matter the timeframe. The preparation will exhaust me and exacerbate my already debilitating symptoms for months.
- More frequent disability reviews will create additional burdens for people with disabilities who cannot work and are already struggling with income insecurity.
- It took me more than 2 weeks to compile these few thoughts. I had to ask for help writing this (short) comment and in completing the original SSDI application. I will require help for any CDR audit as well.
- My retirement savings are devastated.
- For someone with my illness, the CDR is not only a nerve-wracking process, but it is an exhausting one, which is harmful to my health.
- MSS list: Relapsing Chronic Fatigue, Short Term Memory Loss, Arthritis Pain, Lyme Disease, Disturbed Sleep (onset, maintenance, quality), Depression, Anxiety, Cognitive Difficulty

Please do not further tax a population (the disabled as well as their caregivers) that has already had their retirement savings devastated.

Thank you.

Comment #2



I cannot adequately describe the emotional cost of depending on government aid. Being limited and needing help feels shameful in our culture--feeling disbelieved on top of that can build to mental health crises far too easily. The fear of losing the aid that makes life possible can feel like too much to bear.

It is not exaggeration to say that there will be higher rates of suicide in the disabled if this rule goes through, as well as many preventable deaths from lack of medical care.

Please act against cuts to social security and review increases. Thank you for your time.

Comment #3

I oppose the Social Security Administration's proposed Disability Rule. It is difficult and stressful to apply for disability, and it takes a long time to get approval. It is especially difficult for people who have illnesses that are not well understood by the medical community. People have to prove that they are disabled, but for illnesses that are not well understood, it is difficult to get definitive testing. It is also often difficult for people to find a doctor who can treat this type of illness, because there are few doctors who are informed about it, and treatment methods are often not approved by the medical community.

The SSA should make it easier for people on disability to extend their benefits, not more difficult. Most people are struggling to get by on the meager income that the disability payments provide. They should not be subjected to further testing and proof of their illnesses when it is often so difficult for them to complete their daily tasks.

We have a serious problem with homelessness in this country, and many people who are homeless have disabilities. The SSA should not push more people onto the streets by denying the continuation of their disability benefits. If 60% of people over a certain age find work within 5 years of losing benefits, that means that 40% of people do not, and that is a lot of people.

Comment #4

Changing the time table for re-examinations would be arduous for most people with ME/CFS. Even as the re-exam schedule is now, it is quite tough to go through this every few years. I was disabled in 1992-93. Following my diagnosis of CFS (ME/CFS) I have not been able to work successfully since. I had periods when I felt a bit better, but usually not for long. During my relapse phases it was so tough if a re-exam was called for. It was almost unbearable and untenable with the forms, scheduled appointments and then going the the grueling exam.

I am retired now, but still suffer every day. I beg you not to speed up your re-examination time table.

Comment #5

With our disease, since we're not missing an arm or a leg for instance, we must go through several denials and appear before a judge. That is the usual process. It was with me. I had to travel to see a specialist to get documentation, a tilt table for example, to provide evidence for the judge. Now I remember, I never would have even applied for disability had I not been able to see a specialist to get proof. My local physician just was not going to be helpful. He is a good doctor.

I was lucky. I am articulate and educated. My ME/CFS physician had a disability form that he used to ask me questions about what daily activities I could or couldn't do. No one had shown me this form before. It certainly isn't utilized in a 10 minute physician visit. It asked what can I lift how many flight of stairs can I do. Can I bend down etc.

As our mental capabilities are so very diminished in this disease, we need special provisions regardless of whether or not the law is made more restrictive. We need help with the disability process. I don't know if this is something a research group has come up with or not.



My disability check is virtually my only income. I cannot save for a retirement fund. I imagine if I am reviewed more often I can handle it but oh the stress it will cause. I live alone and only drive a couple of days a week. I am more levelheaded and calm than most people. As you know, the alternatives can be tragic without some means of support. There is only so much fight one can have.

Comment #6

My everyday life is a struggle to barely get by in life. It takes an extreme effort to simply shower a couple of times each week. To burden the very ill with more obstacles to keep what they have already proved they need is cruel at best. I am totally against these new proposed disability regulations that further harm those in need of help.

Comment #7

Thank you for this platform to air our opinions. My son has had ME/CFS, and multiple co-morbidities for over 10 years, but only having been diagnosed since 2017. Our continued struggle with SSA, as he has not been able to work for this time has been exhausting and arduous at best. Even now we have lost out ALJ case hearing only to be told that we can continue to appeal. Even with the best information for navigating this process available on the internet and in the hands of an attorney has been impossible, as the system has little idea as to what ME/CFS is and what outliers (additional medical conditions) fall into their criteria. I can only imagine the continued impossibility for patients to receive support as they decline. SSA has little idea about this disease and now little interest in its application for stricter regulatory actions.

I pray that sometimes truly only divine intervention and compassion in our government is our only hope.

I am a registered nurse and spend 2 years researching this condition and addition co-morbidities associated with it. I have worked in the health industry for over 20 years in medical administration and know all too well that this is truly an outrage for suffering people of all ages.

God help us!

Comment #8

I have a very disabling and poorly understood disease called myalgic encephalomyelitis, commonly known as chronic fatigue syndrome. For the past several years I have relied on SSDI to support. It took an enormous amount of time, effort and money to support and continue supporting my disability claim. SSDI is not easy to be approved for and adding these additional CDR for an already poorly understood disease will cause an undue burden on patients like myself and could lead to an unjustified termination of benefits. According to the SSA's own estimates, the SSDI fraud rate is less than a fraction of one percent.

A potentially more effective long term strategy to address SSA and Medicare shortfalls would be to look into the ERISA laws which allow private disability insurers (provided as a workplace benefit) to include language in their benefit Summary Plan Descriptions that force claimants to apply for SSDI, then offset their payments to claimants, eliminating the lion's share of their payment liability. This is a huge draw on SSDI funds and an enormous benefit to disability insurers.

Please reconsider placing these additional burdens on disabled people whose already fragile income and health are at stake.

Comment #9



I am writing to urge rejection of the Social Security Administration's proposed rule changes for determining ongoing disability. Increasing requirements will make it difficult or impossible for the ones most unarguably qualified, the severely, bedbound disabled, to continue to qualify - an illogical and cruel result of the proposed rules.

Chronic disabilities are named such for a reason - because they are chronic. Requiring increased and more strenuous documentation of something that is known to be and has a continued diagnosis of chronicity is a waste, not a savings, of OUR earned benefits that are entrusted to your management.

Don't waste our earned benefits on increasing superfluous bureaucracy. The assumption behind this proposed ruling, that people with disabilities are fraudulent, is an insult to all of us who would give anything to have our full, healthy, working lives back. Stop abusing our trust, and OUR earned benefits, this way.

Comment #10

I have had two major ME/CFS episodes. The most severe symptoms lasted two years each. The first one was in the early 1990's. I was unable to write my name, but somehow I knew I had a Masters Degree, and I must have been taught to write my name by first grade. I would forget that I had a child that needed to be picked up from school. One time we went to the store together. I told her to go get an item, and I went to get the other item. I paid for my item, and drove away. About a mile away, I thought I forgot something. Then I remembered. The nerve pain was debilitating for at least a year and gradually I was able to have better days. Many days I thought of suicide as the only option to ending the pain. I was bedridden for months at a time. It was like having a severe flu that fooled you into believing it was coming to an end, and then would start over, leaving you feel you are being burned from the inside out. The brain fog took about 10 years to finally get better. Then I got the second episode. I was a school social worker who worked 4 days a week, with Wednesday off, so I could sleep that day, and then work again for two days and then sleep all weekend.

In 2003, I came in contact with the flu and mono which set me into another major episode. My throat was so sore I couldn't speak for a year and a half. I couldn't stand. When I sat the nerve pain was excruciating and felt like a group of bees stinging me in my heart, brain, lower back. I lost my job of 19 years, because the CFS specialist could not give a guarantee to when I could return to work. With brain fog, I had to fill out the SS forms and it took 2 years to finally get the final approval of my disability, and eligible for Medicare. This was 2006. It has taken me many years to deal with the depression, aphasia, and trying to return to working 4-6 hours a week, just so I can feel I am alive and part of the mainstream of life. The stress of having to prove my illness is chronic with Social Security, contributes to a mini or medium episode. My symptoms improves at times, but it is always like a monster that easily can rear itself, if I don't avoid stress or get the flu, a cold, mono, not enough sleep. I was told it was a virus that I may be able to keep in control, if I can constantly intervene in keeping myself healthy. It is haphazard. Some days are better than others. I am embarrassed and humiliated that in my 50's and up to 63, I still have to prove the debilitating symptoms of this illness. Most days I want to just pretend it's gone, but the reality is that I am always skating on thin ice, always praying...

Comment #11

Hi,

Being one of those whom is disabled, I find it amazing that anyone in their right mind would try to trick anyone into thinking they were disabled. You do not get enough to live on, are homeless, low income, low status, and looked down upon by everyone else. I find it hard to believe that anyone would try to get this status for any reason. Making more money in society is much easier than getting S.S.

Everyone is denied at the onset of their first try. Lawyers must be engaged to try to get another hearing. Lawyers taking 1/3 of any back pay you might receive. Not to mention the time, and energy it takes to get approved. Usually more than one hearing and at times taking several years to get. Let alone all the medical reviews where the burden of proof is on the disabled shoulders to prove they are disabled.



Very few doctors today have time to sit and write up paperwork stating your disability and proof of inability to work. The doctors that do the reviews for disability for the S.S. are very difficult to endure, asking you to do things that are painful and ignoring your statement that you are in pain, or that you have trouble doing this or that. . ME's are horrible to go through, are one sided and distressful, making the disabled feel even worse than they do mentally.

Asking those whom are disabled and have issues just getting through the ADL's of daily living should not be asked to prove this over and over again. Making them live in constant fear, of being denied basic life support. The amount that SS awards those disabled is not enough to live on in anyway shape or form. Independence living is impossible, who would want this?

I find it extremely hard to believe any doctor would say someone is disabled if they were not, and why anyone in their right mind would go through all this just to get hardly no money out of it. I find this idea of making people prove themselves over and over again, a horrible/cruel/destructive/trickery and inconvenience to those whom are disabled and have enough issues with just surviving. Let alone be asked to jump through hoop after hoop to prove themselves unable to work.

The amount of fake disability claims has got to be super low, is this the best way to spend your money. Why not add this money to the meager monthly allowance these folks get to try to survive on. And I mean survive only, choosing between meds and food.

Thanks for your time, kindly.

Comment #11

It is unbelievable to me that those suffering/coping with M.E. Would be denied benefits.

Clearly those making that judgement do not understand the disease. My daughter has lived with M.E. For over 16 years. There are days she cannot function beyond bed and bathroom and many days where she leads a "normal" life albeit with less energy than most folks. As always I will continue to write to my elected officials and protest this travesty.

Comment #12

When having to prove that you STILL are suffering it puts more stress on the person trying to prove they still have CFS/M.E. and are eligible for disability pay.

Comment #13

These proposal changes add yet another layer of bureaucracy to an already compromised segment of our vulnerable population who are just trying to survive their circumstances. Folks on SSDI have a lot on their hands with managing their physical challenges while living on such limited financial means. And these new proposals will make it even harder for them.

It very difficult to get SSDI to begin with and between what it requires, plus the waiting periods, many folks die before ever receiving an appeal hearing. And if they do get awarded, people who are sick have a hard enough time dealing with the current, stringent CDR process on top of having to manage their illness and other aspects of life. So it is beyond me why they need to jump through more hoops than what is currently in place. Since the disabled don't have any major organization defending them, it's usually up to them to fend for themselves which makes them an easy target for proposals such as this.

I urge you to reject these proposed rule changes, which will certainly hurt a lot of people.



ⁱ IOM (Institute of Medicine). 2015. *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. Washington, DC: The National Academies Press.

ⁱⁱ Stein. Jonthan M. (2020) 'Another Disability Disaster in the Making', *The New York Times*. 16 Jan, <https://nyti.ms/2NvyauW>

ⁱⁱⁱ *ibid*