

## **Your Questions Answered!**

### **Responses/Answers to the Chat Log of the Mass. ME/CFS & Fibromyalgia Zoom Presentation on Applying for Social Security Disability Presentation – February 20, 2022**

*Disclaimer: The Massachusetts ME/CFS&FM Association, Kenneth Casanova, and any and all persons who participated in authoring, contributing to, or producing this entire chat log answer narrative 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 and use of this document. Note: Social Security regulations and disability practice may change over time – along with those of other programs discussed below.*

Thank you Karin and the Sunday Conversations team!

#### Introductory Links:

Here's a link to the handbook: [www.massmecfs.org/disability-handbook](http://www.massmecfs.org/disability-handbook)

Here's a link to the resource guide:

<https://www.massmecfs.org/images/pdf/SundayConversations2022/ResourceListforDisabilityPanel.pdf>

Also see our articles on the following subjects:

How Social Security Disability determines whether a person is disabled - that is, whether a person is able to perform Substantial Gainful Activity: *How does Social Security determine whether a person is disabled and qualified to receive disability benefits?*

Issues involved with working while applying for Social Security and working while on Social Security: *The Question of Working When a Person is Either Applying For, or Going Back to Work, While on Social Security Disability Insurance (SSDI)*

*Long COVID and Social Security Disability*

These articles can be found on our website - [www.massmecfs.org](http://www.massmecfs.org)

## Answers to Questions and Comments

*Question: Does Social Security use the 2015 IOM ME/CFS Diagnostic Criteria in evaluating disability cases?*

The 2014 Social Security Ruling on ME/CFS, SSR 14-1p: “Evaluating Cases Involving Chronic Fatigue Syndrome (CFS)”, does not include the 2015 IOM Diagnostic Criteria – although the IOM Criteria is now preferred CDC by the CDC. The 2014 Ruling includes the more comprehensive 2003 Canadian Criteria and the 2011 ME International Consensus Criteria.

All of these illness definitions Ken mentions are linked to in the resource guide: <https://www.massmecfs.org/images/pdf/SundayConversations2022/ResourceListforDisabilityPanel.pdf>

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*Request: Please tell people under what circumstances children (and adult children disabled before the age of 22) can receive SSDI (as opposed to SSI). For instance, if a parent is on disability or is retired. (If a parent has died, the child, even adult child, would receive survivor benefits.)*

Please see Social Security Pamphlet, “Benefits for Children with Disabilities” at <https://www.ssa.gov/pubs/EN-05-10026.pdf> See below for more information on Children’s benefits.

*Comment: I won SSDI in Dec. 1994. My judge was most persuaded to grant SSDI based on results of Neuro-Psych Testing by someone who knows/understands CFIDS/M.E. and the specific cognitive deficits.*

It is essential to find a neuropsychologist who knows how to interpret the neuropsychological test results in accordance with the neurocognitive difficulties imposed by ME/CFS. A tester unfamiliar with ME/CFS may interpret the test results as showing a psychological condition such as depression and/or anxiety, rather than the cognitive deficits characteristic of ME/CFS. Such a test misdiagnosis could undermine the documentation of ME/CFS and harm your disability case. Unless the tester is familiar with ME/CFS, it is better not to undertake neuropsychological testing.

*Comment: I found an ME/CFS knowledgeable neuropsychologist and those two days of testing were INVALUABLE. She clearly wrote that I was not suffering from depression. That's the difference in finding a Neuro-Psych who knows/understands ME/CFS.*

See the Sleepy Girls Guide on finding a neuropsychologist -

<https://howtogeton.wordpress.com/how-to-find-a-neuropsychologist-me-lyme-toxic-mold-chronic-fatigue-syndrome/>

One ME/CFS expert neuropsychologist mentioned is Dr. Sheila Bastien in Calif. She may or may not be retired. One can inquire 2126 Los Angeles Avenue Berkeley, CA 94707-2618 Tel: (510) 526-7391

*Comment: One of the problems with sleep studies is that they commonly are only screening to rule out sleep apnea, and narcolepsy. You really need to impress upon them and your doctor that they also need to address unrefreshing sleep, fragmented sleep architecture, and insomnia.*

An ME/CFS patient seeking a sleep study should find a sleep specialist familiar with ME/CFS sleep architecture and sleep abnormalities. Often ME/CFS patients do not access stage 4 deep sleep adequately and remain in stages 1-3, thereby waking up more frequently. A tester familiar with the problem and ME/CFS can interpret the results to help confirm the ME/CFS diagnosis, rather than overlooking them or misdiagnosing the sleep difficulty. Such misdiagnosis of the sleep study could undermine the ME/CFS diagnosis and be harmful to the disability claim.

*Comment: Some doctors ask for payment for writing out an SSDI report for a patient applying to SSDI. Is that okay, is it legal?*

Many doctors do ask for payment for their time in documenting Social Security disability cases.

For Mass. regulations on what doctors can charge for providing you with medical records, see <https://www.mass.gov/service-details/medical-records-obligations#:~:text=The%20fee%20may%20not%20include,page%20in%20excess%20of%20100.>

Although doctors and hospitals in Massachusetts cannot charge you for copies of your medical records “for the purpose of supporting a claim or appeal under any

provision of the Social Security Act,” doctors may charge you to write a statement in support of your claim for SSDI or SSI benefits. If your doctor does charge for this report and you cannot afford it, then you could consider finding an experienced attorney whose fee agreement states they will pay the out-of-pocket costs up front for you and can only request reimbursement from you if you are successful in your claim for benefits.

Asking a doctor to complete paperwork or write a statement for you to support your claim for SSDI or SSI benefits is excluded from a patient's right of access to protected health information (“PHI”) because it is “information compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding (emphasis added). See <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html> citing 45 CFR 164.524(a)(1)(ii).

However, you may certainly ask your physician(s) for a copy of any documentation they provide to Social Security. Also, your attorney will likely have access to this information.

*Comment: We found it helpful to write up a comprehensive medical history to give to providers. It is much faster for them to understand the situation. Also nowadays, you usually can download office notes and other documents from your online medical system. Patients in the Mass. General/Brigham's Partners Gateway in Massachusetts can obtain their records online.*

If the doctor is reasonably open, she or he may appreciate patient submitted draft disability histories, medical and functional reports/letters to assist them in writing their reports to Social Security. See our Disability Booklet at “Your Doctor's Letters” Appendix IV. <https://www.massmecfs.org/disability-handbook>

*Several Comments: How do I find a physician who will help me document my diagnosis and disability to Social Security?*

The first advice is to try to find a patient support group in your area or region. Local patients are likely to know of knowledgeable doctors in your area. For doctors in Massachusetts and New England, you can go to our website [www.massmecfs.org](http://www.massmecfs.org) and through “Contact Us” request physician/healthcare

provider referrals. For those in other states Mass. ME/CFS&FM can send you lists of physicians, treatment centers, and local support groups. Make these requests also through Contact Us.

*Question: How much added value is there to having Third Party Reports submitted along with the SSDI application?*

Third Party Reports generally refer to letters submitted to Social Security from people in various capacities who have had direct observation of your illness-related limitations and your inability to carry-out various work and daily tasks.

A former co-worker or supervisor who can attest to your declining function at work to the point that you could no longer perform your work tasks at even a minimal level could write a report in letter form. This letter could document your inability to lift objects, frequent tardiness, and your being forced to take frequent breaks. A letter from a family clergyman or a professional person who knows you well could corroborate your serious limitations and how your life has changed as a result of your illness. Social Security is likely to give more weight to letters/reports from individuals they would consider to be objective and unbiased.

Social Security uses the term “Third Party Report” to refer to Reports by Vocational Experts. Usually there is a Vocational Expert at the Administrative Law Judge Hearing to assist the Judge in evaluating the type of work a claimant can do and if there are jobs in the national economy a patient can do. Some attorneys use their own recommended Vocational experts to submit the claimant’s own Report at the Hearing.

There is also a 10-page Social Security *Third Party Adult Function Report*. The Report is lengthy and complex and would require very careful and accurate reporting of an individual’s functional limitations. Any omission or mischaracterization of the individual’s functional limitations could allow Social Security to misunderstand the person’s level of disability. Any superficial use of this form by a Third Party should therefore be avoided. Such use could well do more harm than good. Therefore it is probably better for a third party to write an accurate letter rather than using the third party report form - unless the third party is scrupulous and careful not to leave their answers open to a mischaracterization of the person’s actual disability.

See this link for a short explanation on Third Party Reports and how they may help your claim for SSDI or SSI benefits: <https://www.nolo.com/legal-encyclopedia/how-increase-your-credibility-social-security-disability-case.html>

*Comments from several participants offered their knowledge of ME/CFS physicians and/or Centers: ‘There are some doctors who will treat across state lines. You may be able to get into the Bateman Horne in Salt Lake City, or the Center for Complex Diseases in Seattle. I see both of these clinics via telehealth, partly thanks to the pandemic creating expansion of telehealth services.’*

[Since this chat now in August 2022 it may be more difficult to see doctors by telehealth across state lines.]

*Encouragingly, more local doctors seem to be aware of ME/CFS now through Long haul Covid patients.’*

*A request from a patient in Arizona for a physician:*

*Answers from the group: “There is the Workwell Foundation in Arizona that may know of doctors near you. See <https://workwellfoundation.org/> Contact Theresa McDowell in Flagstaff. Also the Workwell office in Calif. There is an Arizona healthcare clinic that knows ME/CFS very well. Maybe they are close enough to Nevada...? It is here: <https://fourpeakshealthcare.com/>*

*In an answer to another request for a physician: I’d also recommend checking out the Institute for Neuro-Immune Medicine led by Dr. Nancy Klimas. It’s in Florida but they’re doing some telehealth appointments. I’ve had the chance to see Dr. Klimas speak and she’s wonderful. I don’t know her office’s involvement with Social Security benefits. [Dr. Klimas has a long waiting list.]*

*There is also Dr. Darren Lynch, of Northampton Integrative Medicine, in Northampton, Massachusetts. He can help with an SSDI report. They do see folks from out of state now, too, via Telehealth. [As of November 2022 this service has been curtailed.]*

MassME can help people in Massachusetts find medical practitioners who people have told us are either knowledgeable or sympathetic. Go to

<https://www.massmecfs.org/contact-us-form> and select ‘Physician Referral’ as the subject.

One attendee mentioned that during the pandemic state limitations on payment for out of state doctors may have been suspended.

*Questions: Several people have asked if they can go to an Administrative Law Judge hearing without an attorney or other professional advocate and instead represent themselves. How would this impact on receiving a favorable decision?*

Representing yourself at a Hearing is generally a bad idea. Representation generally requires knowledge of the law and Social Security regulations – as well as the working experience of attorneys as to how Judges evaluate disability cases and how to best represent your case given your individual disability and circumstances. Also, as a sick person you may find it difficult to understand and process what the Judge and the vocational expert are looking for.

Surveys have generally shown that a person with an attorney has twice the chance of receiving a favorable decision than a person without an attorney.

*Another person commented: “I had to present my case in front of a SSDI federal “Administrative Judge” — but I was too sick to go to make my case. So my disability attorney did, and he succeeded.*

Patients should make every effort to attend their hearing unless severe illness makes it impossible. In this case, consult with your attorney to see if the Hearing can be rescheduled. Currently most hearings are conducted by teleconference which makes it much easier for sick patients to attend.

SSA does continue to conduct hearings by telephone and by video using Microsoft Teams.

It is very rare for an Administrative Law Judge to proceed forward with a hearing if the patient is not present, even if that patient is represented by an attorney or a non-attorney representative.

Patients should also know that failure to attend your hearing could result in a “Notice of Dismissal” unless the patient can show “good cause” for missing the

hearing. See HALLEX I-2-4-25: [https://www.ssa.gov/OP\\_Home/hallex/I-02/I-2-4-25.html#:~:text=Good%20cause%20for%20failing%20to%20appear%20at%20the%20scheduled%20time,time%20before%20the%20scheduled%20hearing](https://www.ssa.gov/OP_Home/hallex/I-02/I-2-4-25.html#:~:text=Good%20cause%20for%20failing%20to%20appear%20at%20the%20scheduled%20time,time%20before%20the%20scheduled%20hearing).

*Questions: What about hiring a new attorney during Social Security disability evaluation if I am dissatisfied with him or her?*

*I hired an attorney in 2021 and we've appealed and they are going to schedule a hearing with a judge. However I'm considering hiring a new attorney because my current attorney knows nothing about ME/CFS. I was wondering if changing attorneys is a difficult process?*

First, before hiring an attorney, make sure she or he has some knowledge of your illness so that your medical and functional disability can be represented adequately.

When you first hire an attorney, be sure to ask about how the attorney will prepare your case: what s/he needs from you and when; what you can expect the attorney to do at the various stages of your disability case; and how often you can check in with the attorney. Will the attorney contact your physicians if needed? Attorneys are busy, but if an important issue comes up your calls should be returned. Your attorney should definitely be in contact with you prior to the Hearing to help you prepare for the Hearing. You should be sure the Attorney has obtained your case record well before the hearing and will obtain further documentation from your providers if necessary to fill-in any gaps in the record.

If you are concerned about how the attorney is representing you it is best to clarify with the attorney exactly how the attorney is preparing your case and if the attorney is doing so in a timely and serious manner. You do not want to change attorneys because of a correctable misunderstanding.

However, if you determine after due consideration that the attorney cannot represent you adequately because of lack of knowledge or diligence, then you should change attorneys and, if possible, do so well before a Hearing.

It's not so easy to change attorneys mid-stream, but it is better to work to find a new qualified attorney than to have your benefits rejected. Some new attorneys may not want to represent you because they may have to share the attorney's fee



with your previous attorney. Or some attorneys may not want to represent you at the last minute.

However, disability claimants do change attorneys when for whatever reason they are not being represented adequately – and are then often “rewarded” when they obtain a favorable decision.

Also, if you need to change attorneys and you have a hearing coming up, you may call the Hearing Office and ask for a “postponement.” The Administrative Law Judge assigned to your case should grant the request for postponement.”

*More comments on attorneys: When choosing an attorney, does the attorney need to be from the state of the applicant?*

Not necessarily. There are national attorneys who know how to do ME/CFS cases. However, Ron in his talk explained the “home field” advantage of having an illness knowledgeable attorney who knows the local judges.

When choosing an attorney, it does not matter what state they practice in because Social Security law is federal therefore it does not change by state-to-state. Also, it is not a guarantee that an Administrative Law Judges will be located in the state the patient is in. A majority of our cases before the pandemic were in front of Administrative Law Judges that were videoed in from another office in another state. What matters most in choosing an attorney is one that knows the law and will do the work on your claim and provide you with periodic and detailed updates on the status of your case.

When choosing an attorney, important things to look for are 1) the length of time the attorney has been practicing Social Security law; 2) how the attorney or their firm operates; and 3) whether the attorney is enrolled in the Social Security Administration’s Appointed Representative Services that grants them access to view a patient’s electronic folder and quickly submit evidence to the Social Security Administration.”

It is also very important to ask if the attorney has handled cases involving your illness: ME/CFS, fibromyalgia, Long COVID, etc.; or at the least whether the attorney has medical knowledge of your illness, its severity, and disabling effects.

You will want to gauge their knowledge of illness symptoms, their disabling severity and objective signs, relevant testing, etc.

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More on the role of attorneys in Social Security Disability Cases:

The role of attorneys and their staff in assisting patients fill-out Social Security forms and when necessary assisting physicians document the applicant's case:

Ideally an applicant would have professional legal assistance from an experienced attorney/paralegal staff when they first apply for SSDI or SSI. Some attorneys or their staff will assist patients in properly filling out the *Adult Function Report* and the *Work History Report*, as well as other forms. They will work with the applicant through the various steps of the disability process to ensure that Social Security receives the optimum documentation. Some attorneys with this type of practice may visit the applicant at home or assist the patient by phone to fill-out the required forms. There are also experienced, non-attorney, disability advocates who may also assist applicants fill-out forms. However, it is probably advantageous to have the same attorney throughout the entire disability process – including if necessary for representation at the hearing level.

The benefit of submitting the necessary comprehensive documentation of the patient's disability at the start of the application process may result in an earlier favorable decision to award benefits. Without a full and properly documented submission the applicant may have to go through a long, multi-step review process that might result in serious financial difficulty.

A requirement in choosing an attorney is for him/her to be experienced in Social Security Disability representation. The attorney should also have a working knowledge of the patient's chronic illness so that s/he can be sure that the medical and functional documentation of the disability is accurately described. The patient should ask about the attorney's experience and track-record in representing their illness condition.

Unfortunately, many knowledgeable and experienced attorneys do not have the time to closely work and collaborate with the patient in filling-out forms during the

time of first application, or even during reconsideration. Some patients, being ill, understandably would like to hand-over their application and associated forms to an attorney to fill-out and submit. However some patients, months later, have found when inquiring of the attorney as to the status of their case that their application had not yet been submitted.

Therefore, the applicant when seeking representation at the start of their case must be certain as to whether the attorney can closely assist them with their application. If the patient cannot find such an attorney, then the applicant will need to fill-out the application forms themselves – carefully, step-by-step, during periods of cognitive clarity. They can seek the help of family members or friends. If such help is obtained the patient should state they required help in submitting the forms.

As a point of clarification – many attorneys only become directly involved with a disability case at the 3<sup>rd</sup> disability approval stage – at the Administrative Law Judge hearing level. At this point an attorney is absolutely needed. Patients who represent themselves at a hearing are twice as likely not to be approved if they do not have legal representation.

Also before hiring an attorney – no matter at what stage – make sure you clarify how often the attorney will inform you as to the status of your case and your ability to call with questions.

If you hire an attorney at the application stage, she or he may work with your doctors to make sure all medical records are submitted. They also may provide the doctor with some guidance in terms of medical and functional submissions. At the administrative law judge level, all attorneys no matter when hired should review the entire case record and communicate with the applicant's physicians in order to add or correct any necessary medical or functional information.

If the person is also applying for or already receiving Long-term Disability benefits, it is best to hire one's own attorney for Social Security representation. One should almost never use an attorney recommended by the Insurance Company as there may be a conflict of interest.

Some further questions you should ask when looking for an attorney: Will they submit the application/appeal for you? Will they request and submit medical

source statements and medical records on your behalf? Does the attorney or their staff fill out the Adult Function Report and Work History Questionnaires and other questionnaires sent by Disability Determination Services (the state agency making the medical determination on your case) with you and submit it to SSA for you?

How often will the attorney or their staff provide you with an update on the status of your claim? Is the attorney's fee contingent on them winning your case? That is, if the patient is unfavorable in their SSDI or SSI claim, then the attorney cannot charge for any time or out-of-pocket expenses spent on your claim for benefits. Make sure that the attorney's fee is a contingency agreement.

If the attorney's fee is contingent on their winning your case, then how will the attorney collect their fee? There are two choices: 1) the attorney may by agreement have your retroactive check first sent to him or her who will then take their fee and send you the remaining amount. 2) the check will be sent to you and you will then pay the attorney his or her fee and other charges.

It is important to note that the Work History <https://www.ssa.gov/forms/ssa-3369.pdf> and Adult Function Report <https://www.ssa.gov/forms/ssa-3373-bk.pdf> Questionnaires are important questionnaires you will fill out. It would be very favorable if you can hire an attorney when you apply who is very familiar with them and will submit them on your behalf.

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If the applicant is unable to work with an attorney in filling out these forms: They must be filled-out carefully so that they truly reflect the person's condition. It can be easy for an ill person to make omissions or errors that may hurt their case.

Therefore, the patient must take the time to fill-out the forms so they accurately reflect their actual condition and their limitations. Some of the forms do not provide enough space to provide the necessary information. The applicant may attach extra sheets. However, the answers should be succinct and not unnecessarily long – otherwise Social Security could judge that the person is cognitively and physically able to do some work.

The patient should take some time to fill-out these forms step-by-step as their illness allows. They can seek the assistance of helpful family members or friends. If the applicant does need help in submitting the forms, they should so note this necessity to Social Security. If the applicant finds that they need more time in submitting the forms, they can call their Social Security case worker and see if an extension can be granted.

*Comment: An out of state attorney told me that since SSI is a federal benefit, they do not need to be in the same state. It may be desirable though.*

*Comment: The lawyers in your state are also more likely to know the judges in your state, which could be helpful.*

*Question: What additional lawyer fees (printing, postage, etc.) are we responsible for that are not included in the back pay?*

Lawyers can charge for reasonable expenses, including copying, printing, postage, etc. But the charges must be reasonable and detailed for you in writing. Make sure you receive an itemized list of hours spent working on your case as well as expenses charged. The amount of hours spent working on your case must be reasonable given the work done.

*Question: Do all SSDI attorneys get the same pay?*

The attorney's fee for doing your Social Security disability case is regulated by law. The fee is known as a contingency fee: If you win your case the attorney is allowed to take 25% of your retroactive benefits up to a total amount of \$6,000, no matter the amount of your retroactive benefits. If you do not win your case, then the attorney is not paid.

Your attorney is normally able to charge out of pocket expenses to you directly – normally this should not exceed several hundred dollars.

If you decide after rejections of your case to go into federal Court, your attorney will normally charge more. Make sure you read the attorney fee agreement carefully before signing it.

Also, if you lose your case, the attorney has the right to petition Social Security for payment.

Your retroactive check may be received first by the attorney who will then take his fee and pass on the remainder to you. Or you may receive the full check and then pay the attorney fee.

See this link to understand how attorneys using a “contingent fee agreement” get paid: [https://www.scotusblog.com/2019/01/opinion-analysis-social-security-cap-on-attorneys-fees-applies-separately-to-successful-representation-before-a-court/#:~:text=Section%20406\(a\)%20applies%20to,past%2Ddue%20benefits%20or%20%246%2C000](https://www.scotusblog.com/2019/01/opinion-analysis-social-security-cap-on-attorneys-fees-applies-separately-to-successful-representation-before-a-court/#:~:text=Section%20406(a)%20applies%20to,past%2Ddue%20benefits%20or%20%246%2C000)

42 U.S.C. § 406(a)(2) governs fee agreements and states an attorney’s fee for winning a case at the initial, reconsideration or initial hearing before an Administrative Law Judge shall be either 25% of the past due benefits (aka “back pay”) OR \$6,000.00, whichever is less. In other words, the max amount the attorney can collect for their fee is \$6,000; however, if 25% of the past due benefits is less than \$6,000, then the attorney must be paid the lesser the amount.

*How do retroactive benefits work?*

For SSDI applications ONLY, the Social Security Administration has a **5-month waiting period**. This means you must be disabled for 5 full calendar months before you are entitled to your first monthly disability check. For example, if the Social Security Administration finds you disabled as of January 1<sup>st</sup>, then you are entitled to begin receiving your disability benefits in July; however, you will receive that first payment for July in August.

The 5-month waiting period does not apply to certain conditions (e.g., ALS), and it does not apply to SSI claims.

For SSDI applications ONLY: The date your disability began **and** the date of your application determine how far back your retroactive benefits will go; The Social Security Administration does not allow you to accrue benefits 12 months past the date of application. For example, if you became disabled March 1, 2005 and file your SSDI application March 1, 2007, then March 1, 2006 is the earliest your retroactive check will begin to accrue. See POMS GN 00204.030E: <https://secure.ssa.gov/poms.nsf/lnx/0410105015>”

*How much documentation is too much? My daughter has been ill for 10+ years, but I don't think SS wants documents for the entire time period.*

*We have heard conflicting messages: 1) include long-term medical issues (some of which go back nearly 12 years) and 2) do NOT include any medical documentation older than 12 months because they won't read it. Which is the safer way to go?*

Social Security states that they give the most weight to the medical records and disability documentation from the past 12 months. So make sure that you do have current records and documentation from the past 12 months.

Some patients applying for disability do not have current records. Before applying, or if necessary after applying, make sure you go to a doctor who understands your illness/your need for disability and then develop some current records in the process of applying. Also, Social Security will periodically want continuing records both during the application process and after you receive benefits, so make sure to have periodic doctors' appointments. You will need these records when you are up for a Review at some point after you are approved.

Social Security is looking for longitudinal records, both past and present. These sequential records allow Social Security to see the course of your illness and the results of any treatments. These record "updates" give Social Security an ongoing picture of your disability.

It is important to include relevant historical medical records that document the history and course of the illness going back to onset - at least in summary form. These records can show the increasing severity of the illness - that it has become chronic. Historical records can also show how the illness worsened and became more disabling, and often how symptoms worsened/fluctuated, including how treatments may have failed.

They can also show the increasing difficulty of continuing work and the eventual inability to work on any predictable basis because of the decline in function over time.

It is helpful to have a current provider review your historical records and compile a summary report on them, emphasizing the important aspects in the records, including tests, diagnostic evaluations, and important provider assessments of your illness and disability.

*Questions: If judges see 3-4 month gaps in medical records, how do PwMEs who cannot get to/attend appointments with HCPs more often than every (for instance 6-8 months) get sufficient HCP documentation for SSDI? How often should a person applying for or on disability be seeing a doctor re: ME/CFS?*

*What does consistency of treatment mean? Regular appointments w. specialists?*

When applying for disability a person with their doctor should develop a medical record of their disabling illness diagnosis – how the diagnosis was made; what the diagnostic symptoms and objective signs are that confirm the diagnosis. Necessary tests need to be done to document and confirm the diagnosis. You must have a doctor who will support and document your diagnosis. Either you will already have a doctor(s) who will document your illness and support your claim, or you will have to find one. You may also need specialists to do the necessary testing.

At the start of your application process, you may need to see the primary doctor supporting your disability application somewhat frequently in order to have him or her develop the medical diagnosis and evaluate your inability to work – often 2 to 3 appointments. You may also be seeing specialists for diagnosis or testing. Then as the evaluation process continues you should see your doctor at least every 4-6 months to develop an ongoing “longitudinal record” of the course of your illness and any changes, any treatments/treatment failures, whether your ability to function changes or becomes

If your application is turned down at the first stage, then you can submit new records at reconsideration, and especially before the Administrative Law Judge Hearing.

The doctor’s office notes are important. In one visit the doctor may notice a symptom or sign that was not previously noticed and recorded. Social Security will also take your physician’s observations more seriously if they are made over time.

After you are accepted by Social Security, it is advisable to see your doctor at least every six months. Social Security makes periodic reviews of your disability and will want to see a continuing record of the course of your illness and continuing disability. If you receive a full review, you will have to submit records and a doctor’s report just as you did when you applied. See our Disability Handbook, the Appendix VIII on Reviews.



<https://www.massmecfs.org/images/pdf/handbook/Disability%20Handbook-Appendix%20VIII.pdf>

*One patient said: “It seems so overwhelming.”*

*Another patient responded: “DON'T GIVE UP!”*

The process can feel overwhelming at times; the best and most doable approach is to pace yourself and take the entire process in steps, in terms of filling out forms and obtaining your medical and functional documentation from your providers.

Do what you can on the better days. If you need an extension, call your Social Security case manager and ask for an extension. Get family or friends to help you with what you need help with. Remember, there are thousands of ME/CFS patients just like you who have managed to get through the process and who have won their cases. Just stick to it. Don't be discouraged if you are rejected at one of the first two levels. Just appeal your case to the next level. For Administrative Law Judge Hearings hire an attorney who knows how to help. And remember, most cases that are approved are approved at the Law Judge level. So just persisting can eventually mean you will win your case.

Also, the better and more complete your medical records that document your medical diagnosis and illness severity, and the more complete your documentation of your inability to work at any job, even part-time, on a predictable basis, the more likely you will be approved sooner rather than later. Obviously receiving benefits sooner will likely save some financial hardship. But whether benefits are awarded sooner or later, **JUST DON'T GIVE UP.**

A major question is whether the individual should hire an attorney at the time they apply for benefits. See our article “How does Social Security determine whether a person is disabled and qualified to receive disability benefits?” starting on page 16 for a discussion of the pros and cons of hiring an attorney at the time of application.

Sign up for patient portals with all providers, hospitals, and test sites. Most patient portals have all your diagnostic test results, and some allow you to download your

records right from the portal! Portals that do not allow you to download your entire record usually allow you to request your records via the portal.

Also, patient portals allow you to message with your doctors and medical team and you can print off those messages to submit as medical evidence on your claim! Your medical providers will not include these conversations from your patient portal in your medical records when SSA requests them, so it is on the patient to ensure they are submitted to SSA.

*How far back do work credits count?* Work credits in quarters that you have earned over your lifetime remain in your record. However, you only need work credits during the eligibility period prior to your becoming disabled. Your SSDI payment is the highest amount of earnings during your working years.

*How much are the SSDI benefits?*

You can figure out how much your monthly SSDI benefit will be by signing up for your “my Social Security” account on ssa.gov. Once you create your account, you can review your earnings and it will tell you how much you would receive in SSDI each month.

*Comment: I am leery of having Soc. Sec. Disability decided based on a mental health diagnosis as it reinforces the stigma that people with ME/CFS are “lazy/crazy.” We’ve fought this for decades. As Ken said, depression is secondary to any debilitating chronic illness.*

See Appendix VI in our Disability Handbook – “The Use of a Diagnosis of Depression or Other Mental Impairments in a CFS Disability Application” for a full discussion of including mental health diagnoses in ME/CFS, FM, and other chronic physical illness disability applications. <https://www.massmecfs.org/images/pdf/handbook/Disability%20Handbook-Appendix%20VI.pdf>

This question can be complex. Secondary depression and/or anxiety that result from ME/CFS may assist in making Social Security disability approval more likely, since these conditions may make working even more difficult. However, your doctor must clearly state that the depression/anxiety are a result of the primary ME/CFS diagnosis and would not exist if you did not have ME/CFS in the

first place. Without this clarification Social Security might consider that you have anxiety/depression and not ME/CFS.

Also be sure to have your physicians document the cognitive impairments that accompany ME/CFS, fibromyalgia, Long-COVID and chronic Lyme. These include short-term memory deficits, word-finding, comprehension loss, etc.

If you had primary depression before developing the chronic physical illness make sure that your ME/CFS is diagnostically confirmed so that your physical illness is not side-lined.

*Problems with mental impairment diagnoses when you are also applying for long-term disability insurance:*

If you are also applying for or receiving Long-term disability insurance, the introduction of a psychiatric diagnosis may give the insurance company the opportunity to deny you benefits. So in the case of applying for Social Security if you have the expectation of receiving or are receiving LTD, it is generally better not to introduce psychiatric diagnoses into your general records. If these diagnoses are already medical records, you must have your doctor clarify their secondary nature to the insurance company. If you have been given incorrect psychiatric diagnoses, you should have your current doctor rebut them. See also pgs 13-15 in Appendix I of the booklet.

<https://www.massmecfs.org/images/pdf/handbook/Disability%20Handbook-Appendix%20I.pdf>

*Comment: So many of those with Long COVID are young so don't have the threshold work years for SSDI.*

The number of quarters required to qualify for Social Security Disability Insurance depend on age. See page 7 of our Disability Handbook at

[https://www.massmecfs.org/images/pdf/handbook/Disability\\_Handbook.pdf](https://www.massmecfs.org/images/pdf/handbook/Disability_Handbook.pdf) For instance, if you are 30 or older you have to have earned 20 quarters over the 10 year period prior to your becoming disabled. If you are 25, you only have had to earn 10 quarters over a preceding 5 years (2.5 years of quarters.)

*Comment: The so-called “Independent Medical Examiner” from Soc. Sec. said that I could work as a security guard. Ludicrous.*

If Social Security requires you to see an Independent examiner you must keep the appointment. If you are too sick, try to reschedule. Unless you have a good reason, refusal to keep the appointment may lead to denial of benefits.

Unfortunately, Independent examiners may know little or nothing about ME/CFS or other chronic illnesses.

SSA calls this a “Consultative Examination.” ALWAYS request a copy of this examination to be mailed to you or to your doctor. Here is information regarding the consultative examination:

<https://www.ssa.gov/disability/professionals/greenbook/ce-guidelines.htm>”

*If you lose at the post-decision phase but later become even worse, can you apply again?*

If you lose at the ALJ Hearing, you and your attorney can appeal to the Appeals Council for a review. A majority of these appeals are rejected. However, at times, the Council decides the finding Judge made an error in his/her decision. The case is then returned to the Judge for a correction of the finding(s) and you may be awarded benefits. However, it may be best to make the Appeals Council appeal, but also to make a new application and submit new medical/functional documentation, so that if rejected you have saved time and are on track for a new determination – Consult with your attorney.

*My doctor does not cooperate but I have been with her for 12 years and she diagnosed me. Should I switch docs while in the reconsideration stage of disability?*

If your doctor is not willing to truthfully document your disabling physical diagnosis (medically-determinable impairment) or is unwilling to document your severe inability to carry out work tasks and daily activities, you must find another doctor who will do so. If necessary, you should do this at any stage of the disability evaluation process as soon as you learn that the main provider(s) you are depending on to support your claim is not supporting your claim. Obtain your medical records so that your new doctor can see your history and use these records

to support his/her documentation of your disability. You must find a doctor to state you are disabled from a medically-determinable impairment and as a result you are not able to work at even part time sedentary work on any predictable basis.

*After my doctor has documented the severity and chronicity of my medical impairment, how should s/he document my functional limitations that prevent me from doing sedentary work?*

See our article on cited in the Introduction above for information on how a physician should document an applicant's functional limitations: *How does Social Security determine whether a person is disabled and qualified to receive disability benefits?*

Also, see the article by James Ratchford:

<https://www.jamesratchford.com/blog/2020/03/less-than-sedentary-the-standard-of-disability-for-individuals-under-50/>

*Questions: Can a multi-year stipend for attending a PhD program (equivalent to an entry-level salary) count for your work history?*

Social Security benefits are based on a person's work history/earnings. A person's work history for Social Security benefits are only those earnings for which the person and the employer paid Social Security payroll taxes. A self-employed person will pay the entire amount of Social Security and Medicare payroll taxes.

Work for which Social Security taxes were not paid is not work history that Social Security counts for program benefits.

"...Let's review a couple of basic concepts that will affect your benefit. The first is that a Social Security benefit is an earned benefit. It's not a freebie. We Americans earn our benefits by working for many years and paying the Social Security tax in each of those years." AARP *What Will Your Social Security Benefit Be?* Stan Hiden, 2017 <https://www.aarp.org/retirement/social-security/info-2016/how-social-security-calculates-benefits.html>

*This is separate from teaching some semesters which are paid separately.*

For a person to accrue quarters and for pay to be included in a person's work history, Social Security payroll taxes must be paid.

*Would an unpaid full-time multi-year internship in Congress count as a work period?*

Again, a work period is only counted if the person accrues a sufficient amount of pay to count as a quarter, and if Social Security taxes are paid.

*In applying for Social Security, is unpaid work which may or may not include certain other benefits be counted as substantial gainful activity.*

Engaging in substantial gainful activity as defined by Social Security means that a person is not considered disabled. Part-time sedentary work performed on an unpredictable basis may or may not be substantial gainful activity depending on a person's residual functional capacity and availability of such jobs. See our article on Substantial Gainful Activity cited above.

See: <https://www.ssa.gov/redbook/eng/definedisability.htm?tl=0%2C1%2C2>

(Note this link is not found in Google; use another browser.) “We use the term ‘substantial gainful activity’ to describe a level of work activity and earnings. Work is ‘substantial’ if it involves doing significant physical or mental activities or a combination of both.

‘Gainful’ work activity may include: 1) Work performed for pay or profit; 2) work of a nature generally performed for pay or profit; 3) Work intended for profit, whether or not a profit is realized.” Hence some work without pay, but which might include paid for benefits might be considered substantial gainful activity either by a calculated dollar amount or by one's residual functional capacity.

Please see our extensive article on what Social Security considers Substantial Gainful Activity (SGA), cited in the Introduction above and available at our website.

Here is a great article explaining SGA and even when volunteer work may be considered SGA: <https://www.nolo.com/legal-encyclopedia/what-is-substantial-gainful-activity-work-social-security.html>

*Question: And what if taxes were only paid on some of the years? Would back taxes need to be paid first to count as work history?*

From Investopedia “How Social Security Works for the Self-Employed” – Amy Fontinelle 10/21 “If You Fail to File” “If you don’t file a tax return reporting your self-employment income, you have a limited time to file a return and still get credit with the [Social Security Administration](#) (SSA) for your work time and income. You must file the return within three years, three months, and 15 days after the tax year for which you earned the income for which you want credit.<sup>10\*</sup>

*Question: What to state as the date of onset when the pwME has been sick for decades and stopped working many years ago?*

There are 3 important dates: 1) date of onset; 2) date of disability; 3) date you apply for benefits.

You should state the date of onset – when you first became ill.

Your *date of disability* is generally when you could no longer do any work, even part-time sedentary work on a predictable basis.

Some patients may have stayed at work while they were sick for some months or even years despite the fact that they were frequently absent and really unable to perform their job. The person might be considered disabled for some of this time; but generally a person becomes disabled when they no longer can work due to illness.

When patients have been out of work for some years before they apply for disability, they should put down as their date of disability when they could no longer work on a predictable basis. However, to receive back benefits they must show through medical records that they were disabled during this past period – that they had a disabling medical diagnosis and they were too disabled to carry out work tasks and activities of daily living. Social Security, however, under most circumstances will only pay retroactive benefits for one year prior to application.

*Question: Wouldn't a case with someone with Long COVID be difficult to win when the science isn't clear on what is going on? I have Long COVID and am*

*currently on PFML disability but almost all of my testing has come back “normal.”*

See our Resource Guide with this presentation for the information for how to document Long-COVID as a disabling medical impairment.

<https://www.massmecfs.org/images/pdf/SundayConversations2022/ResourceListforDisabilityPanel.pdf>

Please see our extensive article on applying for Social Security Disability if you have Long COVID cited above in our Introduction.

It is difficult, but not impossible. For Long COVID, it is extremely important you report all your symptoms to your doctor and that you review your medical records to ensure the doctors are documenting your symptoms. SSR 16-3p states SSA must have objective medical evidence, which it defines as medical evidence providing *signs or laboratory findings*, from an acceptable medical source to establish the existence of a medically determinable impairment. “Signs” are what the doctor finds upon physical and/or mental examination of a patient. Therefore, a test could come back “normal” but what your doctor finds upon examining you may be “abnormal” and that will be considered objective evidence.”

*Question: I do have a question if I’m on SSDI for another Disorder is it worthwhile to apply to add my FM to my SSDI. I feel like it would be a good thing, but not sure if/how that works.*

Once you are found eligible for SSDI based on a medically-determinable impairment and remain disabled, it is not usually necessary to submit any new diagnoses/medical records until you come up for a Review. (You can check with an attorney.) When you do come up for a review, Social Security will ask for any changes in your medical diagnoses, their severity, and your level of disability. So you could then add another diagnosis(es) to your record.

However, if you add fibromyalgia you would have to obtain good medical documentation that you still have severe ME/CFS and that the fibromyalgia diagnosis has not replaced your ME/CFS diagnosis. Social Security could construe that since FM and ME/CFS are similar that you now have FM instead of ME/CFS.



FM is on average less disabling than ME/CFS, so Social Security might want to do a reassessment of your level of disability. Adding a diagnosis to your medical records and submitting the documentation during a Review can be positive if it demonstrates further medical disability. However, make sure a new diagnosis does not falsely supplant the original diagnosis on which the disability is based - unless the new diagnosis does medically change your original diagnosis.

*Question: If awarded benefits, how often do you have to “prove” you’re still disabled? Do you need regular medical documentation for that?*

See our explanation of Reviews

at <https://www.massmecfs.org/images/pdf/handbook/Disability%20Handbook-Appendix%20VIII.pdf>

Also see the section on Continuing Reviews in our article “Working While on Social Security” found on our website.

Your Notice of Award will tell you when to expect your first medical review. If SSA determines improvement in your condition(s) is expected, your first review will usually be 6-18 months from the date SSA found your disability began. If SSA determines improvement is possible, but can’t be predicted, then your case will be reviewed 1x every 3 years. If your improvement is not expected, then your review will be 1x every 7 years. See: <https://www.ssa.gov/pubs/EN-05-10053.pdf>

If you need a copy of your Notice of Award, call your local SSA and they will mail it to you.

*Comment: Lots of people probably don't know about the two day in a row exercise test (CPET), I had this done in 2010. Not cheap, but I think it's hard to dispute. The CPET test is a very good diagnostic test to document ME/CFS to Social Security.*

The two day CPET test is much better than the one day test, since the one day test may not show the level of post-exertional malaise and symptom exacerbation.

*What if some of my medical records contain incorrect info? Like the year I graduated or the symptoms I have?*

If the errors are non-medical like graduation year you can ask the provider or the Records Dept. of the medical office/Hospital to make the correction in the electronic records.

However, if a doctor recorded symptoms or a diagnosis incorrectly, ask them to make the correction. If they will not, you will probably need a current doctor to note that the error in the historical record, in his or her judgment, based on current medical findings and evaluation, has now been found to be incorrect. This necessity sometimes occurs when a past doctor ignorant of ME/CFS, fibromyalgia, etc. had rendered a psychiatric diagnosis. A current doctor can rebut this finding based on a more qualified and documented diagnosis – and so note this to Social Security in his/her medical report. This is especially important in documenting the true medically-determinable impairment(s). A false psychiatric diagnosis may be assumed not to create a severe disability making a person incapable of working – especially if psychiatric medication might relieve the symptoms.

*Comment: Some primary care doctors' offices have social workers to assist patients and this type of question can be posed to the social worker.*

*Question: Does being married or engaged affect SSDI - NO not in the case of an adult recipient.*

Being married can affect eligibility for SSI, as the spouse's income is counted in the disabled person's income eligibility.

A disabled child receiving SSDI benefits on the record of a parent may lose these benefits when they get married. See <https://www.nolo.com/legal-encyclopedia/dependent-benefits-children-ssdi-recipients.html> See also <https://www.ssa.gov/pubs/EN-05-10085.pdf>

Children may also receive benefits under SSI – see [https://www.ssa.gov/benefits/disability/apply-child.html?gclid=CjwKCAjw\\_tWRBhAwEiwALxFPoeB0KxvI1vVischJ\\_fUZD6UJ9iuEkKQSWyyaTIYtJm52OISkF1AUFRoCgeoQA\\_vD\\_BwE](https://www.ssa.gov/benefits/disability/apply-child.html?gclid=CjwKCAjw_tWRBhAwEiwALxFPoeB0KxvI1vVischJ_fUZD6UJ9iuEkKQSWyyaTIYtJm52OISkF1AUFRoCgeoQA_vD_BwE)

*Question: How many doctors do we think we have in Mass. who are competent to deal with ME/CFS? 15? That many?* The Mass. Association is constantly attempting to identify physicians who are interested in or have knowledge/experience with ME/CFS, Fibromyalgia, chronic Lyme and Long-COVID. There are thousands of doctors in Mass. Some of them must be unbiased and aware of these illnesses. How do we find them? Don't hesitate to recommend such doctors or other providers to us. You can do this at our site online at <https://www.massmecfs.org/contact-our-association>

### *Questions on Supplemental Security Income (SSI)*

SSI is for those who do not qualify for SSDI because they lack a sufficient number of quarters. Unfortunately SSI is for people with very low income and few assets. A person cannot have more income than the SSI monthly payment amount, which in most states is less than a thousand dollars. Any other income less than that amount is deducted from the SSI check.

For SSI purposes, SSA does not require you to be “legally married” to someone for them to be considered your spouse. SSA will consider a boyfriend, girlfriend, or significant other as a “spouse.”

For SSI purposes, SSA will not consider someone your “spouse” even though you are still legally married so long as you show you both are no longer live together.”

*Question: If a person does not have enough working quarters and their spouse makes too much does that mean you cannot get the SSI or SSDI - or is it worth trying?*

SSDI eligibility and benefits are not dependent on any other income a person receives, including spousal income. If a person lacks just a few quarters it may be possible to find a legitimate way to obtain them. Check with a competent attorney. If back payroll taxes are owed, you may be able to repay them and then accrue the quarters. Make sure you state the actual date of disability (see above) since this can determine the number of quarters you have accrued.

SSI eligibility takes into account a spouse's income – so if the spouse's income, depending on the amount, can make a person ineligible for SSI.

*What about a person's assets when applying for SSI?*

A person cannot have more than \$2,000 in assets to be eligible for SSI. However one car and one house do not count as assets.

*What happens to my SSI if I transfer a resource?*

If you, your spouse, or a co-owner give away a resource or sell it for less than it is worth, you may be ineligible for SSI for up to 36 months. How long you are ineligible for SSI depends on the value of the resource you transferred. There is a "look back period for SSI". <https://www.ssa.gov/ssi/spotlights/spot-transfer-resources.htm> Also Here is SSA's SSI Guide: <https://www.ssa.gov/ssi/text-understanding-ssi.htm>

The "look back" period for the transfer of assets applies to both the time of initial application and to post application transfers. If you transferred assets within 3 years of applying, you will be ineligible until the 3 years is up.

Placing money in a Trust may or may not disqualify you depending on the type of Trust. This information applies to SSI. For more information on setting up Trusts for SSI see <https://www.ssa.gov/ssi/spotlights/spot-trusts.htm>

*Question: We moved some of our daughter's money to an ABLE account a while ago, but will SSI care if we move some monies just 1 month before we apply?*

Setting up an ABLE account does not appear to trigger a look-back period in terms of eligibility for SSI. Check with Social Security.

Money deposited in an ABLE Account is not counted as an asset by Social Security for SSI. The ABLE Account can only be used for disability-related expenses. The ABLE Accounts are limited to people who become disabled before the age of 26. The account can be controlled by the disabled person or a person with a power of attorney. ABLE accounts are controlled by the States – some States do not have ABLE Accounts. See:

<https://www.disabilitysecrets.com/resources/able-savings-accounts-allow-ssi-and-medicaid-recipients-to-save-money.html>

*Does Medicaid have a look-back period for assets?*

Look-back periods for assets for Medicaid vary by States. In Massachusetts there is no resource limit for obtaining Mass. Health/Medicaid. However, there is an income limit. Other states may have a five year period look-back for transfer of assets prior to the date of application. This is where “Medicaid planning” comes in. By consulting a knowledgeable attorney – and not all attorneys are the most knowledgeable – you can determine how to maintain/protect your assets for designated use within a legal framework - or legally give away your assets.

*Does a retirement account count in assets for SSI? Yes, see*

<https://www.tcnf.legal/will-a-401k-make-me-ineligible-for-ssi/>

**Self-employment and Social Security Disability:**

*Any information regarding the issues surrounding SSDI and self-employment would be appreciated. Seconding self-employment question Ron, are there any “pitfalls” that self-employed people should be careful about when applying for SSDI? Such as documenting past earnings- is there more than required than tax returns?*

Self-employed individuals may qualify for SSDI if they have paid Social Security taxes. While employees pay into the Social Security system automatically when taxes are deducted from their paychecks, self-employed workers must pay these taxes on their own.

If you are self-employed, you likely file a Schedule SE at tax time. To be eligible for Social Security benefits, you have to pay the self-employment tax, which consists of Social Security and Medicaid taxes. The self-employment tax rate was 15.3%. Part of this, 12.4%, goes to Social Security, and the remainder to Medicaid.

**View again the presentation:**

MassME YouTube channel:

[https://www.youtube.com/channel/UCLPXDOWDiK0V3UaHsiqa\\_JA/](https://www.youtube.com/channel/UCLPXDOWDiK0V3UaHsiqa_JA/)

<https://www.massmecfs.org>