



WIN YOUR EDS
DISABILITY
CLAIM:
A STEP-BY-
STEP
TRAINING

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Win Your EDS Disability Claim: A Step-by-Step Basic Training

Empower yourself for the challenging battle for disability support with these boot camp-style power tips. You've earned it, warrior!

Here are a few key lessons learned from the scars of battle as patients with EDS and how to prepare yourself and your troops. Disability is an enormous topic with many nuances, so **do your research**. Start by learning the [basics of when a chronic illness becomes a disability](#). Ensure you are well informed if you enter the battlefield, armed with your best weapons, allies, and bunker buddies, because you will need all the help you can get.

Note and Disclaimer:

Because of the highly variable nature of disability, chronic illness, and needs of each patient, this volunteer-curated insight offers neither an authoritative nor exhaustive description of the process, which will necessarily depend on the individual and their needs. Instead, it is designed to serve as a starting point to become aware of and acquainted with different aspects of the complex system, as well as their rights under the Americans with Disabilities Act (ADA) in the US using the [Guide to Disability Rights Laws at ADA.gov](#)

TIPS FROM THE TRENCHES

Before we start, we'd like to mention that we know many people with EDS have not been able to work at all and this is a tremendous burden in many ways. We also understand that many severely affected children have been too disabled to be able to have a regular job later in life. Many of us might not be eligible for disability support. Despite those hard facts, we collected insights in this guide for those of you who have been able to work, contribute to the US Social Security system and may be eligible for financial support acting as a step-by-step guide on how to do so effectively based on patient experiences.

1. Know the lay of the land; identify the landmines early.

Work as long as you are able but without pushing your limits. The benefits from employment financially and in potential benefits are tremendous. When and if the time comes that you need to step away from work to care for your health or you are no longer able to do your job duties, research wisely *beforehand* so you can properly use and effectively exhaust all your available options. There are so many potential options available such as sick/vacation time, PTO, leave of absence (LOA), Family Medical Leave Act (FMLA), and then more options in short-term disability (STD) and any potential long-term disability (LTD) benefits and policies your employers may offer (or you can get privately) before resorting to file with the Social Security Administration (for US for citizens who have earned enough income- learn more [qualifying for SSA eligibility](#)).

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Also, be aware of potential landmines you might encounter and avoid walking right into them. You can do this by knowing your medical history and carefully reviewing copies to ensure accuracy – and request any necessary changes be made. It's also essential to monitor your privacy settings on any social profiles for onlookers, who could be potential hurdles later as you post what you're doing in your life.

2. Demonstrate the burden.

Next, if not already, start tracking. Yes, it can be tedious but track everything! Having in-depth and accurate documentation and records matter. You will need your own (symptoms, pain/fatigue trackers) and from your doctors (records, diagnosis, treatments prevention plans, mitigation risk plans, and any procure notes and results). The data spoken *in writing in your doctor's voice* is the most valuable piece of this, so ensure your records indicate what you need. This is important and is tremendously helpful to the auditors and reviewers from either the Social Security Administration (SSA), your lawyer, any disability advocate(s), and to your overall case, no matter how you choose to file. Admittedly, this part sucks! But you cannot win without documents, trackers, or apps with data evidence of your medical condition. Be sure it states not only diagnoses but, more importantly - how chronic illness *affects your ability to function* on the job and in activities of daily living (ADLs). Yes, this will become your full-time job for a while. Be sure to track the following:

- your symptoms, reactions
- treatments tried and results
- contact info for all doctors and medical providers
- dates of all appointments *plus* the list of future upcoming follow-up appointments with each provider
- a confirmed list of diagnoses, plus any suspected diagnoses currently under evaluation
- a list of all current prescriptions (and ones tried in the past and failed), plus OTC and supplements
- documentation of all medical procedures, surgeries, outpatient procedures, etc., you have had related to the condition(s)
- a list any alternative or experimental options you've tried (like prolotherapy or PRP) and their results and any follow-up schedule
- a list of your historical medical insurance claims data from your healthcare provider (usually exportable online)
- an ongoing list of all of the out-of-pocket expenses for all of the products, PT, tools, and other self-management expenses you cover outside of insurance
- Yes, I am exhausted for you after all of that!

Then, consider filing for Short-Term Disability (STD) BEFORE you quit your job *if it's an option*

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This private insurance offered by some companies can be an important temporary stopgap if you face a one-off surgery and recovery or need a short period of time to regain wellness to work. It can be in place, depending on the policy, for 90 days up to 6 months. Get a copy of your policy and read the details.

Then, file for SSDI Support (US only)

This is an entire volume of books, but here are some great resources to investigate further. Learn the difference between SSI and SSDI. Remember, you will need documentation and support as evidence of your case. At the end, there are numerous resources to expand your knowledge and advocates who can help guide you. If you need some nighttime reading to conquer your 'painsomnia,' here is a list of several

Now, hurry up and wait! And wait...then file for LTD Support

Next, if your need continues and you have the option file for long-term disability (LTD) *exactly as stated per your policy*. I strongly recommend you get a legal review beforehand, and many attorneys offer free case consults. The nitty is in the gritty, so get an expert to read your LTD policy and its specifics before proceeding!

Still waiting...??

3. Pass or fail, do not stop, keep going warriors

This time goes very slowly. Find a fruitful hobby or enrich your soul in any way possible while you wait. The letter will come eventually with news one way or another.

Once approved

(sometimes months, even years later) Spend your time completely focused on your own health to try to restore as much as possible in hopes you can return to gainful employment someday, maybe in a different capacity and level. It is possible. But it may look different, maybe even by choice.

If denied...If you haven't already- seek professional legal advice and help from an attorney. Research the resources provided below and ask in online forums what worked. This is another dense topic that is too much to cover in this boot camp in any level of detail. Again, get professional advice.

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4. March to your own drumbeat

If not able to return to full functionality, seek a means to purpose, hobbies, and meaning other ways, such as testing out productivity in online forums of support to be accountable to others. Or maybe try volunteering using the online match-making service .

5. Watch out for enemy troops

When going through this process, you will feel like someone is watching you. Paranoid? No – they *are* watching! Insurance companies hire surveillance detectives, send drones, and place motion cameras on poles near your house/car to track and monitor your activities. Some even use drones. Seriously. They will follow you to report, video, detail, and ensure you're doing only what you said you could do, and they will make note if you do more *just that one time to make you seem like you are misrepresenting the truth!* Unfortunately, some bad apples have spoiled the bowl for everyone as they jet ski while on disability.

Choose your words carefully in your reports to insurance, doctors, and the like (i.e., don't report you *never* go to the grocery store if you went once). They will twist your words and use them against you based on what they can try to prove. Such as, "subject seen ambulatory with a steady gait carrying a dog and an unknown object in their hand." That means they saw you walking your dog and carrying the poop bag. Really!

But it's also important not to disable your mindset because they're watching. It is critical to live cautiously, especially on your public platforms and in any public online social presence. What you do 'out loud' will be noted and probably held against you as 'your capabilities' and why you can return to work. It is their job to find a reason to disqualify and stop paying your claim as best they can - don't give them one! Live your life without the shadow, but do so wisely - that means no more all-night salsa dancing and white water rafting trips anymore, you wild zebra! Huh, as if! Seriously, remember, you have to prove that you are **consistently unreliable**. The burden is on you, not them, in the eyes of the courts.

6. Go back! But don't retreat

Being able to work means so much more than the money we earn. Having a job or even a career can give our lives a sense of purposeful accomplishment while providing opportunities to learn, grow, and meet others. The employment benefits you receive, in addition to your salary, can also provide you and your family with an important financial safety net. Take serious consideration to determine when and if you're well enough to go back to the working world. To test the waters if you have the physical and/or mental capacity to return to work, figure out workplace accommodation needs, or if you want to explore a new path, consider starting with a volunteer job.

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Either way, get yourself prepared by realigning your expectations and your resume for the new you and decide if you will disclose your disability during the application process (learn how to disclose and your rights). Check out Ability Magazine's career site or Chronically Capable, - both free job seekers search sites for disabled people. Know your rights or watch this video on disability rights from Dysautonomia International. Get more from a patient point of view on this blog series from an advocate, including how to keep your benefits. Remember to ask for reasonable accommodations (a few EDS accommodations ideas) and seek out friendly environments, companies, and cultures in the places you search. Bottom line, try not to be an overachiever by bringing back the ole 'can do' attitude which can lead to wearing yourself out too quickly.

7. Resources, incoming...BOOM! Help can soon be on the way

Consider very seriously outsourcing your needs, including hiring an attorney. The process will test your patience and your resilience to keep fighting. I encourage you to speak to others and disability advocates and get sage advice on ways you can outsource help – especially with an expert ERISA attorney for LTD claims and appeals. Many people have said they could do some of this on their own, but once they got denied by SSA or their private insurance, a lawyer needed to take over. I know you don't really want to give up any financial rewards to them, but also keep in mind the maximum attorney fees they can recoup in 2023. Social Security limits attorney fees to 25% of your back pay, up to \$7,200—whichever is lower, according to [Nolo](#) legal resources. While attorney fees are capped at \$7,200 for SSA, it's important to know that the typical fees for disability claim fees for lawyers on LTD or ERISA claims are typically 20-35% of any retained earnings depending on the individual firm. That may sound like a lot, but two-thirds of anything they can retain for you is 100% more than you had before! Understand and be comfortable with the fee structure before you engage an advisor.

If you choose to hire an attorney, seriously consider hiring an expert lawyer from a specialty disability firm who understands not only ERISA laws and disability but the not well-understood disorders, including EDS, POTS, etc. One such firm (of a few) that we had a good experience with is Dell Disability Lawyers. You can check out their YouTube channel or their website resource for EDS at <https://www.diattorney.com/ehlers-danlos-syndrome-disability-benefit-claims>. The real benefit of outsourcing to an expert attorney means you do not have to carry the paperwork proof burden anymore, which is a huge relief when it's hard to think clearly and fight the system with limited energy.

8. Strengthen your army with weapons to use to your advantage to win

Utilize several resources available, including these:

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- The best tip we have is to use the newly published National Academies of Science and Medicine published a specific connective tissue and EDS report that the SSA requested from a team of medical professionals in "[Selected Heritable Disorders of Connective Tissue and Disability](#)." It is by far the best resource out there and is specifically **designed for your attorney** to leverage on your behalf in terms of which comorbidities you might have and how they impact your function. It is a hefty report. To utilize it, find the diagnosis you have in the TOC, then read those sections only. It helps keep you from being overwhelmed. Be sure to leverage the tables in the back for lists of symptoms and how it impacts your level of function – which is what you must outline for the insurers and disability evaluators. They don't want your disease to resume of all your diagnoses. Yes, it's probably impressively long, but not what they are looking for unless it's from your medical records. Seriously, the doctors who painstakingly contributed and people who edited it crafted a marvel with this report! Thank you all from the EDS community!
- Reach out to appropriate and supportive non-profits or foundations to request medical information on your diagnosis to share and add credibility to your case, like the Marfan's Foundation, which is one of the few non-profits willing to write letters of support.
- Kindly request your key doctors (**preferably the MDs**) to write you a letter of support confirming your diagnosis, its effects, and limitations on your functional capabilities. Here is a [sample letter template](#) you can start with and ask your doctor to complete and customize for your situation.
- Ask for help from EDS advocates such as well-known connective tissue disorders advocate Jon Rodis. He is a 20+ year veteran of supporting Marfans and EDS hypermobile patients through Social Security Disability support and wrote the disability chapter for the renowned guide to EDS book *Disjointed* by Diana Jovin. Below is his "What Makes You Disabled" summary for specific ways to explain to a judge, a lawyer, or the insurance company to understand what daily life is like for you as a disabled person. Jon uses this to help people with their SSI/SSDI cases and reminds us that all the limitations need to be backed up by your medical records. He guides people on how to do this as a pro-bono advocate by teaching you how to talk to your doctor and get the testing necessary to support your claim. He was featured on a [webinar with EDS Wellness shared on YouTube](#).
His recommended way to explain why you cannot work a regular 40-hour-a-week job (edit as you need for your personal situation):
"What makes you disabled: Can't stand or sit for long periods of time, can't walk for long distances, daily pain-moderate to mostly severe-in joints, knees, hips, fingers, wrists, shoulders, head, neck, ribs and ankles, daily fatigue-moderate to mostly severe-can get more fatigued with low exertion, daily dizziness, weekly headaches, and occasional migraines, daily subluxations and occasional dislocations, issues with memory and concentration, frequent bathroom visits, shortness of breath, occasional nausea, issues with loud sounds, occasional loss of balance and occasional falls, low grip strength and higher chronic pain in hands from daily use."
- Consider compiling a list of potential expert witnesses who are very familiar with and study the disorder, such as doctors, researchers, and others who might be willing to speak on your behalf.
- For more information, see our listed resources below or check out this [List](#) of disability for chronic illness books currently available on Amazon.

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9. Never underestimate the enemy and learn the rules of the game

Don't be naïve. It is the private insurers' business to find a way to get you *off* the claim and *off their payroll*. You will be subject to countless reviews, miles of red tape, and systematic tactics designed to wear you down, designed to make you give up. Remember that! Think like a veteran (with all due respect given and earned) who was wounded and rightfully deserves ongoing support, knowing there will be a cost to you and your loved ones that you've yet to imagine. It can be an emotional ride full of frustrations with what 'should be done' as the 'right thing,' but the system doesn't work that way. Be ever resilient, and never let them see you sweat!

Be sure you know the current guidelines and limits on income maximums with SSA if you work a little while receiving benefits. For example, if you qualify for Social Security's Supplemental Security Income (SSI) program, your cash benefits can be suspended if your earnings exceed "substantial levels." In 2022, average earnings of \$1,350 or more per month were usually considered substantial. The good news is that Social Security also has special rules called 'work incentives' that enable people receiving disability benefits or SSI payments to work and still receive monthly payments. Learn in-depth about these rules of the game to ensure you don't lose any benefits you might already receive by working or appearing to work in any form. This is another topic too dense to cover here.

10. Have a strategy for the long game in the war on your health

Your top priority must be to get as healthy and well as you can. If you can gain these needed financial benefits like SSDI, Medicare, or LTD benefits – think of it as a bonus. It will be helpful in your journey to survive without the financial burden and medical debt, giving you the independence you want. And if you do win benefits, my best advice is to *do everything you have to do to keep them!* Follow the rules.

11. Arm yourself with the power of a professional

The best weapon you have is the prioritizing your own care. Act as if you were working for the CEO of Y-O-U! You are now your own new boss, in the new role of 'professional patient' or 'full-time caregiver'! Keep in mind, it's not PJs and bonbons; it's the hardest job you'll ever have to do (except being a parent, maybe). It's an immense amount of unrecognized and unadmired work. It will likely not be what you expected. There will be no starting or end-of-year bonuses, no promotions, no raises (except cost-of-living increases occasionally), no annual performance reviews touting how well you did that year on your goals, nor any recommendation on how to improve. You will be in a process of reinventing yourself because you have to. It is likely not what you had set out for your life plan or career, but you can make the most of it. Think of it like this - now, you're self-employed in a way! Life goal achieved, right?

In essence, you are the captain of your own army, a force of one, and an elite-trained NAVY SEAL-like warrior ready for the battle of your life. In honor of all deserving veterans, do us proud! Get yourself ready, put your armor on, gather your weapons to protect yourself, and find your true allies. This war is worth it for your ongoing health and financial well-being, stability, and security. So, add your camouflage-style zebra stripes of protection as you paint on your warrior's face. Hold steady, soldier; you're ready!

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Written by the EDS Awareness volunteer media team members from one zebra's perspective to another (as guided by our attorneys to remain unknown soldiers).

Sources and Key Resources

- The best resource on how to file for disability if you have Ehlers-Danlos syndrome (EDS) is the 2022 publication from the National Academies of Science, Engineering, and Medicine Social Security Sponsored Report, "[Selected Heritable Disorders of Connective Tissue and Disability](#)." Also check out one of the report's authors and medical experts, Dr. Eric Singman, who shared how to get help in [this article](#) and [video](#).
- The major resource is the Social Security's own [The Red Book](#), which guides you through all rules around working while using SSI or SSDI.
- The Global Genes [2022 FAIR Toolkit: Understanding Employment Benefits](#) outlines several key aspects of the disability process when you have a rare disease.
- Learn more about [how to qualify for disability if you have spine-related conditions](#) from this non-profit.
- Learn from an EDS expert medical provider [Dr. Alan Spanos who shares tools for patients applying for disability](#).
- A well-informed personal blogger with rich chronic illness and disability resources <https://howtogeton.wordpress.com/social-security-disability/>

More Resources on Disability

- [Centers for Disease Control and Prevention: Learn about Disability and Health.](#)
- [Centers for Disease Control and Prevention: COVID-19 information and resources: People with disabilities.](#)
- [World Health Organization: Disability.](#)
- [Healthy People 2030: People With Disabilities.](#)
- [World Institute on Disability: Access to Medical Care: Training Tools for Health Care Providers, Disabled Patients, and Advocates on Culturally Competent Care and Compliance with Disability Law.](#) Published 2011.
- [Alliance for Disability in Health Care Education \(ADCHE\). Core Competencies on Disability for Health Care Education.](#) Published 2019.
- [National Council on Disability](#)
- [Physicians' Perceptions of People with Disability and their Health Care.](#) Authors: lezzoni et al. Published 2021.
- [US Physicians' Knowledge About the Americans with Disabilities Act and Accommodation of Patients with Disability.](#) Authors: lezzoni et al. Published 2022.

Resources for Legal Action Related to Disability

- [Disability Rights Legal Center](#)
- [Disability Rights Education and Defense Fund](#)