

# Applying for Disability due to EDS

## Tools for patients and their doctors

*Medical problems due to EDS can be so severe that employment becomes impossible. If you can't work, you may be eligible for financial support under federal programs. Applying for these benefits presents a big hurdle. EDS causes "invisible disability," that requires validation from medical records in order for a disability adjudicator to assess it properly. But doctors' records fail to capture the complex effects of EDS on what people can do. So this article offers two tools to help you and your doctor provide the authorities with a proper assessment of your difficulties.*

### How to use this document

I suggest that you read this document all the way through. Then consider if you want to interest your doctor in using the page, *Causes of Medical Impairments in EDS*, to report on your medical condition to the disability authorities. Also consider completing the page, *Questionnaire: Daily Activities in EDS*. If you do decide to use them, make copies of both pages for yourself, and also for your doctor. Schedule an appointment with your doctor to go over both with them. Be aware that doctors don't relish doing disability reports, and are not legally obliged to provide them. So you may have to persuade your doctor to get involved in this. The doctor is more likely to help you if you explain two things to them. The first is that the two pages you're giving them actually make preparing a report very much easier. The second is that if the doctor's report helps you to "get disability" then this will bring a huge and lifelong benefit to you.

### Disability benefits for people with EDS

Ehlers Danlos Syndromes are complex disorders with very variable severity. For some, an EDS prevents any chance of earning a living. In the USA, federal law provides support to people who can't work because of chronic medical problems. These include financial support, and health care. The federal Social Security Administration (SSA) has rules defining who is eligible for these benefits. There are many online resources that explain this system. The main one provided by the federal government is at <https://www.ssa.gov/benefits/disability>. Most of the others are put out by attorneys specializing in disability claims. They mainly work to help people who want to appeal against a disability application that has been denied.

### The doctor's role in disability assessment

Disability benefits are initially assessed by a "disability adjudicator" called a *disability examiner*. If a hearing is necessary, then the adjudication is done by an *administrative law judge*. Neither of these is a doctor, and doctors don't get to tell them who is disabled and who isn't. For the purposes of disability benefits, *disability is an administrative concept, not a medical one*. The doctor's role is to supply the disability adjudicator with the applicant's diagnosis, and explain how their "medical impairments" interfere with activities relevant for employment. It is the adjudicator who decides if the patient's "medical impairments" do actually add up to "disability" as defined by the law.

### Describing "medical impairments" in people with an EDS

People with an Ehlers Danlos Syndrome have a big disadvantage in applying for disability benefits. They don't have conditions that can obviously prevent people from working, such as amputated limbs or paralysis from a stroke. Their limitations are due to "invisible" problems like pain, lack of stamina, "brain fog," or a need to lie down and rest frequently. Such difficulties, called "medical impairments," are not only invisible, they are also *largely unknown to doctors*. The great majority of doctors know nothing about EDS, except perhaps a sentence dimly remembered from medical school – that Ehlers Danlos Syndrome is "an inherited condition of lax joints and stretchy skin." Doctors, and disability adjudicators, are equally unaware of how *medical problems, that span multiple body organs and systems, conspire to make daily activities difficult or impossible*.

Because their ailments span several body systems, people with an EDS typically have seen a number of different specialists. Records from each of them will need to be sent to the SSA when applying for disability benefits. But the specialists' records will likely reflect only the symptoms of the diseases in which they specialize. For instance, orthopedists' notes may mention loose or injured joints, but not exhaustion, or dizziness, or headaches etc. Also, the difficulties of EDS *fit together so that they multiply*, and this can make many daily activities difficult, or even impossible. A primary care doctor, like a family physician or internist, should be able to put together an account of all the patient's problems - but they can only do this if they know what questions to ask about the patient's symptoms. They also need to know what specific symptoms EDS can cause.

So you have two problems in getting a medical report in support of a disability application. One is that neither your doctor nor the disability adjudicator knows all the symptoms EDS causes. The other is that your doctor is not used to quizzing you on how those symptoms interfere with normal daily activities, which is what the adjudicator needs to hear.

Below are two modest contributions that may help you with this predicament. The first is on page 3. It is a list of the ways in which EDS symptoms can affect normal activities. These are called "Activities of Daily Living" or ADL for short. I've briefly explained these symptoms in footnotes. Note that I have not overloaded the list with all EDS symptoms: only the ones that commonly affect activities enough that this could be relevant to whether or not you could work a paid job. This page is suitable for copying directly into a disability application from you, or a medical report from your doctor.

The second item is on page 4. It's a list of questions about how you manage daily activities that are relevant for employment, as seen by a disability adjudicator. I strongly recommend that you print page 4, write answers to all these questions and hand them in to your primary care doctor, when you request that they send a report to SSA. If you have engaged an attorney to help you, then give a copy to them too.

If you don't write this out yourself, you will probably be sent a standard form on which to list your "impairments" by the SSA, or your attorney. This standard form is called a Physical Residual Functional Capacity Assessment (PRFCA). The trouble is, it doesn't come anywhere close to capturing the difficulties that people with EDS have. Although it's used all the time, the PRFCA is not legally required for disability assessment, so it's appropriate for you (or your doctor or attorney) to refuse to complete it, and instead offer the questionnaire. You should explain why, namely that "the PRFCA fails to capture the EDS symptoms affecting ADL, which are better presented in question-and-answer form."

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## CAUSES OF “MEDICAL IMPAIRMENTS” IN EDS

The following is a summary of the main medical factors that may have implications for employment, for people with Ehlers Danlos Syndrome. It would be appropriate for a patient’s doctor to copy this list and insert it into a report in connection with an application for disability benefits. It clarifies for the disability adjudicator that EDS symptoms and complications may be multiple, and interact with one another to impair activities of daily living.

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**The Ehlers Danlos Syndromes (EDS) are a group of *inherited, multisystem disorders*.<sup>1</sup> Their effects may include:**

- **Widespread pain** in joints and muscles (due to unstable joints and neuropathies).<sup>2</sup>
- **Joint displacements** (dislocations and subluxations) at multiple sites due to lax joints.<sup>2</sup>
- **Permanent joint damage** (osteoarthritis) at an early age due to these displacements.<sup>2</sup>
- **Weakness and poor stamina**, from childhood.<sup>2</sup>
- **Clumsiness**, from childhood (due to defective sensation of body position).<sup>2</sup>
- **Disrupted sleep** due to pain, sometimes with a need for much more sleep than normal.<sup>3</sup>
- **Gastro-intestinal upset**: abdominal pains, nausea, constipation, diarrhea, due mainly to dysautonomia.<sup>4</sup>
- **Faintness and cognitive decline on prolonged standing**: “orthostatic intolerance,” due to dysautonomia.<sup>4</sup>
- **Anxiety and panic attacks**, largely due to dysautonomia.<sup>4</sup>

An individual with an Ehlers Danlos Syndrome may have any or all of the above problems, with any degree of severity. They commonly conspire together to interfere with activities. For instance, housework can be impaired by a combination of joint pains, frequent dislocations, muscle weakness and poor stamina.

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1. There are 14 named types of EDS. By far the most common is hypermobile EDS (hEDS). This is at one end of a spectrum of Hypermobility Spectrum Disorders (HSD). These two terms have not proven to be helpful, so patients who have acquired either label are often now referred to as having “HSD/hEDS.” The prevalence HSD/hEDS is thought to be at least one in 500, so this is not a rare disease. (Demmler JC, et al. *BMJ Open* 2019;9:e031365.) There is at present no genetic test for this type of EDS: the diagnosis is entirely clinical. The symptoms affecting employment are roughly similar across all the main types of EDS, but their *severity* varies greatly from one individual to another.

2. Voermans NC et al. *Ann Neurol* 2009;65:687– 697. Rombaut et al. *Arthritis Care* 2012;64(10):1584-1592.

3. Domany KA et al. <https://doi.org/10.5664/jcsm.7058>.

4. “Dysautonomia” signifies a disorder of the autonomic nervous system, that controls automatic processes like heartbeat, breathing and the function of the gut and kidneys, as well as orchestrating the “fight or flight” response. The dysautonomia of EDS explains many of its complications, including anxiety and panic attacks, that were previously misdiagnosed as primary psychiatric disorders. Two chapters are devoted to this in the textbook *Disjointed*, ed. Diana Jovin.

## QUESTIONNAIRE: DAILY ACTIVITIES FOR PEOPLE WITH EDS

Your name and date of birth: \_\_\_\_\_ Date: \_\_\_\_\_

After each activity listed below, write down whether you have difficulty doing it due to your medical conditions. If so, be as specific and detailed as you need, in order to convey what the difficulty is, and how severe it is. Return the completed questionnaire to your doctor for use in preparing a report to the disability authorities.

<b>Sleeping</b>	
<b>Getting dressed</b>	
<b>Batheing</b>	
<b>Walking</b>	
<b>Shopping</b>	
<b>Driving</b>	
<b>Doing laundry</b>	
<b>Cleaning house</b>	
<b>Cooking</b>	
<b>Sitting at a desk</b>	
<b>Doing paperwork</b>	
<b>Dealing with people</b>	
<b>Lifting and carrying</b>	
<b>Other activities you have difficulty with</b>	