



Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Contents

A Guide for Health Professionals	1
Definition of Disability	1
What We Need from You	2
Evaluating Disability for Individuals with ME/CFS	3
Contacting Social Security	3

A Guide for Health Professionals

This fact sheet is a guide to assist you in providing the kinds of medical evidence we need to evaluate disability claims filed by individuals with ME/CFS (also known as exertion intolerance disease, or SEID). When an individual with ME/CFS applies for Social Security disability benefits, we must decide whether he or she is disabled under the law. We make our determination or decision based on the information you provide and other evidence, including information provided by the individual.

We appreciate your assistance in providing us with timely reports and other medical records. You may send medical records to us by mail or by using Social Security's Electronic

Records Express service to fax documents or submit them online via Social Security's secure website.

Definition of Disability

Federal law requires a very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not. An individual is considered disabled by Social Security if he or she is unable to do any substantial gainful work activity because of a medical condition(s) that has lasted, or can be expected to last, for at least 12 months, or that is expected to result in death. A child under the age of 18 is considered disabled if he or she suffers from any medical condition(s) that results in marked and severe functional

limitations that has lasted, or can be expected to last, for at least 12 months or that is expected to result in death.

The medical condition(s) must be shown to exist by means of medically acceptable clinical and laboratory findings. Under the law, symptoms alone cannot be the basis for a finding of disability, although the effects of symptoms may be an important factor in our determination or decision whether an individual is disabled. If the medical evidence alone shows that an individual is clearly disabled or not disabled, we decide the case on that information. Otherwise, we go on to consider other factors, such as functional capacity in light of the individual's medical condition(s), age, education, and work background. If a child under age 18 has a functional limitation because of his or her medical condition(s), we consider the child's functioning in relation to other children of the same age who do not have the medical condition(s). You can find more detailed information about our disability evaluation process on the Disability Evaluation Under Social Security page of the Medical/Professional Relations section of our website.

What We Need from You

We need information from you that will help us to determine the existence, severity, and duration of the individual's impairment(s).

Medical reports you provide to us should include a thorough description of the individual's medical history with the information on the diagnosis, onset, duration, and prognosis of the individual's ME/CFS and any other conditions. Longitudinal clinical records and detailed historical notes discussing the course of the disorder, including any treatment prescribed and the individual's response to treatment, are very useful for us since we are interested in the impact of the illness over a period of time.

Include in your reports all clinical findings (such as results of physical examinations and mental status examinations) and laboratory findings (such as blood tests, magnetic resonance imaging, or any other clinically accepted form

of testing), both positive and negative. It is essential that you submit all available objective findings concerning your patient's condition, even if they relate to another disorder or establish that the individual has a co-occurring condition other than ME/CFS.

Please report any medical signs you have observed. Examples include:

- Orthostatic intolerance (symptoms worsen on maintaining upright posture and improve by lying down);
- Palpably swollen or tender axillary or cervical lymph nodes;
- Persistent, reproducible muscle tenderness on examinations;
- Abnormal immune function, including frequent viral infections with prolonged recovery; and
- Non-exudative pharyngitis.

Also, include in your reports any symptoms or other effects of ME/CFS, such as:

- Persistent or relapsing fatigue resulting in reduction or impairment in ability to carry out daily or work-related activities
- Post-exertional malaise (worsening of symptoms after physical, cognitive, or emotional effort)
- Waking unrefreshed (individual is still fatigued after sleep);
- Disturbed sleep patterns, such as insomnia or prolonged sleeping;
- Cognitive impairment(s) such as having difficulty with information processing, short-term memory, reduced concentration and attention;
- Persistent muscle pain, tenderness, stiffness, or weakness;
- Multi-joint pain without swelling or redness;
- Headaches of a new type, pattern or severity;
- Sore throat that is frequent or that reoccurs;
- Cardiovascular abnormalities, such as palpitations;

- Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain);
- Respiratory difficulties, such as labored breathing or sudden breathlessness;
- Urinary or bladder problems, such as urinary frequency, nocturia, dysuria, or pain in the bladder region); or
- Visual difficulties, such as difficulty with visual focus, impaired depth perception, or severe photosensitivity.

Your descriptions of any functional limitations you noted throughout the time you examined or treated the patient are very important. If possible, provide your opinion of the individual's ability to do daily activities or work-related physical and mental activities. Tell us your opinions about both the individual's physical and mental functions and, to the extent possible, the reasons for your opinions, such as the clinical findings and your observations of the individual.

Examples of work-related functions include:

- Physical functions: Walking, standing, sitting, lifting, pushing, pulling, reaching, carrying, and handling.
- Mental functions: The ability to understand, remember, and carry out simple instructions, the ability to use appropriate judgment, and the ability to respond appropriately to supervision, co-workers, and usual work situations, including changes in a routine work setting.

Evaluating Disability for Individuals with ME/CFS

As you may know, state Disability Determination Services (DDS) evaluate claims for Social Security. The DDS adjudication team consists of a physician or psychologist and a specially trained disability examiner. In evaluating disability for individuals with ME/CFS, the team looks at all of the available evidence, including the clinical course from the onset of the illness, and considers the impact of the illness on each affected body system.

If the team determines there is not enough information to make a determination, they may call or write you to find out if you have the needed information. If you do not, they may ask you or, in some circumstances, an independent medical source, to provide the information by performing tests or an examination for a fee paid by the DDS.

Contacting Social Security

The most convenient way to contact us anytime, anywhere is to visit www.socialsecurity.gov where you can also take care of some business with an online *my* Social Security account.

Call us toll-free at **1-800-772-1213** or at **1-800-325-0778** (TTY) if you're deaf or hard of hearing. We can answer your calls from 7 a.m. to 7 p.m., week days. Or use our automated services via telephone, 24 hours a day. We look forward to serving you.



Securing today
and tomorrow

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