

Preparing Your Medical Record for Disability

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No one plans on becoming disabled. Even people with chronic diseases plan for and hope for a healthy future. They try to maintain a healthy lifestyle; they stay current with the latest, available treatments.

Yet, no one knows what the future will bring. Although everyone should consider alternatives if the future holds problems, persons with a chronic conditions such as hepatitis C have a special need to look ahead and prepare for alternatives. They should consider carefully in advance at what point, if their disease progresses in such a way, they would prepare to stop work and file for disability.

In addition to knowing what benefits are available should disability arise, there is one other thing you should be doing – just in case. And that involves your medical records.

Whether it is a private disability insurance company or Social Security, disability is virtually always determined by a review of your medical records. Only rarely are you asked to take a physical exam from what they call an “independent” physician who is truly “independent.”

Transitioning from work to disability is a major life event with all the confusion, frustration, and emotional upheaval such events can bring. Being awarded disability benefits can also be a challenge. Sixty per cent of initial applications for Social Security Disability are rejected. Insurance companies don't release their numbers, but it is probably not much better considering they are profit-making organizations that have to account to stockholders for the level of their profits.

Therefore, it is very important that your medical records be thorough and complete, and now is the time to start getting your medical record into a shape that will support disability, if and when it is needed.

This is not going to happen without your participation. The tendency in modern healthcare is for medical records to be heavy on testing, diagnosing, and treating. Due to the limited amount of time doctors spend with their patients, and the predetermined entries in electronic medical records, there is frequently little information on your symptoms, including their severity and frequency or your quality of life, or lack thereof.

There are items that should be in the medical record in order to be approved for disability that are not always included:

Objective Symptoms are symptoms that can be measured in a laboratory or otherwise confirmed objectively. While blood tests may measure viral load, immune response, and multiple other measurements, they do not directly relate to current symptoms.

Unfortunately, most of the symptoms of a person with HCV are “Subjective Symptoms.” However, there may be tests that are not normally part of the tests regularly performed that may provide some evidence or help objectively to explain why certain symptoms are present. The record also rarely describes what symptoms are related to which lab result. That should be spelled out in the record as claims examiners do not usually seek out such connections.

If and when your condition progresses towards cirrhosis, more symptoms will develop which can be measured by laboratory tests or clinical observation by the physician; but you do not have to be at that stage before you are physically and mentally unable to continue working. Subjective Symptoms alone may be disabling.

Subjective Symptoms are symptoms that tend to be self-reported or observed by the physician and not measurable by a lab test. The primary subjective symptoms experienced by persons dealing with HCV can include:

- Headaches
- Night sweats or fevers
- Insomnia
- Depression
- Brain fog
- Feeling very tired, fatigued, or lethargic
- Joint and muscle pains
- Nausea or poor appetite
- Stomach pain
- Itchy skin
- A yellow discoloration of the skin and whites of the eyes, called jaundice
- Abnormalities in urine or bowel movements

Some of these symptoms are “indirectly” documented by certain readings on lab tests or as side effects of the medications being prescribed; but, again, claim examiners usually do not have the time or the training to make such connections unless spelled out in the record. Those symptoms affecting you should be noted in the record even if this is repeated every office visit.

Symptom Diaries are logs, usually kept daily or weekly, that the patient maintains. If, for example, fevers are a symptom, taking the temperature several times a day at regular intervals and recording it can support that. Activities cut short, canceled, or avoided due to fatigue can be entered as well as pain with its location, frequency, and severity.

NOTE: Many with HCV have been dealing with it for several years. When observing your symptoms, do not compare them to yesterday or last month. Spend some time remembering what your life was like well before infection. It was probably a lot different than it was last month. Think of the things you used to do without a thought that you would not consider attempting now. Also, think back to all the accommodations you

made due to your condition: What short cuts or easier methods have you adopted to make life easier for you? Any changes should not automatically be attributed to aging.

Clinical Observations are your doctor's (and nurse's) observations while meeting with you. He or she may observe symptoms or results of symptoms as well as how you appear. In addition to looking for signs of fatigue or jaundice, the doctor may also observe changes in your posture, gait as you walk, your mood, attentiveness, and other factors that can help confirm some of your subjective symptoms. These observations should be noted in the file.

Other medical conditions frequently accompany HCV. Whether it is Fibromyalgia, Major Depression, or HIV, they should be included in the medical records used to claim disability whether from the same treating physician or another doctor.

Restrictions and Limitations are the effects of your symptoms on your ability to function. Restrictions are activities your doctor believes you should not do at all. Limitations are activities you should do only with limits. The specific restrictions and limitations should be noted along with itemized justification for them.

Listing of Impairments, by the Social Security Administration, is the best tool to use when applying for Social Security Disability and can be helpful with private disability plans as well. This booklet lists specific events, diagnoses, and laboratory tests, which they believe are sufficient to qualify for disability.

The listing for HCV is located under "Digestive Disorders – Chronic Liver Disease" which is found at http://www.ssa.gov/disability/professionals/bluebook/5.00-Digestive-Adult.htm#5_05. There is a long list of conditions that will support disability. If you have any of those conditions, they should be clearly noted in the medical record along with any lab tests or supporting evidence. Also, note the various explanations at the beginning of that chapter. They explain how Social Security defines or measures the various conditions in the listing.

Talk to your doctor

Now you know what should be in your medical record to demonstrate disability. How do you discuss this with your doctor(s)? Not all physicians are going to welcome this discussion, and what is being recommended here may be somewhat idealistic, but you won't know how successful this will be unless you try.

This is probably not going to be easy. Doctors do not have a lot of extra time, and do not like to deal with insurance companies. But, remember, it will benefit both you and your doctor in the long run if everything is in the record and your doctor doesn't have to deal with repeated requests for more information later.

Remember a doctor is focused on treating you and your condition, not preparing for disability so, in most cases, you will be asking him or her to maintain your record differently than is probably customary.

The next time you see your doctor, ask if you can discuss your medical record and what is going into it. If a doctor says there is no time, ask for a separate appointment or try to have this discussion with the doctor's lead nurse.

You may want to go to the appointment early and ask if you can take a look at your medical record while waiting to see the doctor. You may determine that the record is more complete than might be expected or find areas you want to emphasize with the doctor.

During this discussion, there are several points you want to make:

- While I am doing fine now, I realize that this condition may someday cause me to have to leave work and file for disability.
- I have learned that neither private insurance nor Social Security will accept your word without some documentation and the best documentation is the complete medical record.
- I believe that if we build a thorough medical record now that includes more than office notes and laboratory results, it will save both you and me time should we have to deal with insurance companies and/or Social Security.
- Would you highlight any objective symptoms you find and any subjective symptoms you discover through clinical observation? The insurance companies and/or Social Security may not connect the lab result with the symptoms unless it is noted in the record, and some of the subjective symptoms may have to be repeated every visit.
- Would you list and explain the reason for any Restrictions and Limitations in my activities that you recommend?
- If I bring you a Symptom Diary that I keep between visits, would you see that it gets entered into my record each time we meet?

While following these suggestions can make transitioning to disability easier and less stressful, be aware that, emotionally, such a close examination of your medical problems is not pleasant. Be aware of that. Better to deal with it in small doses over a period of time and avoid the frustration and stress of having to appeal denied claims.