A Guide to
HEPATITIS &
DISABILITY

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The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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# TABLE OF CONTENTS

1. Introduction .............................................. 2
2. What Is Disability Insurance, and When Are You Sick Enough to Get It? .......................... 3
3. What Role Does Your Doctor Play in Your Disability Decision and Application? ............. 7
4. What to Do before (and after) You Apply for Disability at Work .................................. 15
5. What You Should Know about Your Health Insurance before You Apply for Disability .......... 19
6. Disability Insurance Terms You Should Know .......................................................... 22
7. How to Buy an Individual Disability Insurance Policy ............................................... 27
8. How to Get Disability Coverage at Work
   When You Have Hepatitis B/C ........................................... 29
9. Introduction to Short Term Disability ........................................................................... 33
10. Tips for Filing for Disability ......................................................................................... 37
11. Introduction to Long Term Disability ........................................................................... 41
12. Do You Qualify for Social Security Disability Insurance? ......................................... 44
13. How to Apply for Social Security Disability Insurance ............................................... 47
14. How to Answer the Daily Activities Questionnaire .................................................... 58
15. How to Help Your Social Security Claim through the System ..................................... 62
17. How Social Security Monitors Your Disability ............................................................ 70
18. How to Appeal if Social Security Denies Your Claim .................................................. 72
19. How Medicare Assists Social Security Disability Recipients ....................................... 76
20. Medicaid: Why You Need It, Despite the Bureaucratic Challenges ............................... 82
21. Helpful Disability-Related Websites ............................................................................ 93
22. Directory of State Medicaid Offices ........................................................................... 96
The majority of people infected with hepatitis B or hepatitis C lead normal healthy lives. However, some people will develop serious liver disease that will dramatically affect their quality of life. This could mean the loss of gainful employment and the inability to support themselves and their loved ones.

*A Guide to Hepatitis and Disability* is meant for anyone affected by hepatitis B or hepatitis C including patients, loved ones, advocates, medical professionals and others. This “guide” is intended to be a valuable tool in helping people advocate for themselves or in advocating for others who have hepatitis B or hepatitis C.

Be forewarned that this is a very dense and extensive document about disability. At first it might seem overwhelming, but after you read and study it in detail you will find that it is one of the best advocacy tools at your disposal. A simple strategy for getting as much out of this guide as possible is to read the entire document from front to back. Don’t be concerned with retaining the information – just familiarize yourself with the content and terminology. After you read the guide from front to back, start reading and studying the chapters one at a time. Take extensive notes and refer back to your notes when you are researching disability issues.

It is important to remember to involve a care-giver or advocate in the process of learning about the disability process. Unfortunately, by the time that someone files for disability his or her physical and cognitive abilities might be impaired to the point that he or she may be unable to follow the necessary steps or procedures needed to file for disability. This is where a loved one or an advocate can help with the process of filing for disability.

Many people have a notion that filing for disability is a mysterious process; but, as you will find out after reading the guide, the process simply requires that certain steps (forms, records, etc.,) be followed. This document will discuss the necessary steps and procedures you will need to follow in order for your disability claim to be approved.

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1. INTRODUCTION

If you have hepatitis B or C, you may need to take a few weeks or months off or stop working altogether because symptoms from your infection or side effects from treatment have become so disabling.

If you do not work outside the home, you may still require financial assistance because fatigue and other symptoms related to your infection are hindering your ability to function and perform daily household tasks.

There are a number of employer- or privately-funded disability insurance programs and government programs available that can pay you a percentage of your salary – or provide financial assistance – if you cannot work or function because of hepatitis B/C.

If you need to take just a couple of weeks off work, you may use sick time. But if you need more time, you may qualify for short-term disability coverage. This disability insurance will subsidize you if you need a few weeks or months away from work.

If you require a longer period away from work, you may qualify for long-term disability coverage.

If you are self-employed, or if your employer doesn’t offer disability insurance, you may have purchased an individual disability insurance policy. This disability insurance coverage provides benefits similar to employer-funded disability insurance if you become disabled.

If you are not working, the Social Security Administration’s disability program provides two programs to people who cannot work because they have a medical condition that is expected to last at least one year or result in death.

The Social Security Disability Insurance program pays benefits to you and certain members of your family if you have worked in the past and paid Social Security taxes. The Supplemental Security Income program pays benefits based simply on your financial need if you are disabled.

Social Security also offers some healthcare assistance programs to people who receive its disability benefits. These programs are all different, and you may be eligible for them now, or in the future.
If your need for financial help is immediate – or if you think you may need to take time off in the future – it helps to educate yourself about these programs. You may find it makes sense to purchase additional coverage if you think you may need it one day.

What follows is a step-by-step guide to disability, and how you can help yourself.

2. WHAT IS DISABILITY INSURANCE, AND WHEN ARE YOU SICK ENOUGH TO GET IT?

You go on disability when you can’t work, right? Unfortunately, the answer’s not really that simple. It’s easy when something immediate and major happens, like getting hit by a bus, for example. If you break both legs and your job involves walking, the answer’s easy: it’s time to file for disability. If you’re a surgeon (or basketball star) and you break a finger, the answer’s also easy: you’re disabled.

But what if it’s not that simple?

- What if your hepatitis B or C symptoms come and go, or gradually become more troublesome?
- What if it is the side effects from your pegylated interferon and/or antiviral treatment that are disabling you, rather than symptoms directly resulting from liver damage?
- How do you recognize when you can no longer work even though you were able to work the day before?
- And what if your symptoms are subjective, involving pain and fatigue, as is often the case with viral hepatitis?
- What if your medication causes mood swings that make it difficult to deal with others, or make working under pressure virtually impossible?

• **When Is It Time to Stop Working?**

Timing is important. You really shouldn’t leave when your symptoms are too minor to qualify for benefits, but you really don’t want to wait until you have no quality of life remaining. Also, the process of transitioning from work to disability involves more than a little paperwork and planning, so you don’t want to wait until you are unable to function at all to leave work.

• **Is It up to Your Doctor to Decide When You’re Disabled?**

You might think your doctor will be the best judge of when you should stop working. But
doctors are individuals, and they all have different views and ideas of when a patient should apply for disability. Some will support your taking a leave from work whenever you want to, but other physicians resist ever putting a patient on disability, probably out of concern that it will hasten his or her decline.

Here are some questions to ask:

- Is your doctor familiar with your employer’s definition of disability in your disability insurance policy so he or she will recognize when the time is right for your policy to pay benefits?
- Does your doctor understand how Social Security determines disability? As good as doctors are at treating medical conditions, they are rarely aware of the current details involved in the process of leaving work on disability.

Your doctor indeed plays a vital role in your decision. If your doctor won’t support your decision that you are unable to work, then you will have trouble obtaining disability benefits because you need your doctor to confirm and document your debilitating symptoms. **Bottom line:** you will not get disability benefits without your doctor’s support so make sure you talk to your doctor frequently about your symptoms and about taking time off work. Find out his or her philosophy about disability and knowledge about the application process.

**When Is It time? The Emotional Analysis**

“I’ll know when it’s time to leave.” That sounds very comforting, but it isn’t that simple either. When you are dealing with a life event as major as stopping work and becoming “disabled,” there is frequently an emotional backlash that makes it very difficult to think and reason objectively. It’s not easy to recognize the “right” decision when your ability to think rationally is impaired.

Despite that, you are still the best person to decide upon the right time to leave work. You know how you feel; you know what your work involves and what it costs you physically and emotionally to continue working. If you can filter out the static and focus on the issues, then you’ll know when it’s time to leave.

First, organize your thoughts and put them on paper. Make a list of things you need to consider in making this decision (see below). Look over the list for a day or two and add other items as you think of them. Then, review each item. Does it support continuing to work or support leaving on disability?

What should go on your list? That is for you to decide, but here are some suggestions:
• Your doctor’s opinion AND your medical record – Your doctor will play a key role in obtaining disability benefits, but so will your medical record. Remember, insurance companies and Social Security rarely look at you, the person. They prefer to look at your medical records for proof that you are unable to work. How complete are your records? Do they reflect your condition? Do they list all the symptoms you are experiencing? Are they legible? Have the appropriate lab tests and diagnostic studies been documented in the file?

• At your next doctor’s appointment, ask him or her about disability, and, after the appointment, ask to take your record to an empty office and review it page by page. Look for comments about your limitations from both work and daily activities. Are frequency and severity of symptoms included? Play detective; how disabled would you believe you are from your medical records?

• How will you survive if you leave work disabled? What benefits are available to you? How much income will you have from Social Security and from Long Term Disability insurance? Can you live on that and pay your bills, or what changes in your lifestyle will have to be made? How will you maintain your health insurance and how much will it cost? It’s time to dig out those benefits books from work and start looking for answers to those questions. It’s also a good time to visit Social Security’s website and get an estimate of what you would receive from them. (www.ssa.gov)

• What price are you paying to keep working? Most people find work beneficial. It gives them a purpose, someplace to go, something to do, and even some social contacts in addition to providing income. When someone is slightly ill, work can actually be beneficial. It provides something to occupy the mind and time. It’s an incentive to get up and go.

• However, as an illness progresses and health declines, work takes more and more energy. There comes a time when work no longer helps you stay healthy, instead it accelerates your decline. It’s not always easy to know when that point arrives.

• What sometimes happens is that work will start to require more and more of your shrinking energy supply, you’ll need more and more time to recover from work in order to go back to work. You will find yourself starting to cut back on your activities outside work so you can save your energy just for work. If you find yourself dragging home after work and going to bed just so you’ll be able to get up and go back to work the next day, it’s past time to take a serious look at leaving work on disability.

Don’t leave out personal items that are important to you. This is the time to be a little selfish and put yourself first. This is your body, and possibly your life that you need to take care of. Now is not the time to worry how they will get along at work without you. Regardless of the importance of the work you do, no one is indispensable. They will
survive, and it’s time that you focus on your own survival.

Your family is also important, but remember people naturally resist change, so their input may be somewhat distorted. A major change like a spouse or parent stopping work full-time “to become disabled” is a scary change that many would rather postpone as long as possible. Again, don’t worry about them. They will be fine. Your family loves you, and, deep down, they really want what’s best for you.

It’s really up to you to do what is best for you, and with the right information you will make the correct decision.

• **What If Your Symptoms Are “Subjective”?**

Many of the most common symptoms of hepatitis infections, as well as side effects from treatment are subjective symptoms, including primarily pain and fatigue, but also loss of mental acuity, nausea, diarrhea, and others as well. This can complicate the disability benefits process because they are difficult, if not impossible, to clearly document.

Doctors are also just learning about the full scope of symptoms associated with viral hepatitis. The Social Security Administration has re-evaluated the symptoms related to hepatitis and has revised and expanded them to include some of these “subjective” symptoms.

Also, insurance companies and Social Security are constantly looking for “objective manifestations” of symptoms, which is difficult when the symptom can’t be measured in any lab test invented so far. Some insurance companies will discount subjective symptoms as if they don’t exist. A few have gone so far as to try to claim that “subjective symptoms can’t be considered in determining disability.”

One more reason that you’re the expert in knowing when it’s time to leave work is that you’re the only one who knows how badly the symptoms affect you. Everyone has different thresholds of pain and fatigue. What may be totally debilitating to your spouse may not seem so severe to you. You are the only one who can know when the symptoms reach the level that they interfere with your ability to function.

Although it sometimes seems that way, no one is asking you to work through an unbearable level of pain or discomfort. Remember, it’s not important how severe the symptom may seem to someone else, it’s the impact of that symptom on you that determines whether or not you can still work.

However, communicating the impact of those symptoms on you and your ability to work
will become an issue when you decide it is time to stop work and file for the benefits available to you. Planning ahead, knowing what you need to show, and making sure the documentation is in your records will help you decide just when the right time is for you to stop working and to start focusing on your health.

### 3. WHAT ROLE DOES YOUR DOCTOR PLAY IN YOUR DISABILITY DECISION?

In order to qualify for and obtain disability benefits from your employer-provided disability insurance program or the Social Security Administration (SSA), you must prove that your health problems are serious enough to prevent you from working and functioning normally.

- **Your Doctor Is Your Most Important Ally**

Your doctor or health care professional provides the most important evidence you need to convince an insurer or the SSA that you deserve disability benefits. Ultimately, it is the SSA or the disability insurance company that will decide if you are disabled, not your doctor. Therefore it is very important that your doctor provides documentation written in terms that reflect your medical condition while, at the same time, meeting the requirements of the insurer.

*Having a hepatitis B (HBV) or hepatitis C virus infection (HCV) is not enough to automatically qualify you for disability benefits. Often, years or decades may pass before people with hepatitis B or C experience debilitating symptoms related to liver damage.*

To qualify for disability, your hepatitis infection must have disabled you to such a degree that you are unable to work. To document and corroborate the progression and severity of your infection, your insurer or Social Security will consider medical and non-medical quality of life issues, but your doctor’s report will carry the most weight.

- **According to Social Security, acceptable health care providers include a physician, psychologist, or another acceptable medical source that has (or had) an “ongoing treatment relationship” with you and provided medical treatment or an evaluation (not just a report to support your disability claim). The treating source may be a health care provider with a clinical doctoral degree, such as an MD (Doctor of Medicine), DO (Doctor of Osteopathy), OD (Doctor of Optometry), or PhD (Doctor of Philosophy, e.g., a psychologist) as long as the impairment addressed is within his or her licensed scope of practice.**
A doctor may report an impairment related to mental illness, such as depression, even if he or she is not a psychiatrist, if it is part of the reasonable assessment the physician provides in the care of the patient.

Social Security also requests copies of medical evidence from hospitals, clinics, or other health facilities where you have been treated. All medical reports received are considered during the disability determination process.

A doctor who has treated you, preferably for several years, has a lot of credibility because he or she can provide a detailed, long-term view of your disability that would normally not be obtained from reports of individual examinations, brief hospitalizations or lab tests. Timely, accurate, and adequate medical reports from your treating physician strengthens your application and allows it to be more quickly processed.

Information from other sources, to support your claim that you can no longer function normally, can also come from public and private social welfare agencies, non-medical sources such as teachers, day care providers, social workers and employers, and other practitioners such as naturopaths, chiropractors, audiologists, and speech and language pathologists.

• What Your Doctors Must Provide

Physicians, psychologists, and other health professionals are frequently asked by SSA to submit reports about an individual’s impairment. Therefore, it is important to know what evidence SSA needs. Medical reports should include:

• Medical history
• Clinical findings (such as the results of physical or mental status examinations)
• Laboratory findings (such as ALT, viral load, liver biopsy results, ultrasounds etc.)
• Diagnosis
• Treatment prescribed with response and prognosis, and
• A statement providing an opinion about what you can still do despite your impairment(s) based on your doctor’s findings on the above factors. This statement should describe your ability to perform work-related activities, such as sitting, standing, walking, lifting, carrying, handling objects, hearing, speaking, and traveling. In cases involving mental impairments, it should describe the individual’s ability to understand, to carry out and remember instructions, and to respond appropriately to supervision, coworkers, and work pressures in a work setting. For a child, the statement should describe the child’s ability to function in an age-appropriate manner in the areas of functioning appropriate for the child’s age.
**Substantiating Symptoms**

In developing evidence about your ability to function and the effects of your symptoms, the insurer will scour your doctor’s reports about your:

- Daily activities
- Location, duration, frequency, and intensity of the pain or other symptoms
- Aggravating factors, such as the type, dosage, effectiveness, and side effects of any medication
- Treatments you are receiving, other than medications, for the relief of pain or other symptoms
- Any measures you use or have used to relieve pain or other symptoms, and
- Other factors concerning your functional limitations due to pain or other symptoms.

In assessing your pain or other symptoms, the insurer or the SSA must give full consideration to all of these factors. It is important that your healthcare providers address these issues in the reports they provide. Sometimes, doctors aren’t aware of the disability criteria required by insurers and the SSA. This is especially important in cases of hepatitis B and C, which are two infections whose symptoms and treatment side effects are just now being uniformly identified by doctors. Because these infections are so “new” to SSA and private insurers, you must make sure that your doctor has included a record of your symptoms in his or her charts, so they can mirror the “disability criteria” established by insurers.

“Trust and mutual respect are critical, as this process often requires the patient to reveal a detailed and painful history to fill voids in the medical record,” wrote doctors who authored a U.S. Department of Health and Human Services report entitled Documenting Disability: Simple Strategies for Medical Providers. ([www.nhchc.org/DocumentingDisability.pdf](http://www.nhchc.org/DocumentingDisability.pdf))

“Documenting disability, long the bane of the busy clinician and the overwhelmed patient, can become the cornerstone of a trusting therapeutic relationship that promotes patient adherence to the plan of care,” the doctors wrote. “[T]he clinical team should routinely document their patients’ medical impairments in office charts and medical records. Careful specification of medical disorders that meet SSA disability criteria and thorough documentation of functional impairments that result from disabling health conditions, observed over time, are essential elements of providing quality health care—especially for patients at highest risk of falling through the cracks in our fragmented health and social service systems.”
• What Hepatitis-Related Symptoms Qualify You for Disability Benefits?

Social Security and insurers have “Listing of Impairments” that show what symptoms and impairments you must have to qualify for disability. They are found in the Disability Evaluation Under Social Security, or “The Blue Book.” There are a set of requirements for children (up to age 17) and a set for adults, age 18 and older.

SSA’s Blue Book categorizes impairments by 14 body systems. Each body system has criteria or “listed impairments” that are severe enough to prevent an adult from doing substantial gainful activity. The “Blue Book” and the relevant listings can be found at www.ssa.gov/disability/professionals/bluebook/5.00-Digestive-Adult.htm#5_05

In the Blue Book, viral hepatitis and liver disease is found in the Digestive System list of impairments.

To Social Security, hepatitis B and C are relatively new disabling conditions and officials haven’t developed an organized approach to review and screen hepatitis claims. Also, hepatitis symptoms can vary from none at all to completely debilitating, so the diagnosis of hepatitis alone doesn’t have much impact in determining disability.

Unfortunately, many of the most common hepatitis symptoms are also “subjective,” in that they can’t be readily measured in a laboratory test. Examples are fatigue, headaches, memory loss, and depression. Therefore, medical records alone often don’t adequately describe the functional problems the applicant has trying to work.

For example, when SSA officials consider disability applications from people infected with HIV, they include symptoms that are not directly related to just the immune system. They also consider fatigue and pain; the impact of treatment on a person’s ability to work and function, and the person's ability to function socially, concentrate or complete tasks in a timely manner. Many doctors and patient advocates are now urging SSA to incorporate these symptoms in their “liver disease” guidelines and consider these impairments when evaluating disability applications from hepatitis B and C patients. Because of this, it is important that your medical records document these symptoms if you are experiencing them.

As of March 2005, these are the adult chronic liver disease symptoms that SSA will
A Guide to Hepatitis and Disability

consider disabling. They are found in Section 5.05 of the SSA’s Blue Book:
www.ssa.gov/disability/professionals/bluebook/5.00-Digestive-Adult.htm#5_05

5.05 Chronic liver disease, with:

A. Hemorrhaging from esophageal, gastric, or ectopic varices or from portal hypertensive gastropathy, demonstrated by endoscopy, x-ray, or other appropriate medically acceptable imaging, resulting in hemodynamic instability as defined in 5.00D5, and requiring hospitalization for transfusion of at least 2 units of blood. Consider under disability for 1 year following the last documented transfusion; thereafter, evaluate the residual impairment(s).

OR

B. Ascites or hydrothorax not attributable to other causes, despite continuing treatment as prescribed, present on at least 2 evaluations at least 60 days apart within a consecutive 6-month period. Each evaluation must be documented by:
   1. Paracentesis or thoracentesis; or
   2. Appropriate medically acceptable imaging or physical examination and one of the following:
      a. Serum albumin of 3.0 g/dL or less; or
      b. International Normalized Ratio (INR) of at least 1.5.

OR

C. Spontaneous bacterial peritonitis with peritoneal fluid containing an absolute neutrophil count of at least 250 cells/mm³.

OR

D. Hepatorenal syndrome as described in 5.00D8, with one of the following:
   1. Serum creatinine elevation of at least 2 mg/dL; or
   2. Oliguria with 24-hour urine output less than 500 mL; or
   3. Sodium retention with urine sodium less than 10 mEq per liter.

OR

E. Hepatopulmonary syndrome as described in 5.00D9, with:
   1. Arterial oxygenation (PaO₂) on room air of:
      a. 60 mm Hg or less, at test sites less than 3000 feet above sea level, or
      b. 55 mm Hg or less, at test sites from 3000 to 6000 feet, or
      c. 50 mm Hg or less, at test sites above 6000 feet; or
   2. Documentation of intrapulmonary arteriovenous shunting by contrast-enhanced echocardiography or macroaggregated albumin lung perfusion scan.
F. Hepatic encephalopathy as described in 5.00D10, with 1 and either 2 or 3:
   1. Documentation of abnormal behavior, cognitive dysfunction, changes in mental status, or altered state of consciousness (for example, confusion, delirium, stupor, or coma), present on at least two evaluations at least 60 days apart within a consecutive 6-month period; and
   2. History of transjugular intrahepatic portosystemic shunt (TIPS) or any surgical portosystemic shunt; or
   3. One of the following occurring on at least two evaluations at least 60 days apart within the same consecutive 6-month period as in F1:
      a. Asterixis or other fluctuating physical neurological abnormalities; or
      b. Electroencephalogram (EEG) demonstrating triphasic slow wave activity; or
      c. Serum albumin of 3.0 g/dL or less; or
      d. International Normalized Ratio (INR) of 1.5 or greater.

OR

G. End stage liver disease with SSA CLD scores of 22 or greater calculated as described in 5.00D11. Consider under a disability from at least the date of the first score.

If your medical condition meets one of these criteria, your claim should be approved provided it is well-documented in your medical records. However, it will help if your physician states the condition in a letter to Social Security, using terms and results as shown in the listing.

If your condition does not meet any of these criteria, all is not lost. It is still possible to have your claim approved if the symptoms you exhibit are as severe as one of the listings. Usually, however, more medical evidence will be required to get the claim accepted. In that case, you should make sure you submit all the medical evidence that you can with the application.

• Verifying “Fatigue” as a Symptom

Many people with chronic hepatitis B or C experience fatigue. However, fatigue is not one of the symptoms listed under SSA’s definition of chronic liver disease. Therefore, it is important there be an underlying diagnosis which supports the symptom of fatigue.

Among people with hepatitis C, the SSA-sanctioned diagnosis is frequently fibromyalgia
or chronic fatigue syndrome (CFS). Often, the symptoms of the fibromyalgia are more disabling than those of hepatitis.

Because the symptoms of fibromyalgia are subjective (not measurable by any lab test) and because there is no definitive test to diagnose fibromyalgia, it has been difficult to qualify for Social Security disability benefits. This has been an issue with both fibromyalgia and with chronic fatigue syndrome (CFS), also called chronic fatigue and immune dysfunction syndrome (CFIDS).

Although similar in symptoms, Social Security looks at each differently. In many cases, there will be an overlap of symptoms between fibromyalgia and CFS so that the distinction between the two is relatively blurred, but either can be considered as a “medically determinable impairment.”

For fibromyalgia, in the absence of any specific diagnostic test, Social Security recognizes the diagnostic criteria as set forth by the American College of Rheumatology. Under their guidelines, they will determine a diagnosis of fibromyalgia if there is documentation of both:

1. History of widespread pain which includes pain on right and left sides of the body and pain above and below the waist; AND,
2. Pain in 11 of 18 tender point sites on digital palpation, which means a force of 4 kilograms on the tender point is “painful” and not simply “tender.”

After a review of current medical information, Social Security has determined that they will consider both fibromyalgia and CFS to be “medically determinable impairment” provided there are appropriate medical signs or laboratory findings, and they have put out a bulletin to their disability examiners on what is needed to approve disability with that diagnosis. They have issued a Policy Interpretation Ruling on how they evaluate cases involving CFS. It can be found on Social Security’s website at: www.ssa.gov/OP_Home/rulings/di/01/SSR99-02-di-01.html.

Persons with CFS may not fulfill the requirements for a diagnosis of fibromyalgia but Social Security will consider CFS as disabling if the guidelines set forth in the ruling are met. To meet the Social Security criteria for CFS, one or more of the following medical signs must be clinically documented over a period of at least six consecutive months:

- Palpably swollen or tender lymph nodes on physical examination
- Nonexudative pharyngitis (swelling in the upper throat)
- Persistent, reproducible muscle tenderness on repeated examinations, including the presence of positive tender points, OR
- Any other medical signs that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record.

While there are no specific laboratory findings that are widely accepted as being associated with either fibromyalgia or CFS, certain laboratory findings may establish the existence of a medically determinable impairment in persons with CFS or fibromyalgia. Those laboratory tests include:

- Elevated antibody titer to Epstein Barr virus (EBV) capsid antigen equal to or greater than 1:5120, or early antigen equal to or greater than 1:1640
- An abnormal MRI brain scan
- Neuromediated hypotension as shown by tilt table testing or another clinically accepted form of testing, or
- Other laboratory findings that are consistent with medically accepted clinical practice such as an abnormal exercise stress test or abnormal sleep studies.

They will also consider mental symptoms as well in arriving at a “medically determinable impairment.” Some of the symptoms reported by people with CFS include short term memory loss, difficulty with information processing, visual-spatial difficulties, problems with comprehension, concentration, speech, word-finding, calculation and other symptoms pointing to ongoing neurocognitive impairment. When these symptoms are documented with neurocognitive evaluations, psychological testing and other mental status examinations, they may establish a “medically determinable impairment.”

**Depression and Anxiety as Symptoms**

Properly documented symptoms of affective disorders such as depression or anxiety may also establish impairment. It is important, however, that if there is a diagnosis of depression that there be some form of treatment either ongoing or attempted, such as therapy or prescribed anti-depressants.

Establishing a “medically determinable impairment” is only the first step in the disability process. Next it is necessary to determine the severity of the impairment. According to Social Security, the severity of an individual’s impairment is determined based on the totality of medical signs, symptoms, and laboratory findings as well as the effects of the impairment on the person’s ability to function.
It is difficult enough to establish the existence of subjective symptoms such as pain and fatigue; it can be even more challenging to show that the severity of the symptoms are sufficient to prevent performance of any meaningful work. The level of impairment(s) must be considered “severe” to be considered disabling.

This is where it is important that the physicians note the symptoms at each visit and include a brief notation as to level of severity. When visiting the doctor, describe an incident that illustrates the level of fatigue and insist that it be included in the record. All attempts at treating the fatigue should be well-documented even if unsuccessful.

In addition, a symptom diary may be helpful – a daily diary that records symptoms, their severity and their impact on the day’s activities. Any accommodations before leaving work, such as longer lunch hours, longer breaks, or reduced hours should also be documented.

When completing Social Security’s questionnaires, such as the Fatigue Questionnaire or the Daily Activities Questionnaire, it is important to note how fatigue has affected daily activities and the efforts made to ration energy.

Fatigue is never an easy symptom to document; however, careful notation in the medical records and multiple diagnoses of conditions that exacerbate fatigue will improve your chances of obtaining disability benefits.

4. WHAT TO DO BEFORE AND AFTER YOU LEAVE WORK DUE TO DISABILITY

Before you tell your supervisor that you need to take a leave of absence from work, it is important that you do some research to prevent any missteps along the way. You may not feel up to plowing through more paperwork and planning right now, but it is imperative that you know what benefits you can expect, and what you will need to do to obtain them.

**Step 1: Assemble and organize all your insurance and benefits documents**

You need to obtain current copies of all the “rulebooks” for all the employee benefits that you are covered by, even the ones you may not need immediately. They include the
Summary Plan Descriptions, another term for a complete summary of the plans for:

- Health, vision, and dental benefits
- Short term and long term disability benefits
- Leave of Absence Policy (This will tell you how long you will be kept as an employee once you leave work on disability)
- Group life insurance policy
- 401(k) or other pension plans under which you are covered

These can be obtained from your Benefits Department, or Human Resources Manager, or whoever handles benefits in your company. You don’t have to tell them you are planning to leave. If you are concerned that they will suspect something, simply tell them that you are doing some estate planning and your planner needs to know all your current benefits to get a better idea of what additional benefits you may need.

Step 2: Know your benefits

The main questions you need to ask, and get answers to, are:

- How long will you be on disability before your employment is terminated? This will tell you how long they will save your position for and maintain your benefits. Depending on the employer, it may be longer than the 12 weeks provided by the Family and Medical Leave Act
- What happens to your health insurance upon termination? COBRA, or is your company one of the few that will continue health coverage as long as you are disabled?
- What short term disability benefits are available from sick leave or short term benefits? Do you live in one of the five states that mandates short term disability (California, Hawaii, New Jersey, New York, Rhode Island)?
- When do long term disability benefits start and how much will they pay?
- Is there a period between sick leave and short term disability, and the start of long term disability, that you will be without income?
- Does your life insurance have a Disability Waiver of Premium benefit that will continue the coverage without premium payment as long as you remain disabled?

Step 3: Set the date for your leave

Work with your doctor and identify an appropriate date for you to leave work. Make sure that you see the doctor again on or about the time you leave or announce your intention to take a leave due to disability to your employer so your medical record will match your actions.
Step 4: One to two weeks before you plan to leave work, notify your employer

Tell your employer, “My doctor has said I must take some time off,” and ask what documentation is needed. It is recommended that you tell this to the highest level person in your Human Resources Department with whom you feel comfortable, not your immediate supervisor.

You should not announce your intention more than a few days to a week before leaving, never more than two weeks. Remember, you are not leaving by choice. Your health problems require you to leave.

If pushed to give your diagnosis in the interview, and you are not comfortable doing so, you can divert it by saying, “That will all be in the paperwork.” If they are persistent about a diagnosis, you may want to ask, “Who besides you will need to know my actual diagnosis? I really don’t want it spread all over.” If you are dealing with a high-level human resources official, he or she will know the confidentiality laws about disclosing your condition and will be more likely to abide by them.

When asked when you plan to return, be vague: “The doctor says at least four to six weeks, possibly eight to ten weeks.” Keep it below the 12-week limit in order to qualify for the Family and Medical Leave Act.

Step 5. Request all the paperwork

You will need some paperwork to start the process, including:

- A Family and Medical Leave Act claim form (this may be combined with a short term disability form)
- Short Term Disability claim form
- State Disability claim form if you live in New York, Rhode Island, New Jersey, California or Hawaii
- It is not necessary to request the long term disability or other forms needed for a longer disability yet

Confirm whether your payroll deductions that cover your portion of the benefits will be taken from the short term disability payment or if they must be paid by you directly to the employer. Note especially how you can continue to pay for the supplemental life insurance if you have it.

It is a personal decision whether to tell your immediate supervisor directly. If you feel you must tell him or her personally, don’t divulge or discuss the diagnosis or actual time
you expect to be out.

Step 6: Immediately upon stopping work do the following

- File for benefits. Complete claim forms and submit them. If possible, have the employer and doctor return their completed portions of the form to you so you can file them in one package and track it to make sure it is received.
- Pay for your portion of the benefits. Make arrangements with payroll to pay your portion of insurance if they are not going to be withheld from your short term check.
- Stay in touch. Ask human resources or a payroll person how often they need to hear from you while you are out.

Remember: As far as they know, you are leaving for a brief period and will return.

Step 7: Six weeks after last day worked do the following

1. Extend your disability. Notify human resources that the doctor does not feel you are able to return yet. Request:
   - Paperwork to extend your medical leave to its maximum. If asked about permanent leaving, simply tell them the truth, “I hope not, but my doctor can’t comment one way or another. It’s clearly not resolved yet.”
   - Confirm how long you will be kept as an employee before being terminated (along with your benefits and job protection), “just in case” you are disabled that long.

2. Get the appropriate claim forms. Now is the time to collect all the claim forms you will need for the extended disability, including:
   - Long term disability claim form (“just in case”) – This assumes a three- to six-month elimination period before long term disability benefits start.
   - Claim form for Life Insurance Waiver of Premium.
   - Paperwork to access 401(k) funds (“just in case”)

Step 8: Six to eight weeks before long term benefits will start, file for long term disability benefits

Complete claim forms and submit them. If possible, have the employer and doctor return their completed portions of the form to you so you can file them in one package and track it to make sure it is received.

Step 9: Two to Four months after last day worked, file for Social Security Disability benefits
Step 10: When your employment is terminated, do the following:

- Confirm COBRA Notice and/or when COBRA notice will be sent
- File for Life Insurance Disability Waiver of Premium
- Request disbursement of retirement fund if needed. Some people may prefer to postpone this since the fund continues to earn interest. Also, an award of Social Security disability benefits is generally considered to be sufficient proof to the plan administrator and IRS that you are exempt from any early withdrawal penalties or reduced vesting.

5. WHAT YOU SHOULD KNOW ABOUT YOUR HEALTH INSURANCE, NOW

If your hepatitis B or C infection is starting to cause disabling symptoms, you should take some time to familiarize yourself with your health insurance coverage – if you haven’t already.

Dealing with health insurance and how it covers your medical bills can be complicated and stressful, but you cannot ignore it. You may have an Indemnity or Preferred Provider Organization (PPO) Plan that pays medical bills after they are incurred. Or you may be covered under one of the many varieties of Health Maintenance Organization (HMO) Plans that “pre-authorize” certain treatments and disallow others.

However, under either type of health plan, problems can arise depending on how the claims are handled. Unless caught early, these problems can mushroom into major financial and legal dilemmas and affect your medical care and your health.

It’s tempting to ignore the whole medical payment process and assume that the insurance company and the doctors are handling everything satisfactorily. However, a rude awakening awaits you if your insurer decides to reduce or deny coverage of a costly medical treatment or procedure. It is also possible that your HMO doctor will suddenly discover that some of the treatments he or she recommended were not approved by the “HMO Committee.”

Whether it is a claims payment or pretreatment authorization, most billing and pre-certification communication between a doctor and the insurance company is done in codes, and one misplaced digit can have a huge impact on what is allowed or how much is paid. It is important to catch those small errors early, and you, as the claimant,
are the best person to do it.

You do not have to become an insurance expert to monitor how your insurance company is processing the medical bills you are incurring. But at the very least, you can get minor errors corrected quickly; at worst, you will build a solid file of documentation that will save the attorney or benefits counselor you hire a lot of billable time. It will take some time and energy on your part to understand how the process works and how you can best manage it, but it will be well worth the effort.

**Step 1: Know your coverage**

Easy advice to give, but this is often the biggest challenge in managing your coverage. Insurance contracts are scary. They’re difficult to understand and they don’t make a lot of sense unless you’re a lawyer. But you don’t need to memorize your plan or know every single provision to understand how the plan works and how it pays your medical bills.

First, get a copy of your coverage. It may be an insurance policy, a booklet of coverage, a Summary Plan Description, or a chapter in an employee benefits manual. However, a paragraph or two in an announcement, or even a two-page overview in the enrollment material, is not sufficient for your needs. A complete description of your health plan will probably cover 20 to 30 pages or more.

If your health plan comes through your employer, your company is required under a federal law called ERISA to provide you with a Summary Plan Description of all of your benefit plans. If you have misplaced your copy, request another one from your Human Resources or Benefits Department.

If you’re concerned about raising suspicion when you ask for a summary of your health plan, just tell your employer that you are doing some financial planning with an insurance agent or planner, and they need the information for their analysis.

Don’t try to sit down and read your plan all the way through. That would put anyone to sleep. But, look through it. Note the different parts. There is usually an overview or Summary of Benefits at the front that will give the details of your specific plan, including what the dollar amounts are. Then there will be sections that describe different provisions of the plan.

Don’t try to understand and remember everything in every section. Just get familiar with where things are so you can find specific sections as you deal with the insurance company.
Things You Should Try to Find Are:

- **Schedule of Benefits**: This is often at the front of the plan. It’s the part that explains what the insurance company pays and what you pay. It lists the deductibles, the insurance percentages they pay, and the co-pays you are expected to pay at each doctor’s visit, etc.

- **Covered Benefits**: Often separate from the schedule of benefits, this will be a listing of what is covered. In some plans this will be a fairly long list; others will give a short list of a broad range of benefits covered. This section will also give greater detail about what and how things are covered.

- **Definitions**: There is usually a separate section that defines terms used in the plan. If your plan has one, watch for words throughout the plan that are capitalized, italicized, or in bold, as that usually means it is a term that has a special meaning and is defined in the definitions section. Other plans will define terms throughout the document as the terms are used.

- **Exclusions and Limitations**: This lists the things that the plan will not cover such as, experimental treatment, or cosmetic surgery. It also lists the things that it will cover but puts special limits on, such as mental health, or convalescent home care, or treatment for conditions that existed when your coverage started, pre-existing conditions. You may want to paperclip this section, as you may need to refer to it more frequently.

- **Eligibility**: This is important if you are a relatively new employee as it tells just when your coverage actually begins. A similar section, usually in a different part of the book is the Termination of Coverage that describes when coverage ends. This section will usually include a description of how to extend coverage under COBRA and possibly other means.

- **Claims Procedures**: This will be a couple of pages that describes the claim filing procedure. The important section here is the part that tells you how to appeal denials. You may want to read that through, as there are usually some important time limits and other information there.

Don’t be afraid to mark up the book. This is the rulebook that your insurance company must play by so don’t hesitate to use paperclips, sticky notes, “dog ears,” highlighting, underlining, margin notes or any other notations to make it easier for you to use. Gummed tabs that label important sections are especially helpful.

Once you understand the plan’s different parts, you can focus on the part that fits your particular situation and learn what the plan does and doesn’t do. The abstract descriptions of each provision may not seem very helpful at first glance, but you will find it valuable as you work with the insurance company and your medical provider when there
are claims questions. The information in this book contains the grounds for their denial or cutbacks. To put it in sports terms, it is the rulebook and you’re at a disadvantage trying to “play” without knowing these rules.

How you monitor your medical claims depends on your type of health plan. If you have coverage through an Indemnity Plan or a Preferred Provider Organization (PPO) Plan, the insurance company will process the claims and pay their portion only after you receive treatment.

With these plans you will receive an Explanation of Benefits (EOB) every time your insurer processes a medical bill. Review each EOB carefully. Was everything “allowed” in full even if only a percentage was paid? If not, a code by the charge should lead to a reason for the denial or reduction.

If it is not clear, call and ask for an explanation. There will usually be a toll-free number on the EOB. Make a note of whom you talk to and what they say. Don’t be bashful about asking for clarification. Follow the appeal procedures to challenge their decision, if you disagree. Ask for your doctor to help you with the appeal.

For Health Maintenance Organization (HMO) Plans, most of the claims work is done between your doctor and the HMO and consists of authorizing treatment before it is given, not in paying the bill after the treatment is received. Learn about your medical condition. Know what alternatives to treatment are available.

You need to spend some time with your doctor (or your doctor’s insurance clerk) to understand when and what has to be pre-authorized by the HMO. How successful are they in obtaining approvals? How often are they denied? Can you be notified of denials and participate in the appeals?

Health insurance is not maintenance-free. It can’t be just “turned on and forgotten.” Just as you must take an active role in your health care and treatment as a patient, you must also stay alert and active as an insured individual with respect to how your medical care is authorized and paid for.

6. DISABILITY INSURANCE TERMS YOU SHOULD KNOW

The purpose of disability insurance is to replace a portion of your salary if you are unable to work due to medical problems related to hepatitis B or C. As you may know, disability coverage is a benefit often offered by your employer, or you can purchase
an individual disability insurance policy if you are self-employed or are not covered through work.

You may have access to two types of disability insurance, long term disability and short term disability. A description of these benefits is often provided when you are enrolled in those programs.

It is important that you know what your company offers, and specifically what benefits your disability insurance coverage provides. Although it is not necessary to read and understand every word in your disability insurance policy, there are some basic provisions that you should be aware of. The provisions below are all part of an employer-provided long term disability (LTD) policy. Individual policies will have similar provisions except where noted.

If you don’t have a copy of the paperwork describing your disability insurance programs, ask for a copy of them from your human resources officer.

**Summary Plan Description:** Under federal law (ERISA), an employer is required to provide you with a copy of the Summary Plan Description (SPD) of the disability insurance plan when you enroll in the program, and also upon request. That SPD will have virtually all the provisions of the coverage listed in it.

**Eligibility:** Employers usually make long term disability coverage effective for all eligible, active, full-time employees upon completion of their initial probation or waiting period, which is usually one to three months after date of hire.

Eligibility ends when employment ends, usually the very same day or occasionally to the end of the month. As long as a person becomes disabled while eligible for coverage, it makes no difference if coverage is later stopped; disability benefits will still be available.

An individual policy becomes effective on the Policy Date and remains in effect as long as the insured continues to pay premiums.

**Total Disability:** A long term disability income policy pays benefits should you become totally disabled, which begs the question: how do they define total disability? The policy will always define “total disability.” It is important that you read and understand the contract’s definition of disability.

Generally, a plan will have two definitions of total disability: “own occupation” and
“any suitable occupation.” Most group policies use both definitions. They apply the “own-occupation” definition during the first two years of disability, and apply the other after you’ve been disabled for two years. Some older, individual policies will use “own occupation” for the entire length of the claim.

Own-Occupation: Under an “own-occupation” definition of disability, you are considered to be totally disabled if you are unable to perform the material duties of your own occupation.

For example, if you are a switchboard operator and have polyps removed from your vocal cords, you are totally disabled because you can’t speak on the telephone, and that is clearly a material duty of your own occupation. On the other hand, if you are a typist and occasionally cover the switchboard when the operator is at lunch or on breaks, you can still perform the “material” duties of your own occupation and would not be able to get benefits under this definition.

Any-Suitable-Occupation: Under an “any-suitable-occupation” definition of disability, you are totally disabled if you are unable to perform the material duties of any occupation for which you are reasonably suited by education, training, or experience. As you can imagine, it is harder to be considered disabled under this definition than under an “own-occupation” definition of disability.

An example of being disabled from performing your own-occupation, but not any-suitable-occupation, is the surgeon with arthritis in her hands so that she can’t perform surgery, but is capable of teaching or consulting on surgery.

Elimination Period: The elimination period is the period of time between leaving work on disability and the start of benefit payments to you. Unless there is income from another source during that period, such as sick leave or short term disability, you will have no income at all until the elimination period is over.

Many employers will have a 90-day waiting or elimination period. Some may offer shorter periods. Others, especially those in states that have mandatory short term disability plans, may have an elimination period of six months or longer.

Benefit: The benefit or amount of money you’ll receive under group Long Term Disability plans is a percentage of your salary at the time of disability, with a maximum cap. A typical plan reads: a benefit in an amount equal to “60% of your Basic Monthly Earnings to a maximum monthly benefit of $5,000.” Individual policies have a benefit that is a flat dollar amount, such as $2,000 per month, rather than a percentage of salary.
at time of disability.

**Basic Monthly Earnings:** Each plan defines the earnings on which the benefit is based. Generally, the earnings on which the benefit is based is your gross (not your take-home) salary at the time you become disabled. The definition will also state whether Basic Monthly Earnings include overtime, commissions, bonuses, etc., although generally they are not included.

**Offsets:** Group Long Term Disability Plans will not pay full benefits if there are other disability payments being made. These are called “offsets” or simply “other income.” Only income listed in the policy can offset LTD benefits. Income sources that can offset LTD payments generally include:
- State mandated disability payments
- Social Security Disability Insurance (SSDI) which you are receiving and other government disability benefits
- Disability payments from a pension or retirement plan, and
- Disability payments from another group LTD policy

*For Example:* The plan pays 60% of salary and your monthly gross income is $3,000 per month. 60% is $1,800 but the plan will subtract your SSDI payment of $1,000 so, while you will receive 60% of your salary in total, only $800 will come from the LTD plan.

**Minimum Monthly Benefit:** There will almost always be a minimum benefit an LTD Policy will pay despite any other income you receive. It is usually either a flat amount such as $50 or a percentage such as 10% of your normal benefit but not less than $100. Individual policies do not offset their benefits. You receive the full dollar amount of the policy over and above any other disability income you receive.

**Maximum Benefit Period:** The Maximum Benefit Period is the longest period during which benefits will be paid. The typical period is “to age 65” although some plans will only pay for five years or other limited periods. Many plans will show a schedule for maximum benefit period such as:
- Claims starting before age 60..............to Age 65
- Claims starting when age 61.................4 years
- Claims starting at age 62......................3 years
- Claims starting at age 63 or later...........2 years
Many plans are now paying benefits to “Normal Retirement Age” because Social Security retirement is slowly increasing to age 67.

**Limitations:** There are some limitations inserted in some disability packages for certain disabilities.

- **Mental and Nervous:** Most plans limit the Benefit Period if the disability is due to a mental or nervous disorder. The plans typically pay such claims only for twenty-four (24) months.
- **Subjective Symptoms:** Some plans limit to 12 or 24 months the benefit period for claims that are solely due to “subjective” symptoms such as fatigue or pain or “soft-tissue” damage. It should be noted that this limit will not apply if there is an underlying, organic cause for the symptoms, such as hepatitis B or C.
- **Pre-Existing Condition Provisions:** A major provision for newly hired employees is the exclusion for disabilities caused by a pre-existing condition. Every employer provided LTD policy will have such a provision. Each pre-existing condition provision will include two time periods: a “look back period” and a “pre-existing condition waiting period:”
  - **Look Back Provision:** This provision defines which conditions are considered to be “pre-existing.” Typical wording is something like: “A condition for which medical treatment or advice was rendered, prescribed, or recommended or medications taken within the six months prior to effective date of coverage.” Ninety days to six months is the norm for a look back period.
  - **Pre-Existing Condition Waiting Period:** This is the period of time you must be covered before a pre-existing condition, as defined above, will be covered. It is usually one year, but can be longer depending on the plan.

**Example:** Your plan has a Look Back Period of six months and a Waiting Period of 12 months. You are being treated for hepatitis C and you see the doctor every three months. Because you had medical treatment in the six months before the coverage started, the plan will not cover a disability related to hepatitis C if you stop work due to a hepatitis-related disability during the first 12 months of coverage. If, however, you go out on a hepatitis-related disability after that, the plan will pay full benefits.

**Other Exclusions:** All plans have exclusions and limitations beyond the Pre-Existing Conditions Exclusion and the Mental and Nervous Limitation. They usually include disability due to:

- Declared or undeclared war
- Injury incurred while participating in the commission of a felony
- Work-related injury
- Substance abuse – although some plans will pay benefits provided the claimant is participating in an approved treatment program
- Self-inflicted injuries

**Income Taxability of Benefits:** Whether or not your benefits are subject to federal and state income tax depends on how the premiums were paid. Under those rules, either the premium or the benefits will be subject to income tax, but not both. Generally, this means:

- If the employer pays for the Long Term Disability plan, any benefits you receive will be income taxable
- If you pay all the premiums with after-tax dollars, the benefits are not-taxable. If you pay the entire cost yourself either directly or through payroll deduction with dollars that will be included in your W-2, then the premiums are paid with after-tax dollars so the benefits are not taxable
- If you pay a part of the premiums and your employer pays the remainder, you will only be taxed on the portion that your employer paid – in the same proportion as payment for the premiums. For Example: If your employer pays 70 percent of the premium and you pay 30 percent through payroll deduction, then 70 percent of each benefit check will be taxable and 30 percent won’t

Group long term disability plans and individual disability income policies can be instrumental in supplementing other disability income that helps a disabled person and his or her family maintain some quality of life economically. But they are all legal contracts that need to be understood prior to accessing them. Understanding these policies should be an important part of your pre-disability planning.

### 7. HOW TO BUY INDIVIDUAL DISABILITY INSURANCE

If your employer does not offer disability insurance coverage, or if you feel your company’s group disability policy does not provide adequate coverage, you may want to consider buying a short term or long term individual disability policy.

You can buy this through financial planners or from the same agents who sell life insurance or annuities, or, more rarely, though, auto and homeowners insurance agents. If you choose to buy it individually, the cost may be five to 10 times higher than the cost of a group policy, depending on your age, occupation, and annual income. You must
take a medical exam to prove your insurability.

Individual disability pays you a flat amount each month, and most often you will not be paid more than 80 percent of your current salary. The insurance company examines your occupation, income, and other sources of insurance when determining whether it will cover you, and what your premium will cost. When it determines your rate, the insurance company places you in a rating class with people who have similar characteristics such as age, occupation, medical condition, and income.

Most policies are sold on a “non-cancelable” or a “guaranteed renewable” basis. Non-cancelable means that after you take a medical exam and the insurer issues the policy, the insurer cannot cancel the coverage or raise your premiums. If you buy a policy solely on a guaranteed renewable basis, the insurer cannot cancel the coverage as long as you pay premiums. However, the insurer can raise rates if you are part of an insured group that experiences a high number of claims.

Generally, you can buy policies that will cover you for two years, five years, or until you reach age 65. Most individual policies also have features that allow benefits to keep pace with inflation or gradual salary increases, such as a cost of living adjustment, which adds a percentage to your coverage each year.

Though disability insurance can be costly if you buy it on your own, many planners say it is an essential part of a person’s financial plan.

The top 10 long term disability insurance companies, based on their sales in 2009, are:

- Hartford Life
- MetLife
- Standard
- Unum
- CIGNA
- Reliance Standard
- Aetna
- Sun Life Financial
- Prudential
- Lincoln National
It is important if you have hepatitis B or C to get the best health insurance and disability insurance coverage through your employer in the event that you ever need this critical financial assistance. But because you may have a “pre-existing medical condition,” it is important to know when it’s best for you to sign up for this important benefit.

- **Short Term Disability Programs**

When your company begins a new disability insurance program, there will be an initial enrollment period. This is the first time you are eligible to enroll in the group’s benefits programs. During this period, your medical history is not subject to review.

However, once enrolled, if you have a pre-existing medical condition, it may delay coverage for six to 12 months. A pre-existing condition is defined as any medical condition for which “medical care” was received three to six months prior to the date when coverage began.

Your employer’s short term disability (STD) plan may have a pre-existing conditions exclusionary period. During this period of time, your pre-existing medical condition will not be covered by the policy. However, after the pre-existing exclusionary period expires, your hepatitis B or C infection will be covered under the STD plan.

Also, during certain times of year, employees offer an “open enrollment period,” during which, you can sign up for additional benefits, including disability insurance. The federal government calls this enrollment period “open season” for federal employees.

In many cases, rules and limits on enrollment (such as pre-existing conditions) are set aside during this period and employees are allowed to make changes in their health or disability insurance. For persons dealing with a serious medical condition such as hepatitis B or C, this is a great time to review and change disability insurance coverage.

But remember, the best time to enroll in a group short term disability insurance program is during the initial enrollment.

To meet the pre-existing condition exclusionary period for short term disability coverage:

- You should enroll during the initial enrollment period
• Continue membership in the group
• And, remain enrolled in the disability insurance program during the pre-existing conditions exclusionary period.

Once the exclusionary period has passed, you will then be covered for any pre-existing disability.

• **Long Term Disability Programs**

Less common, but still occasionally available, is the opportunity to increase the benefit of your long term disability (LTD) plan. Some employers will provide a basic benefit for LTD, such as 50% or 60% of your monthly earnings, and allow employees to purchase an additional 10% or 15% to raise the benefit you would receive in the event of disability.

Some employers may allow you to add this benefit if you did not sign up for it originally. Again, it is important to read your Open Enrollment material to see if your employer offers this.

• **Revising Your LTD Premium Payment**

Another possibility to explore is how you pay for LTD coverage. Some employers will allow you to pay for the LTD coverage through payroll deduction rather than receiving it as a gift. If this is possible you may want to jump at the chance, and the reason is taxes.

If you pay for the LTD coverage with money you earn and pay taxes on, then the benefits you receive if you become disabled will be income tax free, substantially increasing the spendable dollars you would receive as a disability benefit. Conversely, if the employer “gives” you LTD coverage and pays for it, then any benefits you would receive upon disability are fully taxed.

• **Health Insurance and Related Benefits**

Many employers, especially larger ones, offer a variety of health, dental, and vision plans that employees choose from. At Open Enrollment, you have the opportunity to change your coverage from one plan to another regardless of your medical condition, and sometimes have the opportunity to make choices within your plan, such as increase or decrease the size of the deductible.

If you have hepatitis, this can be an important choice, especially if this is the first Open Enrollment opportunity since your diagnosis. There is no one plan that is best for ev-
A Guide to Hepatitis and Disability

...r everyone, but a brief review of the different types of plans may help you decide which would be best for you:

Preference Provider Organization Plan (PPO): These plans allow you to choose your own medical providers and decide for yourself when and what specialist you will see. PPO plans pay more if you go to one of their contracting, or “in-network,” providers, but some benefits are available if you go “out-of-network.” The price for this increased flexibility of choice is that the premiums are higher than other health plans, and the amount of money you will pay out of your pocket will be higher, especially if using out-of-network providers.

It is important that you review the drug coverage of these plans as many will require you to pay 20% or more of the cost of prescription medication, which can be burdensome given the high price of medications, especially pegylated interferon, and newly approved antivirals for hepatitis B.

The PPO plan is the closest plan currently in use that is similar to the old Indemnity Plans that used to pay the same benefit regardless of which provider was used. Indemnity Plans are virtually non-existent today.

Health Maintenance Organization (HMO): These plans require you to get all your medical care (except emergency care) through their network of providers. They also require you to obtain a referral from your Primary Care Physician (appropriately called the Gatekeeper) in order to see a specialist or obtain diagnostic testing.

The advantage to these plans is that the premiums are less than PPO plans, and by paying copays instead of a percentage of the charge, your out-of-pocket expenses are substantially reduced. Again, check the drug benefit. Usually there will be copays. The trend is to dramatically increase the size of the copay for brand-name drugs to $25, $35, or even $50 in an effort to encourage use of generics when available.

Flexible Spending Accounts (FSA): These accounts are very common, not only with large groups but with medium-sized employers as well. They are an excellent way to reduce your out-of-pocket expenses through the tax savings they provide.

At the beginning of the year, you determine how much you will be spending out of your pocket for deductibles, copays, or co-insurance. Medically related items that are not covered under regular insurance, such as cosmetic surgery, laser eye surgery, or other non-covered procedures, may be paid for out of this fund as well. Based on that estimate you agree to set aside a certain amount from each paycheck, which is then...
deposited in your FSA. The advantage is that money set aside in an FSA is not subject to income taxes or regular payroll taxes. This means that, if you are in a 25% income tax bracket, the federal government, by not collecting taxes, is, letting you have $1.25 to spend on medical bills for each dollar you set aside in the FSA.

However, nothing is perfect. Any money left in the FSA at the end of the year is lost. Therefore, it is important that you estimate your medical expenditures carefully, and set aside a conservative amount that you know will be spent during the coming year.

_Dental and Vision Plans:_ With dental and vision benefits, if there is a choice of plans it is often between an HMO style plan which offers broader benefits for less out-of-pocket expense, but requires you to use a “contracting” provider, or an indemnity plan which allows you to go to any provider, but will require you to pay more out of your pocket. Based on the cost, expected usage, and list of providers, you can decide which is best for you and your family.

_Consumer-Driven Health Plans:_ Employers are increasingly worried about the rise in health insurance costs and are looking to reduce their expenses. Premiums for health insurance are rising dramatically, more of which is being passed on to employees.

One option that many employers are exploring is “Consumer Driven Health Plans.” This is really just a marketable title for health insurance plans that pass more of the costs of medical care onto the employee.

These are health insurance plans in which the deductibles and copays are raised. Insurance companies maintain that medical costs will be more effectively controlled by the patients if they have a stronger financial interest in making sure they are not over-treated. Such a concept makes a certain amount of sense when talking about a relatively healthy family that may only occasionally require medical care for minor issues.

However, this concept severely penalizes the seriously ill who must have frequent and extensive medical care. If you are dealing with hepatitis B or C, this may be one type of plan you might wish to avoid, if possible.

_Health Savings Accounts (HSA):_ This is one of the newest health plans to attempt to provide health benefits while attempting to control costs. In many ways, it appears to combine the Flexible Spending Accounts (FSA) with the Consumer Driven Health Plan, yet it is a totally different product.

Under these plans an employer provides a health insurance plan for employees and
their families, but with a high deductible such as $3,000 or $5,000 per year. At the beginning of each plan year, the employer deposits a specific amount of money into each employee’s Reimbursement Account. The amount deposited may be several thousand dollars, but it intentionally is not enough to cover the entire deductible of the health insurance plan that overlays it. Unlike HSA’s, however, any money remaining in the fund at the end of the year can be carried over to future years.

The fund is available to handle routine or initial medical costs. In a healthy person, it would probably be enough to provide all their medical care for the year. If the fund is depleted, then the insured person must pay their own medical bills until the total of medical bills for the year exceed the deductible of the insurance policy after which the bills will be paid, usually in full, by the insurance company. Not very common yet, it is being touted by the insurance industry as an effective alternate to ever-increasing premiums, and the IRS has encouraged this plan through revised regulations.

It will take some time and work on your part to carefully read the Open Enrollment literature and determine your specific needs; however, Open Enrollment can provide an excellent opportunity to fine tune your benefits package in order to provide maximum assistance based on your family and medical needs.

9. INTRODUCTION TO SHORT TERM DISABILITY

There may come a time when symptoms resulting from your hepatitis B or C, or side effects from treatment, require you to take several weeks or even months off work.

Employer-provided time off, which includes continued compensation, has three levels:
- Sick leave for the person needing a few days away from work
- Short term disability (STD) for brief absences from work, ranging from one to several weeks
- And long term disability (LTD), for extended periods of disability

**Sick Leave**

It is important that you understand your employer’s policy on time off. Some employers provide sick leave as separate from vacation and other time off. Some employers let employees carry over all or part of unused sick leave into future years, while others wipe the slate clean and start over each year.

Some employers place all paid time off under one label such as personal time, paid
time off, etc. Whatever the program, it should be in writing and you should make sure you have a current copy of the current plan.

Virtually all employers require employees to use all their sick leave prior to utilizing any disability plan. After sick leave is used, short term disability benefits begin.

• **Short Term Disability (STD) Benefits**

Short term disability pays a portion of your salary between the time sick leave is exhausted and long term disability starts. The typical benefit is between 50% and 75% of your salary. Some larger employers will pay 100% of the salary for a period of time based on the employee’s length of service before dropping to a lesser percentage.

For example, an STD plan may pay 60% of salary for 13 weeks; however, employees with five to 10 years of service will get 100% of salary for four weeks and 60% for the remaining nine weeks, while employees with 10 or more years of service will get 100% of salary for eight weeks and 60% for the remaining five weeks.

The benefit is usually a percentage of gross weekly salary without bonuses, commissions or overtime. This will be spelled out in the plan’s document.

- **Waiting Period**: Most STD plans won’t start paying until the employee has been absent for one week or until the sick leave has expired, whichever comes first.
- **Maximum Benefit Period**: The typical STD plan pays benefits for 13 to 26 weeks. Many employers time the STD plan to cover the waiting period of the long term disability coverage.
- **Filing an STD Claim**: Larger employers usually process and pay STD claims internally so there is little paperwork to complete beyond a statement from the physician. Other employers purchase STD coverage from an insurance company that handles the claims in a manner similar to any other disability benefits provider. Your plan document should give directions on how to file a claim.

• **State-Mandated Short Term Disability Coverage**

Five states plus Puerto Rico require employers to provide short term disability benefits for all employees.

These states require employers to provide a minimum amount of short term disability benefits to all employees while disabled. Some states permit insurance companies to provide the coverage; others insist that all coverage be provided by the state and paid for through payroll taxes. Each state’s plan and administration is handled differently.
• California: By far the broadest of the mandated plans, it provides payment of 55% of the employee’s gross salary up to a maximum of $987 per week (as of 2010) after a one-week waiting period for up to 52 weeks

• New York: New York requires employers to provide coverage for employees of 50% of salary up to $170 per week after a one week waiting period for up to 26 weeks

• New Jersey: New Jersey’s law requires payment of two-thirds of salary up to $561 per week (as of 2010) after one week and payment of benefits for up to 26 weeks. After three weeks of disability, the plan goes back and retroactively pays the first week of disability as well

• Rhode Island: Benefits start after seven days and pay benefits up to thirty weeks. The first week is paid retroactively after four weeks of disability. The benefit paid is based on a percentage of your quarterly earnings over a base period with a maximum benefit of $700 per week (as of 2010). Rhode Island’s program is unusual in that it increases the benefit payable for each of the claimant’s dependent children under age 18

• Hawaii: Hawaii’s disability plan pays 58% of salary up to $510 per week (as of 2009) after 7 days for up to 26 weeks

For additional information on the state programs as well as claim forms, you should contact your state’s Department of Labor or Office of Unemployment.

• Family & Medical Leave Act

The federal government passed the Family & Medical Leave Act in 1992, and it provides some job protections for persons who must take time off for medical reasons.

• Eligibility: The law generally applies to all employees of an employer with 50 or more employees working in the same geographical area. To be protected under this law, the employee must have been with the employer for at least 12 months and have worked at least 1,250 hours in the most recent 12 months, and NOT be a “key” employee

• Availability: Employees covered under the law may access the protections if they must take time off due to either their own medical condition or to care for a spouse, child or parent who is seriously ill. Note that domestic partners do not come under this law. Benefits are also available at the birth or adoption of a child

• Benefit/Protection: The law itself does not require that a salary replacement benefit be paid; that is left to the employer to provide. The benefit under this law focuses on job and benefits protection

When you return to work after taking a FMLA leave, you must be restored to the job
you had when FMLA leave started OR, at the employer’s option, to an equivalent position with equivalent benefits, pay, working conditions and seniority.

The employer must also continue all employee benefits while the employee is on FMLA leave, in the same manner as when the employee was actively at work. If you were paying a portion of the cost of your employee benefits through payroll deduction, you will need to make arrangements to continue payments when the paychecks stop.

- **Maximum Benefit Period:** The federal FMLA law provides protection for only 12 weeks per year. The leave does not have to be taken consecutively, and may be taken in increments with periods of work in between. This is especially helpful for persons undergoing treatment that may leave them incapacitated for a week or more.

The annual maximum is determined not by calendar year, but for the prior 12 months. When 12 weeks of FMLA have been taken within a 12-month period, the maximum is reached.

For example, if a person goes out on FMLA for seven weeks, then returns to work, there will be only five more weeks of FMLA available. However, once the prior period of disability is more than 12 months in the past, then there will again be 12 weeks available.

- **State Disability Leave Statutes**

Most states have enacted their own statutes to protect employees’ benefits and their jobs while out on disability. Three states have comprehensive family and medical leave laws that apply to employers of fewer than 50 employees:

- **Vermont** (10 or more employees for leaves for new child or adoption; 15 or more employees for leaves for family member’s or own medical condition)
- **District of Columbia** (20 or more employees)
- **Oregon** (25 or more employees)

Four states use a more expansive definition of a “family member” for whose illness an employee may take family medical leave:

- **District of Columbia** (includes all relatives by blood, legal custody, or marriage, and people with whom employees live and have a committed relationship)
- **Hawaii** (includes in-laws, grandparents, and grandparents-in-law)
- **Oregon** (includes spouse’s parent)
- **Vermont** (includes spouse’s parent)
Eight states provide longer periods of family and medical leave:

- **California** (12 weeks family leave plus four months maternity disability leave may be combined for a total of 28 weeks/year)
- **Connecticut** (16 weeks/2 years)
- **District of Columbia** (16 weeks of family leave plus 16 weeks of medical leave/2 years)
- **Louisiana** (4 months for maternity disability)
- **Oregon** (12 weeks family leave plus 12 weeks maternity disability per year)
- **Puerto Rico** (up to 20 weeks for complicated pregnancies)
- **Rhode Island** (13 weeks/year)
- **Tennessee** (4 months for maternity disability)

STD benefit plans can offer income for a temporary respite from work when you need to take some time off but plan to return in a few weeks. With the federal and state disability leave statutes protecting your position and your benefits, the two programs work together to provide needed time off with both income and job protection.

When your STD benefits expire, you can apply for long term disability.

### 10. TIPS FOR FILING FOR DISABILITY BENEFITS

Disability insurance experts who work with people filing for benefits have identified some techniques and procedures that are helpful when filing claims. Here are some suggestions that will help you get organized and prepare for any potential problems.

#### Before You Leave Work

1. **Plan.** Once you have a diagnosis or other indication that you may have to stop working at some time in the future, you should do a “Benefit Review” so you will know what benefits are available, what you have to do to become eligible for them, and how much income you will receive when you stop working.

The earlier you perform this review, the greater the possibility of making changes to enhance your benefits for when and if you become disabled.

If you have benefits through your employer, you should first obtain a copy of the Summary Plan Descriptions that employers are required to provide all employees. Person-
nel departments should have them available and you can request them, simply saying something like you are working with a financial planner and he/she needs them. This way, no “red flags” are raised.

2. Be careful about switching to part-time work. Under the Americans with Disabilities Act (ADA), an employer must make “reasonable accommodation” for your medical condition to help you continue working. In many cases, however, the accommodation is reduced hours, with accompanying reduced pay. If you have a long term disability (LTD) program available through your work, the benefits are often tied to what you were earning at the time you stopped work. If you reduce your hours, you will also reduce your income, which in turn will reduce any LTD benefits you may be eligible for later.

If your hours drop low enough, you may even lose eligibility for the benefits because they’re usually only available to full-time employees.

3. Be careful how you tell your employer. When telling your employer that you are leaving, do not announce that you are leaving work permanently and never plan to return – even if that is the case. It is better to preserve your benefits and rights by telling the employer that your doctor is making you take some time off for a medical condition. When asked for how long, you can tell the truth; you don’t know for sure – at least a month or two. The employer will tell you what paperwork is needed to process the absence.

4. Don’t burn any bridges when leaving work. Tempting though it is to tell your bosses just what you thought of their abilities, hold it in, even if you know you will never return to that workplace. Your employer is important to a smooth transition to disability and most employers recognize that helping an employee go on disability is good for the company as well.

• Do the Paperwork

1. Copy! Copy! Copy! Nothing should leave your hands that you don’t have a copy of and that includes every letter, every form, every application. Keep a copy!

2. Check all paperwork before submitting it. Let the forms sit at least overnight and review them again before submitting them. If possible, look them over several times. It is amazing what additional information you will recall and be able to add, especially if your medical condition is one you have had for some time. People frequently forget about symptoms they have when they have lived with them long enough.

3. Don’t let small spaces on the forms scare you. Some experts say they’re convinced
some claim forms purposely have a tiny amount of space for answers just to keep you off-balance and encourage you not to say much. Experts report they don’t know of a single carrier or government agency that won’t accept additional sheets of information. Simply label “See attached” in the space on the form, and put your full answer on an attached sheet. Make sure you carefully label the question and answer.

4. **You can’t overdo it with identification.** It’s so easy for papers to get lost or misplaced. Experts recommend clients put their name and Social Security number (or other identifying number) at the top of every page of every form.

5. **Don’t be too perfect.** If you use a computer to complete your forms and they end up looking very “professional,” be sure to explain the time you had to spend getting them to look that good. You may even want to describe how many revisions you had to make and who assisted you with the process.

6. **Track all documents.** Send forms and correspondence “Return Receipt Requested.” While it isn’t foolproof, it can provide some help in tracking down lost mail. When possible, deliver Social Security forms and correspondence to the local Social Security office personally and request an itemized, written receipt or enclose a handwritten receipt and self-addressed stamped envelope and ask them to sign the receipt and return it to you.

**Phone Calls and Follow-Up**

1. **Don’t sit and wait.** Stay involved in the claim process. Contact the analyst and examiner to make sure mailed forms were received. Follow up with doctors who haven’t submitted their records. This not only reduces the time it takes to process the paperwork, but it helps personalize your claim to the examiner.

2. **Maintain a phone log.** Every time you talk to the insurance company or Social Security or your employer or anyone regarding your benefits, keep a written record of the call. Name, phone number, date and time of call, what was said, outcome or next step.

3. **Get it in writing.** The best record is the written record. It’s not always possible and it may be slower than phone calls, but it’s much easier to reconstruct if necessary. What you are told by the insurance company over the phone doesn’t mean a thing. Some people will say almost anything over the phone, knowing that they won’t be held responsible. If they have to put it in writing, chances are they will make sure they are right before writing it down. Try asking something like, “I have trouble remembering things and this is so complicated. Could you put that in writing and send it to me?”
4. Talk to the person, not the office. It’s easy to picture monsters and ogres working for the companies and squealing with glee when they refuse your claim (and there are enough like that to be really scary), but these people are mostly human and just trying to do their jobs. Treat each one as a person, try to be friendly, try to personalize the conversation, and you may find you have an ally who will help and not be an obstacle. Then again, don’t expect miracles.

5. Be generous with compliments. If the claims representative goes out of his/her way or gives you better than expected service, let them know.

6. Play dumb. You’re much more likely to get the attention and advice of a claims representative by playing the helpless, ill, lost-in-the-system role. Demands, orders and threats won’t help your case move any faster, at least not initially.

7. Watch what you say on the telephone. When you call an insurance company or Social Security, you often get the recording, “Your call may be monitored or recorded for quality assurance.” That means the phone call is being recorded. Even a comment like, “I’m fine thanks. How are you?” can be turned against you.

8. Don’t bother with threats. These people are regularly threatened with lawsuits and insurance department complaints. It doesn’t scare them, but it does make you “an enemy.” Don’t threaten legal action, but if warranted, take it. Exhaust all internal appeals processes first though.

9. Double-check what you are told. Admittedly, this sounds very cynical; it doesn’t mean you should distrust everyone. However, in this case, you can’t be too careful. This is your life, your income, your continued health insurance we’re talking about, and no one cares about it as much as you do. People will sometimes give you information off the top of their heads without realizing that the wrong information can cost you money and/or insurance coverage. You’re trying to find the answers to surviving in the future; they’re trying to get off the phone. It’s important that you try to double-check such information.

10. Give the full story. It is often amazing how one little piece of information, which may seem unimportant to you, can change the whole picture. Be sure when asking for advice that you give as complete a description of the situation as possible, and answer all questions completely. Focus on the facts and try to avoid assigning motives to someone’s actions.

The process of moving from work to disability is not an easy one. The paperwork is
difficult enough without having to complete it when you are already preoccupied with health problems. By following these suggestions, you can make the process more organized and easier to follow. It also puts you back in control of the process so you are not at the mercy of the programs you are trying to access.

11. Introduction to Long Term Disability Benefits

Long term disability (LTD) policies provide you with a percentage of your income if you are seriously disabled for a long period of time, such as two or five years, or until you retire. LTD coverage begins after the short term disability benefits period expires.

For example, under some policies, LTD benefits begin after you have been disabled for 90 consecutive days and typically pay about 60% of your salary.

Most people get LTD insurance coverage through their employers, but you can also purchase an individual LTD insurance policy, called Disability Income Insurance, on your own if you are not covered through work or if you desire additional coverage.

Most disability insurers work with employers to try to get disabled workers back to work as soon as possible. While disability insurers want to see people healthy, rehabilitated, and back to work, keep in mind that they also save significant dollars if you return to work quickly. Once you receive LTD, you are basically on your own in terms of managing the claim and coping with the insurance company’s efforts to get you back to work.

You may find that if you can still work – though in a job that pays substantially less than what you were making before you became disabled – your LTD will pay you additional money if you decide to take the lower-paying job.

Here’s an example. You are no longer able to work for your construction company that paid you $40,000 because of your hepatitis-related symptoms and fatigue. You are forced to take a desk job that pays $20,000 annually. If your LTD policy was paying you 60 percent of your original $40,000 salary, it will now pay you 60 percent of the difference between the old and the new salary. So, instead of staying at home and collecting $24,000 from your LTD policy only, you work at the lower paying job and make $32,000 (in addition to the $20,000 salary, you also get $12,000 in disability benefits, which is 60% of $20,000).

Some disability insurers give employers an incentive to have workers return to work on a part-time basis. It’s common for insurers to give employers a premium reduction on
the group policy if they allow a partially-disabled person to come back to work on a part time basis.

If you become disabled and begin receiving benefits, you will no longer have to pay premiums. Also, if you pay your premiums with after-tax dollars, your disability payments will not be treated as taxable income. If your employer pays for your group disability insurance with pre-tax dollars, your benefits will be treated as taxable income.

• Types of Disability Policies

There are three main types of disability coverage:

• **Own-occupation plans** compensate you when you can’t work in your current profession. This is the most lenient definition of disability

• **Education, training and experience plans** compensate you when you can’t work in any job for which you are qualified by virtue of your education, training and experience

• **Any-occupation plans** compensate you when you can’t work in any job. This definition is similar to Social Security’s definition of disability, and is the most stringent type of policy

Before applying for disability, claimants should obtain a complete copy of their insurance policies, including the definition of disability section, and review it carefully to make certain their claims meet the plans’ requirements.

• Protect Yourself

Document all communications with anyone involved in your LTD claim. All telephone calls should be followed with a letter re-stating the conversation. Keep copies of this and other relevant correspondence, including postmarked envelopes from the insurance company, in a file.

Occasionally, insurers will require that claimants go for an “Independent Medical Exam” (IME). Remember that IMEs are paid by the insurance company to evaluate your disability. It is wise to bring a friend or family member (preferably someone with a medical background) to an IME to document the visit, help ask questions, especially if you are having a bad day. You should ask the claims representative for a copy of the report when available.

Though this is rare, some LTD companies employ investigators to observe claimants as part of their fraud-prevention strategy. Don’t be surprised if you are videotaped, visited or secretly watched, and make sure to keep brief notes on your daily activities and
symptoms in the event the insurance company uses surveillance to deny or revoke your benefits.1

Employer-sponsored LTD plans are governed by a federal law called ERISA (Employee Retirement Income Security Act). This is the same law that governs employer-sponsored health and pension plans. Originally written to protect employee benefit plans, it has an unfortunate loophole in that it makes it legally difficult for dissatisfied claimants to take their cases to court.

Some patients who have been denied benefits by their LTD plans have complained that ERISA gives insurance companies an advantage. Because claimants can usually only recover back benefits (and not damages), attorneys may be reluctant to take on these difficult cases.

LTD policies purchased by individuals are not subject to ERISA and claimants are permitted to take their cases to court. Unfortunately, it is very expensive to pursue legal action against large insurers, so many individuals find it almost as difficult to pursue lawsuits in these cases as they do in ERISA cases.

Complaints about handling of LTD claims can be made to the U.S. Department of Labor’s Employee Benefits Security Administration, your state’s insurance commission, and your representatives in Congress.

• **When Do LTD and Social Security Overlap?**

Virtually all LTD plans provided by employers require claimants to apply for Social Security Administration (SSA) benefits and will reduce their payments by the amount the SSA pays. Having the SSA declare you disabled may provide additional support for an LTD claim, even though the SSA’s definition of disability is different than that of most private companies. For this reason, you may wish to submit an SSA disability claim shortly after you submit a request for LTD benefits.

An additional benefit to having SSA disability benefits is that after two years you become eligible for Medicare, the federal government’s health insurance program for the elderly and disabled. For hepatitis patients who have no other medical insurance, this benefit can be as important as the cash benefits they receive from the SSA.

**References**

Social Security offers two plans that provide financial assistance to disabled people.

- **Supplemental Security Income (SSI)** is a needs-based program that requires proof of limited income and resources in order to qualify for benefits.

- **Social Security Disability (SSDI or SSD),** and sometimes called Disability Insurance Benefits (DIB), also has financial requirements. However, because SSD is an entitlement program, its financial requirements are based on whether you paid into the system adequately enough to be eligible for disability benefits. SSD is only available to you if you are disabled and if you meet the one financial eligibility requirement: Did you pay Social Security payroll taxes (F.I.C.A.) long enough and recently enough to qualify?

Social Security doesn’t care whether you are rich or poor or what your resources or other income are as long as you paid Social Security payroll taxes and are considered disabled. If Bill Gates or Donald Trump became disabled, they would be eligible for SSD benefits.

- **The Easy Way to Determine Financial Eligibility**

  Once a year, about three months before your birthday, Social Security sends everyone older than age 25 a summary of their total earnings by year and shows the amount of FICA taxes paid. It also estimates what your retirement and disability benefits would be. If you have not paid into the system enough to qualify for disability benefits, the statement will say so. If you have lost or misplaced this statement, you may order another one.

  The easiest way to check your financial eligibility is to request a Summary of Earnings and Benefits. You can obtain a request form as well as apply on-line at www.ssa.gov/howto.htm and click on: “How To Request a Social Security Statement of Earnings and Benefits.”

  You may also obtain a form to request the statement at any Social Security office and most post offices. Ask for: “Request for Social Security Statement (SSA-7004).”

- **SSD Financial Eligibility Rules**

  Like all government programs, the rules for determining financial eligibility can become very complex, but the average worker need not worry about the complicated details. If you have been employed on a full-time basis, fairly continuously, the following deter-
mines your financial eligibility:

- If you become disabled before age 24, you generally need to have paid F.I.C.A. payroll taxes in six calendar quarters (also called work credits) during the three-year period ending when your disability begins.

- If you are between the ages of 24 through 30, you generally need to have paid payroll taxes for half of the period between age 21 and the time you become disabled.

- If you’re disabled at age 31 or older, you need to have paid F.I.C.A. payroll taxes in the number of calendar quarters shown in the following table. Also, at least 20 of those calendar quarters have to have occurred within the 10 years (40 quarters) immediately before you became disabled.

<table>
<thead>
<tr>
<th>Disabled At Age</th>
<th>Quarters (Work Credits) Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>31 through 42</td>
<td>20</td>
</tr>
<tr>
<td>43-44</td>
<td>22</td>
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<tr>
<td>45-46</td>
<td>24</td>
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<td>47-48</td>
<td>26</td>
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<td>49-50</td>
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<td>55-56</td>
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<td>57-58</td>
<td>36</td>
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<tr>
<td>59-60</td>
<td>38</td>
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<tr>
<td>61 or older</td>
<td>40</td>
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</tbody>
</table>

For example, if you are age 44 and have been working steadily and paying F.I.C.A. taxes since you were 20, you are eligible for SSD benefits if you are disabled because you have more than 22 quarters including the most recent 40 quarters.

Another example: You become disabled at age 50. For the past six years you were a school teacher and did not pay F.I.C.A. payroll taxes. Before that you worked in private industry and paid F.I.C.A. taxes for more 20 years. You are not eligible for SSD benefits. Although you paid F.I.C.A. taxes for more than the 28 quarters required, only 16 (four years) of the quarters were paid in the last 10 years instead of the required 20. (You will still be eligible for retirement benefits beginning as early as age 62, however.)

- If Your Employment Was Part-Time or Irregular

Social Security actually measures what they call “work credits” rather than actual cal-
endar quarters in determining eligibility. So if some of your work history was part-time or your income otherwise low, then you need to know how much you actually earned or how much you paid in payroll taxes.

*One work credit equals one calendar quarter* as long as you earned the minimum required earnings for that quarter. You can earn up to four work credits each calendar year.

The minimum amount of earnings changes each year. Below is a table that shows the minimum quarterly earnings required for each quarter to count as one work credit.

<table>
<thead>
<tr>
<th>Year</th>
<th>Earned Amount of Wages or Self-Employment Income that Must Be Earned in Order to Acquire a Work Credit of Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1978</td>
<td>$250</td>
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<tr>
<td>1979</td>
<td>$260</td>
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<tr>
<td>1980</td>
<td>$290</td>
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<td>$780</td>
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<tr>
<td>2001</td>
<td>$830</td>
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<tr>
<td>2002</td>
<td>$870</td>
</tr>
</tbody>
</table>
You don’t have to work during all four calendar quarters of that year to get four work credits, as long as your earnings in that year are four times the quarterly minimum for that year or greater. However, you can never earn more than four work credits in any one calendar year.

- **If You Are a Military Veteran**

Veterans of the military are eligible to receive extra work credits based on their active duty:

<table>
<thead>
<tr>
<th>Period When on Active Duty</th>
<th>Extra Amount Counted Toward Work Credit as if It Were Earned Wages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between 09-01-1940 and 12-31-1956</td>
<td>$160 for each month of active duty</td>
</tr>
<tr>
<td>Between 01-01-1957 and 12-31-1977</td>
<td>$300 for each quarter of active duty</td>
</tr>
<tr>
<td>01-01-1978 and After</td>
<td>$100 for each $300 of actual military pay up to a maximum extra credit of $1,200 per year</td>
</tr>
</tbody>
</table>

All these rules may seem daunting, but remember, if you have worked most of your adult life and paid F.I.C.A. through your paycheck, chances are you will be eligible for Social Security Disability (SSD) if you become unable to work. If there is any doubt about your financial eligibility, start the application process anyway. Social Security will advise you early in the process if there is a problem.

### 13. How to Apply for Social Security Disability

The Social Security Administration (SSA) offers several types of monthly benefits to a disabled person, including Social Security Disability Insurance (SSDI), Supplemental
Security Income (SSI) and disability benefits for widows, children, and adult children disabled since childhood. Each program has its own eligibility requirements, but they all use the same definition of total disability and use the same method to determine if a person is “disabled enough” to qualify for benefits.

Under Social Security you are considered disabled if:

- Due to a medical condition you are unable to perform the tasks of a job for which you are suited, AND
- The condition either has or will last for at least 12 months or is expected to result in death

More than half of first-time applications for disability benefits are denied, not because the disability definition is difficult to meet, but because the applicant didn’t understand the disability determination process and didn’t give Social Security the information it needed to award benefits.

Denial of Social Security disability benefits appears to affect people with hepatitis B or C disproportionately, for several additional reasons:

- To Social Security, hepatitis B and C are relatively new disabling conditions and they really haven’t develop an organized approach to reviewing hepatitis claims
- Hepatitis symptoms can vary from none to completely debilitating, so you need more than just a hepatitis diagnosis to qualify for benefits
- Many hepatitis symptoms are “subjective” and can’t be easily documented by a laboratory test. Examples include fatigue, headaches, memory loss, and depression. Therefore, medical records alone often don’t adequately describe the functional problems hepatitis-infected applicants struggle with when trying to work

A person with viral hepatitis typically experiences a gradual deterioration in their ability to work. Work becomes more and more difficult; finding the energy to work is more and more time-consuming. Some reach the point where they only work and spend the remainder of their time in bed trying to regain enough strength to return to work.

If you believe that the time to apply for Social Security disability is approaching, especially in the next few months, there are two things you can do now that can greatly increase your chances of getting your claim approved the first time around:

1. Learn how Social Security processes a claim for disability; and,
2. Assemble and review the “medical evidence” they will use to determine if you are disabled, based on their guidelines
• How Social Security Processes a Disability Claim

When examining a disability claim, there are five questions a Social Security disability analyst wants answers to:

1. Are you working?
2. Is there a medical problem that affects your ability to work to any degree?
3. Is your condition found in SSA’s Listing of Impairments?
4. Can you do the work you did previously?
5. Can you do any other type of work?

To be eligible for benefits, the answer to #1 must be “No,” and the answer to #2 must be “Yes.”

If the answer to #3 is “Yes,” your claim will be approved. If not, then both #4 and #5 must be “No.”

To facilitate the process and to maintain some uniformity throughout the country, Social Security publishes a book called, Disability Evaluation Under Social Security, or “The Blue Book” which includes a Listing of Impairments. If your doctor has listed an impairment found in the Blue Book and it meets the criteria given, then your claim is routinely approved.

The listings, unfortunately, do not directly deal with hepatitis B or C, and you may have to document other symptoms, not found in the listing’s chronic liver disease section, to qualify for this benefit. For more information about specific impairments, go to www.ssa.gov/disability/professionals/bluebook/.

There is a listing for **Chronic Liver Disease** that includes **chronic active hepatitis**. However, because the symptoms can vary substantially, they include some guidelines on how severe the condition must be. (See pages 11 - 12 of this guide)

If your condition meets one of the current listings, your claim should be quickly approved. If, however, it does not meet any of these criteria, all is not lost. It is still possible to have your claim approved if the symptoms you exhibit are as severe as one of the listings. If your symptoms clearly show that the answers to questions #4 and #5 are both no, your claim will also be approved.

Usually, however, more medical evidence will be required to get your claim accepted. In that case, you should make sure you submit all the medical evidence that you can
• Assemble and Review Your Medical Evidence

The most important piece of evidence in determining disability is the records of your medical providers. This could also include the records of your therapist, chiropractor, acupuncturist and other medical practitioner. “Non-medical establishment” providers won’t carry the weight of “regular” doctors, but they can support your claim by documenting your symptoms and your efforts to relieve them.

Disability determination focuses on your symptoms and how they prevent you from working so it is a good idea to make sure your physicians enter your symptoms into the record with each visit, even if it is repetitive.

To greatly speed up processing time, it is also recommended that you take copies of your medical records when you go to your initial interview with Social Security.

While the medical records of your providers are the primary “evidence” when your application is reviewed, there are other documents and records that can help your claim as well. These include:

1. Questionnaires – Once you apply for disability benefits, the disability analyst will send you questionnaires to get specific information. They may be about pain, fatigue, your daily activities, or other conditions or symptoms. These questionnaires are your opportunity to transform the medical data from your physicians into actual descriptions of the problems your condition causes you when working and in your daily routine. You should not skimp on these or rush through them. Take your time, add extra sheets of paper, well-labeled, and thoroughly describe in detail exactly how your symptoms affect your routine. (See Section 14: “How to Answer Your Daily Living Activities Questionnaire”).

2. Letters from Physicians – Ask each of your doctors to write a thorough summary of your condition. They should focus on relating the medical conditions and test results to the symptoms you are experiencing. To adequately do the job, each letter should be several pages long, not just a couple of paragraphs saying it is their opinion that you’re disabled. That will not help.

3. Third Party Testimony – These are letters from friends, family, or co-workers that describe their observations of your problems trying to function. These should be anecdotes and descriptions of what they have observed in your performance. One of the best is a copy of a “write-up” by your supervisor on your deteriorating performance from your personnel file. Not everyone will have one of these as many people work that much harder to make sure their performance doesn’t deteriorate. Letters from a
spouse, housemate or co-worker on how your activities and abilities have changed due to your condition are good also. A description through anecdotes of how your ability to function has deteriorated should be their goal. While these alone won’t get your claim approved, they do help provide a good picture of how your medical condition affects your activities.

4. **Symptom Diary** – This can be an especially helpful tool when the symptoms are primarily subjective. Psychologically it is not fun to do, but it can help confirm the impact of the symptoms on your activities. A symptom diary is simply a daily log in which you enter the symptoms you experienced during the day, their severity, including how long they lasted, and their impact on your daily activities, such as requiring you to rest, cancel planned appointments, etc.

This seems like a lot of work to obtain benefits that you deserve, but, remember, Social Security is so big that they can’t be bothered with “what’s fair” or “what you deserve.” You need to know the rules and “play by the rules.” Making the effort with the initial application can avoid having to drag through a year or more of appeals and sharing your award with an attorney, which will save you time, money, and lots of stress.

**• Which Social Security Program Should You Apply For?**

Social Security should screen you for both disability programs at your interview, but you should understand the two plans and their differences.

It’s complicating enough that Social Security operates two entirely separate disability benefit plans whose initials differ by only one letter; it practically guarantees confusion. Yet that one letter can be very important, there is a world of difference between the two plans. The two plans are SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance). Perhaps the best way to clear the confusion is to look at them together.

**NOTE:** This is an overview only to clarify the distinctions between SSI and SSDI. This is not intended to provide a comprehensive description of either plan.

First, the concept and goal of each plan shows why there are major differences:

- **SSI** is a “needs-based” benefit. In addition to providing benefits to persons who are disabled of any age including children, it also pays monthly benefits to people over age 65 whether or not they are disabled. The key to SSI benefits is “financial need.” The “Financial Eligibility,” discussed below, is based on the person’s lack of personal resources and income to meet the necessities of life.

- **SSDI** is also called SSD. Social Security calls it just “Disability” and refers to it as
the DIB, or the Disability Insurance Benefit. Whatever it’s called (we’ll use SSDI), the program was created so workers who become disabled and unable to work to their normal retirement age will be able to access their Social Security retirement benefit early. Private pension plans would call this a “disability retirement” benefit. “Financial eligibility,” discussed below, is solely based on the length of time and amount paid in F.I.C.A. payroll taxes.

There are some similarities between the plans.
Both SSI and SSDI:
• Are administered by the Social Security Administration.
• Pay a monthly benefit to totally disabled persons who qualify.
• Require the very same level of medical disability to qualify for benefits, and follow the same procedure in determining whether or not an applicant is disabled.

Now, here are the major differences:
• Amount of Monthly Benefit
• SSI pays a set amount each month. The amount will vary some depending on whether the beneficiary lives independently, lives in a board and care facility, has cooking facilities, lives rent-free, is blind, and several other factors.
  ♦ A disabled person living alone in his/her own apartment with cooking facilities is eligible to receive up to $674 per month during 2010 from the federal government. However, SSI functions as a safety net, or a floor of income; any other income received is deducted from that SSI base amount.
  ♦ Some states supplement the federal SSI payment with an additional payment, which will increase the monthly payment. Check with your local Social Security office to see what your state does.
• SSDI pays a monthly benefit based on the amount of F.I.C.A. payroll taxes the person has paid into Social Security over his/her working career. The benefit may be anywhere from one dollar per month to around $2,500 per month. The calculation attempts to estimate what the retirement benefit would be if the person continued working until retirement and pays that amount as the SSDI monthly benefit.

• Financial Eligibility
These are the non-medical requirements for disability benefits. One is based on what you “don’t have”; the other looks only at payroll taxes you paid. SSI benefits are only available if you can show you have very few assets or resources and low income.
Your resources and assets must be less than $2,000 ($3,000 for a married couple). This includes all money in checking, savings, as well as retirement savings accounts. It also includes real estate (except your home), stocks, bonds, mutual funds, and other investments. It does NOT include one car, the residence you live in, most personal property including furniture and clothing, and certain other exempt items.

Income is more complicated because it is related to the amount of SSI benefits you are eligible to receive and that varies. Generally, your income must be less than the amount of benefit you would be eligible to receive, and SSI will only pay the difference between your other income and the amount you would be entitled to receive based on your residence and living situation.

For example, if you are eligible to receive $674 from SSI but your SSDI pays you $700 per month, you would not be eligible for any SSI benefit. However, if your SSDI payment were only $300, you would be eligible for a partial payment from SSI that would take your total income up to approximately $674 per month.

SSDI financial eligibility is based solely on the Social Security (F.I.C.A.) payroll taxes you paid over your working career. It totally ignores how much money you do or don’t have. To be eligible for SSDI, you must have paid F.I.C.A. taxes in 20 out of the last 40 calendar quarters (five out of the last 10 years). If you are under age 31, that number is reduced. If you are over age 42, the minimum number of quarters increases approximately one quarter for each year over age 42. (See Section 12 for the complete eligibility tables.)

As long as you can meet the payroll tax payment requirement, you may receive SSDI benefits if you become totally disabled, regardless of what other income or assets you may have.

• **When Do Monthly Payments Start?**

When monthly benefits start varies between the two plans:

• SSI benefits start on the first of the month that you first submit your application, even if it takes several months to get approval. For example, if you submit your SSI application on April 14 and your claim is approved on July 25, Social Security will owe you benefits from April 1, which they will send you in a lump sum payment. Once you are approved, SSI checks arrive on the first of each month.

• SSDI benefits start in a totally different manner. First, you are not eligible to receive any SSDI benefits during the first five calendar months of your disability, regardless of when you apply for benefits.
For example, you stop working due to symptoms of hepatitis on Feb. 14, 2005 and don’t get around to applying for SSDI benefits until Sept. 3. On Nov. 10, 2005, Social Security sends you a letter saying that you were approved for SSDI benefits and the Onset Date (the day they consider your total disability to have started) is Feb. 15, 2005, the day after your last day of work. You would be eligible for benefits beginning Aug. 1, 2005 (five calendar months after your Onset Date). You would receive a lump sum check for the benefits from August through November.

The regular monthly checks for SSDI come in the month following the month that you “earn” the benefit. Your SSDI check for April will come during May.

• What about Medical Coverage?

In most states, once you receive SSI or SSDI, you also get coverage for medical bills.

SSI will vary some by state, but in almost all states, you are eligible for Medicaid if you receive even one dollar from SSI. In most states, Medicaid comes automatically with approval for SSI benefits. In some states you must make separate application to your state’s Department of Human Services.

SSDI is accompanied by Medicare, the federal healthcare plan, regardless of what state you live in. However, a person receiving SSDI benefits does not become eligible for Medicare until they have received benefits for 24 months (29 months after the date of disability counting the five month waiting period for SSDI benefits).

For example above, the person who started receiving SSDI benefits on Aug. 1, 2004 will be eligible for Medicare on Aug. 1, 2006.

• How Social Security Monitors Your Eligibility for Disability Benefits

Both plans will periodically re-examine your medical records to see if you are still totally disabled. The review to see if you are still disabled is called a Continuing Disability Review. It will occur every three to seven years, depending on the nature of your disability. For people with hepatitis C, for example, disability reviews will usually be every five to seven years.

SSI will review your financial records every year to see if you still qualify for SSI benefits. If your income or resources exceed their maximums, your benefits will stop.

SSDI has no ongoing review of financial eligibility. SSDI beneficiaries only have the Continuing Disability Reviews.
If you apply to Social Security for disability benefits, they are supposed to screen you for both SSI and SSDI. Just to be sure, if you find your SSDI is less than $1,000 per month, ask the representative about SSI to see if you might be eligible.

When you apply for SSI, in addition to medical records, Social Security will want to see financial records, including bank statements, lease and mortgage agreements, savings and other documentation of your financial status.

Social Security Disability can be applied for online, and it is a fairly easy process. Social Security has issued a press release on this program. It is available for anyone wishing to apply for Social Security Disability Benefits as well as retirement. It is not yet available to persons applying for Supplemental Security Income (SSI) benefits due to the need for financial information to determine eligibility.

Below is the complete press release from Social Security, followed by more information on the process:

### EASIER WAY TO COMPLETE DISABILITY REPORT — ONLINE

Applying for disability benefits from Social Security is easier than it’s ever been before. Until recently, the disability report had to be completed manually. Now, you can save time by completing it online and sending it to us electronically.

An important part of applying for disability benefits for adults is completing the adult disability report, or form 3368. The report asks important questions about your disabling condition, medical records, health care provider contact information, and information about your educational and work history. This information is important to help us determine your disability.

We use your disability report and information to help us answer these five questions:

1. Are you working?
2. Is your disabling condition severe enough to limit your ability to do work?
3. Is your condition on our list of impairments, and is it expected to last for at least a year or end in death?
4. Can you do the work now that you did in the past?
5. Can you do any other work?

There are two versions of the adult disability report that can be completed online, depending on whether you are the person applying for benefits, or a professional representative.

If you are applying for disability benefits on your own behalf, you can complete the online disability report at the following link. www.socialsecurity.gov/disabilityreport
If you are representing a disabled person, you can complete our professional version of the disability report. Examples of representatives include attorneys and non-attorney representatives, employees of government agencies, social agencies, hospitals, nursing care facilities, homeless shelters, or non-profit agencies, and anyone else who assists applicants in applying for disability benefits.

If you are representing someone and want to apply for benefits on their behalf, you can go to the following website to complete their adult disability report. www.socialsecurity.gov/i3368prohelp/

Keep in mind that in addition to the disability report, we will also need a completed application for disability benefits. The online application can be found at the following address. www.socialsecurity.gov/applyfordisability/

To learn more about Social Security, visit our website at www.socialsecurity.gov, or call us at 1-800-772-1213 (TTY 1-800-325-0778).

To open a file for disability, there are two primary forms that must be completed, the Adult Disability Report (SSA-3368-BK) and the Application for Disability (formerly SSA-16-F6). The 3368 report can be found in two places on line as shown in the above article. This is because the 3368 can be completed by you personally or it can be completed by your appointed representative if you have hired one.

However, the Application for Disability must be completed by you because it requires an electronic signature, swearing to the accuracy of the statements. Your representative can help you complete it as long as you are present to “sign” the document.

There are several advantages to filing these documents on line. First, the forms ask for a substantial amount of information. They want to know not only about your condition and when you stopped work, but they also need all your medical providers’ names, addresses, phone numbers, as well as when they were seen and why. They want a list of all your prescriptions and your educational background. They also want to know all the different types of jobs you have had in the past fifteen years and the job duties of each. It takes time and research to complete these forms. Filing on line allows you to research the information and go back to the saved applications multiple times before actually submitting it.

It is very easy to complete these forms on line. They automatically adjust questions based on your prior statements; they give you ample opportunity to make comments about your condition. They even have an option that allows you to stop, save your work, and come back to it later. Your file is assigned a code which you can reenter and start back
on the form where you left off.

Once you have completed the documents, the program will question possible errors, note blanks, and allow you to check them for completeness. You also are able to and really should print out a complete copy of the forms. You will also need to print out and sign and date a Medical Release Form (SSA-827) giving them the right to obtain your medical records.

Then you are ready to submit the forms. You will receive receipts confirming they have been submitted. Be sure to print them out also. Once submitted, they can no longer be retrieved or revised. When the Submit button is clicked, the documents are sent electronically to the Social Security Field Office nearest your ZIP Code.

Normally, you will be called by that office within three working days of submitting the forms. If you don’t hear from them, you will need to call the toll-free number (800-772-1213) as local offices do not list their numbers. Ask them to follow up on your submission.

Often you will need to show an original or certified copy of your birth certificate. They may ask to see other items as well, such as military discharge papers, or recent paycheck stubs or W-2 forms. They will also need your signed medical release.

It is recommended that you personally take those requested items into Social Security. They will examine the documents, photocopy them, and return them to you. Note that many advocates do not recommend going to Social Security personally if you “don’t look sick.” That advice doesn’t really make much sense. First, you don’t want to trust valuable documents like an original birth certificate to the mails.

Second, the person you meet with at Social Security is not the one who decides if you are disabled. That person has no medical training at all. It is an entirely different office, a state agency, which reviews medical records and determines disability,

Once you are in touch with the local office, you can schedule an appointment to go in to present any requested documents. You can speed up the process by taking copies of your medical records when you go in.

By initially filing your disability forms on line, you shorten the processing time by at least two weeks, plus you can make sure that the information is entered correctly.
Once you decide you can no longer perform your duties at work or function as you should, you need to prepare yourself for the paperwork required to apply for disability benefits.

Once you’ve notified Social Security or your company’s human resources person that you need to apply for disability, you will be sent a questionnaire once your claim has been filed. This is a normal part of the disability claims review process. Some questionnaires will focus on specific conditions, such as pain, fatigue, or diabetes.

The most common type of questionnaire, however, is the Daily Activities Questionnaire. This questionnaire may have a different name in different states, but it is designed to ask how your medical condition affects your daily life and your ability to function.

Questionnaires are a very important part of the claims process and you should spend the time and effort necessary to give them a clear picture of your inability to function on a daily basis.

Often, Social Security demands that the form be returned in 10 days. If that is the case with your questionnaire and you will not have it completed in time, call your Disability Evaluation Analyst. The analyst’s name and telephone number should be on the cover letter of the questionnaire. Tell him/her that you are working on it as rapidly as you are able, but that it may be a few days late. You should not be penalized as long as the analyst has been told in advance about the lateness and it is not more than a few days to a week late.

The Daily Activities Questionnaire is an important document because it is your opportunity to take all the medical information they are getting from your doctors and connect it to your medical problems and detail how they affect your daily life and hinder your ability to function. It is especially important to illustrate and describe the negative impact that fatigue, pain, cognitive limitations, and other “subjective” symptoms have on your life.

You need to plan and think through what you are going to write, so it’s a good idea to make a photocopy of the questionnaire to make notes on, or to put trial answers on a blank sheet of paper before completing the actual questionnaire. Basically, make a draft version first.
First, review your symptoms. Make a list of them. Some people have been dealing with certain symptoms for such a long time that they have learned to accommodate them and no longer consider them “symptoms” resulting from hepatitis B or C. However, it is these symptoms that should appear frequently in your questionnaire.

As you go through the next day or two, you may find yourself doing something differently than you used to. Often that is due to a symptom that you accommodated for so well that you have forgotten about it. Do you take longer to groom yourself in the morning? Do you take short cuts when you prepare meals? Are there certain foods you no longer prepare because they are too exhausting to make? Do you ration how often you go outside or upstairs? Have your reading, TV, or computer habits changed? Do you nap more frequently than you used to? Note these shifts in habits on your sheet along with your symptoms. After two or three days, you will be ready to draft answers to the questionnaire.

Regardless of how the questions are worded, they want to know what adjustments you have had to make in your lifestyle to accommodate your symptoms and what problems you still have even with your accommodation.

Some general rules to follow as you answer the questionnaire are:

• Print or otherwise make sure you write legibly. No points are given for neatness, so don’t worry about strikeovers or cross-outs, but make sure what you write is readable

• Consider using a computer. It will be much easier to read. Be sure to include every question, preferably typed in bold to distinguish it from your answer. Sometimes, when you use a computer, your completed questionnaire looks “too good for a disabled person to complete.” However, you know how many hours and how many separate sittings you spent getting it to look good. If the questionnaire looks “too good,” note at the end of the questionnaire just how much time you spent completing it as well as any symptoms exacerbated by it. If someone assisted by writing, typing, or reviewing, acknowledge that as well

• Don’t leave any blanks. If there is nothing to say, write “N/A” or “None” to let them know you didn’t overlook or ignore the question

• Avoid one-word answers. Explain why “yes” or “no” is the answer, and, when possible, give an example or anecdote that illustrates your reply

• Don’t be intimidated by small space for answers. If you require more space, simply note “See Attached Sheet,” and put the answer on a blank sheet of paper. Make sure you put your name and Social Security or Claim number on every sheet, and number the answer to match the question
The questions on a Daily Activities Questionnaire may vary slightly, but they generally cover the same areas in various degrees of detail:

- **What are your living arrangements?** Do you live alone, or is there someone to help with the chores? Do you live in a house or apartment? Give appropriate details. For example, if you live in a two-story dwelling, comment on how you limit your trips up and/or down stairs due to pain/fatigue/etc., and on any accommodations you have made in your living arrangements.

- **Describe what you do on an average day.** This is the most important question and should be answered in some detail. Start with what time you get up and why you get up at that time. How long does it take to groom yourself? What do you have for breakfast and who prepares it, or is it just cold cereal or something else easy? How do you typically spend your morning – resting, running errands, going to the doctor?

- **What do you have for lunch?** What do you usually eat? What shortcuts are taken in preparing lunch?

- **How do you spend the afternoon?** Do you read, watch TV, nap, do some housework?

- **What about dinner?** Who fixes it? What is it, if you prepare it? How is this different from when you were healthy? Again, note all shortcuts that you use in meal preparation and clean-up, if you do it yourself. When you answer this question, be sure to describe how your condition affects your daily life, particularly the changes you have had to make in your daily life due to your condition. While many of these items may be covered in later parts of the questionnaire, it never hurts to repeat or mention them and to note that there is a more elaborate answer later in the questionnaire.

- **Do you need help completing your housekeeping tasks?** Here you can explain who helps or does the housekeeping, cleaning, laundry, yard work, and meal preparation. If you do these yourself, be sure to explain how you have adjusted to accommodate these tasks to your condition, i.e., whether you do them more slowly or not as often or in brief periods. Again, as you answer this question, indicate how your health condition has affected your ability to complete your chores. For example, “I used to be able to change the sheets on the bed, but now I get so dizzy when I bend over my husband (or friends) do it so they only get changed twice a month now.”

- **Personal care.** This gives you the opportunity to tell how your grooming habits have changed, that it takes longer to complete, or that you don’t groom as carefully or as often as before. What special adjustments have you made due to your condition? One client who had memory problems said: “I keep all my grooming needs in a basket and take them out as I use them so I will know when I have done everything.”

- **Hobbies and interests. Reading and TV viewing habits.** It is more important in this
section to contrast your current interests and habits with those when you were healthy. Depending on the symptoms, many people are no longer able to engage in many of the physical activities they enjoyed when they were healthy. They also often find that because of fatigue or loss of cognitive ability, they don’t read novels or watch heavy dramas but favor, lighter and shorter fare. If you still engage in some activities, be sure to give details of any adjustments you had to make because of your condition.

- **Errands and transportation.** They usually will ask about your driving ability or how you get around. They will also ask about shopping, who does it or, if you do, how often. Again, it is important to note any changes in your routine that you have made to accommodate your symptoms. Do you limit your driving to the neighborhood and daytime only? Do you buy smaller sizes so they are easier to carry or does a friend or spouse help with the major shopping trips? Do you have a spouse or friend accompany you on most outings?

- **Money and bills.** This is usually a small section of the questionnaire; however, it can be an important one. If any problems are shown in this area, Social Security may approve benefits, but will insist that you appoint a Representative Payee to receive the benefits and disburse the money on your behalf. Should this occur to you and you believe you are able to handle your own finances, SSA is usually willing to drop that requirement.

Sometimes, you will have issues that aren’t directly addressed in the questions, but they show ways that your disability has affected you and your life. If there is no “catch-all” question at the end, add one to it labeled, “Additional Information.”

If your condition has changed your level of patience or the way in which you deal with your family or with others, be sure to note that, even if not asked. If you have gone from being socially active to a more reclusive lifestyle, tell them about that.

When possible, give an anecdote that illustrates the change you are describing. For example, name the TV show you turned off because it was too complicated to follow, or, tell about the stool or small table you placed just outside your door to set items on while unlocking the door. Describe what tools and assists you purchased or created to make certain tasks easier on you, and describe how you leave some groceries in the car and take them in at a later time.

This is the only opportunity you have to show how the medical condition has affected your life and your ability to function, so be sure to give all details of your changes, limitations and accommodations. It is important to explain it in detail. Do not presume
that the analyst will assume anything; explain it thoroughly. In addition to showing how you are unable to work because of your condition, it will also give the analyst a more vivid picture of the human being that is suffering – something that can’t be learned from reading the medical facts.

15. Helping Your Social Security Claim through the System

Most people who file for Social Security disability benefits – either Supplemental Security Income (SSI) or Social Security Disability (SSDI) – complete the required paperwork, submit it, and then they wait. And wait.

Sometimes you can wait for months without hearing a word. Failing to follow up on the claim and track it through the system may be one reason why more than half of all disability applications are denied the first time around.

After you submit your initial paperwork, there is a lot you can do that will improve your chance of approval. In addition to making sure your claim doesn’t get lost or sidetracked, tracking your claim ensures Social Security has received every piece of information needed to approve your claim.

First, understand that the Social Security Administration is not “out to deny your claim.” The people who decide whether or not you qualify for benefits would just as soon approve your claim as deny it. It’s not their money; they’re happy for you to get it. The problem they have is the small amount of time they can spend on each claim.

They work in a huge bureaucracy. That bureaucracy, in its attempt to decide claims in the same manner in all offices, requires that specific information and documents must be in the file before a claim can be approved. A Claims Service Representative or a Claims Analyst’s performance is measured by how quickly and thoroughly they can complete and close their claim files.

Their workload is so large they can’t follow up and track down everything they need or have requested. If they don’t have enough information to approve your claim and if they do not receive the medical records they need after a few requests, they will simply deny the claim. You can prevent that by staying in touch with the people handling your claim. They will appreciate any help you can give them.

Your first step is to take all the necessary information and documents needed to the initial interview. You can obtain a list of what you will need at www.ssa.gov, at other
websites, from Social Security literature, or from the telephone clerk who schedules your initial appointment.

The person you meet with at the initial interview is not the person who will be reviewing your medical records. Once a disability file is opened at Social Security, officials send your file to the local state office that examines all disability claims in your state and determines if you meet Social Security’s definition of disability. A Claims Analyst in that office will be assigned to your claim and will order the medical records from your doctors, send you and your doctors questionnaires to complete, decide whether you need to see a Social Security doctor, and finally decide whether or not you are eligible for benefits. You can provide invaluable help to the analyst through the process.

When you have your initial interview, ask the Claims Representative how long it will take to assign a Claims Analyst. This will vary by office and can be anywhere from two or three days to two or three weeks. Ask for the phone number you can call to find the name of the Claims Analyst once your file is assigned. Following the timeline recommended by the Social Security Representative, call the number and get the name and phone number of the analyst assigned to your claim.

Call the analyst. Introduce yourself. Usually he or she will need your name and Social Security number to locate your file. Ask her for the Case or File Number. This is an internal number that the Disability Evaluations Department assigns to each application. Using that number during future calls will help the analyst find your file faster. Let her know (the analyst may be a “he” but most are women) that you are calling simply to offer your help in obtaining all the information needed to make a determination.

When talking to the analyst (or the Social Security Representative), stay helpful and empathetic to her workload. While you want to make each contact as pleasant as possible, don’t expect her to have the time to “visit” with you. Keep your contact brief and to the point.

A good way to avoid calling too often and becoming a “pest” is, at the end of each conversation, tell the analyst, “I don’t want to bother you but I want to stay on top of my claim. When would be a good time to check back with you? In a week?” That lets the analyst stay “in control” of your contacts. She won’t feel so intruded upon if you call back after an interval that she has already agreed to.

Also remember that your contacts are to help the analyst perform her job. Trying to persuade her to approve your claim is no help. Focus on getting her what she needs to decide your claim. And arguing with her is downright harmful. In fact, if you end up in
a conflict with the analyst, I encourage you to hire an attorney or advocate to deal with her directly. That will get things off to a fresh start.

During the first phone call, ask her if she has had a chance to look at your file to see what medical records she will need to obtain. It is entirely possible that she has not. Ask her to let you know when she sends out requests (if she hasn’t already) for medical records. Ask her to send you copies of the requests so you can follow up with each doctor to make sure the records are sent promptly.

Once you know which doctors she is sending requests to, you should contact each doctor’s office, advise the office staff that the request is coming, and ask them to send the information as quickly as possible. If the staff is busy, you or your spouse may even want to offer to come in and do the photocopying of the medical record for them.

Once you have the date that the records were sent to the analyst, allow for mail time, then call the analyst to make sure she got them. You may have to go back and forth between the various doctors and the analyst several times. Do not be impatient, and don’t blame either the analyst or the office staff. Be patient and persistent. Just keep calling and asking and checking. In other words, do everything possible to see that the requested records get to the analyst. If necessary, go to the doctor’s office, photocopy the records yourself and send them by registered mail to the analyst.

If the analyst sends you a questionnaire to complete, it is usually due back within ten days. However, if you call the Analyst, she will always allow you extra time to complete and submit it.

If the analyst wants you to see a Social Security doctor, call her and ask if your own doctor can perform the examination. They will approve that most of the time provided your doctor agrees and is willing to accept Social Security’s fee.

There are some things that an analyst will not do, however, so it is better not to ask. They will not help you fill out the questionnaires they send. Those are for you and your advocate to do. Also, they are not allowed to tell you whether your claim has been approved or denied. As long as the analyst wants more information, you know that there is not yet enough information in your file to approve your claim, but she is willing to approve it if she can obtain the documentation she needs.

As long as you are willing to continue to provide information, whether it is medical records, physician statements, additional diagnostic examinations, or statements from third party friends or family, most analysts will keep your file open as long as they know
you are working to provide additional evidence.

Once the analyst states that all the necessary information is in, there is nothing more she can tell you. You need to direct further questions back to your local Social Security office. However, you may get a clue to the decision by what happens next. The analyst sends out the denial letters, but acceptances must be sent from the Social Security Administration. So once all the information is in, if you don’t receive a denial fairly quickly, that’s a good sign.

Occasionally, a claim is sent to the Regional Headquarters for a “quality review,” before being returned to the SSA office. The good news there is most claims sent for a quality review are approved claims.

One final note, some analysts never answer their phones and rely on voicemail for client contact or only take calls at certain times. Don’t let that deter you. Conduct your business by voicemail, just as if you are talking to her. Offer to help; ask for the doctors she is contacting; offer to follow up. It is the rare analyst that won’t take advantage of your offer. Your assistance makes it easier for her to do her job.


Many who collect disability benefits under either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) would like to try to do some work. Working can supplement your income, but more importantly, it can improve your spirits and help lessen the depression that can accompany total disability.

For people with hepatitis B or C, there are days when some work is possible even though it may not be 40 hours a week. But many people are hesitant to try any type of work for fear it will jeopardize their Social Security benefits.

Both SSDI and SSI have programs that permit you to earn some money without losing disability benefits. However, before you start working and earning any wages it is important that you thoroughly understand Social Security’s rules about work. Mistakes and misunderstandings can result in overpayments that must be paid back to Social Security as well as potential loss of benefits.

The types of restrictions that Social Security imposes on work are totally different under SSDI and SSI. If you are receiving both SSDI and SSI, both sets of rules apply, which can really complicate your return to work.
Before going into the rules of the two plans, there are some important health and financial issues to consider:

- **First, consider a “dry run” at work**

Before attempting to do any type of work for wages, make sure you can physically and emotionally handle a regular schedule. A person who has not had to maintain a regular schedule in some time may find that the stress and physical demands can quickly overwhelm someone with fragile health.

Start with a volunteer project, doing anything as long as it involves some regular hours and no wages. It may be at a child care center, stuffing envelopes for a political candidate, or whatever you may feel capable of doing for one to four hours a day. The important issue is the schedule, not the work.

See how you react to having to get up every morning and go somewhere for a few hours, five days a week. Two or three weeks of this will give you a good idea of how well you might handle some employment.

- **Keep careful records of income and hours worked**

Once you start working for wages, keep all paycheck stubs. Also, keep careful records of your work hours. Make sure your records show not only gross pay, but also net pay, hours worked, and time period when the wages were earned.

While you may think that Social Security will have all it needs from your payroll records, keep in mind the records that Social Security receives only show gross pay and what tax year they were paid in. Also, Social Security is usually about two years behind in posting them to your Social Security account.

- **Keep receipts and records of any additional expenses you incur due to working and your disability**

Social Security allows you to subtract from your earnings any expenses you incur that are necessary for you to work. This can include the cost of special transportation to and from work, prostheses and assisting devices, even medical expenses such as acupuncture, massage therapy or chiropractic treatments.

- **Tell Social Security of your plans to work**

Unless you are going to be earning very small amounts, you should notify Social Security of your plans to attempt to do some work. To preserve a record of your notification, either mail them a certified letter while keeping a copy, or personally deliver a letter
outlining your plans to your local office and get a signed receipt for it.

• Some people are afraid to tell Social Security about working because they fear that it will trigger a review of their disabled status

While that may seem like a rational concern, it does not work out to be the case. The time for the next Continuing Disability Review is set at the time one is completed. Social Security is much too overloaded with work to track and compare people trying to work with their Disability Review date.

• Don’t follow the wage maximums too closely, however

If your wages are just below the maximum limits on a consistent basis month after month, then sooner or later, Social Security will become “curious” to determine if your limited work is really due to your medical condition or if you are intentionally keeping your income low to qualify for benefits.

• Do some more research on Social Security and work before starting back to work.

The rules are pretty complicated. The Social Security website has a wealth of information about working while collecting benefits. Here are two good websites:

- Working While Disabled at www.ssa.gov/pubs/10095.pdf

• How SSDI and SSI Calculate Your Work Income

Both look at what is called “Countable Income.” That is the gross amount of your earnings after any expenses necessary to keep you working and less any subsidized earnings provided by your employer. Social Security deducts work expenses related to your disability from your earnings before it determines if you are still eligible for benefits. These expenses may include the cost of any item or service you need to work, even if the item or service was also useful to you in your daily living. Examples include prescription drugs, transportation to and from work (under certain conditions), a personal attendant or job coach, a wheelchair or any specialized work equipment.

• Social Security Disability Insurance (SSDI)

You can collect your full SSDI benefits and earn all you are able to earn for nine months. These nine months are called the Trial Work Period.

The trial work period allows you to test your ability to work for at least nine months. During your trial work period you will receive your full Social Security benefits regardless
of how much you are earning. The trial work period continues until you have worked nine months within a 60-month period. Any month that your Countable Earnings exceed $780 (for 2010) counts as a Trial Work Month.

Extended period of eligibility – After your nine-month trial work period, you have 36 months during which you can work and still receive benefits for any month your earnings are not “substantial.” In 2010, earnings of $1,000 per month or more ($1,640 if you are blind) are considered substantial. No new application or disability decision is needed for you to receive a Social Security disability benefit during this period.

Quick benefit restart – After your benefits stop because your earnings are substantial, you have five years during which you may ask to restart your benefits immediately if you find yourself unable to continue working because of your condition. You will not have to file a new disability application and you will not have to wait for your benefits to start while your medical condition is being reviewed to make sure you are still disabled.

Continuation of Medicare – If your Social Security disability benefits stop because of your earnings, but you are still disabled, your free Medicare Part A coverage will continue for at least 8½ years after the nine-month trial work period. After that, you can buy Medicare Part A coverage by paying a monthly premium.

During the trial work period, there are no limits on your earnings. During the 36-month extended period of eligibility you usually can make no more than $1,000 a month or your benefits will stop. But, the work expenses you have as a result of your disability are deducted when Social Security counts your earnings to see if it can help you keep more of your benefits. If you have extra work expenses, your earnings could be substantially higher than $1,000 before they affect your benefits. This substantial earnings amount usually increases each year.

If you lose your job during a trial work period, your benefits are not affected. If you lose your job during the 36-month extended period of eligibility, call Social Security and your benefits will be reinstated as long as you are still disabled.

Note to self-employed persons – For a self-employed person, Social Security considers any month that you work over 80 hours in the month as exceeding Substantial Gainful Activity, regardless of your countable income. Also, regular business expenses are subtracted from earnings to arrive at countable income.

• **Supplemental Security Income (SSI)**
SSI treats wages from work more as an ongoing possibility where SSDI considers it to
be part of a progression back to full-time employment.

The amount of your SSI payments is based on how much other income you have. When your other income goes up, your SSI payments usually go down. So when you earn more than the SSI limit, your payments will stop for those months. But, your payments will automatically start again for any month your income drops to less than the SSI limits. Just tell Social Security if your earnings are reduced, or if you stop working.

If your only income besides SSI is the money you make from your job, then Social Security does not count the first $85 of your monthly earnings. It deducts from your SSI payments half of what you earn after the $85 deduction.

Example: You work and earn $1,000 in December. You receive no other income besides your earnings and your SSI payment. Social Security would deduct $457.50 from your SSI payment for December. It subtracts $85 from $1,000 and divides the sum in half:

\[
\begin{array}{c}
  \$1,000 \\
  - \$85 \\
  \$915 \text{ divided by } 2 = \$457.50 \\
\end{array}
\]

You may be eligible for a “plan for achieving self-support” which allows you to use money and resources for a specific work goal. These funds do not count when Social Security figures out how your current income and resources affect your benefit amount.

• How Long Will Medicaid Continue?
In general, your Medicaid coverage will continue, even after your SSI payments stop, until your income reaches a certain level. That level varies with each state and reflects the cost of health care in your state.

However, if your health care costs are higher than this level, you can have more income and keep your Medicaid. In most states, for your Medicaid to continue, you must:
• Need it in order to work
• Be unable to afford similar medical coverage without SSI
• Continue to have a disabling condition, and
• Meet all other SSI eligibility requirements

If you qualify for Medicaid under these rules, Social Security will review your case from time to time to see if you are still disabled or blind and still earn less than your state’s
allowable level.

• **Ticket to Work Program**

Social Security offers a “Ticket to Work” program. It sends you a “ticket” you can use to obtain vocational rehabilitation, training, job referrals and other employment support services free of charge. You will not need to undergo medical reviews while you are using the ticket.

You can get more information on the Ticket to Work program by calling Maximus, Inc., the ticket program manager, at 866-968-7842 toll-free (TTY 1-866-833-2967). Or you can call the toll-free number, 800-772-1213 (TTY number 800-325-0778) and ask for a copy of Your Ticket To Work (Publication No. 05-10061).

Additional information is available at Social Security’s Ticket to Work website, at www.ssa.gov/pubs/10061.html

17. **How Social Security Monitors Your Disability**

If you are collecting either Social Security Disability (SSDI) or Supplemental Security Income (SSI), your medical records will be reviewed periodically to see if you are still disabled enough to continue to qualify for benefits.

Social Security calls these medical reviews “Continuing Disability Reviews,” or CDRs. They should not be confused with the financial reviews that SSI recipients receive every year to confirm their financial need for SSI.

Each time Social Security reviews your medical file, they set the schedule for the next medical review. Your initial Notice of Award of benefits will tell you approximately when they next plan to review your medical record to determine if you remain disabled.

For claims in which they expect to see some medical improvement, they schedule the next review for three years. For claims in which they do not expect to see improvement, they schedule the next review in five to seven years. Claimants disabled due to hepatitis C, for example, are usually scheduled for review in five to seven years, however, in some cases, they will schedule it sooner.

Because of these reviews, it is important that you continue to report all your symptoms to your physician and make sure they are entered into the record.
When it’s time for a CDR, Social Security will send you one of two forms:

- Short Form CDR (SSA-455-OCR-SM)
- Long Form CDR (SSA-454-BK)

The “right” way to fill them out depends on which form of CDR you are sent.

**The short form (SSA-455-OCR-SM)** is the “easy” one. It is only two pages long and is read by computer (OCR stands for Optical Character Reader). Because it is sent primarily to beneficiaries who have a low probability of medical improvement, this is probably the form you will receive.

This is good in that the short form assumes you are still disabled unless you give them reason to question that. A human only looks at the short form if the computer kicks it out for one reason or another. If it isn’t sent to a human for further review, then your benefits continue uninterrupted.

Assuming you are still disabled and your condition has not measurably improved, there are some things you can do to see that the computer accepts the form without sending it for further review:

- Fill out the form exactly as instructed. Use a box for each letter or number. If the boxes run out, stop, even if it’s mid-word.
- Do not offer any new information. The goal of this form is to simply confirm the information they already have, so you don’t want to include any changes, not even administrative changes such as an address change on this form. New information will cause the form to be kicked out for human review.
- Use your original diagnosis. Under “Reason for Last Visit,” use the same diagnosis for which you were approved.

**The long form (SSA-454-BK)** is 10 pages and is very similar to the original forms that you filled out when you first applied for Social Security Disability. It primarily asks for the names and addresses of all your providers. They will obtain your medical records directly from them.

This form not only goes to persons whose condition is expected to improve, it is also sent to persons whose short form was “kicked” by the computer, and is randomly sent to persons as part of a trial or study that Social Security may be conducting. The long form should be filled out just as thoroughly and completely as when you initially applied for disability benefits.

On this form, it is important to note any changes in your medical condition, especially new
infections, symptoms or diagnoses. Make sure your doctors are alerted to the review and that they submit new medical records since your last review promptly.

Be sure to make copies of the completed CDR, including the short form, before sending it in. This will facilitate the next review when it comes.

The CDR performed by Social Security is entirely different from the periodic reviews conducted by disability insurance carriers. Social Security does not necessarily “try” to find reasons to terminate benefits. Current medical records that show you are still under a doctor’s care and that you still have the condition and the symptoms that prevented you from working initially are usually all that is needed to continue your Social Security benefits without interruption.

18. How to Appeal if Social Security Denies Your Disability Benefits Claim

More than half of the people who apply for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) are denied benefits the first time they apply. This denial does not necessarily mean you do not deserve benefits, instead, it may mean that you or your healthcare provider did not provide all the information needed to prove your claim.

The Social Security Administration (SSA) does offer a way to appeal the denial, and if you appeal you can get the denial overturned and benefits awarded about 60 percent of the time. The appeal procedures are the same throughout the United States, with the exception of a few areas that participate in a Disability Redesign Protocol pilot program that is described below.

The appeal process starts when you receive a denial letter from Social Security. The letter gives the reason(s) that your benefits are denied and it lists the medical records that they used to make their decision to deny you benefits. The letter is also dated, and that date starts the clock for the first level of appeal.

• Reconsideration

After you receive your letter of denial, you have 65 days from that date to ask Social Security to “reconsider” its decision. The agency gives you 60 days from the time you receive the letter to submit an appeal, and they assume you will receive the denial letter five days after the letter is dated.
To have your claim reconsidered, you must submit two forms:

- Reconsideration Disability Report (SSA-3441-F6 found at www.ssa.gov/online/ssa-3441.pdf) – This form consists of a series of questions that allow you to provide any new or additional information about your medical condition and to list any medical providers whose records weren’t used in the initial decision. (For more information on filling out this form, go to SSA’s website at www.ssa.gov/online/ssa-3441.html)

- Request for Reconsideration (SSA-561-U2, found at www.ssa.gov/online/ssa-561.pdf) – This is the actual request for review; however, it can practically guarantee another denial if you aren’t careful. This form gives you three lines on which to explain why you don’t agree with the denial. I have never seen a denial overturned because of three lines of information. (For more information about this form, go to SSA’s website at www.ssa.gov/online/ssa-561.html)

However, an approval is rarely granted based on the information conveyed in these two forms. To get your denial changed to an approval, you must provide much more information. You must write “see attached documents” on the request form and submit:

- Medical records that show your symptoms are more severe than the original medical records stated

- New medical records and test results that provide more objective proof of your condition

- Documentation that shows your condition meets one of the listings of impairments used by Social Security

- And any other documentation that supports your claim, such as third party testimony, symptom diaries, etc.

Once you submit your Request for Reconsideration and accompanying documentation, the process is very similar to that used with the initial application. Your claim will be assigned to a claims or disability analyst, and that person will review all the medical information and determine whether or not you are disabled. Just as with the initial application, the analyst may request additional medical records or schedule you to have a consultative examination by one of their doctors.

Sixty-five days is not a lot of time, so it is necessary to work quickly to obtain all the necessary documentation you need to overturn your denial. Start with examining the denial letter. Although it appears to be a form letter, it really contains information important to the preparation of your appeal.

First, look at the medical records the officials used in their examination of your claim. What is missing? Did they miss a report submitted by one of the specialists? How about
your therapist? What is not on their list that would have supported your claim? Next, look at the reason for the denial. This will give you an idea of just how much is missing to qualify for benefits. Often, the officials will claim they didn’t find evidence that your symptoms were severe enough to prevent you from working. In that case, they believe you can go back to your prior work so they really don’t consider you disabled at all.

Other times, they will claim that while you may be disabled enough to be prevented from performing your old work, there is other work available that you can do. Essentially, they agree that you are disabled, but not disabled enough to prevent you from doing some other job.

When preparing your reconsideration appeal, start with the listing of impairments and the medical records you will need to show how your symptoms prevent you from doing any kind of work. (Make sure your symptoms reflect symptoms in the SSA Blue Book that result from hepatitis.) Assemble your documentation and submit it with the required reconsideration forms.

Once your information is received, you need to follow up during this process just as you did with your initial application because this level of appeal is basically a replay of the initial application process.

Don’t take the denial personally. Social Security officials are not saying that you are not disabled; they are not saying you are able to work; and they are certainly not saying that your symptoms don’t exist. They are examining medical records, which are not always the most complete or easy to read. The people who review your claim have certain steps they must follow and certain information they must find. If they don’t find it, they have no choice but to deny your claim. If you work with the analyst handling your reconsideration appeal, you can frequently provide him or her with the information needed to get your claim approved.

Many people, especially attorneys, will advise you not to waste time on the reconsideration step, but just file the necessary forms and wait for the denial. They will warn you that about 80 percent of all reconsiderations are denied. However, some believe that this very advice is what has created these distorted statistics. If you follow the advice in this handbook and study some of the many websites dedicated to Social Security disability, including Social Security’s own site at www.ssa.gov, you have a good chance of being one of the 20 percent who gets their application approved and of avoiding the necessity of waiting the many months it takes to get to the next level of appeal – as well as having to share your benefits with an advocate.
• Disability Redesign Prototype

In an effort to reduce the amount of time it takes to appeal denials, Social Security launched a pilot program in certain parts of the country. While the results of this program have been mixed, it is still followed in those areas where it was first launched, which includes the states of Alabama, Alaska, Colorado, Louisiana, Michigan, Missouri, New Hampshire, Pennsylvania as well as Albany and Brooklyn in New York, and certain Social Security offices in the Los Angeles area: Metro (Alhambra, Burbank, Chatsworth, Glendale, Glendora, Tujunga, University Village, Watts), Sierra West (Crenshaw, Culver City, Inglewood, Torrance), and South Coast (Compton, Huntington Park, Norwalk, Whittier).

Under this prototype program, the reconsideration stage of appeals is eliminated. Instead, the Social Security representative is to contact you, inform you that the medical record as examined does not support a claim for disability, and give you the opportunity to add additional documentation and medical evidence to the file before it is officially denied. Unfortunately, the letter being used to notify you does not clearly spell out that your claim will be denied unless you either submit more documentation or request an interview with the representative.

If your claim is filed in one of the above areas, you should carefully read every piece of correspondence from Social Security and call if you are not clear about what they are telling you. (Of course, you should do that anyway, regardless of where your claim is filed.)

• Administrative Law Judge (ALJ) Hearing

If your reconsideration appeal is denied, the next level of appeal is a hearing before an Administrative Law Judge (ALJ). This is a somewhat informal version of a trial, except there is no opposing counsel. You are given an opportunity to present your case to the judge and, for the record, additional documentation, and to explain how the documentation they already have should be sufficient to allow your claim. The judge then decides whether your claim should be approved or denied. Many claims are approved at this level.

While you may appear on your own behalf without an advocate, virtually everyone who knows the system strongly recommends that you obtain an advocate to help you argue your case at this level. The advocate may or may not be an attorney, but it should be someone who specializes in Social Security appeals.

Social Security requires that these advocates only charge you a fee if they are successful.
in obtaining your benefits. That contingency fee is limited by Social Security to 25 percent of any retrospective payment you receive from Social Security to cover the months during which you should have received benefits. Be aware, however, that the advocate may charge for “expenses” in addition to the fee and may charge for them whether or not your claim is approved. Before signing up with an advocate, make sure you know just how these expenses will be determined. You also need to have a clear understanding of your involvement in the process. Many excellent advocates are so involved in their cases that they neglect to keep their clients informed of the process and their progress, creating unnecessary stress and worry for you.

• The Appeals Council
If your case is denied at the ALJ level, you may appeal to an Appeals Council, which will decide, not if you are disabled or not, but rather, if the ALJ hearing was conducted appropriately and the evidence examined correctly. If not, they will return it for another ALJ hearing.

At this level an advocate is practically a requirement, and, because there is only one Appeals Council, it may take one, two, or more years for it to review your case. You do not appear before the council; it reviews your file and the transcript of the ALJ hearing in order to make a decision.

• Lawsuit in Federal Court
Your final level of appeal is to file suit in federal court against Social Security for your benefits. Clearly, this requires an attorney and years before a decision is finally made. Instead of going to this level, many claimants will abandon their old claim and file a new one, although approval of the new claim will result in loss of all the past benefits under the old claim.

19. Getting Medicare When You Receive SSDI

In addition to providing health coverage for people age 65 and older, the federal Medicare program also covers people who collect disability benefits from Social Security Disability Insurance (SSDI). That’s the good news.

Now for the bad news. A person collecting SSDI benefits does not become eligible for Medicare until he or she has collected SSDI benefits for 24 months. Factoring in the five month waiting period for SSDI benefits, Medicare ultimately doesn’t start until 29 months after the Onset Date of the disability.
Just like SSDI, if you didn’t pay into the Medicare system through Med/F.I.C.A. payroll deductions, you will not be eligible for Medicare coverage. People collecting Supplemental Security Income (SSI) are not eligible for Medicare, although in most states they will get Medicaid.

The actual benefits provided by traditional Medicare, also called fee-for-service Medicare, are, like most health insurance benefits, fairly complicated. You can obtain an excellent summary of Medicare benefits at: www.medicare.gov.

Traditional Medicare comes in two parts:
- Part A – Hospital: This portion covers hospitalization, skilled nursing facilities and some home health nursing
- Part B – Medical: This portion covers other medical charges, such as physicians, diagnostic testing, outpatient hospital services, some home health services, and some medical equipment

Part A is automatic. Part B is considered voluntary and once coverage starts, $110.50 (in 2010) will be deducted from each monthly Social Security payment to pay for it. Persons already on Part B at the beginning of 2010 will continue to pay the 2009 premium of $96.40 since there was no Social Security Cost of Living Increase in 2010.

Medicare has also increased the premiums for Part B coverage for higher income beneficiaries:

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*Most people will continue to pay the 2009 Part B premium of $96.40 in 2010.

The Medicare card will arrive in the mail about two months before the eligibility date. Because Part B is considered such an important part of the coverage, you will be automatically enrolled in it. If you decide you do not need the Part B coverage, you should return your Medicare card and “disenroll” from the Part B coverage. The instructions come with the card.

Be careful before dropping Part B, you will face penalties if you later find that you
need to obtain the coverage. Just because you have other coverage does not mean
that you don’t need Medicare Part B. Many health plans reduce their benefits by what
Medicare Part A and Part B would pay, whether or not you are actually enrolled in
Part B. Before refusing Part B, talk to a knowledgeable person about your specific
situation.

Even with both parts of Medicare, not all medical bills will be covered or paid. While
Part A covers most hospital charges, there is a $1,100 (in 2010) hospital deductible.
Medical charges under Part B are covered only up to 80 percent of physician’s
charges and other covered medical expenses after a $155 annual deductible.

The Part A deductible is the beneficiary’s only cost for up to 60 days of Medicare-
covered inpatient hospital care in a benefit period. Beneficiaries must pay an
additional $275 per day for days 61 through 90 in 2010, and $550 per day for
hospital stays beyond the 90th day in a benefit period.

For beneficiaries in skilled nursing facilities, the daily co-insurance for days 21
through 100 in a benefit period will be $137.50 in 2010.

About 99 percent of Medicare beneficiaries do not pay a premium for Part A services
because they have at least 40 quarters of Medicare-covered employment. However,
other seniors and certain persons under age 65 with disabilities who have fewer
than 30 quarters of coverage may obtain Part A coverage by paying a monthly
premium set according to a statutory formula. This premium will be $461 for 2010.
In addition, seniors with 30 to 39 quarters of coverage, and certain disabled persons
with 30 or more quarters of coverage, pay a reduced premium of $254.

There are several ways to augment the traditional Medicare coverage including some
special programs for persons with limited income. Some of the ways to get assistance
with what Medicare does not cover include:

Trading traditional Medicare for a different Medicare product. Private insurance com-
panies and HMOs offer Medicare plans that you may join as a replacement of tradi-
tional Medicare. When you join one of these plans, your regular Medicare stops and
the federal government pays the insurance company to provide for your care. In some
areas of the country, the insurance company may charge the member a premium as
well, but it is usually low.

While the law permits many different types of these “Medicare+Choice” plans, the
most common type available at present is the Medicare Health Maintenance Organi-
zation (HMO). By law, every Medicare HMO must cover all that traditional Medicare covers, but many HMOs will offer additional benefits such as eyeglass coverage, hearing aids, some prescription drug coverage and other incentives to join their plan.

Anyone who is enrolled in both Parts A & B of Medicare may switch their coverage to one of the Medicare+Choice products or back to traditional Medicare only during each year’s open enrollment period.

**Other health insurance plans.** If you have other health insurance, either an individual policy or are able to continue coverage under your employer’s policy, it will coordinate with your Medicare coverage to pay for what Medicare does not cover. In many ways this is the best possible supplement to traditional Medicare since these plans usually provide broad coverage with unlimited prescription coverage. Between the insurance plan and Medicare, it is possible that you will not have to make any payment for medical care at all.

The primary drawback to these plans is that the premiums are not discounted in cost even though Medicare may pay most of the bill, and health insurance premiums can be expensive. Also, unless you are already covered under another health insurance plan, it will be practically impossible to obtain private insurance coverage once you become eligible for Medicare.

**Medicare Supplement (Medigap) plans.** Insurance companies offer plans that are specifically designed to supplement traditional Medicare. There are 10 different Medigap plan designs. They cover things such as the deductibles, 20 percent of doctor’s fees, coverage when out of the country, and other benefits. Three of the plans provide a limited amount of prescription drug coverage as well.

Medicare requires that Medigap plans be offered during an open enrollment period when a person first gets Medicare at age 65. Unfortunately, there is no provision from the federal government for a similar open enrollment for persons under age 65, so, in many states, these plans are not available to persons under age 65. If they are, the insurance company requires evidence of good health. That effectively blocks coverage since you can’t get Medicare under age 65 unless you are disabled, which means “uninsurable” to an insurance company.

Some states, however, California and New York being two of the larger ones, have enacted legislation that requires an open enrollment period for all persons getting Medicare, even those under age 65. Call your state’s Department of Insurance to see what is available in your state.
Medicaid (called Medi-Cal, TennCare and other names in different states). The health program available in each state for the medically needy provides an excellent supplement to Medicare if you can meet the financial limitations to qualify. In addition to paying what Medicare doesn’t cover, including prescription drugs, Medicaid will also pay the Part B Medicare premium for you.

Medicaid usually is automatic if you get any payment at all from SSI. If not, you may still be eligible for it, but you must apply for it directly. To enroll in Medicaid, contact your state or county Department of Social Services. Because these offices are the same offices that handle food stamps, general relief and other needs-based programs, they are often crowded with long waits, but if you can get Medicaid to cover what Medicare does not, it may be worth the inconvenience.

Other federal assistance. The federal government makes available several other programs to assist persons whose income is low, but not low enough to qualify for Medicaid directly. Even though these are federal programs, application must be made at your local Medicaid office.

To qualify for these programs, assets need to be less than $4,000 for a single individual and $6,000 for a couple. The maximum income to qualify varies by program. The primary programs are:

Qualified Medicare Beneficiary (QMB) – Generally, your assets, (bank accounts, stocks and bonds, for example), must be less than $4,000 for a single person or $6,000 for married persons. Your home and furnishings, a vehicle you use to go to medical care, and some types of burial plans are not counted as assets. Your monthly income, after deductions, must be less than $696 per month for single persons, or $938 for married persons if both are eligible for Medicare. The income deduction for Social Security and other retirement and disability benefits is $20. There are other deductions if you are working.

Specified Low Income Beneficiary (SLMB) – You must be eligible for Medicare Part A, (hospital coverage). Your assets, (bank accounts, stocks and bonds, for example), must be less than $4,000 for a single person or $6,000 for married persons. Your home and furnishings, a vehicle you use to go to medical care, and some types of burial plans are not counted. Your monthly income, after deductions, must be less than $835 per month for single persons, or $1,125 for married persons if both are eligible for Medicare. The income deduction for Social Security and other retirement and disability benefits is $20. There are other deductions if you are working.
The table following shows estimated income limits and program payments.

<table>
<thead>
<tr>
<th>Program</th>
<th>Monthly Income Limit* Effective: 04-01-09 to 03/31/10</th>
<th>Program Pays Medicare’s:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Individual</td>
<td>Couple</td>
</tr>
<tr>
<td>Qualified Medicare Beneficiary (QMB)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pronounced “Quimby”</td>
<td>$ 903</td>
<td>1,215</td>
</tr>
<tr>
<td>Specified Low Income Beneficiary (SLMB)</td>
<td>$ 1,083</td>
<td>$ 1,457</td>
</tr>
<tr>
<td>pronounced “Slimby”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified Individual 1 (QI1)</td>
<td>$ 1,219</td>
<td>$ 1,640</td>
</tr>
</tbody>
</table>

* If you live in Alaska or Hawaii income limits are slightly higher.

If your income is close to any of the figures above, you should apply as certain types of income may be disregarded for eligibility purposes.

Medicare is a fairly broad health insurance plan. Most hospitals are happy to serve Medicare patients. Although there have been articles lately about doctors dropping out of Medicare coverage, a large number still participate. It is possible to find participating doctors experienced in viral hepatitis in most parts of the country.

Like most other health insurance plans, however, Medicare has some gaps that can have a major impact on your finances, so take advantage of whatever programs you may qualify for to help pay your medical expenses.
Medicaid is one of the least understood of any government health programs. It can be a bureaucratic nightmare, which is not surprising when the federal government and each state work together to create health insurance, which is what Medicaid is. While Medicaid provides healthcare coverage for many, there are many more who are eligible for and would derive some benefit from Medicaid could they but get through the bureaucracy to receive it.

Although not a simple process to obtain, Medicaid offers a broad range of coverage. Medicaid is one of the best supplements to Medicare coverage. Medicaid is one of the country’s leading payers of prescription drugs. Medicaid pays more for nursing home care than all the Long Term Care insurance products put together. Medicaid will even pay private health insurance premiums.

A lot of the confusion starts with the fact that, although Medicaid was created under the federal Social Security Act, there are really 50 separate Medicaid programs. Implementation of Medicaid is the responsibility of each state. In some states, it’s not even called Medicaid, e.g., Medi-Cal in California, TennCare in Tennessee.

While the federal government provides some basic requirements for determining eligibility for coverage and benefits to be provided, each state can expand Medicaid beyond that level. As a result of this flexibility each state’s Medicaid program covers a slightly different group of people with a slightly different set of benefits.

• Eligibility
Medicaid was created to be the payer of last resort for people who had no other means of receiving healthcare. It covers anyone over age 65 and anyone who is disabled according to Social Security’s standards if they also meet Medicaid’s financial requirements. Unlike Medicare, Medicaid eligibility is based on need.

Others also may be eligible for Medicaid due to single parent family status or special children’s programs; however, this article will focus on Medicaid for persons who are disabled.

The financial requirements for Medicaid are very similar to those for Supplemental Security Income (SSI). In fact, in most states, if you qualify for SSI benefits, you will automatically get Medicaid. Those states are: Alabama, Arizona, Arkansas,
Persons in those states who don’t qualify for SSI or persons living in other states must apply for Medicaid separately, at their state’s Department of Health Services.

In all states, the maximum resources or assets you can have are the same as for SSI, $2,000 for an individual and $3,000 for a married couple. As with SSI, they do not count the residence you live in, one vehicle, or most personal property such as clothing and furniture.

The income limit for eligibility varies by state. In some states, you are not eligible for Medicaid if your income is higher than the federal SSI level ($674 single; $1,011 couple in 2010). A small number of states have even lower income limits. Other states have higher income limits. Some states will cover people regardless of the size of their income, provided their medical bills are high enough to cause them to be what is called “medically needy.” In those states, Medicaid will pick up all medical bills above a certain level, based on income.

To summarize, in order to be eligible for Medicaid, you must:

- Be declared disabled according to Social Security’s definition of disability;
- Have less than $2,000 ($3,000 for couples) in countable assets; and,
- Have an income that is less than the income limit in your state.

But these rules may not apply if Medicaid is needed to pay nursing home bills (See below).

**Benefits**

The federal government requires at a minimum that the following services must be provided to Medicaid beneficiaries without charge provided they are “medically necessary”:

- Inpatient and out-patient hospital services
- Physician services
- Medical and surgical dental services
• Nursing facility services for individuals aged 21 or older
• Home health care for people eligible for nursing facility services
• Family planning services and supplies
• Clinic treatment
• Laboratory and x-ray services
• Pediatric and family nurse practitioner services
• Nurse-midwife services, to the extent authorized under state law; and
• Early and periodic screening, diagnosis, and treatment services for people under age 21.

In addition to those required benefits states may opt to offer additional benefits. For example, at the present time, every state’s Medicaid program provides coverage for out-patient prescription medications.

Other optional benefits covered in most states include: optometrist services and eyeglasses, medical transportation, physical therapy, prosthetic devices, dental services and dentures.

Other benefits covered to varying degrees in a few states include: chiropractic care, podiatry, preventive care, and speech and occupational therapy.

As you can see, the benefits provided under Medicaid are fairly broad. In addition, persons covered under Medicaid programs do not pay anything towards those services, no deductible, no percentage of the bill. Only certain optional benefits will require a co-payment and virtually every state waives those for Medicaid beneficiaries with very low incomes.

The quality of care can vary widely under Medicaid. Each state determines the amount it will pay medical providers for their services. In some states the reimbursement level is sufficient enough that many providers will participate. In other states, the reimbursement level is so low that most private physicians will not accept a patient whose only coverage is Medicaid, and Medicaid beneficiaries must seek their medical care at public health clinics, free clinics, government hospitals, and non-profit medical facilities.

• Medicaid HMO’s
As is popular in private health insurance, many states are looking to Managed Care Programs, usually Health Maintenance Organizations (HMOs), to provide
care under Medicaid. In some states, the only option under Medicaid is an HMO-type plan, which limits your choice of medical providers and requires you to let a Primary Care Physician direct all of your care.

Some states require HMOs for certain Medicaid beneficiaries, such as single parents and children’s programs, but permit those who are disabled to remain under a fee-for-service program if they choose. If HMOs prove to be an efficient way to provide care and control costs, you may expect to see more and more states move exclusively to them.

• Nursing Home (Custodial) Care

“Custodial care” is medical care, usually in a special facility such as a nursing home, where a person requires assistance and care supervised by a medical staff, but no aggressive treatment is sought and no recovery is anticipated. In addition to a housing facility, custodial care may be provided in the home through home health agencies.

Custodial care usually involves some basic medical care, but primarily the patient requires assistance with activities of daily living, such as bathing, eating, moving from bed, etc. Insurance plans and Medicare do not provide coverage for custodial care for any extended period of time. What custodial care they provide is always short term, such as under a hospice benefit.

Long Term Care insurance which is designed to cover these charges is still relatively new on the market and can be very expensive to purchase. Medicaid does cover custodial care expenses and will provide coverage for years, if necessary.

Many people, especially middle income earners, do not think of Medicaid as an option for them. However, when it comes to nursing home coverage, Medicaid can be very generous in providing coverage, especially in the situation where one member of a married couple requires custodial care in a facility, while the healthy spouse seeks to remain in the family home.

Medicaid will cover the nursing home charges, and will still allow the healthy spouse to stay at home to receive the lion’s share of the couple’s income and have assets of as high as $90,000 not counting the family home, or higher.

These rules are very complicated so if you are considering using Medicaid for this purpose, I strongly encourage you to seek the advice of an attorney who specializes in Elder Law and knows Medicaid law.
• Medicaid and Other Health Insurance

Most states offer another benefit to those disabled persons who become eligible for Medicaid but also have some form of private health insurance. For a person incurring high medical bills, it is much cheaper for Medicaid to take over payment of the insurance premiums than it would be to pay the bills if the insurance lapsed.

Because of this cost effectiveness, most Medicaid plans have a Health Insurance Premium Payment program which will pay health insurance premiums. Each state sets its own rules for eligibility in this program.

• Finding out about your state’s Medicaid coverage

Because of the variety of Medicaid rules in each state, it is impossible to know whether you would be eligible for or would benefit from Medicaid coverage in your own state. Before dismissing it completely, however, you should explore more about your state’s Medicaid coverage.

The best place to start is at the website of the Centers for Medicare and Medicaid Services, the federal agency that oversees those programs. It is located at http://cms.hhs.gov/. It will give you information about Medicaid in general as well provide contact information for each state’s Medicaid offices.

Also, most states have a Medicaid website as part of the state website; however, not all give helpful information on the eligibility and application process.

One of the best resources for information on your state’s Medicaid program is local non-profit organizations whose clientele utilize Medicaid and Medicare. Some states have advocacy organizations specifically for these government programs. In California, for example, HICAP (www.cahealthadvocates.org/) provides assistance to people concerning Medicaid. Some web-searching and inquiries among disabled groups should guide you to the information you need.

Below is a list of the Medicaid offices in each state:
State Medicaid Offices

Alaska
Alaska Department of Health and Social Services
350 Main Street, Room 229
P.O. Box 110601
Juneau, AK 99811-0601
Local: 1-907-465-3030

Alabama
Medicaid Agency of Alabama
501 Dexter Avenue
P.O. Box 5624
Montgomery, AL 36103-5624
Local: 1-334-242-5000
Toll-Free: 1-800-362-1504
Fax: 1-334-353-5989

Arkansas
Department of Human Services of Arkansas
P.O. Box 1437, Slot 1100
Donaghey Plaza South
Little Rock, AR 72203-1437
Local: 1-501-682-8292
Toll-Free: 1-800-482-5431 (Eligibility call 1-800-482-8988)
Spanish Phone: 1-800-482-8988
Local TTY: 1-501-682-6789
Fax: 1-501-682-1197

American Samoa
Department of Human Services of Hawaii
P.O. Box 339
Honolulu, AS 96809
Toll-Free: 1-800-882-4608
Local TTY: 1-808-692-7182

Arizona
Health Care Cost Containment of Arizona
801 E. Jefferson
Phoenix, AZ 85034
Toll-Free: 1-800-962-6690
Spanish Phone: 1-602-417-7700
Local TTY: 1-602-417-4191
Fax: 1-602-252-2136

California
California Department of Health Services
P.O. Box 942732
Sacramento, CA 94234-7320
Local: 1-916-440-7400
Local TTY: 1-916-445-0553

Colorado
Department of Health Care Policy and Financing of Colorado
1570 Grant Street
Denver, CO 80203-1818
Local: 1-303-866-2993
Toll-Free: 1-800-221-3943
Spanish Phone: 1-303-866-1416
Local TTY: 1-303-866-3883
Fax: 1-303-866-4411

Connecticut
Department of Social Services of Connecticut
25 Sigourney Street
Hartford, CT 06106-5033
Local: 1-860-424-4908
Toll-Free: 1-800-842-1508
Fax: 1-860-951-9544
**District of Columbia**
DC Department of Health
825 North Capitol Street, NE
5th Floor
Washington, DC 20002
Local: 1-202-442-5999

**Delaware**
Delaware Health and Social Services
1901 N. DuPont Highway
P.O. Box 906, Lewis Bldg.
New Castle, DE 19720
Local: 1-302-255-9040
Fax: 1-302-255-4429

**Florida**
Agency for Health Care Administration of Florida
P.O. Box 13000
Tallahassee, FL 32317-3000
Toll-Free: 1-888-419-3456
Fax: 1-850-922-7703

**Georgia**
Georgia Department of Community Health
2 Peachtree Street, NW
Atlanta, GA 30303
Local: 1-770-570-3300
Toll-Free: 1-866-322-4260
Fax: 1-270-804-7442

**Hawaii**
Department of Human Services of Hawaii
P.O. Box 339
Honolulu, HI 96809
Toll-Free: 1-800-882-4608
Local TTY: 1-808-692-7182

**Iowa**
Department of Human Services of Iowa
Hoover State Office Building
5th Floor
Des Moines, IA 50319-0114
Local: 1-515-327-5121
Toll-Free: 1-800-338-8366
Fax: 1-515-281-4597

**Idaho**
Idaho Department of Health and Welfare
450 West State Street
Boise, ID 83720-0036
Local: 1-208-334-5500
Toll-Free: 1-800-685-3757
Local TTY: 1-208-332-7205

**Illinois**
Department of Public Aid of Illinois
201 South Grand Avenue, East
Springfield, IL 62763
Local: 1-217-782-1200
Toll-Free: 1-800-226-0768
Spanish Phone: 1-217-785-8036
Local TTY: 1-800-526-5812

**Indiana**
Family and Social Services Administration of Indiana
402 W. Washington Street
P.O. Box 7083
Indianapolis, IN 46207-7083
Local: 1-317-233-4455
Toll-Free: 1-800-889-9949
Spanish Phone: 1-317-234-0225
Fax: 1-317-232-7382

**Kansas**
Department of Social and Rehabilitation Services of Kansas
Kentucky
Cabinet for Health Services of Kentucky
P.O. Box 2110
Frankfort, KY 40602-2110
Local: 1-502-564-4321
Toll-Free: 1-800-635-2570
Fax: 1-502-226-1898

Louisiana
Louisiana Department of Health and Hospital
1201 Capitol Access Road
P.O. Box 629
Baton Rouge, LA 70821-0629
Local: 1-225-342-9500
Fax: 1-225-342-5568

Massachusetts
Office of Health and Human Services of Massachusetts
600 Washington Street
Boston, MA 02111
Local: 1-617-628-4141 (for provider only)
Toll-Free: 1-800-841-2900
Fax: 1-617-210-5820

Maryland
Department of Human Resources of Maryland
P.O. Box 17259
Baltimore, MD 21203-7259
Local: 1-410-767-5800

Maine
Maine Department of Health and Human Services
442 Civic Center Drive
11 State House Station
Augusta, ME 04333-0011
Local: 1-207-624-7539 (Eligibility)
Toll-Free: 1-800-977-6740 (option 2)
Local TTY: 1-207-287-1828
Fax: 1-207-287-9229

Michigan
Michigan Department Community Health
Sixth Floor, Lewis Cass Building
320 South Walnut Street
Lansing, MI 48913
Local: 1-517-373-3500
Local TTY: 1-517-373-3573
Fax: 1-517-296-5690

Minnesota
Department of Human Services of Minnesota
444 Lafayette Road North
St. Paul, MN 55155
Local: 1-651-297-3933
Toll-Free: 1-800-333-2433
Local TTY: 1-651-296-5705
Fax: 1-651-296-5690

Missouri
Department of Social Services of Missouri
221 West High Street
P.O. Box 1527
Jefferson City, MO 65102-1527
Local: 1-573-751-4815
Toll-Free: In-State Calls Only 1-800-392-2161
Mississippi
Office of the Governor of Mississippi
239 North Lamar Street, Suite 801
Robert E. Lee Bldg.
Jackson, MS 39201-1399
Local: 1-601-359-6050
Toll-Free: 1-800-421-2408
Fax: 1-601-359-6048

Montana
Montana Department of Public Health & Human Services-Division of Child and Adult Health Resources
1400 Broadway, Cogswell Building
P.O. Box 8005
Helena, MT 59604-8005
Local: 1-406-444-4540
Toll-Free: In-State Calls Only 1-800-362-8312
Fax: 1-406-444-2547

North Carolina
North Carolina Department of Health and Human Services
1918 Umstead Drive
Kirby Building
Raleigh, NC 27699-2501
Local: 1-919-857-4011
Toll-Free: In-State Calls Only 1-800-662-7030
Local TTY: 1-877-733-4851
Fax: 1-919-733-6608

North Dakota
Dept of Human Services of North Dakota - Medical Services
600 E. Boulevard Avenue
Bismarck, ND 58505-0250

New Jersey
Department of Human Services of New Jersey
Quakerbridge Plaza, Building 6
P.O. Box 716
Trenton, NJ 08625-0716
Local: 1-609-588-2600
Toll-Free: In-State Calls Only 1-800-356-1561
Spanish Phone: In-State Calls Only 1-609-588-3844
Fax: 1-609-588-3583

New Mexico
Department of Human Services of New Mexico
P.O. Box 2348
Sante Fe, NM 87504-2348
Local: 1-505-827-3100
Toll-Free: 1-888-997-2583
Spanish Phone: 1-800-432-6217
Local TTY: 1-505-827-3184
Fax: 1-505-827-3185

Nevada
Nevada Department of Human Resources, Aging Division
1100 East William Street
Suite 101
Carson City, NV 89701
Local: 1-775-684-7200
Fax: 1-775-687-3893

New York
New York State Department of Health
Office of Medicaid Management
Governor Nelson A. Rockefeller Empire State Plaza, Corning Tower Building
Albany, NY 12237
Local: 1-518-747-8887
Toll-Free: 1-800-541-2831
Fax: 1-518-486-6852

Ohio
Department of Job and Family Services of Ohio - Ohio Health Plans
30 East Broad Street
31st Floor
Columbus, OH 43215-3414
Local: 1-614-728-3288
Toll-Free: 1-800-324-8680
Fax: 1-614-752-3986

Oklahoma
Health Care Authority of Oklahoma
4545 N. Lincoln Boulevard
Suite 124
Oklahoma City, OK 73105

Local: 1-405-522-7171 (also (405) 522-7300)
Toll-Free: 1-800-522-0310
Local TTY: 1-405-522-7179
Fax: 1-405-522-7100

Oregon
Oregon Department of Human Services
500 Summer Street, NE
3rd Floor
Salem, OR 94310-1014
Local: 1-503-945-5772
Toll-Free: 1-800-527-5772
Local TTY: 1-503-945-5895
Fax: 1-503-373-7689

Pennsylvania
Department of Public Welfare of Pennsylvania
Health and Welfare Building, Rm 515
P.O. Box 2675
Harrisburg, PA 17105
Local: 1-717-787-1870
Toll-Free: 1-800-692-7462
Local TTY: 1-717-705-7103

Puerto Rico
Medicaid Office of Puerto Rico and Virgin Islands
GPO Box 70184
San Juan, PR 00936
Local: 1-787-765-1230
Fax: 1-787-759-8179

Rhode Island
Department of Human Services of Rhode Island
Louis Pasteur Building
600 New London Avenue
Cranston, RI 02921
Local: 1-401-462-5300
Spanish Phone: 1-401-462-1500
Local TTY: 1-401-462-3363
Fax: 1-401-521-4875

South Carolina
South Carolina Department of Health and Human Services
P.O. Box 8206
Columbia, SC 29202-8206
Local: 1-803-898-2500

South Dakota
Department of Social Services of South Dakota
700 Governors Drive
Richard F Kneip Bldg,
Pierre, SD 57501
Local: 1-605-773-3495
Toll-Free: 1-800-223-3131
Spanish Phone: 1-800-305-9673
Fax: 1-605-773-5246

Tennessee
Department of Finance and Administration of Tennessee
729 Church Street
Nashville, TN 37247
Local: 1-615-741-0192
Toll-Free: 1-800-669-1851
Spanish Phone: 1-800-522-7568
Local TTY: 1-615-313-9240
Fax: 1-800-772-7647

Texas
Health and Human Services Commission of Texas
4900 N. Lamar Boulevard
4th Floor
Austin, TX 78701

Local: 1-512-424-6500
Toll-Free: 1-888-834-7406
Local TTY: 1-512-407-3250

Utah
Utah Department of Health
288 North 1460 West
P.O. Box 143101
Salt Lake City, UT 84114-3101
Local: 1-801-538-6155
Toll-Free: 1-800-662-9651
Spanish Phone: 1-800-662-9651
Fax: 1-801-538-6805

Virginia
Department of Medical Assistance Services
600 East Broad Street
Suite 1300
Richmond, VA 23219
Local: 1-804-786-7933
Fax: 1-804-225-4512

US Virgin Islands
Medicaid Office of Puerto Rico and Virgin Islands
GPO Box 70184
San Juan, VI 00936
Local: 1-787-765-1230
Fax: 1-787-759-8179

Vermont
Agency of Human Services of Vermont
103 South Main Street
Waterbury, VT 05676-1201
Local: 1-802-241-2800
Toll-Free: In-State Calls Only 1-800-250-8427
Local TTY: 1-802-241-1282
Fax: 1-802-241-2897
21. Helpful Disability-Related Websites

Social Security
- Glossary of Social Security Administration Terms: Can’t understand the initials and terms? This website offers a glossary and definition of all those confusing terms and acronyms. www.ssa.gov/glossary.htm
- Social Security Benefits for People with Disabilities: This is the main index page to Social Security Administration’s website for people who want to apply for disability insurance. www.ssa.gov/disability/
- Social Security Administration Disability Definitions: Social Security evaluates disability using its own medical experts, based on a list of physical and mental conditions contained in its regulations (Title 20 of the Code of Federal Regulations, Part 404, Subpart P, Appendix 1). These are available on the SSA’s website, at www.ssa.gov/
But be prepared, these listings are highly complex and full of medical terminology and discussions of such issues as severity and residual functional capacity levels.

- **Social Security Online Forms:** All the forms you need to apply for disability benefits are at [www.socialsecurity.gov/applyfordisability](http://www.socialsecurity.gov/applyfordisability).

- **Social Security Disability Start Kit:** Reviewing and collecting the information shown in the Social Security Administration’s Disability Starter Kit will help prepare you for your disability interview or help you to complete your online Disability Report. The Disability Report Form asks for information about your conditions or impairments that prevent you from working. The Disability Starter Kit will help you get ready for your disability interview or online application. Kits are available for adults and for children younger than age 18. [www.socialsecurity.gov/disability/disability_starter_kits.htm](http://www.socialsecurity.gov/disability/disability_starter_kits.htm)

- **Social Security Fact Sheet:** What you should know before you apply for Social Security disability benefits. [www.socialsecurity.gov/disability/Adult_StarterKit_Factsheet.pdf](http://www.socialsecurity.gov/disability/Adult_StarterKit_Factsheet.pdf)

- **Checklist of what you need for your disability interview with Social Security:** [www.socialsecurity.gov/disability/Adult_StarterKit_Checklist.pdf](http://www.socialsecurity.gov/disability/Adult_StarterKit_Checklist.pdf)


- **Social Security’s Ticket to Work and Self Sufficiency program** is for people who receive Social Security Disability Insurance benefits and Supplemental Security Income (SSI) benefits. You can use the “ticket” to obtain job training and other employment support free of charge. You do not need to undergo medical reviews when you use this ticket. [www.ssa.gov/pubs/10061.html](http://www.ssa.gov/pubs/10061.html).

- **The Role of Doctors in Attaining Social Security Disability Support:** This website, “Consultative Examinations: A Guide for Health Professionals” explains the role healthcare providers should play in documenting a person’s health problems, which would enable them to obtain disability payments. [www.ssa.gov/disability/professionals/greenbook/ce-evidence.htm](http://www.ssa.gov/disability/professionals/greenbook/ce-evidence.htm)

- **How to Contact Social Security:** Visit Social Security’s website at [www.socialsecurity.gov](http://www.socialsecurity.gov) or call 800-772-1213 (for the deaf or hard of hearing, call our TTY number, 800-325-0778. The agency can answer specific questions and provide information by automated phone service 24 hours a day. All calls are confidential.

### Appealing a Social Security Disability Denial
This form offers a series of questions that allow you to provide any new or additional information about your medical condition and to list any medical providers whose records weren’t used in the initial decision. (For more information on filling out this form, go to SSA’s website at www.ssa.gov/online/ssa-3441.html)

- **Request for Reconsideration (SSA-561-U2, www.ssa.gov/online/ssa-561.pdf)** – This is the actual request for review; however, it can practically guarantee another denial if you aren’t careful. This form gives you three lines on which to explain why you don’t agree with the denial. I have never seen a denial overturned because of three lines of information. (For more information about this form, go to SSA’s website at www.ssa.gov/online/ssa-561.html)

### Medicaid and Medicare Websites

- **Navigating Medicare and Medicaid, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates**: This guide explains the critical role Medicare and Medicaid have come to play in the lives and the futures of roughly 20 million children, adults, and seniors with disabilities - and gives people with disabilities new information to help them get the most from these programs. www.kff.org/medicare/7240.cfm

- **Keeping Medicare and Medicaid When You Work, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates**: This guide helps to explain the program rules for Medicare and Medicaid with regard to work. Medicare and Medicaid have come to play important roles in the lives and the futures of roughly 20 million children, adults, and seniors with disabilities - and this guide gives people with disabilities new information to help them get the most from these programs. www.kff.org/medicare/7241.cfm

**Medicare Rights Center**: Medicare Rights Center (MRC) is the largest independent source of health care information and assistance in the United States for people with Medicare. Founded in 1989, MRC helps older adults and people with disabilities get good, affordable health care. The website is at www.medicarerights.org.

**Centers for Medicaid and Medicare Services website**: www.cms.hhs.gov/medicare/

The official U.S. government site for people receiving or interested in Medicare: www.medicare.gov/

To Find & Compare Plans that Cover Drugs go to the Medicare Prescription Drug Plan Finder www.medicare.gov/MPDPF/Public/Include/DataSection/Questions/MPDPFIntro.asp?version=default&browser=Firefox%7C2%7CWInXP&language=English&defaultsta
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**State Medicaid Websites**

**Alabama**
www.medicaid.state.al.us

**Alaska**
http://www.hss.state.ak.us/dpa/programs/medicaid/

**Arizona**
www.ahcccs.state.az.us

**Arkansas**
www.state.ar.us/dhs/homepage.html

**California**
http://www.dhcs.ca.gov/services/medica/Pages/default.aspx

**Colorado**
www.chcpf.state.co.us/

**Connecticut**

**Delaware**
www.DMAP.state.de.us

**District of Columbia**
http://dhcf.dc.gov/dhcf/cwp/view,A,1412,Q,609122,dhcfNav,|34820|,asp

**Florida**
http://www.fdhc.state.fl.us/Medicaid/about/about2.shtm

**Georgia**
http://www.georgia.gov/00/channel_title/0,2094,31446711_31944826,00.html

**Hawaii**
https://hiweb.statemedicaid.us/Home.asp

**Idaho**
http://www.healthandwelfare.idaho.gov/

**Illinois**
www.hfs.illinois.gov/

**Indiana**
http://www.indianamedicaid.com/

**Iowa**
http://www.ime.state.ia.us/

**Kansas**
http://www.khpa.ks.gov/healthwave/default.htm

**Kentucky**
http://chfs.ky.gov/dms/

**Louisiana**
www.dhh.state.la.us/offices/?ID=92

**Maine**
www.maine.gov/portal/family/health_safety/health_insurance.html

**Maryland**
www.dhmh.state.md.us

**Massachusetts**
http://www.mass.gov/masshealth

**Michigan**
http://michigan.gov/mdch/0,1607,7-132-2943_4860--,00.html

**Minnesota**
www.dhs.state.mn.us
Mississippi
http://www.medicaid.ms.gov

Missouri
www.dhss.mo.gov/index.html

Montana
www.dphhs.state.mt.us

Nebraska
www.hhs.state.ne.us/med/medindex.htm

Nevada
www.dhcfp.state.nv.us/

New Hampshire
www.dhhs.state.nh.us

New Jersey
http://www.nj.gov/humanservices/dmahs/info/resources/macc/index.html

New Mexico
www.state.nm.us/hsd/

New York
http://www.health.state.ny.us/health_care/medicaid/

North Carolina
http://www.dhhs.state.nc.us/dma/medicaid/index.htm

North Dakota
http://www.nd.gov/dhs/services/medicalserv/medicaid/

Ohio
http://jfs.ohio.gov/OHP/index.stm

Oklahoma
http://www.okhca.org/

Oregon

Pennsylvania
http://www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance/

Rhode Island
http://www.dhs.ri.gov/Adults/HealthMedicalServices/tabid/807/

South Carolina
http://www.dhhs.state.sc.us/dhhsnew/medicaid.asp

South Dakota
http://dss.sd.gov/sdmedx/includes/portal/verifyeligibility/index.aspx

Tennessee
http://www.state.tn.us/tenncare/

Texas
http://www.dads.state.tx.us/ltss/texasmedicaid.html

Utah
http://health.utah.gov/medicaid

Vermont
http://www.greenmountaincare.org/vermont-health-insurance-plans/medicaid

Virginia
http://www.dss.virginia.gov/benefit/medical_assistance/index.cgi

Washington
http://hrsa.dshs.wa.gov/

West Virginia
http://www.wvdhhr.org/bms/

Wisconsin
http://www.dhs.wisconsin.gov/medicaid/

Wyoming
http://wdh.state.wy.us/healthcarefin/equalitycare/index.html

This information is provided by the Hepatitis C Support Project, a nonprofit organization for HCV education, support and advocacy.

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# HCSP Guides

## Basic Information
- Easy C - A Guide to Understanding Hepatitis
- A Guide to Understanding Hepatitis C
- Understanding HCV: A Patient Pocket Guide
- Easy C - A Guide to HIV and Hep C Coinfection
- Easy C Guide to Depression

## General Topic Specific Guides
- Making Sense of Hepatitis C Research and Medical Literature
- Aging and Hepatitis C: An HCSP Guide
- Final Steps with HCV: An HCSP Guide on Death and Dying For Family and Friends: Caring for Someone with Hepatitis C
- Hepatitis C Support Group Manual
- Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines
- Stigma and Hepatitis C
- Women and Hepatitis C: An HCSP Guide

## HCV and Work-Related Issues
- A Guide to HCV Disclosure
- A Guide to Hepatitis and Disability

## Managing HCV
- A Guide to Healthy Living with HCV
- A Guide to Understanding and Managing Fatigue
- Coping with Depression and Hepatitis C

## Newly Diagnosed
- First Steps with HCV for the Newly Diagnosed

## Treatment Issues
- A Guide to Hepatitis C: Making Treatment Decisions
- A Guide to Hepatitis C: Preparing for Treatment
- A Guide to Hepatitis C: Treatment Side Effect Management
- After HCV Treatment: An HCSP Guide
- HCV Negative: A Guide for Healthy Living without HCV
- HCV Treatment: A Guide to Help You Stay on Treatment
- Next Steps: When HCV Treatment Isn’t Working

## HIV & HCV Coinfection
- Easy C - A Guide to HIV and Hep C Coinfection
The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.