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“The Shadow Epidemic”: Hepatitis C and the Law

By Linda S. Good

The hepatitis C virus (HCV) infects approximately four million Americans, is the leading cause of liver transplants in the United States, and infects nearly 170 million people worldwide. The AIDS (Acquired Immune Deficiency Syndrome) epidemic has overshadowed hepatitis C even though four times as many Americans have hepatitis C and few are even aware of it. As many as 20 percent of patients with hepatitis C will progress to cirrhosis of the liver, primary liver cancer, or both. When end-stage liver failure occurs, the patient’s only hope is a liver transplant, but the need far outstrips the supply.

Hepatitis C has no sure cure and no vaccine, and the few available treatments are lengthy, costly, and often debilitating. Appropriate monitoring is essential but expensive. Patients can have hepatitis C unknowingly for a decade or more while the virus slowly, silently damages the liver. Not surprisingly, hepatitis C strikes hardest at the poor but is nondiscriminatory. The disease affects all races, both genders, all ages, and all socioeconomic levels. Robbing individuals of health at the peak of their prime earning years, hepatitis C also becomes an intergenerational issue as parents become unable to provide for their children, children lose parental attention and guidance, and adult children must bear the burdens of caring for infected parents.

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Along the way, the disease has an impact on many legal issues for low-income patients, yet few legal services advocates know much about the disease, its symptoms, or the debilitating effects of treatment. Advocates for hepatitis C patients consequently may misunderstand their clients’ legal needs and their difficulty in fighting depression and memory loss, keeping appointments, conveying information, or understanding complex instructions. In this article I attempt to rectify this problem by supplying information about the disease and the legal issues that arise in the context of hepatitis C.

I. Client Stories

Frantic for help, Ms. P came to East Texas Legal Services. By the time doctors diagnosed her with hepatitis C, too much liver damage had occurred and her only hope was a transplant. Unfortunately her COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985) health insurance was about to expire, and, because she had no source of funds to pay for the transplant, doctors could not even place her on the transplant waiting list.

To make matters worse, she was deteriorating so quickly that her doctors feared she would not be able to resolve the funding issue while she was still a viable transplant recipient. The Social Security Administration had denied Ms. P’s application for disability benefits, and she would have to wait months before her administrative law judge hearing. For Ms. P, the denial of disability benefits was a virtual death sentence.

Like Ms. P, Mr. H came to our office for assistance with his disability claim. Under 50 and a high school graduate, Mr. H had always worked at hard manual labor in the oil fields. He had been a single parent for ten years and gradually experienced increasing symptoms of fatigue and stomach upset. Eventually serious symptoms landed him in the emergency room; doctors diagnosed him with hepatitis C and significant liver damage. On monotherapy (interferon alone), he soon was unable to work because of side effects.

As a single parent, Mr. H began receiving food stamps, Temporary Assistance for Needy Families benefits, and Medicaid. However, the Social Security Administration denied his claim for disability benefits because, according to the agency, his condition was not severe enough and the interferon should keep the condition under control. Severe psychological side effects led to a temporary suspension of treatment. Soon after he resumed treatment and while he was awaiting his administrative law judge hearing, his son turned 18, and Mr. H lost his welfare benefits and his Medicaid. In the middle of treatment, he no longer had any way to pay for its extremely high cost.

II. Hepatitis C Statistics and Costs

Chronic liver disease is the tenth leading cause of death in the United States, and, according to the Centers for Disease Control and Prevention, 40 percent of such deaths (10,000 annually) are the result of hepatitis C. The centers estimate that by the year 2010 the annual death toll from hepatitis C could increase to 38,000, approximately equal to the current number of deaths annually from breast cancer. In 1992 in the United States 558 patients died while awaiting liver transplants.

An estimated 10 percent of American veterans have hepatitis C. The prison inmates of Texas and California have infection rates of 28 percent to 41 percent. The Federal Bureau of Prisons was
treating 8,000 inmates for hepatitis C as of April 2000.13

Health care costs for this disease are staggering. In 1994 the cost at nonfederal hospitals for the treatment of hepatitis B and C was, in the American Liver Foundation’s estimate, $619 million.14 The average cost of a liver transplant is $300,000.15

III. Medical Aspects

Weighing about three pounds, the liver is the largest internal organ and performs more than 500 chemical functions, eventually processing every chemical that the body swallows, inhales, injects, or absorbs.16 The liver cleans our blood of toxins and is key in the production of red blood cells and clotting factor.” Researchers have not yet developed a substitute for the liver unlike some other organs.18 “The consequences of a ravaged liver can be hemorrhage, delirium, and death,” Jerome Groopman reports in his New Yorker article.19

Several viruses cause liver inflammation, but in this article I focus only on HCV, which causes hepatitis C.20 Formerly known as “non-A, non-B hepatitis;” hepatitis C has been in our blood supply for decades, but researchers did not discover the specific virus until 1989 and a refined test for HCV was not available until 1992.21 Fortunately the other hepatitis viruses are not as problematic as HCV. Vaccines can protect against hepatitis A and hepatitis B.22 However, no vaccine exists against hepatitis C, and only about 15 percent of patients will fully recover without medical intervention.23

A. Symptoms

Typically HCV triggers only a mild immune response and, like HIV (human immunodeficiency virus), hides from the body’s defenses by changing forms.24 The
patient frequently has no obvious symptoms for years or only vague symptoms such as fatigue, stomach upset, nausea, vomiting, itching, and skin rashes.\(^{25}\) Meanwhile, the virus is slowly damaging the liver. Acute symptoms, if any, are usually mild. If the liver enzymes are elevated during the acute phase, the elevation is often slight and dismissed as a temporary aberration.\(^{26}\)

\textbf{No vaccine exists against hepatitis C, and only about 15 percent of patients will fully recover without medical intervention.}

Unfortunately 85 percent of patients become chronic, with the progression from no symptoms to serious liver impairment being highly unpredictable; the progression varies from patient to patient and even varies over time for the same patient.\(^{27}\) Liver fibrosis is commonly present, and HCV has strong links with liver cirrhosis and cancer.\(^{28}\) Without treatment, damage to the liver continues, as do the symptoms of liver impairment, such as headaches, muscle aches, depression jaundice, ascites, mental confusion esophageal hemorrhage, thinning of bones and fractures, blood clotting problems, thyroid disease, and kidney problems.\(^{29}\)

\section*{B. Transmission}

HCV spreads primarily through blood-to-blood contact.\(^{30}\) Ten percent to 30 percent of hepatitis C patients have no known risk factor.\(^{31}\) Any activity that permits the blood of an infected person to come into contact with another person’s blood can transmit the virus.

Recipients of contaminated blood products are at high risk of contracting the virus; such recipients include hemophiliacs, surgery patients, dialysis patients, and women who received “routine” blood transfusions during a cesarean birth or Rh factor immunoglobulin injections following childbirth before the discovery of HCV and reliable testing for it.\(^{32}\) Sharing needles or other paraphernalia in the intravenous or intranasal use of recreational drugs is an excellent way to transmit the virus.\(^{33}\) Body piercing and tattooing are

\(^{25}\) Askari, supra note 1, at 4; Everson & Weinberg, supra note 1, at 40-41; Recommendations, supra note 1, at 12-13; Groopman, supra note 1, at 49-50.

\(^{26}\) Interview with Francisco Ruiz, M.D., clinical physician, Gastroenterology, Sadler Clinic. in The Woodlands, Tex. (Feb. 23, 1998).

\(^{27}\) Askari, supra note 1, at 40-60; Everson & Weinberg, supra note 1, at 59-71; Recommendations, supra note 1, at 12-15.

\(^{28}\) Askari, supra note 1, at 34; Everson & Weinberg, supra note 1, at 58-60. “Fibrosis” means “abnormal formation of fibrous tissue.” Taber’s Cyclopedic Medical Dictionary 729 (17th ed. 1993).

\(^{29}\) Askari, supra note 1, at 43-60; Everson & Weinberg, supra note 1, at 59-71; Frank Anderson et al., Hep C: Progression, Pathology, Hep C Connections, Sept.–Oct. 2000, at 5-6. “Ascites” is the accumulation of fluid in the abdomen. Taber’s, supra note 28, at 159.

\(^{30}\) Askari, supra note 1, at 75; Everson & Weinberg, supra note 1, at 31; Recommendations, supra note 1, at 1.

\(^{31}\) Askari, supra note 1, at 82; Recommendations, supra note 1, at 9; Henkel, supra note 21, \S 12.

\(^{32}\) Askari, supra note 1, at 75; Everson & Weinberg, supra note 1, at 31-45; Recommendations, supra note 1, at 1 (regarding recipients of contaminated blood products); Hepatitis C and Blood Safety: Hearing Before the Advisory Comm. on Blood Safety & Availability of the Dept. of Health & Human Servs., 105th Congress \S 20 (Nov. 24, 1998) (statement of Adrian M. Di Bisceglie, medical director, American Liver Foundation) (regarding blood transfusions during cesarean births), www.liverfoundation.org/html/adl3dox.fol/adl3dox.fol_ate003cb.htm; Steven K. Herrine, Treat Everyone or Watchful Waiting?, Hep C Connections, Nov.–Dec. 2000, at 6 (regarding Rh factor immunoglobulin injections).

\(^{33}\) Groopman, supra note 1, at 49-50.
also potential routes of transmission.\textsuperscript{34} Even if a tattoo artist uses a new sterile needle for each client but draws ink from the same pot for more than one client, the virus can be spread through the ink.\textsuperscript{35} Because HCV tends to be quite concentrated in the blood of infected individuals, several seemingly innocuous activities, such as sharing toothbrushes, razors, nail clippers, nail files, or even scissors, can be routes of transmission.\textsuperscript{36}

Because drinking from an infected person’s glass, kissing, being sneezed on, hugging, or shaking hands does not spread the virus, the rate of household transmission is extremely low.\textsuperscript{37} In fact, many doctors are now advising couples in long-term monogamous relationships that safe sex practices are not necessary.\textsuperscript{38} At least one researcher claims to have “proven for certain there [is] no Hepatitis C virus present in the sexual fluids of male or female partners.”\textsuperscript{39} Of course, if a couple engages in sexual practices that could bring the blood of one partner into contact with the blood of the other, transmission can occur. Transmission of the virus from an otherwise healthy mother to her newborn child is extremely rare. Researchers believe that transmission via breast milk rarely, if ever, occurs and that, if it does, the baby’s stomach acid kills the virus.\textsuperscript{40}

\section*{C. Testing}

The decision to be tested for HCV is an important personal choice that one should make only after careful reflection and consultation with a trusted doctor. Hepatitis C patients have experienced various forms of discrimination, similar to the experiences of many AIDS patients.\textsuperscript{41} However, early treatment is much more likely to be effective, and thus patients should have complete information about the benefits that they can gain from testing—treatment and its efficacy, avoiding transmission, and planning for the future—as well as the potential problems.\textsuperscript{42}

Persons at high risk or with certain clinical signs, including the following groups, should seriously consider testing:

\begin{itemize}
\item blood transfusion recipients who receive notice that one of their donors has tested positive for HCV;
\item chronic hemodialysis patients;
\item recipients of blood transfusion or solid organs before July 1992;
\item recipients of clotting factor concentrates before 1987;
\item persons who ever injected or snorted illegal drugs, even if only a few times years ago;
\end{itemize}

\textsuperscript{34} \textit{Id.} at 49.
\textsuperscript{35} \textit{Askari, supra} note 1, at 84.
\textsuperscript{36} \textit{Askari, strpra} note 1, at 75, 84-88; \textit{Everson \\ Weinberg, supra} note 1, at 32, 41.
\textsuperscript{37} \textit{Askari, supra} note 1, at 79; \textit{Everson \\ Weinberg, supra} note 1, at 41, 45-46; \textit{Recommendations, supra} note 1, at 8-9.
\textsuperscript{39} \textit{Update on Sexual Transmission, Hope for Hepatitis C: A NewsL. for Hepatitis C Patients \\ Their Families} (Hep C Hope Inc. Found., Houston, Tex.), Summer 1999, at 5 (reporting on remarks of Norah Terrault, M.D., M.P.H., University of California at San Francisco, speaking on “Research Update on Sexual Transmission of HCV” at the National Hepatitis Congress in Washington, D.C., in March 1999).
\textsuperscript{40} \textit{Everson \\ Weinberg, supra} note 1, at 42. See also \textit{Askari, supra} note 1, at 79-80; \textit{Recommendations, supra} note 1, at 9.
\textsuperscript{41} \textit{Recommendations, supra} note 1, at 17; my discussions with patients and their families.
\textsuperscript{42} Groopman, \textit{supra} note 1, at 59; \textit{Recommendations, supra} note 1, at 26.
- health care and public safety workers after exposure to HCV-positive blood;
- children born to HCV-positive women; and
- veterans who served before 1992.3

A liver enzyme test is not a direct test for hepatitis C. Until the virus causes enough damage, which could take years, the enzymes may show no detectable increase.4 Therefore, persons with known risk factors should undergo more reliable and direct testing.45 Doctors may suspect HCV infection when routine blood tests reveal persistently elevated liver enzymes or when the patient complains of certain symptoms.46

If testing shows active infection and the patient wishes to explore treatment options, most doctors then will perform a CT (computed tomography) scan of the liver and a liver biopsy to establish a baseline against which to measure the patient’s treatment response. The CT scan, which is noninvasive and practically risk free, will show if certain lesions have already developed within the liver. The biopsy carries some risk but will reveal most clearly the present condition of the liver.47

D. Treatment

Research indicates that HCV infection, not alcohol consumption, is the primary cause of liver cirrhosis, but the use of alcohol and hepatotoxic drugs greatly speeds disease progression.6 For this reason, many doctors will not treat patients who continue to consume alcohol or use harmful drugs.39

At present patients have five treatment options for hepatitis C: watchful waiting, liver transplants, monotherapy, combination therapy, and experimental treatments. Because the side effects of the current drug treatments for hepatitis C can be debilitating and do not guarantee a positive clinical outcome, some doctors recommend a wait-and-see approach. If the patient feels well and has little inflammation or damage in the liver, the doctor may advise “watchful waiting” in the hope that the Food and Drug Administration will approve better therapies before more aggressive action is necessary.50 Some patients choose to postpone treatment until a period in which other demands or stresses will diminish. In either case, the doctor carefully monitors the patient’s viral load, liver enzymes, and general health for signs of further deterioration.51 Because knowledge
of and attitudes toward treatment for hepatitis C vary greatly among doctors, even among gastroenterologists who specialize in diseases of the liver, the patient should get a second opinion.52

When the disease progresses beyond the effective point of current treatments, a liver transplant is the only treatment option. Sadly many end-stage liver patients do not survive the wait to the top of the transplant list. Distribution of livers for transplantation has become so controversial that the U.S. Department of Health and Human Services ordered the United Network for Organ Sharing to submit a new policy on liver distribution before developing policies for other organs.53 A member of the Liver Transplant Evaluation Committee at the University of Michigan Medical Center stated: “Liver transplantation is degenerating into a surreal lottery in which a new organ and the promise of renewed life are the ultimate prize. This has resulted from a severe shortage of donor livers, necessitating a prolonged wait on the liver transplant list.”54

To address the demand for livers, a new technique permits doctors to transplant one liver into two waiting patients. Because the liver comprises two sections, or lobes, and is the only internal organ capable of regenerating, the doctor can transplant each lobe separately; if all else goes well, the lobe will quickly grow to nearly full size and function.55 For a patient whose own liver is barely functioning, this is a life saver. Doctors do not automatically disqualify XV-infected livers from transplantation.56 A patient whose liver is barely functioning may welcome the valuable time a less-diseased liver can buy.

While many patients will die before a liver is available for them, others experience transplantation barriers that costs and lack of insurance impose. Therefore, treatment to avoid serious liver impairment is the goal of many patients and their doctors.57 Since 1991, doctors have used interferon alone (or monotherapy) to treat hepatitis C even though its success rate is low.58 A naturally occurring product of the immune system’s response to a virus, interferon causes the fever and muscle and joint aches that make one so uncomfortable when one has the flu. Because HCV usually does not trigger a sufficient immune response, doctors prescribe interferon injections to boost the body’s immune response.59

Monotherapy for hepatitis C typically consists of three injections per week of three million units of interferon, although the dose and frequency can vary with the patient’s condition and response.60 The patient administers the injections at home, and the doctor carefully monitors the patient’s response to the treatment through performing blood tests to check viral load, measuring liver enzyme levels, and watching for the development of serious side effects.61 The initial course of treatment usually lasts for six to twelve months. Approximately 20 percent of patients who receive monotherapy experience a de-

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52 Askari, supra note 1, at 95-137; Everson & Weinberg, supra note 1, at 128-47.
54 Askari, supra note 1, at 62.
56 Askari, supra note 1, at 67–68, Everson & Weinberg, supra note 1, at 157-58.
58 Id.; Groopman, supra note 1, at 59–60.
59 Askari, supra note 1, at 115-32; Everson & Weinberg, supra note 1, at 130-47.
60 Askari, supra note 1, at 115-32; Everson & Weinberg, supra note 1, at 130-47.
61 “Viral load” refers to the number of RNA (ribonucleic acid) particles of hepatitis C present in a milliliter of blood and is a direct measure of the concentration of the virus in the body and of treatment efficacy. Askari, supra note 1, at 122.
crease in their viral load and liver enzyme levels; they are "responders."\(^{62}\)

Those for whom treatment has little or no impact are "nonresponders."\(^{63}\) Unfortunately many of the responders will relapse, that is, the viral load, enzymes, or both will increase again after the responder stops treatment. Because 80 percent of patients are nonresponders to monotherapy and many of the responders later relapse, researchers developed other treatment options.\(^{64}\)

In 1998 the Food and Drug Administration approved the use of interferon with the antiviral drug ribavirin for treating hepatitis C—"combination therapy."\(^{65}\) Like monotherapy, combination therapy requires interferon injections three times per week. The patient also takes ribavirin capsules orally every day. The usual course of treatment is six to twelve months. Approximately 40 percent to 50 percent of patients on combination therapy have a positive response and some experience what may be a "cure," that is, the viral load remains below detectable levels (less than 500 particles per milliliter) and liver enzymes remain normal for at least six months after treatment stops.\(^{66}\)

The search continues for a more effective treatment. Researchers, doctors, and patients are experimenting with other forms of interferon and with other drugs and treatments.\(^{67}\) Through the effort to treat hepatitis C, doctors have learned that cirrhosis of the liver is not necessarily permanent, as liver biopsies after treatment with some experimental agents have shown reversal of cirrhosis for some patients.\(^{68}\) This news gives hope to patients and incentive to researchers. If current treatments can reverse some of the damage that the virus has already caused, perhaps patients can live long enough to try developing treatment modalities that may lead to a cure.

**E. Side Effects**

Monotherapy and combination therapy are not appropriate for all hepatitis C patients because of other underlying conditions or the treatment's side effects, which can be quite significant.\(^{69}\) Some patients consider the "cure" worse than the disease, especially those who are asymptomatic or have only mild symptoms before beginning treatment. As I mentioned above, interferon naturally causes the aches, pains, fever, and dehydration that commonly occur with the flu. In undergoing hepatitis C treatment, the patient receives, three times per week for as long as a year, a much greater concentration of interferon than the body normally produces at one time.\(^{70}\) Many patients experience flu-like symptoms for at least the first few weeks: fever, chills, nausea, vomiting, diarrhea, fatigue, and muscle and joint aches.\(^{71}\) After the first weeks of treatment, some patients experience low-grade fever and other flu symptoms throughout the rest of the treatment.\(^{72}\)

\(^{62}\) Ruiz, supra note 26.

\(^{63}\) Everson & Weinberg, supra note 1, at 133.

\(^{64}\) Id. at 130-47. See also Askari, supra note 1, at 115-32.

\(^{65}\) Henkel, supra note 21, ¶16.

\(^{66}\) Askari, supra note 1, at 122-30; Everson & Weinberg, supra note 1, at 135-37.

\(^{67}\) Askari, supra note 1, at 95-103; Everson & Weinberg, supra note 1, at 211-22.


\(^{69}\) Askari, supra note 1, at 122-30; Everson & Weinberg, supra note 1, at 131-40; Recommendations, supra note 1, at 14-15.

\(^{70}\) Interview with John Rodgers, Ph.D., assistant professor, Department of Microbiology and Immunology, Baylor College of Medicine, Houston, Tex., in The Woodlands, Tex. (Mar. 1998).


\(^{72}\) Askari, supra note 1, at 119-20; Everson & Weinberg, supra note 1, at 138-42; Recommendations, supra note 1, at 15; FAQs, supra note 38 ("What are the side effects of interferon therapy?" and "What are the side effects of combination (ribavirin + interferon) treatment?").
The Five Faces of Hepatitis

Scientists have identified five different hepatitis viruses. All are serious infections that can attack and damage the liver.

<table>
<thead>
<tr>
<th>How It Is Spread</th>
<th>Hepatitis A</th>
<th>Hepatitis B</th>
<th>Hepatitis C</th>
<th>Hepatitis D</th>
<th>Hepatitis E</th>
</tr>
</thead>
<tbody>
<tr>
<td>By drinking water or eating food contaminated with fecal material that contains the virus</td>
<td>Exposure to infected blood, unprotected sex with an infected person, sharing contaminated needles, and travel to countries with a high rate of infection. Infected mothers also may infect newborns</td>
<td>Direct contact with human blood; this can occur from being pricked accidentally by a contaminated needle, injecting illegal drugs, and sharing razors or toothbrushes with an infected person</td>
<td>Contact with infected blood. Requires the hepatitis B virus to replicate, so it infects either at the same time as hepatitis B or those who already have hepatitis B</td>
<td>Water contaminated with fecal material, especially in developing countries, and contaminated uncooked shellfish, fruits, and vegetables</td>
<td></td>
</tr>
</tbody>
</table>

| Symptoms | Flu-like symptoms such as fatigue, nausea, vomiting, abdominal discomfort, dark urine, and jaundice (yellowing of the skin and eyes). Liver tests may be elevated | Loss of appetite, nausea, vomiting, fever, fatigue, abdominal pain, dark urine, or jaundice. No symptoms in some people | More than half have no symptoms. Others have appetite loss, fatigue, nausea, fever, dark-yellow urine, and jaundice. Liver tests may be elevated | Same as for hepatitis B but typically more severe: appetite loss, fatigue, nausea, vomiting, abdominal pain | Abdominal pain, dark urine, fever, jaundice, nausea, and vomiting |

| Treatment | Bed rest and avoidance of intimate contact. Can last between three weeks and six months. Two approved vaccines: immune globulin for short-term protection and for patients already exposed, and hepatitis A vaccine for long-term protection | Interferon alpha. A vaccine-recommended for newborns, infants, and teenagers—provides immunity for at least five years | Interferon or a combination of interferon and the drug ribavirin. No vaccine | Interferon alpha for hepatitis B may have some effect | Bed rest. No drug treatment or vaccine |


Depression is a common problem, not only because of the grief and fear that come with having a potentially life-threatening illness for which no cure exists and the only treatment is debilitating and unpleasant, but also because interferon lowers serotonin levels, causing clinical depression. \(^{73}\) HCV can impair mental functioning, and interferon can cause memory loss, confusion, and irritability.\(^{\ast}\)

For patients on combination therapy, \(^{74}\) ribavirin can cause additional psychological side effects, including mood swings, psychosis, insomnia, extreme fatigue, inability to concentrate, and loss of short-term memory. \(^{75}\) Some doctors will not prescribe interferon treatment for hepatitis C patients with significant psychiatric histo-

\(^{73}\) Askari, supra note 1, at 168–73; Everson & Weinberg, supra note 1, at 139; Groopman, supra note 1, at 59; Henkel, supra note 21, §§ 19–22; FAQs, supra note 38 ("What are the side effects of interferon therapy?");

\(^{74}\) Askari, supra note 1, at 43–44, 120; Everson & Weinberg, supra note 1, at 138-39; FAQs, supra note 38 ("What are the side effects of interferon therapy?");

\(^{75}\) Askari, supra note 1, at 125–26, Ruiz, supra note 26 (Dec. 1998).
ries because suicidal ideation and suicide have been problems.76

Along with impaired mental functioning, the physical side effects of ribavirin can include stomach cramps, muscle cramps, loss of appetite, weight loss, and hair loss.77 As many as 10 percent of patients receiving ribavirin develop hemolytic anemia, which causes marked shortness of breath, weakness, and gray skin color.78 If the anemia becomes severe enough, the doctor must reduce the ribavirin dose or discontinue treatment.79 Because ribavirin is teratogenic, women capable of becoming pregnant should not take it for six months before or after or during pregnancy.80 Men on ribavirin should not father children during or for six months after treatment.81

Anemia coupled with weight loss from anorexia, vomiting, and diarrhea can leave the patient feeling incredibly weak and looking very ill. The patient may frequently require as much as twenty hours of sleep per day on those days when insomnia does not prevent sleep. The patient with whom I am most familiar lost fifty-five pounds over the course of fourteen months and by the time treatment ended was eating little more than smoothies from fresh-frozen strawberries, frozen bananas, organic apple juice, and local honey. This homemade concoction tast-
ed good, supplied nutrition, and soothed a cramping stomach; an irritated digestive system did not quickly expel it. Doctors can prescribe medication to ameliorate some of the side effects, but such medication often has its own side effects that doctor and patient also must consider. Many patients discontinue treatment before completing the full course because of problems with medication side effects.82

F. Costs of Treatment

Treatment for hepatitis C is costly.83 Liver transplants cost about $300,000, and treatment with monotherapy or combination therapy, which must include a doctor’s monitoring, can be quite expensive. The most reliable test for viral load costs approximately $150 to $200. The baseline liver CT scan and biopsy can cost from $2,000 to $3,000. The doctor must monitor in addition to viral load–liver enzyme levels as well as other indicators of health and liver function.84 In the first few weeks of treatment, the doctor may test liver enzymes and perform a complete blood count on a weekly basis.

Interferon can cost from $350 for a four-week supply of vials, which a local pharmacy must specially order, to $1,200 for a four-week supply from a company that specializes in providing injectable drugs for patients who may require assis-

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76 ASKARI, supra note 1, at 119-28; EVERSON & WEINBERG, supra note 1, at 138-42; Recommendations, supra note 1, at 15; Groopman, supra note 1, at 59.
77 ASKARI, supra note 1, at 125-28; EVERSON & WEINBERG, supra note 1, at 140.
78 Ruiz, supra note 26 (Dec. 1998); EVERSON & WEINBERG, supra note 1, at 140; Recommendations, supra note 1, at 15. Hemolytic anemia occurs when red blood cells prematurely cease functioning or when the body does not produce red blood cells fast enough to keep pace with the rate of natural destruction, impairing the blood’s ability to transport oxygen throughout the body. Eugene P. Frenkel, Hematology and Oncology, in The Merck Manual 1161 (Robert Berkow et al. eds., 16th ed. 19921; ASKARI, supra note 1, at 126-27.
79 ASKARI, supra note 1, at 126-30; EVERSON & WEINBERG, supra note 1, at 140; FAQs, supra note 38 (“What are the side effects of combination (ribavirin + interferon) treatment?”); Recommendations, supra note 1, at 15.
80 Teratogenic substances cause “the development of abnormal structures in an embryo resulting in a severely deformed fetus.” TABER’S, supra note 28, at 1,064.
81 ASKARI, supra note 1, at 79; Recommendations, supra note 1, at 15.
82 Ruiz, supra note 26 (Feb. 23, 1998; Dec. 1998); Recommendations, supra note 1, at 15.
83 All cost figures derive from bills and receipts that my “patient” generated in 1998–99. Costs now may be different. For a general discussion of the direct financial impact on patients of hepatitis C and its treatment, see ASKARI, supra note 1, at 173–74; EVERSON & WEINBERG, supra note 1, at 110–27.
84 ASKARI, supra note 1, at 30; EVERSON & WEINBERG, supra note 1, at 139; Recommendations, supra note 1, at 14-15.
tance in completing the full course of treatment. Such companies deliver the interferon in prefilled syringes by overnight delivery to the patient’s door and offer supportive telephone counseling from trained professionals. This can be important for patients struggling with the medication side effects—including mental confusion, which literally makes it difficult for them to remember what day it is—because these patients may have significant difficulty drawing up an appropriate dose of interferon. For patients receiving the combination therapy, ribavirin can cost as much as $24 per capsule at six capsules per day, or about $4,000 for a four-week supply, in addition to the cost of the interferon.

**G. Access to Care and Treatment**

For many of our clients, access to treatment comes in the form of Medicaid, often tied to Temporary Assistance for Needy Families benefits. Others are at the mercy of the local indigent health care programs, which are free to establish policies that seem counterproductive. In a particularly cruel twist, a county program near our office will provide only specialty care and only with a referral from a primary care physician. The individuals who are income eligible for the program cannot afford to see a primary care physician because the income limit is a mere fraction of the poverty level. Short of some other emergent condition that sends such a person into the hospital via the emergency room, how can such a patient obtain the tests necessary for a primary care doctor to diagnose hepatitis C, much less refer the patient for specialty care?

Some indigent health care programs, because of severely limited funds, are unable to supply more than a limited number of prescriptions; this forces some patients to choose between taking thera-

PY without medication to ease the side effects and going without therapy and hoping for the best. For all low-income persons on prescription medication, the advocate should be aware of the Cost Containment Research Institute, which maintains a Web site from which one can order a publication entitled *Free and Low Cost Prescription Drugs.* The booklet, which lists more than 1,100 drugs and more than seventy-five pharmaceutical companies, gives information on how to obtain free and low-cost prescriptions from drug manufacturers. Usually families with annual incomes up to $50,000 are eligible, and the application procedures are fast and uncomplicated. When Mr. H suddenly lost his Medicaid, he received quick approval for treatment through the local hospital’s indigent health care program and approval to receive his hepatitis C treatment free from the drug manufacturer.

**IV. Legal Issues**

As of September 2000, Westlaw’s ALLFEDS directory had 116 cases that mentioned “hepatitis C,” including social security claims, Americans with Disabilities Act claims, Employee Retirement Income Security Act (ERISA)/insurance denial cases, claims for veterans’ benefits, claims filed by inmates, and personal injury claims due to HCV exposure. Twenty-three of the cases were unpublished opinions. Social security disability cases constituted the single largest category of cases.

**A. Social Security Disability Claims**

For hepatitis C sufferers, access to proper health care through enrollment in disability insurance benefit programs, Supplemental Security Income programs, or both may be as important as the cash benefits. Listing 5.05, chronic liver disease, specifically addresses hepatitis and

86 Id. at 30.
87 For a topical list of the 116 cases, see the National Center on Poverty Law’s Web site, www.povertylaw.org.
gives six options for meeting the listing. If the claimant is indigent and qualifies under either of the first two subsections (esophageal varices with massive hemorrhage or performance of a shunt operation for such varices), the treating hospital will probably submit the claim to the Social Security Administration for approval with little delay. The remaining subsections require a longitudinal treating history that may be difficult for indigent patients to acquire. Furthermore, many hepatitis C patients do not meet Listing 5.05 when they apply for benefits because their disease has not progressed yet to listing-level severity; others were asymptomatic before treatment, but its side effects have severely debilitated them.

Claimants who do not meet Listing 5.05 face two primary obstacles: the twelve-month durational requirement and the subjective nature of most of the symptoms. If the claimant’s symptoms improve after treatment ends, the advocate should argue for a closed period of eligibility if treatment and its side effects debilitated the claimant for at least twelve months. Many of the most debilitating symptoms are subjective: headache, muscle ache, nausea, irritability, depression, mood swings, weakness, and difficulty concentrating. Because the administrative law judge determines the claimant’s credibility, advocates should be aware that the judge cannot simply find the claimant to be “not wholly credible.” The claimant must report all troubling symptoms to the treating doctor at each visit and the doctor should be informed that the claimant is pursuing a disability claim and that the treatment records will be critical.

In Geiger v. Apfel the claimant alleged disability due to chronic hepatitis C and its treatment. The 57-year-old high school graduate had worked for many years for a local phone company until fatigue forced him to leave. During his last two working years, his supervisor tried to accommodate his needs by permitting him to nap for two hours each workday. The claimant’s primary complaints were of debilitating fatigue, achingness, and tiredness. Throughout treatment he reported problems with fatigue and low-grade fevers.

At the conclusion of treatment, doctors reported that he had tolerated the treatment well with only an occasional low-grade fever. A consultative examiner noted that the claimant had complained of fever, aches in his joints, and fatigue; stated the diagnosis as active HCV with cirrhosis; described the prognosis as guarded; and found that the claimant could not do any physical work because of his liver condition. The employer’s nurse stated

90 Id. §§ 404.1505(a), 416.905(a).
91 See Meyer v. Apfel, No. C 96-1006 MJM, 1999 WL 68139, at *2 n.2 (N.D. Iowa Jan. 21, 1999) (decision without published opinion) (case in which advocate failed to pursue a potential closed period of eligibility), aff’d, 221 F.3d 1343 (8th Cir. 2000).
93 See Townsend v. Apfel, No. 98-6239, 176 F.3d 489, 1999 WL 203069, at *2 (10th Cir. Apr. 9, 1999) (unpublished opinion) (listing factors to be considered by administrative law judge).
95 Id.
96 Id. at *1-2.
97 Id. at *2.
98 Id. at *3.
that the claimant required significant work restrictions.99 The administrative law judge rejected the opinions of the primary treating physician, the consultative examiner, and the nurse and, finding the claimant’s complaints to be “clearly inflated,” issued an unfavorable decision.100

The federal court held that, absent good cause, the administrative law judge must give substantial weight to the treating doctor’s opinion, diagnosis, and medical evidence.101 The court explained that if the treating doctor’s opinion is “well-supported . . . and is not inconsistent with the other substantial evidence, the [administrative law judge] must give it controlling weight.”102 The court found that substantial evidence did not support the administrative law judge’s findings and that the administrative law judge failed to explain how the treating doctor’s findings conflicted with any of the other medical evidence in the record.103 The court further found that the administrative law judge had not established good cause to disregard the treating doctor’s opinions and that the record did not support the judge’s conclusion that the claimant’s complaints were inflated.104 It reversed the judge’s decision and remanded solely for a calculation of benefits.105

In contrast to Geil v. Apfel a similarly situated claimant lost his disability case, which was based on hepatitis C, depression, and fatigue.106 Interestingly an earlier unpublished opinion from the same circuit held that even the subjective and retrospective statements and ultimate conclusions of the treating doctor were entitled to special weight unless the administrative law judge noted clear and convincing evidence for rejecting them.107 Without adequate reasons for rejecting the treating doctor’s statements and conclusions, the Ninth Circuit credited them as a matter of law.108

Another Ninth Circuit case stated that the administrative law judge must defer to the treating doctor, even if another doctor contradicted the treating doctor, unless the administrative law judge found specific, legitimate reasons based on substantial evidence for rejecting the treating doctors opinions.109 The court also stated that the administrative law judge’s observations that the claimant did not appear distressed or depressed at the hearing did not constitute a substantial reason for rejecting a treating doctor’s opinions.110

Hepatitis C patients often struggle through the treatment’s side effects, which many refer to as “brain fog,” and try to stay as active as possible, easing the inevitable depression. However, sometimes those efforts are harmful to claims for disability benefits. If the record contains no evidence of the degree of impair-

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99 Id.
100 Id.
101 Id. at *4.
102 Id.
103 Id. at *5–6.
104 Id. at *6.
105 Id. at *8.
108 Id. at *4.
110 Id. at *4.
ment or insufficient evidence of subjective complaints, a reviewing court will have difficulty finding the claimant disabled. Therefore, presenting specific evidence about the claimant’s daily activities, such as how long it takes to perform tasks, how fatigued the claimant becomes as a result, and whether help is reasonably available, is important.

*Sherman v. Apfel* illustrates the problems that claimants’ answers on the Social Security Administration’s disability questionnaire can cause; in *Sherman* the claimant alleged disability due to hepatitis C, depression, fatigue, and substance abuse.111 The record revealed that the claimant complained frequently of numerous hepatitis-related symptoms, such as headaches, diarrhea, stomach pain, fatigue, forgetfulness, depression, and nausea.112 Because of preexisting depression, the claimant’s treating doctor advised against interferon treatment until the resolution of the underlying depression.113 However, the administrative law judge latched onto the activities that the claimant listed on her disability questionnaire as evidence that she could perform light work and found her not disabled.114

The court stated that “the [administrative law judge] engaged in the kind of selective and misleading evidentiary review that this and other courts have rejected.”115 The court found that the administrative law judge had mischaracterized the claimant’s daily activities, had ignored the claimant’s other statements on the same forms, used his mischaracterization to discount her subjective complaints, incorrectly used a lack of corroborating objective medical evidence to disregard the claimant’s complaints, improperly discounted the claimant’s depression as merely situational, selectively credited some parts and rejected other parts of a key medical report, and improperly rejected the residual functioning capacity assessment.116 Before remanding for further proceedings, the court stated that “[a] physician’s medical opinion includes not only his clinical findings and test interpretations, but also his subjective judgments.”117

Because a large number of hepatitis C patients have a history of prior substance abuse, which could prohibit an award of benefits, the advocate must take care to develop hepatitis C and its treatment as an independent basis for disability.118 The advocate should appeal unfavorable decisions in which the administrative law judge fails to consider an independent basis properly. In *Davis v. Apfel* the court remanded the case for the administrative law judge’s further consideration as to whether the claimant had a basis, independent of alcoholism, for disability.119 The court found that the administrative law judge did not properly consider the treating doctors’ statements and an independent basis, if any, for the disability.120

By forging a partnership with the client’s doctor’s office, the advocate may be able to obtain stronger medical records and far greater cooperation. Our letter requesting medical records makes it clear that we are representing the patient free

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112 Id. at ‘1-2.

113 Id.

114 Id. at ‘5.

115 Id.

116 Id. at *5-8.

117 Id. at ‘8 (citations omitted).

118 *Askari*, supra note 1, at 82-83; *Everson & Weinberg*, supra note 1, at 32; *Recommendations*, supra note 1, at 5-6 (stating that many HCV patients have a prior substance abuse history); 42 U.S.C. §§ 423(d)(2)(C), 1382c(a)(3)(J) (2000) (stating that such history could prohibit an award of benefits); 20 C.F.R. §§ 404.1535, 416.935 (2000) (regarding determining whether drug addiction or alcoholism is a contributing factor material to the disability determination).


120 Id. at *3-4.
of charge and not on a contingent-fee basis. I explain to the doctor or nurse how important the doctor’s opinion is and how important documentation of the patient’s subjective complaints is. I also give the client’s primary doctor or hepatitis specialist, if the client has one, a copy of Listing 5.05 and ask the doctor or specialist to tell me if the client meet5 the listing. If so, I request a detailed statement setting forth the objective medical evidence, as well as the doctor’s subjective opinions, to support this conclusion.

If the client has difficulty obtaining the tests and procedures necessary to document the claim because of limitations on indigent health care, the advocate should try contacting the director of the program. Sometimes we can grease the proverbial wheels when the director understands that proving our mutual client to be disabled will create a source of funds to pay for care. I explain that without access to required testing and treatment, the client may end up on the liver transplant list at worst and a frequent emergency room consumer at best. The advocate at least should try to obtain a statement or copies of written policies showing the severe access limitations on certain tests and procedures and prepare the client to testify about the inability to obtain necessary medical evidence because of the high cost. The advocate should also submit documentary evidence where appropriate to build a record that the client’s file is lacking certain medical evidence because the client could not afford it and had no way to obtain it.

In addition to preparing the client to testify specifically and in detail about how hepatitis C and its treatment impair functioning, the advocate should obtain detailed evidence, especially statements from supervisors, about the client’s last work or work attempt(s). One administrative law judge found that the hepatitis C claimant could perform his past relevant work as a real estate agent.121 Fortunately the claimant’s advocate was able to show that in fact the claimant was unable to work a full day on most days because of fatigue and that he had received no salary and earned no commissions.122 The court ruled that the claimant’s experience as a real estate agent could not be “past relevant work” because it had not generated income equal to substantial gainful activity.123

Time can be a critical issue for some seriously ill hepatitis C patients. If the client is at risk of suffering serious and irreparable harm if the client does not receive benefits quickly, an advocate can request an on-the-record decision from the chief administrative law judge if the case has not yet been assigned to an administrative law judge. The advocate should reserve such requests for only truly critical situations in which the records are clear that the client is disabled. If the advocate makes too-frequent requests or requests for questionable cases, the chief administrative law judge will not view favorably and may even ignore the advocate’s future requests. However, in appropriate cases, this can be an excellent way to move the process along.

In representing hepatitis C patients in disability claims, advocates should keep in mind that such clients really cannot remember and that, if they are in treatment, they may have incredible difficulty accomplishing the simplest tasks. The hepatitis C clients in our office receive much more than the usual hand-holding and reminders. We found it especially helpful to give them written instructions and reminders and to call them the day before and again on the day of appointments to help them remember their commitments. Documentation of missed appointments and efforts to avoid missing them are further evidence of the client’s impaired mental functioning.

Although expending extra effort in reminding hepatitis C clients of appointments and commitments may be helpful and although they certainly can benefit from advocates’ direct involvement in their access to and documentation of treatment, advocates should take care to maintain

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122 Id.
123 Id.
appropriate professional boundaries. For clients whose lives are at risk from a mysterious disease, this can be difficult to do. However, if advocates do not maintain boundaries, their clients may suffer.

Mr. H failed to recognize those boundaries. When he experienced a severe psychotic reaction to his treatment, he called his attorney instead of his physician. The resulting events converted the attorney into a fact witness days before the administrative law judge hearing. Fortunately, we were able to secure private counsel on a pro bono basis. The advocate-turned-witness testified at the hearing on the claimant’s behalf, and the administrative law judge rendered a fully favorable decision.

### B. Discrimination Claims Under the Americans with Disabilities Act

Congress enacted the Americans with Disabilities Act to address lack of equal opportunity for disabled persons, not to grant special treatment to disabled persons. Because truly viable claims under the Act are fee generating, 45 C.F.R. § 1609 generally prohibits Legal Services Corporation-funded advocates from accepting such cases. However, recognizing issues inherent in claims under the Americans with Disabilities Act is nevertheless useful. I will limit this discussion to only a few interesting points.

Although the plaintiff in *Bragdon v. Abbott* had HIV, not HCV, the case is an important Americans with Disabilities Act case, in which the U.S. Supreme Court said that Congress did not intend for the Act to “only cover those aspects of a person’s life which have a public, economic, or daily character.” In finding procreation to be a major life activity that HIV infection had substantially limited, the Court stated:

The Act addresses substantial limitations on major life activities, not utter disabilities. Conception and childbirth are not impossible for an HIV victim but, without doubt, are dangerous to the public health. This meets the definition of a subcranial limitation. The decision to reproduce carries economic and legal consequences as well. In the end, the disability definition does not turn on personal choice. When significant limitations result from the impairments, the definition is met even if the difficulties are not insurmountable.

The Court did not require a nexus between the substantially limited major life activity and the specific act of discrimination. Therefore, a plaintiff in an employment discrimination case need not show that working is substantially limited; proving that any major life activity is substantially limited is enough to meet the “disabled” requirement under the Act. Some cases, however, impose specific evidentiary burdens for proving that certain life activities have been substantially limited.

While the courts must consider those job functions the employer deems “essential” and while written job descriptions

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128 Id. at 641.
129 Quick, 43 F. Supp. 2d at 1367 (interpreting *Bragdon v. Abbott*).
130 See id.
serve as evidence, employers are not free to include job requirements that have the effect of vitiating the intent of the Act. In Echazabal v. Chevron USA the employer tried to defend rescinding a job offer, after the preemployment physical revealed that the applicant had HCV, by claiming that it was merely protecting the applicant’s liver from exposure to refinery chemicals. Such “paternalism,” said the court, “is perhaps the most pervasive form of discrimination” that disabled face and is what Congress enacted the Act to address.

The employer also argued that the “direct-threat defense” under the Americans with Disabilities Act permitted measures to address direct threats to the safety of others and that an essential function of the job was that the employee not pose a threat to others. The employer further argued that the phrase “threat to others” included a threat to one’s self and that, because the applicant would not be able to comply with the essential function of not posing a threat to himself, he was not “qualified” under the Act. To permit such an argument to succeed, said the court, would be to permit employers to avoid the Act by merely including spurious functions in job descriptions.

However, the Americans with Disabilities Act does not require an employer to relieve a disabled employee of any of the legitimate essential functions of the employee’s job. Nor does the Act require the employer to shift any of the disabled employee’s responsibilities to other employees. Nor does the Act require the employer to lay off a nondisabled employee to create a vacancy in a position that the disabled employee can perform. The law entitles the disabled employee to a reasonable accommodation, not necessarily the preferred accommodation.

The advocate should be aware of the inherent tension between social security disability claims and Americans with Disabilities Act claims.

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132Echazabal v. Chevron USA, 226 F.3d 1063, 1071-72 (9th Cir. 2000) (Clearinghouse No. 53,141).
133Id. at 1065-66.
134Id. at 1068.
135Id. at 1065-68.
136Id. at 1067.
137Id. at 1067-68.
139Id.
140Pond v. Michelin N 183 F.3d 592, 596 (7th Cir. 1999); Quick, 43 F. Supp. 2d 1357, 1368-69.
141Quick, 43 F. Supp. 2d at 1369.
144Id. at *5.
expressed concern about the financial impact the employee’s condition would have on the company.  

A jury found that the employer violated the Americans with Disabilities Act and awarded the employee $73,000 in compensatory damages, $120,000 in punitive damages, costs, and attorney fees.

The advocate should be aware, however, of the inherent tension between social security disability claims and Americans with Disabilities Act claims. Courts have not necessarily found the two claims to be mutually exclusive. Instead the courts have recognized that the Social Security Administration requires that one be totally unable to perform any work without regard to whether reasonable accommodation would make working possible. A much lower level of impairment can trigger the Americans with Disabilities Act; the Act requires consideration of the impact of reasonable accommodations. Therefore, one could be “disabled” under the Americans with Disabilities Act but not under the Social Security Act and regulations governing social security disability. At least one circuit requires “strong countervailing evidence” that the plaintiff can perform the essential job functions with reasonable accommodation in a later Americans with Disabilities Act claim to overcome the effect of having alleged total disability in a Social Security Administration claim. The plaintiff in a later Americans with Disabilities Act claim would be held to the factual allegations of the earlier social security disability claim.

Last, but certainly not least, is a warning for advocates to stay abreast of important developments that may have an impact on their clients’ cases—especially U.S. Supreme Court cases on point. In Qualls v. Luck’s Stores the Court found that the plaintiff in this -Americans with Disabilities Act case was not disabled, although he suffered from HCV and alleged-based on his doctor’s warning that HCV could be transmitted sexually—substantial impairment in the major life activity of procreation. Contrary to Bragdon, the Court here found that reproduction and sexual relations were not “major life activities” under the Act because they were not daily in character.

Although the Court had decided Bragdon seven months before the plaintiff responded to the defendant’s motion for summary judgment in Qualls, the opinion neither cited nor factually distinguished the case at bar from the Bragdon decision. Because the Court in Bragdon specifically said, “When significant limitations result from the impairments, the definition is met even if the difficulties are not insurmountable,” the plaintiff’s attorney in Qualls might have exposed himself to a potential malpractice claim if he failed to bring the Bragdon decision to the court’s attention. However, Qualls may have foundered on its facts. Although the plaintiff alleged impaired reproduction, the evidence showed that he did not wear a condom consistently as his doctor instructed; he could not father children because of a vasectomy; and he never did undergo treatment for his HCV infection.
C. ERISA Claims

If an ERISA plan grants discretion to the administrator in determining eligibility for benefits, the courts will review denials under an abuse-of-discretion standard, which can be difficult to overcome. In Tolson v. Avondale Industries the court warned other similarly situated litigants that attacks on ERISA plans that grant discretion to the administrator could be deemed frivolous litigation and expose the plaintiff to liability for attorney fees and double costs under the Federal Rules of Appellate Procedure. Tolson also made clear that, at least in the Fifth Circuit, depression was a “mental or nervous disorder” as usually defined in most ERISA plans and did not become a physical disorder because interferon treatment for HCV might have caused it. In Tolson the plan required precertification; it also required that a specific provider for the treatment of mental or nervous disorders perform the services. Long-term disability benefits were payable for such disorders only if the patient had been in the hospital for treatment of the disorder. The plaintiff sought treatment for interferon-induced depression from a different provider and without obtaining precertification; the plan administrator denied his claim for plan benefits. He unsuccessfully argued that the depression should have been treated as a physical illness because of its cause. The court disagreed, stating that the cause was irrelevant to the determination of whether a disorder was physical or mental.

Gallegos v. Mt. Sinai Medical Center teaches the distinction between being unable to perform one’s job, and therefore eligible for short-term disability benefits, and being unable to perform one’s occupation, a common condition precedent to eligibility for long-term disability benefits. The tasks necessary to perform a specific job depend on a particular employer’s requirements of a particular position. However, how most employers view an occupation generally predetermines on a theoretical basis the tasks of the occupation. While an employee may not be capable of performing the specific tasks of the job for which a particular employer employs that employee, such an employee still theoretically may be capable of performing within the chosen occupation.

D. Veterans’ Benefits

Veterans test positive for HCV at a far greater rate than the general population, with the highest concentration being among veterans of the Vietnam war. A veteran can show a service connection for HCV that the veteran contracted even long before discovery of the virus, provided that the veteran proves a nexus between HCV infection and the treatment or diagnoses the veteran received during service or shortly after separation from service. Where medical evidence is not

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156 Tolson, 141 F.3d at 611.
157 Id. at 609–10.
158 Id. at 606–7.
159 Id. at 607.
160 Id. at 609.
161 Id. at 610.
163 Id. at *4–5.
available, lay testimony may be sufficient for the claim to be "well grounded." 166

Courts have noted the problems of veterans who underwent treatment for or were exposed to HCV during military service long ago but who did not receive a diagnosis for the disease until recently because of the lag in medical knowledge about the disease. 167 Legislation has been pending in Congress for some time to establish a presumption of service connection for veterans with hepatitis C. 168

In the meantime, the Department of Veterans Affairs issued on August 7, 2000, a proposed rule that dramatically alters the criteria for evaluating liver disorders and specifically deals with the fatigue of chronic hepatitis. 169

V. Conclusion

Hepatitis C is a serious disease that can cause cirrhosis and primary liver cancer. The virus can cause extreme fatigue, depression, and various mental and physical symptoms. The psychological features of the disease and treatment compound the stresses of everyday life. The long, debilitating, and expensive treatments are somewhat effective in less than one-half of those patients whose other underlying conditions do not preclude them from treatment. Without effective treatment, a liver transplant may be the patient's only option, but current demand for new livers far exceeds the available supply. Hope comes from research for new treatments and development of techniques that expand the supply of livers for transplants.

The legal issues that hepatitis C sufferers face are wide-ranging. Common problems involve access to proper care and treatment, disability claims, employment discrimination, insurance benefit denials, and veterans' benefits. Often the most useful role the advocate can play is that of counselor and protector. Through patience, persistence, and understanding, the legal advocate can help the hepatitis C client understand and remember important concepts and tasks. By being aware of the disease's impact and by serving as a buffer between the client and the outside world, the advocate can resolve through correspondence and negotiation many issues that hepatitis C clients face. Forging partnerships with health care providers enables legal advocates to gain better cooperation and more fully documented records, thereby increasing the chances of favorable outcomes for their clients. Working together, we can all make a difference in the lives of hepatitis C clients.


Get More from the Center’s Web Site

A topical list of the 116 cases mentioning “hepatitis C” that appeared in Westlaw's ALLFEDS directory as of September 2000—are as well as links to other resources that Linda S. Good cites in “‘The Shadow Epidemic’: Hepatitis C and the Law” is available on the National Center on Poverty Law’s Web site, www.povertylaw.org.