

ON THE BAD DAYS, WHEN SHE PRIES HERSELF OUT OF BED AFTER A 14-hour sleep wondering how she'll manage to get dressed—let alone work or take care of her husband and two teenage children—Becky Lorenz, 44, tries to think about what it's like in outer space. With every muscle in her body aching, she puts her mind aboard the Cassini spacecraft, currently winging its way toward Saturn. Lorenz, a welder and machinist at the University of Maryland, can imagine it well because she helped build some of the calibration instruments in the Cassini. As she ponders this high-tech wonder, whirling through the solar system, she dreams of the day when science will lead to a cure for hepatitis C, the liver disease that has nearly destroyed her life.

Mainly, though, Lorenz thinks about just making it through the next weeks, months, and years. For that, her only hope is to keep on taking a combination of pills and injections that cause a host of debilitating side effects—and have less than a 30 percent chance of ridding the potentially fatal virus from her blood. A compact, muscular woman, Lorenz used to spend weekends with her children rock climbing or exploring caves in West Virginia. But these simple pleasures of painless work and play seem about as far away as the ringed planet. “I feel ripped off. I feel cheated. I used to climb mountains and now I can't even climb the stairs. I'm uncoordinated, and my muscles and bones ache,” she says. “Most of the time I walk around in a fog and can't think straight. It's hard to fight the feelings that I'm worthless, lazy, and a bad mother. I come

home from work mentally and physically exhausted and don't have the energy to cope with parenting."

She's afraid to cook because she worries that blood from a chopping-board cut could contaminate someone in her family. Her daughter tries to be helpful, she says, "But she's 16—the world revolves around her." And her 14-year-old son? "Can't deal with it. I'll tell him, 'Leave me alone, I'm so tired,' and he says, 'You're always sick!' And he's right. I'm so afraid that my kids will grow up and all they'll remember about their childhood is that their mother wasn't there for them. It's so depressing. I've always considered myself a strong person, and I was always very active," she says. "But the person I was is dead."

Lorenz is among the estimated 1.8 percent of the population—almost four million Americans—who harbor the hepatitis C virus. Hepatitis C apparently began to proliferate in the mid-1960s in drug users, who spread it among themselves through shared needles and on to the world at large by selling their blood to banks.

Hepatitis C infection is already estimated to be more than four times as common in the U.S. as the virus that causes AIDS. It is the leading cause of chronic liver disease, and at least 8,000 Americans die each year of its complications. The virus, identified just 11 years ago, has already mutated into at least six major types and a wide array of subtypes, which vary in responsiveness to drugs. Researchers are struggling to catch up, but government scientists say the number of annual deaths may triple by 2015.

People who received blood transfusions or an organ transplant before July 1992 or who have shared dirty hypodermic

PROTECT YOURSELF

Be wary of situations that may put you at risk:

Hygiene: Don't share razors or toothbrushes.

Needles: Although the Centers for Disease Control and Prevention says it's "not confirmed" that the virus can be spread by the needles used in acupuncture, electrolysis, ear-piercing, or tattooing, or other tools that may pierce the skin, it's wise to play it safe. Ideally, that means making sure a new needle is used for each person. If that's not possible, the equipment should be sterilized.

Manicures: Bring your own tools, or make sure the salon's tools are thor-

oughly disinfected.

Sex: If you and your partner are monogamous, and neither of you have any other risk factors for hepatitis C, you don't need to worry. In all other cases, use condoms. If you or someone in your home has hepatitis C, cover any cuts immediately. Clean up spilled blood with bleach (which kills the virus), wearing protective gloves. Avoid sexual contact during your period; menstrual blood may carry the virus. If you know you are positive, stop drinking alcohol and start eating healthfully, says Joan Bennett Nayeri, who has the disease and runs a support group for patients in the Washington, D.C., area. "You can stave off cirrhosis."

6 4 MILLION AMERICANS ARE THOUGHT TO BE

needles are the most likely to be infected. (Starting in the mid-1980s, blood banks began more comprehensive screening of donors. In May 1990, the first test for hepatitis C was introduced, and an improved test became available in July 1992. As a result, the number of new infections has fallen off—from an estimated 230,000 a year in the 1980s, to about 36,000 in 1996.) Still, because those carrying the virus may not become sick until decades later, growing numbers of people are now finding out that they are infected.

And hepatitis C can spread any time an infected person's blood gets into the bloodstream of another—through unsterilized tattoo or other body-piercing needles, through shared toothbrushes and razors, through straws shared by cocaine users, and, under certain conditions, through sex. Even more disturbing: In about ten percent of cases, doctors and patients have no idea how the infection was contracted.

Lorenz is fairly certain that she was exposed to the virus 14 years ago, during the delivery of her second child, Ryan, by cesarean section. Lorenz lost blood during the operation and received a transfusion. Seven years later, when she was 37, she started feeling unusually tired and irritable. A single mother of two (Lorenz and her first husband had divorced five years earlier) working full-time, she chalked it up to stress. So did her doctor, who suggested she try the antidepressant Paxil. "The doctors told me I was exhausted because I was depressed,"

Lorenz remembers. "Actually, it was the other way around, but I didn't realize it."

Then, in 1993, during a routine screening of university employees, the campus clinic found elevated liver enzymes in Lorenz's blood—a red flag for disease. Further tests showed that she carried the hepatitis C virus, but because a biopsy showed that her liver was still in good shape, Lorenz wasn't a candidate for treatment with the then-new drug alpha-interferon, which was mainly given to people with more severe liver disease. She would have to get worse before she could have a chance at getting better.

AN "EPIDEMIC OF DISCOVERY"

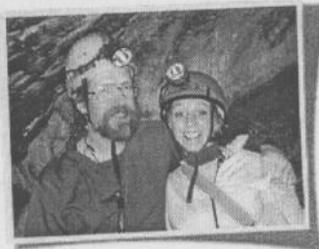
"The liver is a noncomplaining organ," says Thelma King Thiel, chairwoman of the Hepatitis Foundation International. "It doesn't give you any warning signs until the danger is pretty severe." The disease can take more than 30 years to move from infection to noticeable symptoms. What is happening now, explains Leonard Seeff, M.D., who directs research on hepatitis at the National

Institute of Diabetes and Digestive and Kidney Diseases in Bethesda, Maryland, is actually an outbreak of *discovery*. Thousands of people are getting bad news—but most of them were infected years ago.

Hepatitis C has an insidious method of attack. A few weeks after exposure, some people experience fatigue or flu-like symp-

"My husband, Les, and I used to go caving. I don't have the energy now."

—BECKY LORENZ, 44,
IN A 1994 PHOTO



toms. But most people have no symptoms at all. After many years of stealthy attacks on the liver, the patient may begin to show obvious signs of sickness, such as exhaustion and bloating in the abdomen. Some patients may also experience yellowing of the eyes and skin, known as jaundice, caused by an inability of the liver to excrete a variety of substances from the blood. At this point, blood tests can detect hepatitis C antibodies (immune cells that are manufactured in response to the viral threat) and the virus itself. A biopsy—in which a long needle is punched through the abdomen and into the liver to extract a thin strip of tissue—is the only way to determine just how much damage has been done.

If a biopsy shows the liver is inflamed or scarred, cirrhosis is a serious threat. “Once you get cirrhosis, you’re set up for liver failure or liver cancer,” says Joan Bennett Nayeri, 52, who runs a support group for hepatitis C patients in the Washington, D.C., area and has the disease herself. Scarring can choke off the portal vein, which brings blood from the intestine to the liver for cleaning. Unable to flow into the liver, blood backs up into veins in the stomach and esophagus. The veins **around** the esophagus can become so overloaded that they burst and the patient spits blood. Eventually, toxins may travel to the brain and cause confusion or delirium. That puts the patient at the transplant stage, along with 11,000 or so people currently waiting for new



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-PA TRICIA NOLAN, 35

came seemingly out of the blue in October 1997. “I would sleep for days,” she remembers. “I had enough energy to go to work and that was it. I couldn’t concentrate. I’d try to go to the gym, drive into the parking lot, turn right around, and go home. I was bouncing from doctor to doctor, but they thought it was all in my head.” She finally convinced her HMO to send her to a specialist, who did tests that confirmed she had the virus in her blood.

Nolan has no idea how she came in contact with hepatitis C—she never used drugs, never got a blood transfusion, and “lived a pretty boring life” as far as sex is concerned. The social stigma of the disease hit her hard: “I was engaged, but my boyfriend couldn’t handle it,” she says. “Hepatitis C has put a damper on any plans I had for getting married or having kids—at least for now.”

IS MORE TESTING THE ANSWER?

Most Americans thought to be infected with hepatitis C don’t know they have it—leading to fears that they may be unwittingly spreading the virus further. The testing question is tricky for people who fall outside the highest risk groups (see, “Should You Get Tested?” below), however, because the majority of people who carry hepatitis C will never get sick from it—the virus will remain dormant or, in a small number of cases, disappear from their blood on its own.

INFECTED—BUT MOST OF THEM DON’T KNOW IT YET

livers—a number expected to triple within the next 20 to 30 years. Five percent of those infected may die. “Hepatitis,” Nayeri says, “is not for sissies.”

Yet aside from occasional bags under the eyes, people in the early stages of hepatitis C often look perfectly normal, even when they feel horrible. “People say, ‘You don’t look sick,’” says Nayeri, “and yet you feel like you can’t make it through another moment.” Many patients have also gotten the runaround from their own doctors.

For Patricia Nolan, a 35-year-old business development specialist in Washington, D.C., the harsh realities of hepatitis C

Some people worry that past sexual activity makes them vulnerable. Because the virus is believed to travel mainly through blood-to-blood contact, anal intercourse (which is more likely to cause tearing) and sex in which one partner has exposed **cuts or venereal sores** do pose some risk. An estimated 15 to 20 percent of the most recent cases of hepatitis C, the Centers for Disease Control and Prevention (CDC) estimates, were contracted through sex. Women can also pass the **virus to their babies during** pregnancy. But a great many **questions simply** haven’t been answered to the CDC’s satisfaction. Given all the uncertain- (continued on page 150)

Should you get tested?

If you’ve received a blood transfusion or an organ transplant before July 1992, or blood products made before 1987, have been on kidney dialysis, or if you ever injected illegal drugs, you should be tested for Hepatitis C.

It’s less clear to what extent people who may have been exposed in other ways—e.g., through sex with an infected

person, cocaine use, contaminated body-piercing needles, or shared toothbrushes and razors—are at risk. If you do opt for testing, here’s what’s involved:

AT THE DOCTOR’S OFFICE A normal blood work-up done in a routine exam won’t test for hepatitis C, but it can show whether you have higher-than-normal liver enzyme levels. Further blood tests check for the virus and antibodies to it. A biopsy is the only way to determine the extent of liver damage.

AT HOME The American Liver Foundation has teamed up with a private company

called Home Access Health that has manufactured a home-testing kit for hepatitis C, in which you draw your own blood through a finger-stick needle and send the sample in for testing. As we went to press, and pending FDA approval, the company expected to begin selling the kits in late spring.

“This gives you the opportunity to privately check it out,” says Alan P. Brownstein, president of the American Liver Foundation in New York. The kits will be available for under \$70 at drug-stores or by calling 888-888-HEPC.

hepatitis c

(continued from page 117)

ties, Alan P. Brownstein, president of the American Liver Foundation in New York, says, "If you are in doubt—get tested."

WHERE TREATMENTS FALL SHORT

Whether or not to test isn't the only gray area: If you do test positive for hepatitis C, there's uncertainty about what to do next. At the very least, people with hepatitis C need to protect their vulnerable livers by cutting out alcohol. They may want to get vaccinated for hep A and hep B, too, since either virus can cause liver damage (see "The ABC's of Hepatitis," page 152). But treatment options are still limited. The FDA approved the first treatment, the antiviral drug alpha-interferon, in 1991, but only 10 to 20 percent of alpha-interferon patients benefit from it. Since last year, a second drug, ribavirin, has been added to the mix, and the combination seems to work well enough that in as many as 40 percent of patients the virus stays at an undetectable level for at least six months beyond the end of therapy.

hepatitis c

(continued)

nosed, the virus in her blood was 2,000 units per milliliter—a level so low, in the opinion of some of her doctors, that it couldn't be making her feel as bad as she said. (Lorenz's blood has 1,000 times more virus.) But Nolan wanted to try treatment. "They found just enough inflammation in my liver to get me in [a National Institutes of Health study]," she says.

Nolan has found it easier than Lorenz to temper the side effects of the combination drug therapy. For the first several weeks, after injecting herself with alpha-interferon at 4 P.M., she'd wake up the next morning feeling lousy. But within five weeks, the virus virtually disappeared from her blood, and since then she has felt pretty good. She lifts weights and works out on the nights of the injections, and finds that exercise makes her feel better. She takes a lot of vitamins and eats pesticide-free organic food (to protect her liver from all possible chemicals). "There's always a chance the virus will come back," she says. "But I'm hopeful." □

THE ABCs OF HEPATITIS

Hepatitis C is an altogether different—and more dangerous—beast than its cousins, A and B.

● **HEPATITIS A**, which spreads through contaminated food and water, is contracted by an estimated 125,000 to 200,000 Americans every year. It can be debilitating for a month or so. But for those who rest and abstain from alcohol for six months, it goes away.

● **HEPATITIS B**, which an estimated 140,000 to 320,000 Americans contract each year—mostly from sex or IV drug use—is more serious, but also treatable; in about nine out of ten adult cases, it runs its course in a few months. Vaccines protect against both hepatitis A and B.

● **HEPATITIS C** mutates rapidly, making a vaccine especially hard to develop. It's estimated that of the almost 4 million Americans thought to be infected with hepatitis C, 15 percent may develop cirrhosis over a period of 20 to 30 years and 5 percent may die from the consequences of long-term infection.