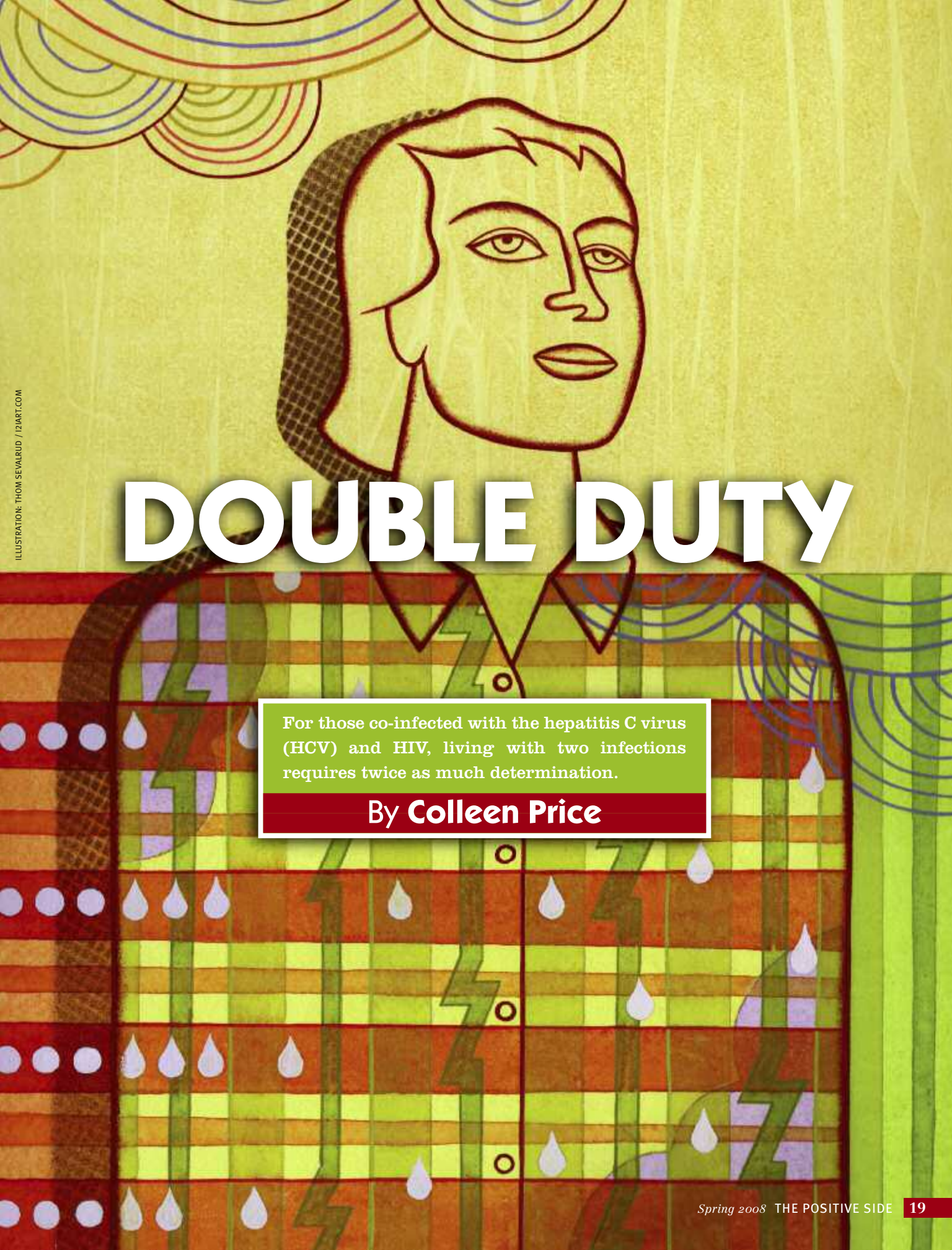

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DOUBLE DUTY

For those co-infected with the hepatitis C virus (HCV) and HIV, living with two infections requires twice as much determination.

By **Colleen Price**

My story

The mind can transcend trauma, illness and addiction and I believe that everyone has this capacity to heal mind, body and soul. Sometimes, it just needs to be fostered.

I am a survivor of trauma, addiction, hepatitis C virus (HCV) and HIV. I no longer feel shame, guilt or fear. Instead, I found a way out of my depression, anger and despair by addressing issues of childhood trauma and that helped me heal for the first time.

It has been a long journey, but I have found acceptance, empowerment and hope, something that I never valued before being treated for HCV. In moving beyond my past, I chose to accept myself for who I am and found that I no longer need my addictions to survive. I also realize this will be an ongoing process, as I am in recovery and face chronic illness.

In June 2005, I completed 48 weeks of HCV treatment. It was not an easy process as I am infected with a strain of HCV known as HCV genotype 1, but I learned to cope.

I am grateful for all the support I received from my partner, Sandie, as well as from long-term survivors of HCV, HIV

Treatment tango

In Canada, it is estimated that more than 10,000 people living with HIV (PHAs) are also infected with the hepatitis C virus (HCV). That's about 20 percent of the estimated 58,000 PHAs in the country.

About 70 percent to 80 percent of people with HCV in Canada got the virus when they injected drugs, and shared needles or other drug-related equipment. Many people also get HIV this way, so it's little surprise that injection drug users are particularly vulnerable to co-infection (that is, infection by both viruses). It is estimated that between 50 percent to 90 percent of all PHAs who inject drugs also have HCV.

Sex appears to account for only a small percentage of new HCV infections, but the risk of transmission increases with the presence of sexually transmitted infections, HIV, menstruation or through rough sex, fisting, anal enemas, group sex or sex with multiple partners.

Perhaps the most worrisome part is that about 65 percent of all people with hepatitis C don't know they have it. (See *Are you at risk?* page 21.) The only way to know if you have HCV is to be tested. If there is a chance you could be co-infected, ask your doctor for testing for HIV and HCV, as each virus requires separate tests.

HCV is a virus that causes inflammation and scarring (fibrosis) of the liver and, in more serious cases, can lead to cirrhosis or liver cancer. There are six genotypes or strains and some people are infected with more than one genotype as a result of being exposed to HCV more than once. In Canada, the most common HCV infection is with genotype 1, which is also the most difficult to treat.

In most cases, HCV is a manageable, treatable disease, especially when it is diagnosed early. And while treatment for HCV/HIV co-infection tends to be more complex than therapy for either infection alone, the bottom line is that even when you are co-infected there is a lot you can do to stay as healthy as possible. In some cases, HCV can be treated prior to HIV therapy; in others, liver-friendly anti-HIV meds can be given and then the status of both HCV and HIV carefully monitored.

HCV treatment is a combination of two antiviral drugs: ribavirin (Pegetron capsules or Copegus) and a long-lasting form of interferon called pegylated interferon (Pegetron or Pegasys). For co-infected people, both drugs are usually taken for 48 weeks. Ribavirin is a pill you take twice every day. The pegylated interferon is injected once a week. Once you start taking these medications, your doctor will monitor the level of virus in your blood (HCV viral load) regularly, just as with anti-HIV meds, to see whether or not the drugs are working. Also like HIV, HCV viral load can become undetectable, though with HCV, undetectable means fewer than 15–50 IU/mL, depending on the test. If your HCV viral load is undetectable six months after treatment, it's called sustained virological response (SVR) and you have cleared the virus. Many consider this a cure. However, you are not protected from HCV and you can be re-infected.

Note that some anti-HIV meds—specifically AZT (Retrovir and in Combivir and Trizivir), d4T (Zerit) and ddI (Videx EC)—can interact with anti-HCV meds. If you are taking any of these meds and you're considering HCV treatment, make sure you talk with your doctor.

Anti-HCV drugs come with side effects, including flu-like symptoms (headaches, fatigue and muscle pain), depression or irritability and low red blood cell counts (anemia), as well as low white blood cell counts (neutropenia). There are ways to manage them. For example, you might be able to cope better with the flu-like symptoms by doing interferon injections at night, taking an over-the-counter pain medication and sleeping through the worst side effects.

Anti-HCV drugs can affect your mood, making you feel blue or even depressed. If you have a history of depression, mention it to your doctor while you are discussing HCV treatment. There are ways to manage depression before and during treatment. And it's really important that you let your doctor, nurse and other caregivers know if your mood changes once you start therapy.

How well you respond to HCV treatment depends on a number of factors, including the strain of HCV you are infected with, as well as the amount of damage the virus has caused to your liver. The good news here is that response rates to HCV treatment have generally improved. This means that even if therapy didn't work for you in the past, you might be able to undergo treatment again with better results. That's definitely something you'll want to talk with your doctor about.

and HCV/HIV co-infection who shared their stories and knowledge. Without it, I may not have stuck with treatment. Along the way, I learned that HCV/HIV co-infection is not a death sentence. Now, two-and-a-half years after treatment, I have tested "undetectable" for HCV and I am not on HIV medications.

People with HCV/HIV co-infection have unique social, treatment and support needs, but many fall between the cracks of HIV or HCV service organizations. Just who is responsible for the co-infected? Right now, it's a grey area with no dedicated government support.

Co-infected people need to be identified as a special-needs population, and policy, program and support services developed accordingly. Most people living with HCV/HIV are former or current drug users and this can be a barrier to treatment. The kind of treatment that you have access to also depends very much on which province you live in, whether you're in an urban or rural centre, on or off reserve, and whether or not you are incarcerated. Co-infection protocols that would standardize services and access to services are desperately needed.

We need comprehensive, multi-disciplinary treatment plans to support co-infected individuals. Healthcare professionals as well as mental-health and addictions specialists must be trained in HCV/HIV co-infection so that services can assist not only with prevention, but also help rebuild shattered lives.

Regressive government policies remain one of the greatest challenges in HCV-HIV co-infection, despite the vast amount of scientific research that supports the effectiveness of harm reduction. Harm-reduction services help people change ingrained patterns of thinking, feeling and behaving, improving quality of life and increasing the chances they will stick with treatment.

More and better support services are also desperately needed. HCV treatment can cause psychiatric complications including depression, aggression and suicidal thoughts. Antidepressants, individual counselling and peer-support groups are often needed to reduce clinical and emotional side effects and to strengthen coping strategies. Diet, use of micronutrients and exercise are also important.

More needs to be done. This includes research on disease interaction, HCV and HIV drug interactions, interactions with street drugs and issues related to aging and organ transplantation. Everyone must have the opportunity to be tested and treated, and research must focus on those who are difficult to treat.

My experience with HCV treatment has motivated me to advocate for those who are HCV/HIV co-infected. I will never give up my fight against these devastating infections. I know firsthand that with dual diagnosis comes dual stigma and complex treatment options. I also know that treatments can and do work, so never give up hope, never give up on yourself. Keep positive and take care of your mental, physical and spiritual health.

Colleen Price is a board member of the Canadian Treatment Action Council (CTAC) and chair of the CTAC HCV/HIV Working Group.

Are you at risk?

Many of the behaviours that put people at risk for HCV are similar to those associated with HIV and many of the steps to prevent HCV also apply to preventing HIV.

Hepatitis C virus (HCV) is transmitted when the blood of an infected person comes in contact with the blood of someone else. The virus itself is quite resilient and can survive outside the body for four or more days. The activities with the highest risk are those that have the highest potential for blood-to-blood contact.

HIGH-RISK FACTORS/BEHAVIOURS

- **Sharing drug-use equipment**: Equipment for injection drug use, smoking crack, using steroids or snorting drugs can be contaminated with microscopic blood particles and transmit HCV. Even a single episode of sharing drug-use equipment (syringes, cookers, water, filters, tourniquets, straws or pipes) means that you should consider being tested for HCV.
- **Sharing tattoo or body-piercing equipment**: Needles, equipment and ink can be contaminated with infected blood and transmit HCV. This is most likely to happen when single-use equipment is re-used or proper sterilization techniques are not used.
- **Blood transfusions prior to 1992**: Blood transfusions received before blood screening began in 1992 are considered high risk.
- **Unsterilized medical equipment**: Shared medical or surgical equipment can transmit HCV.
- **Blood or cutting rituals**: Rituals that involve cutting with shared tools or the exchange of infected blood can also transmit HCV.
- **Unprotected anal intercourse if you are positive**: HIV-positive men who have unprotected anal intercourse with people who either have HCV or don't know their HCV status.

MODERATE RISK

- **Sharing personal hygiene and grooming supplies**: Sharing razors, toothbrushes, nail clippers and other household items contaminated with infected blood can transmit HCV.
- **Sexual intercourse**: HCV can be transmitted sexually when infected blood is present, such as during menstruation or when other sexually transmitted infections are present.
- **Mother-to-child transmission** during childbirth.
- **Needlestick injuries in health-care settings** when there is the possibility of exposure to HCV-infected blood.

NO RISK

- **Casual contact** with a person living with HCV, including sharing toilets, drinking glasses and eating utensils.
- **Hugging, kissing or touching** a person living with HCV.
- **Employing harm-reduction** principles, using new drug equipment for injecting, snorting or smoking drugs, or using new/sterile tattoo and piercing equipment.
- **Using new or sterilized medical equipment** during medical procedures.

Getting involved and giving back

I am passionate about volunteering with AIDS service organizations, sitting on the board of directors (AIDS Thunder Bay and Ontario AIDS Network) and public speaking. If I was not involved in these ways, I wouldn't feel the way I do now about my future. Now I understand what I need to do to have a long life.

—**Greg Simmons**, 40, Toronto

When I awoke early on Dec. 20, 2003, I knew my life had changed dramatically. Someone was injecting me with their blood. I didn't die from a drug overdose, but I realized that something much more profound had happened instead.

The next few months flew by in a blur as I self-medicated instead of trying to deal with what I knew—that I had been infected with HIV. The day I got my diagnosis, I tried to kill myself, but a friend found me and called an ambulance. When I learned that I had been diagnosed with HCV and HIV, I thought my life was over.

How wrong I was. Since that day, I have begun to live my life the way I dreamed of as a child. I applied to go back to school and I am on the board of directors for AIDS Thunder Bay and on the board of the Ontario AIDS Network. My volunteer work has been a source of pride for me, since I was incarcerated for several years when I was younger.

It feels good giving back to society and trying to help my fellow PHAs. It hasn't been easy and I couldn't have done this without the guidance of some remarkable people, as well as my ASO and the Canadian Mental Health Association. The Ontario AIDS Network Leadership training also assisted me and I recommend this training for people living with HIV/AIDS and those who are HCV/HIV co-infected. ✚

Where to find information about HCV/HIV co-infection online

www.hepCinfo.ca is part of **CATIE's Hepatitis C Key Messages Toolkit Project**. This new bilingual Web site contains downloadable **prevention education/harm reduction** resource materials for service providers and people living with and affected by hepatitis C virus (HCV).

"Infections and Bugs and Germs… Oh My!" in the Fall/Winter 2004 issue of *The Positive Side*, available at www.positiveside.ca, provides info about how to avoid all the hepatitis viruses.

www.catie.ca provides several resources on HCV/HIV co-infection, including:

- a brochure on co-infection
- pre*fix: harm reduction for + users
- in-depth fact sheets on hepatitis C and its treatment

www.hivandhepatitis.com

www.thebody.com/content/art44395.html – U.S.-based *The Body* provides an overview of HCV/HIV co-infection.

OTHER HCV RESOURCES

The Canadian Harm Reduction Network is the virtual meeting place for individuals and organizations dedicated to reducing the social, health and economic harms associated with drugs and drug policies.

- www.canadianharmreduction.com

The Hepatitis C Support Project (HCSP) is a registered non-profit organization that provides advocacy to communities affected by HCV and HCV/HIV co-infection, including medical providers.

- www.hcvadvocate.org

HepCBC is a non-profit organization that provides education, prevention and support to those living with HCV.

- www.hepcbc.ca

www.hemophilia.ca from the Canadian Hemophilia Society. (Look under "Infectious diseases" in the left-hand navigation bar.)

The Canadian Aboriginal AIDS Network (CAAN) has excellent resources and a paper on Aboriginal HCV/HIV co-infection.

- www.caan.ca

WHERE TO FIND INFO ABOUT SUPPORT

www.cmha.ca – Canadian Mental Health Association