

STIGMA & HEPATITIS C: A FACT SHEET FOR HEALTH CARE PROVIDERS

Stigma: A Side Effect of Hepatitis C

Hepatitis C (HCV) is a widely stigmatized disease. People living with HCV experience stigma in all areas of life, most frequently in health care settings. Living with a stigmatized disease can significantly affect quality of life & lead to loss of income, financial instability, housing insecurity, isolation & depression. Stigma increases disease burden because it leads to a lack of testing, treatment & primary care.

This question-&-answer resource sheet is meant to:

- 1) Answer some basic questions about stigma & its health effects
- 2) Describe prevention strategies for stigma & remedies for discrimination
- 3) Provide stigma resources for people with HCV

Q. What is stigma?

Stigma is a process where a person is negatively judged & devalued because of a particular characteristic. Judgments are interpersonal but can also involve self-judgments or media portrayals - all of which may create discriminatory behaviour.

HCV is stigmatized because it's a contagious disease & is associated with illicit drug use. Fears about transmission, fueled by misinformation about HCV, combine with moral judgments about drug use leading to judgments that people with HCV are "less worthy" of help.

Discrimination occurs, even if unintentional, when someone is treated differently because of their HCV diagnosis (eg. avoidance of people with HCV, inappropriate precautions against infection & breaches of confidentiality).

"I went to the dentist & told her I have hep C. They're supposed to follow standard infection control but I told her, just in case. Her attitude toward me totally changed. She told me I'd have to wait until the end of the day for my appointment because they'd have to do extra clean up afterward."

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Q. What can health care providers do to prevent stigma?

Stigma is frequently occurring in healthcare often at diagnosis when people are most vulnerable & need significant support. It's notable that many people disclose only to their health care providers. The health care setting thus pivotal in how people cope with the physical & social consequences of HCV.

“People have been avoiding me since it got out at work that I have hep C. I found out recently my co-workers have been bleaching my coffee cup & utensils after I leave the lunch room.”

Providers, aware of the stigma toward HCV, can play two important roles. They can:

1. Create a safe & positive health environment to encourage help-seeking
2. Provide assistance & support for stigmatized people to prevent declines in quality of life.

1. Prevent stigma & create a safe health care environment

These tips for establishing a non-judgmental environment are from persons living with HCV who are often anxious about the reactions of others & anticipate being stigmatized.

- Use standard infection control precautions with everyone & then no one will feel pressured to disclose their status to protect others
- Avoid the question about how HCV was acquired so people won't fear being treated badly because of associations with drug use
- Follow policies of confidentiality
- Acknowledge active drug users' expectations about problems obtaining pain relief to open communication about appropriate dosing
- Establish a trust relationship by:
 - Using precise, non-judgmental language about substance use like injecting (rather than intravenous) & drug use (instead of drug abuse)
 - Avoid terms that may be considered offensive, misleading or discriminatory like addict, addiction, drug addict, drug abuser
 - Consider information needs related to HCV as involving transmission risks, the social, psychological & physical effects of drug use, the effectiveness of & access to treatment

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If you lack experience in areas such as providing HCV education or in working with people who inject drugs spend time with more experienced co-workers or your supervisor. Discuss any fears or concerns you have with colleagues. Practice how you would answer particular questions & how you would handle specific situations. Ask a colleague to share some first sessions with clients who inject drugs.

2. Strategies & interventions to reduce the impacts of stigma

Anticipate: Inform people they are not required to disclose their hepatitis C status except in very specialized circumstances. At diagnosis many know little about the virus & its social implications. Assisting the newly diagnosed with decisions about disclosure can prevent negative experiences at this vulnerable time.

Monitor: Stigma may narrow social support networks and personal responses vary. For some these changes may be adaptive while for others negative health impacts involving isolation & depression may accrue.

Unfortunately, those most likely to be discriminated against are usually already marginalized & are least able to access resources to improve their situation - they may not recognize when they are being treated poorly. Identify discriminatory treatment to increase knowledge of rights & increase their expectations of service.

“I went to a lab for a blood test for my hepatitis C. While she was reading my form I told her I had hepatitis C. Her eyes got wide & she took a step back. It was subtle & she didn’t say anything but I could tell she didn’t want me in there.”

Refer: If stigma appears to be part of a person’s experience you can refer them to “**Stigma & Hepatitis C**” - a helpful resource providing tools to confront labels associated with HCV.

Internalized stigma is common with a diagnosis of HCV reflected in feelings of shame & dirtiness. If a person’s feelings are causing distress, **cognitive behavioural therapy** can uncover beliefs about the virus & self-identity.

Support groups are a place to experience a positive identity with HCV. Self-care education, a component of many groups, builds confidence. Research shows gains in self-management abilities can create resilience to stigma.

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For those who do not find groups helpful or do not want to be associated with a disease specific group, the “**Advocacy for Hepatitis Care and Support Handbook**” may be useful. It’s a resource for building effective approaches to problem resolution & a self-managed health care plan.

It is important for people to know that discrimination toward persons because of their HCV status, real or assumed, is against the law.

Treating people differently because of their HCV status, a physical disability, is a “**prohibited ground**” of discrimination according to federal & provincial law. Legal definitions limit discrimination to defined settings such as the workplace, when using services, or in property transactions such as rental accommodation. Refer persons to the appropriate human rights agency for advice on how to proceed in making a complaint.

Canadian Human Rights Commission – deals with discrimination complaints filed against federally regulated services & agencies (chartered banks, airlines, federal departments, agencies & crown corporations).
Toll free: 1-888-214-1090

BC Human Rights Tribunal - handles complaints for provincially regulated businesses & agencies (retail shops & hospitality businesses, hospitals, healthcare providers, schools, colleges or universities, & manufacturers).
Toll free (in B.C.) 1-888-440-8844
Vancouver (604)-775-2000

Both these agencies resolve complaints first through mediation. If mediation fails, the agencies investigate further & may hold a hearing, which results in a ruling that can set out the terms of remedy, for example, awarding monetary damages or job reinstatement.

If you see discriminatory practice in your workplace, recommend the need for further staff education to your manager.