STIGMA & HEPATITIS C: A QUESTION & ANSWER RESOURCE FOR PEOPLE LIVING WITH HEPATITIS C

Introduction

A diagnosis of hepatitis C can lead to experiences of stigma. Negative attitudes & discrimination toward people with hep C happen in all areas of life, including health care. People report they've been refused services &/or negatively judged because of their condition during visits to the doctor or dentist & during medical procedures.

Living with a stigmatized disease can have important effects on your health & the quality of your life by interfering with relationships at home, work, & in your health care. Effects of stigma include isolation & depression, & suffering financial or housing issues. Some people withdraw from care & don't tell anyone they have hep C to avoid stigma, which can make health problems worse.

DID YOU KNOW?

It's illegal to discriminate against someone because they have an illness or disability.

Hopefully, stigma is not part of your experience. But knowing hepatitis C can be stigmatized will help you to prepare & respond to stigma should you need to. This Q & A resource sheet includes strategies & resources to prevent & deal with hep C-related stigma & discrimination.

Q. What is stigma?

Stigma happens when people are negatively judged & devalued because they have hepatitis C. These judgments happen between people and may cause discrimination – treating people differently because of their diagnosis with hep C.

People who are newly diagnosed often judge themselves harshly. Diagnosis can bring on feelings of shame, guilt & uncleanliness. Feelings like these can reflect social attitudes including prejudices & inaccurate beliefs about hep C. Negative media stories and images of hepatitis C are where some people first learn about the illness.

Q. Why is hep C stigmatized?

Hep C is stigmatized for many reasons. Hepatitis C is still a new disease so many people don't have correct information about how the disease is passed from person to person, how it affects health & how it is treated. But hep C is also stigmatized because of assumptions & judgments about injecting drug use. Since many drug users acquire hep C through their drug use, there is now an often automatic association between the two.

Examples of what stigma looks like include avoidance of the person with hepatitis C, inappropriate precautions against infection by health care workers & breaches of confidentiality. Actions like these often happen at diagnosis & are deeply hurtful.

Q. Is stigma toward people with hepatitis C against the law?

If discrimination occurs in the workplace, when using services, or when trying to find accommodation it may be illegal. Being treated differently because of a hepatitis C diagnosis, whether confirmed or suspected, is discrimination.

Hep C is considered a physical disability. According to the law, people who have, or are thought to have, an illness like hepatitis C cannot be treated differently because of their illness.

Two important federal & provincial human rights laws you should know about are:

1. The Canadian Human Rights Act (R.S., 1985, H-6)

The Canadian Human Rights Commission is responsible for this act that gives all Canadians equal opportunity to work & live without being discriminated against. Section 25 of the Act defines disability as a current or past physical or mental condition that may be permanent or temporary (e.g., a treatable illness like hepatitis C).

2. The BC Human Rights Code (RSBC 1996)

Considered a physical disability, hepatitis C, cannot be used to discriminate against people in BC. The areas this Code protects include: 1) employment 2) rental accommodation (or tenancy) & purchase of property 3) accommodation, services & facilities usually available to the public.

Q. I think that I am being stigmatized against because of my hepatitis C status – what should I do?

The <u>Canadian Human Rights Commission</u> looks after complaints of discrimination filed against <u>federally</u> regulated services & agencies (such as chartered banks, airlines, federal departments, agencies & crown corporations).

The <u>BC Human Rights Tribunal</u> considers complaints for all <u>provincially</u> regulated businesses & agencies (such as retail shops & hospitality businesses, hospitals or healthcare providers, schools, colleges or universities, & most manufacturers).

Both agencies will use mediation first when they receive a complaint and if this process fails, they will investigate further & may hold a hearing. A hearing can result in a ruling that sets out the terms of redress, for example job reinstatement or monetary compensation for lost wages.

To help you decide which agency would handle your complaint visit the website of or telephone:

The Canadian Human Rights Commission http://www.chrc-ccdp.ca/default-en.asp

(Toll Free: 1-888-214-1090)

& The BC Human Rights Tribunal (<u>http://www.bchrt.bc.ca/</u>) 1-888-440-8844 toll free (in B.C.) or in Vancouver (604) 775-2000

Stigma & discrimination in health care

If you experience stigma during visits with doctors, nurses, lab workers, physiotherapists or other health care workers, first discuss your experience & concerns with the person who provided or supervised the care. Explain why you are not satisfied with their actions. If you are not satisfied with the results of this discussion send a complaint to the health facility that provided the care, & then to the provincial (e.g. BC Medical Association) or national professional association (e.g. Canadian Medical Association) of which they are a member. You are also entitled to change providers.

For how-to help to make a complaint, check out the <u>hepatitis C advocacy</u> <u>package</u>. This package has information to help you communicate

constructively, either in-person or in writing, with service providers so you can get what you need to live well with hep C.

Q. How do I cope with the stigma of hepatitis C?

There are effective strategies to cope with stigma. To find the strategy best suited to you, consider your needs & experiences. For example, if your own feelings about hep C are causing difficulties or keeping you isolated, talk with a trusted health care provider, consider joining a support group, or seek cognitive behavioural therapy which can help you understand & change how your beliefs are linked to your feelings. Disclose your diagnosis to those you feel need to know but know that there are few instances where you must disclose. Remember there are laws to help you against discrimination.

"Stigma & Hepatitis C", is a booklet that explains how hep C is stigmatized & provides tools to confront the labels associated with hepatitis C.

Hep C Stigma Experiences & Recommendations

"I applied to my local police force to become a member. When they reviewed my medical records & saw I was hepatitis C positive they rejected my application. Is there anything I can do?"

Get advice from the BC Human Rights Tribunal or other human rights advocacy groups. You might want to consider making a complaint to the chief of police & to the city.

"I was recently promoted to kitchen manager at the restaurant I've worked in for three years. After my promotion I found out I had hepatitis C. I told the owner about my diagnosis because I was worried about the company benefit plan & whether I would be covered. He told me he had to let me go. What can I do?"

Contact the BC Human Rights Tribunal for advice. The Tribunal attempts to resolve issues like these through mediation but can award damages such as lost wages in successful cases. Ensure you have adequate support for yourself during events like these.

"I disclosed my hepatitis C to my boss. He makes me use one particular washroom & asked that I not use the other facilities in the building. I feel very uncomfortable at work & don't know what to do."

Hepatitis advocacy & information groups may be able to assist you with on-site education for the whole company or the specific individuals aware of your hepatitis C status. Enlist the aid of another manager to provide education about hepatitis C & human rights. Sometimes accurate information about hepatitis C is enough to eliminate discrimination. If this choice is not open to you, contact either the BC Human Rights Tribunal or the Canadian Human Rights Commission depending on whether your employer is federally or provincially regulated.

"I went home to visit my family when I was diagnosed. When I told them I had hepatitis C they asked me not to share the family utensils or the bathroom & not to kiss or cuddle my nieces & nephews."

Get some support for yourself from non-judgmental sources like friends or support groups during this difficult time. Because hepatitis C is a recently discovered illness lack of knowledge & confusion with other illnesses such as HIV is common. Your family's response comes from their fear & is not about you as a person. Hepatitis advocacy groups such as the Canadian Liver Foundation can help you figure out how best to educate your family. A knowledgeable & supportive friend could meet with your family to provide accurate information about the virus & answer questions.

I've been discriminated against in a health care setting. What can I do?

First, you might want to talk to the manager or supervisor in that setting to tell them about your experience & how it has affected you. Let them know that the behaviour/policy/procedure is not acceptable. If you are not satisfied with the response, you can make a complaint to the facility. Contact the BC Human Rights Tribunal for further advice.

Further Assistance & Related Information

BC Human Rights Clinic Vancouver Region

Phone: 604-689-8474

Toll Free: 1-877-689-8474

BC Human Rights Coalition Vancouver Island Region

Phone: 250-382-3012 E-mail: vihrc@telus.net The Law Centre Victoria, BC

Phone: 250-385-1221

250-385-1226

UBC Law Students' Legal Advice

Program

Vancouver, BC

Phone: 604-822-5791

Western Canada Society to Access

Justice

Phone: 604-878-7400

Web site: www.accessjustice.ca

B.C. government Web site

http://www.gov.bc.ca/index.html

Canadian Human Rights Reporter

www.cdn-hr-reporter.ca