Stigma and Hepatitis C: A question and answer resource for people living with hepatitis C

Introduction

Stigma is one of six main factors that can make it difficult for people to get the hepatitis C care they need (click image to view details).

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

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

Hopefully, stigma is not part of your experience, but knowing hepatitis C can be stigmatizing can help you to prepare and respond to stigma if it happens. This Q&A resource sheet includes strategies and resources to prevent and deal with hepatitis C-related stigma and discrimination.
Q. What is stigma?

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

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

Q. Why is hepatitis C stigmatized?

Hepatitis C is stigmatized for many reasons. Many people don’t have correct information about how the disease is passed from person to person, how it affects health and how it is treated. But hepatitis C is also stigmatized because of assumptions and judgments about injecting drug use. Since many drug users acquire hepatitis 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 and breaches of confidentiality. Actions like these often happen at diagnosis and 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.

Hepatitis 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.

The federal human rights laws you should know about is:
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 and 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).

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

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

For provincially or territorially regulated businesses and agencies (such as retail shops and hospitality businesses, hospitals or healthcare providers, schools, colleges or universities, and most manufacturers) visit the Canadian Human Rights Commission for a list of provincial/territorial organizations.

These agencies will use mediation first when they receive a complaint and if this process fails, they will investigate further and 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.

The Canadian Human Rights Commission can help you to decide which agency would handle your complaint. You can visit their website (http://www.chrc-ccdp.gc.ca/index.html) or call their toll-free phone number (1-888-214-1090).

Stigma and 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 and 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, and then to a provincial (e.g. 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 information to help you communicate effectively, check out Speaking up for Hepatitis C Care and Support booklet. This book 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 hepatitis 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 and experiences. For example, if your own feelings about hepatitis 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 and 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 and Hepatitis C” (by Lucinda Porter), is a booklet that explains how hepatitis C is stigmatized and provides tools to confront the labels associated with hepatitis C.

**Hepatitis C Stigma Experiences and Recommendations**

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

Get advice from a human rights advocacy groups for advice that can try to resolve issues like these through mediation but can also award damages such as lost wages in successful cases. Ensure you have adequate support for yourself during events like these.

“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 and whether I would be covered. He told me he had to let me go. What can I do?”

You might want to consider making a complaint to the chief of police and to the city.

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

Hepatitis advocacy and 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 and human rights. Sometimes accurate information about hepatitis C is enough to eliminate discrimination. If this choice is not open to you, contact 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 and not to kiss or cuddle my nieces and 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 and confusion with other illnesses such as HIV is common. Your family’s response comes from their fear and 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 and supportive friend could meet with your family to provide accurate information about the virus and 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 and 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 a human rights group for further advice.

Further Assistance and Related Information visit:

Canadian Human Rights Reporter: http://www.cdn-hr-reporter.ca/