

Introduction

This report is our way of giving something back to all those people who took part in the From Silence to Voice project, those who took the time to sit down and tell us their story. Having completed our final research interviews in early December 2005, bringing to an end the data collection period of our study, we wanted to provide a brief glimpse of what we've learned so far.

Funded by the Canadian Institutes of Health Research, the federal research granting council for health related research, the From Silence to Voice project interviewed 101 people from across Canada to learn about their experiences of living with hepatitis C and how it has affected their quality of life.

Given that there are few studies into the experiences of people living with this new, emerging disease, we hope to contribute by providing a greater understanding of what it is like to live with hepatitis C in Canada. It is our hope that this glimpse into the day-to-day reality of hepatitis C may provide policy makers in this area with a greater appreciation of life with hepatitis C. In addition, we hope that people with hepatitis C will find in these narratives a reflection and validation of their own experiences.

This document is only a snapshot of our research to-date, based on a preliminary analysis of findings in a few broad areas. A much more detailed and complex picture of living with hepatitis C in Canada will emerge as we continue to analyze the data over the next year or so. But until then, this is the story thus far.

-September 2006



What was it like to find out you have hepatitis C?

“...it [getting the news] was done very unprofessionally...she just said, “Your results are back and you’ve got hepatitis C.” Boom, that was it, cold—see ya! I think she [doctor] needed to be educated a little more, how to be a little bit more sensitive.” Male, 55

“I think that [telling my parents] was one of the hardest parts because my father, he didn’t even want to hug me anymore. It was like I wasn’t his daughter anymore. He told me...I ruined the family name.” Woman, 21

“I actually wrote my will. I was ready to buy a plot. Emotionally it was devastating. My life changed completely. When you’re told that you have something...that I might not live five more years, your life changes. Your perspective on life changes and it really changed me a great deal.” Male, 64

“Thank God, because now I understand. Now it makes sense. Now all these things that never made sense before fell into place. After reading the symptoms and listening to people talk it’s like, “oh my god, this is everything”...I mean I’d been like a textbook case...Now I know it’s [my tiredness, depression] not a personal weakness.” Woman, 34.

“At first I was relieved. I didn’t know what hepatitis C was but at least I know I can do something about it.” Male, 64

To say that for most finding out they had hepatitis C was a shock, is an understatement. Even people who had considered the possibility because they had received blood products or had surgery during the 1980s, or had engaged in IV drug use, actually hearing the words “You have hepatitis C”— was devastating.

This difficult news was often made all the more difficult because of the manner in which they were told and/or because of the huge number of questions this news raised. Often it would take further blood tests and procedures to learn just what it meant for them.

Learning you had tested positive for hepatitis C was only the beginning of the story. This generated intense anxieties in people who felt they faced an uncertain future, who often feared they may have put their partners or children at risk.

At the same time, devastating as the news typically was for some, learning they had hepatitis C capped off a long period during which they had felt ill without knowing why. To finally have an explanation as to why they felt ill, a name for their pain, provided a strange sense of relief.



What is it like to live with hepatitis C?

Living with hepatitis C is, in a word — exhausting. Fatigue, tiredness, lack of energy, and an intense need for rest was a recurring theme. People who had been highly active, energetic and sociable found hepatitis C left them with no energy and made day-to-day life difficult. They were simply too tired.

Many people described how their memory, especially short-term memory, had become poor or was ‘gone’ altogether. In addition they had problems concentrating and staying alert. Being able to read for more than a few minutes, follow the plot of a movie or even a conversation was challenging, a condition that people often described as ‘brain fog.’ People also described that living with hepatitis C left them moody, quick to anger or cry, and generally emotionally conflicted. People described a host of physical ailments ranging from digestion problems to bodily pain, coupled with an overwhelming sense of feeling unwell. Their experience of all of these symptoms was made all the more stressful as there seemed no apparent explanation as to why they felt this way.

“What I find the most difficult about it all is I have gone through years and years and years of having really strange things happening to my body and everything like that. The doctor couldn’t figure out what the hell was going on.” Man, 52

“And weekends are spent pretty much entirely in bed recuperating...to find the strength to get through the next 4 or 5 days. It’s limited my social life extremely. It’s limited my work life. Hey, I don’t have a life anymore really, other than kind of this mechanical walk through.” Woman, 48

“It was difficult; you were always tired. You didn’t get to go out and do things that other people get to do because you were too tired.” Woman, 44

“In a nutshell, exhausting. Mentally, physically, emotionally absolutely draining...it got to the point where I couldn’t do an 8 hour day anymore. I went to work exhausted and I came home exhausted...” Woman, 54

“We call it brain fog...it’s more common with the later disease. We do all notice it. I did. But I didn’t know what it was caused by before...Forgetfulness. You just did something or you just talked to somebody and you can’t remember what you said five minutes later. Short-term stuff mostly.” Woman, 44

What has been your experience of dealing with health care providers?

“Some people I’ve dealt with, including my old general practitioner, had absolutely no idea or no concept what it was about and probably didn’t care to know.” Man, 52

“I told him [doctor] I was having major problems with my health. But it took him approximately six years to find out I had hepatitis C. He kept on accusing me that I drink too much and that I should cut down on my drinking...when I don’t drink at all.” Male, 64

“Finally, because I insisted upon it [being sent to a liver specialist]. I insisted. They [general practitioner] didn’t want to... “The more you know about hepatitis C, you’re making yourself sick.” That’s the attitude from the medical profession. You don’t need to know that stuff because when you do you psychologically, you get sick. You’re a hypochondriac.” Woman, 34

“...when I mentioned hepatitis C they [nurse] immediately asked me if I was one of the people who got a settlement for it. I told her basically that it was [not an issue] but I got attitude immediately. Not answering the questions. I got “oh”. I got that instant, “okay we’re dealing with a drug addict.” Man, 36.

“Nobody knew what it was. Nobody. I mean my doctor knew as much as I did about hepatitis C, which is nothing.” Woman, 54

Discussions about working and interacting with health care providers, such as general practitioners, community health nurses or liver specialists revealed a diversity of experiences. There was a general consensus that on average, general practitioners know very little about hepatitis C and are often unable to provide much assistance. While we heard stories of truly exemplary physicians and nurses, in the main most people’s experiences revealed a decidedly mixed bag of interactions with health care providers.

Generally the interactions hepatitis C patients have with health care providers occur in two distinct phases. The first phase usually involves working with a general practitioner, attempting to find out why they had been feeling ill and learn hepatitis C may be the cause. The second phase involved greater interaction with a liver specialist while their health was monitored prior to or during, treatment for hepatitis C. During the first phase when people were trying to find out why they felt ill, people experienced a marked sense of frustration, generally feeling their concerns were not taken seriously. For example, it was not uncommon that when discussing their constant fatigue and lack of energy, people were often told by a health care provider something along the lines of, “well, we’re all tired...life’s tiring... you’re getting older.”

A person’s sense of frustration only increased as their various physical complaints were found to have no apparent cause, leading many people to say they felt dismissed or written off as ‘crazy.’

People described having to pressure their health care providers to examine their health issues in greater depth. In addition, some people noted that the manner in which one contracted hepatitis C coloured their interactions with health care providers.



When you were first told about your hepatitis C infection, did you feel that it was properly explained to you?

41% Answered : Yes

59% Answered : No

“His [general practitioner] the specialist] bedside manner is awful. He never once spoke with me during the 2 years I saw him with the door closed...he had his hands on the doorknob the whole time, with the door half open. So I wanted just to not go to see him any more.” Woman, 54

“My doctor, it seems kind of weird, but I was in for a physical....and he didn’t want to touch me. He really didn’t want to touch my body...physically. He touched me twice and then walked out of the room. And didn’t come back.” Woman, 48

“...I had an appointment with a new psychiatrist. She found that I had hepatitis C and these were her words, “Oh, my goodness, you’re dangerous. You’re not dangerous to yourself but you’re dangerous to other people.” Well, needless to say, that was my first and last appointment with her.” Woman, 34

“[my liver specialist] ... sort of pooh-pooed it [hepatitis C] a little bit and said, “you know it’s no big deal and you can drink once in awhile and things like that.” And I just thought, well this is totally opposite of anything and I’m reading, right. That alcohol is considered poison to me.” Woman, 44

Upon learning they had hepatitis C, people were often confronted by health care providers who knew little about the disease. This meant that the diagnosis could be seen as either a major cause for worry, as literally a death sentence or in contrast, something of no concern at all. Some doctors were quite open to learning more about hepatitis C, while others expressed little interest in the disease, even demonstrating a lack of empathy or respect for the patient, growing cold, distant and even fearful. That being said, it should also be noted that the picture of hepatitis C care is changing for the better, as the number of people living with it increases and health care providers become more aware.

After their diagnosis people entered into the second phase of their interactions with health care providers. Here they often faced difficulties either in being referred to a liver specialist or even finding one. As they underwent further testing, learning either that they were not yet eligible for treatment or that they should undergo treatment, they often found themselves dealing with health care providers and health facilities that were unfamiliar and often at some distance from home. Here experiences were decidedly mixed in that for every welcoming and helpful practitioner there seemed twice as many who were less so.

What was it like being on treatment for hepatitis C?

“At the time I was very gung-ho on treatment...then I started to read about it. And the stories I heard...and I thought, you know what, I don’t know...If I’m dealing with depression...what’s it [treatment] going to do to me?...and the doctor’s “oh, we’ll just up your antidepressants.” Oh God, I can’t imagine having all these chemicals in my body...I was just scared. I’m still scared.”

Woman, 34

“The whole year of drugs, I thought I was dying. I had lost seventy pounds through the year...it was like chemo to me.” Woman, 44

“I spent eight months from my bedroom to my sofa, from the sofa to the bedroom. Now I was in a new relationship. My sexual libido was shot...I mean it’s the intimacy. Your body’s aching, it’s the last thing you want...who feels like kissing or this or that when you feel like shit.” Man, 47

“Someone can only tell you how bad it is but how bad you [will] feel is a different matter. You know I see one person in our [support] group who works. I couldn’t possibly. I had this house sterilized, I couldn’t stand the sight of food or smell.”

Woman, 54

“No, the treatment damn near killed me. And it took me a good couple of months to just recover from what the treatment did to me. It didn’t work on me...if I was ever asked to try that stuff again, I will refuse...unless it was an absolute last resort and unless it was something different, I would really have to think about it.” Man 52

“But if I had to do it over again, I’m not sure that I would have done treatment....I’m worried. I’m not fit to go back to work yet. Unfortunately with that treatment...the medical society says, well, six months after your treatment you should be feeling this way [feeling better]. I’m not a machine you know. I don’t feel that way. Just my whole life has changed. I can’t quite pinpoint how—it just is.”

Woman, 54

Those who participated in the study experienced the full range of hepatitis C treatments. Some learned of their infection when there was no treatment, back when hepatitis C was known by what it was not, non A, non B hepatitis. Others had undergone the initial form of treatment, receiving three shots of Pegylated interferon, while others received or were receiving the current form of treatment, which involves a weekly injection of interferon and daily antiviral medication. Prior to starting treatment, it was impossible to know how side effects might affect any one person, side effects which were generally described as difficult. There was therefore great anxiety about just how bad these side effects could be and the degree to which daily life would be affected.

While some were able to continue working (if not working was an option) while undergoing treatment, most found treatment to be quite taxing. The degree to which people experienced the flu-like symptoms that accompanied the interferon injections varied, but most felt very ill. Coupled with the additional and compounding effects of the antiviral medication, many people described having no energy, little desire for food and an intense need for rest. Of those who were able to continue working, many were surprised that they had managed to do so. In the main, the experience of being on treatment was highly isolating and depressing, with treatment only worsening existing problems with energy levels, digestion, memory and concentration.

Some who had undergone treatment speculated that if they were ever in the position to do treatment again, they would find it almost impossible to do so. Some dreaded considering taking the treatment again because of what it had been like. Others feared needing to do treatment again because even after completing it, they still did not feel like themselves. They had yet to feel better.

How do you think the public perceives people with hepatitis C?

Discussions about public perceptions of hepatitis C and those living with it were marked by a clear consensus that the public knows little about the disease. Those living with hepatitis C encountered widespread ignorance of the illness both as to how it was contracted but also its effect on people. While the public was seen as largely sympathetic to the plight of those who contracted it through the blood system, many believed the public saw the matter as having been dealt with. For those who contracted hepatitis C via IV drug use, there was little or no sympathy or acknowledgement of their needs. It was clear that the general public strongly associated hepatitis C with HIV infection, believing them to be interchangeable. As well the public seemed all too quick in assuming that hepatitis C was the result of IV drug use.

The linking of hepatitis C infection with IV drug use enhanced the sense of stigma those who had contracted hepatitis C via a blood transfusion experienced. However all those living with hepatitis C felt keenly stigmatized no matter their mode of infection. Many people reported having at one time or continuing to be, highly cautious about disclosing their condition to anyone beyond immediate family. Faced with a general public largely ignorant of hepatitis C, highly judgemental of all those infected, many actively hide their infection even after being treated for it.

How would you describe the attitude of the general public towards people with hepatitis C?

Positive : 36 %
Negative : 74 %

"[public perceptions of people with hepatitis C]...Just like, you know, pitying them and stuff. But at the same time thinking they're dirty and wondering how they got it and you're probably a drug addict." Woman, 19

"...They're [people with hepatitis C] a bunch of drug addicts like. "They're no good sort of drugs. To hell with 'em. They should all be put on an island." Man, 52

"[the public] Oh, well, mostly that [people with hepatitis C] they're of course people that are dirty. It's not really a big city around here when you hear somebody has HepC and right away people just shun them." Woman, 21.

"I think they [general public] think you are either a drug addict or you're gay. And I think it's predominantly that it's gay...Like even my daughter in school she'll come back and talk to me about like lectures, like people'll come in and stuff. Those are the kinds of messages they're giving in school." Woman, 50

"There's a lot of blame there. There's still, not just the government but society in general view addicts as criminals more so than healthcare outpatients. So you're always going to have a problem with attitudes." Man, 36

Do you think the general public associates hepatitis C with HIV?

34% Answered : Yes

Do you think the general public associates hepatitis C with IV drug use?

59% Answered : Yes



How do you think the government perceives people with hepatitis C?

“I’m sure they [the government] wish we’d just go away...they don’t want to deal with extra costs for treatment, they don’t want to deal with compensation.” Woman, 58

“They [the government] paid off that one group of people for transfusions. I don’t know. They don’t do anything for anyone else who just acquired the disease. They’ve never done anything for me...it comes hand-in-hand with addiction issues. And it’s whether the government wants to view addiction as a healthcare issue.” Man, 36

“I think it’s pitiful. I think they’re [the government] in denial that they have a sleeping giant going around...the political system, that it just isn’t looking at treatment...it isn’t making it financially able for someone to go on treatment without putting them well below the poverty level...I think the attitude of politicians is that people who are carrying this disease aren’t worthy of it.” Woman, 48

“The people who make decisions on policy or make the decision on funding and what not, knew very little about us...they know very little about what we need and who we are. Very few of them have probably ever even actually attended a drop-in centre or met the street youth...” Man 25

“I think that the government’s attitude is that the sooner everything is cleared up and shut down and quiet, the better it will be.” Man, 46

During the period when the Project was interviewing people, the issue of hepatitis C compensation was much in the news as the federal government debated expanding the period for which they would compensate those who contracted the virus through the blood system. This was seen as a very favourable development by those we spoke to, but it was also seen as but a small step in getting people’s needs adequately met. In describing how the government perceived people with hepatitis C, governments were described as generally failing to do enough or grasp fully the enormity of the problem.

While some saw governments as hostile and unsympathetic, it would perhaps be more accurate to say that governments were regarded as indifferent, willing to respond only when forced and generally wishing that the problem of hepatitis C would just go away.



What's next for the project?

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What's next for the project?

This community report is not the final word on hepatitis C. We are currently preparing a number of articles and book chapters dealing with specific findings from the project. If you would like further information about the study, please contact:

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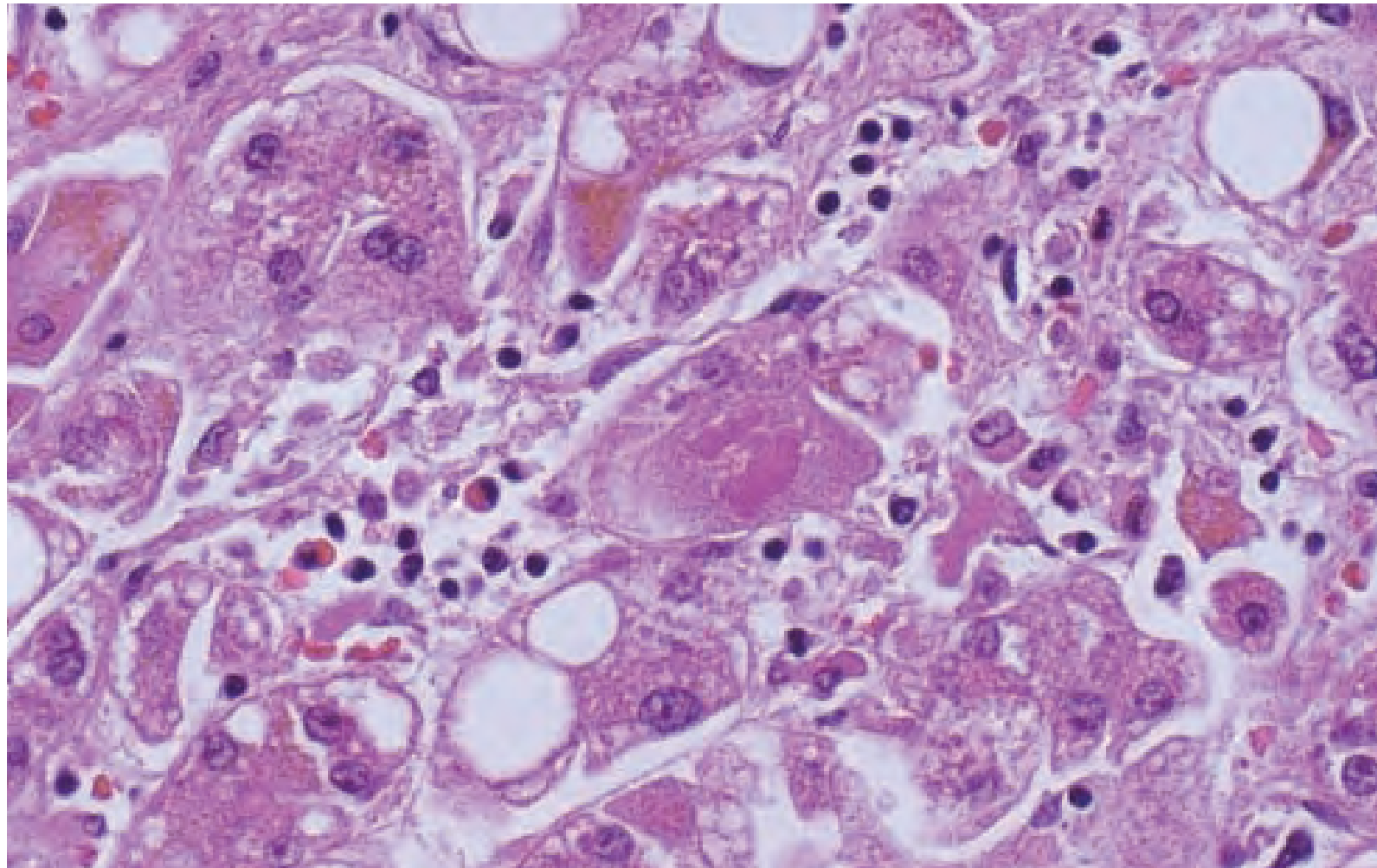
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