# “We’re People Too!”*

## Persons Living with Hepatitis C and Those Involved in Injection Drug Use~ Examining the Issues in NNS

3/1/2010

**Northern AIDS Connection Society * Male Key Informant**

# Table of Contents

# Introduction

As part of the objective of the Hep C Aware Project, undertaken by the Northern AIDS Connection Society (NACS) in 2009-2010 a series of two sets of interviews and data collection occurred. One, interviewing key populations of Persons Living with Hepatitis C, those most at risk and those affected by Hepatitis C. The second data series of data gathered was from Service Providers and Community Partners. Within the data collection for PLWHC a specific segment of vulnerable population were interviewed, those who engaged in the use of Intravenous Drugs.

Data gathered examined main health concerns, effects of a Hep C diagnosis on family, barriers in accessing health care, what barriers are real or perceived from the community.

Initially NACS tried to gather participation for a focus group setting. Almost all PLWCH expressed reticence in talking in front of others about their Hepatitis C. The approach became exclusively an interview format. Data was manually and digitally recorded. An honorarium ($25 per participant) was provided to offset time and travel costs to those being interviewed.

This report is based on the input from PLWHC (total 11 interviewed), 1 individual who is co-infected HIV and Hep C, and PLWHC that engage in Injection Drug Use (total interviewed 9). Individuals that participated were from town settings, Aboriginal Communities and rural areas of Northern NS (NNS) which is defined geographically as Colchester, Cumberland, Pictou and East Hants Counties.

Data was gathered during interviews conducted either within the individual's home or the NACS office in Truro dependant on the individual's level of comfort or the ease of access to the Truro office. Data collected was gathered in person, via telephone and through interview responses completed on-line and emailed to NACS office. Data was gathered in a single format:

1. Qualitative (individual level). Interviews with key informants in one-on-one format using a moderately structured interview instrument to address the identification of issues and health concerns for PLWHC. This format allows for the inclusion of lateral information from participants that may be useful to add to the inquiry and/or point to information not identified by structured questions or otherwise identified.

## Determinants of Health

NACS's work is based on a population framework and health strategy. Throughout interviews particularly with marginalized populations there are key messages that are based on the determinants of health which are the signposts to direct our work.

| Key Determinant[1] | Underlying Premise[2] | What We Heard and Observed |
|---|---|---|
| Income and Social Status | High Income determines living conditions such as safe housing and ability to buy sufficient nutritious food. | • Single mothers on Social Assistance are living in unsafe housing and find it difficult to provide for their children and to meet their basic needs (good food, clothing, school supplies)<br>• Lack of knowledge of good nutrition<br>• People on Long Term Disability or social assistance who are at a much lower income level – report being unable to meet their own basic needs for nutritious foods, Persons on Social Assistance do have access to drug cards for perscriptions<br>• Treatment costs have forced people in mortgaging houses and barely able to make ends meet – "junk food is much cheaper ~ interview informant<br>• Treatment costs range between $25,000 to $35,000<br>• One interview respondent said they can't afford treatment nor to get any sicker |
| Social Support Networks | Support from families, friends and communities is associated with better health. | • Overall respondents have low rates of familial supports and report a fear of confiding or disclosing HC+ status to friends<br>• Support is relative to real or perceived mode of transmission<br>• Fear and shame marginalize persons interviewed majority report they are ashamed of disclosing a positive status to friends and family (eg told husband but never children for fear they would disclose)<br>• Treatment side effects change the dynamics and level of social involvement and interaction<br>• Communities knowledge level and acceptance is seen as low by interview participants – HC is seen as |

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[1] Public Health Agency of Canada Website: www.phac-aspc.gc.ca
[2] Public Health Agency of Canada Website: www.phac-aspc.gc.ca

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| Education and Literacy | Health status improves with level of education. | • Majority of those interviewed self-reported a maximum of high school education levels |
| Employment/Working Conditions | Unemployment, underemployment, stressful or unsafe work are associated with poorer health. | • Persons interviewed reported discrimination and fear in their workplace as their HC+ status became known<br>• Unemployment rates are high in IDU and Aboriginal communities<br>• Treatment, side-effects of treatment or symptoms of HC caused individuals to be unable to work full time or have to go on sick leave |
| Social Environments | The importance of social support also extends to the broader community. Civic vitality refers to the strength of social networks within a community or region. It is reflected in the institutions, organizations that build attachments with others. | • Information sharing and knowledge exchange is requested by community partners and stakeholders. They reported low knowledge of the prevalence of HC amongst clients.<br>• There is an increase in community mobilization. Partners are disseminating HC materials to clients and HC information has become more of a priority.<br>• Social environment within Aboriginal Communities Health Centre supports are often mistrusted. |
| Physical Environments | The physical environment is an important determinant of health. At certain levels of exposure, contaminants in our air, water, food and soil can cause a variety of adverse health effects. | • Rural water supplies and well water in Aboriginal communities is poor.<br>• Individuals report dirty needles in playgrounds and school grounds. |
| Personal Health Practices and Coping Skills | Personal Health Practices and Coping Skills refer to those actions by which individuals can prevent diseases and promote self care, cope with challenges, and develop self-reliance, solve problems and make choices that enhance health. | • Many PLWCH interviewed reported difficulty in being 'their own' health care advocates.<br>• Lack of familial/friend support leads to choices such as increased drinking or other risk taking behaviours which attribute to overall health and the health of liver.<br>• Many persons reported a lack of knowledge about healthy eating choices to better support the health |

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| | | of their liver.<br>• Access to basic HC knowledge was acknowledged to be important to individuals to help understand their positive diagnosis and support healthier choices.<br>• Many IDUs are caught in a cycle of health vs drug habit (purchase of drugs over payment of rent or basic food and necessities)<br>• Addictions and dependence on drugs control their lives |
| Healthy Child Development | A young person's developments is greatly affected by his or her housing and neighbourhood, family income and level of parents' education, access to nutritious foods and physical recreation, genetic makeup and access to dental and medical care. | • Single mothers on social supports and Transition houses for women report food safety issues, lack of safe places for their children to play (exposure to dirty needles in play spaces)<br>• Children growing up in IDU culture experience role reversal with parents who are addicts, they often 'miss out' on the growth and development of childhood development.<br>• Aboriginal communities and rural parks and school grounds also report dirty needles found. |
| Biology and Genetic Endowment | Genetic endowment provides an inherited predisposition to a wide range of individual responses that affect health status. | • Reported mental health issues as co-factor with HC and co-infection. |
| Health Services | The health services continuum of care includes treatment and secondary prevention. | • Identified low levels of awareness in medical community of HC.<br>• Long wait time reported.<br>• Lack of GP's in NNS is a concern<br>• After Hours clinic closed in rural areas.<br>• Have to travel to Halifax for Liver Clinic Services.<br>• Files reported flagged once + diagnosis of HC or if individual is IDU. |
| Culture | Some persons or groups may face additional health risks, due to a socio-economic environment, which is largely | • Transgendered individuals report multiple layers of stigma (HC+, sexual orientation, being 1st Nations)<br>• 1st Nations persons report |

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| | determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services. | compounded and internalized racism<br>• 1st Nations Persons report a lack of trust and confidentiality with services (such as Health Centres) |

## Highlights

Highlights from the data gathered were gauged by the level of repetition throughout the interview assessments. The key messages are as follows:

| Persons Living with Hepatitis C and Those Involved in Injection Drug Use |
|---|
| Preference of Medical Services in Halifax Due to Perceived Anonymity and Knowledge Level of Medial Staff |
| Socio and Economic Barriers for Both Non and Currently Using Injection Drugs |
| More Knowledge and Empathy Required in Medical Community of NNS |
| Overall Interest Expressed for Peer to Peer Learning and Support Network |
| Current Needle Exchange and Alternative Options Offer Very Good Service to IDU Community |
| High rates of reported Isolation, Fear, Stigma and Marginalization |
| Knowledge Exchange and Increasing General Publics' Awareness Frequent Theme |

***It is interesting to note while it was challenging to have PLWHC respond to tertiary requests for information, once their hesitation to approach the project staff about interviewing, the majority stated they would be interested in and would attend peer to peer support and learning groups. Several of those interviewed had participated several years ago in a support group at the Truro hospital, which was disbanded following staff turnover.***

## Ethical Considerations

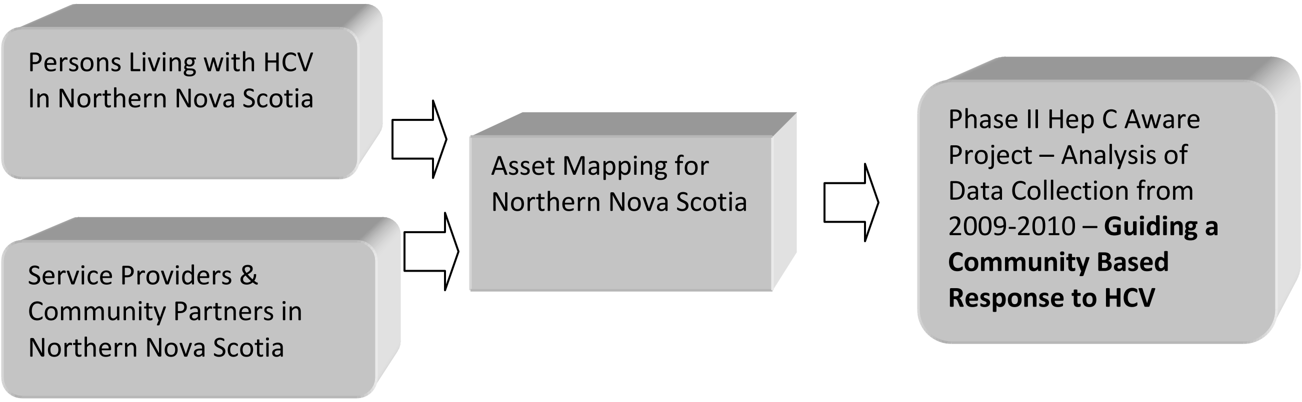
Ethical considerations for community based research were examined by NACS project staff, in general the ethical challenges of this assessment and their respective requirements were:

| Ethical Challenge | Response |
|---|---|
| Access to Interview Participants | Referral by trusted insiders, Project information conveyed in public spaces. |
| Informed Consent by Participants | Signed statement of informed consent and voluntary participation with right of withdrawal at any point. |
| Preservation of confidentiality and Anonymity | Aggregation of the data at the reporting stage and referral to individual informants by code rather |

| | |
|---|---|
| | than name.  Signed confidentiality agreements with all project and contract staff. |
| Safekeeping of documents during the project and subsequent 2 years. | Backup of electronic documents; lock up of paper documents including informed consent forms. |
| Raw data safety | Raw data shredded or erased at the conclusion of project. |

## Process

This report is one part of a two part examination of issues that includes a second stream of qualitative and quantitative data gathered from Service Providers and Community Partners of NACS.



This report is intended for the following audiences:   Public Health Agency of Canada (PHAC), Project Funders; NACS Board of Directors' Pyra Management Consultants (Project Evaluators); and Community Partners/Service Providers.

## Environmental Scan of NNS

### Population Demographics

The population of Northern NS is over 132,000 with slightly more rural that urban demographic mix.  The towns or more 'urban' centres for Northern NS are Truro in Colchester County, Amherst in Cumberland County and New Glasgow in Pictou County.  Median income in Northern NS is approximately $20,000 with the majority in each county earning $5,000-10,000.. The area can be generally described as a predominately Caucasian population.  There are 3 Aboriginal communities in Northern NS being Millbrook First Nations, Indian Brook First Nations (Shubenacadie) and Pictou Landing First Nations.

The more 'urban' town settings are where the location of primary health care providers occur. Distances for travel to Halifax for Liver Clinic Services are 1 hour from Truro; 1.45 from New

Glasgow and 2 hours from Amherst. Hospitals in outlying rural communities such as Parsborro and Joggins/River Hebert are frequently closed due to staffing shortages and the 'Walk in Clinic' in Amherst closed before Christmas 2009. Amherst residents wanting to see a specialist report crossing the boarder to Moncton where there is a larger service centre.

NACS has been unsuccessful to date to find the specific numbers of PLWHC in NNS; however, we have the knowledge of the rates for the province through epidemiological reports. Anecdotally, however, in an interview with a Public Health Nurse in Truro, she commented that particularly in Truro and the immediately surrounding intake area she would characterize Hep C rates as being "epidemic proportions".

## Harm vs Risk Reduction

Harm and risk reduction must be defined for the benefit of this report. The words have been used in some cases interchangeably. A harm reduction model is a policy or program directed towards decreasing the adverse health, social and economic consequences of drug use without requiring abstinence from drug use. This is a more individualistic approach.

Risk reduction is the expectation that a threat may succeed and potential damage can occur. It is the minimization of dangerous elements that affects the broader community. For example, a program in Lethbridge, Alberta utilizes green mailboxes for individuals to drop off used needles keeping them off of the playgrounds and schoolyards. An additional example is the distribution of condoms to student populations for the prevention of STIs – protecting others through behavioural modification.

## Injection Drug Use

According to a 2000 report to the Public Health Agency of Canada, half of injection drug users in the Atlantic Region share needles and engage in unsafe sexual activity.[3] 6 Hotspots of Injection Drug use were identified within this report. 5 of 6 of these hotspots are located in Northern NS (Amherst, Trenton, New Glasgow, Pictou and Stellarton). Due to the prevalence rate of Hepatitis C transmission with needle usage, NACS felt it important to interview individuals that were Hep C positive and involved in Injection Drug Use Activity. One purpose was to look at risk reduction practices and the level of service being provided. Within the Injection Drug Use Community the data collected specific to this point has been shared with our key partner Mainline Needle Exchange with whom we have conducted our IDU outreach work.

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[3] Ploem, C. *Profile of Injection Drug Use in Atlantic Canada*, prepared for the Population and Public Health Branch, Atlantic Regional Office, Health Canada Halifax, 2000

## HCV in Official Statistics

| Aspect | HCV |
|---|---|
| Number of Cases | By 2007, 242,521 cases estimated (7, 440 in NS) |
| Rates of Primary Positive Transmissions | Rising drastically |
| Dominant Positive Transmission Modes | Contaminated needles from injecting drugs followed by tattooing and piercing |
| Incubation Period | Delayed onset of up to 15-20 years before symptoms appear |
| Groups at Highest Risk | Women, youth, Aboriginals, prisoners |
| Major Concerns | Costs of delayed onset to health care system; strong correlation between HIV and HCV infection due to similarity in modes of transmission |

## Top Priorities ~ Where to From Here?

<table>
<tr><th>PLWHC</th><th>PLWHC Involved in Injection Drug Use</th></tr>
<tr><td colspan="2">Formation Peer to Peer Learning and Support Group</td></tr>
<tr><td>Message of “Getting Tested”</td><td>Maintain Level of Risk Reduction Services – Needle Exchange</td></tr>
<tr><td colspan="2">Education, Information and Messages to General Public</td></tr>
<tr><td colspan="2">Education, Information and Messages to Medical Community in NNS</td></tr>
</table>

## Interview Data

**It is important to the overall Hep C Aware Project to note that individuals participating in interviews upon being asked the 1st question almost overwhelmed the interviewers with a great level of detail. We feel this reflected the need of interviewees to feel listened to, valued and to be part of the process. Individuals reported a sense of relief and were able to provide a great level of detail. This was an opportunity for Individuals within this population with a sense of ownership.**

### 1. What are your main health concerns?

***“The GP said to me ‘What do you want me to do?’ and I said I wanted him to save my life, that I was scared. I want this for sure in your report. I also took my skin, I lifted up my shirt and I showed him, I said I can take my skin and pull it and it hangs over. I said there’s nothing left to me. I’m fading away. Please help me. He didn’t say anything. We have no support.”***

When asked this question some respondents began by describing the length of time living with Hep C the range in categories were under 1 year (only 1 participant) to the majority being 15 to 35 years having had a positive diagnosis.

### Participants that indicated length of time living with Hep C

- 15 years (3 Respondents)

- 18 months (lost her job)
- 4 years (2 Respondents)
- 6 years
- 20 years (blood transfusion – 2 respondents)
- Only found out 5 months ago
- 35 years

In addition to the length of time living with a diagnosis many interviewees went into high levels of detail about each health aspect: how they thought it related to Hep C, which doctors they had to see, how long they were receiving treatment etc.. The summary is as follows:

### Mental Health

- Depression and anxiety
- When I cleared virus my main concerns were Mental Health Issues
- On anti-depressants (5 interviewees)
- I suffer from depression and was told that when I start the treatment for Hep C I would really know what depression was. The medicine for Hep C will cause depression. (IDU)
- It's pretty stressful…to know that I could be dying from it [Hep C]
- You worry, like what causes it
- There should be more access to information about Hepatitis C like mental health should be included on the waiting list
- Financially it's hitting me – mentally that's stressful

### Addictions (other than IDU)

- Alcohol (4 interviewees) NOTE: Frequently in NNS Rural IDUs tend to inject opiates and consume alcohol [4]
- I was told I had to be off alcohol for 6 months and I was for 5 months – I was preparing for treatment and then I started drinking again (IDU)
- I told the specialist I was addicted to alcohol. I've been an alcoholic – I guess I started when I was about 11 (IDU)

### Signs attributed to Hepatitis C

- Liver wasn't strong enough to take the full treatment, needed transplant first.
- Fatigue (3 respondents)
- Brain Fog
- I'm tired. I'm really tired.
- I have no appetite, no energy. When I eat food is rejecting my body, it's hard to swallow, I have no taste buds, no sweet tooth, and I want help to build it up. I'm scared, very scared.
- Deathly sick flu (rapid progression may have spontaneously cleared the virus)
- Dizziness (couldn't read, have the TV on, bothered by noise)

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[4] Ploem, C. Profile of Injection Drug Use in Atlantic Canada, Prepared for Health Canada Population Health Branch, 2000 pg. 38

- Thrush, oral candidiasis
- When I get a pain in my right side I know I have to be careful
- I had all this weight loss
- I've lost a lot of weight I was up to 175 pounds and now I'm down to about 128-130
- This stuff gets worse right? I worry about that…whether its 'gonna get worse. What's that 'gonna do?
- I was tired and fatigued and I didn't know what was wrong. Itching under my skin that bothered me so bad and scratching didn't help it. So when I went to the doctor and he said that my eyes were yellow and my skin was yellow and it was – like okay.
- Within 2 months [after my blood transfusion] I had all this problem with tiredness, jaundice, everything – the itching was the worst
- I had to have a liver transplant – there was a lot of cancer in my liver
- I'm really dry – the doctor said "keep drinking", throat sore, hard to swallow

## Other Primary Health Concerns

- Colitis
- Chrones
- Gall Bladder Surgery (2 respondents)
- Appendix operation
- Hernia operation
- Abscesses, Fistulas
- Cystic Fibrosis (since birth)
- Diabetes (3 respondents)
- Back Problems
- Cancer
- Cirrhosis
- Really poor circulation
- Bowel Problems
- Sleep apnoea
- I suffered a major concussion about 2 years ago and I have short term memory toss.

## Knowledge and Lack of Awareness

- I don't really know much about it so…more explanation and information would be nice
- I am worried about passing it on to other people…that's my biggest worry
- They keep taking blood from me. Sometimes 3, 4 and 5 vials at a time and they don't tell me why or give me any information. Every week it seems like I was going to get blood work done. I need to know something instead of being pushed away.
- I'm not sure what that current information is on the transmission…particularly when it comes to the, I guess you would call it the sexual thing
- It's too bad you have to go through so may to get information
- Becoming this sick this fast there just wasn't enough information being provided to me.
- What does a normal Hep C patient feel?

- I finally got a booklet from the hospital how you can catch it, what you should do, things that are helpful for you [from the Liver Clinic]. They told me not to go on the internet and get myself all worked up because everything is on the internet and it would be too much to take in at once but it was too late because I had already spent the first night on the internet looking up stuff.

***Cost that is associated with Hep C treatment was mentioned under this question***. It was also mentioned under the question: “Do you ever experience difficulty in getting the health services you need? If you do, what health services are difficult to get and why?” For this report specific references to cost and financial aspects have been recorded under this question.

## 2. How do you get your health concerns looked after?

A great deal of information came out of the question about the KNOWLEDGE LEVEL of the local medical community. There are many issues around trust in GP's and their supporting medical staff. Specific comments about supporting medical services (addictions, mental health and dietetics) were pulled out separately to include in this document. Interview respondents that had the resources (vehicle, money for travel) go out of their way to travel to Halifax for medical services rather than seek services in their local area.

***"At this time (when I'm writing this in 2010) I am very sure that if I had of opted to go to a local internist in New Glasgow when first diagnosed I would not have been allowed to treat or if I had of been allowed to get treatment there it wouldn't have been successful as I wouldn't have had a dedicated enough doctor nor would have he/she had the knowledge to treat Hepatitis C. The support would not have been here as it was in the Halifax Clinic."***

### Metro Halifax

- I prefer Halifax – I don't see anyone I know
- Have to go to Halifax for a neurologist
- Everything in Halifax – I've been to Truro Hospital twice to get blood drawn for HIV/HCV testing and when I travel all the way to Halifax to Infectious Disease Clinic – they don't have my blood, it's gone missing, I'll never go back to Truro hospital – I'll get it all done in Halifax
- Would definitely have to go someplace else. I was recommended to go to Halifax by a friend. (IDU)
- Had to go to Halifax for an operation on the veins in my legs-circulation is bad due to diabetes. (IDU)
- My GP asked me if I wanted to see an internist in Pictou County or to go to the clinic in Halifax. I jumped for the clinic in Halifax as I knew I would have more privacy and a more knowledgeable medical team.
- 99% of all my health concerns are taken care of in Halifax. We go clean to Halifax just to get blood work done. It takes 6 weeks to get from Pugwash hospital.
- I go to Halifax rather than Truro.
- My doctor in Halifax sent me for testing at the Dixon Building over at the VG – he sends all his patients over that are IDUs. It was then I tested positive for Hepatitis C.
- All my doctors are in the city, up in Dartmouth

### Getting Health Care in Local Area

- Health centre in Indian Brook
- I have a GP in Millbrook, except everyone knows your business
- VON-Diabetes and Circulatory Concerns
- Sees local internist
- It's too bad we have to go to so many different Doctors
- I was diagnosed with HCV but my GP's have lost track of me I've moved so many times(IDU)
- I've gotten my Twinrix Shots from Local GP (3 respondents)

- I have to tell my doctor, my family doctor that I want to have a referral to the Liver Clinic, I want to know how my liver is doing (IDU)

## Local Knowledge Level

- GP's not much good in Hep C area
- GP's not much help doesn't know anything in PEI
- Limited knowledge of HCV (among GP's)
- I go to a Truro GP – but he's not good in the HC area.
- My GP said they weren't familiar with a viral load count for HCV
- I was dealing with a family doctor who had some experience with patients with HC (he counted 13 in his head one time when I asked him during an appointment) however his knowledge was limited, but he did not know that I had to be tested for a genotype.

## Mental Health

- I go to counselling – I have to work on not wanting to hide
- I see a psychologist and psychiatrist in my own Community

## Dieticians

- I needed a dietician to learn how to eat more healthy
- The dietician taught me how to eat smaller meals more frequently
- A dietician would have been helpful. I called everywhere trying to find out what I am supposed to eat. I wanted to know: what can I eat that the liver doesn't have to work to hard on.

## Opiate Treatment

- I want to get off of Methadone
- My partner was on Methadone but we can't keep driving to Mudcreek it's 40-50 miles and we can't afford it
- A few people couldn't give me a referral you know what I mean by saying that I want to go see a methadone doctor 'cause I don't want to continue with the needles anymore

## 3. Do you ever experience difficulty in getting the health services you need? If you do, what health services are difficult to get and why?

This question (as with others in the survey) elicited strong feelings. Throughout this report some of those responses have been italicized. The responses to this question were about general medical care but basic barriers to health services such as financial, transportation and having basic access to a telephone were indicated. With this question the interviewers prompted more information from the IDU community surrounding risk reduction and clean needle exchange.

***"I want to be treated like everyone else not treated differently because I have an addiction and I shoot up." ~ Female key informant***

### Risk Reduction-Clean Needle Exchange

- I use Mainline
- If I miss Mainline I can access needles during the day at Glenwood Drive
- Mainline is in once a week to do needle exchange, here in Truro anyway
- Mainline takes good care of me
- Mainline is how I get my clean needles
- Mainline
- Mainline from Halifax come up every two weeks and drops off anything we need
- Mainline comes here every two weeks, never have difficulty getting clean works
- I use Mainline but I have also used dirty needles, found them looking under kitchen sinks, cupboards, I've found needles not clean and not sharp,
- I forget where I sometimes find my syringes

***"Traffic comes in and out where I live. It's a shoot up shack – how are you supposed to stop with that environment." ~ Male key informant***

### General Medical Care

- I lived in Boston for 20 years, you have an appointment and they take good care of you but up here you have to wait and wait for hours.
- 6 months is a long time to wait for a specialist, especially when I wasn't sure what was wrong with me.
- My outpatients chart is marked with red indicating I'm a Drug User, even if I have a bladder infection it is marked on the top of the paper and that makes me not want to go to the hospital half the time
- I lost a tooth six months ago and called Family Dentistry in Bible Hill 7 or 8 times and haven't heard a thing back.
- More cooperation from the health centre in Millbrook has a beef with the receptionist not sure if she is passing on the messages feels that this could be why I have not had my tooth looked after.

- I should note here that when I received my liver biopsy in Halifax I was quizzed by the nurse in the operating room why wasn't I getting this biopsy done in Pictou County as they were able to do the procedure there.
- I had to talk to the Dean of Student Service to get test results sent to the Liver Clinic in Halifax

## Transportation

- They try to get drivers for Millbrook Health Services so you end up bumming a drive or take a cab – transportation is an issue (IDU)
- I have to hitchhike most of the time IDU)
- Cost of transportation
- Transportation by bus is expensive and then you have to wait around a lot , their schedule sucks
- Copious amounts of trips to the city for checkups along with overnight stays in a city hotel when I had my liver biopsy done
- It's really hard for us to get out there transportation wise [to Halifax]
- We don't have a vehicle so I don't know how I'm going to get out to see her this time [Carla Burgess, Liver Clinic Halifax]
- I don't like it because I gotta hitchhike the majority of the time and that is very frustrating, very frustrating
- I can drive but I don't have a vehicle

## Telephone

- I have to borrow telephones to make appointments for Halifax
- I don't have a telephone
- A lot of people out there [Indian Brook] don't have phones that you can call long distance unfortunately – so…the telephone access to call the IWK or call my doctors yes are a very troublesome thing to me because I take my CF very seriously…I've watched a lot of my friends die from it (IDU)
- Having a phone would help
- Transportation and a phone are main priorities

## Financial

***"With my distrust of people regarding my privacy I refused to include the receipts for Interferon and Ribaviron in my 2007/2008/2009 income tax claim. We use a local income tax accounting service and because of a breach of confidentiality regarding another issue years ago in another situation I was reluctant to let them have access to my medical receipts for those years. My concern was justified because eventually my young son came to me and told me that a friend of his mother told her daughter (his friend) that she does my income tax for her employer. I felt justified, that in itself told me that confidentiality had been breached and what else would have been told had I of allowed my medical receipts to be viewed locally."***

- Thank God I had coverage through my husband's Blue Cross treatment in total has cost me about $60,000.00
- Travel Costs we claimed on Income Tax

- It’s costly I’m not sure how some people do it
- 46 out of 52 weeks one year we were in Halifax for Appointments, because my husband works for the government he could get time off to take me.
- I was very fortunate that my health plan agreed to treat for Hepatitis C.
- Even with a health plan it cost well over $7,000 for me to go through the Hep C treatment.
- I ran out of sick time at work and lost wages while undergoing treatment.
- The cost of drugs is extremely expensive. I’m a college student – where the heck am I ‘gonna get and extra $20,000?
- We were thinking we’ve got something seriously wrong we’ll sell the house, we’ll do anything and the doctor said it wouldn’t be covered through medical plans – then he [GP] said it would be $25-30,000 and that’s all he could talk about. He [GP] said we could probably borrow the money
- I’m trying to get my social assistance from Dartmouth to Indian Brook. They gave me an occupancy tour and said you gotta take this back and have your worker fill it out and I got frustrated and reason I got frustrated was ‘cause I said why can’t you just call my worker and get everything faxed down here…I got so frustrated so I just got up and left but that was due to because I was crashing off opiates.
- Also there were many over the counter drugs I had to buy to help ease side effects. Copious amounts of trips to the city for checkups along with an overnight stay in city hotel when I had my liver biopsy done.

## 4. What do you think would make it easier for you to access health services?

For those involved in injection drug use we again asked specifically about harm reduction and needle exchange. The responses from this question ranged from the very specific financial, ease of access to broader concepts around societies acceptance and peer learning. A level of support group and peer to peer sharing arose from this question as learning about access from other PLWHC and finding out about how they navigated the system.

### Risk/Harm Reduction

- If I ran out or missed Mainline yes I would need clean needles – I try to always stock up a weeks worth of supplies
- It's more convenient for Mainline to come to me that having to go somewhere
- Yes I would use a site for clean needles
- I access Mainline, or I go to Glenwood to pick needles up
- I've gone to NACS office to get clean needles, swabs and condoms
- Mainline is a good service. I get new needles for other people too.
- If I miss Mainline I've looked under the kitchen sink, cupboards. I've found them but they are used and not sharp.
- There's a health centre [Indian Brook] that will distribute clean needles, and um…the disposable boxes
- I always just go to Mainline they bring them here to me and I give them my old dirty stuff and a few other people bring their stuff here and drop it off and I make sure it goes

### Financial

- Very expensive to go to Halifax, it's not working.
- I'm on a disability pension it takes a lot of my income to travel.
- $1,000 a week had to go through Medicaid. I had to fill out so much paperwork to get the funding I needed.
- Unfair. It's tough financially for me but not everyone even has that much (money).
- There was a payout to the Provinces but not for individuals. Should be made available not to have to go looking for it.
- Going back and forth to Halifax is expensive. Some sort of support. Liver Foundation does not give any support; all of their money goes to research.
- Having a phone would help
- Transportation and telephone
- I was hoping to have a specialist in Truro because it is an hour drive in and an hour drive home and now I don't have the financial support that I had when I was in school. I am unable to work now.
- Well I suppose, well it's like going back and forth to Halifax if there was some sort of financial system available because that's very expensive, you know like, we're very fortunate, both of us drive and we have a vehicle a reliable vehicle we can use

- The Liver Foundation doesn't assist families financially as far as providing funds for gas, living, accommodations while you're there or your spouse
- There was a payout to the province or whatever, to the provinces for Hepatitis C from what I understand in Nova Scotia the government instead of paying individuals they decided to well, they were going to put it in whatever set up some kind of a health service to help people with Hep C. But I don't know if anything has ever really become of that.

## Ease of Access

- Having and making appointments on time. Seems to be a problem but I have my own car now so it's better.
- It would be easier for me to live in Halifax to get to QEII. But if I went back I know I'd start smoking crack again.
- Medications could get transferred here – help with travel.
- Now within our community [Millbrook 1st Nations] there's medical drivers that will drive me as long as I provide them with the specialist the appointment and the place and they can confirm this. But I don't want them to know I have Hep C.
- Move Halifax to Cumberland County other than that, we need more doctors and everybody knows that. Why we can't get them I have no idea
- Transportation to go see Carla [Liver Clinic]. I worry about that every time I have to go out there.
- I think that file sharing should be more important. At the very least, the doctor who gets the file, they should read the file. You keep having to re-tell and re-live your life everytime.

## Specialists

- Hoping to have a specialist in Truro with the new hospital.
- Move Halifax to Cumberland County
- Probably having access to a doctor or nurse practitioner who could be a liaison between this area (where I live Truro) and the clinic in Halifax where I could have been 'co-treated". More or less, checkups and blood tests done locally in cooperation with the specialist in Halifax.
- We need more doctors. To go to outpatients you wait 4-6 hours
- I need someone to help get my strength back like a dietician or something.

## Societal Acceptance

- Explain better to everyone in this population so we can get help without being shamed or embarrassed.
- You scare people when you tell them about what you have
- Would be easier if my family knew.
- Need to take the stigma because people can live for years and years.
- More advertising about Hep C is what it's about.
- There is a lack of knowledge out there.
- Someone to stop by like before someone stopped by every one in a while and see how I am
- And just somehow getting the word out there that it is curable and it's not something you have to hide from, not everyone gets it from using dirty needles

## Peer Learning and Knowledge Exchange

- A support group would be nice, someone to talk to, found there were times it was depressing and it would have been nice to know someone else going through treatment that you could call locally.
- The word is out that Hep C is curable. You shouldn't have to prove how you got it.
- People at the ER should be familiar with HC if possible
- I feel that HC persons require treatment they need to be seen as soon as possible before it progresses.
- Dentist office file is marked Hep C Positive. I once had a tech come in not wearing a mask and goggles on when I was having a tooth removed.
- I've been in and out of hospital for Hep C since 1984 and it's getting worse.
- They used to have a support group here [in Truro] Scott from Halifax [formerly with Hep Outreach Society] used to have Hep C meetings here at the Truro hospital I went a few times
- Give me encouragement to because your friends get tired of it…your friends get tired of you know, "there's always something wrong with {Female C} when {Female C} used to be a happy-go-lucky person.
- Another thing for the medical thing is if it were put out there, like it was explained better to everyone in the population, like, it would be easier for someone to go get the help instead of being shying away from getting the help, like from embarrassment they have it, scared they're going to be shunned like it's any kind of disease you can catch like, a lot of people are scared like they have AIDS
- There should be someone local that you could call or talk to about the Hep C. What it is and what to expect from it – a lot like we had to learn basically on our own you know. But just to have someone to talk to about it and who knows about it or even has been through it would be a big help in even for like myself
- I do think maybe a little more advertising on, just like, more to do. I guess…so it takes away from what people have to explain

## 5. Think back for a moment to when you were first diagnosed with Hepatitis C. What helped you cope with your new diagnosis? Is there anything you can think of that might have helped you cope better during those initial days and weeks?

*"People [General Public] should know more about it so you don't have to explain it all. And that I don't even know if people know that it's something you can get treated for. It doesn't have the stigma of AIDS but it does have a stigma. So I guess if we just try to take away the stigma that goes with Hep C, the fact that people can live with it for years and years and years and not have any signs." Female Respondent*

*"The first person I told was my daughter because I had to tell someone and that was who I told. When I spoke to my daughter about the Hep C I told her to keep it under her hat and not to tell anybody. Just to deal with it, I had to burden my daughter. If she did tell then people would look down on us because of it. At that time my husband and I had first separated. My daughter was 12 at the time."~Female Respondent*

*"I think it's just as bad as catching AIDS."~ Male Respondent (IDU)*

*"The second day I was thinking I was lucky I didn't have AIDS."~Male Respondent (IDU)*

*"My mom told me I chose to put the dirty needle in my arm. That gave me a lot of hateful feelings, towards myself mostly."~Male Respondent (IDU)*

*"I had nothing to help me cope with my new diagnosis."~Female Respondent*

*"I was young and stupid and did not care, I was drinking and I didn't care. The doctor told me I was going to die from it….young immature and foolish. It was known back then as 'Non A, Non B'". ~Male Respondent*

### Support Needs

- I needed Counselling but didn't know how to ask for it.
- Felt alone.
- I was embarrassed. I got to the point I couldn't cry anymore.
- Wouldn't talk about it to anyone, it was a secret between my husband and I.
- I panicked.
- My former boyfriend told everyone he knew in the small town we live in. Then he left me. Everyone knows.
- Knowledge would have been helpful more than what the nurse had to tell me or even what the doctor had to tell me.
- There was no psychological help what so ever for it, there was no support groups that I know of. I was left to my own devices, as usual

- Oh this place has no support groups what so ever NONE! It would be nice to be able to talk to somebody who's got…deals with the same stuff that I do
- I had nothing to help me cope with my new diagnosis.
- Sometimes I'm afraid he's going to walk away. We don't fight. We don't argue. He's just there for me but we need other supporters there for me.
- I don't know of any support services. Like I say I'm not originally from around here and I have no support. Nobody comes except for you today.

## Information and Awareness

- I was given an information package; I looked at it in private. I just kept reading it.
- No one should go on the internet. I did and I just got totally overwhelmed
- I asked questions but then forgot all the answers by the time I got home.
- "Don't do this. Don't do that"
- Should have NACS posters right where you give blood.
- GP I had 20 years ago told me. He did not have a lot of information to give me.
- The more information I could find the more I could deal with it.
- I couldn't go to a support group if I wasn't feeling well.
- It was 20 years ago something there wasn't a whole lot of information on it – nothing he could give me
- I've been incarcerated and when I was incarcerated that's when I found out I had Hep C and I went and I got pamphlet, after pamphlet, after pamphlet and like I said I read up on it
- Oh ya because I didn't know what the disease was all about you know. I never really found out anything about it til I came up to Truro then I started going to meetings at the Hep C thing and that's when I found out all the information about it you know.
- The first thing that I would have liked was something that I could look at in private and understood a little bit better. Then I would like to have had somebody that in after reading through the information packet and there was something that I didn't understand or scared me I know more based on that I could have gone to that would have had the time to sit down with me and talk to me.
- To me it was an illness you get. You get over it, you're done. And that's the end of it; but the problem is that's not the end of it. That's why they call it the SILENT KILLER. God knows how may people out on the street don't know they do have it. And I don't mean they feel bad, they feel good. And next month from now they may not but by then it may be too late.
- A place that they can say to you is this enough for your or if this isn't enough then doctors appointments are going to be x number of weeks apart here is a phone number of a place you could call that has more information that somebody that can sit down and talk to you and explain things a little bit better
- I know with my old doctor in Halifax Cowie Hill Medical when you come out of that doctor's office in the waiting area both sides of the room two shelves that is just loaded with pamphlets and I mean I haven't seen that anywhere else. I mean there should be a little waiting area because everybody can see what you're picking off that shelf

## Initial Reactions

- I'll never forget that day. I said no way to an HIV test but I agreed to take the Hep C test

- So the last thing I wanted to know was if I had AIDS. I was less terrified of Hepatitis C because it was a liver thing right
- Telling my brother was the worst thing I could have done. He was terrified of me. Literally. He didn't want to be in the same room, he thought my breathing on him would infect him with this germ
- My biggest fear was passing it on to my kids and my husband. Then the second biggest fear was to protect other people around me that I didn't pass it on to them. I think that probably was my biggest fear when I found out…that you carry this virus that is contagious and not pass it on to anyone
- I was bummed and stressed out. I wish I could turn back time and I wouldn't have caught it but you can't wheel back time.
- I didn't cope with nothing-it was just words
- Well it was a shock but I just took a deep breath and grin and bear it
- I took sedatives too which would be clonazapam just to help deal with the stress and everything
- When I first found out I fought-I fought with two people that I think that I caught it from-cause I didn't know how to cope with it – cause it was one thing I tried to avoid my whole life was catching Hep C
- I just didn't know how to cope with it at first I just had a lot of hate
- I think when I found out I had it, it changed my life style. I used to be a heavy drinker. I just didn't feel like drinking any more I guess 'cause they were saying that one of the worst things you could do – 'cause your liver you know. I guess it filters all the poison out of your system. But I just kind of changed my lifestyle, eating habits and drinking and stuff.
- I could care less I never felt so cold hearted or shallow or selfish and it is all anger because normally I would do anything for anybody and not ask don't ask nothing
- I'm angry, I'm angry and I am probably going to stay angry. It's unfortunate but I didn't get to find out in the privacy of my own home I got to find out by mistake in a Hep Clinic in the hospital. I'm just so angry.
- I was distraught and newly diagnosed and I can remember waiting weeks before I actually returned the call to the nurse who contacted me.
- I panicked at first.
- I had a fear of passing it on to my kids and husband (they were tested), also passing it on to others
- Anger at first but guilt about blood I had donated before I found out and who got it [prior screening]
- Sort of like in denial
- Then there is that gut wrenching feeling leaving an office where you've been diagnosed to walking back out into the everyday life when your life doesn't seem like it's going to be normal

## 6. Are there any services/supports you feel are missing from our community that would help you live with Hepatitis C?

***"I deal with isolation regarding my diagnosis on a daily basis. Even having the option of bonding with "someone like me" would have helped with coping with being first diagnosed."~Female Respondent***

### Addictions

- What would really help in the community are AA and NA meetings. When I was in New England the meeting there on a scale of one to ten was a ten and here it is a one. You could access the meetings 4 times a day. They could be accessed at 6 in the morning before work, at noon and then they were in the evenings from 8-10 pm and they were good meetings. You got the truth from people about what drinking and drugs and junk have done to them. They tell you how they are now, how they are able to get a car and a job and back into society.
- The only thing I would like to see in the community is a Methadone Clinic. People here only go to AA meetings because the judge sent them and they don't take it seriously enough or else some take it too serious. I haven't had a drink in 4 years and I had to do it on my own.

### Risk/Harm Reduction

- If you are sharing needles please tell people you have hep C.
- Our own needle exchange. It keeps Hep C from being passed on to others.
- People should have had the respect to sit there and say listen, by the way, I have Hep before you use it, please bleach it. I know bleach doesn't kill it 100% and I know that, that's just to me I think it's a fiction like 'cause I don't believe that's killing it at all.
- Like I said that is where Mainline comes in. Cause with your dirty needle exchange and stuff like that it's a lot of it and they do provide a valuable service as far as I'm concerned and a few other people I know to believe that same thing.
- I'm interested in this girl and its like…it always ends up with that question "how the hell am I going to tell this person"
- If I'm doing anything you know volunteering to help with, working with food and stuff like that I take a few more precautions I wouldn't normally.

### Information

- No one gets information, there is some supplied at Indian Brook now.
- Information to read or people to talk to.
- A phone number where you can ask questions and access information. Doctor's appointments are too fast. There also needs to be consistency in information.
- The only place I know of for information is the Hep Outreach Society and here (NACS).
- I've never called the Outreach Society but I keep in touch with their newsletters.
- GP should know more, must know more or become more informed when they get a Hep C patient.
- There is information, right, but…nobody goes and grabs it or anything but the information is there if you need it [Indian Brook 1st Nations]

## Peer Support

- I didn't know the support group here disbanded. I learned a lot from it. Should have another support group meeting.
- I would have talked to someone who had Hep C when I was first diagnosed.
- I started writing before I went on treatment, keeping notes and a journal.
- I have an email account where I offer an opportunity to share my experiences about HC.
- There should be local chapters of support groups who deal with people infected with Hepatitis C and people affected by it in our community. People who are not comfortable in their own community should be able to go another Chapter in another community.
- I can remember craning my neck from my chair in many doctors' waiting rooms to see if there was any information about support groups for Hepatitis C. I was never rewarded.
- GP's should have more information on where to go for support even if it's telling the newly diagnosed patient to contact the Department of Health (for support). In turn the Department of Health has to have someone on staff that is knowledgeable about Hep C and has something to offer in the way of support.
- My doctor told me there is a fair amount of persons in this area, (with HCV) there is no reason we shouldn't have a support group, especially when first diagnosed with it and needing information.
- I don't think there's any form of support here. If I want to go to a support group I have to go to Halifax for that so I don't understand why there is no support here. They have AA they have everything else

## 7. How has being Hepatitis C positive affected your life within your community?

Within the Drug Community there is an apparent openness about disclosing HC Status trying to use clean works and telling people they are shooting up with about their Hep C, being conscious of even using clean water. Individuals report employment issues surrounding being an IDU and people within the community knowing and not hiring for small jobs. Lack of understanding of Hep C among family members was a reoccurring theme for PLWHC.

### Protecting Others

- The only way to eliminate double dipping is to make up all of the drug at once into needles and the only way that others would be able to get your stuff would be to take a full clean needles.
- I'm careful with my works. I think I caught Hep C by using the same water. Others were using my water. Doubling dipping in my cup.
- People we hit with are more informed about Hep C. Things are not what they once were; I have to be more careful.

### Fear

- My doctor, medical personnel and the Health Department succeeded in making me paranoid and made me feel as if I were a threat to society. My job is within the school system, therefore I wonder if I would become labelled if they knew and considered unsuitable? This is my livelihood.
- Unfortunately, I work in an environment that is supposed to be of a confidential nature and I see this trust broken quite often. People's private lives are spouted off without hesitation and I have experienced other situations personally knowing someone who was in the health care employment telling stuff on the streets about patients that shocked and horrified me that this personal information would be repeated to someone in the public. Pictou County is a small close knit area the same as any other rural area of NS.
- I'm afraid of what the treatment will do to me, the side effects. This plays on my mind.
- People don't say anything to me but talk behind my back. They are not brave enough to say it to my face.

### Marginalization and Stigma

Marginalization and stigmas are themes repeated quite frequently through the interview data. For consistency following are definitions on the two descriptors:

- ***Marginalization Defined- to regulate to an unimportant or powerless position within a society or group (Webster's Dictionary 2010).***
- ***Definition of Stigma – A mark of shame or discredit; an identifying mark or characteristic, a specific diagnostic sign of disease.***

- I stay home and don't get involved in any community activities.
- People feel they will catch Hep C from me.
- Other employees point out to others that don't know that I have Hep C.

- The public attitude about Hep C is an issue.
- I only tell someone I am convinced won't judge.
- Stigma is a big issue with the community – I keep my diagnosis hidden.
- I hide my diagnosis both with Hep C and AIDS. I'll be judged by my community.
- I have had a few bad experiences with people finding out about my Hep C status in my lifetime to date. When I was first diagnosed I kept remembering the heinous situation regarding Eric Smith the HIV positive school teacher who was outed by his doctor's secretary to the local school system in Cape Sable, NS. His life was destroyed and I keep asking, 'Whatever happened to the secretary who divulged private information'.
- Because I use needles people know I use needles it has not gotten me far. Up here there are no jobs for me, my younger brother will not even hire me because I use needles.
- It's like walking up to somebody, just before you get to them they tell you that they have AIDS/Hepatitis or whatever and they kind of stop and back away and walk in a big circle right around you, I guess. People don't know that there's anything wrong with that, I guess.
- I took my First Aid course at work, I was the only one to make a hundred on it. A couple of people found out I had this and they went to the management and I was taken aside and asked not to perform first aid on anybody that got hurt.

Isolation

- One friend was bringing food once a week because I wasn't feeling well and then stopped coming and I don't understand why.
- I don't tell anyone I have Hep C.
- I don't want people to know.
- You see they're not knowledgeable they don't understand you know like they find especially at first, I don't find it now but at first it was like "Jesus get away" you know "don't come around me" or something.
- I'm not working now. I used to love to dance

## 8. Has being Hepatitis C positive affected your relationship within your family? If so how?

***"I would have to defend myself and the fact that I didn't do intravenous drugs as I am on the defensive with this diagnosis. There is so much misinformation out there regarding the virus that I would be struggling to have people believe me. I always felt that the people that did know (in the medical profession) doubted that I didn't do drugs I became on the defensive and often wished that I did receive it through a blood transfusion as who will believe me that I don't know where I picked up the virus?"~Female Respondent***

***All others including my mother and brother were not told. It has made me secretive and aloof with family members that do not know. ~ Female Respondent***

### Protecting others

- My family did not understand at first
- My mother is petrified of that stuff. She has even mentioned to him that she should have plastic cups for when I come over. She tells me to bring my own coffee cup. She's making a big deal out of nothing.
- I've made it clear to everyone that I have it, if my sister asks for a drag off my cigarette I won't let her have it.
- My Hep C diagnosis is my family's biggest worry. My father died of Hep C 20 years ago from liver failure.
- I wasn't allowed to go through my father's funeral. My family didn't tell me he died. I was in detox – drug rehab, after I was discharged I found out my father had been buried.
- My father was more concerned that I took care of myself. He eventually accepted it.
- It's hard to hide so I told my children and they don't judge but my brothers don't know.
- My family was concerned about me passing it on to my grandson and granddaughter.
- Only some family know.
- My mother became paranoid and was up to her death.
- [My Mom told me]You can't come around here til I find out more about it because I don't want you drinking out of my cup
- I made it clear to everyone that I have it. I won't let anyone drink from the same cup. I clean my own glass

### Supportive Environments

- I've been married to the same person for 34 years, my husband is very supportive.
- Not my wife and my family were concerned at first, until they found out more about it. When I was diagnosed with cancer from Hep C my family was worried about me, not about the Hep C.
- At work some people are concerned for me
- My uncle is supportive. He is familiar with stigma. He is gay. He visits and is very supportive.

- My father from day one has been very supportive. He is helpful and will not tolerate bullshit when it comes to my health.
- At first they were you know…and then once they learned about it and I explained to them you know they accepted it. And like we get along, we are a close knit family anyway.
- [My father] knew ya know like and I told him how I got it and stuff and he just said "well you'll have to look after yourself" you know. He wasn't negative about it, he just wanted to know about it you know and I told him about it and how I got it and stuff and he accepted it
- I've been married to the same person for 34 years. They are supportive.
- They [family] were worried for me not against me.

## Isolation

- My sister had a baby on my birthday. I'm afraid to go see her – I've only seen her four times.
- My family is close with each other – but now I stay away
- It's hard to hide from my kids – I don't want them to judge me
- My brothers don't know
- I am stuck in "nowhere land" with my diagnosis of Hepatitis C
- You take more precautions. They all know.
- No my family doesn't know.

## 9. What do you think should be done in the community to help deal with the challenges of Hepatitis C?

***"Prior to being diagnosed I thought that AIDS was the most prevalent blood borne virus and had no idea the gigantic proportion of the general public that is walking around with Hepatitis C. Most people don't even know they have it. I was one of those people and could have never known I had Hep C until it was too late" ~Male Respondent***

***"The media works against people diagnosed with Hepatitis C as the virus is mainly depicted with unsavoury activity and that Hepatitis C is brought on to the patient by something they did to themselves…..Basically, how someone contracts the virus should be insignificant information about the person, however, it seems to be the most important issue of having the virus…"What did you do to have acquired this virus?". This is the message I received loud and clear since being diagnosed." ~Female Respondent***

***"I think we are at the stage with Hepatitis C now that people with AIDS were years ago." ~Male Respondent***

### Support

- Some place to go to for information and just a place to talk.
- A support group – we should join forces with persons living with HIV to get help.
- We need information so people being diagnosed are not so scared.
- I need some place just to talk and have a coffee
- I realize that you can't have support groups in all towns, whether people would join forces with HIV I don't know
- I'd like to be able to go somewhere and get a little more information without having to search for it. I don't even think in the hospital there was really much that you could find for information on it. I think when you first get diagnosed with it that's what you need 'cause there's so many fears with it.
- When people are getting treatments somehow they've got to be able to step away from their jobs or whatever and feel comfortable they can step back into them when the time comes they are able to go back to work.

### Awareness

- More awareness is needed, a lot more not just on May 19th being World Hep Day as a flash on the news.
- Education is the key. I hardly know a thing about Hepatitis C prior to being diagnosed other than you had to be a drug user or had a blood transfusion. This is misinformation.
- I see misinformation quite often regarding Hep C and the media has to be educated.
- Make more information more readily available.
- People should be more informed (General Public) about Hep C. It should be brought out to the forefront so people can have a better understanding how the disease works. Need to know how it can be cured, how people get it, how to protect themselves.

- More public awareness and at the university.
- It should be brought out to the forefront just like AIDS was and people can understand the disease a little differently. See, like you said some people thought you could get it from a toilet seat, like, these weren't kids saying it, were they, it was adults. So they're ignorant to the fact of what it is. Until we get the word out and say well it is a life threatening disease but there's also a cure for it and there's also preventative measures. How to not get it and how to get it and how they are getting it now a days through tattoos and using needles
- Other then besides informing the people like through meetings and stuff that about the only thing I can see and if they don't have them other than having just literature around I guess at doctors' offices and stuff and they do that know don't they, and at the hospital

## Services

- We need to educate professionals because it takes a long time to see a doctor.
- There should be a nurse/nurse practitioner trained to work with Hepatitis patients only in the Truro, New Glasgow and surrounding areas.
- Make treatment easier to obtain.
- Someone to take you there [to Halifax], transportation if you don't have a vehicle to get there.
- There's nothing out there for teens to do and they get into drugs and stuff [Indian Brook 1st Nations]…a lot start off with benzos and I'm going back to as far as 10 years old and progresses from there. We got a community center up there but there's nothing , it's shut down right now, because whenever they were abusing up there.

## 10. Would you be interested in participating in a support group for persons with Hepatitis C here in your community? If so, how should we get the word out so people like you can hear about such a group, or other activities for people with Hepatitis C?

During the interviewing process it was mentioned by several individuals that had been diagnosed with Hep C for 10-15 years or more that there had been a support group offered at the Hospital which ended years ago several participants mentioned this service. The group was facilitated by the Hepatitis Outreach Society of NS. The group fell apart as it was divided between the definitions and language around how individuals received a positive transmission.

**Respondents indicated specific barriers to participation**: transportation, would participate but if saw someone from my own community I would leave.

### Participation

A number of participants said they would attend support groups but it was under certain conditions.

- I would participate in that but transportation would be a problem
- Would unless it was someone she meet up with that was from her community (Millbrook) then I would leave
- I wouldn't meet with somebody, I could email somebody. My e-mail is out there for people…and information in the [Hepatitis Outreach Society] newsletters.
- I probably wouldn't participate in a support group at this time. I am still coping with my diagnosis.
- Yes
- Most definitely
- Yeah I can do what I can do hopefully to help so many.
- Yes I would do it in two seconds
- We need more things – even like this interview

### Getting the Word Out

- Facebook, web-site
- Fliers and memos
- Advertising in the local paper
- Post information/flyers in Doctor's Offices
- Post flyers where people go to have their blood drawn at the hospital.
- Word of mouth will be best way – the word will spread.
- Letter sent to doctors so they can tell HC+ patients.
- Well through advertising I would say in the local paper more people read the papers than they do listen to the radio and stuff

### Support to Others

- I would meet people, starting an email group but it is very dependant on how my health is on a given day.
- I would participate as a guest speaker at presentations
- I want to be able to give back to someone else – someday when I'm ready
- Should be a Hep C 'Buddy System" like they have in AA

## 11. Are there any other issues that you would like to discuss to help us better understand the needs of people living with Hepatitis C in our community?

***"The one line I heard from three people in the medical profession (my doctor, department of health nurse contact and my nurse practitioner) that should NEVER be said to anyone diagnosed with Hepatitis C is…any people with Hepatitis C never die from it". It's a dismissive statement and each and every medical personnel should eliminate such a stupid statement from their dialogue when dealing with Hep C patients." ~Female Respondent***

***"I was due for my five year bone scan and on his request [doctor] to have it done my doctor added that I was labelled. I will never be able to shake this diagnosis nor will I be able to shake the stigma that is associated with Hep C. I should go to a physiotherapist (for my joints and muscles), but I won't go because my doctor will add to my request…"this patient has completed 72 weeks of treatment for Hepatitis C" I should have a colonoscopy done, but I won't because my doctor will add to the request…"this patient has completed 72 weeks" and so on I will not ask for any tests as I will be labelled a "bio-hazard" here by my doctor and the Aberdeen Hospital." ~Female Respondent***

### Get Tested

- Most people out there don't know they are Hep C + they should get tested
- People don't want to know they have it
- If people want to be ignorant that is their problem. They think along the line of AIDS. They just don't understand.
- People keep it all bottled up inside which isn't good or they say they don't want to get tested for Hepatitis C
- People that do know [they have Hep C] should have at least awareness anyways so nobody gets hurt

### Messages I Want to Convey

- Positive people that do know should talk.
- Stigma and discrimination is wrong – it's a health issue
- I will not ask for any tests as I will be labelled a "bio-hazard" here by my doctor at the Aberdeen Hospital
- Don't worry someday people will understand.
- Do what they tell you BE HAPPY. There are people out there that are worse off than you are. Find a friend who understands you.
- We are people too.

- Positive people that have Hep C stay in denial.
- Hep C is a taboo subject.
- Everything is in the city and there is no-one locally to deal with the mental health issues of being diagnosed with a chronic illness.
- I have been discriminated against by my insurance provider and I will never be ‘allowed’ to buy life insurance. I am officially a ‘marked’ person somewhere out there in their databases. If I ever try to buy life insurance from any company my hep C status has deemed me unworthy of their coverage.