

**Reaching Across Communities
Hepatitis C**

**Alberta
Hepatitis C and Peer Support Group Toolkit**

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Reaching Across Communities Hepatitis C Peer Support Group Toolkit

Reaching Across Communities is a project collaboration between the Bissell Centre Edmonton, the Life with Hepatitis C Society Red Deer, and the Lethbridge HIV Connection Society. All three projects have been successful in establishing and maintaining Hepatitis C peer support groups for at risk populations for the last three years. The experience that we have gained in establishing and maintaining these support groups are the source for this toolkit. We have developed this Hepatitis C peer support group toolkit to assist agencies throughout Alberta establish local support groups for at risk populations.

This guide is for both peers and agencies and is intended to provide information to those who are interested in helping individuals live healthier lives. Reaching Across Communities' aim is to provide support and educational materials to people infected or affected by Hepatitis C. The project helps to raise awareness of the public and health professionals by providing education facts about the disease and offers resources on how to establish support groups for at risk populations in their local areas.

This toolkit includes information and resources that you will need to establish a Hepatitis C peer support group in your local area. It contains examples of educational pamphlets about the virus that could be developed by agencies, and an education presentation for both front line workers and at risk populations to promote awareness about the virus. Further, it provides a Hepatitis C Alberta resource guide of community agencies that serve people infected with HCV (NPNU) 2003, Community mental health clinics in Alberta, peer resources and various other links to Hepatitis C information.

For agencies it will provide basic information about high-risk groups, the benefits of peer support projects, and ways to establish a successful peer support project at their agency. For peers, it will provide information about how to run a successful group and education about Hepatitis C.

We hope that you find this toolkit useful and informative. A presentation of this toolkit will be available in your local area soon. If you would like a presentation on this toolkit, please contact any of the three groups involved with this project.

We would appreciate your comments. Please complete and fax us in the evaluation at the back of this document.

Acknowledgements

The following people and community organizations have contributed to the production of this resource in many ways. Thanks to everyone.

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Most, for all the peers we have met along the way that have provided education to and received education from peer support groups or projects.

Story Of A Dead Head

My name is Todd; I am forty years old, and Hepatitis C positive. I am not exactly sure how I became infected because I had always been paranoid about getting infected with HIV. I am quite sure that I became infected while in jail in 1998. We had access to only one needle (rig) that was shared by twenty other guys on a unit. I tested negative in 1996, and later tested positive after I was released in 1998. I was not surprised to test positive for HCV but was also thankful that I did not contract HIV.

For a couple of years I did not change my lifestyle. I was a heavy drinker and continued to drink until April 2001. I have drunk some but very little since then and now I am pretty well alcohol free. It is funny, I had always wanted to quit drinking and the one positive result from my Hepatitis C infection, is that it stopped my hard drinking.

I have pretty well stopped using IV drugs and have been involved in the Hepatitis C Peer Project with Sylvie for almost two years now. I am on a Methadone program that has helped put my life back together. Our weekly Hepatitis C group has been a big help for me. I have met new friends through our group and learned that I am not alone. I am thankful that I am able to come to our weekly meetings and have been able to talk with Sylvie one to one. Also, the meetings have been open to my family. They have been able to learn from other people what it is like to live with Hepatitis C. My life has become more manageable and the Hepatitis C program at Bissell has been a positive note in my life with Hepatitis C.

Todd D.

The Helping Hand

When you fell like giving up
 When you feel like there is
 No hope,
 When you feel like everyone
 Is against you,
 When you don't see a
 Future for yourself,
 When you're upset because
 Family has turned their backs
 Against you,
 When you are depressed
 And you feel hopelessness,
 When your so called friends
 Turned against you,
 When you can't find
 A job,
 When you don't have
 A shelter,
 When you are hungry
 And cold,
 Remember there is a
 Helping hand,
 All you need to do is
 Find him,
THE CREATOR.

Marjorie Whelan

Thankfulness

When The Sun Shines,
 Remember Me.
 When The Wind Blows,
 Remember My Temper.
 When The Snow Flies,
 Remember My Helpfulness.
 When The Rain flows
 Remember My Tears.
 When You See The Clouds,
 Remember My Pain And Loneliness
 When You Look At Your Children
 With Love,
 Remember I Carried You.
 When You Cry And Hurt,
 Remember Life Is Not Easy.
 When You are Confused,
 Remember There Is Reason.
 When You Are In Trouble,
 Remember Prayer And the
 CREATOR.
 When You Are Lost Like Me,
 Remember My Love Around You.
 Remember To Thank Mother
 Earth,
 When You Feel Pain, Depression
 And Lost in Heart,
THANK THE CREATOR
 For All Your Feelings.

Marjorie Whelan

At risk populations for HCV, and Mental Health Issues

Who is at risk for a Hepatitis C infection in Canada? A Discussion Paper prepared by Health Canada (2000), identified that 70% of HCV cases were a result of Injection Drug Use (IDU). It also acknowledged the following groups as being at high risk for infection:

Prison populations-These populations have up to 40% of infection rates. IDU use and sharing of needles in the prison system increases spread of infection. About 25% of all who inject started while in prison.

Street Involved-Use and misuse of drugs/IDU is higher in younger populations. Many who are using drugs are displaying symptoms of dysfunctional family backgrounds and a highly stressful street life involvement. IDU is the highest reported risk factor and women become involved in drug use earlier than males. Women are less likely to do drugs alone and are more influenced by others. They are often powerless to resist sharing needles with male partners and engaging in unsafe sexual practices.

Aboriginals-The incidence of HCV in this population is on average 7.6 times higher than in the non-Aboriginal population. This group has many social disadvantages frequently associated with the use and misuse of drugs. Poverty, low education, unstable family structure, physical abuse, and poor social support networks all contribute to high rates of infection in this group.

There are other groups at risk for Hepatitis C infection. Those suffering from mental illness are also at risk for HCV infections. According to National Institute of Mental Health (2001), mental illness strikes one in five people, aged eighteen and up, in any given year. In fact, many suffer from more than one mental disorder at a time.

- Bipolar Disorder
- Schizophrenia
- Anxiety Disorders
- Obsessive Compulsive Disorder
- Panic Disorders
- Depressive Disorders
- Major Depressive.
- Dysthymic Disorder

The most prevalent of all mental health issues however, is depression.

Risk of Depression and Hepatitis C

Depression plays a very important role with a Hepatitis C infection. It places an individual at extremely high risk of contracting HCV especially when those individuals have compounded factors that predispose them to it.

For example

- **A mental health diagnosis** such as schizophrenia, addictions, and major mood disorders such as borderline and antisocial personality disorder are classically associated with serious suicide risks and completed suicides Lambert (2003).
- **Substance use**, as many people with HCV are current or past users. McKay (2002), states that there is comorbid depression in individuals with alcohol/drug addiction. Users with depression find it harder to achieve and maintain sobriety because using temporarily counteracts the primary symptom of depression.
- **HCV infection** of which a common symptom of a HCV infection is depression and according to Heathcote (2002), some studies have shown that depressive disorders are a major reason why some people have trouble coping with day-to-day activities.
- **Treatment for HCV** of which a common side effect of treatment is depression. A severe psychiatric side effect to treatment includes depression, suicidal ideation, suicidal behaviour, including attempts and suicides. This occurs in patients with and without a past history of behaviour Birkel (2002).

A person may have one or all of these predisposing factors for depression. Clients should be highly encouraged and/or accompanied to seek psychiatric help to deal with issues of depression.

All of these issues in combination with chronic homelessness, poverty, poor diet, and various medical issues SERVE TO INCREASE THE LIKELIHOOD OF THE DEVELOPMENT OF DEPRESSION.

Mental Health and associated detrimental issues

At risk populations and mental health clients must not only deal with their illness but also face chronic issues that can lead to a reduced life expectancy. Crews (2001), states that while most die of illnesses traced to environmental factors like unhealthy lifestyle, lower socio-economic status (SES), and complications of many psychotropic medications, they are also more likely to die of unnatural causes, suicide, or violence. Further certain behaviours contribute to the worsened health status of these populations.

Addictions:

- Higher incidence of smoking
- Increased rates of alcohol and substance abuse
- Men more likely to have dual diagnosis than women.
- Substance abuse worsens psychiatric symptoms, medical complications, treatment non-compliance, poor self-care, and increases rates of violence, incarcerations, and hospitalization.

Higher rates of HIV and Hepatitis C (HCV) infections:

- Unsafe sexual practices and Injection Drug Users (IDU's)
- Their relationships tend to be transient and involved with other high risk groups like other homeless people, commercial sex workers,
- Deficits in basic knowledge about harm reduction (HR), and safe sex practices
- Sexual activity while under the influence contributes to deficits in judgment and poor impulse control.

Medical Complications

- Poor diet, lack of physical activity, obesity, low fibre and high fat diets can lead to cardiovascular disease, diabetes.
- Less able to prepare food at community kitchens, group homes and boarding rooms. No involvement in cooking or choice.

Poverty and Homelessness

- Both associated with poor health outcomes
- Disabled unable to find or maintain employment. Often have to rely on Social Services or AISH.
- Providing health care is more complicated with the homeless. Unable to find individual, appointments are not consistent or forgotten, there are transportation issues. These factors may make it appear that the client is being non compliant. However, you must keep in mind that this population has many issues to contend with especially their more immediate needs on a day-to-day basis.

Benefits of Peers and support groups

What is a peer, and how are peer led support groups beneficial to at risk populations? The Toronto Harm Reduction (2003), defines "peers" as someone who has a kind of "insider knowledge" gained through his/her present or past street involvement, age, sexual identity, life-situation, even specific substance use which can have a positive result in providing services to a particular group. Moreover, peer workers are the "bridge" or conduit between service users (or potential) and the agency. Taylor (2001) refers to peers as Natural Helpers, community members that are leaders but received little or no recognition for the work they did.

Benefits of Peers to agencies:

- **Connect with a Hidden Population**-Making or maintaining contact with isolated populations in an effective way to reach them and provide them with information about the resource, agency, and programs it provides.
- **Better service for clients**-Peers can also be a connection to socially isolated communities. Through the peers knowledge of and intimacy with those communities, agency staff can increase their knowledge and better serve their clients.
- **Potential to Improve the Health of the Entire Community**-Peers can promote and provide written and verbal information on health and harm reduction strategies.

Benefits to peers:

- **Empowerment and Building on Strengths**- Recognizing strength and positively reinforcing them. This helps build self-esteem, self-confidence and provide opportunity for development and personal growth.
- **Training and skills enhancement**-Provide training and opportunity and potential for future employment.
- **Some type of payment**- This acknowledges that their knowledge and work is valued, and payment can help ease the burden of poverty.

Benefits to clients:

- Access to community resources
- Education
- Reduces isolation

Benefits of support groups:

The goals of a support group can vary. They could provide education, coping skills, harm reduction strategies. According to The Wellness Community (2003), support groups can offer the following:

- **Reduced feelings of isolation**-Meetings offer a safe, caring community of support to talk about their issues. There is comfort in knowing you are not alone with your issues.
- **Sense of control**-Learning about the issues, and other peoples' experiences give a greater sense of control.
- **Hope**-You will meet and hear about people who are surviving with the virus. You may also meet others who have been through successful treatment. Their positive experiences can provide people with hope about their own issues.
- **Education**-Meetings can provide a variety of educational information including other health topics and harm reduction strategies.

What support group do not offer

Support Groups ARE NOT A SUBSTITUTE FOR MEDICAL, PSYCHOLOGICAL OR PSYCHIATRIC OPINION.

If a medical issue arises, refer or accompany the individual to a community nurse or doctor. Groups can provide HCV education, information about nutrition, harm reduction strategies, and general medical information but they are NOT A MEDICAL OPINION.

If individuals are severely depressed or suicidal, refer or accompany the individual to a community mental health clinic or doctor. Groups can offer guidance around coping strategies but they are NOT A SUBSTITUTE FOR A PSYCHIATRIC OPINION OR DIAGNOSIS.

If individuals are displaying psychotic behaviour, delusions, or paranoia, refer the individual a community mental health clinic or doctor. Groups can offer social support but are NOT A SUBSTITUTE FOR A PSYCHIATRIC OPINION OR DIAGNOSIS.

Facilitator Training

Peers will require some training to deliver their services more effectively and they will also need regular supervision. According to the Toronto Harm Reduction (2001), training is often available through other community agencies is usually free for peers and staff. Contact other agencies that offer this training and apply for a scholarship. Peers or facilitators should be given some information as to knowledge of job duties and provided with education and training around the following areas:

- **Boundaries**-Peers are meant to connect with clients in a way that professionals cannot, yet maintain a certain distance. It is more difficult for peers to set and maintain boundaries.
- **Confidentiality**-Must understand confidentiality and agrees in contract to uphold. May have to be reminded from time to time.
- **Communications**-Effective communication skills. Approachable and non judgemental. Easily understood by at risk populations.
- **Conflict Resolution**-Understanding of how to deal with conflict and how to avoid escalation of violence. Nonviolent Crisis Intervention Training, Crisis Prevention Institute (CPI), training is available at some community agencies such as Bissell Centre.
- **Harm Reduction**-Must understand and promote harm reduction strategies to high-risk population. Acceptance of drug-using history and/or knowledge is necessary. A person who sees addiction as a health issue rather than a criminal justice one.
- **Anti-discrimination**-Must be aware of different populations and offer non-judgemental support regardless of race, sexual gender, lifestyle, circumstance etc.
- **Safety Protocols**-Universal precautions, Basic First Aid, and suicide prevention. Must be able to recognize serious mental health issues.
- **Specific job related tasks**-Computers skills, telephone, photocopy, if required, what is the specific job description and what duties are required.

Peer workers will also need a great deal of supervision. Peers can be triggered or vulnerable in particular situations. Supervisors should be able to understand how a person comes to be a peer and the special concerns that arise.

- **Drug users' history**-Some peers may be abstaining from their drug of choice and being around it while others use may trigger them to relapse. Older users may need to educate themselves about new drugs and methods of use. A person who has fostered mistrust within the using community, through bad deals, not paying for drugs, or accused of talking to the police can negatively impact the success of the project.
- **Peer/drug user stigma**-Agencies should focus on strengths of peers and not on their current or past lifestyle. Seeing that peers have a great deal to offer in skills, ideas can help alleviate some stigma.

Further, supervisors of peers need to be wary of burnout; they often need additional support too. Supervising peer workers can be a demanding and sometimes frustrating job. Some peers require a great deal of supervision, as some clients are in perpetual crisis or require constant positive reinforcement.

Getting Started

If you decide that you would like to create a peer program the following, according to Toronto Harm Reduction (2003), should be considered to ensure it's successful.

Compensations and Cost of project

Wage

- Agencies should be prepared to pay a compensation to peer workers for their work. Peers should be paid an honoraria of \$10 to \$15 /hour and work on a part time basis. They should also be paid for training. Honoraria are usually a cash payment with no deductions and no GST. There are some legal restrictions about how much a person can be paid in honoraria. Income should always be reported.

Individuals on Supports for Independence (SFI) and Assured Income for Severely Handicapped AISH are able to earn \$115 and \$200 respectively before they are penalized for their income. Additionally, individuals are able to have groceries bought, utility bills and rent paid for and it is not considered income. AS LONG AS THE INDIVIDUAL IS NOT IN CONTACT WITH THE PAYMENT, AND IT DOES NOT CROSS THEIR HANDS IT IS NOT CONSIDERED INCOME. (Contact your local SFI or AISH office for more information)

Food and Transportation costs

- Cost of public transportation (bus tickets)
- Cost for food-Nutrition very important in this population.

Cost for Space

- Space to run a support group. Look for donated space by approaching other agencies like community centres and health clinics. The use of computers, telephone, etc may also be needed depending of the level of responsibility.

Make Connections

- Angus (2003) recommends that you find and contact others who run support groups or deal with people infected with Hepatitis C. Meet with them and learn from them. The information and contacts you make will help you with the success of your group. Collect as much information and education as possible. There is a great deal of free training and educational materials about hepatitis C and other blood borne infections. You can provide this information to group participants.

The following local agencies around your area should be able to provide you with a wealth of education and information about Hepatitis C.

- | | |
|--|-------------------------------------|
| • AIDS Service Organization | • Community Centres / Drop ins |
| • Local Needle Exchange Program | • Doctors, nurses |
| • Canadian Liver Foundation | • Local Drug rehabilitation centres |
| • Local health authority, medical centres, hospitals that see patients | |

Populations at high risk of a Hepatitis C infection are most often marginalized. They are often of low income, live in substandard housing or homeless, and they may have chronic mental health and/or addictions issues. They may be regularly hungry, keep erratic hours and usually have little access to transportation. When establishing support groups for high-risk populations, the following objectives should be considered.

Facilitator-The facilitator must have some knowledge of or personal attachment with Hepatitis C. A person who is approachable, non judgmental and understands issues faced by the target population is necessary. Facilitators help ensure orderly meetings plus make certain that group meetings take place on a consistent basis.

Location-Find a location that is safe and easily accessible by most participants but also gives the individual a sense of confidentiality. Community agencies that deal with Hepatitis C infections such as local AIDS Service Organizations, Needle Exchange Programs, substance rehabilitation centres, and local community centres may be a more comfortable setting for at risk populations rather than institution based settings like hospitals or prisons.

Provide food and transportation-Proper nutrition is important with a Hepatitis C infection and many do not have access to a proper nutritious diet. Try to provide group members with a nutritional meal and access to transportation to and from the group. This could be in the form of a ride or bus tickets. Establishing meetings near local shelters, in a more central location, can save on cost for transportation.

Time-Establish a meeting time that is consistent and easy to remember. Do not make the time too early or too late as many at risk populations keep erratic schedules.

Advertising the Group

Posters-Your poster should be a positive, open invitation for people who are affected/infected with Hepatitis C. Include the time, location, and what the group provides such as beverages, food, or transportation. Have a contact name, number, and distribute them to the local agencies that you have already visited.

Brochures-Produce an easy, inexpensive yet informative brochure about your support group. Include contact person, what the group provides, and information on time, meeting place, and who can attend.

Information Board-Construct an information board about Hepatitis C and transmission modes while advertising your support group. Pictures can help

in drawing attention to the issue and create a greater likelihood that persons with a low literacy rate will understand the information.

Word of Mouth-Once people become more familiar and comfortable with the resource and the facilitator, the word of mouth will get out. Peers will start to refer each other to the resource.

Topics for meetings

Once you have established your group, you may find attendance is poor at the beginning. Do not be discouraged. Attendance will vary but it also takes a bit of time for the word about the group to get out. At times, you may find yourself without any members but it is important that you keep on meeting consistently.

Guest Speakers-Approach the community contacts and invite them as a guest to discuss their areas of expertise. Expert presentations can cover a variety of topics that are of concern to group members. These can include dieticians, person on treatment, people who have been cured of their infection through treatment, housing workers, and harm reduction specialists.

Show educational movies-About various subjects. The public library is a good place to look for this type of material. There are inexpensive and informative videos about harm reduction, drug use, chronic illness etc.

*** Clean Points by Streetworks is a very informative video and information about the video is included at the back of this document.**

Offer entertainment-Frequently attending members sometime become bored with always talking about Hepatitis C. Offer entertainment movies, or have parties for upcoming holidays.

Teaching Opportunities-Offer members the opportunity to develop educational material. Members will feel empowered by learning about the virus and being able to teach others about it.

Group dynamics and the need for establishing more than one group

As your group grows and you have a few regular members in attendance, you will find both similarities & differences in the issues that are put forward. You will also become aware of the different stages that members are at with their own acceptance of hepatitis C. These are some of the reasons for establishing more than one group.

Modes of transmission-Many individuals are co infected with HIV and Hepatitis C through IDU. This is a different group than those who acquired HCV through a blood transfusion or other means. The dynamics of these two groups may result in conflict. Such conflicts may make it necessary to establish different groups.

Newly Diagnosed - These members tend to be quite needy at first. Let these members grow as they need to, they will let you know when it is time for them to move on. This is an important step towards acceptance so do not let this get you down. It can be satisfying to watch their growth and this can leave you with the feeling of a job well done.

Intermediate Stage - This is an important area of their acceptance, the in between stage. You will note that some of these members will feel the need to group hop between being newly diagnosed and this second stage or even step up to the acceptance stage, just to feel things out. Again group members will come and go, so don't get discouraged.

Acceptance - At this stage you will feel some relief from the pressure. Members have fewer issues to deal with and some will want to volunteer some of their time to help newly diagnosed people, facilitate groups or assist with the society that supports the groups.

Treatment - This is a very important group and should be facilitated by someone who has taken the treatment successfully. Side effects of treatment can be numerous and debilitating, which in turn can result in these members being very needy, especially with mental issues. You will observe issues like depression, anorexic eating habits, vomiting, fatigue, and irritability. This may likely be the most difficult group to facilitate. Patience will be your best ally with people on treatment.

Facilitators - Facilitating groups can be very tiring and stressful, and you may find yourself burning out. Peer support workers may need a lot of support from their superior, and will need a place to vent or get ideas. Remember that you do not have to do this alone; there are people who will give you the support you need to carry on.

Affected-Hepatitis C not only affects the person who is infected but also those who are close to them. Affected people are also in need of support. They may be frightened, angry and many are ignorant about the virus. If you educate and provide support for these people, they will be better equipped to take care of their loved one and to keep themselves healthy.

You do not have to run many support groups. You can run one weekly, monthly support meeting for people in all stages. Some agencies run HIV, HCV, or co-infection groups. You will have to look at your own HCV + population, and decide what groups you want to establish and go from there. These groups should not be run by professionals, but by peers to the members it serves. Good luck and remember to stay optimistic and that you don't have to do this alone. As your groups evolve, recruit more people to help you, as this will lessen the burden.

Why are Aboriginal people are at risk for HIV/HCV

Aboriginal populations in Canada are 7.6 times more likely to be infected with HCV than non-aboriginals. According to Chee Mamuk (2001), the following factors are responsible contributing factors:

- Nomadic lifestyle
- Residential school syndrome
- Loss of culture and spirituality
- Language and literacy issues
- Loss of traditional parenting skills
- Breakdown of the family
- Unhealthy foster care
- Sexual Abuse
- Low self esteem
- Isolation
- Lack of awareness
- Alcohol abuse
- Time in prison
- Tattooing
- Poor access to health services
- Poverty
- Unemployment
- Homelessness

Establishing support groups for Aboriginal populations

One of the most important things to remember when establishing a support group is always treat the members of the group with the utmost respect.

Start and end the meeting with a prayer.

Try to have an assortment of culturally sensitive reading material available. Aboriginal people are a visual group; the more visual aids you have on hand to explain the disease the greater the likelihood they will understand it.

Because of our love of stories, it is a good idea to relate different issues in story form.

Laughter is the best medicine; we can and do find humour in the most unusual circumstances.

If possible, offer incentives such as food or cash.

Be consistent with the time and place of your meetings.

Talk to the group, not above or beyond their capabilities to comprehend the information.

Offer a variety of ideas on having guest speakers, presenters or information on topics they are interested in learning about.

Try to get everyone in the group involved in where the group is going, what the group is all about, or what they expect the group to be.

Stress to the group that whatever is said in the group stays there and that no one is to be judgemental of others.

Encourage and provide means for personal strength building. Reinforce positive qualities and provide means for education.

Encourage members to speak out and educate others in their communities about Hep C.

Elders can play an important role in our everyday lives; try to encourage them to become involved in the meetings. Let them know what is going to be happening in their community and ask them for their support.

Try to involve members of council to advocate for Hep C. Educate them through workshops and presentations. The more people who are aware and educated about the virus the greater likelihood that more people will benefit.

Offer sage and sweet grass to smudge with before the beginning of each meeting.

Offer spiritual guidance as well as education on HCV, perhaps through a sweat or having an elder available at the meetings.

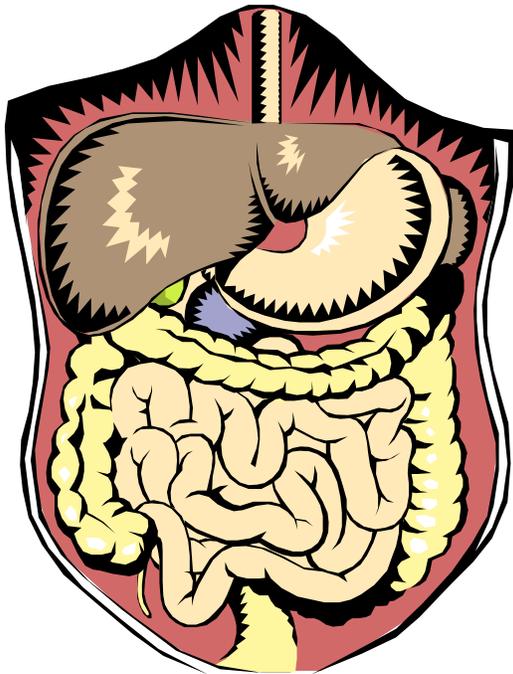
Reaching Across Communities

Hepatitis C and Mental Health Support

Hepatitis C 101

For Peers and Professionals

Where is and what does the liver do?



- Does over 500 jobs in the body
- Underneath your right rib cage
- Besides the skin, the liver is the second biggest organ in your body
- It works like a filter to clean out most drugs and all alcohol in your system
- It filters things we breathe including solvents
- It stores energy for your body when you do not have the chance to eat properly
- It helps build muscles and hormones
- You cannot live without your liver. You need to take care of it

What is Hepatitis C and how does it affect you?

- **Hepa** = liver **itis** = inflamed or swollen
- Hepatitis C is a virus that is a result of blood-to-blood contact with an infected person
- The virus gets in through an opening somewhere on your body
- The virus gets into your body, goes straight to the liver, and starts to make copies of itself
- 6 different genotypes of Hepatitis C virus. In Canada, most infections with 1a and 1b genotype
- Most Hepatitis C infection (80%) is chronic and can develop into cirrhosis or liver cancer
- Over time the virus can cause cirrhosis (hardening) of the liver or liver cancer
- In optimal conditions, the virus can live outside the body for over two weeks
- Before 1989 called Non A-Non B Hepatitis

Who is at risk for Hepatitis C?

- Injection drug users (IDU's) are at highest risk. People who share needles, cookers, water or filters. 80% of IDU'S are infected during their first year of using
- People who share pipes for smoking crack with someone who is infected
- People who get tattoos or piercing with equipment that is not properly sterilized. This includes the tattoo gun, needle and ink
- People who share razors, toothbrushes or nail clippers with someone who is infected
- People who had blood transfusions before 1990
- Babies born to Hep C+ mothers (3-7%)
- Through sex but risk not high
- People who work in areas of high exposure

Symptoms

MOST people have NO symptoms for years

Those who do have symptoms will have a few or can have all of these symptoms:

- Tired all the time
- Diarrhoea
- Depression
- Headaches
- Feeling sick to your stomach or cramps
- Joint and muscle pain
- Yellow eyes and skin (jaundice)
- Dark urine (pee)
- Light coloured stools

How to deal with symptoms

Tired all the time

- Exercise -even just a little
- Go for a walk
- Get rest when you are tired
- Take naps

Headaches

- Get enough sleep
- Drink plenty of water
- TRY to reduce stress

Not feeling hungry/Sick to stomach

- Try to eat-even a little or try eating smaller meals
- Eat larger meals in the morning

Joint/muscle ache

- Try a hot bath

If you use Tylenol®, use only the recommended dose. Acetaminophen, the main ingredient in Tylenol® is really hard on the liver. This includes Tylenol 1,2,3,4, Regular, and Extra Strength. NEVER USE MORE THAN THE RECOMMENDED DAILY AMOUNT

Ask a doctor or nurse before you take any medication

Diet and Hepatitis C

- A person with liver disease can lose up to 35-40% of their weight
- EATING right helps the liver grow new liver cells
- Sometimes eating small meals causes less stress on your liver and may help with bloating and digestion and when you feel sick to your stomach
- Sometimes a person may have changes in taste and smell
- It is very important to eat right EVERYDAY if you have Hepatitis C

Follow the Canada Food Guide

According to Health Canada (2003), people with Hepatitis C should try and follow the Canada Food Guide. It is important to try and eat regularly, even if in small amounts. Below is a simplified version of the Canada Food Guide.

Milk, cheese, ice cream
 1 serving = 1 cup of milk
 1 serving = 2 oz of cheese

Meat and Alternatives
 2-3 servings
 1 serving = 2 oz of meat
 1 serving = 2 small eggs



Grains and Bread (pasta, rice, bread, cereal)
 6 to 12 servings a day
 1 serving = 1 slice of bread
 1 serving = $\frac{1}{2}$ cup of spaghetti, macaroni, rice

Fruits and Vegetables (apples, pears, bananas, potatoes, carrots)
 5 to 10 servings a day
 1 serving = 1 apple
 1 serving = $\frac{1}{2}$ cup of vegetable

You should always to talk to your community health nurse or doctor first before you begin changes in your diet.

For Persons With Cirrhosis and diet

What to eat if you have scarring of the liver (CIRROHSIS)

- Cut down on salt
- Cut down on fats
- Drink Ensure or Boost or other nutritional drink supplements.
- Ask your doctor about vitamins

For water accumulation in the stomach (ASCITES)

- Cut down on salt

For swelling in the feet, legs, or back (EDEMA)

- Cut down on salt

For changes in taste

- Red meat may taste bitter; try eating chicken, fish, cheese, beans, tuna, eggs, are peanut butter are good alternatives
- Try eating meat at room temperature (Never leave food at room temperature for any length of time, this could result in food poisoning)

For changes in smell

- Try serving food cold or at room temperature
- Turning on a kitchen fan while food is cooking
- Grill foods outside
- Use a microwave or cook in boiling bags

Sex and Hepatitis C

- Current statistics show that transmission of Hepatitis C through sexual transmission is close to 15% and as high as 30%
- If you are in a long-term monogamous relationship, (having sex with only one person) the risk of getting Hepatitis C is low (wear a condom during a period)
- Rough sex increases the chances of being infected with Hepatitis C
- It is possible for a woman with Hepatitis C who has sex during a period to infect her partner
- It is possible to infect a person using a Hepatitis C infected sex toy

If you have Hepatitis C ALWAYS

- Use lots of lube
- Wear a condom
- Avoid sex during a period
- Tell your partner
- Use a condom on Sex Toys

YOU CAN:

- Kiss/French Kiss (Do not if you have open sores)
- Give or receive oral sex and swallow (Do not if you have open sores)
- Finger penetration (Do not if your finger is cut)

Hepatitis C and Pregnant Women

- 3-7% of Hep C+ will pass the virus on to the baby
- Nineteen per cent 19% co-infected women will pass Hep C on to their babies (this could be up to 60%)
- Method of delivery does not appear to be a factor in the transmission of Hepatitis C from mother to child
- Babies should be tested for Hepatitis C 12 to 18 months after birth
- If child tests positive, another test should be done at 2 years old
- If your baby tests Hep C+ at 2 years
 - Get Hepatitis A, and B vaccines
- Hepatitis has not been found in breast milk. Hep C+ women CAN BREAST FEED as long as their nipples are not cracked or bleeding

How to Stay Healthy

- **Eat Well**
Eating helps the liver regenerate growth; it is good for the liver, and helps in the later stages of liver damage
 - Follow Canada Food Guide
 - Take a multi vitamin everyday
- **Get Enough Sleep**
 - Tiredness is a serious and common side effect of HCV infection
 - Rest when you need to

- **Exercise**
 - This can help alleviate tiredness a common symptom of HCV
 - Helps maintain a healthy weight and this is beneficial for the entire body

- **Vaccines- Get Hepatitis A and B vaccinations**
 - Helps to ensure no additional stress on the liver. This is especially true for persons already infected with HCV
 - You can be infected with more than Hepatitis C. A person can be infected with Hepatitis A, B, C and HIV
 - Hepatitis B vaccines are free from most community health centres and free Hepatitis A may be available at local Needle Exchange Programs

- **Get regular blood work**
 - Monitor the progression of the disease helps people feel and maintain control of the disease
 - Regular blood work should be followed up at least yearly

- **Cut down or quit drinking alcohol and doing drugs**
 - Alcohol is the hardest substance on the liver
 - Crack, crystal Meth, Cocaine are also hard on the liver
 - Solvent like thinners, lacquers, and adhesives are also hard on the liver

- **Emotional Support**
 - Somewhere to have support and freedom to talk about your situation
 - A place to gain knowledge and empowerment

- **Avoid taking Acetaminophen**
 - All Tylenol® product contain acetaminophen which is hard on the liver
 - There are more than 200 medications that contain acetaminophen. Most cough, fever, pain medications have this active ingredient

Co Infection: HIV and Hepatitis C

Co infection of HIV and HCV in IDU's is a concern in Canada. HIV Edmonton (2001), quote following about co infection:

- Nearly 11,200 people in Canada and Co-infected with HIV and Hepatitis C
- About 80% of HIV infected people who contracted HIV through IV drug use also have Hepatitis C
- Up to 10% of HIV positive people may have negative Hepatitis C test even though they are infected with the virus

How does HCV affect HIV?

- As the liver progresses to cirrhosis, it is less able to metabolize medications
- As the liver gets worse, dosages of medications must be adjusted

How does HIV affect HCV?

- It appears that HIV has a more negative affect on HCV than vice versa
- HIV affects immune system which could result in higher levels of HCV
- You may get cirrhosis quicker
- HIV makes HCV symptoms worse

Treatment for Hepatitis C

Rebetron: Two different medications. Works best for people infected with Genotype 2. A majority of Hepatitis C infections are of Genotype 1. About **4 out of 10 (40%)** of people who finish the treatment will get rid of the virus

- **Interferon:** Drug that helps the body's immune system to fight infection. It is injected 3 times a week
- **Riboviron:** An antiviral drug that helps fight the Hepatitis C virus. It is taken by mouth 2 times a day
- Treatment lasts for 24 to 48 weeks

SIDE EFFECTS

- Depression, memory loss, mood swings
- Flu like symptoms, fevers, chills
- Headaches
- Tired
- Lose weight, vomiting, diarrhoea, anorexia
- Insomnia -Cannot sleep

Pegylated Interferon-PEGETRON

Combination of Interferon and Ribovarin

- Interferon injected once a week instead of 3 times a week
- Ribovarin taken by mouth 2 time daily
- Can tell if you will respond to treatment much sooner than in the past
At 12 weeks of treatment viral load measured
- Has greater success with women up to 70%
- Treatment more readily available

SIDE EFFECTS

- Depression and irritability
- Headaches and muscle aches
- Hair loss
- Flu like, chills and fever
- Anorexia and weight loss

If you get rid of the virus through treatment, you could still be re-infected in the future if you are not careful

How to Avoid Getting Hepatitis C

- DO NOT share needles, spoons, filter, or water if you are using IV drugs
- DO NOT share straws or pipes if snorting or smoking
- DO NOT share needles or ink for tattooing or needles for piercing
- Avoid getting into fights
- Practice SAFE SEX (use condoms especially during a period)

References

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Reaching Across Communities
Hepatitis C and Mental Health Peer Support Toolkit
EVALUATION

We welcome your feedback on this toolkit! When you have had time to look over this toolkit, please take a few moments to fill out this evaluation form and return it to any three of the three contacts listed below.

Experience working with Peers

- Yes
- No

The nature of my work is _____

On a rate 1 to 10 please rate the toolkit

Clarity_____ Relevance_____ Engages Reader_____

Content_____ Reading level_____ Balance (peers/agencies)_____

What do you like best about the manual?_____

What do you like least, or what would you change?_____

THANKS

Please fax or email your evaluation to the following contacts.

Hepatitis C Project
Bissell Centre
10527 96 Street
Edmonton, AB
T5H 2H6
(780) 423-2285 ext
257
FAX (780) 425-6594
ssequin@bissellcentre.org

**Living With
Hepatitis C Society**
4611 Gaetz Ave.
Red Deer, AB
T4N 3Z9
(403) 341-6026
FAX(403)346-2352
curtis@turningpointagencies.org

**Lethbridge HIV
Connection Society**
1206 Ave S
Lethbridge, AB
T1J 1A4
(403) 328-8186
FAX(403)328-8564
lethhiv@telusplanet.net

Resources

Community Supports and Services in Alberta

- List of HIV/AIDS and Hepatitis C and Non Prescription Needle Users (NPNU) Resources in Alberta

www.johnhoward.ab.ca/PUB/res_list/cover.htm#V

- Community Alberta Mental Health Clinics

www.amhb.ab.ca/comm_services/clinic_map.html

Hepatitis C Information

- Canadian Liver Foundation
Toll Free in Alberta 1-888-557-5516

www.liver.ca/english/index.html

- Health Canada- Hepatitis C
www.hc-sc.gc.ca/hppb/hepatitis_c/index.html

- <http://www.hepc.cpha.ca/start.htm>

- Canadian Hepatitis C Information Library
www.hepc.cpha.ca/start.htm

- HepNet
The Hepatitis Information Networks Hep B and C
<http://hepnet.com/charge/chapl.html>

- BC Centre for disease control resources
www.bccdc.org/content.php?item=6

- Hepatitis C Association
LINKS TO Education/Awareness
www.hepcassoc.org/links.html

- Nutrition Guidelines
www.dieticians.ca/resources/HepC_Guidelines_enB.pdf

Peer Support Information

- <http://www.mentors.ca/mentortips.html>
- http://canadianharmreduction.com/readmore/ichip_peerManual.pdf
- <http://www.hcvadvocate.org/library/library.asp>

Streetworks

Clean Points Video

An educational hepatitis C video produced by peers for peers. The video discusses HCV transmission modes and provides harm reduction strategies for those infected.

Cost is

\$ 20 for peers

\$100 for governmental agencies

To order this great resource contact:

Marliss Taylor

Program Manager

Streetworks

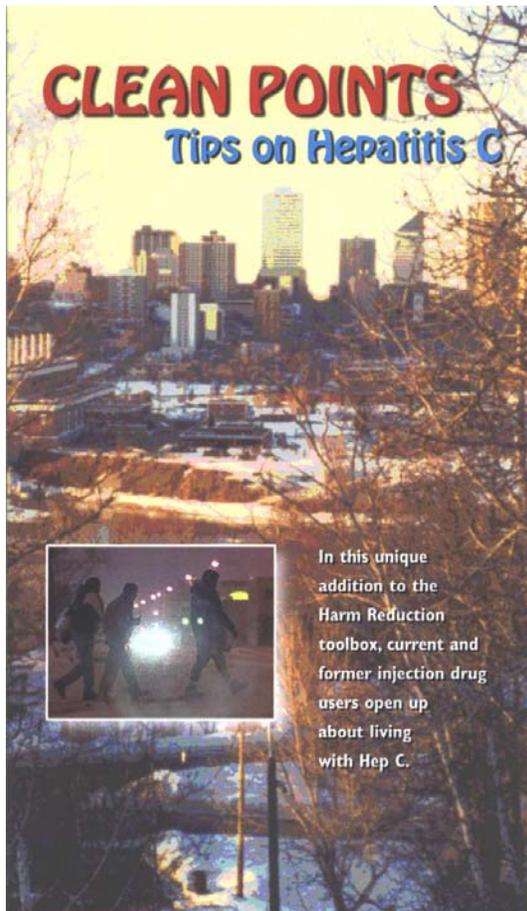
10116 105 Avenue

Edmonton, AB

T5H 0K2

(780) 423-2285 ext 210

mtaylor@boylestco-op.org



Protect yourself and others from getting Hepatitis C

- Keep other people's blood out of your body
- Do not share rigs, water, spoons, filters, cookers, or vials if fixing
- Do not share tubes, straws or pipes if snorting or smoking
- Do not share earrings, studs or needles used for body piercing
- Do not share needles or ink for tattooing
- Do not share razors, toothbrushes, or nail clippers
- Avoid getting into fights
- Cover open sores or breaks in the skin
- Practice safe sex (use condoms especially during a period)

List of places to get food

- Main Food Bank 425-4190
- Anawin Food Bank
10635 96 St. DROP IN
- Mustard Seed 429-0400
- Salvation Army 424-9222
- Bissell Centre 423-2285
- Humans on Welfare
471-2187

Free Meals

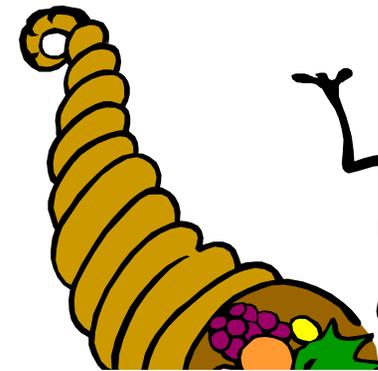
- Mustard Seed 10635 96 St.
Lunch 12:00 noon
Thurs/Fri. 7:30 pm
- Bissell 10527 96 St.
Mon to Fri. 10:30 am
- Mission 10304 96 St.
Sat 5:30 - 7:00 pm
Sun 6:00 - 8:00 pm

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DIET

And

Hepatitis C



Hepatitis C Peer Support Project Bissell Centre 10527 96 Street 423-2285

ext 257

DID YOU KNOW:

- A person with liver disease can lose up to 35-40% of their weight
- EATING right helps the liver grow new liver cells

- Sometimes eating small meals causes less stress on your liver and may help with bloating and digestion and when you feel sick to your stomach



It is very important to eat right EVERYDAY if you have Hepatitis C

WHAT YOU SHOULD TRY TO EAT EVERYDAY:

- Fruits and Vegetables (apples, pears, bananas, potatoes, carrots)

5 to 10 servings a day
 1 serving = 1 apple
 1 serving = $\frac{1}{2}$ cup of vegetable

- **Grains and Bread (pasta, rice, bread, cereal)**

6 to 12 servings a day
 1 serving = 1 slice of bread
 1 serving = $\frac{1}{2}$ cup of spaghetti, macaroni, rice

- **Milk (milk, cheese, yogurt, ice cream)**

2 to 4 servings a day
 1 serving = 1 cup of milk
 1 serving = 2 oz of cheese

- **Meat and Alternatives (chicken, pork, fish, beef, nuts, beans, peanut butter, eggs)**

2 to 3 servings a day
 1 serving = 2 oz of meat
 1 serving = 2 small eggs

WHAT YOU SHOULD EAT IF YOU HAVE SCARRING OF THE LIVER (CIRROHSIS):

It is important that you eat all food groups if you can

- Cut down on salt
- Cut down on fats
- Drink Ensure or Boost
- Ask your doctor about vitamins
- Mineral supplements

For Bloating (ASCITES)

- Cut down on salt

For swelling in the feet, legs, or back (EDEMA)

- Cut down on salt



Don't give it to anybody else:

- Keep other people's blood out of your body

- Do not share rigs, water, spoons, filters, cookers, or vials if fixing
- Do not share straws or pipes if snorting or smoking
- Do not share needles or ink for tattooing
- Do not share razors, toothbrushes, or nail clippers
- Avoid getting into fights
- Cover open sores or breaks in the skin
- Practice safe sex (use condoms especially during a period)

For more information contact:

- Your Doctor
- Bissell Centre 423-2285
- STD Clinic 413-5156
- Streetworks 424-4106
- HIV Edmonton 488-5742
- Boyle McCauley 422-7333
- Canadian Liver Foundation
444-1547 or Toll Free at
1-888-557-5516

Babies And Hepatitis C



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Pregnancy

Produced by
Hepatitis C Peer Support Project
Bissell Centre
10527 96 Street
Edmonton, AB
423-2285 ext 257

DID YOU KNOW:

- Most Hepatitis C+ mothers have no symptoms while they are pregnant
- 3-7% of mothers who are Hepatitis C+ will pass the virus to their babies
- There is a higher risk that the baby will be infected with Hepatitis C if the mother is also HIV positive.
- If you fix now or did fix in the past, you increase the chance of infecting your baby
- It is Okay to get pregnant and breastfeed if you are Hepatitis C+



If you are pregnant and Hepatitis C+ you SHOULD:

- Find a doctor or nurse that you feel comfortable with
- Quit or cut down on drinking alcohol (not only because it is hard on the liver but your baby could be born with Fetal Alcohol Syndrome (FAS))
- Eat Right
- Rest
- Get a vaccine for Hepatitis A and Hepatitis B
- Try not to use drugs that are hard on the liver especially acetaminophen (ask a doctor, pharmacist, or nurse)
- Try to find support from friends, family, or join a support group



If you have just had a baby and you have Hepatitis C:

- You can breastfeed as long as your nipples are not cracked or bleeding
- Babies should be tested for Hepatitis C antibodies at 12-18 months old
- If your child tests negative for Hepatitis C at 18 months your child is not infected with Hepatitis C
- If your child tests positive for Hepatitis C at 18 months, another test should be done at 2 years old
- If your baby tests positive for Hepatitis C at 2 years:
 - Get Hepatitis A and B vaccines
 - See the doctor regularly

Never share toothbrushes or nail clippers with your child.

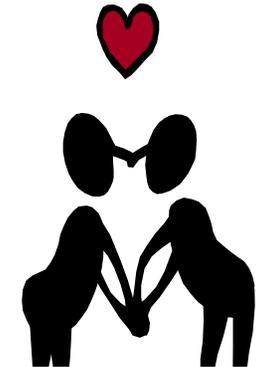
**Protect yourself and
others from getting
Hepatitis C**

- Keep other people's blood out of your body
- Do not share needles, rigs, water, spoons, filters, cookers,
- Do not share tubes, straws, or pipes if snorting or smoking
- Do not share needles, caps or ink for tattooing
- Do not share earrings, studs or needles used for body piercing
- Do not share razors, toothbrushes, or nail clippers
- Avoid getting into fights
- Cover open sores or breaks in the skin
- Practice safe sex (use condoms especially during a period)

For more information contact:

- Your Doctor
- Bissell Centre 423-2285
- STD Clinic 413-5156
- Streetworks 424-4106
- HIV Edmonton 488-5742
- Boyle McCauley 422-7333
- Public Health 413-4977
- Canadian Liver Foundation
444-1547 or Toll Free at
1-888-557-5516

Sex And Hepatitis C



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Produced by
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Bissell Centre
10527 96 Street
Edmonton, AB
423-2285 ext 257

Did you know:

- About 1-3% of people get Hepatitis C by having sex with someone who is infected with the Hepatitis C virus
- If you are in a long term monogamous relationship, (having sex with only one person) the risk of getting Hepatitis C is very low (wear a condom during a period)
- Rough sex increases the chances of being infected with Hepatitis C
- It is possible for a woman with Hepatitis C who has sex during a period to infect her partner.
- It is possible to infect a person using a Hepatitis C infected Sex Toy

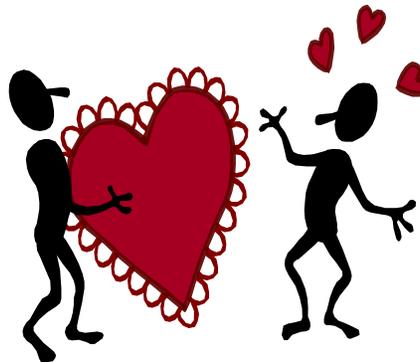
If you have Hepatitis C

ALWAYS

- Use lots of lube
- Wear a condom
- Avoid sex during a period
- Tell your partner
- Use a condom on Sex Toys

YOU CAN:

- Kiss/French Kiss
(Do not if you have open sores)
- Give or receive oral sex and swallow (do not if you have open sores)
- Finger penetration (do not if your finger is cut)



You are more likely to become infected with Hepatitis C if you have a lot of sex partners



**ALWAYS USE A
CONDOM**

You can get free condoms at:

- Streetworks 424-4106
- STD Clinic 413-5156
- HIV Edmonton 488-5742
- Bissell Centre 423-2285
- Boyle McCauley Health Centre 422-7333
- Boyle Street Co-Op 424-4106

**Protect yourself and
others from getting
Hepatitis C**

- Keep other people's blood out of your body
- Do not share rigs, water, spoons, filters, cookers, or vials if fixing
- Do not share tubes, straws or pipes if snorting or smoking
- Do not share earrings, studs or needles used for body piercing
- Do not share needles or ink for tattooing
- Do not share razors, toothbrushes, or nail clippers
- Avoid getting into fights
- Cover open sores or breaks in the skin
- Practice safe sex (use condoms especially during a period)

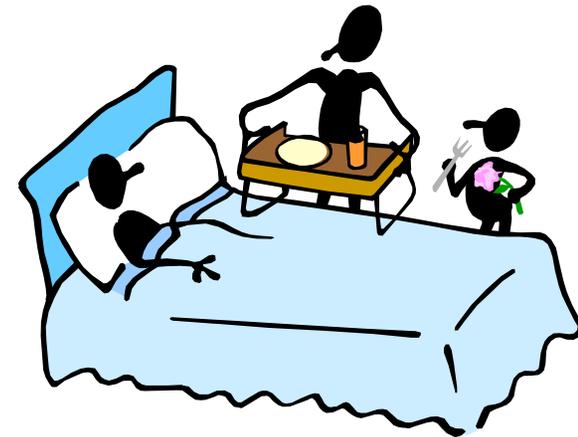
For more information contact:

- Your Doctor
- Bissell Centre 423-2285
- STD Clinic 413-5156
- Streetworks 424-4106
- HIV Edmonton 488-5742
- Boyle McCauley 422-7333
- Canadian Liver Foundation 444-1547 or Toll Free at 1-888-557-5516
- Public Health 413-4977

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Hepatitis C

Symptoms And How to deal with them



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10527 96 Street
Edmonton, AB
423-2285 ext 257

Did you know:

- Hepatitis C is a virus that attacks the liver
- In Canada, there are about 300,000 people infected with Hepatitis C but only 30% know they have it
- Hepatitis C is much easier to catch than HIV
- There is no vaccine for Hepatitis C
- Most people with Hepatitis C have the disease for years and years and do not know
- **A person who has Hepatitis C can live a long and normal life if they take care of themselves**

Symptoms

SOME PEOPLE HAVE NO SYMPTOMS FOR YEARS

Symptoms Include:

- Tired all the time
- Headaches
- Not feeling hungry
- Stomach cramps and puking
- Fever
- Dark pee
- Feeling itchy
- Jaundice (Yellow eyes or skin)
- Stomach cramps
- Joint and muscle aches



Symptoms

How to deal with them

Tired all the time: Exercise - even just a little. Go for a walk. Get rest when you are tired. Take naps.

Headaches: Get enough sleep, drink plenty of water, TRY to reduce stress

Not feeling hungry/Sick to stomach, puking: Try to eat - even a little or try eating smaller meals. Eat larger meals in the morning.

Joint/muscle aches: Try a hot bath.

If you use Tylenol, use only the recommended dose. **NEVER USE MORE THAN THE RECOMMENDED DAILY AMOUNT**

Ask a doctor or nurse before you take any medication

Protect yourself and others from getting

Hepatitis C:

- Keep other people's blood out of your body
- Do not share rigs, water, spoons, filters, cookers, or vials if fixing
- Do not share straws or pipes if snorting or smoking
- Do not share needles or ink for tattooing
- Do not share razors, toothbrushes, or nail clippers
- Avoid getting into fights
- Cover open sores or breaks in the skin
- Practice safe sex (use condoms especially during a period)

For more information contact:

- Your Doctor
- Bissell Centre 423-2285
- STD Clinic 413-5156
- Streetworks 424-4106
- HIV Edmonton 488-5742
- Boyle McCauley 422-7333
- Public Health 413-4977
- Canadian Liver Foundation (780) 444-1547 or Toll Free 1-888-557-5516

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Resource List

For People with Hepatitis C

Produced by
Hepatitis C Peer Support Project
Bissell Centre
10527 96 Street
Edmonton, AB
423-2285 ext 257

Clean Works - Needle

Exchange

- Streetworks 424-4106
- HIV Edmonton 488-5742
- Boyle McCauley 422-7333
- STD Centre 413-5156
- Eastwood Health 413-5645
- Bissell Centre 423-2285
(Drop off only)



Medical Services - Testing, Follow Up, Treatment, Referral

- Boyle McCauley 422-7333
- STD Centre 413-5156
- Northeast Health Centre
472-5027
- Streetworks 424-4106



Food Assistance

- Main Food Bank 425-4190
- Anawin 10635 96 Street
- Mustard Seed 429-0400
- Salvation Army 424-9222
- Bissell Centre 423-2285



Special Services for People infected with Hepatitis C

- Bissell Centre 423-2285
- Streetworks 424-4106
- Canadian Liver Foundation
444-1547 or Toll Free
1-888-557-5516

Referral to Community Resources

- Bissell Centre 423-2285
- Boyle McCauley 422-7333
- HIV Edmonton 488-5742
- Living Positive 488-5768
- Streetworks 424-4106
- Interfaith Centre of Aids
Resources and Education
(ICARE) 448-1768
- Boyle Street Co-op
424-4106

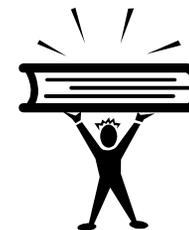
Advocacy

- Bissell Centre 423-2285
- Streetworks 424-4106
- STD Clinic 413-5156
- HIV Edmonton 488-5742
- Living Positive 488-5768
- Interfaith Centre of Aids
Resources and Education
(ICARE) 448-1768

Prevention/Education

Information

- Bissell Centre 423-2285
- Streetworks 424-4106
- HIV Edmonton 488-5742
- Living Positive 413-5768
- STD Centre 413-5156



Support: Peer, Group, Counseling, and Advocacy

- Bissell Centre 423-2285
- HIV Edmonton 488-5742
- Streetworks 424-4106