Hepatitis C

A Practical Guide for Incorporating Hepatitis C Services into Existing Programs

New York City Department of Health and Mental Hygiene
Hepatitis C Program, Division of Disease Control

Hepatitis C: A Practical Guide for Incorporating Hepatitis C Services into Existing Programs

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"The most effective means to prevent HCV infection and its consequences is to integrate HCV prevention activities into existing services, such as those for the prevention and treatment of human immunodeficiency virus (HIV), sexually transmitted diseases (STDs), and substance abuse."

- CDC National Hepatitis C Prevention Strategy

Very few communities have experience combining hepatitis C (HCV) testing, counseling, prevention, and treatment services with HIV/AIDS or any other healthcare system. Recent demonstration projects have shown that integrating HCV counseling, testing, education, and treatment into existing systems of care is feasible and can enhance identification of people at risk or needing care for HCV. This manual provides concise, accurate information and practical strategies that will help agencies integrate HCV prevention, care, and treatment issues into their programs.

The manual has two purposes:

1) To stimulate thought regarding the needs of clients who may be at risk or infected with HCV.
2) To serve as a resource for agencies working on integrating HCV prevention, care, and treatment into their existing services.

In many ways, the current challenges of HCV resemble those of HIV in the late 1980s.

"Individuals with hepatitis C are often grappling with other issues: HIV coinfection, the stress involved with illicit drug use, maintaining recovery from addiction, severe, debilitating fatigue, poverty, homelessness, or incarceration"

- Tracy Swan, *Research & Policy Recommendation for Hepatitis C Virus HCV/HIV Coinfection*

Awareness of HCV as an important public health issue is growing, but agencies, medical providers, community-based organizations, and others who work with those at risk or infected with HCV must address several key issues:

- prevention of HCV infection;
- identification of people infected with HCV;
- preventing transmission to others;
- capacity for care and treatment;
- provision of support for people living with HCV; and
- education for staff and people at risk.

A wide range of HCV activities can be integrated into existing programs and services relatively easily. Many of the activities discussed in this manual require little or no additional funding and can be incorporated without additional burden on staff or other organizational resources.

The Unfolding of an Epidemic

Hepatitis C virus is the most common chronic blood borne viral infection in the United States. First identified and named in 1988 and previously called non-A non-B hepatitis, it is estimated to have infected as many as 242,000 Americans annually during the 1980s. Because many people were unaware that they were infected, the risks of transmitting the infection to others were extremely high. Since 1989, the incidence of HCV has declined dramatically to an estimated 30,000 new infections in 2000. Most of the decline has occurred among injection drug users (IDUs). While the reasons for the dramatic decline are not fully understood, it may be due to safer injection practices resulting from intensive HIV prevention programs as well as to the very high proportion of injection drug users already infected.

While the number of new infections has dropped dramatically in the last 10 years, most people with chronic HCV are still unaware of their infection and have not sought medical care. Given the slow progression of HCV disease in most people, the impact of HCV infection may explode over the next 10-20 years. Because it usually takes 20-30 years for chronic liver disease, cirrhosis, and liver cancer to develop, it is conservatively estimated that illness and deaths from HCV-related liver disease among the millions of people infected during earlier years will increase 2-to 3-fold over the next two decades. Direct medical costs may range from $6.5 to $13.6 billion, with even greater indirect and societal costs.

The National Hepatitis C Prevention Strategy

In 2001, the Centers for Disease Control and Prevention (CDC) launched the ***National Hepatitis C Prevention Strategy*** in partnership with other federal, state, and private sector agencies. This comprehensive plan is designed to lower the incidence of acute HCV in the United States and reduce the disease burden from chronic HCV.

The principal components of the ***National Hepatitis C Prevention Strategy*** are:

- *education of healthcare and public health professionals* to improve the identification of people at risk for HCV infection and ensure appropriate counseling, diagnosis, medical management, and treatment;
- *education of the public and people at risk for infection* about risk factors for HCV transmission, and the need for testing and medical evaluation;
- *clinical and public health activities* to identify, counsel, and test people at risk for HCV infection, and medical evaluation or referral for those found to be infected;
- *outreach and community-based programs* to prevent practices that put people at risk for HCV infection, and to identify people who need to get tested;
- *surveillance* to monitor acute and chronic disease trends and evaluate the effectiveness of prevention and medical care activities; and
- *research* to better guide prevention efforts.

The agencies involved in the development of the ***National Hepatitis C Prevention Strategy*** concur that, *"the most effective means to prevent HCV infection and its consequences is to integrate HCV prevention activities into existing services, such as those for the prevention and treatment of human immunodeficiency virus (HIV), sexually transmitted diseases (STDs), and substance abuse."*

INTEGRATING HEPATITIS C INTO EXISTING SERVICES

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TYPES OF HCV SERVICES

The following HCV services can be integrated into existing programs serving populations at risk and people infected with HCV. Many require little or no funding and can readily be incorporated without additional burden on staff or other resources.

- HCV pre- and post-counseling and testing on-site
- Formalized linkages in the community for HCV testing and counseling
- HCV testing offered in conjunction with HIV testing
- Hepatitis A and B vaccines available on site
- Formalized linkages in the community for hepatitis A and B vaccinations
- HCV risk assessment at intake for every new client/patient
- Case management for HIV and HCV co-infected clients
- HCV care goals incorporated into case management assessment and reassessment
- Ongoing HCV staff trainings and client workshops
- HCV printed materials and visuals available and accessible to clients and staff
- HCV harm reduction information for injection drug users
- HCV community resource list developed and distributed to all staff
- Appropriate medical referrals to clients/residents who test antibody-positive or present as HCV positive
- Individual counseling for clients at risk for or living with HCV
- HCV support groups
- Support groups for people receiving HCV treatment
- Educational materials and programs for people living with an HCV infected person
- Outreach programs targeting those at greatest risk
- Mobile HCV testing and hepatitis A and B vaccination clinics
- HCV testing and hepatitis A and B vaccinations for people using syringe exchange programs
- HCV prevention and liver health information integrated into alcohol and substance abuse services
- Agency HCV integration task force
- Formalized linkages between primary care clinics and specialists such as: infectious disease, gastroenterology, hepatology, and psychiatry

CORE EDUCATION AND COUNSELING MESSAGES

The following Core Education and Counseling Messages are designed to help providers readily integrate HCV information into their work with clients. These messages form the foundation of effective hepatitis C integration and should be provided and reinforced to all clients at risk or infected with HCV.

Effective prevention counseling helps individuals assess their own risk behaviors, consider their options, and develop a plan to reduce their risk of contracting HCV, as well as HIV, STDs, and other forms of hepatitis. Because an individual's risk for HCV is likely to put him/her at risk for other infections, prevention counseling that helps reduce the harm from one disease also helps reduce the harm from a number of other infections.

Likewise, HCV education and counseling messages that encourage medical monitoring and positive self-care are often applicable to many differing infections. Case managers, HIV pre- and post-test counselors, medical providers, and others who have one-on-one or small group interactions are in a unique position to readily integrate important HCV education and counseling messages into their work.

"These messages … should be provided and reinforced to all clients at risk or infected with HCV."

Core Education and Counseling Messages when HCV Status is Unknown

For all people at risk:

- Any activity that lets one person's blood come into contact with another person's blood can potentially transmit HCV.
- Injection drug use is the primary way HCV is transmitted.
- Transmission can occur by:
  - sharing needles or equipment to inject drugs (cotton, cookers, water, etc.)
  - high-risk sex with an infected person
  - occupational exposure to infected blood
  - tattooing/body piercing with contaminated equipment
  - mother-to-infant
  - the use of blood products such as clotting factor prior to 1988 or
  - through blood transfusions and tissue transplants prior to 1992.
- People who have shared injection equipment, even once, are at risk for HCV infection.
- If you are at risk, consider testing for HCV.
- People living with HCV-infected individuals should avoid sharing household items that may have blood on them, such as razors and toothbrushes.
- HCV is *not* spread by hugging, coughing, sharing utensils, or any other casual contact.

If injecting:

- Consider a drug treatment program.
- Always use a new sterile syringe, cotton, cooker and fresh water *for each injection*. Do not share syringes, cotton, cooker or water.
- Sterile syringes are available at syringe exchange programs and at ESAP pharmacies.
- If you are splitting drugs, split them when they are dry (in powder form) or use a new sterile syringe to split them.
- Don't backload into someone else's syringe.
- Clean the injection site and avoid contact with blood.
- If you must share, use bleach to clean your syringe before injecting. It is still unknown if bleach effectively kills HCV.

When having sex:

- Sex that may involve blood, such as rough sex, anal sex, or fisting, increases the chance of transmission
- Sex with multiple partners or in the presence of STDs with open sores greatly increases risk of transmission
- Using a latex condom, latex glove, or other barrier method will reduce your risk of becoming infected with HCV, as well as HIV, hepatitis B and other STDs
- Talk with sexual partners about using protection, as well as past and current risk

If you are at risk, consider testing for HCV:

- Knowing your HCV status can help you make choices about liver health even without other treatment options.
- If your results are negative, you can get information to make sure you stay that way!

<u>Core Education and Counseling Messages for HCV Negative People</u>

- You can take steps now to keep from becoming infected in the future
- If you continue to put yourself at risk, testing negative now does not ensure a negative test result in the future

If injecting:

- Consider a drug treatment program.
- Always use a new sterile syringe, cotton, cooker and fresh water *for each injection*. Do not share syringes, cotton, cooker or water.
- Sterile syringes are available at syringe exchange programs and at ESAP pharmacies.
- If you are splitting drugs, split them when they are dry (in powder form) or use a new sterile syringe to split them.
- Don't backload into someone else's syringe.
- Clean the injection site and avoid contact with blood.

- If you must share, use bleach to clean your syringe before injecting. It is still unknown if bleach effectively kills HCV.

When having sex:

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Core Education and Counseling Messages for HCV Positive People

People who test positive for HCV may need:

1) Counseling and education to understand HCV disease and reduce the risk of transmission to others;
2) Counseling on liver health and positive self-care, including the effects of alcohol;
3) Education that HCV is usually a slowly progressive disease and there's a lot they can do to take care of themselves;
4) Medical referrals to monitor their health and determine the extent of their liver disease;
5) Referrals to drug and alcohol treatment, support groups and mental health care, as needed; and
6) Vaccination for hepatitis A and B, if not previously exposed.

Education and Counseling Messages to Reduce the Risk of Transmission to Others

- HCV is not transmitted by casual contact
- Don't share syringes, cotton, cooker or water used to prepare or inject drugs
- Discuss your HCV status with sexual and/or needle sharing partner(s) and encourage them to get tested
- Use barrier protection when having sex that may involve blood
- Don't share items that may have blood on them (razor, toothbrush, clippers)
- Don't get tattoos or body piercing in unlicensed settings
- Don't donate blood, body organs, other tissue, or semen
- Clean up blood spills with bleach solution.
- Cover cuts and sores on the skin

Education and Counseling Messages to Reduce Harm from Injection Drugs

- Offer a referral to substance abuse treatment, if interested
- Try to abstain from or reduce the use of injection drugs.
- If possible, get sterile needles from a syringe exchange program or ESAP pharmacy
- Always try to use sterile syringes and clean unused cooker, cotton and water. Don't share any of this equipment.
- If you need to split drugs, use a new sterile syringe to divide up the drugs or split them when dry (in powder form)
- Don't backload into someone else's syringe
- If you need to share syringes or a cooker, use bleach to clean your equipment

Education and Counseling Messages to Reduce the Risk of Disease Progression

- Get a medical evaluation as soon as possible (even if not currently ill)
- Try to be open with your healthcare provider about your health and about alcohol and substance use
- See a specialist who understands HCV
- Consider getting vaccinated for hepatitis A and B, if not previously exposed
- *Alcohol has serious consequences for the liver.* If you can, abstain from drinking or reduce alcohol consumption.
- Take care of your liver
- Drink plenty of water and eat well
- Cigarette smoking increases the progression of disease. Consider help to quit or cut down.
- Talk to your doctor before starting any medications, including over-the-counter and herbal medicines. They may be harmful to the liver.
- Get plenty of rest

REACHING POPULATIONS AT RISK: Suggested Activities & Services

HIV/AIDS Services

HIV and HCV have similar modes of transmission – primarily sharing injection drug equipment and high-risk sexual activity. HIV program staff are already talking about prevention, harm reduction, and accessing services. Since staff are also accustomed to incorporating HIV treatment issues into case management, messages and treatment plans can easily be tailored to include HCV.

HIV Client Service Programs can:

- Provide information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all clients seeking or receiving services from the program, regardless of their HCV status.
- Integrate specific questions about HCV risk, HCV risk reduction efforts, HCV care, and HCV treatment into assessment and service plans.
- Develop formal linkages with medical providers who specialize in HCV or HIV/HCV co-infection (hepatologist, gastroenterologist, and/or infectious disease specialist).
- Offer hepatitis A and hepatitis B vaccinations on-site or in the community to all clients at risk for or infected with HCV, as needed.
- Provide family members and/or needle sharing and sexual partners with information about HCV transmission and testing as part of a comprehensive systems approach to care.
- Educate **all** client service staff about HCV and the importance of integrating counseling messages and care into all aspects of case management from assessment to discharge and follow-up.
- Educate **all** staff about the unique needs of clients who are co-infected with HIV and HCV.
- Develop ongoing HCV-specific education programs to inform and update clients.
- Develop and/or acquire written materials about HCV prevention, testing, care, and treatment.
- Modify program requirements to meet the individual needs of people undergoing HCV treatment and/or with advanced liver disease.
- Develop service plans that include goals specific to the needs of people with chronic HCV.
- Advocate for clients who are denied HCV treatment due to drug use.
- Inform co-infected clients that Medicaid now pays for HCV viral load and genotyping.
- Offer an HCV/HIV co-infection support group on site.

HIV Prevention, Education and Outreach Programs can:

- Educate **all** program staff about HCV and other forms of hepatitis.
- Incorporate HCV information into existing HIV education and training programs.
- Develop HCV-specific education programs to inform and update clients, staff and the community.
- Develop and/or acquire written materials about HCV prevention, testing, care, and treatment.

- Incorporate HCV harm reduction messages into all prevention activities, including safer injection practices and safer sex.
- Incorporate messages about stopping or reducing alcohol intake and provide referrals to detox/treatment programs and AA meetings if interested.
- Develop a comprehensive HCV resource list for the community being served.

HIV Counseling and Testing Programs can:

- Educate **all** staff about HCV and the importance of integrating counseling messages into HIV pre- and post-test counseling sessions.
- Educate **all** staff about the unique needs of clients who are co-infected with HIV and HCV.
- Educate clients seeking HIV testing about HCV risk.
- Offer HCV testing in combination with HIV testing and counseling.
- Integrate information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all clients seeking or receiving services from the program.
- Develop literature and advertising in the community about HCV testing and counseling.
- Develop a comprehensive resource list for clients seeking information or testing positive for HCV.
- Track HCV risk of clients in order to advocate for funding and services.
- Offer hepatitis A and hepatitis B vaccine to all clients at risk or testing positive for HCV.

Needle Exchange Programs can:

- Provide information about HCV transmission and safer sex for all clients regardless of their HCV status.
- Offer HCV testing and HAV/HBV vaccines on site for all people at risk.
- Utilize the needle exchange database to track HAV/HBV vaccine needs.
- Develop formal linkages with medical providers who specialize in HCV or HIV/HCV co-infection (hepatologist, gastroenterologist, and/or infectious disease specialist).
- Update safer injection information to include the increased risk of HCV transmission through needles and works (cotton, cookers, water, etc.).
- Educate **all** staff about HCV and the importance of integrating counseling messages and care into all contacts with people who are injection drug users.
- Educate **all** staff about the unique needs of clients who are active drug users and infected with HCV.
- Offer to escort clients to medical care appointments and advocate for HCV care and treatment.
- Advocate for clients who are denied HCV treatment due to drug use.

Alcohol and Substance Abuse Treatment

Today, the leading cause of new HCV infections in the United States is the use of shared needles or other equipment (e.g., cotton, cookers, water) to inject drugs.

Alcohol and substance abuse treatment programs have the unique opportunity to reach those people at greatest risk for infection or progression of HCV disease.

Alcohol Detox Programs can:

- Educate **all** staff about HCV and the importance of integrating counseling messages and care into treatment.
- Provide HCV assessment and screening for people at risk.
- Offer hepatitis A and hepatitis B vaccinations, where appropriate, to all clients at risk for or infected with HCV.
- Provide harm reduction counseling regarding alcohol's impact on the liver and ways to maintain liver health.
- Provide or refer patients to appropriate medical care and HCV support groups upon release.

Outpatient Substance Abuse Treatment Programs can:

- Provide information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all clients entering the program.
- Provide HCV assessment and screening for people at risk.
- Offer hepatitis A and hepatitis B vaccinations, where appropriate, to all clients at risk for or infected with HCV.
- Integrate HCV risk reduction or care into treatment plan.
- Provide or refer patients to appropriate medical care (hepatologist, gastroenterologist, and/or infectious disease specialist), and HCV support groups.
- Provide family members and/or needle sharing and sexual partners with information about HCV transmission and testing as part of a comprehensive systems approach to education.
- Educate **all** staff about HCV and the importance of integrating counseling messages and care into treatment.
- Educate **all** staff about the unique needs of clients facing treatment for addiction and HCV.
- Offer a supportive counseling group for people with HCV in treatment.
- Address the physical and psychological difficulties of injecting interferon or taking drugs while in treatment.

Inpatient Substance Abuse Treatment Programs can:

- Provide information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all clients entering the program.
- Provide HCV assessment and/or screening for all people upon entry.
- Offer "split kits" or "clean needle kits" to anyone who chooses to leave the program.
- Integrate HCV risk reduction or care into treatment plan.
- Provide or refer clients to appropriate medical care (hepatologist, gastroenterologist, and/or infectious disease specialist).
- Offer an HCV support group on site, or refer clients to local support groups.

- Offer hepatitis A and hepatitis B vaccinations, where appropriate, to all clients at risk for or infected with HCV.
- Provide family members and/or needle sharing and sexual partners with information about HCV transmission and testing as part of a comprehensive systems approach to education.
- Educate **all** staff about HCV and the importance of integrating counseling messages and care into treatment.
- Educate **all** staff about the unique needs of clients facing treatment for addiction and HCV.
- Modify treatment program requirements to meet the individual needs of people undergoing HCV treatment and/or with advanced liver disease.
- Offer a supportive counseling group for people with HCV in treatment.
- Address the physical and psychological difficulties of injecting interferon while in treatment.

Correctional Health Services

In the United States, two million individuals are incarcerated. National figures for HCV infection estimate that 15-42% of inmates across the country may be HCV infected. Injection drug use is the primary transmission route for HCV, and a substantial majority of prison and jail inmates – as much as 80% - have serious drug problems.

Many inmates have chronic HCV infection when they enter prison or jail but do not know they are infected. Injection drug use, consensual sex, rape, tattooing with contaminated equipment, and sharing personal items can lead to transmission of the virus within the corrections setting. In January of 2003, the CDC released *Prevention and Control of Infections with Hepatitis Viruses in Correctional Settings*, which outlined the following recommendations for hepatitis C in correctional facilities:

<u>Correctional Facilities can:</u>

- Ask all inmates about risk factors for HCV during entry evaluations.
- Provide testing for all inmates reporting risk factors for HCV.
- Provide diagnostic testing to determine if patient has chronic HCV and further medical evaluation to determine extent of liver disease.
- Assess for treatment candidacy in consultation with a specialist familiar with HCV treatment.
- Provide hepatitis A and hepatitis B vaccination, where appropriate, to all inmates with chronic HCV.
- Follow latest treatment guidelines to establish criteria for the identification of prisoners who may benefit from antiviral treatment.
- Incorporate prevention education into health education programs, including information about transmission, prevention, risk reduction, immunization, and disease outcomes.
- Utilize trained professionals or inmate peers with specific training to teach comprehensive information and skills.

- Establish links with community and public health facilities.
- Incorporate messages about stopping or reducing alcohol intake and refer interested persons to AA meetings.
- Provide counseling for people with chronic HCV regarding preventing transmission to household, sexual and drug-use contacts, as well as ways to reduce further liver damage, including limiting alcohol and drug use, substance-abuse treatment where appropriate, and aftercare that includes medical follow-up.

Correctional Viral Hepatitis Health Education Programs can include:

- Routes of transmission;
- Risk factors for infection;
- Disease outcomes, the need for medical management and treatment options;
- Methods to prevent infection, including immunization and harm and risk reduction;
- The importance of substance abuse treatment, when appropriate;
- Sexual precautions including condom use and abstinence counseling;
- Risk reduction counseling, including not sharing drug paraphernalia; and
- Resources in the community available to support and sustain a reduction in risk behaviors.

Sexually Transmitted Disease Clinics

Sexually Transmitted Disease (STD) clinics are often an entrée to primary care for individuals at greatest risk. STD clinics can provide harm reduction education to patients at risk for HCV due to unprotected sex. Although HCV is not easily transmitted by sexual activity, people with STDs, multiple sexual partners, or who have high-risk sex involving blood or torn tissue are at increased risk for HCV infection.

STD Clinics can:

- Educate **all** staff and clients about HCV transmission and risk associated with STDs.
- Educate **all** staff about the importance of integrating HCV education and counseling messages into routine care.
- Provide information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all clients seeking care.
- Create an environment that says “Hepatitis C Spoken Here” by providing written materials about HCV prevention, testing, care, and treatment in waiting rooms and exam rooms.
- Show a hepatitis C educational video in the waiting room.
- Offer HCV testing singularly or in combination with HAV/HBV/HIV testing and counseling for all clients at risk.
- Offer hepatitis A and hepatitis B vaccines to all clients at risk or testing positive for HCV.
- Utilize existing patient tracking system to provide and follow-up on hepatitis A and hepatitis B vaccine series.

- Develop formal links to primary care and specialists for people testing positive for HCV.
- Incorporate messages about stopping or reducing alcohol intake and provide referrals to detox/treatment programs and AA meetings if interested.

Primary Care Clinics

Primary care clinics and family health centers are often the only source of health care for populations at risk. By helping patients to feel connected and cared for, clinics have the opportunity to identify those at greatest risk for infection or disease progression, as well as ensure coordinated care for people who have hepatitis C. Most people will not initiate a discussion of hepatitis C unless asked. Creating opportunities for education, dialogue, and testing will help ensure that primary care clinics identify all patients who are at risk for HCV infection or disease progression.

- Provide information about HCV transmission, local ESAP pharmacies and syringe exchange programs, safer injecting practices, and safer sex for all patients seeking care, regardless of their HCV status.
- Integrate specific questions about HCV risk, risk reduction efforts, testing and hepatitis history into initial patient assessment.
- Offer HCV testing singularly or in combination with HAV/HBV/HIV testing and counseling for all patients at risk.
- Offer walk-in hepatitis A and hepatitis B vaccination clinics for all patients and community members at risk.
- Offer HCV education programs for the community.
- Create an environment that says “Hepatitis C Spoken Here” by providing written materials about HCV prevention, testing, care, and treatment in waiting rooms and exam rooms.
- Show a hepatitis C educational video in the waiting room.
- Educate **all** staff who have patient contact about HCV transmission and the importance of integrating counseling messages into all aspects of care.
- Develop formal HCV coordinated care linkages with specialists such as hepatologists, gastroenterologists, psychiatrists, and infectious disease specialists.
- Provide a list of questions for patients to ask specialists about their HCV care and treatment.
- Educate **all** staff who have patient contact about the unique needs of clients who are co-infected with HIV and HCV.
- Inform HCV positive patients that Medicaid now pays for HCV viral load and genotyping.
- Provide family members and sexual partners with information about HCV transmission and testing as part of comprehensive medical care.
- Incorporate messages about stopping or reducing alcohol intake and provide referrals to detox/treatment programs and AA meetings if interested.

HCV INTEGRATION: Works in Progress

The following section highlights the ingenuity and resourcefulness of six organizations in New York City. While different in their scope of services and level of HCV service provided, each program has demonstrated a commitment to integrating HCV and continues to look for ways to improve and expand services. Each *Work in Progress* describes the agency and its efforts to integrate HCV, barriers encountered, and recommendations for others.

For many organizations, integration begins by listening to the voices of the people being served. For others, it begins with the passion and dedication of one staff member or the commitment of an organizational leader. Whatever the impetus, organizations that offer services ranging from needle exchange to primary health care are finding creative and thoughtful ways to meet the prevention, care, and treatment needs of their clients who are at risk for or infected with HCV.

HCV INTEGRATION: Works in Progress

"When we realized about five years ago that people weren't even able to get treatment, we began to broach and address the HCV problem in our community in a comprehensive way."

The Hepatitis Project at the Lower East Side Harm Reduction Center

The Lower East Side Harm Reduction Center (LESHRC) was founded in 1990 as an all-volunteer, community-based effort to stop the rapidly expanding HIV/AIDS epidemic. Neighborhood activists, religious leaders, residents, and service providers joined forces in the streets to provide harm reduction services to the diverse communities of New York City's Lower East Side, who were particularly hard hit by this health crisis. The Center's primary objectives have been to decrease risk factors such as syringe sharing among injection drug users and to educate them about other ways to reduce their risk. An equally important concern has been reducing the harmful impact of drug use on individuals, their families, their friends, and the community.

Of great concern to injection drug users is the increased risk of hepatitis A, B and C viruses. The combination of limited access to health care and prevention education sparked LESHRC to begin the Hepatitis Project in 1999. This important and innovative program directly addresses the barriers many injection drug users face by offering hepatitis A, B and C prevention counseling, testing, vaccination and referrals for follow-up care. "The HCV epidemic has been alarming for the longest time," states Mark Gerse, Executive Director. "When we realized about five years ago that people weren't even able to get treatment, we began to broach and address the HCV problem in our community in a comprehensive way. Anything that comes from LESHRC comes from people we know who have it (HCV), and we feel we have to do something about it." To date, the program has tested over 600 individuals, with 25% of people testing positive for hepatitis A, 39% testing positive for hepatitis B, and 51% testing positive for hepatitis C.

The LESHRC believes that screening without offering a link to follow-up care contradicts the purpose of screening. The goal of the Hepatitis Project is to offer accessible and affordable medical providers to perform testing for hepatitis and follow-up medical care if necessary. New to the project is a Hepatitis C Care Coordinator who actively networks with medical practitioners and other service providers to ensure a continuum of care for all clients. Staff of the Hepatitis Project work to develop a network of medical practitioners in the community who are sensitive to the needs of injection drug users. Anyone who tests positive has immediate access to follow-up services on-site, which may include case management services, advocacy at medical appointments, and/or an HCV support group. At the heart of the project is the "Hepatitis Team," a committed group of compassionate medical, nursing, and public health students from New York University under the direct supervision of a licensed physician from the NYU School of Medicine. The team offers free and confidential prevention counseling, testing, and

vaccination every Friday evening from 6:00-8:00 p.m. and Saturday from 11:00 a.m. – 2:00 p.m.

Most people using the clinic are participants in the LESHRC needle exchange program. Since confidentiality is crucial to the success of both programs, the clinic uses the needle exchange database to follow-up with people who are receiving HAV/HBV vaccinations.

Barriers encountered

A major expense of staffing the Hepatitis Project is the salary of trained medical professionals. The LESHRC overcame this barrier by using volunteer medical students and attending physicians from the NYU School of Medicine. In addition, the school picks up the benefit costs associated with paid salaries and medical malpractice insurance.

The biggest obstacle faced by the Hepatitis Project isn't lack of funding but, instead, prejudice and ignorance on the part of the medical and health community regarding HCV treatment for active users and lack of broad support for syringe exchange.

Recommendations for others

Since sharing syringes is the number one way HCV is spread, everyone in the health business needs to support syringe exchange! "There must be a political commitment on the part of physicians, public health officials, and the community to actually address this issue head-on to reduce harm and not increase it," says Gerse. "That will be the litmus test. Are you coming from an old approach – and if so, is it working – if not, what are the new approaches we need to take?"

HCV INTEGRATION: Works in Progress

"People had to wait a very long time to see the specialist, sometimes up to two months after calling for an appointment – a real problem with our clients since they have trouble making appointments."

COBRA Case Management at Project Samaritan AIDS Services, Inc.

Project Samaritan AIDS Services, Inc. (PSI AIDS Services) was founded in 1988 as a joint venture of The Project Return Foundation, Inc. and Samaritan Village, Inc., two widely recognized substance abuse recovery organizations. The C.O.B.R.A. Case Management program of PSI AIDS Services helps people with HIV/AIDS and their families get the services they need to remain healthy and independent. The C.O.B.R.A. team offers comprehensive and intensive Medicaid case management and advocacy with concrete supportive services including medical and mental health care, substance abuse treatment, housing, and legal services.

With three case management sites and twenty case management teams, the COBRA program serves up to 800 people in the Bronx and Queens. For the past year, they have tracked HCV among their clients and found a 43% co-infection rate.

As part of standard practice for NYS AIDS Institute COBRA programs, each client is asked questions about the need for hepatitis A, B, and C testing and treatment upon entry into the program. Project Samaritan staff saw a need for more information and enhanced the AIDS Institute's intake and reassessment forms to include more detailed questions about an individual's risk, testing history, and experience with HCV treatment. This information is used throughout case planning and helps to shape goals in the initial assessment and subsequent reassessments. In addition, Project Samaritan created a new medical tracking form that includes HCV diagnostic testing information. All co-infected clients work with their case management team to identify an HCV-specific goal to include in their service plan. For many, an initial goal is to get vaccinated against hepatitis A and B.

Barriers encountered

One of the biggest barriers to service is the lack of medical providers who understand HIV/HCV co-infection. "People had to wait a very long time to see a specialist, sometimes up to two months after calling for an appointment," reports Roberto Rodriguez, Vice President of COBRA Services. "….a real problem with our clients since they have trouble making appointments." The program only refers clients to medical providers well versed in co-infection. They have developed a positive working relationship with several hospitals and clinics and find that clients are better served – even if they have to wait – by a specialist who understands co-infection than by providers who can see them sooner but are uninformed or biased against clients struggling with addiction.

Repeated training and regular updates are important components of staff education. “Ideally, we should have hepatitis C training at least every six months.” states Rodriguez. Case management teams try to integrate HCV education and care into all aspects of case planning. Unfortunately, program staff cannot offer group educational programs or HCV support groups since they are not part of the COBRA contract. There is a need for additional services and linkages to pick up the pieces the program is unable to offer.

Recommendations for others

“Put HCV on the agenda,” states Rodriguez. Everyone that works with former or current injection drug users or people living with HIV should be providing hepatitis education and services.

HCV INTEGRATION: Works in Progress

"People who are in substance abuse treatment and have HCV but not HIV don't have access to the same level of service."

The Hepatitis C Task Force at Daytop Village

Daytop Village, Inc., of New York is committed to addressing the substance abuse and life problems of adolescents and adults. Positive peer interaction is emphasized in a highly structured familial environment known as a Therapeutic Community. Within this setting, Daytop offers an integrated comprehensive treatment regime, which is multi-disciplinary in nature. Daytop is committed to returning clients to society as productive, responsible and drug-free citizens. Daytop's Medical Division provides comprehensive primary medical care with an emphasis on health promotion and disease prevention. One of the Medical Department's primary areas of focus is the treatment and management of Hepatitis C.

Daytop Village has recognized Hepatitis C (HCV) as a major health threat to its population. In 1992, Daytop added the HCV antibody test to the Hepatitis A and B profile. Testing for HCV was offered to clients after completing one year of residential treatment unless they showed signs or symptoms of infection, and then testing was done on an as needed basis. But the medical staff began to notice an alarmingly high number of HCV positive clients and as a result research was initiated in 1998 to formally determine the prevalence of HCV in Daytop's residential clients. This data collection continues perennially and the prevalence of HCV among clients is approximately 25%. In other words, one quarter of all clients tested have to deal with a potentially life-threatening diagnosis in addition to their substance abuse disorder. As the scope of Hepatitis C among the substance abusing population became apparent it was clear that Daytop had to become more proactive in the treatment and prevention of HCV.

In 2000, Daytop created an official Policy and Procedures Manual for the prevention and management of Hepatitis C. For the first time, Daytop had a protocol for medical, mental health, and nutritional services to follow for those clients infected with HCV. All clients are offered educational sessions upon entering residential treatment on the modes of transmission, the risk factors for acquiring and spreading the HCV infection, the symptoms of the infection, and the natural history of the disease. Routine HCV testing continues, however, the time period for testing changed from one year to six months in treatment. This was done to test a larger number of clients, earlier on in treatment, so that medical staff could work with infected clients and present them with treatment options and monitor their progress while they remain in treatment.

For those clients that test positive, counseling and other mental health services are available. They take place in the form of support groups run by either the HCV coordinator or a staff nurse. Or, if a client requires a more confidential setting, one-on-one sessions are available to help the client cope with the implications of living with HCV. Also, nutritional guidelines are in place to provide nutritional counseling that

promotes liver health and prevents further liver damage. Nutritional counseling includes a dietary assessment and a dietary care plan.

Daytop performs services under an MHRA HIV/HCV co-infection grant. This grant covers HCV screening and medical services to uninsured or underinsured HIV positive clients. Under this grant, a case management technician assists HIV/HCV positive clients with negotiating off-site medical appointments and escorts them to those appointments. Also, Daytop works with HIV/HCV physician consultants who screen, diagnose and treat our co-infected clients. This grant emphasizes a strong educational/preventive component, which focuses on both clients and their families. These efforts include HIV/HCV educational presentations to the Daytop Family Association and the quarterly publication of a HIV/HCV Newsletter. The breadth of HCV related programs and policies are consistently growing.

A driving force behind all of the policymaking and HCV related programs at Daytop is the Hepatitis C Task Force. The Task Force is made up of nursing supervisors, nurses, mental health supervisors, social workers, administrators, facility directors, and research psychologists and is headed by the medical director. The Task Force meets on a quarterly basis to discuss issues relating to HCV and Daytop clients, including advances in the medical field that may have implications for Daytop. Most recently, the Task Force agreed to put into policy an advanced screening, the Qualitative PCR test, for those clients who test positive for the HCV antibody.

The Task Force provides a great forum for Daytop staff to share information, make decisions affecting policy, and make suggestions for future improvements. Another recent program initiated by members of the Task Force was a spiritual retreat for HCV positive clients. The first retreat happened in July and was well received by clients. Finally, data collected by the research psychologists is shared at Task Force meetings and then disseminated to the rest of Daytop staff. An HCV Risk-Behavior Assessment was recently given to clients in order to get a handle on how HCV is being contracted by Daytop clients. This data will be analyzed and shared at a Task Force meeting and may influence how staff handle educational components of HCV counseling within each facility.

The medical department at Daytop continues to re-evaluate “best-practice” methods for preventing, screening and treating Hepatitis C for this population in residential and outpatient drug rehabilitation. Because a vaccine for Hepatitis C may not be available for years to come, an unswerving commitment to diligence in this effort remains a necessity.

HCV INTEGRATION: Works in Progress

"You have to jump through hoops in a New York State prison to be treated for HCV."

CHOICES II at Center for Community Alternatives

The Center for Community Alternatives (CCA) is a private, not-for-profit agency that provides service to adults and juveniles who are incarcerated, recently released, mandated to alternative programs, or otherwise involved in the criminal justice system. CCA is an alternative to incarceration agency that helps connect people with the community in which they live. Through the CHOICES II project, CCA provides case management, one-on-one counseling, HIV risk reduction education, a men's HIV support group, and peer educator training in its Brooklyn office. In addition, the program offers HIV risk reduction education, anonymous HIV counseling and testing services, and discharge planning assistance for inmates who are nearing their parole hearing or release date. The discharge planning staff assist inmates in securing residence, medical care, support services, and employment assistance while planning for their release.

When Ted Weston, CHOICES II-NYC Project Director, talks to people in the program about HCV, for many of them it's the first time they've discussed their risk or current HCV positive status. One of the first questions asked of each participant is, "Do you know your HCV status?" According to Weston, the answer is often no. Getting people tested for HCV and other health related issues is a priority in the program. According to Weston, up to 70% of program participants are infected with HCV. Even among those who know they're infected, care and treatment have largely been left unattended. The New York State Department of Correctional Services (DOCS) estimates that between 4,000 and 6,000 people are infected with HCV in NYS prisons. Of those, currently 130 are being treated. "You have to jump through hoops in a New York State prison to be treated for HCV," states Weston, referring to treatment criteria in the DOCS Hepatitis C Primary Care Practice Guidelines that specify individuals must have at least 15 months left on a sentence and complete a treatment program if current or recent substance abuse is suspected. CHOICES II doesn't have specific funding for HCV education or care. While the program does not have any formalized HCV services, questions about need and care are readily integrated at intake, in case management notes, in on-going psychoeducational groups, and during training programs in prisons. "It's a personal commitment," states Weston. "It has to be done."

Barriers encountered

Housing is always a barrier to success for anyone coming out of prison, says Weston. "When they come out of prison, if they don't have any place to go, they often end up in an SRO. That's when we lose them." Getting people stabilized and connected is the only way HCV can effectively be addressed.

CCA also recognizes a need for on going staff education. Unfortunately, trainings that take place off-site often have waiting lists. Increasing staff education opportunities, both on and off-site, will be important for successful integration of HCV.

Recommendations for others

Weston and CCA staff believe that talking about overall health is key to opening the door to HCV. “Corrections hasn’t opened it up yet,” says Weston, “but you need to do it anyway.”

HCV INTEGRATION: Works in Progress

"Make sure staff know HCV is really of concern. Getting staff buy-in … this is important!"

Viral Hepatitis Testing and Vaccination Program at Riverside Sexually Transmitted Disease Clinic

The Riverside Sexually Transmitted Disease (STD) Clinic is a walk-in clinic run by the New York City Department of Health and Mental Hygiene (NYCDOHMH). The Center offer exams, diagnosis, and treatment for sexually transmitted diseases (STDs), as well as anonymous and confidential HIV counseling and testing, partner notification and investigation, and routine pap smears for women. In May of 2000, the Center began the Hepatitis Project, offering free viral hepatitis testing and vaccination to the community. Services include hepatitis A and B vaccinations to people who are at risk, hepatitis B and C counseling and testing, and referrals for positives. Some people are referred for hepatitis services while at the clinic for HIV or STD services. Others are referred by the staff of community-based organizations (CBOs) that have received fact cards and announcements about the Project. Funding from the Centers for Disease Control helps support this program.

The Riverside STD Clinic receives over 10,000 visits per year. All clients who come to the Clinic are asked to fill out a viral hepatitis risk assessment form (see Resources and Tools: Sample Hepatitis Screening Form). The responses to the form create a starting point for integration of HCV and help guide the practitioner during the visit. "About one third of the 10,000 people we see each year get some type of hepatitis service," states Robin Hennessy, Hepatitis/STD Clinic Coordinator. Services range from education and counseling to testing, vaccination, and referral. According to Hennessy, over 2,400 HCV tests have been performed since the Project's inception and approximately 200 (8%) have come back positive. Of the people who have tested positive, more than 70% are over the age of 40 and have a previous history of injection drug use.

Barriers encountered

The Project has had "varying degrees of success finding out if someone made it to an appointment after being referred," states Hennessy. "Over time, we've developed stronger referral links so that we are sure people have a place to go."

Hennessy would like to increase staff training to enhance the program, but finds it increasingly difficult to free-up staff time. "If someone at the clinic is giving a vaccine to a person who uses injection drugs, they should make sure the patient has been offered HIV and HCV counseling and testing. We need to help the staff think about care more comprehensively."

Recommendations for others

"Make sure staff know HCV is really of concern," says Hennessy. "Getting staff buy-in…..this is important!" In addition, the Project has found little benefit testing people for

hepatitis C who don't have identifiable risk factors, including multiple sexual partners or a history of an STD. The program is considering other ways to better reach high-risk clients, including off-site counseling and testing.

HCV INTEGRATION: Works in Progress

"In an urban population, you have to coordinate all services in a primary care clinic or people won't go."

Coordinated Care for HCV at the Fulton Family Practice Clinic and Bronx Lebanon Hospital

When Dr. Russell Perry came to the Bronx four years ago from Teaneck, New Jersey, he brought with him a keen awareness of the needs of patients seeking health care in an urban community. As a family practice physician with a specialty in HIV care, Dr. Perry began looking for hepatitis C among his patients. Initially, patients tested negative on the EIA screening due to low CD4 counts and renal failure. Dr. Perry began ordering PCR tests and discovered that many of the patients seeking care were co-infected with HCV and HIV. Patients were referred to Gastroenterology for further treatment only to return to the Fulton Family Practice Clinic untreated and frustrated. Some patients didn't go because they had to wait too long for an appointment. Others didn't want to go to another location and some were sent back because the physicians were unaware of how to effectively treat patients with multiple diseases. That's when Dr. Perry began educating himself about the needs of patients with advancing HCV disease and other co-morbidities. As a result, Dr. Perry developed a coordinated HCV care program that includes Family Health, Gastroenterology, Infectious Disease, and Psychiatry. "In an urban population, you have to coordinate all services in a primary care clinic or people won't go," states Dr. Perry. Currently Dr. Perry serves as Director of the Fulton Family Practice Clinic and is an attending physician at three other clinics that are part of the Bronx Lebanon Family Health Center.

With the support of the hospital, Dr. Perry began a series of Primary Care roundtable discussions to increase awareness of the HCV treatment needs of patients. In addition, he developed a written protocol for HCV treatment and care that gives step-by-step guidelines for physicians who may be less familiar with current treatment standards. The roundtable discussions have become a cornerstone of the residency training program Dr. Perry runs. New residents are taught how to care for patients with HCV, as well as the importance of coordinated care. "It's harder to teach established primary care physicians to treat HCV than it is to train new residents. They're the ones who are going to be treating disease in the next 10-20 years," states Dr. Perry.

Currently, Dr. Perry is working with two residents, Dr. Elizabeth Maxwell and Dr. Daniella Rojas, to document the impact of coordinated care. Together, they are investigating the outcome of patients who received care prior to the Center's coordinated approach, and those who have received care since.

Barriers encountered

"Many patients have other major co-morbidities", states Dr. Maxwell. "That's why coordinated care is so important." According to Dr. Maxwell, substance abuse is a primary barrier to treatment for many patients. "We try to encourage patients to enter

rehab programs and work closely with psychiatry. Given all the other health problems they're facing, without rehab, they can't handle treatment."

Lack of funding for treatment has not stopped the clinic from providing care, says Maxwell. "When patients don't have Medicaid, Schering (Pharmaceutical) has made it available to patients."

Recommendations for others

"Keep in touch with patients and their families," says Dr. Maxwell. "They call me all the time…they're part of the treatment process." Most importantly, everyone that treats patients needs to stay up to date on HCV and treatment recommendations.

ABOUT HEPATITIS C

ABOUT HEPATITIS C

Hepatitis C virus (HCV), formerly known as non-A, non-B hepatitis, is an RNA virus that replicates in the liver, producing up to a trillion HCV particles a day. HCV is spread through blood and is the most common blood-borne infection in the United States. Today, HCV is spread primarily through sharing needles and equipment used to inject drugs.

"In the United States, over 4 million people have been infected with HCV and 2.7 million are chronically infected. Between 8,000-10,000 Americans will die this year from HCV-related complications."

PREVALENCE OF HCV

The National Health and Nutrition Examination Study (NHANES III) tested 21,241 blood samples from participants age six years and older. While this is the most comprehensive study to date, most researchers consider data from NHANES III to significantly underestimate the true prevalence of HCV infection in the United States, since the study did not include certain populations with known high prevalence of HCV infection, including individuals who are incarcerated, homeless or institutionalized. The study found:

- **4 million people in the U.S. have been infected with HCV.**
- **2.7 million are chronically infected.**

In addition, NHANES III and other studies have found:

- People aged 40 to 59 years have the highest prevalence of HCV infection.
- Among 40-59 year olds, African American men have the highest infection rate (9.8%).
- Rates among incarcerated people range from 14% in New York to 42% in California.
- A 2002 survey of 597 homeless veterans found a 42% HCV infection rate.
- 8,000-10,000 Americans will die this year from HCV-related complications.
- Number of deaths expected to increase to 30,000 per year by 2015 since many people have been living with HCV for decades.
- New infections are expected to continue at the rate of 30,000 per year.
- Among injection drug users (IDUs), infection rates range from 60-90%, with most new injection users becoming infected within 5 years.
- In New York City, it is estimated that between 200,000-300,000 people have chronic infection.

Of the millions of people infected with HCV:

- ***75-85% will develop persistent (chronic) infection***

Of the 75-85% with chronic infection:

- ***5-20% will develop cirrhosis (extensive scarring of the liver)***
- ***1-3% will develop liver cancer or need a liver transplant***
- ***1% will die as a result of their disease***

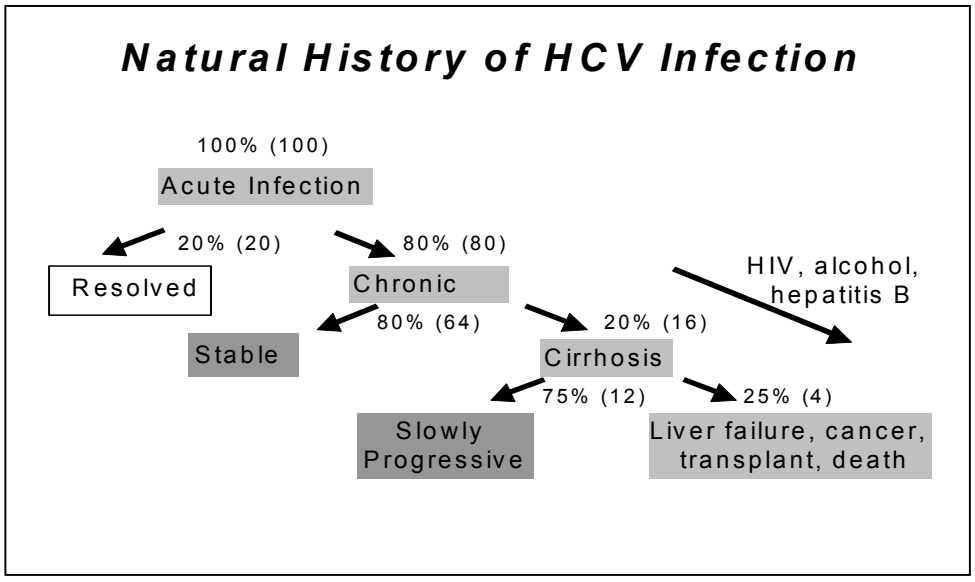
Acute Infection

- HCV can be detected in blood as early as one to two weeks after initial exposure, though the average time before antibodies are detectable is 6-7 weeks.
- After three months, more than 90% of those infected will test positive for antibodies to HCV.
- Most people (75%) do not develop symptoms and, therefore, do not seek testing or medical care.
- Symptoms, if they do occur, can include fatigue, stiff or aching joints, weight loss, or jaundice, among others, and usually subside after several weeks.
- Out of 100 people infected with HCV, approximately 15-25 will spontaneously clear the virus without any treatment. The other 75-85 go on to develop persistent (chronic) infection.

Chronic Infection

- Most people who are infected with HCV will go on to have persistent infection for life (75-85%).
- Most will remain stable over the course of decades and never develop serious liver problems.
- 5-20% of those with chronic HCV infection will develop cirrhosis (severe liver scarring).
- Progression of HCV-related disease is usually slow, taking ten to fifty years before serious liver damage occurs.
- Between 1-3% will develop liver cancer (hepatocellular carcinoma) and/or require a liver transplant.
- An estimated 1% of all people with chronic infection die from HCV disease.
- Factors that may increase the risk of developing liver disease include: older age at time of infection, male sex, HIV, chronic hepatitis B, and high alcohol use.

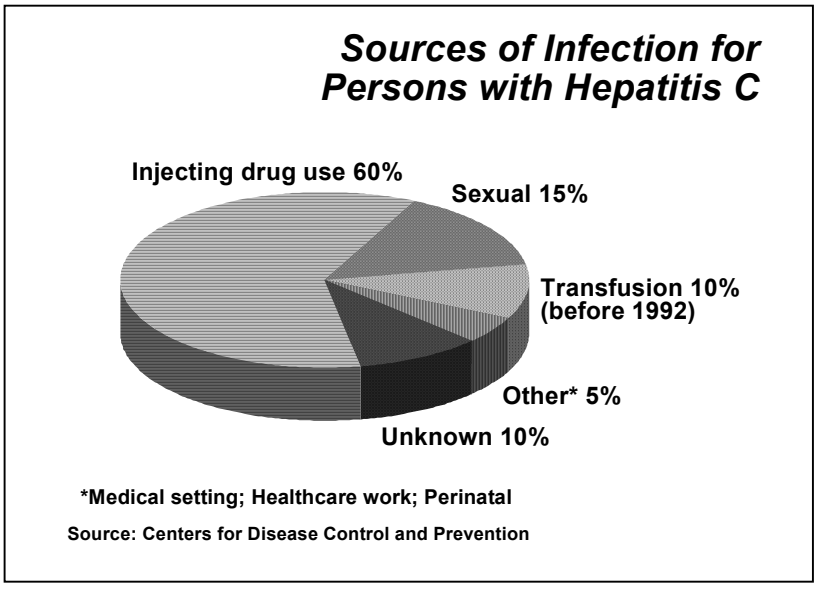
"Factors that may increase the risk of developing liver disease include older age at time of infection, male sex, HIV, chronic hepatitis B, and high alcohol use."



HCV TRANSMISSION AND HARM REDUCTION

Hepatitis C is transmitted through direct blood contact. Any activity that lets one person's blood come into contact with another person's blood can potentially transmit HCV. Transmission can occur by:

- sharing needles, equipment and water used to prepare and inject drugs
- high-risk sex with an infected person
- occupational exposure to infected blood
- tattooing/body piercing with contaminated equipment
- mother-to-infant
- the use of blood products such as clotting factor prior to 1988 or,
- through blood transfusions and tissue transplants prior to 1992.



"Rates of HCV infection among young injecting-drug users are four times higher than rates of HIV infection."

Injection Drug Use

- Injection drug use currently accounts for most HCV transmission in the U.S. and a substantial proportion of HCV infections during the past decades.
- HCV infection is acquired more rapidly after initiation of injecting than HIV.
- After 5 years of injecting, up to 90% of users have become infected with HCV.
- Rates of HCV infection among young injecting-drug users are four times higher than rates of HIV infection.
- High rates of transmission are due to how small HCV is, how quickly it replicates, and, therefore, the high number of viral particles in a drop of blood.
- Many people with chronic HCV became infected 20 to 30 years ago as a result of limited or occasional drug injecting.
- Drug users have shown that they are invested in their own health. When they have access to sterile injection equipment, drug users prefer an unused, sharp syringe to a barbed, clogged and potentially contaminated one.
- Effective strategies talk less in terms of disease prevention and more about healthier injection practices.

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To reduce infection and transmission of HCV, people injecting drugs should be:

- *provided with information about substance abuse treatment options, if desired;*
- *informed about the risks associated with needle and equipment sharing;*
- *given information about syringe exchange programs and participating ESAP (Expanded Syringe Access Program) pharmacies;*
- *taught how to clean their "works";*
- *taught healthy injection practices that normalize common sense approaches to safer injecting (see Safer Injecting in the Handouts section).*

Blood Transfusion/Clotting Factors/Organ Transplant

- Anyone who received a blood transfusion or organ transplant in the U.S. before July, 1992 or used blood products before 1988 is at risk.
- 10% of people infected with HCV report having received a blood transfusion prior to 1992.
- The risk of HCV transmission through transfusions, clotting factors, and transplants has been virtually eliminated due to blood supply screening for HCV.

Sexual Transmission

- About 15% of HCV infections are reported to be sexually transmitted.
- Any sexual activity that involves blood-to-blood contact with an infected person can potentially transmit HCV.
- Most experts believe the risk of sexual transmission of HCV is low.

- Sexual activities that can result in torn tissue and, therefore, blood-to-blood contact, increase the risk of transmission.
- The presence of HIV or any other sexually transmitted diseases (STDs) significantly increases the risk of sexual transmission.
- Traces of virus have been found in semen, saliva, and vaginal secretions in some studies, although there isn't any evidence yet that HCV in these bodily fluids is transmissible.
- There are no known cases of HCV being transmitted through oral sex.
- Long-term monogamous sexual partners of people with chronic HCV infection show a 2-3% infection rate.
- One study indicates that sexual transmission from men to women is more efficient than transmission from women to men.
- Other studies suggest that people who are co-infected with both HCV and HIV or hepatitis B are more likely to transmit HCV.
- More studies are needed to determine the risk for specific sexual activities and transmission of HCV.

"People with multiple sexual partners, high-risk sexual behaviors, or in short-term relationships should practice safer sex, in particular the use of latex condoms or other barriers."

To reduce sexual transmission of HCV:

- *People with multiple sexual partners, high-risk sexual behaviors, or in short-term relationships should practice safer sex.*
- *People with HCV infection or their sexual partners who are in long-term monogamous relationships may choose not to use barrier protection to prevent HCV transmission.*

Perinatal Transmission

- Transmission from mother to baby occurs in less than 5% of births.
- Rates of HCV infection can be as high as 20% if the mother is also HIV positive.
- Mothers in the acute phase of infection or with serious liver damage have a higher risk of transmitting HCV.
- Breast-feeding is considered safe, but cracked and/or bleeding nipples could increase the risk of HCV transmission.
- Children infected with HCV are less likely than infected adults to progress to advanced liver disease throughout their lives.

Healthcare Exposure

- Healthcare workers can be infected through needlesticks or blood splashes, or by using unsterilized medical equipment.
- The risk of HCV infection from a needlestick injury where the source is infected with HCV is estimated to be 2%.

- Transmission from healthcare workers to patients has also been documented, but is rare and is usually associated with improper sterilization of equipment.
- Healthcare workers should use standard precautions to prevent infection with or transmission of HCV.

Tattooing/Body Piercing

- During the past 20 years, fewer than 1% of people with newly acquired HCV gave a history of being tattooed.
- Body piercing and tattooing are potential sources of transmission if contaminated needles or shared ink are used.
- Tattoos in correctional facilities and on the streets are often created using crude and unsterilized instruments such as knives, pens, and paper clips; therefore harm reduction messages should stress the importance of using your own tattoo equipment and ink.
- The Centers for Disease Control and Prevention (CDC) is currently conducting a study to evaluate tattooing as a potential risk.

"Because tattoos in correctional facilities and on the streets are often created using crude and unsterilized instruments such as knives, pens, and paper clips, harm reduction messages should stress the importance of using your own tattoo equipment and ink."

Intranasal Drug Use

- In some studies, HCV infection has been associated with a history of intranasal cocaine use.
- Transmission of HCV could take place through sharing blood-contaminated straws.
- It is unclear whether intranasal drug use is an independent risk factor or, rather, an indication that a person practices both injecting drug use and inhalation of drugs that could get contaminated with blood.

Household Contact

- Sharing items that may be contaminated with blood, such as toothbrushes, razors, or nail clippers, is a potential risk for HCV.
- Blood spills should be cleaned immediately with a 1:10 solution of bleach and water.
- Open sores should be covered to avoid contact with blood.
- There is ***no*** evidence that HCV can be transmitted by kissing, hugging, sneezing, coughing, food, water, sharing eating utensils or drinking glasses, casual contact, or other contact without exposure to blood.

"Confidential testing for HCV should be offered to all people who are at highest risk of infection."

CDC RECOMMENDATIONS FOR HCV TESTING

Confidential testing for HCV should be offered to all people who are at highest risk of infection.

Individuals at highest risk

- People who have ***ever*** injected drugs, even once
- People in receipt of a blood transfusion or blood products before July 1992
- People who received clotting factor concentrates made prior to 1988
- People who are HIV positive
- People who have ever received hemodialysis
- Healthcare workers who received a needlestick injury from a contaminated needle or mucosal exposure to HCV-infected blood.
- Children (over 12 months) born to HCV-infected women

There is less evidence supporting testing of people with the following risks, though testing should be offered at the request of the individual:

Individuals with uncertain risk

- People with a history of tattooing/body piercing in unsanitary conditions
- Long-term sexual partners of HCV positive people
- Sex partners of injection drug users
- People with a history of STDs or multiple sexual partners
- Intranasal and other non-injecting illegal drug users
- Recipients of transplanted tissue

Individuals for whom routine HCV testing is not recommended

- Household (nonsexual) contacts of HCV positive people
- Healthcare, emergency medical, and public safety workers who have ***not*** had a needlestick or been exposed to contaminated blood
- Pregnant women
- The general population

DIAGNOSTIC TESTS FOR HEPATITIS C

HCV Screening

Several different tests are used to screen for HCV infection. The EIA and RIBA are blood tests used to detect antibodies to HCV. The PCR is used to detect the presence of virus.

"A person who was infected but cleared the virus will likely remain antibody positive for the rest of his or her life, but will not have the virus."

EIA (enzyme immunoassay)

- An **antibody test** similar to the HIV antibody test.
- Looks for antibodies that the immune system produces in response to the presence of HCV.
- EIA tests for exposure to HCV (past or present). It does not indicate if someone is chronically infected.
- Positive EIA tests are often followed by a confirmatory RIBA or PCR.
- More than 90% of those infected will test positive for antibodies to HCV three months after infection.

RIBA (recombinant immunoblot assay)

- A more *specific* **antibody test** that looks for and confirms the presence of HCV antibodies.
- Positive results indicate past or present infection with HCV.
- A person who was infected but cleared the virus will likely remain *antibody positive* for the rest of his or her life.

Qualitative PCR (Polymerase Chain Reaction)

- Tests for the presence of *any* hepatitis C virus (HCV RNA) in the blood.
- Does *not* measure *how much* HCV is in the blood.
- Can usually detect virus 1 to 2 weeks after initial exposure.
- Is used as a confirmation of current infection.
- HCV RNA may be detected only intermittently in people with chronic, latent infection; therefore, a single negative PCR does not mean absence of infection.

Most NYC screening sites use the following **HCV Testing Protocol**:

1. EIA
2. If positive, a second EIA is performed
3. RIBA is performed when EIA results are not definitive (rare)
4. If positive, the person is referred to a medical facility for care and PCR testing.

- Most screening sites only perform a confirmatory RIBA if the EIA tests are borderline positive.
- Community HCV screening sites often only perform antibody testing.
- PCR testing is usually only performed at a medical facility where additional follow-up tests are available.
- The EIA is used as an initial screening test because it is inexpensive.
- Health clinics and other medical facilities often go directly to a qualitative PCR following two positive EIA's.

- If someone is EIA+ or RIBA+ on one or more tests, but PCR negative, it is usually recommended that they have a follow-up test six months later to confirm this result.

MONITORING LIVER HEALTH

"Liver enzymes fluctuate during the course of HCV disease and can serve as an indication of possible liver damage but NOT as a definitive marker for liver disease."

Individuals with chronic HCV should be evaluated and monitored for the presence and severity of liver disease. Information about the condition of the liver is important in making treatment decisions.

Liver Function Tests (LFT's) (also called liver biochemical tests):

- Blood tests that measure the level of liver enzymes.
- People with HCV often have elevated liver enzyme levels.
- ALT and AST are two enzymes that are released by the liver and are used to monitor liver health.
- ALT and AST levels fluctuate during the course of HCV disease and can serve as an indication of possible liver damage but NOT as a definitive marker for liver disease.
- People taking medications or drinking alcohol may have higher enzyme levels as the liver works to break down medications and alcohol.
- If the liver is severely damaged, levels may be low because the liver is not producing normal amounts of these enzymes.
- Liver enzymes should be monitored every three to six months.
- If elevated levels continue, a liver biopsy may be recommended.

ALT (alanine aminotransferase): normal range 5-60 IU/L.
AST (aspartate aminotransferase): normal range 5-43 IU/L.
(Note: normal ranges vary from lab to lab.)

Quantitative Hepatitis C PCR (viral load):

- Measures the *amount* of HCV in the blood.
- The level of virus in the blood is useful in determining the likelihood of response to antiviral treatment.
- People with lower HCV viral loads generally respond better to treatment.
- Each quantitative viral load test is different, so it is important to use the same laboratory and the same test whenever viral load is measured.
- Results are generally reported only as low or high.

Low – less than 2 million copies/mL (~800,000 IU/mL)
High – over 2 million copies/mL (~800,000 IU/mL)

- The quantitative PCR is not part of routine care. It is most helpful, and most often used, when a person is considering HCV treatment and/or to monitor the effects of treatment.

Liver biopsy:

- Is an outpatient procedure.
- While the patient is awake, a needle is inserted just below the right ribs, into the liver.
- A small tissue sample is taken and examined by a pathologist.
- The results help the patient and healthcare provider make informed choices about beginning or postponing antiviral treatment.
- Biopsies can be repeated to assess disease progression over time.

Genotype:

- Is the genetic make-up of a particular strain of virus.
- Genotyping is determined by a blood test.
- There are at least six HCV genotypes, numbers 1 through 6.
- Genotype 1 accounts for 70-75% of infections in the United States.
- It is important to determine a person's genotype prior to considering treatment since rates of response to antiviral therapy are substantially lower in people with genotype 1.

"A liver biopsy is the most accurate way to measure the degree of liver damage."

CURRENT TREATMENT

Deciding to start or continue treatment for hepatitis C is complicated – even more complicated than with HIV. Many people with HCV will never need treatment and will experience minimal health consequences as a result of their infection. People with advancing disease, however, must consider the benefits and consequences of beginning a treatment regimen that is not always successful.

Current treatment is a combination of alfa-interferon and ribavirin, taken for six months to one year.

- People with genotype 1 usually undergo treatment for one year, while people with genotypes 2 or 3 typically need treatment for six months.
- Some physicians are treating people with HIV/HCV co-infection for 18 months.

Alfa-Interferon:

- Is a protein that interferes with a virus' ability to infect cells.
- Early versions of alfa-interferon had to be injected subcutaneously (under the skin) three times a week.
- The most recently approved treatment for HCV, pegylated interferon, reduces the frequency of injection to only once a week.

- There are currently two brands of pegylated interferon available: PEG-Intron and Pegasys.

Ribavirin:

- Is an antiviral capsule or tablet taken orally twice a day.
- For reasons that are not well understood, ribavirin makes interferon work better than if the interferon is used alone.
- Ribavirin used alone has no effect on HCV.
- There are currently two brands of ribavirin available: Copegus and Rebetol.
- Generic ribavirin will likely be available in the near future.

The primary goals of HCV treatment are eradication of virus and a healthier liver:

- Liver health (histological improvement) is measured by normalized liver enzymes, lower or undetectable viral load, and possibly a follow-up liver biopsy.
- Treatment success is measured by a sustained virological response, which is an undetectable viral load six months after completing treatment.
- Combination therapy of pegylated interferon and ribavirin achieves a sustained response in approximately 50-60% of people overall.
- People with genotype 1 typically have a sustained response of 42-46% with combination therapy.
- People with genotype 2 or 3 respond more favorably, with 76-82% achieving a sustained response.
- Even without a sustained response or significantly lower viral load, treatment may give the liver a much-needed break and decrease the degree of liver damage.

"Even without a sustained response or significantly lower viral load, treatment may give the liver a much-needed break and decrease the degree of liver damage."

Factors that may influence a successful response to treatment:

Most predictive:

- having genotype 2 or 3
- having a low HCV viral load when starting treatment

Somewhat predictive:

- age under 40
- pre-menopausal female
- little fibrosis (scar tissue)
- no cirrhosis
- low body mass index (BMI)

Sustained response: an undetectable hepatitis C viral load six months after finishing treatment (<50 IU/mL).

- For people with hepatitis C only, combination therapy of pegylated interferon plus ribavirin achieves an overall sustained response rate of 50- 60%.
  - 42-46% of people with genotype 1 get a sustained response with combination therapy.
  - 70-82% of people with genotypes 2 or 3 get a sustained response with combination therapy.
- If hepatitis C viral load doesn't drop at least 2 logs after three months of combination therapy, treatment is often stopped.

Treatment responses in people with HIV/HCV coinfection:

- *Results from studies of people with both HCV and HIV indicate that response rates to interferon plus ribavirin are lower and that the side effects are often worse.*
- In three clinical trials of people with HIV/HCV coinfection (the US study ACTG A5071, the international APRICOT study, and the French RIBAVIC study), the overall sustained response rates for people on pegylated interferon plus ribavirin were between 27% and 40%.
  - 14-29% of those with genotype 1 had a sustained response with combination therapy.
  - 44-73% of people with HCV genotype 2 or 3 had a sustained response with combination therapy.

Treatment Side Effects

The side effects of interferon and ribavirin can be severe. In clinical trials of interferon plus ribavirin, 10-20% of participants dropped out because of side effects or adverse events. Side effects are usually worse during the first few weeks, though each person experiences them very differently. Possible side effects include:

- fatigue
- joint pain
- muscle pain
- fever and/or chills
- nausea
- headaches
- weight loss
- mild hair loss
- low white blood cells and platelets
- rapid heart beat
- irritability
- depression
- suicidal thoughts
- severe anemia
- birth defects

Some people experiencing side effects find relief by:

- Using ibuprofen or acetaminophen to help with flu-like symptoms.
- Getting treated with injections of erythropoetin (Epogen or Procrit) to stimulate the production of more red blood cells to combat anemia.
- Getting treated with injections of Neupogen to stimulate production of white blood cells.
- Starting antidepressants prior to beginning HCV treatment.

- Arranging the timing of interferon shots to allow for rest afterwards (nighttime dosing may allow a person to sleep through some of the side effects).

HCV TREATMENT FOR INJECTION DRUGS USERS

The National Institutes of Health (NIH) Consensus Statement on the Management of Hepatitis C: 2002

In June of 2002, a panel of experts in the field of hepatitis prevention, care, and treatment developed a consensus statement that addressed several key questions:

- What is the natural history of hepatitis C?
- What is the most appropriate approach to diagnose and monitor patients?
- What is the most effective therapy for hepatitis C?
- Which patients with hepatitis C should be treated?
- What recommendations can be made to patients to prevent transmission of hepatitis C?
- What are the most important areas for future research?

While many important recommendations were developed, none have the potential for greater positive impact than the recommendation that active injection drug use in and of itself *not* be used to exclude people from HCV treatment. Prior to this statement, people who injected drugs were often denied access to treatment.

The needs of people who are actively using drugs while receiving treatment are complex but can be addressed with consistent education and support. Alcohol use, however, adversely affects response to treatment, and alcohol abstinence is strongly recommended before and during treatment.

For people with a history of injection drug use, the process of injecting interferon can be difficult while in recovery. Some people prefer to have their healthcare providers inject interferon for them. In addition, interferon side effects can feel similar to drug withdrawal. People with a substance use history need to be prepared for these possibilities and have a support system in place (such as a support group or sponsor) to help them sort through their feelings and impulses.

"The side effects from the interferon injections are similar to those of heroin withdrawal…the fever, the hot/itchy skin, and aching muscles and joints. For me, an attitude of gratitude has helped me immensely. I remind myself that I am taking treatment so I can have a normal life. I go to meetings."

-Ted, hepatitis C-positive person in recovery

SUPPORT DURING TREATMENT

Making the decision to start antiviral therapy is a very personal one.

- Establishing a support network *before* beginning treatment is important. This is true with HCV treatment even more than with HIV treatment.
- The side effects of HCV treatment can be extremely debilitating (especially in the beginning), and some people will need help with everyday tasks such as shopping, food preparation, cleaning, or childcare.
- Psychological support is equally important. The irritability, depression, and suicidal ideation that may accompany treatment often come on slowly, are difficult to identify, and can be unbearable for the person experiencing them.

"All substances, including herbs, can have dangerous side effects and impact the dosing of other drugs."

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Complementary therapies are used together with conventional medicine to treat many illnesses, including HCV and the side effects of treatment. *Alternative* therapies are used instead of conventional medical treatment.

- Complementary and alternative therapies attempt to use the body's natural self-healing abilities to bring the body back into balance.
- These therapies can include acupuncture, massage, yoga, Tai Chi, meditation, and Chinese herbal medicine.
- No complementary or alternative therapies have been scientifically proven to cure or even ease symptoms of HCV.
- All substances, including herbs, can have dangerous side effects and impact the dosing of other drugs.
- Talk with your doctor or pharmacist *before* using any complementary or alternative therapies – including over-the-counter ones.

Herbs and herbal products with the most information, as well as most widely used, include:

- **milk thistle** (**silymarin**)
- **astragalus**
- **dandelion**
- **bupleurum**
- **garlic**
- **licorice root**
- **artichoke**
- **thioctic (alpha-lipoic) acid**
- **gingko biloba**

HCV AND HIV CO-INFECTION

- **In the United States, an estimated 200,000 people are infected with both HCV and HIV.**

- Studies estimate that as many as **25-30% of HIV positive people in the U.S. are co-infected with HCV** and **up to 10% of HCV positive people are HIV infected**.
- In urban areas of the U.S., up to 90% of people who acquired HIV infection from injection drug use also have HCV.
- **In New York, 78% of people with HIV who report injecting drug use are also HCV-infected.**

Both HIV and HCV can be transmitted by blood-to-blood contact, unprotected sex, and from a mother to her infant; however, the efficacy of transmission by these routes varies. **HCV is 10 times more infectious than HIV by direct blood-to-blood contact.** This explains the higher incidence of HCV infection among IDUs. For this reason, and because HCV infection was common in urban areas of the U.S. for decades before HIV was discovered, most HIV/HCV co-infected injection drug users were likely infected with HCV years before HIV.

In addition, studies have found that:

- HIV is more transmissible than HCV between sexual partners.
- HIV is more transmissible than HCV from a mother to her infant.
- There are low rates of transmission to long-term monogamous sexual partners of HCV-infected people.
- Among people engaging in high-risk sexual activity with multiple partners, the rates of HCV transmission are significantly lower than the rates of HIV transmission.
- The risk of sexual transmission of HCV appears to be increased when a person also has HIV.
- The incidence of mother-to-infant HCV transmission increases if the mother is co-infected with HIV, with rates reported as high as 20%.

Effect of HIV on HCV Disease

Most studies indicate that *people with HIV/HCV co-infection experience faster progression to cirrhosis and more liver damage than people who are infected with only hepatitis C.* Faster progression may be less likely if the individual's HIV disease is well under control. A weakened immune system allows HCV to replicate faster, and higher HCV viral load makes a person more infectious. Co-infected people with less than 200 T-cells are at a much higher risk of developing cirrhosis, liver failure, and liver cancer, also called hepatocellular carcinoma (HCC).

Effect of HCV on HIV disease

It is still unclear if HCV accelerates HIV disease but, in most cases, it does not appear to. Studies of people with hemophilia who are co-infected have shown alarming rates of HIV disease progression, but other co-infected populations do not appear to experience this effect. HCV may affect the course of HIV by increasing the incidence of liver toxicity caused by HAART. People with badly damaged livers may have a hard time breaking down HIV medications, especially protease inhibitors and non-nucleosides. This can lead to less antiviral activity, a higher HIV viral load, a lower T-cell count, and, over time,

limited HIV treatment options. As people live longer with HIV, many more HIV deaths are caused by HCV-related end stage liver disease.

Treating co-infected people

- People considering treatment should consult with healthcare providers well versed in HIV and HCV treatment.
- Referrals to specialists (such as a gastroenterologist, hepatologist, and/or infectious disease doctor) are an important part of making informed decisions.
- The treatments for HCV have not been specifically approved by the FDA to treat HCV in HIV-infected people, although they are commonly used in co-infected people.
- Currently, there are no published studies of the most effective way to treat co-infected people.

Most physicians work to get HIV under control first. With reduced HIV-related disease progression as a result of HAART (Highly Active Anti-Retroviral Therapy), the decision of who should be treated for HCV (and when) is often determined by:

- the likelihood of beneficial response to treatment
- the likelihood of adverse reactions to the medications
- the risk of progression of liver disease

While questions about when to start treatment and which treatment to start first are still unresolved, there is important information that should be considered when making treatment decisions:

- Many individuals who are co-infected do not respond as well to HCV therapy as people who are infected only with HCV. Factors affecting a person's response to HCV therapy include age, HIV viral load, CD4 count, HCV viral load, HCV genotype, condition of the liver, and alcohol intake.

- Protease inhibitors and non-nucleosides are processed through the liver. People beginning HIV anti-viral treatment often experience an increase in HCV viral load and liver enzymes. In most cases, this flare-up will go away relatively quickly. Regular bloodwork is particularly important during the first couple of months after starting any antiviral treatment.

- Ribavirin and Retrovir (AZT) can both cause severe anemia in many people, therefore it may be best to avoid using both drugs at the same time. Combivir and Trizivir also include AZT and should likewise be avoided in combination with ribavirin.

- Nucleoside analogues can damage mitochondria, which produce energy for cells. Ribavirin is a nucleoside analogue as are AZT, d4T (Zerit), ddI (Videx), ddC (Hivid), 3TC (Epivir) and abacavir (Ziagen). Mitochondrial toxicity may be more likely in people taking ribavirin in addition to other nucleoside analogues.

- If ribavirin and ddI (Videx) are used together, particular caution is in order! People taking both drugs have a five times greater likelihood of developing mitochondrial toxicity than people taking ribavirin with other nucleoside analogues.

- Viramune (nevirapine) has been associated with an increased risk of liver damage in people with hepatitis C, although not all co-infected people will experience liver problems from this drug. Signs of liver problems usually begin within three months after initiation of use.

- Regular liver function tests are important to monitor the impact of treatment, especially the first 2-3 months after starting a new drug therapy.

- Interferon has been associated with increased irritability, insomnia, and suicidal ideation. Because depression before and while on treatment is common, co-infected people who are considering therapy that includes interferon are strongly encouraged to have a support network in place which includes a mental health professional and /or support group.

- High doses of interferon can lower T-cells (CD4s), at least temporarily, although the CD4 percentage is not usually affected. Although interferon can benefit people's immune response to hepatitis C, it may be harmful to the immune response of some people with HIV.

All people co-infected with HIV and HCV should be:

- Seen by physicians knowledgeable about both HIV and HCV
- Provided with information to maintain liver health
- Counseled about the impact of alcohol on the progression of liver disease
- Counseled on ways to reduce the transmission of HIV and HCV
- Vaccinated against hepatitis A and hepatitis B, if not previously exposed
- Evaluated for chronic liver disease, including HCV viral load, genotype, LFT's and perhaps a biopsy
- Considered for HIV and/or HCV antiviral treatment as needed
- Counseled about drug interactions and side effects of HCV and HIV treatments

FREQUENTLY ASKED QUESTIONS

Hepatitis C Integration
Staff's Frequently Asked Questions

Are HCV prevention messages different than HIV prevention messages?

No, not really. HCV and HIV are both blood-borne viruses that are transmitted largely through injection drug use and unprotected sex. However, HCV is 10 times easier to transmit through blood-to-blood contact than HIV is. In addition, sexual transmission of HCV is rare, the result of blood or open sore contact during sex. For these reasons, HCV prevention messages stress avoiding all contact with blood and the importance of good hygiene (hand washing, covering sores etc.).

Can HCV be spread by sexual activity?

Yes, but it is not the most efficient route. HCV is transmitted primarily through blood. People with multiple sexual partners and those with STDs should practice safer sex to prevent transmission of HCV, as well as other STDs. Currently, there is no evidence that HCV is spread through oral sex.

What should I tell HCV+ people who are in a monogamous relationship?

HCV+ people with one long-term steady sex partner do not need to change their sexual practices. They should, however, discuss the risk of transmission (which is low but not absent) with their partner. If they want to lower the chance of transmitting HCV, they can use barrier protection (e.g., latex condoms, gloves, and/or latex dams) and discuss HCV testing and counseling with their partner.

What is the risk that an HCV infected woman will transmit the virus to her newborn?

Less than 5 out of every 100 infants born to HCV positive women become infected. This occurs at the time of birth, and there is no treatment that can prevent this from happening. Most infants infected with HCV at birth have no symptoms and do well during childhood. It is unknown if children will have problems from the infection as they grow older. There are no approved treatments or guidelines for the treatment of infants or children infected with HCV.

Can an HCV infected woman breastfeed her infant?

Yes. There is no evidence that breastfeeding spreads HCV. Women with cracked or bleeding nipples should consider abstaining from breastfeeding until they heal. If the woman is co-infected with HIV, she should not breastfeed.

Why do most people remain infected after exposure?

When HCV reproduces, it makes a large number of copies that differ slightly from each other in their genetic makeup. Scientists believe that this genetic diversity allows HCV to evade the body's immune system. This may be the reason why such a high percentage

of people infected with HCV (75-85%) develop chronic infection. This genetic diversity is also the likely reason why an effective HCV vaccine has not yet been developed.

Why should I recommend testing if the person can't afford the treatment?

There are many ways that patients can gain access to treatment. Even if the person doesn't qualify for Medicaid or another benefits program, the companies that make the treatments have patient assistance programs that provide free drug to people who qualify. The phone numbers to call for these programs are (800) 521-7157 for PEG-Intron and ribavirin or (800) 387-1258 for Pegasys and ribavirin.

It's also important to remember that treatment is not necessary for many people who have hepatitis C. If a client knows that they have HCV, they can be counseled about preventing transmission of the virus to others as well as being provided with tips to help keep their liver healthy.

If someone isn't a good candidate for HCV treatment, is there anything else available to help?

Yes. There are many things that someone can do to keep their liver as healthy as possible. There are a number of alternative therapies such as herbs that people use to try to strengthen the body's ability to fight infection. Although none of them have been scientifically proven to cure or even ease symptoms of HCV, many people find comfort in using them. Be sure to talk to your doctor before starting any medications, including herbal medicines – some can be harmful to the liver! Other ways to keep your liver healthy include:

- Seeing their healthcare provider on a regular basis
- Getting vaccinated for hepatitis A and B, if not previously exposed
- *A*bstaining from drinking or reducing alcohol consumption.
- Drinking plenty of water and eating well
- Getting plenty of rest.

See "Keeping Your Liver Healthy If You Have Hepatitis C" in the Handouts section of this document.

Hepatitis C Integration
Clients' Frequently Asked Questions

What does hepatitis mean?

Hepatitis is a general term that means inflammation of the liver. "Hepar" means liver and "itis" means inflammation (as in arthr*itis*, pancreat*itis*, and dermat*itis*). Viruses, bacteria, drugs, toxins, excessive alcohol intake, or autoimmunity (your immune system attacking your own body) can cause inflammation of the liver.

Is it possible that at one point I had hepatitis, but now I don't?

At some point in their lives, many people have been told by a healthcare provider that they have hepatitis. Maybe your bloodwork showed that you had antibodies to hepatitis A or B, meaning that you had been exposed to one or both of those viruses. It's important to find out what kind of hepatitis the provider meant so that you're not making guesses about your health.

What is hepatitis C?

Hepatitis C is a virus (a type of germ) that causes liver disease. The hepatitis C virus is found in the blood and liver of people with hepatitis C infection.

How is hepatitis C spread?

The hepatitis C virus is spread primarily through blood. It can be spread whenever blood (or fluids containing blood) comes in contact with an opening in the skin or other tissues. This can occur even when these openings cannot be seen. Hepatitis C virus can also be transmitted by sexual contact, but this does not happen as easily as with HIV, the virus that causes AIDS.

The hepatitis C virus is *not* spread by casual contact like hugging, sneezing, coughing, or sharing food and drinks. You cannot get hepatitis C by donating blood.

What about other kinds of hepatitis?

There are several different kinds of hepatitis viruses. Each hepatitis virus is very different from the others. If you have had one type, you can still get any of the others. The hepatitis A virus is spread by feces (even a small or not visible amount), through close personal contact, or contaminated food and water. The hepatitis B virus is spread through blood and body fluids, like semen. Once you have had either hepatitis A or hepatitis B, your body will develop protective antibodies to keep you from getting infected with that particular virus again. There are also vaccines for hepatitis A and hepatitis B, which can protect you from either hepatitis. If you have hepatitis C, talk to your doctor about getting vaccinated for hepatitis A and B (if you haven't had either before). Blood tests can be done to see if you have been exposed to the different hepatitis viruses.

If you get hepatitis A, does it turn into hepatitis B and then hepatitis C?

No. Hepatitis A, B, and C are very different germs. One doesn't evolve into another. Each one is transmitted differently, and the body reacts to each one differently. The only thing they have in common is that they're all viruses and they all affect the liver.

Who is at risk for getting hepatitis C?

People are at risk for getting hepatitis C infection if they:

- Have ***ever*** shared needles or any works, even once;
- Have had a blood transfusion, received blood products, or had an organ transplant before July 1992;
- Have ever been on kidney dialysis;
- Have had unprotected sex with many partners; or
- Were born to mothers with hepatitis C.

What's so important about the liver?

The liver is the largest organ in the body and plays an important role in hundreds of necessary body functions. It serves as the body's filter and warehouse, filtering our blood and other substances to be used or excreted by the body, and holding onto substances like vitamins, minerals, sugar and fat that the body needs later. The liver is responsible for breaking down food, chemicals, and medications. It even regulates blood clotting. We can't live without our liver, and the healthier it is, the healthier we are overall.

How serious is hepatitis C?

Hepatitis C infection is very serious for some people, but not for others. Some people (15-25%) who have hepatitis C will clear the virus from their body within a few months without treatment. Most people who become infected will carry the virus for the rest of their lives. Some will feel healthy for many years after being diagnosed with hepatitis C infection. A smaller number will develop liver damage and possibly cirrhosis (scarring of the liver) and/or liver cancer. While most people will not develop liver failure or cancer with hepatitis C, how you take care of your liver plays an important role in how slowly or quickly hepatitis C progresses.

What are the symptoms of hepatitis C?

Most people with hepatitis C do not have noticeable symptoms. Even if you feel fine, the virus could be damaging your liver and you could be spreading the virus to others. If you're one of the few people who have symptoms when they're first infected, symptoms could include feeling like you have a slight flu, pale feces, dark urine, and possibly jaundice.

How can I find out if I have hepatitis C?

A simple blood test called the EIA or RIBA can determine if you have been exposed to HCV. Your healthcare provider or local clinic can test your blood for HCV. Consider getting tested if you have put yourself at risk for infection.

How can hepatitis C be prevented?

There is no vaccine for hepatitis C. The best way to keep from getting the hepatitis C virus is to avoid any contact with other people's blood. This includes not sharing needles and "works", razors, toothbrushes, or other household items that may be contaminated with blood. Blood banks now screen donated blood for hepatitis C virus, so your risk of getting infected from a blood transfusion is extremely low. You can also get hepatitis C from sex with an infected partner, though it is uncommon.

To prevent the spread of hepatitis C:

- If you shoot drugs, never share works with anyone.
- Use a latex condom every time you have sex.
- Only get tattoos or body piercings from places using sterile equipment.
- Healthcare workers and people who clean up in hospitals or places where needles or sharps are used should follow standard (universal) precautions for every patient.
- If you have hepatitis C, don't share razors, toothbrushes, nail clippers, etc.
- If you have hepatitis C, don't donate blood, sperm, or organs.

Can I have normal liver enzyme levels and still have liver damage?

Yes. Some people with chronic hepatitis C have liver enzyme levels that are in the normal or even below normal range but still have liver damage. Similarly, some people have consistently high enzyme levels but don't have serious liver damage. Enzyme levels that continue to rise over time or go up suddenly are an indication that something is going on. It's important to have your levels checked regularly (every three to six months), but the results don't give a complete picture of the degree of liver damage or how much damage might occur in the future.

Is there a treatment for hepatitis C?

Two drugs, interferon and ribavirin, may be used in combination to treat hepatitis C infection. Treatment does not work for everyone and often has severe side effects. Ask your doctor about treatment options and steps you can take to protect your liver.

How long does treatment last?

The length of treatment is usually between 6 and 12 months. People co-infected with both HIV and HCV may need treatment for as long as 18 months.

Isn't the treatment worse than the disease?

It's true that the side effects of combination therapy (interferon and ribavirin) can be difficult, and sometimes impossible, to tolerate. What's right for one person isn't necessarily right for someone else. If treatment is indicated, many people would choose 6 to 12 months of difficult side effects over the possibility of worsening liver disease and, possibly, death. It's also important to realize that 40-50% of people who complete the treatment clear the virus, meaning that they no longer have HCV. As with all medical

decisions, it's helpful to have as much information as possible so that you can weigh the potential risks and benefits.

Before beginning treatment, discuss all of the possible side effects with your healthcare provider so that you have a realistic picture of what to expect. It's also important to have a support system in place before starting treatment – people you can count on to help you cope with the possible physical and psychological side effects.

Can I get hepatitis C more than once?

Yes. Even if you're one of the lucky people who clears the virus after infection or through HCV treatment, you could be reinfected with HCV if you put yourself at risk. Unlike the antibodies to hepatitis A and hepatitis B, HCV antibodies do not protect you from future infection.

How much alcohol can I drink if I have hepatitis C?

Alcohol is very difficult for the liver to break down. Even without hepatitis C, excessive alcohol use over an extended period of time is one of the most common reasons for liver disease. If you have chronic hepatitis C, alcohol can make the disease progress much more quickly and can lead to further liver damage. There is strong evidence that 30g/day of alcohol in men (2 beers, 2 glasses of wine, or 2 mixed drinks) and 20g/day in women greatly speeds up the progression of liver disease. Giving up alcohol or at least cutting down on alcohol intake is an important step to reduce the risk of serious liver damage.

How does HIV impact hepatitis C?

Having HIV lessens your body's ability to fight hepatitis C. HIV can also speed up the rate of liver damage caused by hepatitis C. Although both illnesses are serious, they can be treated. It's important to find a healthcare provider who is knowledgeable about both HIV and hepatitis C to ensure that you receive the best care possible.

How does hepatitis C impact HIV?

It's still unclear if hepatitis C speeds up HIV disease but, in most cases, it doesn't seem to. Hepatitis C may affect the course of HIV by increasing the incidence of liver toxicity caused by some anti-HIV medications. Also, people with badly damaged livers as a result of hepatitis C may have a hard time breaking down some anti-HIV medications.

Can I become pregnant if I have hepatitis C?

Hepatitis C is passed to an infant during the birthing process in less than 6% of cases. There are no recommendations against women with hepatitis C becoming pregnant or breastfeeding. You or your partner should not become pregnant while being treated for hepatitis C with ribavirin since it may cause severe birth defects.

If I see a specialist, will they make me have a liver biopsy?

No. As with any medical procedure, it is your right to refuse a liver biopsy. Since a liver biopsy is the most accurate way to measure the degree of liver damage, some liver specialists won't treat someone with HCV without performing a biopsy first. Other specialists don't require a biopsy. It's important to remember that different people respond differently to a biopsy – some find it painful, while most are surprised at how little pain they experience. The risk of complications from the procedure is very small. Many people describe the procedure as boring because they have to remain stationary for hours afterwards. Although it is your right to refuse the procedure, be sure that your decision is based on information rather than fear.

RESOURCES & TOOLS

The following *Resources and Tools* can be useful in the development, implementation, and enhancement of HCV services. The *Resources* include a glossary of terms, immunization and HCV testing sites, HCV clinics, support groups, training opportunities, materials, and websites for both clients and providers. As with all resources, information changes quickly. All resources, locations and phone numbers should be confirmed prior to being given to clients. The *Tools* include sample forms and materials developed by other organizations to help integrate HCV information and care.

GLOSSARY OF TERMS

Acute: Sudden onset of illness. Is of short duration and can be severe (not chronic).

AIDS: Acquired Immune Deficiency Syndrome – the later stage of the illness caused by infection with the Human Immunodeficiency Virus (HIV), which attacks the body's immune system.

ALT: Alanine aminotransferase (ALT) is an enzyme released from liver cells. Persistent elevation of the ALT in the blood may indicate the liver is inflamed or damaged.

AST: Aspartate aminotransferase (AST) is an enzyme released from liver cells. Like ALT, persistent elevation may indicate liver inflammation or damage.

Antibodies: Immune system proteins created in response to an invading pathogen (germ). Antibodies have biochemical coding designed specifically to match (and combat) the invading pathogen.

Blood-borne virus: A virus that is spread primarily by contact with blood.

Chronic: A disease of long duration or frequent recurrences (not acute).

Cirrhosis: The development of severe scar tissue in the liver that results in loss of liver function.

Co-infection: Infection with two or more different diseases at the same time.

Combination therapy: Treatment with more than one drug. HCV combination therapy includes interferon and ribavirin.

EIA: Enzyme immunoassay – this antibody test is the most widely used test to diagnose HCV infection.

ESAP: Expanded Syringe Access Program – New York state program that allows pharmacies to sell syringes to individuals without a prescription.

Fecal/oral route: Transmission of disease by ingesting feces (stool) or food or water that is contaminated with feces.

Fibrosis: Scar tissue in the liver.

Genotype: Genetic information that is unique to an organism. There are six different genotypes of HCV. Genotype 1 is most common in the United States.

HAART: Highly Active Anti-Retroviral Therapy – anti-HIV treatment that uses a combination of drugs to reduce HIV viral load to low or undetectable levels.

Hemodialysis: Also known as kidney dialysis, is a mechanical process that removes the blood from the body, eliminates toxins, and returns it back into the body.

Hepatitis: Inflammation of the liver due to infection or toxins.

Hepatitis A (HAV): Hepatitis A Virus – transmitted primarily by fecal-oral route.

Hepatitis B (HBV): Hepatitis B Virus – transmitted primarily through sexual or blood-to-blood contact.

Hepatitis C (HCV): Hepatitis C Virus – transmitted primarily through blood-to-blood contact.

Hepatitis D (HDV): Hepatitis D Virus – transmitted primarily through blood-to-blood contact; must have HBV to get HDV.

Hepatitis E (HEV): Hepatitis E Virus – transmitted primarily by fecal-oral route. Relatively uncommon in the United States.

HIV: Human Immunodeficiency Virus – transmitted primarily through sexual or blood-to-blood contact, HIV is the virus that causes AIDS by attacking the body's immune system.

IDUs: Injection drug users – people who inject drugs into a vein, muscle, or under the skin.

Incubation: Time between exposure and the development of symptoms.

Interferon: A protein that helps the body fight infections. It occurs naturally in the body and a synthetic version is used as a medication to treat HCV.

Jaundice: Yellowing of skin or whites of the eyes due to high bilirubin levels in the blood, a possible sign of liver damage.

Liver biopsy: Microscopic examination of tissue removed from the liver with a needle to look for the presence of inflammation and liver damage.

Liver function tests: Blood tests to measure the level of liver enzymes (ALT/AST). Sometimes called liver biochemical tests

Liver transplant: The removal of a severely damaged liver and replacement with either the liver from a person who recently died or a part of a living donor's liver.

Monotherapy: Treatment with only one medication.

Non-A non-B Hepatitis: The old term for hepatitis that was not caused by the A or B viruses. In 1987, it was shown to be what is now called hepatitis C.

PCR (polymerase chain reaction): A test that detects HCV in the blood . A positive test confirms HCV infection.

Percutaneous: Through the skin.

Prophylaxis: Preventive.

Qualitative PCR: A test for the presence of *any* hepatitis C virus in the blood. The qualitative PCR can usually detect virus one to two weeks after initial exposure. A positive test confirms HCV infection.

Quantitative PCR: measures the *amount* of HCV in the blood (viral load).

RIBA: Recombinant immunoblot assay – is a more *specific* antibody test that looks for and confirms the presence of HCV antibodies.

Ribavirin: An antiviral medication that is not effective by itself, but, when combined with interferon, improves the effectiveness of interferon at fighting HCV.

Seroconversion: The point at which antibodies may be detected by antibody tests.

Superinfection: Infection with a second virus. People with established HBV infection who contract HDV have *superinfection*; superinfection is usually more severe than co-infection.

Sustained response: The absence of virus in the blood at least six months after HCV treatment has stopped.

Symptom: A noticeable change in the body or its functions, indicating possible disease process.

Vaccine: A synthetic fragment of an infectious agent that stimulates the body's immune system to resist disease caused by the actual germ.

Viral load: A blood test that measures the amount of HCV in the blood (quantitative PCR). Numbers for HCV viral load are significantly higher than HIV viral load values.

HEPATITIS RESOURCES

FREE HEPATITIS C COUNSELING, TESTING AND REFERRAL
FREE HEPATITIS A AND B VACCINATION
New York City Department of Health and Mental Hygiene

Testing and vaccinations available on a first-come, first-served basis

Riverside STD Clinic — Monday - Friday starting at 8:30 a.m.
160 W. 100th Street, 1st Floor
Manhattan
(212) 865-1951

Morrisania STD Clinic — Monday - Friday starting at 8:30 a.m.
1309 Fulton Avenue, 2nd Floor
Bronx
(718) 901-6564

Crown Heights STD Clinic — Monday - Friday starting at 8:30 a.m.
1218 Prospect Place
Brooklyn
(718) 735-0580

Jamaica STD Clinic ***(Hepatitis C Testing Only)*** — Monday - Friday starting at 8:30 a.m.
90-37 Parsons Blvd., 1st Floor
Queens
(718) 262-5572
Beginning Spring 2004

Bulk quantities of a simple fact card that lists these free clinics and provides basic information on hepatitis A, B and C can be ordered by contacting John Thacker at (212) 427-5120.

WORKSHOPS AND TRAININGS

ACRIA (AIDS Community Research Initiative of America)
Workshops for clients & trainings for staff in English and Spanish (free).
www.acria.org
(212) 924-3934 ext. 129

AIDS Institute Regional Training Centers
www.upstate.edu/cei/training.shtml
(518) 474-9866

Harm Reduction Training Institute
Workshops for staff only, will travel off-site (for a fee).
www.harmreduction.org/hrti/index.html
(212) 213-6376

HIV Training Institute (HTI)
New York City Department of Health and Mental Hygiene
40 Worth Street, Rm. 1602
Hepatitis C and a wide range of HIV-related trainings for service providers (free)
For a course catalogue and application, call: (212) 341-9810 or e-mail:
losborne@health.nyc.gov

NATAP (National AIDS Treatment Advocacy Project)
Workshops and forums for clients & trainings for staff in English and Spanish (free).
www.natap.org
(212) 219-0106

New York City Department of Health and Mental Hygiene
Karen Schlanger – Director, Hepatitis C Program (212) 227-6021
Email: kschlang@health.nyc.gov
Workshops in English, will travel off-site (free).

FREE BROCHURES, EDUCATIONAL MATERIALS, TREATMENT INFORMATION

ACRIA (AIDS Community Research Initiative of America)
www.acria.org
(212) 924-3934 ext. 129
Free brochures, educational materials, and treatment newsletter.

AIDS Treatment Data Network
www.atdn.org/hcv.html
(212) 260-8868 ext. 12
Simple fact sheets on Hepatitis C, HIV/HCV Co-infection and Liver Function Tests.

American Liver Foundation
www.liverfoundation.org
(800) 465-4837
Newsletter ($25/yr) and brochure on Hepatitis C (free).

Centers for Disease Control and Prevention
www.cdc.gov/ncidod/diseases/hepatitis/resource/materials.htm
Hepatitis C fact sheets, frequently asked questions, brochures, posters, slides and on-line training, as well as information on prevention and guidelines for treatment.

Harm Reduction Coalition
www.harmreduction.org/pamphlets/brochure_exchange.html
(212) 213-6376
Simple fact sheets, a curriculum on Hepatitis C, and a brochure on liver health.

Hepatitis C Support Project (HCV Advocate)
www.hcvadvocate.org
Fact sheets, listing of national HCV events and support groups, and a newsletter.

HIVandHepatitis.com
www.HIVandhepatitis.com
Regularly updated website which features cutting-edge information on Hepatitis A, B, and C as well as HIV, including reports from recent conferences.

Immunization Action Coalition
www.immunize.org
One-page fact sheet on vaccinations for people living with Hepatitis C.
and
www.hepprograms.org
Links to many hepatitis service organizations, including prevention-based programs.

NATAP (National AIDS Treatment Advocacy Project)
www.natap.org
(212) 219-0106
Co-infection booklet and e-mail update subscription (free).

National Institutes of Health
http://consensus.nih.gov/cons/116/116cdc_intro.htm
Consensus Development Conference Statement, *Management of Hepatitis C: 2002.*

New York City Department of Health and Mental Hygiene
Karen Schlanger – Director, Hepatitis C Program (212) 227-6021
Email: kschlang@health.nyc.gov
Free “Living with Hepatitis C” educational video (in English and Spanish)

New York State AIDS Institute
Literature available. Email hivpubs@health.state.ny.us to request an order form**.**

Veterans Affairs – National Hepatitis C Program
www.va.gov/hepatitisc
Information on Hepatitis C is available on-line through the Education link, in the Hepatitis C section.

SUPPORT GROUPS

American Liver Foundation (ALF)
www.liverfoundation.org
(212) 943-1059 ext. 12
Provides referrals for ALF- and non-ALF-affiliated hepatitis support groups.

H.E.L.P.P. (Hepatitis Education Liver Disease Awareness Patient Support Program)
Teresa Abreu (718) 352-7772
General liver disease support group. Meets every 3rd Sunday of the month at New York Hospital of Queens. Does not meet during summer months.

Latino Organization for Liver Awareness
www.lola-national.org
(718) 892-8697
Bilingual support group in Spanish and English.

NATAP (National AIDS Treatment Advocacy Project)
www.natap.org
(212) 219-0106
Support group for Hepatitis C/HIV co-infected individuals.

St. Vincent's Hospital
(212) 535-1850
Support group for people affected by or infected with Hepatitis C.

Hepatitis C Clinics in New York City Public Hospitals (HHC)

NOTE: All listed clinics will accept patients regardless of insurance status. Other public hospitals may also have clinics for patients with hepatitis C.

Location:	Clinic Details:
Bellevue Hospital Center Virology Clinic 2-South 35 462 First Ave. (at 27th St.) New York, New York 10016 General Information number: (212) 562-4038	Mon. – Fri, 9am – 5pm
East New York Diagnostic & Treatment Center 2094 Pitkin Avenue Brooklyn, NY 11207 General Information number: (718) 240-0400	Tuesdays & Thursdays, 5pm – 8pm
Elmhurst Hospital Center 79-01 Broadway Elmhurst, NY 11373 Clinic Information: (718) 334-3969	Thursdays, 1pm – 4pm Go to walk-in diagnostic (8am-8pm) Call for appointment
Harlem Hospital Center 506 Lenox Avenue New York, NY 10037 General Information number: (212) 939-1000	Every Thursday morning Call (212) 939-2910 to make an appointment
Kings County Hospital Center 470 Clarkson Avenue Brooklyn, NY 11203 General Information: (718) 270-1112	Call for appointment
Metropolitan Hospital Center 1901 First Avenue New York, NY 10029 General Information number: (212) 423-6262	Friday afternoons at 1pm Call (212) 423-6881 for info Need a doctor's referral Call (212) 423-6144 for referral appt.

SAMPLE HEPATITIS C TRAINING SERIES

It can be difficult for staff of any organization to find the time to attend training programs that will allow them to incorporate hepatitis C issues into their work. Sometimes, it's helpful to schedule a series of short, weekly or biweekly trainings instead of all day workshops. When each training lasts an hour or an hour and a half, staff have the opportunity to digest the information presented, review it at the next training, and develop strong HCV counseling skills.

The following sample agenda is for a six-week training series. Due to staff turnover and the need to reinforce and update complex information, it may be useful to repeat the series every six months.

Six-Part Hepatitis C Training

Training #1
Elicit practical questions participants would like addressed by the end of the series
Role of the Liver
Meaning of "Hepatitis"
Brief Overview of Hepatitis A, Hepatitis B & Hepatitis C
HCV Prevalence Statistics
HCV Transmission & Risk Reduction

Training #2
Review content of Training #1
Diagnosing HCV (Antibody Testing & Qualitative PCR)
HCV Symptoms
Progression of Untreated HCV (Prognosis, including HCV/HIV Coinfection)
Monitoring Liver Health (Liver Function Tests, Viral Load, Genotype, Biopsy)

Training #3
Review content of Training #2
Current HCV Treatment
Treatment Side Effects
Side Effect Management

Training #4
Review content of Training #3
HCV and HIV Co-Infection

Training #5
Review content of Training #4
Keeping the Liver Healthy
Counseling Messages

Training #6
Review content of Training #5
Participant Teach-Back
Post-Test & Evaluation

Tips for Starting a Hepatitis C Support Group

Sponsoring or facilitating the creation of a support group requires little additional staff or financial resources, yet has the potential to be an extremely productive integration of HCV services into current programming. Successful support groups tend to take on lives of their own. People at risk for, living with, and providing support to people with hepatitis C have varied needs, some of which might be met in a support group setting. Support groups can be vehicles by which people share information, engage in mutual problem solving, and support one another through a shared experience. Clients or organization staff may initiate a support group, but no matter who starts the ball rolling, agency commitment is essential to the success of the group.

The following are some tips on starting and maintaining a Hepatitis C (HCV) Support Group.

Membership
Establish whose needs the group is intended to serve and who – if anyone – will be excluded from the group. Will the group include only those living with hepatitis C, or could it include individuals living with other types of hepatitis or liver conditions? Would individuals at risk for hepatitis C or those providing support to people with hepatitis C be invited to attend meetings? Will the group include those co-infected with other conditions such as HIV? These questions are essential to decide as a group and re-evaluate as the members of the group change over time. If group membership is left undecided or ambiguous, it can lead to confusion and resentment.

It may be necessary to establish a few support groups – one for people with HCV, one for people undergoing HCV treatment, one for people at risk for HCV, and so on. *A word of caution!* Be careful not to take on too much at once. Begin one group and then, as time goes on, create new ones for people with other needs.

Goals & Format
The next important step is to decide the goals of the group. Is the primary goal of the group to provide emotional support, a safe space in which to discuss the physical and emotional toll of living with HCV (stigma, disclosure issues, coping with fatigue, etc.)? Or is the group's primary goal to provide HCV education to its members, inviting guest speakers such as healthcare providers, social workers, and other community members to address the group on pre-determined topics?

These goals aren't mutually exclusive. Many successful groups incorporate some combination of both. Participants can decide which sessions, or portions of sessions, will focus on emotional support and which will offer education. For example, some support groups begin with 20 to 40 minutes during which members share emotional issues. A presentation by a speaker or panel on a specific topic follows. This format allows members to safely discuss pressing issues with the group before trying to concentrate on the information presented.

Some groups alternate between the two types of meetings – one session devoted to social/emotional support, and the next focusing on HCV health education. Any arrangement can work, if it is one that the group mutually agrees upon.

Mission Statement
Once the membership, goals, and basic format of the group are decided, it can be helpful to develop a simple mission statement. This statement is designed to briefly state the purpose of the group: *What are the goals of the group? What does everyone want to get out of the group?* An example might be:

> *"This neighborhood hepatitis C support group provides a forum in our community for HCV-positive women to receive educational and social support. Education will encourage informed decision-making and include discussions of liver function tests, HCV viral load, biopsy, HCV treatment, and other medical issues. Social support will include discussion of emotional issues that arise from living with HCV."*

Logistics
Several logistical details need to be decided and arranged before a support group can hope to be successfully launched. This is where agency staff can be particularly helpful, facilitating communication between clients and staff, finding and reserving meeting space, figuring out how to provide refreshments for group meetings, photocopying materials, and generally being the liaison between the needs of the group members and the resources of the agency.

How often?
How often does the group want to meet?
- Once a week?
- Every other week?
- Once a month?

As with many aspects of creating a support group, this decision is subject to change depending on how things go and the needs of the group members over time. To start off, though, try to keep to the schedule so that potential group members can count on a meeting when they expect it.

When?
On what day of the week and at what time does the group want to meet?
Select a time that will accommodate the schedules of most people interested in the group (i.e. evenings if many people work during the day or daytime if most people already come by the agency during the day).

Where?
Where will the meetings take place?
If an organization or agency is helping to get the support group started, it might be best to find a meeting location on-site. If your organization doesn't have any available space or the available space is particularly uncomfortable or unwelcoming,

think about an alternative location that everyone can get to easily. Locations might include church halls, community centers, or hospital/clinic settings. Try to find a space that has a bathroom and other features that would be helpful to group members, such as an elevator and wheelchair-accessible entrance. It's also helpful if the space is comfortable and one that everyone feels good about.

Food?

Will refreshments be provided?

The availability of refreshments, whether a full meal, simple snack, or beverage, is sometimes a draw, especially if the group meets in the evening or around mealtime. Since most support groups are relatively small, the expense shouldn't be prohibitive. Some groups may choose to provide the refreshments themselves, potluck style. That isn't practical for every group, so other resources will have to be explored. Since a healthy diet is important to liver health, choosing food can be a challenge. Fried chicken and pizza on a regular basis may not be the best choice, but if that's what the group wants, it's important to remember the importance of emphasizing risk reduction.

Open or Closed?

Will the group be open or closed?

This important decision should be made together by the group members so that there are no misunderstandings or resentments later on. Open groups generally accept new members at any time and continue indefinitely. People can choose to join or leave an open group whenever they like. Closed groups usually continue for a limited period of time (10 weeks, for example) and do not accept new members once the group has started. Most groups are open. Both models have advantages and disadvantages. For example, members of a support group whose stated goal is primarily to explore emotional issues may feel safer sharing in a closed group, while a group whose purpose is primarily educational is less likely to be disadvantaged by being open.

Contact person?

If someone is interested in joining the group, whom should they contact?

Select a person who can be called or e-mailed for information on what the group is like, when it meets, etc. This person's contact information would be listed on any flyers or outreach material. Groups often choose their facilitator to serve as the contact person, but it may also be helpful to list group members as contacts since they may offer a more personal perspective to potential new members.

Childcare?

Will childcare be provided on-site?

Many potential support group members are responsible for children, and the lack of childcare on-site can prohibit their ability to attend meetings. Although there is no simple solution to this challenge, there can be innovative ways to address the situation. A qualified staff member or agency volunteer may be willing to donate their time to watch the children. Another possibility is that the sibling or older child of one

of the group members might be available and willing to give of their time. The group may be able to take up a collection for the person who's offering childcare. Even if the amount collected is minimal, it is usually very much appreciated and could guarantee that he or she will show up the next time. Also, be sure that the children's area is separate from the support group's space so that the members aren't distracted.

Group Ownership
The most successful support groups find ways to allow the members a sense of ownership of the group. For example, one group chose to give their group a fun name. Another group has a steering committee made up of a few members that convenes a half an hour before each meeting to compile future agenda topics that they can run by the group. Another group rotates the responsibility of calling members to remind them about meetings. However the members deem fit, they should develop ways that encourage everyone in the group to feel a sense of ownership, representation, and responsibility for the group. Although it can be personally difficult, agency staff who are helping create and maintain the support group must accept that the group ultimately belongs to its members. Although staff guidance and suggestions are usually welcome, it's up to the group members to decide the format of the group and what subject matter is most valuable to them.

Facilitating the Group
The facilitator(s) are responsible for preparation and mediation of session discussions. For example, the facilitator might confirm that the meeting space will be available, check-in with guests/speakers and provide them with logistical details (directions, time, etc.), and be responsible for the flow of the session. If discussion deviates from the agenda, the facilitator can re-focus the discussion accordingly. The facilitator(s) might also talk with the group about long-term plans that include future agenda items and outreach to new members.

Decide in advance who will facilitate the sessions. Anyone can be a facilitator and, if the group wishes, facilitation can be rotated among participants. Facilitation by group members has its advantages – it can lead to a sense of personal empowerment, the development of leadership skills, and allow members a greater sense of ownership.

Models that are more traditional include facilitation by a professional such as a social worker, especially when the group is just beginning. If the group decides to go with a more traditional non-rotating model, they might consider having two co-facilitators who can alternate facilitation and help one another out.

Setting Ground Rules
Together, the group can, if they choose, establish ground rules that all participants agree to abide by. If rules are established, each new group member should be informed of the rules before joining the group, ideally in writing. Sample ground rules include:

- **Confidentiality.** Everything that is shared within the group (including status and identifying information such as full names) stays within the group and is not

discussed outside of the group space. People have the right to privacy and may not want their status or personal information disclosed outside of the space.

- **No judgment.** It is important that all participants speak from their own experience and keep from attacking others. Judgment can create an unsafe space in which participants can feel threatened from sharing.
- **Attendance.** Some groups view joining a support group as a commitment to the other members of the group. Therefore, some groups ask that if someone is unable to attend a session, they call someone in the group (or the facilitator) to let them know.
- **Punctuality.** Some groups may make decisions about how punctual members need to be.
- **Closing ritual.** Some groups choose to have a closing ritual, such as a prayer, a moment of silence, a moment of appreciation, or a group embrace to provide closure to the meeting.

As the group evolves over time and members of the group change, it's a good idea to re-evaluate any established rules and add new ones that might be necessary.

Outreach

Brainstorm ways to spread the word about your group. The following are some ways that other groups have let people know about their groups:

- Word of mouth can be a very effective way to let people know about your group. Tell people you know who are affected by HCV and those who work with people with HCV about the support group.
- Design an eye-catching flyer. Decide as a group where this flyer might be circulated. Some places might include local hospitals/clinics, other community-based organizations, drug treatment facilities, harm reduction centers, and AIDS service organizations (if your group will include co-infected individuals). Give flyers to group members to help spread the word.
- Consider listing your support group on the American Liver Foundation website (http://www.liverfoundation.org/greaterny/ or call (212) 943-1059), as well as other community websites and bulletin boards.
- If group members feel comfortable with the idea, draft a press release or public service announcement that can be shared with local newspaper, television and radio stations. These announcements should describe the nature of the support group, the time and phone number for more information.
- Try to get a human interest story in the media to focus community awareness on hepatitis C, which could include information about the group.

TOOLS

Sample HCV Pre-Post Test Counselor Checklist

Assess every client for hepatitis C

HCV Pre-Test Counseling Points

☐ **Describe HCV:**
- Slowly progressing liver disease
- Can cause liver damage (cirrhosis, cancer)
- Treatments are available

☐ **Describe test:**
- Test is for antibodies (determines if client was ever infected)
- Accuracy of test
- Window period (average 8-9 weeks, within 6 months of exposure, 97% will develop antibodies)

☐ **What results mean:**
- **Positive**: Means client has been exposed to HCV and is likely chronically infected (85% chance). Refer to a specialist who will perform other tests to see if the virus is currently in the body (chronic infection)
- **Negative**: Means either client has not been exposed to virus OR client is in window period
- **Indeterminate**: Means client should repeat test

☐ **Explain modes of HCV transmission:**
- Direct blood contact (IDU, tattoo, transfusion, etc)
- Injection drug use is most common mode of transmission
- Sexual transmission is less common
- HCV can be spread by contaminated household items such as toothbrushes and razors
- HCV is not spread by casual contact; i.e. eating, drinking, hugging

☐ **HCV Pre-Test Risk Assessment:**
- Why do you think you might be infected with HCV?
- Have you ever injected drugs (shot up) even once?
- Do you currently inject drugs (shoot up)?
- If you're having sex, do you (or your partner/s) use barrier protection when you have sex (i.e. condoms, dental dams, gloves)?
- Have you done so in the past?
- Have you ever had sex that involved tearing of tissues or blood (including menstrual blood)?
- About how many sexual partners have you had in your lifetime?
- Have you EVER had a sexually transmitted disease? Do you know which one?
- Have you ever had sex with someone who had been diagnosed with hepatitis C?
- Have you ever had sex with an injection drug user?
- Did you receive blood (transfusion) or clotting factors before 1992?
- Have you ever been on hemodialysis?
- Have you ever had an organ transplant?
- Have you ever been tattooed or been pierced in a non-professional setting?

☐ **Risk reduction:**
- **IDU**: sharing of any drug paraphernalia, including water, cookers and cotton, is very risky, not just sharing needles and syringes. HCV is more easily transmitted via blood than HIV.
- **Sexual**: safer sex practices including using condoms and avoiding sex that can lead to blood exposure without precautions (dental dams, gloves)

HCV Post-Test Counseling Points

➢ **If Result is Negative**

☐ Explain test results

☐ If risky behavior is continuing:

- Discuss window period
- Risk reduction (refer to drug treatment, preventing initiation of drug injection and safer sex)
- Harm reduction (explain safer injection practices, safer tattooing, needle exchange & ESAP)

➢ **If Result is Positive**

☐ **Prognosis:**

- Majority of HCV cases are chronic, so most people will have it for the rest of their lives
- Most people are asymptomatic and won't feel sick even though they are infected (and infectious)
- The virus may very slowly injure the liver, leading to cirrhosis and potentially liver failure
- Severe disease doesn't always happen, but can over many years (cirrhosis in 10-20% over 20-30 years)
- Having a doctor who is monitoring liver damage is very important
- Alcohol and/or HIV co-infection increases chance and speed of advanced liver disease
- Instill hope. Most people remain healthy for a long time.

☐ **Treatment:**

- Treatment is available and can cure the disease, but has severe side effects
- Treatment is only effective for about 40-50% of HCV+ people and is less effective if also HIV-positive. Liver specialists can help evaluate whether treatment is indicated

☐ **Prevent further damage to liver:**

- Abstain/limit alcohol, refer for treatment if indicated, if drinking alcohol, drink water between drinks
- Refer for medical evaluation (even if they feel well) to assess liver damage and to determine chronic status
- Get vaccinated for hepatitis A and B
- Discuss over-the counter medications and herbal treatments with doctor (could be toxic to liver)
- Eat nutritious food, low in fat and sugar, no iron supplements
- If injecting, refer for treatment, ESAP and needle exchange
- Drink lots of water, moderate exercise, lots of rest, get support

☐ **Prevent transmission to others:**

- If patient injects drugs, they should stop. If they can't, they shouldn't share drugs, cookers, cotton, water or needles. If sharing drugs, use new needle to prepare and split drugs.
- Don't share items that may have blood on them (toothbrushes, razors, nail clippers)
- Don't donate blood, semen, tissues or organs
- Co-infected with HIV may make HCV more transmissible
- Use condoms with sexual partners and avoid sexual activities with blood (including during a woman's period)
- Long-term monogamous couples may want to discuss condom use
- HCV is not spread by casual contact, i.e. eating, drinking, hugging

☐ **Referral:**

- Discuss contacts and offer screening to sexual partners or drug-sharing partners
- Refer to a liver specialist, and or substance abuse programs if indicated
- Brochure on safer injection techniques, ESAP and needle exchange

Sample COBRA Case Management: PROVIDER ASSESSMENT

Section Completed by COBRA Case Manager **Last Update Completed: __/__/__**
Patient's Last Name: _____ First Name: _____
Address: _____
Phone #: ( ) ____-_____ DOB: ___/____/____ SS#: _____-___-_____

Section Completed by Medical Provider
Medical Center/Clinic: _____
Phone #: ( ) ___ -_____
Date Last Patient Visit: ___/____/___

HIV Data
Date First Tested HIV+: ___/___
Status: HIV+ ☐ AIDS ☐ UNK ☐
Last CD4 #/%: __/__% Date: ___/___
Last VL: _____ Date: ___/___
On HAART: Yes ☐ No ☐
↘*IF YES:* Current HAART Regimen:

Medication:	*Dose:*	*Freq:*
_____	____	____
_____	____	____
_____	____	____

Adherence Issues: Yes ☐ No ☐ UNK ☐
Other Medications Taking:

Medication:	*Dose:*	*Freq:*
_____	____	____
_____	____	____
_____	____	____
_____	____	____

Hepatitis A, B, C Status
HAV+: Yes ☐ No ☐ UNK ☐
HAV-: Yes ☐ No ☐ UNK ☐
↘IF HAV-: Vaccinated?
Yes ☐ No ☐ UNK ☐

HBV+: Yes Chronic ☐ Yes Acute ☐
No ☐ UNK ☐
↘IF HBV-: Vaccinated?
Yes ☐ No ☐ UNK ☐

HCV-: Yes ☐ No ☐ UNK ☐
HCV+: Yes ☐ No ☐ UNK ☐
↘IF HCV+: Did Pt get:
HCV VL Yes ☐ No ☐ UNK ☐
Genotype Yes ☐ No ☐ UNK ☐
Biopsy Yes ☐ No ☐ UNK ☐
Candidate for TX Yes ☐ No ☐ UNK ☐
Treatment Yes ☐ No ☐ UNK ☐

PPD+/Hx TB☐ PPD+ ☐ PPD-☐
↘IF PPD+/Hx TB: Date PPD+: __/__
Date TB: __/__ Date Last X-Ray:__/__

↘IF PPD+ Only:
Took Prophy: Yes ☐ No ☐ UNK ☐
Date Last X-Ray:__/___
↘IF PPD-: Date Last PPD: ____/____

FOR WOMEN ONLY
Date Last Pap: ___/___
Last Result: Normal ☐ Abnormal ☐ DK ☐
↘IF ABNORMAL: Colposcopy?
Yes ☐ No ☐ UNK ☐
Since HIV+, changes in period:
Yes ☐ No ☐ UNK ☐

Services
Pt. needs any/all of the following services:

Benefits	**Yes ☐ No ☐ UNK ☐**
Support Groups	**Yes ☐ No ☐ UNK ☐**
Therapy	**Yes ☐ No ☐ UNK ☐**
Housing Assistance	**Yes ☐ No ☐ UNK ☐**
Adherence	**Yes ☐ No ☐ UNK ☐**

Others [SPECIFY] _____
_____

COMMENTS/RECOMMENDATIONS:

Yes y

Completed By: _____ Date: _/_/_

THANK YOU

TB Status

SAMPLE HEPATITIS SCREENING FORM
NYC DEPARTMENT OF HEALTH AND MENTAL HYGIENE (DOHMH)

Hepatitis vaccination and testing are available at this clinic. Hepatitis A, B and C are spread in different ways (see back of this sheet). Read over the NYC Department of Health and Mental Hygiene hepatitis recommendations below and answer the following questions:

Hepatitis A
***Vaccine* (2-doses) *is Strongly* Recommended for:**

- anyone who injects (shoots up) illegal drugs
- all men who have sex with men
- anyone with liver disease or who is HIV positive

1. Do you fit any of these categories for hepatitis A? Yes ____ No _____

Hepatitis B
***Vaccine* (3-doses) *is Strongly* Recommended for:**

- anyone seen at this clinic for STD (sexually transmitted disease) services
- all men who have sex with men
- anyone who injects (shoots up) illegal drugs
- anyone with liver disease or who is HIV positive

2. Do you fit any of these categories for hepatitis B? Yes ____ No _____

Hepatitis C
There is no vaccine for hepatitis C. Testing is Strongly Recommended for:

- anyone who has ever injected (shot up) illegal drugs (even once)
- anyone who has liver disease, been on hemodialysis or is HIV positive
- anyone who received a blood transfusion or blood products before 1992
- anyone who has a tattoo or body piercing from a non-professional
- anyone who has had sex with someone who has hepatitis C
- anyone who has had more than 40 lifetime sexual partners

Note: Hepatitis C is not easily spread through sexual contact but can be.

3. Do you fit any of these categories for hepatitis C? Yes ____ No _____

4. Would you like to get hepatitis services today at the clinic?
Yes _____ No _____
I would like to talk to the Doctor before I decide _____

5. If you answered "Yes" to question #4, which services would you like to receive?
_____ Hepatitis A vaccine
_____ Hepatitis B vaccine
_____ Hepatitis C testing and counseling

10 Key Messages
-Reference Sheet for Outreach Workers And Counselors-

The following 10 key messages about Hepatitis C should be integrated into all counseling sessions with at-risk clients:

1. Hepatitis C is spread through direct blood-to-blood contact.

2. Hepatitis C is spread through injection drug use much more easily than HIV.

3. There is no vaccine available to prevent hepatitis C.

4. If you are at risk for hepatitis C, get tested.

5. Many people with hepatitis C do not feel sick until liver damage is advanced.

6. **The best way to protect yourself from hepatitis C is to never inject drugs.**
   - How to reduce your risk if you already inject:
     - Most people who inject drugs for more than a few years get infected with hepatitis C. If you can't stop using drugs, snorting, smoking or swallowing them is much safer than injecting.
     - NEVER share or reuse needles or works used for injecting drugs (cotton, cookers, water, cups). It's best to use a new syringe every time you inject drugs.

7. Hepatitis C is not spread through breastfeeding, coughing, sneezing, food or drinks, hugging, casual contact, or sharing eating utensils/drinking glasses.

8. The newest combination of treatments can get rid of hepatitis C in half or more of the people who take them. Talk to your doctor to see if treatment is right for you.

9. If you have hepatitis C, take steps to protect your liver:
   - Get regular checkups
   - **Eliminating or reducing alcohol intake is the best thing you can do to protect your liver against serious damage**
   - Get hepatitis A and B vaccines
   - Talk to your doctor before using any medicines (including over-the-counter and herbal medicines)
   - To protect others from getting hepatitis C, don't share drug injection equipment

10. Anyone with HIV should be tested for hepatitis C.
    - HIV can make liver damage from hepatitis C worse in a shorter period of time.
    - Some HIV medications may harm the liver.

HANDOUTS

HEPATITIS A, B and C FACT SHEET

Be smart. Get tested! Get vaccinated!

What is viral hepatitis?

- Viral hepatitis is a liver disease. It can be caused by different viruses.
- The ways you catch these viruses are different, but once infected they can all damage your liver.

HEPATITIS A

Hepatitis A is found in feces

People generally get infected with hepatitis A by:

- eating contaminated food
- getting the virus in your mouth during sex (oral-anal contact) from an infected person

People who get hepatitis A can be sick for weeks to months and feel tired, sick to the stomach, pain in joints, and have yellowish skin and eyes.

2 doses of hepatitis vaccine will prevent you from getting the virus.

HEPATITIS B

Hepatitis B is found in blood and sexual fluids

People generally get infected with hepatitis B by being exposed to blood or sexual fluids from an infected person. Hepatitis B is easy to get through:

- sex with an infected person (even if they have no symptoms).
- sharing needles or other drug equipment with an infected person when injecting drugs

Hepatitis B is very common and can be very serious. Only about half of the people who get hepatitis B have symptoms right away. Early symptoms include feeling tired, sick to the stomach, pain in joints, and yellowish skin and eyes. Many people recover completely from hepatitis B. Other people with hepatitis B will develop severe liver disease, including liver failure and liver cancer.

3 doses of hepatitis vaccine will prevent you from getting the virus.

HEPATITIS C

Hepatitis C is found in blood and possibly sexual fluids

People generally get infected with hepatitis C by having their blood exposed to blood from an infected person:

- Hepatitis C is spread very easily by sharing needles or drug equipment with an infected person while injecting drugs
- Before 1992, people got infected with hepatitis C from blood transfusions or other blood products. The blood supply is safer now,
- Some people get hepatitis C though sex with an infected person

Few people who get infected with hepatitis C develop symptoms right away, but many eventually develop very serious liver disease 10-30 years after getting infected. This liver disease can lead to liver failure and liver cancer. The earlier someone knows they are infected, the better the disease can be managed or possibly cured.

There is no vaccine for hepatitis C

Don't share needles or other drug equipment! Get tested if you are at risk.

Hepatitis can be very serious (even deadly)

Hepatitis A and B vaccines are safe and will prevent you from getting those diseases.

Getting vaccinated hurts for a second.
Getting hepatitis A or B can hurt for weeks or possibly a lifetime.

Protect yourself! Get vaccinated! Get tested!

SAFER INJECTING

- **"Avoid contact with any blood"** means a simple, day-to-day awareness of how blood is present. Conditions are rarely perfect for injection, but think of injecting along the same lines as preparing to eat dinner.
  - Wash your hands and arms.
  - Clear a space that is yours.
  - Use clean surfaces.
  - Make sure your injecting space is clean by wiping it down or spreading out a sheet of newspaper.

- **Use sterile syringes, if possible.** If you must reuse, keep a personal syringe. It's better to use one that's only been used by you.

- **Know which syringes are yours** by marking them before you get off. Remember when you are getting off with other people, syringes look alike. Keep track of how you marked yours, and remember that markings can wipe off. Knowing which are yours is important if you recap your syringes.

- **If you have to share, always clean the needle and syringe with bleach and water.** It is unknown how long you need to clean needles with bleach to kill hepatitis C. To clean:
  - Fill the syringe with water from a clean container. Shake for at least 30 seconds and squirt out. Repeat this step twice, and use new water each time.
  - Do the same thing with bleach.
  - Rinse at least 2 times with water.
  - If possible, take apart the syringe and soak it in bleach (as long as you can) then rinse it out several times with clean water.

- **Use a sterile syringe to split drugs,** if possible.
  - When preparing your shot use your own cooker, cotton and water.
  - Clean out the cooker with an alcohol pad to be sure it's as clean as possible.
  - If you're drawing up from a shared cooker, try to use only new syringes. It's a bad idea to draw up from a cooker if someone else stuck a used syringe in it.

- **Always clean your injection site** by using an alcohol pad or soap and water. During the whole process of injection, be aware of what you touch or handle.

- **Apply gentle pressure to the injection site** after you've shot your drugs.
  - Use tissue or cotton to stop the bleeding.
  - Alcohol pads don't stop bleeding; the alcohol stops your blood from clotting.
  - Dispose of the used cotton or tissue, and dispose of the syringe in a sharps container (or a hard, puncture proof container).

- **Wash your hands and arms.** Be aware that you've been handling syringes, cotton, tissues and other materials that have probably contacted your blood.
  - Re-wipe your surface.
  - Check your tie and remember how your blood could have ended up on anything you touch or use.

- **Take control of your own injection**. Having another person inject you significantly increases your chance of getting infected. But even when someone else injects you, basic hygiene can prevent most infections. If someone injects you after they have gotten themselves off, they should wash their hands, and use a sterile syringe, clean cooker, water and tie for you.

HCV is easy to acquire and transmit and it seems that very small amounts of blood will do the trick. Injecting drugs is the riskiest way to use, due to the variety of complications that can occur. But while some risks may be unavoidable, others can be reduced or eliminated through awareness and planning. Above all, it is time to recognize that hygiene can be a normal part of injection, just like it's a normal part of eating.

Adapted from *Harm Reduction Measures for IV Drug Users*, by Allan Clear, Harm Reduction Coalition. Originally published in *HCV Advocate*, July 2000.

KEEPING YOUR LIVER HEALTHY IF YOU HAVE HEPATITIS C

Talk with your healthcare provider about the health of your liver and consider the following recommendations:

DO:

- Find a doctor who understands HCV – a gastroenterologist (stomach and bowel specialist), hepatologist (liver specialist), some infectious disease doctors and primary care physicians. If you're considering treatment, a team approach, including a psychiatrist, is best.
- Get vaccinated against hepatitis A and hepatitis B. Co-infection with hepatitis C and active hepatitis A or B can be *extremely* dangerous.
- Get regular health check-ups, including liver function tests.
- Consider stopping or reducing your alcohol intake. Alcohol use *significantly* increases the risk of developing cirrhosis and liver cancer. If drinking alcohol, drink plenty of water with it.
- Protect yourself from *reinfection*. If your body has cleared the virus, keep in mind that having hepatitis C antibodies will *not* protect you from becoming infected again!
- Stick to a balanced diet of fresh vegetables, fruits, beans, whole grains, and lean meats.
- Get a healthy balance of protein in your diet – too much protein can stress your liver.
- Drink lots of fluids to flush toxins from your body.
- Get regular exercise and develop a stress reduction plan.

AVOID:

- Drinking alcohol. Even 1 drink a day can greatly accelerate the progression of liver disease.
- Taking large amounts (2,000/mg day) of acetaminophen (Tylenol & other non-aspirin pain relievers) that are toxic to the liver. Acetaminophen is in many medications – so read the labels carefully. Acetaminophen and alcohol together can cause severe liver damage.
- Breathing in pollutants, chemicals, and cleaning products (skin contact & breathing): fumes from paint, paint thinners, chemical solvents, spray adhesives, insect sprays, and cleaners can be harmful to the liver. Always follow manufacturers' precautions.
- Foods with high salt, sugar or fat content such as cheese, fast food and processed foods (cookies, cakes, frozen dinners, packaged foods with long shelf lives, "instant" foods).
- Too much fried foods.
- Eating shellfish and raw fish because of the risk of hepatitis A.
- High-doses of Vitamins A, D, E or K.
- Taking herbs that are toxic to the liver such as peppermint, mistletoe, yerba tea, sassafras, germander, chaparral, skull cap, nutmeg, valerian, Jin Bu Juan, comfrey (bush tea), pennyroyal and tansy ragwortsenna. Always talk to your doctor before trying new herbs or supplements.
- Taking iron supplements unless advised by your doctor.

COMPARISON OF HEPATITIS A – E

	Hepatitis A	Hepatitis B	Hepatitis C	Hepatitis D	Hepatitis E
How do you get it?	Transmitted through fecal-oral contact (changing diapers, rimming, eating contaminated food, etc.)	Transmitted through sexual contact, blood, breast milk, or mother-to-child during birth.	Transmitted by blood-to-blood contact. Sexual transmission is uncommon and mother-to-child transmission is possible.	Transmitted by blood-to-blood contact. Must have active HBV to get HDV. Relatively uncommon virus.	Transmitted through fecal-oral contact. Rare in the U.S.
What are the symptoms of acute infection?	High fever, loss of appetite, fatigue, dark urine, nausea, vomiting, light colored stool and jaundice. Symptoms may last from 1 week to 2 months.	Similar to HAV though many people have no symptoms. 30-50% develop acute (symptomatic) infection within 4 weeks to 6 months.	Similar to HAV though most people with HCV (75%) have no symptoms.	Similar to HAV though usually more severe.	Similar to HAV.
Is it a life-long infection?	NO. HAV is never chronic, and most people clear the virus completely. HAV can cause serious problems for people with other liver diseases.	YES, for some, though most adults clear the virus. Less than 5% become chronically infected. 15-20% of people with chronic HBV will die of cirrhosis or liver cancer after many years.	YES, for most, though 15-25% clear the virus. 75-85% become chronically infected; 5-20% develop cirrhosis; and 1-4% develop liver cancer.	YES. When a person is infected with HDV and HBV simultaneously, it's known as co-infection. Super-infection is when a person with established HBV contracts HDV. Super-infection is more serious than co-infection.	NO. HEV is not chronic, and most people recover completely. Pregnant women, however, can develop serious complications and 20% will die as a result of infection with HEV.
Is there a vaccine? What are the treatments?	The HAV vaccine prevents infection and is given in 2 doses, at least 6 months apart. People exposed to HAV can get immune globulin shots within 2 weeks of exposure to avoid getting sick. No treatment except for symptom relief.	The HBV vaccine prevents infection and is given in 3 doses over a minimum of 6 months. People exposed to HBV can get the HBV vaccine and HBIG to prevent illness or reduce severity. Treatment for chronic HBV may include: alfa-interferon injections, Epivir-B or Hepsera. There is no treatment for acute infection.	There is no vaccine and no post-exposure prophylaxis. Treatment for chronic HCV may include: pegylated alfa-interferon combined with ribavirin. There is no treatment for acute infection.	Vaccination against HBV will prevent HDV infection. There is no specific treatment or vaccine for HDV.	There is no vaccine for HEV. No treatment except for symptom relief.

The Relationship Between HIV and HCV

The following chart can be used when preparing to integrate HCV information into existing programs:

HIV	HCV
• Blood-borne & sexually-transmitted virus	• Blood-borne virus
• Affects the immune system	• Affects the liver
• Infection is lifelong	• Approximately 15-25% of people infected with HCV spontaneously clear the virus. 75-85% go on to develop chronic infection
• IDU is the major risk factor	• IDU is the major risk factor
• No vaccine available	• No vaccine available
• ELISA/EIA screening with Western Blot confirmation	• ELISA/EIA screening with RIBA or PCR confirmation
• Treatment may be for a lifetime or at least many years	• Treatment typically lasts from 6 to 12 months
• High viral load indicates disease progression	• High viral load does not appear to correlate with liver damage
• Viral loads do not randomly fluctuate	• Viral loads fluctuate randomly
• Many anti-viral treatments are available	• Currently only one approved treatment (interferon with ribavirin)
• Appears to accelerate HCV disease progression	• Unclear if HCV accelerates HIV disease progression
• High risk of transmission from blood-to-blood contact	• Rate of transmission from blood-to-blood contact is 10 times higher than HIV
• Transmitted by unprotected vaginal, anal and oral sex	• Significantly lower chance of transmission through unprotected sex
• Mother-to-infant transmission rate is 20-30% without treatment	• Mother-to-infant transmission rate is 2-5%

Questions To Ask Your Healthcare Provider If You Have Hepatitis C

Navigating through hepatitis C (HCV) information can be daunting. Since many people with HCV do not experience symptoms, taking the time to educate yourself about the disease and its treatment is very important. Even if you feel well, don't be afraid to ask your healthcare provider questions. Your provider may have told you not to worry, that your liver is just fine. That may very well be true, but you deserve to know more details. The following questions may be helpful as you meet with your healthcare provider. Ask only the questions you feel comfortable with now, and save others for later. The list is meant to serve as a guide and an opening for further discussions with your healthcare provider.

Keeping a personal journal can also be helpful. Having a space to jot down your daily activities, thoughts, and feelings can help you frame questions for your healthcare provider. For example, if you notice a change in your bowel movements or feel a side effect from treatment more strongly one day, write down the details as you experience them. Bring the journal with you to your medical appointments – the experiences you jotted down will be handy to share with your provider and you'll have a place to write down the things you and your doctor discuss that you don't want to forget.

About my doctor's experience

- ☐ Do you have many other patients with hepatitis C?
- ☐ Are you up-to-date on all the latest changes and advancements in hepatitis C treatment?
- ☐ Do you think I should be referred to a liver specialist for my care?

About my liver health

- ☐ What are the symptoms of liver disease that I should look out for?
- ☐ How healthy is my liver now?
  - What do you base your assessment on?

What are my liver enzyme levels?

- ☐ Are they within normal levels? Are they high?
- ☐ How do these results compare to my previous enzyme levels? Are they remaining steady? Are they climbing?
- ☐ How often should I have liver function tests done?
- ☐ When should I get them done again?
- ☐ May I have a copy of the test results to take home for my records?

What is my hepatitis C viral load?

- ☐ (If you haven't had a viral load test done) When should I have my viral load checked?
- ☐ (If you have had a viral load test) What are the results?
- ☐ How do those results compare to my previous viral load results?
- ☐ How often should I have my viral load checked?
- ☐ May I have a copy of the test results to take home for my records?

What is my hepatitis C genotype?

- ☐ (If you haven't had a genotype test done) When should I have it done?
- ☐ (If you have had a genotype test done) What is the result?
- ☐ How does my genotype affect my illness and treatment?
- ☐ May I have a copy of the test results to take home for my records?

Do you recommend that I have a liver biopsy?

- ☐ If yes, why? If no, why not?
- ☐ Would you recommend starting treatment without having a biopsy done first?
- ☐ What's involved in getting a biopsy?
  - What are the risks?
  - How is the procedure performed?
  - How long does the procedure take?
  - Who performs the biopsy?
- ☐ (If you've had a biopsy done) What were the results?
- ☐ What do the results mean in terms of the health of my liver?
- ☐ What do the results mean in terms of treatment?
- ☐ May I have a copy of the biopsy results to take home for my records?

If You're on Treatment or Thinking about Treatment

Do you think that HCV treatment is a good idea for me?

- ☐ If yes, why?
- ☐ If no, why not?

What are the pros and cons of beginning treatment?

- ☐ What are the potential side effects of pegylated interferon and ribavirin?
- ☐ How is the treatment taken?
- ☐ How may the treatment affect my life and lifestyle?
- ☐ How long would I have to be on treatment?
- ☐ What are my chances of doing well on treatment?
- ☐ Do I have to change how and when I eat while on treatment?
- ☐ If I am also HIV-positive, will the HCV treatment affect my HIV?
- ☐ Should my partner or I use birth control while on the medications?
- ☐ Can my partner or I get pregnant safely while I am on the medications?

What else should I consider before starting treatment?

- ☐ If I'm using drugs, does this mean I won't do as well on treatment?
- ☐ Is it a problem if I'm on methadone maintenance?
  - Will you work with my dispensing/treatment agency to coordinate my care?
- ☐ If I've had trouble with depression or other mental health issues, should I stay away from this treatment?
  - If I decide to go on treatment, is there anything I can do to lower the possibility of my feeling depressed? And what if the depression gets worse?
- ☐ If I have serious liver scarring, will your clinic exclude me from being able to access treatment?

- ☐ Do you recommend that I be treated with a weight-based or fixed dose of pegylated interferon? What dosage of ribavirin would you recommend for me?
- ☐ What types of support might I need if I do start treatment?
- ☐ Are there any new treatments that will soon be available that I should wait for?

About Complementary Therapies

- ☐ How do you feel about complementary and alternative medicine such as Chinese herbs, supplements, and acupuncture to help treat my hepatitis C?
- ☐ Have you read any research on the benefits of herbs and other complementary/alternative therapies for hepatitis C?
- ☐ Will you work together with my complementary care provider should I choose to have one?
- ☐ Can you refer me to a good complementary and alternative medicine provider in my area?

About Hepatitis C and HIV Co-infection

- ☐ Do you provide care to many patients with both HIV and hepatitis C?
- ☐ Are you up-to-date on all the latest treatments for both HIV and hepatitis C?
- ☐ Which do you think I should treat first, my hepatitis C or my HIV?
- ☐ If I'm already on HIV medications, do you recommend treatment for hepatitis C?
- ☐ How long will I need to take pegylated interferon and ribavirin?
- ☐ What side effects can I expect from taking HIV and hepatitis C medications together?
- ☐ Are there any drug interactions between the HIV meds I'm taking and those used in hepatitis C treatment?
- ☐ Should I change the HIV medications I'm on if I start hepatitis C treatment?

About Follow-Up

- ☐ How often should I return for follow-up?
- ☐ Can I schedule an appointment now?
- ☐ What should I do if my health gets worse between now and the next time I'm scheduled to see you?
- ☐ If I have a problem and you are unavailable, is there someone else I could talk to?
- ☐ Are you available by phone?

About Hepatitis C Self Care

- ☐ Are there specific types of foods that can help my liver?
- ☐ Are there foods I should stay away from?
- ☐ Can you refer me to a good nutritionist or dietician for help with my dietary needs?
- ☐ How do alcohol, smoking, and drug use affect my liver or the hepatitis C virus?
- ☐ Do I need to stop drinking alcohol completely?
- ☐ If I want to stop smoking, can you refer me to someone to help me quit?
- ☐ Do I have to change my sexual practices?
- ☐ Should my partner(s) be tested for hepatitis C?
- ☐ Should I be tested for HIV, hepatitis A and hepatitis B?
- ☐ Would it be good for me to get vaccinated against hepatitis A and B?
- ☐ Do you know of a support group I can attend?

Questions to Ask a Complementary/Alternative Health Practitioner

When choosing a complementary/alternative health practitioner, use as much care as when you choose your primary healthcare provider. Here are some useful questions to ask:

- ☐ What is your treatment philosophy or style?
- ☐ How did you become a complementary treatment practitioner? Do you have specific credentials as a practitioner?
- ☐ What is your experience in treating someone with hepatitis C?
- ☐ Is the therapy you're suggesting safe and/or effective in treating hepatitis C?
- ☐ Are there any side effects from this therapy?
- ☐ Is there literature about these treatments that I can read?
- ☐ How long will this treatment last?
- ☐ Can I do this treatment while being treated with the standard medications (interferon + ribavirin)?
- ☐ What is the cost of this treatment, and is it covered by my health insurance?
- ☐ Will you work together with my primary care provider and/or liver specialist?

This list of questions is adapted from "Taking Control – Asking the Right Questions" developed by the Massachusetts Department of Public Health.

Hepatitis Resource Guide

For Clients

Free Hepatitis C
Counseling and Testing

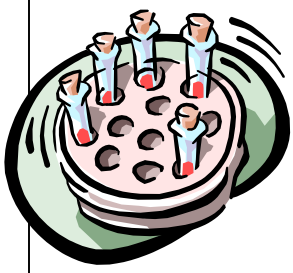
(offered on a first come, first served basis)

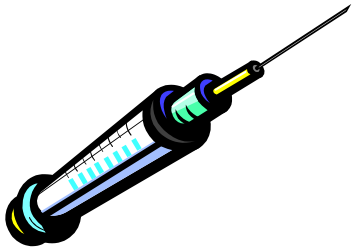
Riverside STD Clinic
160 W. 100th St., 1st Floor
Manhattan (212) 865-1951
Mon. - Fri. starting at 8:30 am

Morrisania STD Clinic
1309 Fulton Ave., 2nd Floor
Bronx (718) 901-6564
Mon. - Fri. starting at 8:30 am

Crown Heights STD Clinic
1218 Prospect Pl.
Brooklyn (718) 735-0580
Mon. - Fri. starting at 8:30 am

Jamaica STD Clinic
Beginning Spring 2004
90-37 Parsons Blvd., 1st Floor
Queens (718) 262-5572
Mon. - Fri. starting at 8:30 am





Free Hepatitis A and B
Vaccination

(offered on a first come, first served basis)

Riverside STD Clinic
160 W. 100th St., 1st Floor
Manhattan (212) 865-1951
Mon. - Fri. starting at 8:30 am

Morrisania STD Clinic
1309 Fulton Ave., 2nd Floor
Bronx (718) 901-6564
Mon. - Fri. starting at 8:30 am

Crown Heights STD Clinic
1218 Prospect Pl.
Brooklyn (718) 735-0580
Mon. - Fri. starting at 8:30 am

Free Hepatitis C Support Groups

American Liver Foundation
www.liverfoundation.org
(212) 943-1059 ext. 12
-call for support group listings

H.E.L.P.P. (Hepatitis Education Liver Disease Awareness Patient Support Program)
Teresa Abreu (718) 352-7772
-general liver disease support group meets every 3rd Sunday of the month at New York Hospital of Queens

Latino Organization for Liver Awareness (LOLA)
www.lola-national.org
(718) 892-8697
-Spanish and English

National AIDS Treatment Advocacy Project (NATAP)
www.natap.org
Dawn Schuk (212) 219-0106
-support group for Hepatitis C/HIV con-infected individuals

St. Vincent's Hospital
(212) 535-1850
-support group for people infected with or affected by Hepatitis C

Hepatitis C Clinics in New York City Public Hospitals (HHC)

Note: All clinics listed will accept patients regardless of insurance status. All hospitals treat individuals with viral hepatitis, but out of various departments (check Gastroenterology, Infectious Disease or Primary Care)

Bellevue Hospital Center
Virology Clinic 2-South 35
462 First Ave. (at 27th St.) Manhattan
Clinic Information: (212) 562-4038
Mon.-Fri. 9:00 am – 5:00 pm

East New York Diagnostic & Treatment Center
2094 Pitkin Ave.
Brooklyn
General Information: (718) 240-0400
Tues. & Thurs. 5:00 pm – 8:00 pm

Elmhurst Hospital Center
79-01 Broadway
Elmhurst, Queens
Clinic Information: (718) 334-3969
Thurs. 1:00 pm – 4:00 pm with referral

Harlem Hospital Center
506 Lenox Ave.
Manhattan
Clinic Information: (212) 939-2910
Thurs. mornings with referral

Kings County Hospital Center
470 Clarkson Ave.
Brooklyn
General Information: (718) 270-1112
Call for appointment

Metropolitan Hospital Center
1901 First Ave.
Manhattan
Clinic Information: (212) 423-6881
Fri. starting at 1:00 pm with referral

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