Hepatitis C Support Groups For Drug Users

FACILITATORS MANUAL
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About the Hepatitis C Harm Reduction Project:
The Hepatitis C Harm Reduction Project is a New York City Council-funded technical assistance project initiated in late 2003 based on advocacy efforts of the Injection Drug User Health Alliance (IDUHA).

The project exists to:
- Increase the capacity of syringe exchange (SEPs) and community-based ESAP programs and other allied health care and drug treatment centers serving IDUs to address the hepatitis C epidemic among drug users.
- Develop interventions to ensure that IDUs have access to a full spectrum of hepatitis C prevention, education, health care and treatment services – including hepatitis A and B vaccinations, HCV diagnostic testing and liver disease monitoring, support, and treatment options for those already infected.
- Promote effective IDU-based HCV program models within SEP and ESAP; Adapt models implemented in these settings to community-based organizations, drug treatment, and health care settings that serve current and former drug users.
- Advance policies to improve drug user health; increase hepatitis C prevention, care and treatment options; and advocate for resources to address this epidemic among IDUs.

About the Harm Reduction Coalition:
The Harm Reduction Coalition (HRC) is a nonprofit organization committed to improving the health and wellbeing of drug users and communities affected by drug-related harm. HRC promotes effective harm reduction services and policies at the national, regional, and local levels; through education and training, community organizing, policy advocacy, and publications. HRC locates itself as part of a broader movement for progressive change that challenges social, cultural and economic structures – including current drug policy – that foster and sustain disadvantage, discrimination, and denial of civil liberties and human rights.
Introduction

This guide was developed with the collective input of syringe exchange participants and service providers actively involved in hepatitis C (HCV) support groups throughout New York City. Together we have compiled some ‘best practices’ for establishing HCV groups within a harm reduction framework. We also offer facilitators practical suggestions and creative tools for effectively maintaining a group that meets the unique and varied needs of former and active drug users.

The majority of existing HCV support groups are connected to hospitals, medical clinics or drug treatment programs. These groups often overlook the physical, emotional, and social realities of drug users, making it difficult for members to talk openly about issues that may impede their ability and/or motivation to pursue HCV care and treatment – like managing their drug use, coping with mental health issues, or dealing with homelessness and a lack of resources. Others simply avoid these groups altogether because of the stigma and discrimination they’ve had to confront over the years from service providers and the health care system.

Part I of this manual includes some effective strategies for developing HCV groups that accommodate the complex support and education needs of individuals with a current or past history of drug use. We have included suggestions for all stages of group development – from assessing participant needs and identifying gaps in knowledge, to determining the overall focus and objectives of the group. To help ensure the greatest needs of group members are met, it is essential that participants are involved in every stage of the planning and initiation process.

Benefits of HCV Support Groups

Below are some of the positive outcomes we’ve observed over the years working in HCV groups with current and former drug users:

- By taking the initiative to increase their knowledge about hepatitis C and acquiring practical strategies to better care for their health, group members feel empowered to take a more active role in their healthcare and initiate other changes to improve their quality of life.

- As their awareness around HCV increases, participants act as peer educators within their social networks, reinforcing HCV prevention and care messages relevant to the community.

- Participants’ motivation to pursue HCV care and treatment is enhanced through the experience of witnessing others actively addressing their health and wellness needs.

- Group cohesion and support can decrease feelings of personal isolation and create positive social networks for individuals with mutual needs and goals.

- By talking openly about their drug use and injection practices, group members can share practical risk-reduction strategies and methods for managing their use.

- Group involvement facilitates linkages to other supportive services and provides facilitators with a non-threatening means of engaging harder-to-reach participants.
• Trust between participants and service providers is strengthened by setting a collaborative tone within the group and actively responding to the feedback and suggestions of members.

HCV groups can also benefit the community as a whole by evolving into a sort of ‘HCV advisory council,’ providing guidance on program development and carrying practical messages around HCV prevention, care and treatment to the wider community.

**Developing New Approaches**

As individual and group needs change over time, facilitators are encouraged to engage participants around developing new and creative approaches for meeting the evolving needs of members. Below are some common examples of projects and "spin off groups" adopted in the past:

- **Peer Education Groups:** offers intensive training opportunities so highly motivated members can fine tune their peer education skills and increase their knowledge on issues related to hepatitis C.

- **HCV Awareness/Working Groups:** participants may be interested in developing creative projects that increase HCV awareness within the agency – like designing an educational 'ad campaign' or starting a magazine to showcase participants' artwork, writing, and other forms of self expression.

- **Treatment Support Groups:** provides a forum for participants undergoing HCV treatment to receive encouragement and support from participants with common issues and concerns.

**Activities and Tools for Group Facilitators**

*Part II* of this guide provides facilitators with useful information and tools for exploring some of the central themes around hepatitis C and drug user health. Facilitators don't need to become experts on hepatitis C to be effective educators. However it is recommended they acquire a basic understanding of the key issues outlined in this manual.

For each section we have included a basic overview of each topic, followed by stimulating discussion questions and interactive group activities that engage participants on issues like treatment readiness, substance use management, coping with depression, communicating with medical providers, and working through feelings around stigma and disclosure. Because participants have unique ways of absorbing, remembering, and processing information, we incorporated exercises that involve written, visual, and verbal approaches to exploring these issues.

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Refer to the *resource section* at the back of this guide for group activity tools, fact sheets, informational brochures, and a listing of useful websites.
PART I

STRATEGIES FOR
HCV GROUP DEVELOPMENT

PLANNING
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INITIATION
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UPKEEP
Phase I: Planning

The first stage of group development involves gathering information and identifying the common needs and concerns of participants. Most likely you already know a lot from day-to-day observations and interactions, but to get a more complete and accurate picture, implementing some form of needs assessment is essential.

1.1. Identifying Common Needs

Consider what sort of information you can obtain in order to identify the greatest needs and common concerns participants have regarding hepatitis C (HCV). Here are a few examples to get you started:

- What’s the ratio between participants who are HCV-positive, negative, or have never been tested? Are most of them actively using drugs, or in recovery? Homeless? Coinfected with hepatitis C and HIV?

- For individuals chronically infected: Have they seen a doctor for routine monitoring and follow up care? Considered (or initiated) treatment? Do they know their genotype? The current condition of their liver?

- Do they suffer from other medical or mental health conditions?

- What’s their level of knowledge about hepatitis C? What do they already know? Where do you notice gaps? What are some common misconceptions?

- If they are actively injecting drugs, what prevention strategies have they adopted? Are they familiar with transmission risks?

- What concerns do they have about hepatitis C? What topics would they like to learn more about? Are they looking primarily for information, social support, a combination of both?

You can also use this opportunity to gather opinions regarding group logistics (when and where to meet, for how long, etc.).

1.2 Choosing Assessment Method(s)

Now it’s time to decide how you’re going to gather this information. Should you organize a focus group? Hold a community forum? Conduct face-to-face interviews? Distribute anonymous surveys to a random sampling of participants?

*Every approach has its limitations so using a combination of strategies is recommended.*
<table>
<thead>
<tr>
<th><strong>Method</strong></th>
<th><strong>Advantages</strong></th>
<th><strong>Disadvantages</strong></th>
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<tbody>
<tr>
<td>Focus Group</td>
<td>Allows for information sharing</td>
<td>Involves a lot of planning</td>
</tr>
<tr>
<td></td>
<td>Focus can be flexible or defined</td>
<td>Levels of individual participation often unbalanced</td>
</tr>
<tr>
<td>Community Forum</td>
<td>Can include a large and varied group of participants</td>
<td>Facilitator must have special skills to manage a guided group discussion and maintain focus</td>
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<tr>
<td></td>
<td>Quickly identifies key themes/issues</td>
<td>Some may be uncomfortable talking about their drug use or disclosing their HCV/HIV status in a large group setting</td>
</tr>
<tr>
<td></td>
<td>Gets people talking about HCV/identifies it as a community issue</td>
<td></td>
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<tr>
<td>Interview</td>
<td>Can be modified to address personal issues/concerns</td>
<td>Can be intimidating to some</td>
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<td></td>
<td>Some are more comfortable sharing one-on-one rather than in a group</td>
<td>Answers may be influenced by what they think you want to hear</td>
</tr>
<tr>
<td>Anonymous Survey</td>
<td>Respondents uncomfortable disclosing personal information (i.e. drug use) can remain anonymous</td>
<td>No opportunity for dialog when issues/questions arise</td>
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<td></td>
<td>Limitations with reading/writing/comprehension</td>
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### 1.3 Examining Your Data

Now it’s time to review and analyze the information you’ve collected. Look for common themes, questions, issues, and concerns that surfaced during your assessments. After answering the following questions, you should get a better sense of who will benefit most from participating in the group and what the overall focus should be.

- Have the majority of participants been tested for HCV? Did a greater number test positive or negative?
- Did respondents demonstrate a strong need for education around treatment and monitoring, or were participants more concerned about risk reduction strategies and avoiding transmission?
- Were many of them newly diagnosed or had the majority been living with the virus for many years?
- Are there a large number of individuals coinfected with HIV?
- What kind of emotional issues surfaced? Was stigma and disclosure a common concern?
- Were a large number of participants considering or undergoing treatment for HCV?
Assessing the needs of participants is an ongoing process. Each new member will bring a unique set of needs to the table, and the prevailing issues of longstanding members will undoubtedly evolve over time. Create an assessment plan that works for you and cultivate a group environment that encourages feedback and the expression of individual needs.

1.4 Determining Group Focus & Themes

Now that you’ve determined who the group intends to reach and what sort of support and guidance they’ll need, it’s time to shape the overall focus of the group. What will the prevailing themes and topics include? Will there be eligibility requirements for group participation?

For example:

If the majority of participants at your agency are chronically infected with hepatitis C, the group may decide to limit participation to HCV-positive participants only. This way, the overall focus of the group remains relevant to people living with HCV. Group themes can focus on things like treatment, monitoring, understanding lab results, or coping with the stress and emotional challenges of living with a chronic illness. Participants can feel safe knowing they’re surrounded by people with shared concerns and goals.

Part II of this manual provides you with information, tools, and exercises on a variety of themes to help get you started.

1.5 Choosing a Facilitator

Although the group is strongly shaped and influenced by participants, the facilitator plays an important role by helping the group accomplish its objectives and ensuring that individual needs are met. They can also help set the tone of the group; providing a positive energy and maintaining a common focus for the group to draw upon.

When choosing a facilitator, first think about who has the requisite knowledge. They don’t need to be experts, but they should have a basic understanding of hepatitis C that is relevant to drug users. It’s also important to find someone that the group can identify with (e.g. not a person who’s going to throw a bunch of medical jargon at them).

It is unlikely that one facilitator will possess all of the skills and knowledge necessary to meet the needs of the group. If this is the case, consider recruiting a co-facilitator with a different set of experience and skills or have guest speakers join the group from time to time. If your group is more process-oriented (where discussions focus largely on sharing thoughts and feelings) teaming up with a mental health professional can also be helpful.

1.6 Meeting Logistics

To maximize participation, be sure to get participant feedback on group logistics. What time and day of the week works best for people? How long should the meetings last? Where is the most convenient place for members to meet?
1.7 Recruitment Strategies

Holding a series of educational forums open to all participants (in your drop-in center for example) is a good way to kick off your group and recruit new members. Cover topics that address participants' most commonly asked questions about hepatitis C and plug your group at the end of each session.

Also, post fliers around the agency announcing the logistics of the group and a monthly schedule of topics, guest speakers, or special activities the group has planned.

1.8 Developing a Support & Referral System

Have a referral system in place so you can support the individual goals of group members and address any other issues that surface during meetings. Include local resources for services such as:

- Case management (benefits, housing, entitlements, etc.)
- Mental health clinics
- Needle exchange and substance use programs
- HCV testing and hepatitis A and B vaccination sites
- Primary care clinics/physicians
- Hepatologists/Gastroenterologists
- Other HCV support groups in the area

Ask group members about clinics, doctors, social service agencies and other ‘user friendly’ support groups they recommend so you can add them to your referral listings.

Phase II: Initiation

2.1 Creating a Safe Environment

To create a positive learning environment, foster a sense of belonging, and encourage mutual support among members, it’s important to set a respectful and collaborative tone from the very beginning.

Establishing Guidelines
To establish effective guidelines, it is essential that group members are involved every step of the way. Determining guidelines as a group will not only foster group cohesion and support, but also encourage individual accountability when difficulties between members surface.

Guidelines can include group expectations around confidentiality, ‘rules’ to ensure everyone’s voice is heard (i.e. no side talking, harassment, discrimination), and policies around lateness and disruptive behavior. Encourage participants to take turns reading the guidelines aloud at the start of each group.

Communication and Facilitation Skills
Because participants bring varying degrees of knowledge, unique perspectives, and a wide range of experiences to every group, information that is shared will likely be
processed and interpreted differently by everyone. For example, a group member who’s only beginning to process her diagnosis may be sitting next to someone struggling with complications from cirrhosis. Be mindful of these differences when you’re conveying information to the group; facts that are enlightening to one can strike fear in another.

On the other hand, groups that include varying degrees of knowledge and members in different stages of disease monitoring and care can inadvertently spark positive peer interventions; especially with participants who have had little or no evaluative testing or follow up care. Exchanging information and witnessing other group members take important steps to care for their health - like getting a liver biopsy or successfully completing treatment - can be a powerful motivating factor for others to do the same.

Of course some members will have “war stories” about treatment or painful biopsies. Respect and validate their feelings and give them space to share their experiences openly, while ensuring a balance of viewpoints (e.g. ask the group if anyone has had a different experience, or emphasize that treatment affects everyone differently).

2.2 Group Objectives

Group objectives should be developed and agreed upon by the group to ensure the interests and needs of each member is met. Start by asking what they hope to gain by participating in the group. Are they here to gain a basic understanding of hepatitis C? To receive guidance and support while undergoing treatment? Or are they just looking for a safe place to express their feelings and reach out for peer support? Most support groups have an educational component and also provide emotional support. Because the needs of participants are so diverse, the group’s mission will likely to encompass a range of objectives.

The following is an example of a mission statement that includes a variety of goals, while maintaining clear objectives:

The UserPower HCV Group encourages active drug injectors to take an active role in their health and to act as peer educators in their communities. This is accomplished by providing members with a weekly forum to receive educational and social support in a non-judgmental, caring and confidential environment.

The group you initiate will undoubtedly change and evolve with time - new people will join, others will drop out, some will start treatment and clear the virus, others may develop serious liver damage. Encourage the group to revisit their objectives on a regular basis to ensure everyone’s needs are still being met.
Phase III: Upkeep

3.1 Evaluations: Listening, Learning, Growing, Evolving

In order to maintain the vitality and integrity of the group, periodically take a step back and ask: Are we still on the right path?

Encourage participants to provide feedback from the very start and demonstrate that their voices matter by altering the group according to their suggestions and needs. Ask for feedback on all aspects of the group:

- Process: facilitation style, group dynamics
- Format: length, meeting time, space
- Content: topics, guest speakers, focused discussions
- Objectives: group mission, needs, goals
- Activities and themes for future groups

If you discover that group objectives (or format, themes) are becoming less relevant to the population, make necessary adjustments. If the gap becomes so wide that you are no longer able to meet the needs of group members, consider initiating a "spin off" group (tailored to people with advanced liver disease for example).

Be sure to employ different methods for collecting feedback. While one may feel at ease voicing concerns in a group environment, another may be more comfortable completing an anonymous evaluation form.
PART II

RUNNING A HEPATITIS C SUPPORT GROUP

INFORMATION, THEMES, ACTIVITIES AND TOOLS FOR GROUP FACILITATORS
Section I: Hepatitis C Transmission and Prevention

1.1 Key Messages

- Hepatitis C (HCV) is a virus spread through direct blood-to-blood contact, meaning: the blood of someone with hepatitis C must directly enter your bloodstream. That's why people who inject drugs are at such high risk of infection, and why simple steps to avoid other people's blood can keep you and others safe.

- Just because you can't see the blood, doesn't mean it's not there. HCV is ten times more likely than HIV to be transmitted through contact with infected blood.

- The most common transmission route is through sharing HCV-infected needles and injection equipment (i.e. cookers, cottons, water) because it provides a direct passage into the bloodstream.

  NOTE: There are other injection practices that may put people at risk for HCV infection. Use the discussion questions at the end of this chapter to explore individual risks (e.g. a transgendered person may be at increased risk from shared hormone therapy injection equipment).

- There are other less common ways HCV can be transmitted, including: shared household items such as razors, toothbrushes and nail clippers; unsterilized tattooing/body piercing/acupuncture instruments; mothers with Hepatitis C passing the virus along to their babies (occurs in less than 5% of births from HCV-positive mothers); shared snorting straws and crack pipes; and through sexual acts where blood may be present.

- HCV cannot be spread by hugging and kissing, sharing utensils and cups, breast feeding, or coughing and sneezing.

- Some people say it’s impossible to avoid hepatitis C if you are still getting high. This isn’t true. Talking about your status, paying attention to how you inject and how you prepare and split your drugs can keep you and others safe.

- Hepatitis A (HAV) is spread through contact with infected feces. The most common way this happens is through swallowing contaminated food or water. Hepatitis B is transmitted most frequently through blood, semen, and vaginal fluids. There are vaccinations for hepatitis A and B but not for hepatitis C. Everyone with hepatitis C should be vaccinated for both.

1.2 Safer Injection Strategies

- When you shoot up, small amounts of blood remain in the syringe. If you have hepatitis C (or HIV), the virus stays in your used needles. That means that anyone who injects later using your needle could get infected.

- Cleaning your syringe with water, bleach, or anything you have can help, but it takes a lot of time—more than most people have—and you must be
extremely thorough when bleaching syringes to get rid of hepatitis C. A brand new syringe is always safer than one that has been bleached or cleaned.

- Don’t stick used needles into shared cookers, glasses of water, or into the water vials given out by needle exchange programs. Also, never do cotton shots with anyone’s leftovers.

**Splitting Drugs Safely:**
- Make sure that everyone has a new needle. Plan ahead and assume you need extras.

- Have everyone use his or her own cooker, cotton, and water. It’s much safer; sharing or reusing cookers can spread blood and blood spreads hepatitis C. If you need to share a cooker and you only have one new syringe, save the clean set for preparing and mixing your shot, and divide it up between everyone.

- Keep a separate needle handy that is only used for preparing and splitting drugs. Mark it so that everyone knows which needle it is, and agree that nobody uses it to inject.

**Surfaces:**
- Injecting drugs can be messy. Watch out for blood – both your own and others’.

- Remember it only takes a small amount of blood for someone to get infected with hepatitis C. Pay attention to other things that could have come in contact with contaminated blood (ties, hands, alcohol swabs, etc.).

- After you pull out the needle, apply pressure to the injection site using a tissue, paper towel, or anything clean and dry. Do not use your fingertips; fingertips spread blood, and blood spreads hepatitis C. Also, avoid using alcohol swabs after you inject – alcohol thins the blood and can interfere with clotting.

### 1.3 Other Risk Reduction Messages

- Sexual transmission is uncommon but can occur from unprotected sex acts where blood is present (i.e. during unprotected anal or rough sex, intercourse while a woman is menstruating or with a partner who has open genital sores). If there is a concern of hepatitis C, use a condom and plenty of lubrication.

- Household items that have come into contact with HCV-infected blood can **potentially** transmit HCV. Have you’re your own toothbrush, nail clippers and razors clearly identified.

- Non-injection drug tools, like snorting straws and crack pipes, can potentially transmit HCV. To be on the safe side, use your own snorting straw - nasal membranes are very delicate and can rupture easily. Also, people who smoke crack may sometimes have bleeding lips or gums; carry your own stem cover to protect yourself.

- When you are getting a tattoo or body piercing, make sure the equipment being used is sterile (including the ink!).
1.4 Discussion Questions

- Do you inject drugs alone or with others? How do you set up to inject with others?
- How do you prepare your shots and divide your drugs?
- What strategies can you think of to avoid contact with other people's blood?
- What are some ways to prevent blood-to-blood contact when having sex?
- If you are concerned about sexual transmission, are there reasons why you don't use condoms?
- If you are getting tattooed or pierced in a place where sterile equipment is unavailable, how can you ensure your own needle or ink supply?

1.5 Activities

**Activity 1: Role Playing Exercise**

Ask group members to split into pairs. Distribute brief scenarios that prompt discussion around safer injection strategies. Have each pair share their thoughts/suggestions for group feedback.

*Example Scenario:* Thelma and Maria pool their money to go in on a bag of heroin together. Thelma has a new syringe and Maria has a used one. They have fresh water, cotton, and a new spoon. How can Thelma and Maria safely split the bag?

*Suggestion:* Thelma puts the powder into the spoon and uses her new needle to fill the spoon with water. Then she draws her shot through the cotton and injects using this clean needle. Maria goes next, using her own syringe to draw the remainder of the heroin for her shot. Even if Thelma has hepatitis C, Maria can't get infected because they used the clean set to prepare and draw the first shot. At no point was blood exchanged. With a little bit of planning, Thelma and Maria protected themselves.

*NOTE:* Group members may have creative and effective strategies to reduce HCV transmission. Often there's a mix of good strategies and not so good strategies; validate the good ones, and be clear about the risks of the not so good ones. Relationship dynamics also play a big role in HCV transmission (e.g. injecting with a friend vs. with a sexual partner). Create a safe environment for the group to discuss these dynamics without judgment or blaming. Also keep in mind that some members may feel uncomfortable discussing injection practices for a variety of reasons (e.g. if they're in recovery or not open about their use). It is the facilitator's responsibility to address these issues and provide the group with options.
Activity 2: Low Risk, High Risk, No Risk?

Place four signs around the room that read "low risk", "medium risk", "high risk" and "no risk". Distribute slips of paper with examples of possible routes of transmission (sharing a used syringe, borrowing someone’s toothbrush who is HCV-positive, having unprotected vaginal sex, etc.). Have group members place their slip of paper under the risk category they think is appropriate. This exercise is designed to convey basic messages around possible transmission routes, explore common risk behaviors, and generate discussions about various strategies to manage these risks.
Section II: Testing and Monitoring for Hepatitis C

2.1 Key Messages

- The most common test that is used to determine if someone has been infected with hepatitis C is the HCV antibody test. A positive result from a HCV antibody test is NOT a definitive sign of chronic infection because approximately one-third of people clear HCV from their system within the first six months after becoming infected.

- Even if you clear the virus on your own or achieve an undetectable viral load through treatment, you will always test positive for HCV antibodies.

- In order to find out if you are chronically infected with HCV (meaning, the virus is in your body and you can pass it onto others), you need to get a confirmatory test, called a PCR or HCV RNA (viral load) test.

- If results indicate you are chronically infected with HCV, it’s important to see a healthcare provider who is knowledgeable about hepatitis C to regularly monitor and gauge disease progression.

- Some tests (i.e. genotype, viral load) are most useful when determining how well you will respond to HCV treatment. Other tests (i.e. LFTs and ultrasounds) are more effective at monitoring liver health and detecting abnormalities.

- A liver biopsy is considered the “gold standard” because it detects precisely how much liver damage/scarring has occurred.

2.2 Types of Diagnostic Testing

HCV Antibody Test (ELISA or RIBA):
- Detects HCV antibodies in the blood; indicating that at some point you were infected with HCV and your immune system tried to fight it off.

Qualitative Hepatitis C PCR:
- A common test used to confirm whether you are currently infected with HCV by detecting the virus in your system. These results are reported as positive or negative.

Note: A positive result from a HCV antibody test can be confusing for the participant, who may wonder if they are actually chronically infected with hepatitis C and what that means for them. It is important that the HCV antibody test and its limitations are clearly explained. Participants should be encouraged to see a doctor for a confirmatory, PCR/HCV RNA test.

2.3 Deciding when to get tested: pros and cons of knowing your status

Some participants may avoid getting tested because they worry a positive HCV result could add more stress to their lives, strain personal relationships, make them
vulnerable to discrimination, or demand they make difficult lifestyle changes (like eliminating or cutting down their alcohol use).

Here are some potential benefits to getting tested that may help in the decision making process.

- If you know you have hepatitis C, you can take care of your liver by avoiding things that harm it (like alcohol) and by doing things that help it (like eating well and getting vaccinated against hepatitis A and B).

- If you're hepatitis C antibody negative, discovering you're not infected can be a big relief!

- You can't get treated if you don't know you're infected. The sooner you get tested, the sooner you can start exploring whether treatment is right for you.

- If you have HIV, you should be tested for hepatitis C because some HIV medications may harm the liver and HCV often progresses faster in people with HIV.

- Symptoms can't tell you whether or not you have hepatitis C. People who don't feel sick can still have significant liver damage.

Regardless of your HCV status, help keep yourself and others safe by using a clean set and works each time you inject. See Section 1 for more information on safer injection strategies.

2.4 HCV Testing and Monitoring for Chronic Infections

If you are chronically infected with hepatitis C, it is recommended that you receive the following evaluative tests to monitor disease progression, determine how well you will likely respond to treatment, and assess the (ongoing) condition of your liver.

If you have a good relationship with your primary care physician (PCP), you can ask for a referral to a doctor who specializes in liver disease - most likely a hepatologist or gastroenterologist. It can also be helpful to ask friends, family members, case managers, or anyone else you trust for their recommendations. For more information on choosing a provider, being your own patient advocate, and making the most of your medical appointments, refer to www.hcvadvocate.org for helpful fact sheets on being an effective healthcare consumer.

Common HCV Evaluative Tests

Quantitative Hepatitis C PCR (viral load):
- Measures the amount of HCV in your blood, which helps predict how well you will respond to treatment (people with lower levels generally respond better). Results are usually reported as low (less than 2 million copies/\~800,000 IU/mL) or high (over 2 million copies/mL/\~800,000 IU/mL).

Genotype:
- Detects the genetic makeup of your particular strain of virus. If you have genotype 1 (the most common in North America), you will be on treatment for one year (minimally) and there is about a 50% chance of you clearing the
virus. Genotypes 2 and 3 respond best to treatment (about 80%) and you
generally stay on treatment for only six months. Note: Genotypes do not
impact HCV disease progression.

Liver Function Tests (LFTs):
• Measures your level of liver enzymes (which may increase when you have
hepatitis C). ALT and AST are the enzymes that are used to monitor liver
health, but because they fluctuate (if you just drank a beer, they could be
much higher for example, because your liver is working harder to filter the
alcohol), they are not a definitive marker for liver health. People will HCV
should get their levels checks every three to six months.

Liver Biopsy:
• A liver biopsy is considered the gold standard for determining the health of
you liver. After administering local anesthesia to the site, a needle is inserted
into your liver just below the ribs to retrieve a small sample to be examined
by a pathologist. Your results indicate exactly how much scarring has
occurred.

Note: Participants may have reservations and fears around getting a liver biopsy,
causing some to avoid monitoring and treatment altogether. Some may find it
reassuring to know that although a biopsy is a useful test to assess degrees of liver
fibrosis, it is not always required to pursue HCV treatment. Also, encourage
participants who have undergone biopsies to share their experiences. More often
than not, people experience little to no pain, and sometimes hearing that firsthand
can help.

Ultrasound:
• An ultrasound shows a "live" image of your liver, and is typically used to
identify liver cancer and severe abnormalities. This test is limited because it
cannot determine degrees of fibrosis (scarring).

2.5 Discussion Questions

• What concerns do you have about hepatitis C?
• What would be your response if you found out you had hepatitis C?
• When you found out that you were hepatitis C positive, did you have any
further tests to confirm you are currently infected?
• Have you seen a healthcare provider for further monitoring and testing? If so,
what tests did you get done?
• Have you ever had a liver biopsy? What was the experience like?
• Have you ever thought about starting treatment? Why or why not?
• Do you have a doctor that explains things in ways that you can understand?
How does your doctor treat you?
2.6 Activities

**Exercise 1: Long and Short-Term Goal Setting**

This activity gives the facilitator an opportunity to find out exactly how much medical care/monitoring group members have received and also allows the facilitator (and participant) to measure their progress incrementally.

Ask group members to come up with three or four long term goals, as well as the short term goals needed to reach them.

Example:
*Tim has never seen a doctor to assess his hepatitis C infection. After attending group and learning more about hepatitis C, he is becoming increasingly motivated to see a hepatologist and begin regular monitoring: hoping eventually to get treated and clear the virus for good. Tim decided a good long term goal was to begin HCV treatment. His short-term goals included 1) asking the HCV Coordinator for a referral to a hepatologist for evaluative testing 2) continue learning more about treatment by participating in group, reading literature, talking to his doctor, and hearing from people who have been through it; and 3) meeting with his case manager before the next group to get his Medicaid reactivated.*

Have each member share their goals with the group, then make copies for yourself so the group can revisit their goals every couple of months.

**Exercise 2: Taking Charge and Asking Questions**

Many people with hepatitis C never experiences symptoms, and therefore often put off talking about it with their doctors. Some may see primary care physicians who don’t know a lot about hepatitis C and have told them not to worry; that their liver is probably just fine. Others may have doctors who said they can’t get treated while they’re still getting high. This exercise encourages participants to become more active patients and take charge of their health.

Have each group member make a list of questions they want to ask their doctor, like: “What is my genotype”, “What are the chances that treatment will be successful for me?”, “If I start treatment and the side effects are too bad, can I stop and try again later?”. Rather than just having them write questions down on a sheet of paper, you can provide members with a notepad so they have an ongoing “health journal” to jot down their daily thoughts and concerns, new symptoms they are experiencing, side effects from medication, etc.

**Exercise 3: Decision Making – To Know or Not to Know!**

See section [6.6] for exercise on decision making strategies around getting tested and knowing your status.
3.1 Key Messages

- About 15-25% of people infected with HCV clear the virus on their own within the first six months, and the rest (75-80%) will go on to have chronic hepatitis C.

- Liver disease related to chronic hepatitis C usually develops slowly; over 10-30 years.

- Long-term inflammation of the liver can lead to scarring (fibrosis). Scarring makes it harder for your liver to function the way it’s supposed to. The more your liver scars, the less it can do.

- Over time the fibrosis increases; sometimes leading to cirrhosis. Most people who are chronically infected remain stable for years. About 5-20% of people living with HCV develop cirrhosis within 30 years.

- You can have liver damage and no symptoms - that’s why it is so important to get checked out by a doctor even if you are not feeling sick. Symptoms often will not appear unless serious liver damage has occurred.

3.2 Functions of the Liver

- The liver is one of the most important organs in our body because it filters everything we breathe, eat, drink, inhale, and inject into our bodies. When we consume things that aren’t good for us, our liver will filter out the toxins and waste before sending it on to other parts of the body.

- The liver also has many other important functions, such as: storing vitamins, minerals, and iron; converting nutrients into energy; regulating levels of sugar and hormones; producing cholesterol; generating platelets, which help clot blood; and making bile necessary for digestion.
• Because the liver plays such an important role in keeping us healthy, when it gets damaged, it can have an ill effect on all our bodily systems. The good news is that the liver has the amazing ability to regenerate, and even when there is (minimal) scarring, it can still function pretty normally.

• Sometimes the scarring can get so severe, however, that the liver stops working properly. That’s why it is so important for people with hepatitis C to avoid things that strain our liver and can lead to further scarring (for more information on liver dos and don’ts, refer to Section Five of this manual).

3.3 Hepatitis C and the Liver

• Hepatitis means "inflammation of the liver". It is usually caused by one of three viruses: Hepatitis A, B, or C. The effects of each virus is different, but in some cases viral hepatitis can lead to cirrhosis (severe scarring) of the liver, eventually causing serious, life-threatening disease, and even liver cancer. Hepatitis can also be caused by heavy long-term alcohol use, some medicines, and certain autoimmune disorders.

• When someone is first infected with HCV, the virus travels to the liver cells and starts to replicate. This causes an immune response, where the body has a chance to clear the virus completely. This can happen sometime in the first six months after being infected and occurs in about 15-25% of people.

---

[Diagram of Natural History of HCV Infection]

*Source: NYC Department of Health*
• A large percentage of people (75-85%) with Hepatitis C never clear the virus out of their system. These people can continue to infect others, and are said to be “chronically infected”.

• When inflammation continues from a chronic infection, it can lead to liver cell death; eventually forming a scar. These scars make it harder for your liver to function the way it is supposed to.

• The liver is capable of repairing itself, but the more liver damage there is, the harder it gets for your liver to regenerate.

• Most people who are chronically infected remain stable for years. Only 5 - 20% of people with HCV develop cirrhosis within 30 years. Each year, 1-4% of people with cirrhosis will go on to develop liver cancer.

3.4 Signs and Symptoms of Hepatitis C

HCV is often called "the silent epidemic" because it progresses slowly and without producing noticeable symptoms. Most symptoms do not appear unless serious liver damage has occurred (usually twenty to thirty years down the road). Sometimes people are asymptomatic even after severe scarring has occurred. Therefore, your symptoms (or lack thereof) are not a direct indicator of how healthy you are. The only way to know for sure is by monitoring your disease progression and liver health with regular visits to your doctor.

Some potential symptoms of hepatitis C include:

• Joint and muscle pain
• Mild stomach pains
• Brain fog
• Nausea/Vomiting
• Depression
• Diarrhea
• Fatigue
• Dark urine
• Trouble sleeping
• Light colored stools
• Loss of appetite
• Jaundice (yellowing of the skin or eyes)

3.5 Discussion Questions

• How soon after you started injecting do you think you were infected with hepatitis C?

• Have you seen a doctor to verify that you are chronically infected? If so, do you have regular check-ups to monitor disease progression?

• Have you ever experienced symptoms related to HCV? What did you do to control or alleviate your symptoms?

• How do you feel about having a chronic illness? Do you think hepatitis C is a serious health threat?
• Have you known someone who has had serious problems with their liver? Do you worry about this happening to you?

3.6 Activities

Exercise 1: Managing Common Symptoms

Split the group into pairs. Distribute a worksheet with two columns: in the first column ask them to list some common symptoms of hepatitis C. In the second column, have partners come up with ideas to manage or alleviate each symptom.

Have everyone share their ideas with the larger group for discussion.

Example

<table>
<thead>
<tr>
<th>Fatigue</th>
<th>Get 7-9 hours of sleep every night. Exercise Eat a healthy balanced diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle aches</td>
<td>Take ibuprofen Stretch</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Keep food you really like around the house Eat small but more frequent meals</td>
</tr>
</tbody>
</table>
"All patients with chronic hepatitis C are potential candidates for antiviral therapy...It is recommended that treatment of active injection drug use be considered on a case-by-case basis, and that active IDU in and of itself not be used to exclude patients from therapy." - National Institute of Health (NIH): Management of Hepatitis C 2002

4.1 Key Messages

- Current HCV treatment consists of Pegylated Interferon and Ribavirin. Depending on factors such as your HIV status and genotype, treatment will last anywhere from 6-12 months.

- The main goals of treatment are to achieve an undetectable HCV viral load six months after finishing treatment and to prevent (or delay) further liver damage.

- How well you respond to treatment is influenced by a number of factors, such as: genotype, HCV viral load, HIV status, degree of liver damage, and ability to take/tolerate the medication consistently.

- The current treatment can have difficult and sometimes serious side effects - but this varies from person to person and can often be reduced by other medications and/or lifestyle changes. If side effects become too much for you to handle, you can stop the treatment and try another time. Talk to your medical providers before making decisions about stopping treatment and be sure to mention any unpleasant side effects you’re experiencing so they can help you manage them.

- Tolerating treatment can be especially difficult (but not impossible) for people facing other life challenges. Having a safe place to rest, a solid support network, and an attentive doctor can make a big difference. Getting treated is rarely urgent - you can choose to postpone it until when you feel most prepared.

- If you are actively using drugs, you are still eligible to receive treatment for HCV. It’s up to you and your doctor to decide if and when beginning treatment is right for you.

4.2 Standard HCV Treatment: What it is and how it works

- Standard HCV treatment is a combination of Pegylated Interferon (taken once weekly by injection into the skin, not the vein) and Ribavirin (pills taken every day). Treatment can last anywhere from 6 months to 12+ months, depending on your HIV status, genotype, and other factors.

- Interferon is a genetically engineered form of immune system proteins found naturally in the human body. Ribavirin is an antiviral medication that in combination with Interferon, has been found to improve treatment response rates.

Note: There are new treatments being trialed that may be more effective and have less side effects. When treatment is not urgent, some individuals may wish to hold off starting the current treatment until these new medications are available.
4.3 Goals of Treatment

- To rid the body of HCV. This is called a Sustained Viral Response (SVR), which means that you have an undetectable HCV viral load 6 months after finishing treatment. Now the damage to your liver stops and it can begin to make repairs (regenerate).

- Delaying disease progression and improving the health of your liver. Even if treatment did not successfully clear the virus from your body, the time you were on treatment gave your liver a rest.

4.4 Why get treated?

- Some people may want to intervene early and rid the virus from their bodies before any damage (or further damage) occurs.

- If you have a lot of liver damage (cirrhosis), to avoid getting really sick or confronting a potential liver transplant, treatment may be critical.

  NOTE: If you have decompensated cirrhosis (where your liver is no longer functioning properly), treatment may no longer be an option because it could make your liver condition worse.

- If you have genotype 2 or 3, your odds of clearing the virus are good.

- If your HIV is under control, you may decide to give treatment a chance because HCV progresses more quickly when you're coinfected. Refer to Section VI on HIV/HCV coinfection for more details.

4.5 Treatment Response Predictors¹

- **If you have Genotype 1** (the most common in North America), you will be on treatment for about one year, and there is about a 50% chance you'll clear the virus. With Genotypes 2 and 3, there is roughly an 80% chance that treatment will be successful and you only need to take it for six months.

- **Race/Ethnicity** - Asians have been shown to respond best to treatment, followed by Caucasians and African Americans. Scientists still do not understand how race affects treatment response, although adherence and socioeconomic factors have been eliminated as possible causes.

- **Liver condition** - The more scarred your liver is, the harder it will be to treat your HCV. Also, people with Steatosis (fatty liver) have lower treatment response rates.

- **Age** - Treatment tends to be more successful in people 40 years or younger. This is possibly because younger people typically have not been infected with HCV as long and they also have stronger immune systems.

¹ Adapted from HCV Treatment: Predictors of Treatment Response; 2006 factsheet; www.hcvadvocate.org
• **Weight** - People who are clinically obese are at risk for faster disease progression and do not respond as well to treatment.

• **Alcohol use** - Drinking alcohol while you are on treatment decreases your chances of attaining an SVR.

• **Adherence** - If you take your medicine on time and as prescribed, you have better odds of clearing the virus. If you have serious side effects, talk to your doctor immediately - the sooner you begin managing them, the less likely a dose reduction will be necessary.

• **HIV** - People with HIV often do not respond as well, and usually need to be treated for a longer period of time.

• **HCV Viral Load** - People with viral loads under 800,000 IU/mL respond better than viral loads over 800,000/mL.

### 4.6 Possible Side Effects of Treatment

Let your doctor know if you experience any side-effects; some could be serious (like anemia) and they can prescribe medications to help you. Also keep in mind that you can stop treatment at any time and try again later - you may tolerate the medication and side effects better in the future.

Some possible side effects include:

• Depression

• Nausea, loss of appetite, weight loss

• Extreme Fatigue

• Temporary hair loss

• Flu-like symptoms

• Anemia

Remember that **everyone is different** - some will have no side effects, some will have a few, and some will have many. Also, there are medications available which can ease or diminish side effects (like ibuprofen for muscle aches or psychiatric medications for depression).

### 4.7 Treatment Readiness - some other things to consider

• Everyone does not need treatment, but everyone needs to get checked out to see if they do.

• Get support; don’t do this alone! Attend a hepatitis C support group, reach out to friends and family, speak to a therapist. Ask for help if you need it!

• Talk to others about how they managed treatment.
• If you are actively using drugs, you can successfully be treated for HCV. If you clear the virus, you are not immune to contracting it again. Refer to Section I for HCV prevention and transmission tips.

• Treatment does not have to begin right away. There is time to learn more and plan carefully. It is rarely an emergency.

4.8 Discussion Questions

• Have you or anyone you've known been on HCV treatment? What was their experience?

• Did you experience any side effects? How did you manage them?

• What factors went in to your decision to get treated (or not)?

• What are your biggest fears or concerns around treatment?

• Have you ever been told by your doctor that you couldn't be treated because you were still getting high (or homeless, drinking alcohol...)? Do you think anyone should be excluded from HCV treatment? Why or why not?

4.9 Activities

Activity 1: Treatment Readiness

Objective: Encouraging group members who have not been treated (or completed treatment but still have HCV) to begin talking about uncertainties and concerns they may have around HCV treatment. It also fosters group unity by identifying mutual emotions and concerns.

Exercise: Go around the circle, asking each participant to tell the group one concern/fear/reservation they may have about starting treatment. If the group is small, go around the circle twice.

Write down what each person shares so that everyone can see the list. After everyone has had a chance to speak, read each point aloud and ask the group to raise their hand if they can relate to that particular fear or concern.

Conclude the group with a discussion about ways to lessen, overcome, or more effectively deal with fears and concerns around treatment (i.e. talk to people who have been through it, learn as much as you can first, take your time).

Activity 2: Treatment Roundtable

Objective: To allow group members the chance to hear firsthand experiences from people who are on/have completed HCV treatment.

Activity: Invite participants who have been through or are currently undergoing treatment share their personal experiences with the group. You can prepare a list of questions for each person to answer, like: what factors went into your decision to
begin treatment? How long were you on it? What was it like? Did you have side effects? How did you manage them? What was administering the medication like? Was it hard remembering to take it everyday?

After each participant shares their personal story, open it up for questions and discussion.

**Activity 3: Pros and Cons of Getting Treated**

Apply treatment readiness decision making skills to *Exercise 1* (6.5).
5.1 Key Messages

- If you are living with hepatitis C, there are many things you can do to slow down disease progression/damage to your liver.

- Drinking alcohol increases the chance and speed of advanced liver disease. Try to eliminate or cut down the amount of alcohol you consume.

- Get vaccinated for hepatitis A and B. Getting these diseases can make your hepatitis C worse.

- See a doctor regularly who understands hepatitis C, and discuss all over-the-counter, prescribed medications and herbal treatments you are taking because some may be toxic to the liver. For example, acetaminophen (Tylenol) in high doses can result in liver toxicity - particularly when mixed with alcohol.

- Be aware that drugs like cocaine, heroin, methadone and buprenorphine are not liver toxic; however some ‘street drugs’ may be cut with other substances that are harmful to the liver.

- Try to maintain a healthy weight and eat a nutritious, balanced diet with plenty of fresh vegetables and whole grains.

- Get regular exercise and develop a stress reduction plan.

5.2 Nutrition

- Drink lots of water. When the liver is stressed, drinking water can help your kidneys share some of the work while ridding the body of toxins.

- Stick to a balanced diet of fresh vegetables, fruits, beans, whole grains, and lean meats.

- Protein is important, but too much can make your liver work overtime. Try to eat fewer dairy products and high protein foods, like red meat (which is also high in iron). Substitute some of your meat intake with beans, lean meats, or meat substitutes.

- Reduce the amount of fast food or processed foods you consume (cookies, cakes, packaged foods with long shelf lives, "instant" foods).

- Try to limit your fat intake. Scientists have discovered that fat can build up around the liver and cause further damage.

- Eat a low-salt diet. Excess salt contributes to bloating, swelling, and water retention - especially in people with cirrhosis.

- Obesity and (uncontrolled) diabetes can aggravate the liver and also make you less responsive to HCV treatment. Getting moderate exercise and adopting a healthier, more balanced diet, can improve insulin sensitivity, ALT levels and overall liver health.
5.3 Alcohol and HCV

- Alcohol is a toxic substance that must be metabolized and excreted by your liver. That’s why if you have hepatitis C and drink alcohol, the risk of developing liver damage increases. The most important step you can take is to stop drinking or reduce the amount of alcohol you consume. Bottom line: if you have hepatitis C, the less you drink the better.

- Often times when asked how much they drink, people will respond “moderately” or “only a couple of drinks a day”. But some people can fit A LOT of alcohol into “a couple of drinks”. If you are trying to limit the amount you drink, it’s helpful to know what a standard drink is.

![WHAT IS A STANDARD DRINK?]

A standard drink contains about 14 grams (about .6 fluid ounces) of pure alcohol. Below are approximate standard drink equivalents.

<table>
<thead>
<tr>
<th>12 oz. of beer or cooler</th>
<th>8.5 oz. of malt liquor</th>
<th>5 oz. of table wine</th>
<th>3.5 oz. of fortified or dessert wine</th>
<th>1.5 oz. of cordial, liqueur, or aperitif</th>
<th>1.5 oz. of brandy (or single jigger)</th>
<th>1.5 oz. of spirits (a single jigger of gin, vodka, whiskey, etc.)</th>
</tr>
</thead>
</table>

Notes: Some of these drinks are sold in containers holding multiple standard drinks. For example, malt liquor is often sold in 16-, 22-, and 40-oz bottles that contain between two and five standard drinks.

Moderate drinking is defined in terms of how many standard drinks you consume in a specific time period. These units differ for men and women since women absorb and metabolize alcohol at different rates – generally requiring less to become intoxicated.

Most drug treatment counselors and medical providers define moderate as follows:

**Men:** 2-3 drinks per day, but less than 14 total per week.
**Women:** 1-2 drinks per day, but less than 7 total per week.

If you’re ready to start reducing or abstaining from alcohol, talk to your doctor about getting tests to determine the current health of your liver and discuss whether prescription medications to help you stop drinking may be helpful. You can also try some of these alcohol reduction strategies and see what works for you.
**Alcohol Reduction Strategies**

- Avoid drinking alone.
- Start off with a non-alcoholic drink.
- Alternate usual drinks with alcohol-free or low alcohol drinks.
- Drink water while drinking alcohol.
- Break the habit of drinking in rounds.
- Have at least two alcohol free days a week and consider increasing the number of alcohol free days each week (note: 1-2 drinks a day is less harmful for the liver than five drinks in three hours).
- Do not drink when you have had a bad day.
- Don’t keep alcohol around your home.
- Drink slowly.
- Substitute drinking with other activities you enjoy doing.
- Avoid situations where there is a pressure to drink.
- Learn how to say no to drinking alcohol when you are in the company of others who are drinking and may pressure you to do likewise.
- Identify the times of day you are prone to drinking alcohol.
- Examine the situations that trigger unhealthy drinking patterns and develop new ways of handling these situations.
- Save the money you would have spent on alcohol in a separate place.
- Use a worksheet for keeping track of cutting down:
  - Set an alcohol limit and write it down.
  - Set a goal.
  - Write down the pros and cons of drinking.
- Celebrate incremental steps in change!

**5.4 Herbs and Supplements**

- Do not take *high doses* of Vitamins A, D, E, or K or take iron supplements - too much can be harmful to you liver.

- Milk thistle acts as an antioxidant, which many believe is helpful to the liver by stimulating the regeneration of liver cells. If you also have HIV, talk to your doctor before taking milk thistle because it may interact with some HIV medications.

- Vitamin E is often used for hepatitis C because it is supposed to assist the liver in detoxifying the blood and slowing down fibrosis (scarring). *NOTE: High doses of vitamin E (more than 800mg a day) can be toxic to the liver.*
• Talk to someone who specializes in therapeutic supplements (i.e. nutritional, herbal, homeopathic). They can help determine what complimentary treatments will be most effective to treat/manage your individual health and wellness needs. Remember to inform your health care providers whenever you start taking herbs or supplements of any kind.

5.5 Discussion Questions

Alcohol
• Are there ways that alcohol (or heroin, crack...) causes problems in your life (i.e. financially, in your relationships, at work)?

• How do you think you could reduce or stop drinking alcohol? Have you tried before? Describe the strategies that worked or didn't work. How can you modify your plan or tactics this time?

• How do you feel right now about your drinking habits? What changes, if any, would you like to see?

• How many days of the week do you drink alcohol? How many drinks on those days do you typically consume?

• What do you see happening five years from now if you continue drinking as you have been? Ten years from now?

• What do you like about drinking alcohol? What don’t you like about it?

Nutrition/Lifestyle
• What are some lifestyle changes you can make to better care for your health? How would you go about implementing these changes? What benefits do you anticipate? Challenges?

• What types of foods do you commonly eat? Why? Are there times when you're triggered to eat even if you're not hungry (like when you're feeling bored, angry, or lonesome)?

• Where can you fit exercise into your daily routine? Are there special circumstances that make increased physical activity difficult for you? What can you do to work around these obstacles?

• Do you feel that your diabetes is under control? What are some things you do (or can do) to better manage it? Do you schedule regular check-ups with your doctor? In what ways has diabetes affected your life?

5.6 Activities

Exercise 1: Food Pyramid

Objective: This exercise gives participants a chance to reflect on the types of foods they usually consume and think about more nutritious “liver-friendly” options to incorporate into their diets.

Supplies: Pens, food pyramid worksheet.
Activity: Distribute a copy of the food pyramid worksheet to each member of the group. Ask them to write down everything they ate in the past two days; listing each food item in the appropriate nutritional category.

Discussion: Where did they notice nutritional deficiencies/excess? What modifications would be needed to better balance their diet? Is adopting a healthier diet important to them? What are some nutritional changes they're willing/ready/planning to make?

Exercise 2: My liver, My life.

Objective: An exercise in positive visualization. As a facilitator this can be an opportunity to bring up nutrition choices and other lifestyle changes that enhance liver health.

Supplies needed: photocopy of liver shape, craft materials (paint, markers, glue, glitter, scissors), stack of old magazines.

Exercise: Supply photocopy of the liver outline. With supplies ask participants to fill in their outlines with whatever they want to make their livers happy (healthy foods, getting more rest, quitting smoking, etc.).

Exercise 3: To Change or Not to Change.

1) Begin by asking each member of the group to identify something about their drug/alcohol use they would like to change (e.g. cutting down on their drinking, using heroin less frequently, switching from injecting to snorting cocaine).

2) Pose some of the discussion questions listed above regarding their feelings about/relationship to alcohol (or drugs) and readiness to change.

3) Have group members complete the "To Change or Not to Change" worksheet.

4) Follow with a discussion about what they discovered or gained perspective on while doing the exercise. What do they see as the downsides/upsides to changing this behavior? How do they feel when they think about actually making this change? Are they ready to implement a plan now? If not, are there smaller changes they could make (or plan for) in the meantime?

Exercise 4: How Much Alcohol am I REALLY Drinking?

Ask group members to self administer either the CAGE or AUDIT assessment tools to explore their patterns of alcohol use. (For copies of the assessments, refer to the Handout/Resources section at the back of this guide.)

Use the discussion questions and standard drink chart to help individuals reflect on their alcohol consumption and the impact it may have on their health and wellbeing.

Use this as an opportunity to review the alcohol reduction tips listed above, and encourage members to share their individual experiences and moderation management techniques.
Section VI: HIV and Hepatitis C Coinfection

6.1 Key Messages

- HCV is ten times easier to transmit than HIV. HCV produces far more copies (so there is a lot more of it in the bloodstream) and can live outside the body for much longer than HIV.

- HIV and HCV are both transmitted through blood-to-blood contact. If you have ever injected drugs and tested positive for either disease, it is important to get tested for both.

- HCV disease progression and liver damage can advance more quickly if you are coinfected with HIV. It is important to find a doctor that understands both diseases and can help you make decisions that keep you healthy.

- Treatment response rates are lower in people coinfected with HIV and hepatitis C; still many have gone through treatment and cleared the virus for good. Even if treatment does not rid your body of the virus, it can still successfully improve the condition of your liver.

6.2 HIV and HCV Transmission: Similarities and Differences

- HIV and hepatitis C can both be transmitted through blood-to-blood contact, but HCV is far more transmissible and can live outside the body longer than HIV.

- Both HIV and HCV can be spread through unprotected sex, but only HIV is considered a sexually transmitted disease. This is because HCV can be transmitted through semen and vaginal fluids, whereas HCV can only be spread through sex if blood is present.

- Unlike hepatitis C, HIV can also be spread from HIV-positive mothers to their babies through breast milk.

<table>
<thead>
<tr>
<th>Infectious Fluids</th>
<th>HIV</th>
<th>HCV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Semen</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Vaginal Fluids</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Breast Milk</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

- Because HCV is ten times easier to transmit than HIV through contact with infected blood, injection drug users (IDUs) are at higher risk for contracting HCV through shared injection equipment and other indirect sources capable of carrying the virus (i.e. infected razors, snorting straws, toothbrushes).

- Mother-to-child transmission (MTCT) during childbirth is a potential risk for both HIV and hepatitis C, however the risks for MTCT are much lower with HCV (<5%); transmission risks increase, however, if the mother is coinfected with HIV.

- Antiretroviral drugs have proven to be effective at both reducing HIV and HCV transmission rates from HIV positive mothers to their infants.
<table>
<thead>
<tr>
<th>Transmission Route</th>
<th>HIV</th>
<th>HCV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Syringes</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Injection equipment - cookers, cotton, water</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Unprotected sex when blood is present</td>
<td>X</td>
<td><strong>0</strong></td>
</tr>
<tr>
<td>Unprotected sex without blood present</td>
<td>X</td>
<td><strong>0</strong></td>
</tr>
<tr>
<td>Crack pipes</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Snorting straws</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Shared household items (razor, toothbrush)</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Mother-to-child Transmission (MTCT) through childbirth</td>
<td>X</td>
<td><strong>0</strong></td>
</tr>
<tr>
<td>MTCT through breast milk</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Blood Transfusions</td>
<td>X (before 1985)</td>
<td>X (before 1992)</td>
</tr>
</tbody>
</table>

* Uncommon transmission route – attributed to <5% of new infections.
* Risk for HCV transmission is greater if the person also has HIV.

6.3 HIV Medications and HCV

- Liver damage can make it harder to tolerate certain HIV drugs, which may result in hepatotoxicity.

- Some HIV medications are less liver friendly than others, but everyone’s body reacts differently. If you are taking HIV medications, it is important to keep regular appointments with your doctor to have your liver enzymes monitored.

6.4 Treatment Issues around Coinfection

- People with HIV usually have higher HCV viral loads, which may impede their response to HCV treatment. However, because hepatitis C progresses faster for those also living with HIV, it is recommended that HCV treatment is started sooner than later, when HIV is under control and the immune system is functioning well.

- Even if treatment does not rid the body of HCV, it can still be beneficial by improving liver health, delaying fibrosis, and also improving HAART tolerability - the less liver damage you have, the better HIV medications will work.

- The HCV treatment duration for coinfected individuals is often longer than for people living with HCV alone - sometimes 18 months or more.

- Treatment response rates tend to be lower in people with CD4 counts less than 240. Also, some side effects from treatment can lower CD4 cells temporarily.

- Because treatment tends to be less successful in coinfected individuals then those mono-infected with just HCV, it is important to get monitored regularly for both diseases and make lifestyle choices that promote good liver health.
6.5 Discussion Questions

Testing
- If you are HIV+ have you been tested for HCV?
- Living with HIV can be stressful in itself. Discovering that you’re chronically infected with two serious illnesses can be downright overwhelming. What are some of the pros and cons of knowing your status?

Monitoring and Treatment
- What are some factors to consider and things you can do when deciding whether to treat HIV or HCV first?
- If you are HIV/HCV coinfected, have you talked to your doctor about monitoring of your liver health or pursuing HCV treatment?
- If the odds are fairly low that someone coinfected with HCV will respond to treatment, why even try at all?
- What are some things you can do to stay healthy if you are coinfected with HIV and HCV?

Disclosure
- Because there is a lot of stigma attached to both diseases, how do you decide whether or not to disclose your status? If you have told people, how/why did you do it? What was the response?
- Have you faced discrimination because of your HIV/HCV status? How did that feel? How did you react?

6.6 Activities

Exercise 1: Healthy Liver, Healthy Body, Healthy Mind.

This is an exercise in positive imagery and useful for generating discussion around liver-friendly lifestyles choices; emphasizing the connection between mind, body and spirit.

Brainstorm with the group about ways someone who is coinfected with both HIV and HCV can help keep their bodies healthy. Break the group into pairs and have them draw an outline of their partner’s body. Ask participants to draw (or collage, paint, write) in their outlines things they can do to improve the health of their bodies, mind and spirit. Give each member a chance to share their artwork with the group. There will be occasions when participants “fill” their body with things they like to consume that are not so liver-friendly. The purpose of this exercise is not to judge participant’s choices, but rather to generate discussion about why they make the choices they do.

Exercise 2: Decision Making – To Know or Not to Know!

If you’re HIV positive, choosing to get tested for HCV (and visa versa) can be a difficult decision to make. Potentially facing another chronic illness can seem so overwhelming that we simply avoid making any decision at all. This exercise will
cultivate decision making skills and help participants who are unsure of their status weigh the pros and cons of getting tested.

Create a worksheet with two columns, labeling one ‘plus’ and the other ‘minus’. In the column underneath ‘plus’, ask group members to write down all the positive outcomes of knowing their status. Underneath ‘minus’ ask them to write down all the negative effects that may come with a positive test result.

By this stage it may already be obvious to them whether or not they should get tested. If it is not, have them assign a positive or negative score to each point subjectively. Then add the totals for each column.

Example: In Emily’s HIV support group they have been learning about hepatitis C and the risks it poses to HIV positive people. Emily has never been tested for HCV. She knows that a lot of her friends have it, and is scared to find out that she does too.

<table>
<thead>
<tr>
<th>Plus</th>
<th>Minus</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I have Hep C, I can start avoiding things that harm my liver (+5)</td>
<td>It could add more stress to my life (-3)</td>
</tr>
<tr>
<td>If I’m HCV-, that will be a big relief (+4)</td>
<td>I would have to stop drinking (-5)</td>
</tr>
<tr>
<td>I can get treated and hopefully clear the virus (+5)</td>
<td>My family would be even more worried about me (-3)</td>
</tr>
<tr>
<td>Total = +14</td>
<td>Total = -11</td>
</tr>
</tbody>
</table>

The table is scored as 14 (Plus) and 11 (Minus). For Emily, the benefits of knowing her HCV status outweigh the potential obstacles.

**Exercise 3: Strategies for Disclosing HIV/HCV Coinfected Status**

Split the group into pairs and place them in concentric circles facing one another. Pose different questions regarding the possible risks of disclosing their status (and strategies to minimize those risks), beginning with the inside group. Give each person a minute to answer, and instruct their partners to sit quietly and listen. After the minute is up, pose the same question to the outside circle. After both parties have answered the question, have the outside circle move a few steps to the right until they are facing the next person on the inside circle. See examples of questions about disclosure above.

This activity encourages the group to think about disclosure and stigma, while fostering active listening skills and allowing everyone to speak and be heard.

Refer to (7.4) for further discussion around disclosure and stigma.

**Exercise 4: Taking Charge and Asking Questions**

Apply HIV/HCV coinfection to Exercise 2 (2.6).
Section VII: Taking Care of Ourselves Emotionally

7.1 Key Messages

- Finding out you have hepatitis C can create a great deal of anxiety; especially when you are informed at an already stressful time in life. Dealing with a chronic illness and potentially shortened life span, often combined with a lack of knowledge about HCV, can lead to feelings of low self-worth, depression, and increased stress.

- There are lifestyle choices we can make to better manage both the disease and the personal impact it has on their lives. Eating nutritious foods and getting adequate rest and exercise can improve the health of your liver, while enhancing overall mental heath and wellness.

- Holding onto stress can make it harder for our bodies to fight hepatitis C. Although we can't completely eliminate stress in our lives, we can adopt strategies to deal with it better.

- Telling others about our HCV status can sometimes be a difficult and scary decision; however there are things we can do and think about ahead of time to make disclosing our status and talking to people about HCV a little easier.

7.2 Stress Management

Holding onto stress can weaken the body’s immune system and contribute to disease progression and ill health. We all experience stress in life. Sometimes it’s from something specific, like the death of a loved one, or the loss of a job. More often the stress stems from something prolonged; like not knowing where our next meal is coming from, living with discrimination, or suffering from low self esteem.

The good news is that we have the power to influence and shape the impact stress has on our health and emotional wellbeing.

Below are some helpful tips to reduce stress and ease symptoms of depression.

- Eat a healthy balanced diet, avoiding fatty, processed foods and excess sugar (including soda). Not only are these foods are hard on our livers, but they also drain our energy. You don’t need a lot of money to eat well – most produce and whole grains are inexpensive and can be stretched a long way.

- Walking is the best overall exercise and helps all bodily processes function better. You don’t need to do a five mile power walk everyday – just take a stroll around the neighborhood, or jump off the train or bus one stop further from home. If you are able, use the stairs rather than an elevator as often as possible.

- Take time to celebrate each incremental step in change - whether it's walking an extra ten minutes a day or eliminating your afternoon soda. Changes you may consider small can have a big impact!

- Close your eyes and focus on your breathing. Try to sit straight and breathe through your nose and into your belly, exhaling slowly. Being present in your body and breath can help you deal with stress.
• Look for those things you haven’t before noticed as you pass familiar scenes and people. Notice what is beautiful, unusual, or striking to your senses. Make no internal comments or judgments – just notice and enjoy.

• Get enough sleep. Adults need 7-9 hours of sleep every night. Too little sleep compromises both your immune system and your mental health.

• Ask a friend for a massage. Massage offers many healing benefits, like calming the nerves, stimulating the elimination of wastes, speeding recovery from illness and injury, and improves your posture, mood, and energy. Remember that you can practice self-massage too.

• Every day try to do something relaxing or creative that you enjoy – read a book, cook a nice meal, play with your kids, or call a friend.

• Reach out to people and take advantage of support groups and individual therapy. Try to avoid “toxic” people who drain your energy. Surround yourself with people who support you, listen to you, and make you feel safe.

7.3 Disclosure & Stigma

You may have concerns about the impact your hepatitis C status will have on significant others, worry about infecting your family and friends, or fear being treated differently and seen as a disease rather than a human being. And because HCV is highly stigmatized, you might keep your status a secret to protect your job or avoid being labeled a “junkie”.

It’s your choice to whom and when you disclose your HCV status. If you are chronically infected, telling people about your disease is something you will deal with throughout your life.

Here are some tips to more effectively communicate your diagnosis to others¹:

• Think about why you’re telling this person. Is it for moral support? To protect them from getting HCV? Why do they need to know? Are they at risk?

• Think about what you need and communicate it to the person you’re telling. Are you just looking for a sympathetic ear? Do you need them to help you get connected to medical care?

• Pick an appropriate time and place to talk. Even if you know a lot about HCV, bring along literature to give them – this will validate what you’re telling them and encourage them to be more informed.

• Be prepared for any reaction. Sometimes people will be caught off guard; especially if they are misinformed or don’t know much about the disease. They might be afraid that you are going die, or worried that they caught it from you. Clearly explain the risk factors and emphasize that HCV is a slowly progressing disease and not a death sentence.

¹ Adapted from The First Year: Hepatitis C; Bruce and Montanarelli, 2002.
7.4 HCV and Depression

There are a number of ways depression can impact people with chronic HCV.

- Sometimes depression sets in soon after we learn about our diagnosis - we may have fears about mortality, getting sick, or passing it onto our spouses and children.

- People with HCV can also suffer from symptoms such as fatigue, malaise, and insomnia. Over time these symptoms can trigger or exacerbate depression.

- A common side effect of interferon and Ribavirin treatment is depression. It is now common to begin patients on an antidepressant before initiating treatment, regardless of their mental health history. Depression can also set in when treatment is over and deemed unsuccessful.

- Depression tends to worsen during the advanced stages of liver disease when symptoms become more severe and individuals are confronting possible liver transplants or even death. Finding ways to cope while we are healthy can better prepare us for potential challenges down the road.

- If your depression is making you feel out of control and hopeless, consider talking to your doctor about medications to help ease your symptoms. If you are having thoughts of death or suicide, see a doctor immediately.

7.5 Discussion Questions

- What are some of feelings you experienced when you first learned you had HCV? How did you learn to cope with or work through these feelings?

- Do you feel differently now about your diagnosis than when you first got your results? How and why has it changed?

- How do you feel about disclosing your HCV status? Who have you told? Why did you tell them? What were the different reactions?

- Do you feel there is a stigma around hepatitis C? Have you ever felt discriminated against because of your status? How did you deal with it?

- Do you feel that stress is affecting your quality of life? What causes you the most stress in life? What things have you tried to help manage it? What makes managing it difficult?
7.6 Activities

**Exercise 1: Disclosing Your Status**

Ask participants to think of one person they need to disclose their status to. Give them time to plan out the conversation - what they hope to achieve by telling this person, what they plan to tell them, etc.

Now break the group into pairs and ask them to role-play the conversation. Make sure partners have a chance to alternate roles, and encourage them to process their feelings with the group when the exercise is over.

**Exercise 2: Stress Reduction Activities**

Get copies of instructional videos for various (low impact) stress reduction activities (yoga, tai chi, light aerobics). This can provide group members with an opportunity to learn and practice new techniques that relax the body and rejuvenate the mind. During the warmer months, take a walk with your group!

**Exercise 3: Identifying Sources of Stress**

*Objective:* To help group members identify individual and mutual source(s) of stress in their lives.

*MATERIALS:* Pens; one copy of "My Stress" activity sheet.

*Activity:*

1) Begin by explaining the impact stress can have on one's health and emotional wellbeing and how identifying the source(s) of stress can help us more effectively cope with and/or find solutions to the problems or situations we are facing. Emphasize that not all stress can be eliminated or even reduced, but that we are all capable of adopting behaviors and strategies to soften the impact it has on our lives.

2) Distribute the "My Stress" self-assessment activity sheet and give members about ten minutes to write down their responses.

3) Encourage members to share the primary stressors they identified. Look for similarities in their responses and highlight two or three for group discussion - exploring why the particular item generated stress for so many of them.

4) End the group by going over some stress reduction tips (7.2) and encourage members to share techniques that have been effective for them.

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2 Adapted from *Group Exercises for Enhancing Social Skills and Self Esteem*; Khalsa 1996.