

Key Messages:

Talking with SSP
participants about
HepC testing and
treatment

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Syringe services programs (SSPs) are essential to hepatitis C virus (HepC) prevention. SSP staff can help participants who may have had limited or negative experiences with the health care system to get HepC testing and treatment. Participants often are more comfortable talking about HepC risk and learning about testing and treatment with SSP staff. Staff can build trusting relationships as they answer participants' questions and help them overcome challenges to obtaining medical care. If your SSP does not offer HepC treatment services, it is recommended that you have at least one referral relationship in place with a provider who does.

This resource is designed to help SSP staff talk about HepC testing and treatment with participants. It was developed for service providers funded by the Massachusetts Department of Public Health Bureau of Infectious Disease and Laboratory Sciences.



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When is a good time to have conversations about HepC?

Any time can be the right time. Normalizing the conversation helps support participants as they make the decisions that work best for them to take care of themselves (and others). Once rapport is established, and a participant knows that a staff member is consistent and trustworthy, conversations about HepC testing and treatment become easier and more natural.

- When a participant is interested in or already practicing other preventive/harm reduction measures:
 - O Celebrate when participants are motivated about their health care! Participants who use SSPs often and who express long-term health goals may be likely to feel ownership over their health care and be motivated to start HepC treatment.
- While discussing infectious disease risk:
 - When participants report risk behaviors such as sharing works, encourage them to get tested.
- During intake:
 - When explaining the services offered at the SSP.

Key Messages

This section contains frequently asked questions (FAQs) about HepC testing and treatment. Answers to each question contain key messages that SSP staff can use during conversations with participants. The goal of these conversations is to convey basic information clearly and minimize participant concerns. Even if every question below doesn't come up in conversation, it's important to cover as much of the information included in the answers as possible.

Note: The messages outlined in this document are intended as a guide. When talking about HepC testing and treatment with SSP participants, use language that they will understand and relate to, rather than repeating the suggestions here word for word.



FAQ: HepC Testing

What is HepC?

• "HepC is a liver infection caused by the hepatitis C virus. It can range from a mild illness lasting a few weeks to a serious, long-term illness."

How is HepC spread?

 "HepC is transmitted through blood-to-blood contact. Some of the most common ways to get HepC include sharing works and getting tattooed with equipment that was not sterilized."

Why is it important to get tested?

- "HepC is common among people who inject drugs."
 - "The most common risk factor for HepC is injection drug use. In Massachusetts in 2021, almost all people who were newly reported with HepC said they had injected drugs at least once in their lives."²
 - "Over half of newly reported cases of HepC in 2021 were among 15–39-year old people who inject drugs."³
- "We encourage everybody to get tested at least once in their lifetime regardless of whether they use drugs. If they have engaged in activities that increase their risk of getting HepC, such as reusing works, we encourage them to get tested at least once a year."
- "Getting tested is beneficial to you and to others in your community. Knowing your status is one way that you can help keep others in your community safe."

How does the testing process work?

"A blood test will be done to determine if you have or have ever had HepC. The testing staff will bring you to a private room or area and draw 2 vials of blood from a vein; you can help us pick the vein that you'd prefer. We like to use your arms if we can and try to avoid more sensitive areas like hands and wrists if possible. It will only take a few minutes (not counting paperwork)."

When will I get my test results?

"We will call you with the results of your lab work in approximately 3-5 business days."
 Note: This response should be tailored based on your SSP's processes.

² MA Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences, Viral Hepatitis Surveillance Program.





¹ "Hepatitis C Questions and Answers for the Public," Centers for Disease Control and Prevention, Last modified July 28, 2020, https://www.cdc.gov/hepatitis/hcv/cfaq.htm#overview

I don't want to get my blood drawn because I don't have good veins anymore. What if the testing staff can't find a good vein?

- "Are there any veins that are better than others? Which veins would you like testing staff to avoid? Which veins are preferable?"
- "We can shine a special light on your skin so we can better see your veins."
- "We recommend drinking water and using a warm compress before the blood draw."
- "Some participants can benefit from some time to rest before testing. This can allow your body to relax if you've been walking or standing for a long time. After you've had a chance to rest, we will be able to feel your veins better."
- "Tell me about your experience accessing your veins. Have you ever used tourniquets or found that drinking water or Gatorade can help make your veins easier to find?"
- "Tell me about your experience getting your blood drawn at a medical site versus at a harm reduction site."

I've had bad experiences in medical settings/with medical providers. What if I don't feel comfortable getting tested for HepC or starting treatment?

- "You deserve to work with providers who treat you with respect and dignity. You deserve to get treated in a space where you feel safe and supported."
- "We can connect you with a health care provider who other participants have had good experiences with."
- "I won't refer you to a provider who you're not comfortable seeing."
- If your SSP offers HepC testing/treatment services on site: "Would you like to meet the provider who you would be working with? You can ask them any questions you may have."
- "Testing is an important first step that you can take. Just knowing your status can lead to less sharing of needles and other behaviors that can spread HepC."
- "It's ok if you're not comfortable getting tested or treated at this time. Please know that staff are here when you're ready."



FAQ: HepC Treatment

What does treatment involve?

• "You will take pills every day for 8–12 weeks, depending on a few factors like other health concerns and conditions."

How often will I need to come for a visit during treatment?

"Your doctor will want to check in to find out how treatment is going, but how often you will need to come for additional blood work will depend on your doctor. Some will only ask you to have additional blood work if you have other conditions like hepatitis B or liver disease. Most doctors will ask you to come in 12 weeks after you finish your treatment so they can do blood work to confirm that you have been cured."

I heard that HepC treatment makes you feel sick; what are the side effects?

- "The old treatment used to cause many side effects and didn't always work. The treatment that's available now is shorter, easier, more tolerable, and more effective than in the past."
- "There is a chance of side effects, but they are treatable and we can talk to your doctor
 if you experience any of them. They are quite minor and can include gastro-intestinal
 (stomach) distress (typically worse at the beginning of treatment and better after the first
 week or so); and headache or exhaustion, both of which usually get better as people get
 used to treatment."

Do I have to stop using drugs to get treated for HepC?

- "No, you do not have to stop using drugs to get treated for HepC. Most people, even those with ongoing injection drug use, can be cured with 8–12 weeks of medication."
- "SSP staff will ask you about what types of medications you are using, but they are only
 asking to make sure that the treatment does not interact with any of them."

How much does HepC treatment cost? Do I have to pay?

"Most people can get HepC treatment costs paid for by insurance and financial assistance."

I tested positive for HepC but I don't feel any symptoms. Why do I need treatment?

- "Every person's body is different. HepC could be progressing in your body and you may not know it."
- "Some people can live with HepC for many years, while it may affect other people's health quickly. It is important to get treated because HepC can be very serious or even deadly, even for young people. Unfortunately, we never know how long it will be before HepC progresses."



- Connect symptoms that a participant may have to what happens in the body when someone has HepC: "Many people think that symptoms like being tired all the time, loss of appetite, and nausea are because of their drug use. They don't realize it could be related to HepC, especially if they don't know they have it."
- "Many people may not think they have HepC symptoms but once they get treated, they
 notice they have more energy and feel better overall."
- Offer general peer testimonials about their experiences with the current HepC treatment regimen. For example:
 - "People have reported that after they finished treatment they felt a lot better."
 - "Other participants have said they don't feel tired anymore and have a lot more energy."
 - "Getting HepC treatment is something that participants associate with taking care
 of themselves. A lot of people are glad and proud that they are able to do this for
 themselves."

Will treatment interact with medications I am currently taking?

- "There are no interactions with common medications for opioid use disorder like methadone and suboxone."
- "There are some interactions with antipsychotics, antiepileptics, and blood pressure, diabetes, reflux, and HIV medicine. Let's talk to your doctor about the potential of any interactions."
- SSP staff can use the user-friendly <u>Hep Drug Interaction Tracker</u> as a reference tool for checking interactions.

Why is it important to be treated for HepC?

- "Treatment cures more than 90% of people with HepC."
- "When someone is cured of HepC, they are no longer able to transmit it to others."
- "If left untreated, HepC can cause serious liver damage."
- "When your organs can't function normally, your risk for overdose is higher."
- "Treatment can improve short-term and prevent long-term HepC-related problems."
 - O Short-term outcomes include: skin disease, fatigue, kidney disease, nerve pain.
 - Long-term outcomes are largely related to liver health.

If I get reinfected with HepC after treatment, can I get treated again?

• "Yes, if you get HepC again, you can get treated again."

What if I have more important things to take care of before I can consider HepC treatment?

• "I understand. How can we work together to figure out how to meet your immediate needs and make it easier for you to get treatment?"

See section on identifying and removing barriers to testing and adherence to treatment (pg. 7).

How will I remember to take my pills every day? How can I keep them safe?

See section on identifying and removing barriers to testing and adherence to treatment (pg. 7).



Sample language

When supporting SSP participants to make decisions about HepC testing and treatment, staff should use a trauma-informed approach and be patient, flexible, and non-judgmental. Motivational interviewing can guide these conversations and ensure that participants are involved in making decisions about HepC testing and treatment. The language outlined in this section will help SSP staff to balance participant-driven goals with HepC-related public health goals.



Trauma-informed Care: "A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization."

Substance Abuse and Mental Health
 Services Administration



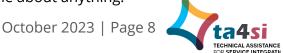
Motivational interviewing is a "collaborative, person-centered counseling approach that aims to strengthen someone's inner motivation for change by exploring and actively considering possibilities for changing one's behavior."

—Justice Resource Institute

Ask permission to begin the conversation:

- "Would you like to hear some information about HepC testing and treatment?"
- "What do you know about HepC treatment? Would you like to learn more?"
- "When was the last time you had an HepC test?"
 - O *If never, or over a year ago:* "Are you open to being tested?"
- It is important to convey that you respect your participant's boundaries, and that your SSP is a place where staff welcome people and encourage honest conversations.

Give permission so that the participant is comfortable asking questions: "If you have questions or worries about HepC testing or treatment, you can ask me about anything."



Ask about behaviors without judgment:

- "When was the last time you used a needle, water, or cotton that someone else used before or after you?"
- "HepC is transmitted through blood-to-blood contact. Have you ever been tattooed with equipment that might not have been sterilized?"

Use wording that is direct and concrete:

• "Do you ever use a cotton or cooker that someone else used before you? When was the last time?"

It is important to ask about all practices/equipment in the injection process. Some participants may not share syringes but may share other injection equipment such as cookers, water, and cotton.

Use language that **motivates participants to be involved in their own care**. Ask questions that make them feel heard and that the care is focused on them. For example:

- "Tell me about your daily routine."
- "Do you already take medication every day?"
- "Do you think that (treatment) is something you could do every day?"
- "How will treatment affect your daily life?"

Maintain a harm reduction, participant-centered approach:

- "What is important to you?"
- "What motivates you to be healthy?"
- "Do you have any health-related goals?"
- Let the participant lead the conversation and respect their autonomy when defining goals.
 If you notice that a participant is trying to change the subject, or if their body language is conveying discomfort, adapt the conversation to make them more comfortable.

Ask open-ended questions to allow the participant to share thoughts, questions, and concerns:

- "What is your understanding of the way HepC is transmitted?"
- "What do you think your risk is for getting HepC?"
- "Tell me about your last HepC test and other tests that went with it."
- "What questions or concerns do you have about HepC testing and treatment?"
- It may be helpful to mention some of the FAQ from pages 3-7, as participants may feel
 negative emotions such as shame or nervousness when directly asked what they do or do
 not know. Also, hearing about common questions may prompt them to think of their own
 questions.

Take cues: Closely listen to and reflect participants' language when you talk with them. This will make them feel that they are part of the conversation, and demonstrate that you are listening carefully, which will help you develop a trusting relationship. For example:

- "What I heard from you is that you don't always have access to new works and sometimes end up sharing with friends."
- "You mentioned that someone you were staying and using with last week might have HepC."
- "I heard you say you needed rigs. Would it be helpful for you to take a few extra bags of rigs with you?"
- "That's really awesome that you've been giving some rigs away to others, that's a great way
 to look out for others in our community."

Normalize:

- "We ask these questions to get a better understanding of people's risks and want everyone to have the chance to get treatment if they need it."
- "Because so many people in SSPs have questions about HepC testing and treatment, I bring this up with all of our participants."

Meet participants where they are: If a participant initially declines testing or treatment, keep the conversation open and ask them to let you know if they change their mind. Check with them again the next time they come in. Let them set the pace and try to make them as comfortable as possible.

- "I understand and support your decision."
- "If you'd like, we can keep talking about this next time you come in."
- "Whenever you're ready, I'm here Monday through Friday, just walk in. I'm here for you and what you need."

Use a **strengths-based approach** to working with participants. Acknowledge that they are taking care of themselves and their community by using the SSP. Safe supplies = HepC prevention!





Identifying and removing barriers to testing and adherence to treatment

When discussing HepC testing and treatment, SSP staff can listen to participants' concerns and tailor counseling to the specific needs of each. SSP participants are the experts on their own lives and navigating the barriers they face. SSP staff can help participants develop a plan to get them through the 8–12 weeks of treatment.

- Consider offering incentives such as gift cards for supermarkets or convenience stores for attending treatment visits or having follow-up labs drawn.
- Try to accommodate the participant's schedule:
 - O Provide flexible appointments/drop-in times.
 - O When a participant comes in regularly, work with the testing team to block time to make sure the participant can get tested quickly and according to their schedule.
 - Conduct HepC treatment follow-up when the participant comes to pick up syringes or use other services.
 - Assess your site's capacity to increase the hours that phlebotomy is available.
- Offer to accompany the participant to the pharmacy, lab, and appointments.
- Provide same-day services to reduce the need for repeated visits.
- Engage participants' friends and offer to test them together. If more than one participant tests positive for HepC they can also get treated at the same time.
- Offer transportation options such as taxi vouchers, <u>Uber Health</u>, or <u>Lyft Healthcare</u> to bring the participant to and from appointments.
- Discuss ways to keep medications safe with participants who are concerned that it may get lost or stolen:
 - Offer medication storage at the SSP.
 - Use nondescript bottles.
 - O Keep only small amounts of pills on their person.
- Establish an adherence plan (e.g., matching HepC to a daily routine, using pill boxes and alarms) that can work no matter the participant's circumstances.

- Verify contact information so if anything comes up you know how to contact the participant and the participant knows how to contact you.
 - O Discuss preferred contact method and frequency.
 - Ensure that participants have access to phones during treatment. If they do not have a
 phone, provide them with a tracfone or phone minutes, or help them set up <u>Assurance</u>
 Wireless or <u>SafeLink</u>.
- Assist participants who need full insurance coverage or help with copays for HepC-related services by submitting MassHealth applications.
 - O The MA HIV/AIDS Drug Assistance Program (HDAP) will cover HepC medications for people with HIV and HepC.
 - O The <u>Gilead Support Path</u> can provide temporary coverage to those who are uninsured.
 - View the <u>Hepatitis C Treatment at a Glance document</u> for more information on insurance coverage.
 - If a participant reports having health insurance but does not have their health insurance card, ask the participant if they need support requesting a new health insurance card or finding out their insurance ID number, and offer to call their insurance company with them.

Resources

- Massachusetts Department of Public Health Hepatitis C Education Materials
- Webinar: Talking with Participants About Hepatitis C Treatment
- CDC Hepatitis C Questions and Answers for the Public
- A Guide to Support Individuals with HIV/ Hepatitis C in Substance Use Service Settings
- Connecting Care Podcast Episodes

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