

BOOKLET 3 OF 3

HEPATITIS C AND HIV CO-INFECTION

Coping with other
aspects of your life

your life matters



P
PROJECT
INFORM

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Finding ways to pay for your health care

Two parts of your health care need to be paid for: your medical visits (doctor, labs, procedures) and your meds. This section is long, but it will help direct you or your case manager to programs that could help with these costs. We cannot explain all programs here, but you can call HELP-4-HEP (1-877-435-7443) for help.

Don't let your ability (or inability) to pay for health care keep you from seeing a doctor, getting tests or deciding to start treatment. There are ways to get this paid for. (For instance, Ryan White and community health centers can serve undocumented people.) The best things you can do are to plan ahead for your care and to keep records of your insurance and contact numbers.

FINDING A BENEFITS COUNSELOR

If you're confused or overwhelmed by how to pay for your care, find a benefits counselor or case manager in your area to help with topics you don't understand. Contact local health departments, clinics or community organizations like AIDS service or legal aid agencies, or dial 211 to find these resources. You can also search online at <http://directory.poz.com> and www.asofinder.com.

SEEING YOUR MEDICAL PROVIDER, GETTING BLOOD WORK

If you have health insurance, call your insurance carrier to see what your policy covers. Important things to check for are: is your doctor covered by your insurance, what drugs related to HIV and HCV does your policy cover, and what are your out-of-pocket costs for things like co-pays and deductibles? These can add up to a lot of money each month. Some assistance programs may help you with your co-pays (see below) and insurance premiums (the money you pay each month for insurance).

If you are uninsured, you can still get medical care. There are more resources for HIV care than there are for HCV, but both are still possible. As stated earlier, the Ryan White Program

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provides HIV care throughout the U.S. and many can help with managing HCV disease. Ask your local health department for clinics in your area. Go online to use the “HIV/AIDS Locator” at <http://locator.aids.gov>. Additionally, most states have an AIDS hotline to help you find local services: <http://hab.hrsa.gov/gethelp/statehotlines.html>.

To prepare for health care reform, some states are expanding their Medicaid programs. Even if you are not disabled, check to see if you qualify for a state or county health care program. Ask a knowledgeable case manager about your options.

If you have VA benefits, contact your local VA clinic, call 1-877-222-8387, or go to www.va.gov for more information. You do not have to use the VA before you get help from Ryan White, but some VA clinics offer good quality care and are very affordable.

KEEPING UP WITH YOUR COVERAGE

Most people who have private insurance get it through employers. If you lose your job or become too sick to work, you should be able to get COBRA insurance. It is good to keep this insurance until you get another job or get disability coverage. COBRA may be expensive but some programs may help you with the costs.

PAYING FOR MEDICATIONS

Private insurance, the VA and some public programs will cover some of the cost of meds. How much you have to pay depends on the type of plan you're in. The next two areas can help both uninsured and under-insured people.

PAPs and Co-Pay Assistance

Most drug companies help people pay for their meds through patient assistance and other programs. You may be limited by certain things, such as your income level, insurance status and

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length of time you can get meds, but they're worth checking into. Go to www.fairpricingcoalition.org/projects/ or ask your doctor's office for a list of contacts.

AIDS Drug Assistance Program (ADAP)

ADAP covers the cost of HIV meds and some other medications that HIV-positive people need, such as some HCV medications. These programs differ from state to state, so talk to a case manager about this.

DISABILITY

Medicaid

This program is run through your state health department and covers doctor visits and meds. It only covers citizens and legal immigrants who have finished a 5-year waiting period. Although some states cover all or some low-income people, others still require that you be *both* low-income *and* disabled. Therefore, people with HIV and HCV often qualify through the “disability” category. You must get this approved through Social Security, as well as meet other requirements such as income and assets. Getting disability can be long and difficult, so find a case manager who can help. If you qualify for SSI (Supplemental Security Income) you automatically qualify for Medicaid. If not, you need to apply for Medicaid as well. HCV Advocate has an excellent benefits section at www.hcvadvocate.org.

Medicare

Medicare is available to people 65 years of age and older and to those who've been getting disability benefits (SSDI) for 24 months. Medicare is a complex program consisting of many parts. It's best to talk to a case manager or benefits counselor to fully understand it and see how you can qualify. Go to www.medicare.gov for more information.

Preparing for and managing side effects

Nearly all medications can cause side effects, including those for HIV and HCV. It's normal to wonder about them, but it's impossible to know which ones you'll experience, if any.

Everyone experiences side effects differently. You may be able to cope with some easier than other people do. On the other hand, something that doesn't bother a friend of yours might be very troublesome for you.

You still want to prepare and plan for possible side effects just in case. That can help you handle them better and keep you on schedule with taking all your medicines as prescribed.

SHORT-TERM SIDE EFFECTS

In general, people with better overall health usually have fewer and milder short-term side effects. In fact, the healthier a person's liver is, the fewer the side effects he/she may have.

Short-term side effects (like headaches, nausea and diarrhea) normally appear within the first few weeks of taking new medicines. They often get better or disappear over time as your body gets used to them. This tends to be truer of HIV meds than HCV meds. HCV treatment can cause ongoing side effects for even the healthiest of people.

Sometimes you can manage side effects by taking other prescriptions. Sometimes over-the-counter products or lifestyle changes can help. Some people find that therapies like acupuncture, herbal products or massage helps them manage symptoms. Talk to your doctor about any that trouble you.

At times, side effects can reappear due to stress or other infections. In fact, the better a person is at managing his or her stress, the better they can cope with side effects as they arise.

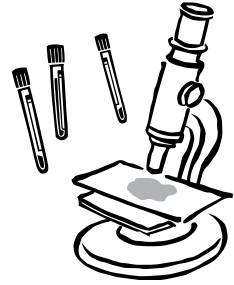


Preparing for and managing side effects

LONG-TERM SIDE EFFECTS

You and your doctor will keep track of long-term side effects by routinely running blood tests and other diagnostic tests. It can be difficult to figure out the cause(s) of some conditions (like diabetes or liver disease).

However, getting physical exams, routine blood and other tests, and talking openly with your provider will help to catch and hopefully prevent or reverse problems.



MOOD-RELATED SIDE EFFECTS

Finally, make sure you keep track of your mood. HCV meds can lead to depression, especially in people with a history of it. Talk to you doctor or therapist about this and if needed, consider taking anti-depressants to help you get through treatment.

Many times, an anti-depressant is prescribed before you start HCV treatment to help prevent depression and to help you cope within the early days of treatment. Use your support network to help you manage and cope with the mental health aspects of treatment ... for both HCV and HIV.

MAIN POINTS TO REMEMBER

- Preparing for side effects can help you deal with them.
- Many side effects are short-term and will pass, but check in with your doctor about any new or troublesome ones.
- Regular blood tests and visits with your doctor will help you prevent long-term side effects.
- If you have a history of depression, or are at risk for it, talk to your doctor or therapist about ways to manage it during treatment, especially HCV treatment.
- Managing stress will help you better deal with side effects.

Drug interactions

Drug interactions are possible whenever you take two or more products together: prescriptions, over-the-counter drugs, herbal products or recreational drugs (including alcohol). The more of these you take, the more interactions can occur. This can lead to more side effects or even make one or more drugs not work as well. Some drug interactions can be very serious and could lead to overdose or organ failure.

If you're only taking HIV meds, then drug interactions are possible with other kinds of medicines, including hormonal birth control and diabetes meds. We know a lot about these interactions, so an experienced medical provider and/or pharmacist can help you prevent these from happening.

If you're going to be taking HIV and HCV meds at the same time, then these drug interactions can be a lot more challenging. Unfortunately, we only know how to "safely" take a few certain HIV meds with the newer HCV medications. And even then, serious drug interactions can occur. Make sure you have a very knowledgeable doctor if you plan to take HIV and HCV meds.

TIPS FOR AVOIDING DRUG INTERACTIONS

- Tell your doctor about all of the drugs and other things you take, like herbs and over-the-counter or recreational drugs.
- Make sure **all** your doctors have the same list of products you take.
- Make sure your provider knows if you are on methadone or buprenorphine for opiate addiction.
- Try to get all your medicines from the same pharmacy to catch drug interactions that might be missed.
- Talk to a pharmacist for a second opinion about all the products you take.
- Use the drug interactions tools at www.hep-druginteractions.org and www.hiv-druginteractions.org.

Adherence and HIV meds

Once you start medications for either HIV or HCV, it's important to take every dose as prescribed. This means taking them at around the same time every day, watching for food restrictions, and paying attention to drug interactions. Make sure you review this with your doctor and pharmacist.

Taking medicines as prescribed is called *adherence*. It's extremely important if the drugs are to do their jobs well and prevent resistance. If you miss doses or entire days of doses, both HIV and HCV have a chance to reproduce again and build resistance to those medications. This may force you to change to other HIV drugs or cause the HCV medicines to fail.

HIV TREATMENT

HIV meds are taken once or twice a day, some with food and others without. They can have side effects, which usually last for 2–6 weeks as your body adjusts to them. To keep your HCV under control, HIV and other medicines should have as little effect on the liver as possible. Make sure you get routine liver function tests.

Take HIV medicines at the same time each day. For example, if you normally take your daily dose at 10p before bedtime, then take it every night at 10p. Prepare for any disruptions: Are you going out and will be late getting home? Then take a dose with you. If you realize that you forgot a dose, take it as soon as you remember. If you forget a dose entirely, never double-dose the next time you have to take one.

MAIN POINTS TO REMEMBER

- Missing doses or entire days of doses increases the risk that HIV and/or HCV may become resistant to your meds, causing them not to work.

Adherence and HCV meds

HCV TREATMENT

Compared to HIV drugs, HCV meds are taken over a short amount of time (normally 6 months to a year). This may motivate you to get through treatment: knowing there's a light at the end of the tunnel.

Stay on schedule with your doses as best you can. HCV side effects can be challenging, so preparing for them and making sure you're physically and emotionally ready is important. If you think you are, talk to your doctor and other support people.

Most co-infected people start on HIV meds first, which gives you time to adjust to taking those pills. Sometimes people take meds for both diseases, which can make it more difficult to build into your routine. In this case, a typical dosing schedule includes: HIV meds taken once or twice a day, one HCV med taken three times a day while another is twice a day, along with a weekly injection of interferon. There are also food requirements that can be difficult (but not impossible) to keep up with.

As challenging as these may sound, you can deal with them with careful planning and support. See page 10 for tips on adhering to both your HIV and HCV regimens.

MAIN POINTS TO REMEMBER

- Take each dose as prescribed at the same time each day and be aware of food restrictions and drug interactions.
- If you forget a dose, take it as soon as you remember. However, never double-dose later. It won't be any better for you and it might just make you sick.
- You take HCV medicines for a limited time, so knowing this might help you to get through it.

Adherence tips

Work the medications into your daily life.

Make the pills a part of your daily routine so you're less likely to miss a dose. What do you do each morning? Or every night? Place them next to your toothbrush. Place them on top of your TV or next to your alarm clock.

Use a pill box.

A pill box, or *medi-set*, is an easy way to organize your meds. Get one that has an “am” and “pm” box and place tablets in each. Check the box as you take your pills. If it's empty, you've taken it. If not, take it on time or ASAP after that time.

Keep a checklist.

Use a daily checklist and mark off each dose as you take it. This works really well when you're using a *medi-set*. Write in the time you took the dose so you'll know when to take the next one.

Use a beeper or alarm.

People use these to remind themselves to take pills. Set your cell phone alarm or watch to go off at the right time. Sign up online at www.care4today.com. Ask your pharmacist about other options.

Arrange for privacy.

If you don't want others to know you're taking medications, make sure you build that into your day. However, taking pills in private can make adherence more difficult.

Ask for help.

If you're comfortable with it and have told others about your status: ask a partner, family member, friend, roommate, etc. to remind you to take your pills.

Remember why you're taking it.

This may sound obvious, but remind yourself why you take these pills: to slow down HIV disease, to cure HCV, and to stay healthy. Each time you take one, you're keeping up your health.

Sexual transmission of hepatitis C

It is believed that getting HCV through sex is rare in HIV-negative people. However, HIV-positive people are at risk for it. The reason(s) for this are unknown.

Sexual activity that causes tears in soft tissue (as in the vagina or rectum) and/or skin may be the cause. If the tear is deep enough, it may expose the partner without HCV to the blood of the person with HCV. This could include sharing sex toys, fisting, whipping, cutting, dry sex or other acts that can cause tears. If menstrual blood is present, this also increases the risk.

It's important to practice safer sex (see TIPS below). If you only have sex with HIV-positive people (*sero-sort*), ask them about their HCV status and when their last test was. If you inject drugs, use clean needles and other equipment and do not share anything, including cottons, cookers, water and even ties.

This is important even if you've been cured of HCV, because you can get the virus again later. They're also important if you partner with HIV-negative people or sero-sort with other HIV-positive partners.

TIPS

- Get tested routinely for HCV and STDs, ideally every 3-6 months or any time you have a symptom.
- Ask sex partners about their HCV status and tell them yours.
- Use condoms, latex gloves for fisting, reduce sex partners, and don't share sex toys.
- Reduce the number of partners you have sex with.



Planning to have a family

Co-infection makes the decision to have a baby more difficult, but it does not mean you can't have one. With careful planning, support and regular medical care, you can greatly reduce the risk of passing HIV and HCV to your newborn.



Four important points:

1. Co-infected women who take HCV meds should not get pregnant during treatment and for up to 3–6 months after it stops. This is because some HCV meds can cause severe birth defects and/or fetal death. Two forms of birth control (such as birth control pill and condom) or one very reliable method (such as IUD or implant) should always be used between the woman and the man.
2. Co-infected men who take HCV meds (and for up to 3–6 months after it stops) also should not get a woman pregnant. HCV meds are found in semen and may get absorbed into the vagina during sex without a condom.
3. The lower the mother's HCV viral load is during pregnancy, labor and delivery, the lower the chance of passing HCV to newborns.
4. Try to find a doctor or doctors who are experienced with pregnancy, HIV and HCV to discuss and fully understand the issues related to transmission.

PREGNANCY

There's about a 5% chance (1 in 20 women) of passing HCV to a newborn during pregnancy when the mother has only HCV. However, in co-infected women the risk goes up to about 25% (1 in 4), and goes up more if she has a high HCV viral load. The good news is that HIV treatment not only greatly reduces the risk of passing HIV, but it appears to lower the risk of HCV as well.

Planning to have a family, *continued*

The US Guidelines recommend that all HIV-positive pregnant women be on HIV treatment, regardless of CD4 count or viral load. To eliminate the risk of passing HCV, you may choose to postpone your pregnancy to go on HCV treatment in the hopes of getting cured.

If you're taking HIV meds and want to get pregnant, talk to your doctor first. Although most HIV meds are probably safe during pregnancy, taking Sustiva (or Atripla) is the exception. This drug is discouraged while trying to get pregnant and during the first few weeks of pregnancy because of possible birth defects.

Co-infected pregnant women may see their liver enzymes increase, especially if your CD4 count is low when you start HIV treatment. Your doctor should check your liver function tests often during pregnancy and tell you about any problems.

LABOR AND DELIVERY

At the time of labor and delivery, there are things you and your doctor can do to reduce the risk of transmission of both viruses. So discuss this with your provider. The lower the HCV viral load during labor, the lower the risk for passing HCV. It is safe to take HIV medicines during labor and delivery.

Your newborn will get HIV meds for a short time to further lower the chance of infection. Your baby will not get HCV meds. Your doctor should test your baby over the first 4–6 months for HIV, and in the first few months for HCV. Babies are tested by using a viral load test, not the typical antibody test.



Planning to have a family, *continued*

BREASTFEEDING

Breastfeeding is not recommended for HIV-positive women. HIV can be passed through breast milk whether or not she's on HIV meds.

Although HCV is not passed through breast milk, it's still possible if the mother's nipples are cracked or brittle. Women also should not breastfeed if they're taking HCV meds. Talk to your medical provider about your options, such as using formula or breast milk from an accredited breast milk bank.



BIRTH CONTROL

Many HIV meds can interact with hormonal birth control pills. This may make the birth control pills not work as well and put you at risk of getting pregnant. Many forms of birth control are safe for HIV-positive women and don't seem to interact with HIV meds. Talk to your doctor about which are best for you.

MAIN POINTS TO REMEMBER

- HIV/HCV co-infected women can have healthy pregnancies and deliver a baby free of HIV and HCV.
- Pregnant women or women trying to get pregnant should not take HCV treatment.
- Pregnancy should not occur until both the woman and man have been off HCV treatment for at least 3-6 months.
- For both women and men, reliable birth control should be used during HCV treatment and up to 3-6 months after it stops.

Co-infection and substance use

Substance use — both legal and illegal — can make it harder to treat HIV and HCV. Some substances (alcohol and HCV) can actually speed up disease progression. Others can prevent your medications to work as well as they could. Finally, it can be a lot harder to remember to take meds if you're under the influence.

Some people think that a person needs to be off all substances in order to take HIV or HCV treatments. Others do not believe that's true. However, if you're using in a way that brings problems into your life, it may be better to hold off on starting treatment. Talk these issues over with a medical provider, therapist, or harm reduction worker who you trust.

The following are some tips for living as healthy as possible while using drugs, for both you and the people you use with.

DON'T SHARE ANYTHING

Both HIV and HCV are passed by sharing things that have blood in or on them. If you inject drugs, don't share anything you use. This includes syringes, obviously, but also all of the other "works" you use: cookers, cotton, water and ties.

HCV is a tough virus. Bleach might kill HIV and even hepatitis B, but not HCV. (Besides, you can't bleach cottons or water.) HCV can live on surfaces for a very long time and still be infectious (even on alcohol wipes). It can live in cookers for up to 16 days and in water for up to 3 weeks! As best you can, use new materials each time you inject. If you re-use works, make sure they're your own by marking them in some way. If you know of syringe exchange programs, make sure you have enough sterile supplies to last, and maybe some extra to pass along to friends.

After you've been treated for HCV, these safe injection practices are still important for you because you can always get re-infected with HCV. Once you're cured, you don't want it again!

Co-infection and substance use, *continued*

ALCOHOL AND HEPATITIS C

Heavy daily alcohol use (50 grams or 4-5 glasses) damages the liver by increasing inflammation and scarring. It also increases HCV viral load, and causes treatment not to work as well or even fail. Also, getting drunk and passing out may lead you to miss doses or think medications aren't a priority.

The less you drink, the better it is for your liver. Quitting can be challenging and — for some people — dangerous. A combination of counseling and Alcoholics Anonymous meetings may work best, while medically supported detox may work for others. Talk to a medical provider or drug treatment counselor to see what options are best for you.

MARIJUANA

Using marijuana is common for both recreational and medical reasons, including its use to help with HIV-related conditions. That said, it is not without its risks. There's some evidence to suggest that daily use in people with HCV can lead to more scarring and damage to the liver. Discuss the benefits and risks with your medical provider, therapist, or a harm reduction worker.

MAIN POINTS TO REMEMBER

- Substance use can lead to problems such as disease progression, drug interactions and adherence problems.
- Don't share any injection equipment, including syringes, cookers, cottons and water.
- Eliminating alcohol can improve liver health, but do it safely.
- Marijuana use can be beneficial, but it may be harmful to some people depending upon the health of your liver.
- Find a medical provider, therapist or harm reduction worker you trust who can discuss non-judgmentally.

Important questions to ask

FOR YOUR DOCTOR:

- How many other co-infected patients do you treat?
- When do you start people on HIV and/or HCV treatment?
- Which one should I do first and why?
- What if I'm not ready to start treatment?
- What could happen if I wait to start treatment?
- What blood tests do I need and how often should I get them?
- What vaccinations should I get and why?
- What do I need to know about drug interactions with the medicines I'm taking?

FOR OTHERS:

- What advice do you have for people living with HIV and HCV?
- Have you done HCV treatment? Why or why not?
- What HIV treatment are you taking, and why?
- How has it been for you to take pills every day? What are the challenges and what do you do to remember to take them?
- Have you had any side effects, and if so, what were they? How did you manage them?
- Where do you go for support?



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