



Next Steps for *Patients*:
An Action Guide on the Newest Treatments
for Chronic Hepatitis C Infection

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Action Steps for Patients

The information in this guide is designed to help patients with hepatitis C, genotype 1 infection. It has information about possible treatments and other things patients can talk about with their doctors. At a public meeting in December 2014, the CTAF Panel reviewed and made judgments on the evidence for treating hepatitis C. A group of doctors, patients, and other experts in managing hepatitis C discussed best practices. The action steps in this guide are based on the CTAF Panel's judgments and on the best practices discussed by experts in the field.

1. Patients should talk to a doctor about treatment options and timing.

The newest treatments for hepatitis C are very effective. In research studies, they removed the virus from the bloodstream in almost all (95-100%) patients for at least 12 weeks. These treatments also have fewer side effects than older treatments. Patients used to need to get care from specialists for older interferon-based treatments that required injections. The new treatments are all pills – no more injections. After there is more experience using these new drugs, some primary care doctors may be able to prescribe the drugs and manage all of your health care. Your primary care doctor may wish to prescribe treatment for you, or they may refer you to a liver specialist for treatment.

Patients without liver fibrosis (scarring) likely have time to think through their treatment options. They should discuss the possible benefits and risks of each treatment option with their doctor. Sometimes, the best option may be waiting to get treatment. Patients may also want to ask about the cost of the drugs. The new drugs may be hard to afford, even with insurance. Because the drugs are very expensive, many health plans are treating patients who are sicker with liver fibrosis (scarring) first. They may also approve treatment sooner for patients who may infect others with the virus through high-risk activities such as using needles for drugs or having sex without a condom. Some health plans may require patients to take a specific drug or set of drugs rather than offering a choice of the new treatments.

Patients and their doctors should decide together when to start treatment by talking through these important issues.

More information on hepatitis C and treatment options may be found at these links. They are listed in alphabetical order:

- American Liver Foundation: <http://hepc.liverfoundation.org>
- Centers for Disease Control and Prevention: <http://www.cdc.gov/Hepatitis/C/index.htm>
- Find a health care provider who evaluates and treats people with liver disorders: <http://hepc.liverfoundation.org/find-a-healthcare-provider/>

- Mayo Clinic: <http://www.mayoclinic.org/diseases-conditions/hepatitis-c/basics/definition/con-20030618>
<http://www.mayoclinic.org/diseases-conditions/hepatitis-c/basics/preparing-for-your-appointment/con-20030618>
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH): http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez/
- Patient Information: Hepatitis C (Beyond the Basics): <http://www.uptodate.com/contents/hepatitis-c-beyond-the-basics>
- Patient Information: Cirrhosis (Beyond the Basics): http://www.uptodate.com/contents/cirrhosis-beyond-the-basics?source=see_link
- US Department of Veterans Affairs (VA): <http://www.hepatitis.va.gov/patient/hcv/index.asp>

2. Patients who begin treatment with the newest hepatitis C drugs need to commit to the entire course of treatment.

For patients to get the full benefit of treatment, they must take all of their prescribed pills. If they do not, the drug can stop working and the virus may stay in their bodies. It is also important to continue taking the drugs so that the hepatitis C virus does not develop resistance to the drugs. The entire treatment can last 8-48 weeks, depending on the treatment that is chosen. Patients should plan ahead to be sure they can afford the copayments for the entire treatment period.

Health care teams may offer programs to help patients take all their pills. Programs may include phone calls from members of the patient's care team, text messages, phone apps, support groups, or other tools. Nurses or pharmacists (doctors who fill drug prescriptions) on a care team can also help patients see if it is safe for them to take their hepatitis drugs along with their other prescriptions or over-the-counter drugs/supplements.

Remember that any treatment, no matter how successful, does not prevent patients from getting re-infected with the virus. Patients can be re-infected if they take part in high-risk activities such as using needles for drugs or having sex without a condom.

Some examples of patient support tools to help patients stay on hepatitis C treatments may be found at these links. They are listed in alphabetical order:

- AbbVie (for patients who take Viekira only, designed to provide personalized treatment support): <https://www.viekira.com/proceed-program>
- Accredo Plus C (a free iPhone application designed to help hepatitis C patients manage treatment): <https://itunes.apple.com/us/app/accredo-plus-c/id885883930?ls=1&mt=8>

3. Seek support for yourself and your family as you are going through treatment.

The newer hepatitis C drugs have fewer side effects as compared to the older ones. But the treatment process can still be difficult for patients, especially for those with more severe liver disease. It may help patients and their families to talk to a social worker or counselor about their health care, housing, food, or employment needs. Patients and families who have a hard time paying for these new drugs may be able to get help through programs offered by the drug manufacturers.

More information on patient assistance programs may be found at these links. They are listed in alphabetical order:

- AbbVie: <https://www.viekira.com/proceed-program>
- Gilead: <http://www.mysupportpath.com/>
- Janssen/Johnson & Johnson: <https://support.olytio.com/co-pay-assistance>
- Partnership for Prescription Assistance: <https://www.pparx.org/>
- Patient Access Network (PAN) Foundation: www.panfoundation.org

4. Help push for lower drug prices.

In the US, the newer hepatitis C drugs can cost from \$63,000 to \$300,000 per patient. There are 3-5 million people in the US infected with hepatitis C, but many do not know they have it. The total cost of treating everyone who has hepatitis C with these new drugs has caused great concern. To pay for the drugs, other health problems may not be treated due to limited funds, or the cost of health insurance may go way up for everyone.

Many groups want lower prices so that more patients can access the treatments they need. These groups include the US Senate Finance Committee, state Medicaid programs, doctors, and advocacy organizations.

More information can be found at these links. They are listed in alphabetical order:

- *Los Angeles Times* article on the high price for hepatitis C drugs: <http://www.latimes.com/business/la-fi-senators-gilead-sciences-20140711-story.html>
- National Association of Medicaid Directors letter to Congress: http://medicaiddirectors.org/sites/medicaiddirectors.org/files/public/namd_sovaldi_letter_to_congress_10-28-14.pdf
- National Coalition on Health Care (NCHC): <http://www.nchcbeta.org/>
- NCHC Campaign for Sustainable Drug Pricing: <http://www.csrpx.org/>

About this Action Guide

Information from research studies is often hard to understand. This Guide is designed to help patients use the results of a recent report on the new drugs for hepatitis C. The report was discussed at a public meeting of the California Technology Assessment Forum (CTAF) on December 18, 2014. An independent group of medical experts from across California reviewed the report. They are practicing doctors, researchers, and patient advocates who meet strict conflict of interest policies. They evaluate research results and vote on the effectiveness and value of care options. When voting, committee members are asked to think like a state Medicaid agency with a fixed budget. The full report with a summary of the discussion and votes is available on the [CTAF website](#).

The content provided here is for informational purposes only. It is not designed to replace professional medical advice.