

Aging and Hepatitis C: An HCSP Guide



HEPATITIS C
SUPPORT PROJECT

Alan Franciscus
Executive Director
Editor-in-Chief, HCSP
Publications

Author
Lucinda K. Porter, RN

Managing Editor / Webmaster
CD Mazoff, PhD

Contact Information
Hepatitis C Support Project
PO Box 427037
San Francisco, CA 94142-7037
alanfranciscus@hcvadvocate.org

The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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Introduction

Hepatitis C virus (HCV) affects all age groups. It is estimated that there are more than 100,000 HCV-positive adults over the age of 70, living in the U.S. The prevalence of those with HCV has remained constant, but the balance is shifting, as patients grow older. In 2011, as Baby Boomers reach retirement age, the U.S. population will have record numbers of aging adults living with HCV.

Modern medicine offers many improvements for the average U.S. resident. Overall, the life expectancy of Americans is increasing. The quality of life is improving for aging adults. Scientists are gaining ground in the areas of viral hepatitis and other liver diseases. Treatment for HCV is easier to tolerate and has better outcomes.

Unfortunately, not much is known about the relationship between aging and chronic HCV infection. In general, aging adults confront different issues than younger adults. The purpose of this guide is to provide information that addresses the needs of older adults living with HCV. Although this guide is aimed at older adults, keep in mind that there is a huge difference between a 65 year old and a 95 year old. This guide is primarily a starting place. The intention is to explore this area and to stimulate a discussion between older HCV patients and their medical team.

Note: Patients receive medical care from doctors, nurse practitioners and physician assistants. For the simplicity, the term “doctor” is used throughout this guide.

Lucinda Porter, RN
Writer, Hepatitis C Support Project
and *HCV Advocate*

1. Hepatitis C

Hepatitis C is a disease caused by the hepatitis C virus (HCV). It primarily affects the liver and over time can harm the liver and health of an individual. Usually it takes a long time to do any damage, especially if the person who has it does not drink alcohol and lives a healthy lifestyle. Sometimes the damage is so minimal that people will go through their entire lives without knowing they have HCV.

2. Coping with an HCV Diagnosis

Most people experience some sort of emotional reaction after being diagnosed with chronic HCV. Fear, anger, sadness, denial and depression are common reactions. Although it is normal to have these short-term reactions, it is not healthy in the long-term.

It is important to get the whole picture. Talk to your doctor about your particular case. Try to establish how long you may have had HCV. People who acquire HCV when they were younger tend to do much better than those who acquired HCV after the age of fifty. Find out if you have mild, moderate, or advanced disease. For instance, if an eighty-five year old with mild disease was exposed forty years ago, the future looks optimistic. Compare this to a sixty-five year old with cirrhosis who had an HCV exposure ten years ago and the picture is less encouraging.

3. Disclosure

For some, disclosure is a sticky issue. HCV is stigmatized for two reasons. First, it is an infectious disease and people may react negatively out of fear of acquiring HCV. Second, injection drug use is the most common route of infection. Some patients do not want to disclose or be associated with injection drug use.

Legally, you are not required to tell anyone.

There are advantages and disadvantages to telling others. Deciding who to tell, when to tell, and how to tell may be complicated. The people you tell may have a strong emotional reaction, usually driven by fear. Before you disclose this information, make sure you have enough facts so you can address their reactions. It may be helpful to have literature on hand to give to them.

Some older adults live in assisted-living programs. You may not want others living in the same facility to know your HCV status. This is perfectly understandable. Think carefully before disclosing to a fellow resident. If the staff knows your HCV status, they are legally bound to protect your privacy. If a staff member violates this, tell the medical director. Your state may have a bill of rights that will tell you how to report privacy violations.

If you receive medical care where blood is involved, you are not required to disclose. Health-care workers use precautions to protect themselves and are at no more risk than the average person is. However, many in the medical and dental profession do appreciate knowing.

Disclosing to a sexual or potential sexual partner is also tricky. Most people do not volunteer this information on a first date. Although sexual transmission of HCV is very low, if a sexual relationship occurs, it is a good idea to be honest about HCV. Keep in mind, that if a long-term relationship develops, your partner might feel angry if you were not honest in the beginning. If you are not honest, be sure you practice safer sex.

When you disclose your HCV status, it is common to be asked, "How did you get it?" How you got HCV is no one's business other than your own. You have the right to be completely honest or to dodge the question. Some patients say they "got it from HCV-infected blood" or "There is no way to know for sure."

4. HCV Symptoms

Some people have little or no symptoms. This could be because they hardly have any liver dam-

age. Unfortunately, it also could be because the liver is a “non-complaining” organ. This means that there could be a lot of liver damage and hardly any symptoms. The most common symptom of HCV is fatigue. Body aches, flu-like symptoms, depression, and abdominal discomfort are also symptoms of HCV.

The issue of symptoms is complicated by the fact that many older adults with or without HCV have these complaints. Aging adults frequently report arthritis, depression, fatigue, sleep problems, memory difficulties, gastrointestinal problems, and dry skin, eyes and mouth. These symptoms also accompany HCV. It is very difficult to tell what is caused by HCV versus what is age-related. Further, these are symptoms of many other medical conditions, so it is important to seek medical help.

5. Prognosis

The age at which HCV was acquired may influence prognosis. Individuals who become infected with HCV at older ages tend to have a worse prognosis than those who acquire HCV while young. Patients over the age of 50 who acquire HCV have a high risk of cirrhosis within 15 years. The National Institutes of Health (NIH) HCV Consensus report lists people over age 40 among those who are more likely to develop HCV-related liver cancer. Age can also have a negative impact on liver transplantation survival. In a study from Spain, Ignacio Herreroa and colleagues reported in the November 2003 issue of the *American Journal of Transplantation* that older liver transplant recipients have a significantly lower survival rate than younger patients.

6. HCV Transmission

There is no data specifically looking at HCV transmission rates in the older population. HCV may be transmitted during activities that involve blood. In order to acquire HCV, a person’s blood

needs to be in contact with HCV-infected blood. This can happen in various ways. Some common ways are from blood transfusions before 1992 and sharing needles or other injection drug utensils. Tattooing is a possible route of infection if contaminated needles or dyes were used. Those who have had a needle-stick injury or mucosal exposure (contact with the mucous membranes of the mouth, vagina, urethra, or rectum) to HCV-positive blood have an occupational risk. There is low risk of acquiring HCV sexually. There are other ways to acquire HCV and it is important to obtain more information about this. It is normal to wonder how you got hepatitis C. However, it can be unhealthy to obsess about this. Try to focus on what you can do for yourself now, rather than on the past.

The rate of infection due to sexual transmission is believed to be quite low in the general population. Presumably, this rate applies to older adults. The risk appears to increase for gay and bisexual men. The same is true for men and women living with HIV. The risk may be higher in the presence of blood, such as during a woman’s menstrual cycle or if there are open sores on one or more of the partners. Sexual transmission rates increase with multiple sexual partners.

7. Protecting Others

The Centers for Disease Control (CDC) does not recommend any changes in sexual practices between monogamous, long-term partners. Current recommendations are that people in stable monogamous relationships do not need to change their sexual practices. Safer sex is recommended for those engaged in sex with multiple partners. Any partner who wants to practice safer sex for whatever reason is encouraged to do so.

Sharing personal items may be a small risk, but it is better to be safe. To protect others, do not share razors, toothbrushes and other tools that may have your blood on it. Always cover any bleeding wounds or sores. If someone helps you with shaving or any grooming where blood

might be present, precautions should be followed to reduce risk of exposure. HCV is not transmitted by hugging, kissing, sneezing, coughing, sharing eating utensils or glasses, or by casual contact.

8. Psychological and Social Issues

Older adults face different psychosocial issues than younger adults do. Loss is a central theme, such as loss of independence, strength, agility and of the ability to perform certain tasks. Death and finding meaning in life take on more importance as people age. Loneliness and grief can bring pain as older adults lose their friends and family members to illness and death.

People living with HCV also cope with difficult issues. Loss of health and fear of death may play a more prominent role in an HCV patient's life. An HCV diagnosis may feel like a double whammy to an aging adult hoping to live in good health during the golden years.

It is recommended that you talk about your thoughts and feelings. You can do this with your doctor, nurse, friends, and family. Talking to others who have HCV may be valuable. Find out if there is an HCV support group in your area. Attend a few times to see if the group is right for you.

Important Note: If you have thoughts of suicide or hurting yourself or others, seek immediate professional help.

For more information about mental health:

- National Foundation For Depressive Illness, Inc
www.depression.org
P.O. Box 2257 New York, NY 10116; (800) 239-1265
- National Institute of Mental Health
www.nimh.nih.gov
Information Resources and Inquiries Branch
6001 Executive Boulevard Room 8184, MSC 9663

Bethesda, MD 20892-9663; (301) 443-4513

- National Alliance for the Mentally Ill (NAMI)
www.nami.org
Colonial Place Three 2107 Wilson Blvd., Suite 300
Arlington, VA 22201;
(800) 950-NAMI (6264) or (703) 524-7600

9. Cognitive Issues

Patients with chronic hepatitis C occasionally report mental or cognitive impairment. Patients refer to this as “brain fog.” This can be especially disconcerting for older adults since Alzheimer’s is a common threat for the aging.

There are many factors that can affect mental sharpness, including stress, depression, and fatigue. If you are experiencing “brain fog,” try to analyze your situation. Are you experiencing stress? Do you have insomnia or other sleep issues? Are you depressed? Do you have any other medical problems or take medications that could cause cognitive impairment? If you answer “no” and your physician has ruled out other causes of impaired cognition, here are some tools to try:

- Be organized; keep lists
- Always put your keys and eyeglasses in the same place
- Challenge your brain; for example, do arithmetic in your head or on paper rather than using a calculator
- Play games, such as crossword puzzles and other word games
- Keep learning
- Learn to laugh at yourself

10. Sexuality

Healthy sexuality can be impaired by many factors. How you feel, both emotionally and physically, may influence how you feel sexually. Older

adults with HCV may find multiple barriers to sexual expression. Pain, fatigue, illness, medications, and fear of transmitting HCV to a partner can present obstacles.

Vaginal dryness can be a problem for post-menopausal women. HCV treatment can contribute to vaginal dryness. This may lead to uncomfortable intercourse. Lubricants may provide relief. If you rely on condoms for protection, never use an oil-based product, such as Vaseline. Oil-based products can break down condoms.

Some patients remark that they have a decreased libido (desire for sex). Patients who are taking certain antidepressants are especially prone to sexual difficulties. Some people have problems with orgasm and arousal. Talk to your medical provider about any sexual concerns. Sometimes there are solutions for these problems.

Pregnancy is not a common issue for adults over 65. However, when HCV treatment is involved, those who have younger fertile partners need to be aware of the “black box warning” imposed on HCV medications. This warning states that two forms of reliable birth control need to be used between couples during and including six months after HCV treatment. For example, a 65-year-old man undergoing HCV treatment must take precautions if his younger partner is at risk for pregnancy.

If you want information about how to practice and enjoy safer sex, talk to your doctor or nurse.

Additional resources can be found at:

About.com - <http://aids.about.com/od/safersex>
Planned Parenthood. - www.plannedparenthood.org/pp2/portal/medicalinfo/sexualhealth/pub-safe-sex.xml

11. Physical Health

The majority of people will die *with* HCV, not *of* HCV. Naturally, it is important to take care of your liver and to learn how to manage the symptoms of HCV. However, health is a package deal, and taking care of your whole body just makes sense. The leading causes of deaths in

the U.S. are from tobacco, alcohol, obesity, and other lifestyle factors. The number of preventable deaths from other causes is overwhelming compared to HCV-related deaths. For instance, more than 700,000 people in the U.S. die annually from heart disease compared to 8,000-12,000 deaths from HCV. Tobacco use contributes to 440,000 deaths a year. The bottom line: you can optimize your chances of living well and living longer if you take preventive health measures.

12. Nutrition

Try to eat a balanced diet and maintain a healthy weight. Obesity can have a negative impact on the liver, heart and overall health. People living with chronic HCV may have additional reasons to be concerned about body weight. Research shows that obesity is a risk factor for cirrhosis-related death and may increase the risk for fibrosis. In addition, obesity is associated with a poor response to HCV therapy.

Unless your doctor has advised you otherwise, a basic healthy heart diet is a good choice for individuals with chronic hepatitis C.

13. Physical Fitness

One of the essential ingredients for good health is regular exercise. Exercise is known to have a positive effect on a number of medical problems including arthritis, osteoporosis (bone loss), back pain, diabetes, depression, and cardiovascular disease. Certain fitness programs can improve flexibility, balance, tone, strength, and stamina. Being physically active may improve sleep, reduce stress, and enhance the immune system. Exercise also reduces food cravings, burns calories, and can improve your energy level.

Gardening, walking, hiking, dancing and swimming are some common recreational activities. Physical fitness is more likely to be successful if it can be done anywhere, not dependent on the

weather, and fits any budget.

Be sensible about exercise. First, discuss any physical fitness plan with your doctor. Start a new exercise program gradually. Remember to drink water, apply sunscreen, and avoid injuries. Pain is not gain. However, sore muscles may occur. Heat, cold packs, and stretching may be beneficial. Consult your doctor should you have any injuries, and do not exercise if you are feeling ill.

14. Sleep

Sleep is an important aspect of health. The function of sleep is to restore your body. Insufficient sleep can negatively influence daily performance and immune function, and has been linked to traffic accidents. Inadequate or poor quality sleep can lead to daytime tiredness.

The National Sleep Foundation states that the average adult needs 7-9 hours of sleep per night. Older adults tend to have more sleep problems. These may be due to medical, psychological or environmental conditions rather than from the actual aging process. If sleep or daytime fatigue are problems, talk to your doctor. Do not use over-the-counter medications or other people's sleeping pills without a doctor's order.

For more information:

- The National Sleep Foundation
www.sleepfoundation.org
729 15th St., NW, 4th Floor, Washington, D.C.
20005

15. Medications and Supplements

Everything passes through the liver - if you do not want something to go through your liver, do not put it in your mouth, inhale it, or apply it to your skin unless medically ordered. Some medications and supplements can damage the liver. Talk to your doctor or nurse about any drugs you are taking including herbs, vitamins, supple-

ments and drugs bought in a store. Do not use other people's pills without a doctor's order. Older adults sometimes develop vitamin deficiencies, particularly vitamin B-12 and D. Ask your doctor if you need to supplement your diet with vitamins.

16. Substance Use

Some older adults have problems with substance use and abuse. Alcohol consumption can accelerate liver disease progression. It can also reduce the effectiveness of HCV therapy. Heavy drinking is associated with cirrhosis of the liver. It is not yet known whether light or moderate alcohol consumption is harmful to the liver, but most experts recommend that people with HCV should avoid alcohol. People with HCV should also avoid recreational drugs and smoking cigarettes. If you have difficulty abstaining from alcohol, drugs, or tobacco, talk to your doctor or consult one of the following resources:

- Alcoholic Anonymous (AA)
www.alcoholics-anonymous.org

To find an AA group near you, look for "Alcoholics Anonymous" in any telephone directory or contact AA World Service, PO Box 459, New York, NY 10163; (212) 870-3400

- Centers for Disease Control and Prevention
www.cdc.gov/tobacco/how2quit.htm

- Narcotic Anonymous (NA)
www.na.org

To find an NA group near you, look in your local telephone directory or contact NA World Services, PO Box 9999, Van Nuys, CA 91409; (818) 773-9999

17. HCV Treatment

The current treatment for HCV is a regimen of pegylated interferon and ribavirin. This combination has many side effects, can be difficult to endure

and carries some risks. Combine the list of treatment side effects with the list of changes that occur during aging and the overall picture becomes more complicated. Some physicians are reluctant to treat elderly HCV patients. The National Institutes of Health HCV Consensus Report states that patients over the age of 60 years old should be managed on an individual basis.

One of the treatment drugs, pegylated interferon, is given by self-injection. If you have problems with vision or fine motor skills, discuss this with your doctor. If you have any concerns about your ability to self-inject the medication, it may be possible to arrange for someone else to do this. Some insurance plans may cover the cost for a nurse to come to your home.

Life expectancy is a factor for older adults considering HCV treatment. People with family members who live past 100 might lean more towards treatment than someone whose family members die before seventy. Further, a report in the medical press preliminarily suggests that life expectancy may be increased in chronic hepatitis C patients undergoing interferon therapy by preventing liver-related deaths.

Older adults are less likely to respond to current HCV treatment. This can be discouraging. Between the side effects, risks and response rates it is easy to understand why some older patients opt out of treatment.

Regardless of age, treatment decisions are always between the medical team and the patient. These decisions are individualized and based on multiple factors. The impact of age is a component of the decision-making process. Hopefully, as new treatments develop, there will be more and easier to tolerate options available to older adults living with HCV.

18. Managing HCV Treatment Side Effects

Although there is not good research on the subject, older adults tend to have similar side effects

as younger adults do. Side effects can be managed, so it is important to report these to your doctor. Early intervention is usually more successful than waiting until the side effects are severe. Your doctor may recommend medication for your side effects. Some medications work differently in older adults. Make sure your doctor has experience working with older adults.

For more information on HCV side effect management, see:

A Guide to Hepatitis C: Treatment Side Effect Management at www.hcvaadvocate.org

19. Medicare and Health Insurance

If your doctor has recommended HCV treatment, it is important to know what your prescription coverage is before you start treatment. HCV treatment is very expensive. The medication costs around \$30,000 for 48 weeks of treatment. Add the cost of medical visits, lab tests, and medications for side effects and this number can be staggering. If your insurance has a 30% co-pay, your out-of-pocket costs for just the treatment drugs may be around \$9000.

The Medicare Prescription Drug Plan begins coverage in 2006. There are different plans in each of the states. Some states have more than 50 plans from which to choose. Selecting a plan is not an easy task. To choose, be sure your medications are covered by the plan's formulary. Find out what your total cost will be for those medications on the plan that you are considering. The cost of HCV medication may be several thousand dollars plus the cost of monthly premiums.

You may qualify for assistance to help pay for your prescriptions. Some states and local organizations offer assistance. Medicare and the National Council on Aging are excellent resources for finding assistance.

- Medicare
www.medicare.gov/pdphome.asp
Centers for Medicare & Medicaid Services, 7500

Security Boulevard, Baltimore MD 21244-1850;
(800) MEDICARE (800) 633-4227

- National Council on Aging Benefits Check-Up
www.benefitscheckup.org

Pharmaceutical companies also offer services and in certain cases, free drugs for those who qualify. To find out more about general patient assistance programs contact the Partnership for Prescription Assistance at (888) 477-2669 or www.pparx.org/Intro.php

20. Life and Death

The majority of people who have HCV will die *with* it and NOT *of* it. However, if you are an older adult with advanced liver disease, death from HCV is a likely possibility. Ask your doctor to be specific about your future. If your HCV has progressed, ask your doctor how much time you are expected to live.

Whether death is imminent or likely to be a long way off, it is a good idea to do advance health care planning. These are usually called advance directives. Doing this makes the dying process easier for our loved ones. The laws governing advance directives differ from state to state.

For more information:

- U.S. Living Will Registry
www.uslivingwillregistry.com/forms.shtm
523 Westfield Ave., P.O. Box 2789, Westfield, NJ 07091-2789; (800) LIV-WILL (800) 548-9455)

21. Complementary and Alternative Medicine

No herbs, supplements, or alternative treatments have been proven to treat HCV effectively. Some herbs can be harmful and even lethal. Some people have experienced health improvement from acupressure, acupuncture, meditation, Tai Chi, Yoga and other complementary health practices.

See the Fact Sheet page at www.hcvadvocate.org for more information about Complementary and Alternative medicine.

22. Healthy Aging with HCV

The recommendations for a healthy lifestyle apply to both aging and HCV. Here are some suggestions for maintaining a healthy liver and body:

- Cultivate a positive attitude
- See your doctor for regular check-ups
- Get protection from the flu, pneumonia and hepatitis A and B. Talk to your doctor or nurse about immunization for these conditions
- Be careful about mixing any drugs especially with alcohol
- Eat a healthy and well-balanced diet
- Drink generous amounts of water – 6 to 8 glasses a day
- Stay away from raw or undercooked shellfish
- Talk to your doctor or nurse about whether you need to be treated for hepatitis C
- Keep physically fit. Ask your doctor about an exercise program that is right for you.
- Maintain a healthy diet. Eat a low fat, low cholesterol, low sodium high-fiber diet with lots of fruits and vegetables. Try to lose weight sensibly if it's advised
- Aim for 7 to 9 hours of sleep every night
- Learn to manage stress
- Drink generous amounts of water – 6 to 8 glasses a day
- Seek support. Join a support group. Maintain friendships and social contacts
- Engage in activities that actively stimulate your brain
- Maintain a sense of humor

23. Resources

- AARP (American Association for Retired People)
601 E Street NW, Washington, DC 20049
(888) 687-2277
www.aarp.org
- AARP Magazine
www.aarpmagazine.org
- Aging in the Know
The Empire State Building, 350 Fifth Avenue, Suite 801, New York, New York 10118
(800) 563-4916
www.healthinaging.org/agingintheknow
- American Geriatrics Society Foundation for Health in Aging
The Empire State Building, 350 Fifth Avenue, Suite 801, New York, New York 10118
(800) 563-4916
www.healthinaging.org
- Dr. Stall's Educational Website
www.acsu.buffalo.edu/~drstall and <http://geridoc.net>
- Family Doctor
<http://familydoctor.org/x2465.xml>
- Health and Human Services: Administration on Aging
www.aoa.gov/eldfam/eldfam.asp
- National Institute on Aging
National Institute on Aging, Building 31, Room 5C27, 31 Center Drive, MSC 2292, Bethesda, MD 20892;
(301) 496-1752 TTY: (800) 222-4225
www.nia.nih.gov
- The National Academy of Elder Law Attorneys
<http://naela.org/>
- For more information about HCV, visit
www.hcvadvocate.org

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HCSP GUIDES

The Hepatitis C Support Project has published various publications in our "Guide" series. The Guides are available on our Web site www.hcvadvocate.org

A Guide to Understanding and Managing Fatigue – this Guide provides a comprehensive overview of the causes of fatigue as well as simple tips to help manage this often debilitating symptom of HCV).

Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines. This Guide provides the medical provider with the necessary information to help identify and manage hepatitis C positive individuals. (Available in English and Spanish.)

A Guide to Hepatitis and Disability is one of the most comprehensive documents available on how to prepare and file for social security disability. There is additional information on commercial disability insurance, and health insurance.

A Guide to Hepatitis C Treatment Side Effect Management provides information on treatment related side effects and simple tips on how to manage the sides of HCV therapy.

First Steps for the Newly Diagnosed is an HCSP guide designed to help the person who is newly diagnosed with the medical aspects of HCV including a lab tracker, questions to ask your medical provider and more.

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