

Women and Hepatitis C: An HCSP Guide



HEPATITIS C
SUPPORT PROJECT

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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 (HCV) is an equal opportunity virus. It affects men and women from all ethnic backgrounds. In the United States, there is a higher prevalence of HCV among men. Although more people will die with HCV than of HCV, it is a complicated disease with a challenging treatment regimen. Women living with HCV have different issues than HCV-positive men. This guide explores some of these issues.

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

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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.

Women are more likely to clear HCV than men are. This means that after they contracted HCV, their bodies successfully fought it off. They will test positive for HCV antibodies, but further tests will show they do not actually have the hepatitis C virus in the blood.

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. Support groups can help women and men cope with HCV, its treatment, and its effect on their lives. See if there is a support group near where you live. Also, make sure you have your facts right. Talk to your doctor about your particular case. It is important to get the whole picture.

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.

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

“No time for your health today, will result in no health for your time tomorrow.”

if you were not honest in the beginning. If you are not honest, be sure you practice safer sex.

If you receive medical care where blood is involved, you are not required to disclose. Healthcare 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.

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

HCV is often a silent disease. Some people report feeling free of symptoms and are often surprised when they learn they have HCV. Sometimes the only sign of HCV is found when a blood test is done. This may occur when one of the liver enzymes, ALT, is abnormally high. This suggests that the liver might be inflamed, so more lab tests are ordered to find out the reason for the inflammation. Sometimes a person can be HCV+ and have normal ALT levels. This means that their medical providers will not have one of the usual clues that would suggest the need for further testing.

Why is this important for women to know? Some experts believe that the cut-off number for abnormal liver tests should actually be lower for women than the numbers most labs use. If you are a woman with any risk factors for HCV or your liver enzymes are on the high side of normal, get tested.

The most common symptom of HCV is fatigue. Body aches, flu-like symptoms, depression, and abdominal discomfort are also symptoms of HCV. It is common for women to have medical condi-

tions with hepatitis-like symptoms. Menopause, anemia, depression and other health problems have similar symptoms, so it is important to seek medical attention for proper diagnosis.

5. Prognosis

Liver disease tends to progress more slowly in women than in men. Women are less likely to die from HCV than men are. Many factors influence prognosis, such as the age at which HCV was acquired or presence of another infectious disease. Avoiding alcohol is one of the most important steps you can take in order to help your liver. The amounts of alcohol for healthy women (without HCV) are lower than the amounts for men. Women are more susceptible to alcohol related health problems. Add in hepatitis C and you have a recipe for disaster.

Pregnancy does not change HCV progression except if cirrhosis is present. Lab tests measuring liver function (liver enzymes) may fluctuate during pregnancy and post-partum. The amount of virus in the blood (viral load) may also fluctuate during pregnancy. It is recommended that women needing a viral load test should wait until after the postpartum period.

6. HCV Transmission

Note: HCV is not transmitted by hugging, kissing, sneezing, coughing, sharing eating utensils or glasses, or by casual contact.

Transfusion Risks

Pregnancy and reproductive organ problems may need emergency blood transfusions. Prior to 1992, some of the blood supply in the U.S. was contaminated with HCV. It is estimated that 250,000 women are infected with HCV because they received blood for cesarean sections prior to 1992. The blood supply in the U.S. has been very safe since 1992.

Sexual Risks

The rate of infection due to sexual transmission is believed to be quite low. Women who are in exclusively monogamous relationships with men have about a 0-3% risk. The risk may be higher in the presence of blood, such as during a woman's menstrual cycle. 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.

The risk increases if a partner has HIV, hepatitis B (HBV), other sexually transmitted diseases, or open sores, cuts, or wounds. Anal sex may have a higher risk, particularly if any tissue is torn. Oral sex appears to be without risk for HCV.

Over a lifetime, sexual activity between women is 8 – 20 %. There is not much research about the transmission of HCV between women who have sex with women. There is a general assumption that sex between women carries little or no HCV transmission risk. However, although this may be true, this assumption may create a barrier between health educators and their female clients. Often, safer sex options are not discussed, thus putting Lesbians and other women at potential risk.

Any partner who wants to practice safer sex for whatever reason is encouraged to do so. Do not let anyone talk you into doing anything you don't feel comfortable about. "No" is a complete sentence. If you are raped or sexually assaulted, ask the trauma team or other medical provider if you should be tested for HCV, along with other diseases. Your HCV risk may be low, but the value of reassurance may be worth it.

For more information, see HCSP FactSheet *Sexual Transmission of Hepatitis C*.

Occupational Risks

Some predominately-female occupations may have more opportunities for blood-to-blood contact. Some of these are nurses and other health-care workers; those in the janitorial and house-cleaning industries; and those in the cosmetic and personal care industry, such as manicurists, facialists, and so on.

The rate of infection for those in healthcare is close to that of the general population. This is likely due to the strict precautions that healthcare workers follow. *For those who work closely with blood:* know what the safety guidelines are for your work situation. Following them may keep you and others safe.

The sex worker industry employs a significant number of women. Although sexual transmission of HCV is normally low, transmission risks increase because of a number of factors. First, the risk of HCV sexual transmission increases with multiple partners. Second, sex workers are less likely to practice safer sex when engaged in sexual activity with someone who is not a client. Third, some women trade sex for drugs. Drugs and all shared drug paraphernalia can be contaminated with HCV or other organisms. The risks are highest if drugs are injectable, although intranasal (snorting) routes are also risky. Fourth, drug use is more likely to lead to unsafe sex. Finally, sex workers are more likely to engage in unprotected sex if there is additional incentive, either financial or drug-related.

The risk of acquiring HCV increases when there are open sores or co-infection with HBV or HIV. Although there is no guaranteed prevention method, the use of barrier protection is advised. Knowing how to correctly use a condom and spermicide can decrease HCV exposure risks. Sex workers who use injectable drugs are encouraged to learn how to do so safely. Community Needle Exchange and Harm Reduction programs offer education and services that promote safer drug use.

Household Risks

Although there has not been a documented case, in theory HCV can be passed via personal items. Do not share razors, cuticle scissors, nail clippers, toothbrushes or other items that may be exposed to blood. Always cover any bleeding wounds or sores. Feminine hygiene products should be discarded properly. Look at the product information insert for proper disposal recommendations for the sanitary product that you use. Most public restrooms have special disposal units for feminine hygiene products. Carry a zip-lock bag with you in case you need to dispose of a product in the trash. You can use this method at home. If you use services where blood might be present, such as application of permanent eyeliner or deep-pore cleaning facials, exercise precautions to reduce risk of exposure.

Transmission During Pregnancy

The overall risk of mothers infecting their unborn is low with estimates ranging from 0.1% to 6%. This rate increases when women also have HIV or hepatitis B. The rate may be higher for those women who have a higher viral load (a higher amount of virus in their blood). There are no recommendations against pregnancy for women with HCV who are not on HCV treatment and whose partners are not on treatment.

If an HCV+ woman becomes pregnant, she should inform her medical team of her HCV status. The rate of mother-to-infant transmission is roughly the same between vaginal and cesarean section delivery. There may be a higher mother-to-infant transmission risk in cases of prolonged rupture of membranes (more than 6 hours) or internal fetal monitoring. Also called fetal scalp monitoring, this procedure records the fetal heartbeat by threading a thin wire into the soon-to-be-born infant's scalp. Alternative monitoring techniques are available. Rupture of membranes refers to the length of time the bag containing the amniotic fluid is broken before delivery occurs. Women should not be offered a cesarean section delivery solely based on HCV.

Some obstetricians avoid performing amniocentesis on HCV-positive women. This procedure tests for fetal abnormalities by inserting a long slender needle into the pregnant woman's abdomen and withdrawing amniotic fluid. This fluid surrounds the fetus. There is no research to support this avoidance and no recommendations against amniocentesis.

After the birth, the mother should tell her infant's pediatrician. All major medical guidelines recommend routine testing of children born to HCV-positive mothers. Infants can begin life with their mother's HCV antibodies but this does not mean they are HCV-positive. Since infants' immune systems take time to develop, testing should not occur for at least 18 months old.

HCV infection is more common in girls than in boys born of HCV-positive mothers. This may be because, in general, there is a higher rate of male fetal death. If females outlive male fetuses, it makes sense that female HCV-positive fetuses will outlive male ones.

HCV-positive children usually have little or no symptoms. According to the AASLD, disease progression is minimal for the first 20 years of a child's life. Children can be treated with antiviral therapy. The response rate for children is better than the adult rate. Children usually tolerate treatment well, some having little or no side effects. At this point, what the long-term effects are on adults who underwent treatment during childhood is unknown.

Transmission During Breastfeeding

Women should not breastfeed during HCV treatment. Otherwise, there are no recommendations against breastfeeding for HCV+ women. During this time, practice good nipple care. If your nipples are cracked or bleeding, stop breastfeeding until you are healed.

7. Psychological and Social Issues

Women living with HCV may cope with difficult issues. 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.

One area of concern for women with HCV is the issue of passing HCV on to children. HCV is not transmitted with casual contact, such as by hugging and kissing. A woman who is considering pregnancy is probably going to have some fears about this.

The vast majority of HCV-positive women will give birth to HCV-negative infants. Statistics may be reassuring, but the reality is that worry is a constant companion for mothers.

If you go ahead with a pregnancy, it will be a long time before you will know if your baby is HCV-free. You may fret about this. Since worrying does more harm than good, it is wise to keep anxiety to a minimum. Try to think positively. Learn how to relax and manage stress. Take good care of yourself. As an HCV-positive mother, your child will need you to be well. Motherhood lasts a long time and learning how to maintain your health and sanity will benefit your family.

After your child is at least 18 months old, you can request HCV testing. This is a blood test and children do not like to have their blood drawn. If your child needs to have blood drawn for another reason, ask the medical provider to include an HCV antibody test on the lab order.

If your child is HCV-positive, request a referral to a pediatric hepatologist or gastroenterologist. If you are not satisfied, find another provider. It is normal to experience strong emotions when children are diagnosed with any disease. Worry, grief, fear and guilt are common reactions. Start by getting good information and support. Other women have children with HCV or other chronic diseases, so learn from their experiences. Lean on others until you are strong enough to cope. Learn how to manage worry and guilt. These two emotions can do more harm than good.

“A woman who is convinced that she deserves to accept only the best challenges herself to give the best. Then she is living phenomenally.”

— Maya Angelou

You may find out you have HCV long after your children are grown. You may be a grandmother when you find out you have HCV. Experts recommend testing for your children.

It may not be easy to discuss this with them, even if they are adults. Reassure them that their chances of having HCV are very low. If you acquired HCV via injection drug use, you do not have to disclose this or other details to your children.

Above all, take care of yourself. If you feel guilty, forgive yourself. You did not intend for this to happen. Learn how to live with a chronic disease. Join a support group. Seek professional counseling if you have trouble coping or experience depression. Be a role model. Show your child how to live well.

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

8. Sexuality

How you feel, both emotionally and physically, may influence how you feel sexually. Pain, fatigue, illness, medications, and fear of transmitting HCV to a partner may impair healthy sexual expression.

If you or your partner is receiving HCV treatment, 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 man undergoing HCV treatment must take precautions if his 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 are listed at the end of this guide.

9. Physical Health

The majority of HCV-positive 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, 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.

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.

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 your immune system. Exercise also reduces food cravings, burns calories, and can improve your energy level.

Biking, dancing, hiking, gardening, swimming and walking are some common recreational activities. Physical fitness is more likely to be successful if it can be done anywhere, is 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.

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. 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 about sleep, see the Resource section at the end of this guide.

10. Autoimmune Diseases

Approximately 5 to 8% of the population has some sort of autoimmune disease. Roughly, 3 out of 4 of these are women. Autoimmunity is a confused immune system in which our body starts attacking its own cells. Some autoimmune diseases share similar symptoms with HCV. Autoimmunity has been linked to HCV, but the relationship is not well understood.

This sounds frightening, but not all autoimmune diseases are serious if treated. The most common autoimmune disease causes a low thyroid problem. For most people, this can be treated easily. There are other more serious autoimmune diseases, such as lupus. Talk to your medical provider about this, especially if you have a family history of autoimmune diseases.

Treatment with interferon may aggravate autoimmune diseases. Treatment is not recommended if you have certain autoimmune diseases. Your doctor and you need to make sure you can go ahead with HCV treatment and, if so, how to do so safely.

11. Substance Use

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 resources listed at the end of this guide.

12. Hormones and Medications

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. Talk to your doctor or nurse about any drugs you are taking including herbs, vitamins, supplements and drugs bought in a store. Do not use other people's pills without a doctor's order.

Women with HCV want to know if it is okay to take hormones, such as birth control pills or hormone replacement therapy (HRT). From an HCV perspective, the answer is yes. HRT is controversial for other reasons not related to liver disease. Talk to your doctor about this. If your doctor has prescribed hormones, such as HRT, it is okay to continue these during HCV therapy.

If you take medication for menstrual cramps or other causes of pain, ask your medical provider what the best medications are for pain management. Although acetaminophen is generally safe, it can cause liver damage at high doses or if taken with alcohol. Some pain medications, such as hydrocodone are combined with acetaminophen. Find out how to use all medications safely.

13. HCV Treatment and Side Effects

There is effective treatment for HCV. It does not always eliminate the virus, but it is more likely to succeed than to not succeed. Even if HCV is not eliminated, people can still reap some benefit from trying it. 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. Treatment decisions are always between the medical team and the patient.

Women have a better chance of eliminating HCV with treatment than men do. Women have a higher success rate if they complete treatment prior to menopause. If you are a woman thinking about treatment, learn about the risks and ben-

efits of treatment. Above all else, know the warnings about pregnancy and breastfeeding.

Many factors influence when to start HCV treatment. Depending on your situation, treatment can last 24 to 48 weeks, or even longer. Women with children are constantly trying to balance work and family issues. HCV treatment can upset this balance. Above all, make your health a priority. There may not be a perfect time to start, but it is important that you have good support and a life that is somewhat settled and flexible.

Pregnancy

Ribavirin is a category X drug. This means it may cause birth defects or death to a fetus. There are strong warnings against this that apply both to female patients and female partners of patients. Patients are told to use two reliable forms of birth control during HCV treatment and for 6 months after treatment has stopped.

Your doctor or nurse should verify that you are not pregnant immediately before you start treatment. This means taking a pregnancy test. This also holds true if you are the female partner of a man planning to undergo HCV treatment. Sometimes a urine pregnancy test is supplied with HCV medications. If not, you can obtain a test through your doctor or drugstore.

Assuming pregnancy is ruled out, then the goal is to avoid pregnancy throughout treatment and for six months after treatment has been stopped. The guidelines are to use two reliable forms of birth control. Birth control should be used in situations where pregnancy is even remotely possible. This includes women who have had tubal sterilizations

and men have had vasectomies. Technically the only conditions in which pregnancy is impossible are for women who are post-menopausal or who have had a hysterectomy. According to the *Menopause Guidebook* published by the North American Menopause Society, menopause is defined as the permanent end of fertility marked by the absence of any menstrual bleeding for 1 year (assuming there are no other causes).

Notice the use of the word reliable when discussing birth control. Reliable means using medically accepted contraceptive methods and using them correctly. Whatever you choose, make sure you are well-informed on how to use the method correctly. Also, notice the word two. This means that if you use two forms of birth control and one fails, then you have back-up protection. If you are not sure about how to use contraception reliably, talk to your medical provider or contact Planned Parenthood.

If pregnancy occurs during or six months after treatment has stopped, report this immediately. Tell your medical provider. All pregnancies should be reported to the Ribavirin Pregnancy Registry. You or your doctor can do this. This is confidential, free, and important. Additional resources about this subject are listed at the end of this guide.

Some HCV+ women wonder what should come first, pregnancy or HCV treatment? There is no clear answer to this. The rate of successful HCV treatment is better than 50%. Women have a slightly higher successful outcome than men do. Those who are younger also have an advantage. However, if your treatment duration is 48 weeks, that means you need to prevent pregnancy for at least 48 weeks plus another 6 months. Some people don't want to wait that long.

Women who start their family first might want to postpone treatment until their children are older. Current HCV treatment has side effects, such as fatigue and depression. It can be hard to take care of young children if you aren't in good physical

“A strong positive mental attitude will create more miracles than any wonder drug.”

and emotional condition. No matter what age your child or children are, get support while you are undergoing treatment.

Breastfeeding

Nursing mothers who want to undergo HCV treatment must choose either breastfeeding or treatment. They should not do both at the same time.

Menstruation and Menopause

Some women report menstrual irregularities during treatment. These can be anywhere from heavier to lighter periods, fewer or more periods, more PMS or less PMS, and so forth. The point is that there is no one single predictable course during treatment.

Women who are approaching menopause also report changes during treatment. Some have more hot flashes; some have fewer. Women report more bleeding; some say their periods are shorter, fewer and lighter. HCV treatment and menopause/menstrual cycles are areas that have not been well studied.

After menopause, women are at risk for bone loss. Abnormal bone loss is called osteopenia. Osteoporosis means the bone loss is significant enough to create a risk of fracture. A number of factors increase this risk, including smoking and family history. There have been small studies linking ribavirin to bone loss. Not enough is known to come to any conclusions about this.

What is known is that inactivity can also increase bone loss. Patients who are normally physically active, find themselves cutting back on the intensity, frequency, and/or duration of their normal fitness routines. This may leave patients with one less tool for bone loss prevention. Calcium, magnesium, vitamin D and other nutrients are necessary for preventing bone loss. Talk to your medical provider about the dosages that would be suitable for you.

Sexual Issues

HCV treatment can affect your sex life. Current HCV medications can cause vaginal dryness. This can lead to uncomfortable intercourse. Lubricants can 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 women have problems with orgasm and arousal. Talk to your medical provider about any sexual concerns. Sometimes there are solutions for these problems.

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.

Vaginal Infections

Most vaginal infections are caused by a fungus and are commonly called yeast infections. Vaginal infections may occur anytime, particularly during treatment. Women who take antibiotics are especially susceptible to these. The symptoms are itching, burning, a thick, white, cheese-like discharge, pain during intercourse, and sometimes swelling in the vaginal area. See your medical provider if you have a vaginal infection. If you have had a yeast infection before, your provider might make recommendations over the telephone, such as to try an over-the-counter antifungal cream. Learn how to avoid future infections.

14. Managing HCV Treatment Side Effects

Most of the side effects of HCV treatment can be managed. Early intervention is important so the side effects don't become big problems. Some of the side effects are cosmetic in nature. They aren't serious and they may not be painful, but they are bothersome. No one likes to admit they have some vanity. However, no one likes to think about some of the cosmetic changes that occur during treatment.

Anemia

Our bodies rely on hemoglobin (a component of our red blood cells) to carry oxygen to our cells. Women have less hemoglobin than men do. Women who are menstruating can have low hemoglobin levels because of the blood they lose every month. Sometimes this blood loss can cause anemia.

Ribavirin can cause the red blood cells to burst before our bodies have a chance to use them. This is called hemolytic anemia. It is different than other causes of anemia and is treated differently. Because women start with lower hemoglobin levels, they risk becoming anemic quite quickly. Menstruating women are even more vulnerable to this. The dose of ribavirin is determined by body weight, with 165 lbs as the cut-off number. Since women tend to weigh less than men, a woman who weighs 110 lbs might react differently than someone who weighs 160 lbs. During treatment, your medical provider will monitor you for this by ordering regular blood tests. If you are prone to anemia, mention this to your provider.

Depression

Depression is a common side effect of HCV treatment medications. In the general population, women are two times more likely than men to suffer from depression. Depression is a serious medical condition that can be life threatening and

life altering. Talk to your medical provider about this issue and mention if you have a history of depression. Some providers recommend that their patients begin anti-depressant medications prior to treatment.

Cosmetic Side Effects

If you ask women which side effects they fear, hair loss is usually mentioned. Most patients think this means baldness, but nothing could be further from the truth. Hair loss becomes noticeable about 3 months after starting HCV treatment. The loss is evenly distributed around the head and the term "thinning" is a better description of what occurs. Patients notice hair on their brushes, their pillows, or in their sinks long before they notice it missing from their heads. The hair loss is usually not apparent to anyone other than the patient. It is most noticeable on patients who start with thin hair. Patients who have very thick hair may even like the change. Hair can be dull, dry and brittle during HCV treatment.

Unfortunately, another side effect, depression, may also start to set in at about the same time a patient's hair begins to thin. This depression is physiological, caused by the HCV medications. Patients can have a hard time feeling good about themselves because their brains are not making enough "feel good" chemicals. Thinning hair can feel like a final straw.

These side effects will go away after HCV treatment has stopped. Your hair will grow back, your nails will get stronger, and your skin will regain its natural oils. If you lost weight, this will also return to your pre-treatment levels. If you like the weight loss, then you can prevent a weight gain with exercise and diet changes.

The following are some tips for common cosmetic side effects:

Hair Loss

- Try washing your hair less often

- Avoid tight braiding or hair weaves
- If you use chemicals on your hair, ask for the mildest product, or even skip them altogether
- Avoid or reduce your use of hair dryers, curling irons, and rollers
- Keep your hair conditioned; use moisturizers and detangling products
- Use hair products that add body and texture
- Some people swear by Nioxin products, which can be purchased at salons or beauty supply stores. For maximum effect, begin using them before you start treatment
- Comb and brush your hair less; choose a soft brush or wide-tooth comb
- Do not “tease” or “back-comb” your hair
- Try a shorter or different hairstyle
- Protect your hair with a hat, scarf, or hair sunscreen products
- Use a satin pillow when you sleep
- Splurge on hats and scarves that accentuate your best features
- Wear a hair piece or wig

Dry skin/rashes

Dry, itchy skin is a common complaint. Make a commitment to care for your skin at the very beginning of treatment.

- Have all rashes evaluated
- Drink sufficient water
- Avoid soap. Use Cetaphil cleanser or a similar substitute
- Hypoallergenic creams and lotions applied immediately following bathing can reduce dry skin. Creams are generally more effective than lotions. Add a couple of drops of unscented, lightweight oil to the lotion for extra protection
- Use sun protection with a high SPF rating
- Scratching leads to more itching. Avoid scratching, especially with fingernails. Cold packs or pressure can be applied to itchy areas

- Try to avoid chapped lips by lubricating frequently, especially with a product that contains sunscreen
- Injection site redness is extremely common. Rotate injection sites. Report any signs of infection, such as red lines running along your skin, or an area that is swollen or hot to the touch
- If you want to wear a bathing suit that exposes your thighs or a top that shows your midriff, make a choice of one over the other. Injection site redness is so common that it is likely that you will not want to walk around exposing red blotches on your skin. For instance, if you are planning a beach vacation where you want to wear a one-piece bathing suit, confine your injections to your abdomen starting about 4 weeks prior to the event. Start rotating your sites after you return

Dry, Brittle nails

- Keep nails short
- Use hand lotions and creams as much as possible, and especially after your hands have been in water
- Wear gloves to protect hands when doing chores such as dishwashing, cleaning, gardening, or using chemicals
- At bedtime, apply oils or thick creams to your hands. Smear extra on your nails. Wear cotton gloves while you sleep to protect your sheets and clothing
- If you polish your nails, use gentle polish removers
- Avoid nail polish altogether. Use nail strengtheners and buffing
- If you have your nails professionally manicured, know how to keep others as well as yourself safe from blood-borne viruses. See the HCSP Factsheet *Preventing HCV Transmission in Personal Care Setting*

Excessive or Unwanted Weight Loss

- Eat small, frequent meals
- Choose foods that are high in calories and protein. Try products designed to promote weight

gain, such as nutritional supplements. Instant breakfast powders, high-calorie puddings, and “shakes” can be easy to digest. For extra calories, add powdered milk to regular milk, soups, mashed potatoes, hot cereal, and puddings. Peanut butter is an excellent source of nutrition and calories

- Consult a nutritionist for further advice

Support groups can help women and men cope with HCV, its treatment, and its impact on their lives. For more information on HCV side effect management, see: HCSP’s *A Guide to Hepatitis C: Treatment Side Effect Management*.

15. 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.

If you use herbs and other supplements, tell your doctor, even if you think she might disapprove. Although they may seem appealing, a number of herbs can cause harm. Herbs can cause hepatotoxicity (poisoning of the liver), so people with HCV should avoid herbs or use them cautiously with the advice of an expert. Drugs, herbs, and supplements can interact with each other, and may affect various health conditions. People with decompensated cirrhosis should never use herbs.

It is not known whether it is safe to take herbs or other supplements while undergoing HCV treatment. It is also not known if herbs can interfere with HCV medications, possibly affecting the treatment outcome. Until more is known about this, the safe choice is to refrain from supplement use until treatment is completed.

If you do use dietary supplements, become informed and be sure your information is current.

Before you take an herb or supplement, find out if it is compatible with other drugs or supplements you are taking. Verify that the supplement is not contraindicated for any other condition you may have. Apply the same caution and commonsense approach to supplements that you would to any drug.

Never take high doses of vitamins, minerals, or other supplements unless you do so under medical care and it has been cleared by the specialist who is following your liver disease.

Multivitamins and minerals – Choose a no or low iron version unless your doctor wants you to have the additional iron. Do not take extra just because you think you need it. More is not better. Never take more than 25,000 IU of vitamin A. The best way to take vitamins and minerals is by eating a nutritional diet.

Calcium – It will not damage your liver if you take the recommended daily allowance of calcium. Talk to your doctor about the correct dose for your needs.

Black Cohosh – This herb has been approved by Germany’s prestigious Commission E for premenstrual complaints, painful periods, and management of menopause symptoms. In Australia, there were 3 reports of severe hepatitis linked to black cohosh use. Two of these cases resulted in liver failure requiring transplant surgery. Since these cases involved the use of herbal blends mixed with other ingredients besides cohosh, experts do not all agree about this risk. Gastric discomfort is the most common side effect. Black cohosh should not be taken by pregnant or lactating women. Safety is unknown for women with endometriosis, breast or uterine cancer. Black cohosh may interact with a number of other drugs, herbs and dietary supplements.

For more information about herbs and supplements, look under Hepatitis C and Complementary and Alternative Medicine in the Factsheet section at www.hcvadvocate.org.

16. Conclusion

You are not alone. There are millions of women in the world living with hepatitis C. You have already begun the process of learning how to live with HCV by gathering information. Add in good medical care, support and a healthy lifestyle, and you have a formula that may keep you healthy for years to come.

Resources

- Hepatitis C Support Project: www.hcvadvocate.org
- Ribavirin Pregnancy Registry: www.ribavirin-pregnancyregistry.com 1-800-593-2214
- Planned Parenthood: 1-800-230-PLAN or 1-800-230-7526 - www.plannedparenthood.org/pp2/portal/medicalinfo
- Hoffman-La Roche (Pegasys™ and Cogegus™): 1-877-PEGASYS (1-877-734-2797) - www.pegasys.com
- Schering Plough (PegIntron® and Rebetol®): 1-888-HEP-2608 (1-888-437-2608) - www.pegintron.com
- InterMune (Infergen): 1-888-ITMN411 (1-888-486-6411) - www.infergen.com (not normally used for initial treatment)

Mental Health

- National Foundation For Depressive Illness, Inc. P.O. Box 2257 New York, NY 10116; (800) 239-1265 - www.depression.org
- National Institute of Mental Health Information Resources and Inquiries Branch, 6001 Executive Boulevard Room 8184, MSC 9663 Bethesda, MD 20892-9663; (301) 443-4513 - www.nimh.nih.gov
- National Alliance for the Mentally Ill (NAMI), Colonial Place Three 2107 Wilson Blvd., Suite 300 Arlington, VA 22201; (800) 950-NAMI (6264) or (703) 524-7600 - www.nami.org

Safer Sex

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

Sleep

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

Substance Use/Abuse

- Alcoholic Anonymous (AA): 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 - www.alcoholics-anonymous.org
- Centers for Disease Control and Prevention - www.cdc.gov/tobacco/how2quit.htm
- Narcotic Anonymous (NA): 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 - www.na.org

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“Be careful about reading health books. You may die of a misprint.”

– Mark Twain