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wise words

hiv/aids treatment information & advocacy by and for women

Hepatitis C and HIV

Liver problems are common in people living with HIV, be they caused by HIV, drug side effects or other conditions (like hepatitis). Hepatitis is a medical term that means inflammation or swelling of the liver. A virus that attacks the liver can cause hepatitis. There are more than fives types of hepatitis viruses (A through E and G) that can be transmitted through sexual contact, contaminated foods, blood and/or other body fluids.

The majority of liver disease in people with HIV is caused by viruses, especially hepatitis B (HBV) and hepatitis C (HCV). Other common HIV-related conditions that can affect the liver include cytomegalovirus (CMV), Epstein-Barr virus (EBV), *Mycobacterium avium* complex (MAC), toxoplasmosis and histoplasmosis. In addition, many medications used to treat HIV can cause liver problems as a side effect.

Hepatitis C is a major concern that many women living with HIV face. This issue of *Wise Words* focuses on HCV and provides information on diagnosing, treating and living with HCV. For more information about the common forms of viral hepatitis, call our hotline at 1-800-822-7422.

Spotlight on HCV

HCV is transmitted through sharing needles, needle sticks, blood transfusion, organ transplantation or from mother-to-child during child delivery. It may also be spread through sexual contact. Ways to prevent becoming infected with HCV include safer sex practices and making sure needles are sterilized before use. This includes needles used for acupuncture, tattooing and body piercing. There is no vaccine against HCV.

Symptoms of HCV infection can occur 2–8 weeks after initial infection. However, most people infected with HCV may experience little to no symptoms. When symptoms do occur, they can include flu-like symptoms (such as fever, fatigue, muscle and joint pain, nausea and vomiting), dark urine, fatigue, loss of appetite, stomach pain, diarrhea and nausea.

WHEN SYMPTOMS DO OCCUR, THEY CAN BE FLU-LIKE.

In a small percentage of cases (15%), HCV infection is cleared spontaneously. But in most cases, HCV infection becomes *chronic* (lasts for 6 months or more) and slowly damages the liver. Over time, liver damage can lead to serious consequences, including scarring of the liver (*cirrhosis*) and liver cancer.

When the liver is damaged it will try to repair itself which forms small scars, a process called *fibrosis*. A greater amount of fibrosis can indicate more severe and more advanced disease.

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WHAT'S INSIDE WISE

Greetings Wise Women!!

Welcome to the second issue of Wise Words for 2003! In this issue we focus on hepatitis C. Many women living with HIV also live with hepatitis C. This can present many challenges such as side effects and when to start treatment for hepatitis C or HIV. However, with accurate information, a good relationship with your provider and a positive outlook, you can work through these challenges.

If you are living with hepatitis C and HIV, there are a lot of factors to consider when making decisions about therapy. As you make these decisions, remember to take your time and ask as many questions as you can. It's also important to have a strong support system, like family, friends, a case manager or your pastor.

This issue provides information on HCV treatment and care, a guide to help you with your treatment decisions, and some resources for more information on hepatitis C.

As always, if you have comments, suggestions or questions, please contact me at *wise@projectinform.org*. Peace and blessings.

Shalini Eddens

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As liver cells are damaged or die, they release high amounts of certain enzymes into the blood. Two important enzymes are ALT (*alanine aminotransferanse*) and AST (*asparate aminotranferase*). High levels of these enzymes may indicate liver damage. Often times, by the time HCV is diagnosed, the liver is already damaged. HCV, like HIV, is very difficult to treat because it can mutate quickly and escape the natural immune response.

Symptoms of ***chronic*** HCV infection can be very minor to non-existent and may be infrequent. They can include joint pain, fatigue, nausea and loss of appetite. Symptoms of ***end-stage*** liver disease can include fatigue, muscle weakness, nausea, weight loss, dark urine, fluid retention and loss of appetite. In addition, the liver or spleen may be enlarged, which can cause yellowing of the skin and eyes (*jaundice*), muscle wasting, swelling of the ankles and accumulation of fluid in the stomach area, called *ascites*.

There are several types of HCV, called *genotypes*. The most common genotype in the U.S. is genotype 1. Genotype 1 is less responsive to treatment and a person may need to stay on treatment longer.

Antibody tests are initially used to diagnose HCV. These tests detect the presence of antibodies (an immune response to the virus), specific for HCV. There are two kinds of tests: ELISA or EIA (*Enzyme-linked immunosorbent assay*) and RIBA (*Recombinant immunoblot assay*).

Usually an EIA will be done first. The RIBA will be done to confirm the presence of HCV antibodies. Antibody tests do not tell whether the infection is acute (new), chronic (long-term) or completely cleared. If an ELISA test is positive, that means that you have been exposed to HCV, but it doesn't tell you if your body cleared the infection or if has established as a chronic infection.

HCV viral load tests directly measure the amount of HCV in the blood and are primarily used to determine if treatment for HCV is working. Unlike viral load tests for HIV, HCV tests are not as useful in predicting the severity of or risks for disease progression. So HCV viral load tests are not used when considering when to start treatment. In most people with HCV who are not on HCV treatment, viral load can range from 100,000–10,000,000 copies per milliliter of blood (in a teaspoon of blood). A high viral load is considered anything greater than 2 million copies/ml.

Some studies have suggested that people living with both HCV and HIV have higher HCV levels and may progress to HCV-related liver disease, such as liver cancer, faster than people who are only HCV-positive. On the other hand, there are conflicting reports as to whether HCV has any impact on HIV levels or disease progression, although one large study found that people with both HIV and HCV who started anti-HIV therapy had a much smaller rise in CD4+ cell counts compared to people only infected with HIV.

The following pages provide information and tools for considering whether HCV treatment is right for you, factors to consider when making a decision and the risks and benefits to treating and not treating.

A little about the liver ...

The liver is the largest organ in the body and one of the most important. It is located behind the lower right part of your ribs. The liver is like the "processor and distributor" of the body, performing several important functions that keep chemicals in our body in balance and clears toxins.

So why is the liver so important?

- Breaks down and removes harmful substances from the body, like alcohol or poisonous chemicals
- Makes cholesterol
- Makes chemicals that help the blood to clot.
- Makes bile, which aids in digestion
- Makes new proteins (for body growth and general well-being)
- Controls blood volume
- Stores iron reserves, vitamins, sugars, fats, and other minerals from the foods that we eat so they are available as our body's need them
- Is the main source of body heat

Negative HCV test results can occur in people living with HIV who are actually infected with HCV, as their immune systems may not be producing enough antibodies.

HCV treatment and monitoring guide ...

Treatment

Ultimately the primary goal of HCV treatment is a cure. Another goal is to reduce the amount of virus in the blood, preventing and/or slowing progression of the disease and further damage to the liver.

Your body naturally produces the chemical, *alpha interferon*. One of the things that it does is boost the antiviral activity of the immune system. All of the currently approved treatments for chronic hepatitis C are made with some form of alpha interferon. Alpha interferon does not attack HCV directly but helps other cells release chemicals that protect them from attack.

INTERFERON

Alpha interferon can be used either alone or combined with an anti-HCV drug called ribavirin. Combination therapy is much more effective in reducing the hepatitis C viral load to undetectable levels than alpha interferon alone. As a result, it has become the standard of care.

Pegylated interferon is a form of alpha interferon that stays in the body longer than regular interferon. The advantage is the drug does not have to be taken as often. Regular interferon is injected three times a week, while pegylated interferon is taken once a week.

There are two types of pegylated alpha interferons: peg-interferon alfa-2a and alfa-2b. The major difference between the two is how they are dosed. The dose of alfa-2a is the same for all patients, regardless of weight or size. The dosing of alfa-2b is based on an individual's weight.

Short-term side effects of interferon can include flu-like symptoms such as fever, chills, headache, muscle and joint aches and fast heart rate. Side effects that can develop later include tiredness, hair loss, low blood count, trouble with thinking, low white blood cell count (*neutropenia*), moodiness and depression. Severe side effects are rare but can include thyroid disease, depression with suicidal thoughts, seizures, acute heart or kidney failure, eye and lung problems, hearing loss and blood infection.

RIBAVIRIN

Ribavirin is in the drug category called *nucleoside analogues*. It is an oral medication taken twice a day. Using ribavirin alone has not been shown to be effective against hepatitis C, but when it's combined with alpha interferon, studies show greater effectiveness than when using alpha interferon alone.

Anemia can develop while taking ribavirin and may result in kidney failure. However, it has been shown that anemia may go away once the treatment is stopped. In addition, some doctors may prescribe Epoetin Alfa (Procrit), a medication used to treat anemia. Some anti-HIV drugs should be avoided when taking ribavirin.

The National Institutes of Health recommends treating patients with chronic hepatitis C using pegylated alpha interferon together with ribavirin. HCV treatment is taken for 6 months to a year and a half. The length of treatment depends on the choice of treatment (interferon alone or combined with ribavirin), HCV genotype and the person's HCV levels before starting therapy.

For people who choose to treat with peg-interferon alone, the recommended length is 48 weeks (about 1 year), regardless of genotype. For people who choose combination therapy, the length depends on the genotype. In general, people with genotype 2 and 3 respond better to combination therapy and 24 weeks (about 6 months) is usually recommended. On the other hand, people with genotype 1 do not respond as well, and therefore 48 weeks is recommended. People who start at a viral load greater than 2 million have a slower response than people who start at less than 2 million.

Studies show that people living with HIV do not respond as well to HCV therapy as HIV-negative people. If you have both HCV and HIV, your doctor may recommend at least 48 weeks of HCV therapy. This could be due in part to the weakened immune system caused by HIV. In addition, people living with HIV may experience more side effects, for example anemia.

There are many factors to consider as you work with your doctor to monitor your liver health and make decisions about therapy. This can often be overwhelming and confusing. While unanswered questions remain around treating people who are HCV- and HIV-positive, there's information that can help guide your decisions.

The information found on pages 3–5 highlights these factors to consider. It may be a good idea to bring this with you to your doctor's appointment. This information is primarily for people who have never used HCV treatment before. Remember to take your time and don't feel pressured to make decisions about treatment today.

How to monitor HCV and liver health?

GET REGULAR CHECK-UPS AND LAB WORK

Going for regular check-ups and getting lab tests done is a key component of monitoring your liver health.

THE CHECK-UP

The doctor will perform a complete physical, including:

- Examine eyes, ears, mouth.
- Check blood pressure and weight.
- Examine the liver from the outside by pressing gently over the area above the liver. The sound that he or she hears indicates abnormality in the size or position of the liver. If liver is normal, it will be normal in size and not shrunken, enlarged or tender to the touch.

LAB WORK

Lab work includes a series of tests that are done to monitor the health and function of the liver.

Liver Function Tests

These tests measure the level of enzymes produced by the liver, including ALT, AST, LDH, alkaline phosphatase and total bilirubin—the yellow or orange pigment in bile. (High levels of bilirubin can lead to jaundice.)

Blood Platelet Count

Platelets are a part of the blood that is needed for clotting. They travel to the site of an injury where they "stick" to the injured site and help develop a clot or scab to stop the bleeding. A normal blood platelet count is 150,000-440,000. A low count may indicate more advanced disease or risks for uncontrolled bleeding (*hemorrhage*).

Alpha Fetoprotein Level (AFP)

This protein stimulates an immune response. Increased AFP levels can indicate liver damage.

Liver Biopsy

A biopsy is used to confirm the diagnosis of liver damage and determine the amount of damage. This procedure is done in the hospital under local anesthesia. A needle is inserted through the abdomen and into the liver. Then, a sample of liver tissue is removed and examined under a microscope. The primary risk associated with a biopsy is bleeding at the site where the needle was inserted. Many liver specialists recommend having a biopsy performed so that the extent of liver damage can be better understood and used to decide on when to start treatment. It is more common for a liver biopsy to be recommended for people with HCV genotype 1.

Other diagnostic tests that may be done:

- CT scan (a tool that creates pictures of the liver using x-rays and may use a special liquid intravenously to outline the liver)
- Ultrasound (a tool that uses sound waves to create pictures)
- MRI (a tool that creates pictures similar to an x-ray, but uses magnetic rays and may use a special liquid intravenously to outline the liver)

For more information, read Project Inform's *Blood Work: A Useful Tool for Monitoring HIV*.

When do I treat?

In general, when to start HCV therapy is based on each person's individual situation. Current guidelines recommend that people with the following conditions consider starting HCV therapy, as they can be signs of liver damage:

- Increased liver enzymes (ALT)
- A liver biopsy that shows some degree of fibrosis or moderate inflammation

There are different opinions as to when to treat people with chronic HCV infection who show no signs of liver damage. Many liver specialists recommend monitoring the health of the liver and starting treatment when there are signs of damage. For example, if you have normal or slightly above normal levels of ALT with little or no fibrosis, your doctor may recommend postponing treatment and closely monitor your liver health.

As you think about anti-HCV therapy there are several factors to consider that can help guide your decision. It is important to consider each of these points:

- Results of blood tests (elevated ALT levels, etc.)
- Liver biopsy results
- HCV viral load
- HCV genotype
- Overall health
- Readiness to start therapy
- Ability to tolerate the side effects

What to treat first, HCV or HIV?

There is no consensus on how to best treat people who have both HIV and HCV. In general, treating HCV or HIV first will depend on the stage of liver disease and the stage of your HIV disease, for example, your CD4+ cell count and/or HIV viral load.

Many researchers believe it is wise to treat HIV first. However, if liver disease is severe, it is recommended that HCV be treated first. Improving the condition of the liver may allow a person to better tolerate anti-HIV therapies.

When treating HIV first, people benefit from being on anti-HIV therapy for at least one year before starting HCV therapy. Talk with your doctor about selecting an anti-HIV regimen that may be less burdensome on your liver.

A minimum of a 1-to-2 month gap is encouraged between starting HCV and HIV treatment. As the side effects for both HCV and HIV therapies can be difficult to manage, it's not recommended that you start treatment for both at the same time.

How do I know if the treatment is working?

Your doctor will use two time points to determine whether you're responding to treatment or not. The end of treatment response (ETR) is 6–12 months after you start. An effective ETR is when liver functions tests are normal, and there's an undetectable HCV viral load 6–12 months after starting treatment.

The sustained virologic response (SVR) is 6 months after treatment was stopped. An effective SVR is when a person's liver function tests remain normal, and HCV viral load remains undetectable 6 months after stopping therapy.

Some studies also show that even if a person with HIV and HCV does not have a sustained viral response, they may have a slower progression to liver damage and liver cancer with HCV treatment.

Dealing with the side effects

THERAPY CAN BE HARD TO TOLERATE

Anti-HCV therapy can be difficult to tolerate and has a number of side effects. Some people may be able to deal with and manage them while others may not. The degree of difficulty varies for each person. Side effects may only last for a few weeks or months, while others may be long-term.

Identifying strategies to cope with and manage the side effects, *before* you start treatment, may help your decision.

In addition, it's helpful to have a strong support system so those who are close to you will be aware of and perhaps help you cope with the side effects you may experience, particularly irritability, fatigue or depression.

Read Project Inform's publication, *Dealing with Drug Side Effects.*

What anti-HIV drugs should I avoid?

Anti-HIV medications pass through the liver, which can result in an increase in liver enzymes (ALT). However, some are more likely to cause this than others. These can include; d4T (stavudine, Zerit), ddI (didanosine, Videx), and the protease inhibitors, especially ritonavir (Norvir). Talk with your doctor about choosing a regimen that will least likely increase ALT levels.

Pregnancy and hepatitis

CONCERNS FOR PREGNANT AND NURSING MOTHERS

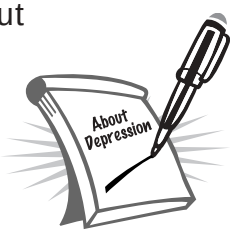
Pregnancy will not speed HCV disease or make it worse. However, if the liver is already damaged or scarred with cirrhosis, the expectant mother could be at risk for fatty liver. (Fatty liver happens when there's not enough of the enzyme that is produced to process fatty acids. This condition can be quite serious and possibly life-threatening.)

There are no preventive therapies to reduce the rate of HCV transmission. The risk of passing HCV to the infant is dependent on two factors:

- ***The mother's HCV viral load:*** If the HCV VL is above 1 million, she's at a greater risk of transmission.
- ***The mother's HIV status:*** If a mother is also HIV-positive, she's more likely to transmit HCV to her infant.

Ribavirin causes severe birth defects, so it cannot be used by pregnant women, women who are breast-feeding or by men whose partners are pregnant. Interferon should not be used during pregnancy, as the effect on the fetus is unknown. For more information, read Project Inform's *Pregnancy and HIV.*

A note about depression



People who have been diagnosed with depression may not be good candidates for anti-HCV therapy. However, taking anti-depressants, attending support groups or therapy may be helpful. Some doctors will recommend that a person with a history of depression be on stable and effective anti-depressant treatment for six months before starting treatment for HCV. Talk with your doctor about getting the proper mental health support.

Read Project Inform's publication, *Wise Words #9: Depression and HIV.*

Other treatment considerations

- If at all possible, work with a doctor experienced in treating people living with both HCV and HIV.
- Always take into consideration other medications that you may be on or other medical conditions you may have and how they may be affected by HCV treatment.
- Alcohol use is very toxic, can further damage your liver, and is a major risk factor for rapid disease progression. Whether you take treatment for HCV or not, it's strongly recommended that you avoid using alcohol. In addition, for people who are heavy drinkers, it's recommended that alcohol is avoided 6 months before starting HCV therapy.

Vaccinations

Vaccinations for both HAV and HBV are recommended. The vaccinations are safe and effective in people living with HIV. Read Project Inform's publication, *Hepatitis*, for more information.

The decision to treat HCV, when to treat and how to manage side effects of treatment, can be difficult. While treating HCV isn't a picnic, end-stage liver disease has far worse side effects and consequences. The only treatment for end-stage liver disease or liver failure is liver transplantation.

Up until recently, hospitals would not perform organ transplants on people living with HIV. Over the past few years, with activist pressure, programs to provide organ transplants to people with HIV have been springing up around the country. The procedure is considered experimental, often difficult to get public or private insurance coverage for and the process for qualifying for an organ transplant is rigid.

Long-term management of a liver transplant requires taking daily, life-long, immune suppressive drugs to prevent rejecting the new liver. These drugs interact with many anti-HIV drugs and must be checked carefully. It's key that blood levels of anti-rejection drugs remain constant. Missing doses of or stopping anti-HIV drugs without the careful support of both an HIV and liver transplant team specialist can alter the blood levels of the anti-rejection medications, which can have serious life-threatening consequences.

in order to qualify for a transplant ...

There are slight variations in eligibility criteria among transplant centers. In general, in order to qualify for a liver transplant, people need to have very advanced liver disease and:

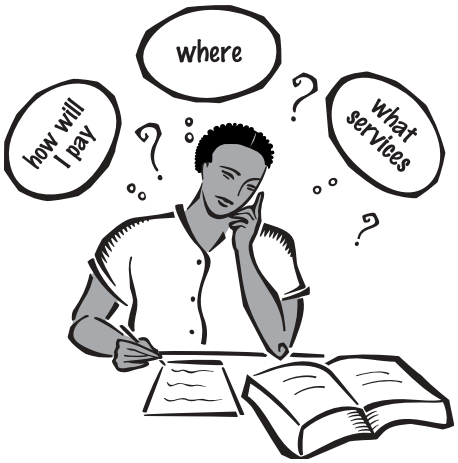
- CD4+ CELL COUNTS CD4+ cell counts above 100 for six months prior to transplantation with no history of active serious life-threatening—OR—if a history (not current) of study-allowed active serious infections and/or cancers, then CD4+ cell counts must be above 200
- HIV LEVELS HIV levels must be optimally controlled (undetectable) by anti-HIV drugs for at least three months prior to transplantation—OR—it must be deemed by HIV experts that an effective anti-HIV regimen is available that is highly likely to control HIV post-transplant.
- PAYMENT A commitment to pay by insurance or other third-party payer coverage is required.
- STABLE LIVING SITUATION People need to show that they have a stable living situation with the support of family and/or friends to help in post-transplant recovery.
- ALCOHOL/DRUG USE Current alcohol or illicit drug use is not allowed and it may be required that transplant candidates participate in a successful alcohol/drug recovery program for at least six months with a long-term commitment to continued sobriety.
- COMMITMENT Commitment to using anti-HIV medications, anti-rejection drugs and various preventive therapies for PCP, fungal infections and herpes post transplantation, as indicated is required.

While liver transplantation provides an option and can save lives, it's certainly not the best, easiest or most optimal way to approach HCV treatment. Unlike treatment for HCV, where support networks are desirable, in the case of transplantation these types of networks and support are fundamentally required. The lifetime cost of a liver transplant far exceeds those for HCV treatment. The challenges of long-term, lifetime use of immune suppressive anti-rejection medications can be far more complicated than HCV treatment. Preventing HCV from progressing to end-stage liver disease and liver failure is far easier, even when considering the difficulty and challenges of HCV treatment. Also, a liver transplant doesn't remove HCV from the body and the virus can infect the liver and again begin the cycle of HCV-related complications—perhaps leading to the need for another transplant.

When weighing the pros and cons and factoring in the challenge of HCV treatment, the alternative to treating if HCV disease should progress to end-stage liver disease/liver failure needs to be taken into consideration. Liver transplantation can save lives and remains an option, but it's by no means a desirable first option.

For more information on sites that perform liver transplantation in people living with HIV, call Project Inform's Hotline or visit The Emmes Corporation website at *www.emmes.com*. The website provides details and contact information for centers participating in the liver transplant project for people living with HIV as well as information of other centers willing to transplant people living with HIV.

access to care and treatment for hcv



A positive hepatitis C antibody test, although a sign of a serious condition, does not exclude you from living a healthy, happy and productive life. However, proper treatment and care is essential. This article discusses ways of accessing HCV treatment and care as well as additional resources for information on hepatitis C.

It is important that you receive well-informed care and treatment when you are both HIV and HCV positive, as there are additional considerations to think about. If it is possible, seek care from a provider(s) who understand HCV and HIV care and treatment. Since depression is a side effect of HCV therapy and many people living with HIV experience depression, it is important to get an evaluation from a psychologist before starting HCV therapy. Anti-depressant medications may be prescribed if appropriate and can be crucial to successfully coping with HCV therapy.

There are several options available to pay for HCV treatment, as outlined below.

Private Insurance

Most private insurers provide coverage for all necessary care and medications.

Medicaid

Medicaid is a federal and state public insurance program for low-income people who meet eligibility requirements. Medicaid programs in every state will cover HCV treatment. However, the enrollment criteria, amount that you pay for prescription drugs, the number of drugs you can get in one month, and the requirements to get drugs may differ from state to state.

ADAP

AIDS Drug Assistance Program (ADAP) is a state and federal program that serves people living with HIV who are uninsured or underinsured. Eligibility criteria and formulary vary widely state to state. Ten ADAPs provide access to both ribavirin and peg-interferon Hepatitis C therapies. A few of the other state APAPs cover either ribavirin or peg-interferon, but most do not cover either drug.

For more information about the specific state ADAPS and Medicaid programs you can consult The Access Project, run by the AIDS Treatment and Data Network, at *www.atdn.org*. Your doctor or clinic may also have information about your options for care and treatment coverage.

Patient Assistance Programs

If you are unable to access care through Medicaid, private insurance or ADAP, both the manufacturers of the peg-interferon (Schering-Plough), and ribavirin (Roche Pharmaceuticals) have Patient Assistance Programs (PAPs). PAPs serve people who don't qualify for other coverage and meet the company's income eligibility requirement for free or low cost drugs. For more information about these programs, contact the companies directly. The toll-free number for the Schering-Plough Patient Assistance Program is 1-800-521-7157, for the Roche Patient Assistance Program it is 1-877-757-6243.

INTERNET RESOURCES

For more information about Hepatitis C, there are a number of Internet resources available.

HepNet
www.hepnet.com

National AIDS Treatment Advocacy Project
www.natap.org

All About Hepatitis C
www.all-about-hepatitisc.com

HIV and Hepatitis
www.HIVandHepatitis.com

Hepatitis C Advocate
www.advocate.org

Do you have a story you would like to share?

Have you had good experiences with the treatment regimen that you are on? Have you decided to wait on using anti-HIV therapy? Are there resources that have been helpful to you that you would like to share with other positive women? Would you like to share your story with other women around the country who receive *Wise Words*?

Hearing the experiences of other positive women can be a source of empowerment, support and guidance. If you are interested in submitting a personal story (this can be anonymous, with no names attached if you wish), please contact the Project Wise Program Manager, Shalini Eddens, at 415-558-8669 x205 or *wise@projectinform.org* or Project Inform, 205 13th Street, #2001, San Francisco, CA 94103.

Here are a few points to consider if you are thinking about writing a story:

- *Wise Words* comes out three times a year and each issue will contain 1 or 2 personal stories.
- Please note that submitting a story is not a guarantee that your story will be in *Wise Words*. All personal stories will be reviewed and will remain confidential. If your story is chosen to be in an issue of *Wise Words*, Shalini will get in touch with you.
- Please include your phone number, address, and email (if you have one).

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