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Words to Live By...
by Stefan, a former inmate living with HIV

In 1999, five days before I was released from prison, I found out I had HIV. I have been living with HIV for 4 years now. It was really hard for me to accept that I had HIV at first, but I have now accepted it and I am dealing with my health accordingly. I have learned a lot about myself, my family and dealing with the system. I would like to share my story with you so that it might help you in some way.

Living with HIV

One day when I was in prison, I felt a lump on my neck, so I put in a sick call slip to get it checked out. The doctor said that it was a cyst and he wanted to test it. The test did not tell the doctor that I was HIV positive, but the doctor recommended that I get tested. My HIV test results came back positive. I had HIV. It was hard for me to accept. I was very depressed. I didn't want to talk to or see anyone. While I was alone, I did a lot of reading. I read the Bible, HIV information, and whatever I could get my hands on. This was my way of coping. **Family**

When I found out I had HIV the only person that I felt comfortable telling was my aunt. My aunt had worked with people who had HIV, so I thought it would be easy to talk to her. But I never expected her to betray me. My aunt told everyone in my family I had HIV. How could she do that to me? I was not ready to tell anyone else yet. I was so upset with her. It took me a long time to forgive her. I was able to forgive her because she didn't tell my family so she could hurt

me. She was concerned about me. I don't agree with what she did, but I understand. You know what? If I ever need anything or want to talk to someone she is the first person I call.

Dealing with the system

Housing. After I got released from prison, I went to live in a shelter. No one told me where to go when I got out, but it did not matter to me. because I had lived in a shelter before, so I knew where to go. I was in a shelter for five months before my case manager helped me find a place to live. I now live in a long-term residential facility for people with mental illnesses. I did not like it here at first, but I eventually got used to it. It is a really nice place. I have cable, I get fed well, and I can wash my clothes here. I get \$205 every month from welfare, and the house takes 70% of it. So I end up with about \$50 a month. It doesn't sound like a lot, but I don't need much. Everything is taken care of, so I just use my money to buy junk food and a hoagie every now and then. Benefits. I applied for SSI, but I got

arrested while my case was being reviewed. When I was released, I found out that my request for SSI was denied. The SSI people said that even though I have HIV, my health is good, and my T-cell count would have to be below 200 for me to qualify for SSI. But I know that because I also have a mental illness, I do qualify for SSI. So I am going to appeal the decision. It's frustrating dealing with the system. But if you deserves something, you need to fight until you get it.

Personal Insights

Honesty. If you want help, you need to be honest. How can someone help you if you do not tell them the truth? The quickest way to lose someone's trust is by lying to them.

In the middle of March I was ready to give up. I was ready to drop my clothes off at a friend's house and go back out on the streets. One day I was sent to the store, but I never made it to the store. Instead of buying food, I bought drugs. When I went back home I had to explain why I didn't have the food or money. I could have easily lied. I wasn't happy with what I had done. But I wanted help, so how would lying get me help? I had to pay back the money I spent, but I gained their trust. Even though I had made a mistake, they understood because I was honest. They trust me enough to send me to the store even today.

Knowing yourself. Whenever I go to the store someone goes with me. They did not say I had to take someone with me. I decided to do that. I feel like I'm not ready to be in that environment yet, so I asked if someone could go with me when I go to the store.

I eventually want to get a job, but not right now. I am not good with money, and I do not want to put myself in a bad situation. I just need to work on one thing at a time.

If you fall, just get back up. I could have easily decided at any point to go back on the streets, but I didn't. I did not because I want more for myself. I also thought about being on the streets and having to deal with the weather. I

have to take care of myself, and hot weather wouldn't help. It is okay for me to make mistakes. Nobody is perfect. What you need to do is get back up and take things one day at a time.

Get connected. Someone asked me once: What advice would I give to someone who was about to be released from prison? I said that people need to find an agency where they can get help and support. I've been going to Philadelphia FIGHT. They are the type of people who do not judge you. They have helped me get housing, medical care, and education.

You also need to find someone you can talk to about HIV/AIDS so you do not feel like you are in this alone. And honestly, you are not. There are people who really care. Whenever you talk with somone, you need be clear about what you want them to do with that information. If you want them to keep it to themselves be sure to tell them that.

Bottom Line

Everybody's experiences with the system are differently. Just because I don't qualify for something doesn't mean you cannot get it.

You may not know where to go or even where to begin when you get out. There is a list of places on the last page of this newsletter, so you can get connected with people who want to help you. If your city is not listed, write to the people at *Prison Health News*. They will find people to help you.

A special thanks to Kimberly Rogers, who helped me write this.

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HIV and Hepatitis C Co-Infection

Hepatitis C Basics

Hepatitis means inflammation of the liver. There are different kinds of hepatitis--it can be caused by a virus (like hepatitis A, B, C, D, E or G) or by heavy drinking, certain medications, or chemicals that a person inhales.

The liver sits under the rib cage on the right side of the body. The liver is the body's filter and processing plant. It breaks down anything that passes through your body: what you eat, drink, and breathe in everyday.

Hepatitis C is a virus that affects the liver. Not everyone with hepatitis C will get sick from it - about 30% of people with hepatitis C will never have any symptoms or any serious liver damage.

Who has hepatitis C?

Globally, about 170 million people have hepatitis C; at least 2.7 million people in the United States are living with hepatitis C. Between 12% and 35% of prisoners have hepatitis C.

Preventing hepatitis C

Hepatitis C is a tiny, tough virus. It lives in blood. Because it is small, there is a lot of it in a drop of blood. And because it is tough, it is hard to kill. No one knows if bleach kills hepatitis C, or how long it takes for bleach to kill hepatitis C.

You can get hepatitis C from sharing injection drug equipment (including cotton, cookers and water). About 70-90% of people who have ever injected drugs, even once, have hepatitis C.

Sharing razors, toothbrushes, and tattoing needles/inkwells can be risky, because they may have an infected person's blood on them.

You can also get hepatitis C from unprotected sex, but it is easier to get hepatitis C from injection drug use.

HIV and hepatitis C

If you are HIV-positive, you should get tested for hepatitis C. About 16-30% of people with HIV are also co-infected with hepatitis C. Most people who got HIV from shooting

drugs also have hepatitis C.

Most co-infected people got hepatitis C before HIV, because hepatitis C is a smaller and tougher virus than HIV, so it is much easier to get than HIV.

Hepatitis C gets worse faster in people with HIV. But remember that everyone's body is different. Some people will get sick quickly, but others stay healthy for many years.



Treatment for hepatitis C

Not everyone with hepatitis C needs treatment. If you do, treatment for hepatitis C is a combination of *ribavirin* (a pill) and *interferon* (given by injection). There are two kinds of interferon: *standard* (one shot three times a week) and *pegylated* (one shot per week, because it stays in the body longer than *standard interferon*). The combination of *pegylated interferon* and *ribavirin* works best. Treatment is usually 48 weeks long and gets rid of hepatitis C in about 50% of people.

No one is sure if *interferon* and *ribavirin* work as well for people with HIV. We do know that hepatitis C treatment does not work well for people with fewer than 200 CD4 cells. If your CD4 count is low, you should see if you can get on HIV meds to strengthen your immune system before thinking about hepatitis C treatment.

Treatment Access in Prison

Access to good medical care and treatment for hepatitis C in prison is very hard. Throughout prisons in the U.S. people with hepatitis C have been denied treatment, and many were not even told been told when they tested positive for hepatitis C.

Activists are fighting for hepatitis C care and treatment for all people in prison, but it is a long struggle. Write to the *National HCV Prison Coalition* for your DOC's policy on hepatitis C. **Keeping Your Liver Healthy**

In the meantime, you can help keep your liver healthy even if you do not have access to good medical care and treatment in prison. *Drink lots of water. Water helps your liver by flushing out the body.

*Eat less fatty and salty foods. They are hard for your liver to break down.

**Cut down or stop drinking.* Alcohol is very hard on your liver and does make hepatitis C worse.

*Get vaccinated against hepatitis A and hepatitis B. Getting another virus in your liver can be dangerous!

*Get your liver enzymes checked regularly. Most facilities offer these tests, because liver enzyme levels are checked when you do a standard blood test. High liver enzyme levels can be a sign that your liver is damaged. (But a liver biopsy is the *only* way to know for certain if you have liver damage.)

*Write to the National HCV Prison Coalition for information and help.

Remember!

Hepatitis C is a slow virus. It takes 15-50 years before people develop serious liver damage from hepatitis C. If you are in prison and cannot get access to medical care or treatment, do not panic. Most people have awhile before their hepatitis C gets serious.

*Take it easy on your liver. Drink lots of water and try not to eat a lot of fatty and salty foods.

*Keep an eye on your health. Put in a sick call slip if you get swelling or pain in the right side of your belly.

*Develop a relationship with the doctor at your facility.

*Write to advocates on the outside like the National HCV Prison Coalition (resource list, page 8) who can help you advocate for the care and treatment you need. ~TS page 5

Nutrition by Kimberly Rogers

We have all heard about the food pyramid, but most of us just eat what we want. Who wants to make a full meal when you can just grab a hoagie and fries? Being nutritious has not always been number one on our list of things to do, but it needs to be.

The Basics

Being infected with HIV/AIDS can be very hard on your body. Your body is constantly fighting an infection, which means your body is using up a lot of energy. It is very important for you to fill your body with food, so that it can continue to fight the infection. Eating a lot of food will not help you if you're eating the wrong foods.

- * You need to eat protein to build and maintain your muscle. *Examples of protein are*: meats, fish, peanut butter, beans, nuts, chicken, milk, and cheese.
- * You need to eat carbohydrates to give you energy. *Examples of carbohydrates are*: pasta, potatoes, bread, cereals, fruits, and vegetables.
- * You need to have some fats in your diet, too. Try to consume more "good fats", which come from plant sources (margarine, olive oil, vegetable oil) and less "bad fats", which come from animal sources (meats, butter).

Good Nutrition on the Inside

In prison it can be hard to get a lot of the foods that are really good for your body. Prison food is generally very starchy and really high in fat. You do not often get fresh fruit, vegetables, or whole grains. Here are some tips for getting better health care on the inside:

*Talk to a doctor at your facility.

You might be able to get a

prescription for multi-vitamins, a snack, or a high-protein diet.

*See if you can order peanut butter or fresh fruit from your *commissary*.

*See if you can get food sent in through care packages. Some facilities will even let you get *care packages* with fresh fruit and vegetables.

*If you can work, try to get a *job in the kitchen* at your facility.

*Drink as much water as you can.

*Educate yourself about what food is good and bad for you.

Exercise!

Exercise will help you keep your body healthy. Try to do something active every day, like jogging or playing basketball. If you have a gym at your facility, lifting weights will also help keep your muscles strong. If not, push-ups and sit-ups will do the job.

Water, Water, Water!

Drinking a lot of fluids is very important, too. Your body needs at least 8-10 glasses of water a day to keep everything working. Caffeinated drinks like coffee and soda make you dehydrated. You are actually losing water when you drink these things! So reach for water or juice if you can.

When you don't feel well...

Your body may go through many changes while you are fighting HIV, but it is important to remember that no matter how bad you feel you must eat.

Here are some tips for when you are not feeling well. If you have...

Diarrhea/Fever/Sweats

*Drink lots of water

*Eat white bread, crackers, white rice, oatmeal, bananas, and applesauce.

*Limit your intake of fatty foods, caffeine, dairy foods

Nausea/Vomiting

*Drink lots of cold drinks (water & juice to replenish the nutrients lost)

**Eat* cold foods & dry, salty foods (crackers, pretzels)

Constipation

*Drink lots of liquids (cold or hot)

*Eat bran cereals, whole grain breads, pastas, brown rice, beans, fresh fruit with skins, and fresh vegetables.

If you have diarrhea, fever, sweats, nausea, vomiting or constipation that last for *more than 24hrs*, <u>PUT IN A SICK CALL SLIP</u>. You need to see a doctor to make sure nothing serious is going on.

The Bottom Line:

- 1. *Eat* well, even if you are not feeling well. Your body is working overtime.
- 2. *Drink* lots of liquids, especially water and juice.
 - 3. Exercise regularly.

~KR

Thank you for all your letters!!!

We have gotten over 500 letters from people in nearly every state.

We are answering letters as quickly as we can, so please keep writing!

For 2004, we will be trying to have a more regular publication schedule.

We are aiming to publish *Prison*Health News four times a year. So keep a look out, and send us any artwork, helpful tips or articles to include in the 2004 issues.

write an article!

We have gotten lots of requests for articles already, and we know that everyone who reads this newsletter will have questions or his or her own story to tell.

If you have advice for other prisoners dealing with health issues, write to us. We will feature you in "Words to Live By."

If you have a question, write to us. We will write you back and may publish an article on your question in *Prison Health News*.

If you want to write an article on something you think is important for prisoners' health, send it and we will consider publishing it in *Prison Health News*. You can also write us first to discuss ideas for articles.

If you want your name kept confidential, you can sign your article with your first name or "anonymous."

In coming issues, we will cover:

- * Nutrition,
- * Exercise,
- * Getting Support While You Are Incarcerated,
- * How to Advocate for Yourself,
- * HIV Treatments,
- * Hepatitis C Treatments,
- * Treatment strategies for HIV and hepatitis C Co-infection,
- * Depression,
- * Getting Out,
- * Staying Clean When You Get Out,
- * Welfare, Food Stamps, and Medical Assistance,
- * Housing, and much more!

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resources for people in prison
If you need help while you are in, or when you get out, contact:

In Philadelphia, PA

Philadelphia FIGHT 1233 Locust Street, 5th Floor Philadelphia PA 19107 (215) 985-4448--no collect calls Contact: Laura McTighe

In New York City, NY

Women Prison Association & Home Inc. 175 Remsen Street, 9th Floor Brooklyn, NY 11201 (718) 797-0300--for collect calls from New York Jails/Prisons

(718) 637-6818-no collect calls Contact: Leah Bundy

In Miami. FL

Care Resource, Miami 225 N.E. 34th Street Miami, FL 33137

(305) 573-5411—no collect calls Contact: Pedro Torres

In San Francisco, CA Continuum Springboard 225 Golden Gate Avenue San Francisco, CA 94102 (415) 823-0414 -no collect calls (415) 823-0415-no collect calls

Contact: Helen Lin or Charlie Wilson

In Houston, TX

Houston Montrose Clinic 215 Westheimer Houston, TX 77006 (713) 830-3000-no collect calls Contact: Chris Jimmerson

Every organization on this list provides case management, medical care and support services for people when they get out of prison. Most of these organizations specialize in care for people with HIV. Every organization distributes *Prison Health News.*

If you need resources in a city not listed here, write to us! We will help you tack down anwers to your specific questions. Write to us if you know a great organization that is missing from this list.

If you need information while you are in, contact:

Project Inform

Outreach and Education Department 205 13th Street, Suite 2001 San Francisco, CA 94103-2461 information & newsletters on HIV *free to prisoners

Fortune News

Subscriptions c/o The Fortune Society 53 West 23rd Street New York, NY 10010 newsletter on criminal justice issues *free to prisoners

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