



The Positive Side

July-September 2006 Volume 14 Number 3

Ruling Your World

by Marie

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I was diagnosed with HIV eight years ago, in 1998. When I was diagnosed, I was not surprised, because I was using really hard at the time. Since then, I feel I have come a long way. HIV doesn't define me. I define me by the choices I make today.

HIV came into my life as my addiction started to progress. My using started because of some very stressful factors- the death of a parent, going through a divorce (losing my best friend) and finally rebounding into a physically abusive relationship. I became overwhelmed with grief, loss and whole lot of hurt. I used drugs as a coping mechanism. Using helped to numb me. From 1995- 1998, I was struggling with drug use that led to addiction. I was working full time at a really good job, but then had to leave due to my addiction.

I used more and more, and then started injecting.

I'm convinced I know the day I got infected. On that day, I feel I was using with the Devil. I knew a huge risk was involved, but by this time, the drugs had impaired my judgement, which in turn led me to make the wrong choice. The control of the drug had overpowered me and won. Sooner or later it does. It was just a matter of time.

I got tested three months after that, and wasn't surprised when I found I was positive. It just confirmed my suspicion.

It was very difficult for me to come to terms with my diagnosis. I just numbed myself even more with drugs and my addiction got worse. I'd lost everything I'd worked for 20 years and now I was HIV positive. I thought, I'd rather go through drug use

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Ruling Your World... continued

than go because of HIV.

But eventually that changed. When I was married and working, I had social acceptance, I had intimacy, confidence and integrity. I had a sense of well-being, and euphoria when I was working out and looking after myself physically. I had been in the military, so I had tested my own limits many times, and knew what I could push myself to do. When my life shifted and the stress led to coping with drugs, I lost all that, but I wanted that back.

I tried to give up drugs many times. Detoxes, recovery homes, transition houses, shelters and safe houses became revolving doors. I stopped counting after I realized I had moved more than 20 times over a couple of years. Eventually, I ended up at New Dawn Recovery house for the second time. I decided to give myself a year at New Dawn, and the director told me I would need a year, and I could stay in the house for that long. So I challenged myself to give it all up once and for all. I felt I had been sitting on the fence far too long. Plus, I realized my health was deteriorating, rather rapidly. I told myself that if I wanted to go back to using at the end of the year,

"I had tested my own limits many times, and knew what I could push myself to do."

I could, but I had to be drug-free for a year. Using was not an option in that time. I gave myself a year so I could eventually deal with my internal demons, for lack of better words.

And now it's been a year. I've learned a lot about myself. I told myself that recovery must come first. I've set goals for myself, and connected to different kinds of support. I've used what I learned in the military to get myself through a lot of barriers: determination, motivation, discipline, and focus. When I signed on for the military, it was a three-

year contract. Recovery became a contract with myself for a year at the very least. I hung on to the phrase "Recovery is the best revenge, really, for anyone and anything".

It's been a discipline of planning- appointments, support, activities that help with my recovery. I plan so that I can have balance: appointments with my addictions counselor, going to NA meetings, going to day programs, seeing my GP, seeing supportive friends, taking care of myself physically and spiritually. I use all the resources I can.

I work out and try to stay connected through the program, do yoga and read. Staying in touch with the elements helps me stay focused, so I exercise outdoors, feeling my place in nature. That's very spiritual to me. I touch base with chiropractic and massage treatments, I pay attention to my physical being a whole lot more now.

Sometimes I struggle with depression and anxiety. I make sure that I am accessing all the support I can when I need it. It can take a lot of figuring out. I try to keep things as simple as

possible.

Everyone needs time to figure out what they need in recovery. It's not just sobriety, it's recovery, which is a spiritual process. You have to allow the process to happen, and you need to allow yourself the time. You can't make it happen or push it. The process has to happen on its own.

First there's the physical detox, and health issues that go with that process. Then there's dealing with the mental and emotional issues of using. After that, there's dealing with the mental and emotional issues that led to

started to focus more on recovery and got myself into a treatment program. Next I slowly started to come off methadone and committed myself to another day program, with Dual Diagnosis, for as long as it took to maintain stability. It became a very vulnerable time for me. I started realizing some of the emotional stuff that had been part of my using, and contributed to my using, making me vulnerable to it. I needed to look at those issues.

In the past year I've gone through a lot of transition, and this can challenge

ing. And it brought up a whole new wave of emotions, because I'm not numb anymore. I've been grieving, and there's been a whole lot of letting go. But because of the past year, I'm accessing support as I go through this. I've learned a whole new way of living and coping and I keep open about incorporating new means. A lot of change and acceptance.

This past year has been dedicated to my recovery. This next year I want to build on that and dedicate the next one even more to my health. My doctor is elated with the dramatic difference in my counts. I'm on HIV meds, and a mild antidepressant to deal with coming off the meth. Before, it was a question of whether I would be healthy enough to do Hep C treatment. Now I can consider it. Health issues become a lot more complicated when you're co-infected, and that becomes an inspiration to stay clean. You must stay clean to stay focused.

I think getting your HIV diagnosis is like a death. You go through anger, denial, and all those stages. You have to allow your grief and come to terms with it. I think it's

“Everyone needs time to figure out what they need in recovery. It's not just sobriety, it's recovery, which is a spiritual process.”

using. It can be very overwhelming, a huge reality check at times, which can be really depressing.

In the first three months, I focused on getting and staying clean. I used no drugs, concentrating on sobriety and healing. Then in the next few months, I

stability. I've transitioned out of the recovery house and back to living on my own. I've come off methadone maintenance too, and that was something I had to really push myself through with the help of a good (methadone) doctor. It caused a mild depression I wasn't expect-

Getting your HIV diagnosis is like a death. You go through anger, denial, all those stages. You have to allow your grief and come to terms with it.

important to realize HIV is not a death sentence. You can choose to die in other ways.

You need to be continuously aware of your emotions and your attitude. It's very important to try to stay positive and reach out for support when you need it. See what others are going through. The goal is balance: being aware of voids, and filling them where needed, with healthy choices. Taking care of the voids is necessary, staying in the here and now, and staying in tune with your emotions, allowing yourself to feel and go through them.

Getting support everywhere you can is important. You can go to your AIDS

organizations and treat yourself to the benefits of what they have to offer. For anyone in early recovery, know there is help for you. For me, a lot of the resources I've accessed throughout my first year really contributed to a successful first year. These resources include New Dawn Recovery Homes, Harbour Light Detox, Vancouver Detox, Vancouver Recovery Club, Pender Clinic, Dual Diagnosis, programs through Family Services, St. Paul's Hospital, Positive Women's Network, BC Persons with AIDS Society, NA, AA, and many support workers. Access and connect with all your resources. Reach out and ask for help. Recovery is a lot of work. You cannot do it alone. You need a support network.

I share my HIV status with some people and not others. It's on a need-to-know basis only. HIV isn't all of me, it's a part of me I've learned to accept, work with and manage, just like the disease of addiction. I'm always learning more ways to take care of myself and to treat myself with kindness. I am gradually setting new goals for myself, keeping in mind one step at a time for

now. I now feel I'm in a much better place physically and spiritually because I'm much more conscious of a healthier way - it's about balance and maintaining it. I have my voice back. I make my own choices. I do what is best for me.

After a year of recovery, using is still not an option, because now I realize there are so many more options that will work for me and not against me in the long run. I no longer take life for granted. Every day truly is a blessing. I am grateful, *just for today!* Yesterday is gone, and tomorrow isn't here yet.

Giving Women Power Over AIDS: Bringing the Message Home

“Hearing stories and the bearing of witness is always compelling”
feedback from a viewer



Giving Women Power Over AIDS exhibit at the Vancouver Public Library

On June 1 and 2, people headed to the Vancouver Public Library got a chance to see Giving Women Power Over AIDS, a powerful photo exhibit on microbicides. It was amazing watching people as they read about microbicide development and the story of Martha, a six year old African girl who lost her mother to AIDS.

I saw their faces turn from curious to concerned, to determined. Then they would approach us to ask for more information and what they could do to make a difference.

If you would like more information on microbicides, visit the website of the Global Campaign for Microbicides (www.global-campaign.org/). Martha makes her next stop in Peterborough before heading to the International Conference in Toronto in August.

- JM



Janet (PWN), Bronwyn (PWN) and Mandip (AIDS Vancouver) answer questions and offer resources.

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“What IS that thing?” Meet Recovery

by Sangam and Helenka

Members worked on her for some time but interest waned... Recovery was put away. Recovery can be like that.

For those of you who visit the drop-in regularly, you may have noticed an interesting piece of work lounging around (see photograph above). “What IS that thing?” you may have asked yourself and others. Well, her name is Recovery and she is a work in progress.

A few months back, in the midst of winter and During a Taking A Break support group held at the PWN, support worker Sangam felt the group needed an injection. So, she came up with the idea to have everyone work together on something. What would the group work on? A life-sized figure of a woman.

“What should the woman represent?”, the group wondered. Should she represent hope? Should she be a symbol of strength? Although there was a lack of certainty on this note from within the group, in time, members decided that the figure should serve to symbolize all women living with HIV.

The woman figure was to be named Recovery. Members worked on her for some time but interest waned, the work stopped, and Recovery was put away. Recovery can be like that.

In late winter a new support group started called: Mind-Body Connection. The emphasis of this group was on reducing stress in our lives. Several of the women

were struggling with their own process in/out of recovery. At this point, Sangam was reminded of the abandoned project named Recovery and a couple of Members took on the task of continuing work on her. Once again, Recovery had the support she needed.

Today, as you can see from the photo, Recovery still has a long way to go. But we need to remember that she certainly has come a long way.

For more on Recovery and her journey, stayed tuned for the next newsletter. Also, note that there will be a new support group with a focus on recovery starting in August (please see page 10).

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Secrets of successful adherence

by Sean Hosein, CATIE News

The ability to take medications as prescribed—a behaviour called adherence—is essential to attaining the full benefit of any therapy used in a chronic health condition. In the case of HIV infection, high levels of adherence to highly active antiretroviral therapy (HAART)—at least 95%—are needed to keep this virus suppressed and maximize the benefit to the immune system. Not surprisingly, at least one study has found that people with HIV/AIDS (PHAs) who are non-adherent are about four times more likely to die than adherent PHAs taking the same regimen.

But sticking to a regimen of pills once or twice daily is not easy for everyone with a chronic health condition. Adherence in PHAs is complex, can change and is affected by many factors, including depression, medication side effects, the belief that treatment prolongs life, substance use, complexity of regimens, relationship with health care providers.

Most research about adherence in PHAs has focused on barriers to taking medications. Now researchers are beginning to take a

different tack by interviewing PHAs who have high rates of adherence and finding out the secrets to their success. These findings could be used in adherence education programs.

Researchers at the University of Pittsburg have conducted in-depth interviews with PHAs who showed high rates of adherence. The research team found that all participants had common beliefs, behaviours and outlooks that helped them integrate medication-taking into their lives.

Study details

The study team interviewed 13 PHAs (4 women and 9 men) who were identified from a larger study on adherence in 253 PHAs. All 253 participants were using specially manufactured pill bottles with caps that recorded the occasions when they were opened. In analysing the data, the researchers decided that participants were 100% adherent if the bottles were opened within certain time periods each day, depending on the regimens used. Out of 253 participants, 13 PHAs were found to be 100% adherent and willing to participate in a further study.

The average age of the

13 participants was 42 years. None of the participants suffered from moderate or severe HIV-related neurological damage. Each was interviewed for about an hour about factors that might have affected their adherence.

In analysing the interviews, the study team found that what they called “successful medication management” emerged as a key behaviour. Participants achieved this by managing their regimens, their immediate environment and themselves. Also, the team said that these PHAs “adopted realistic expectations and pragmatic attitudes in developing medication management strategies.”

Fitting a regimen into their lives

The participants developed the habit of taking their medication on a regular basis and worked with their doctors to choose a regimen that fit their daily schedule. One participant said: “I never looked at the medicine as anything other than a habit. As something like taking vitamins. I take multivitamins every day and I took multivitamins even before I got sick...in my mind, I related it

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Adherence Secrets continued

to something I needed to take.”

Another participant revealed: “When I started on the medication, I told my doctor: Whatever you do, do not give me no complicated medication. I want something that is going to agree with me and agree with my daily work schedule.”

Reality: A bit of give and take

Participants placed their experiences of medication-related side effects in perspective, recognizing that there were tradeoffs when taking HAART. One PHA said that when she felt “lousy” after a dose of medication she sometimes felt that she could not continue on her regimen, so she kept telling herself this: “You know, within a couple of hours I’m going to be fine.”

Another PHA shared this with the team: “I feel better now that I’m on medication. But on the other hand, I can’t do what I used to do. But that is the illness and the medication; so it is good and bad together.”

The study team found out that the PHAs realized that “limited treatment options made adherence to their medications particularly important.” One participant spoke about his hopes and

fears in this way: “I’d really like to stay alive as healthy as possible for as long as possible, and I take the medication religiously, with the hopes that I won’t burn through these two classes of drugs. There are four classes and you get, like, you know, maybe one, maybe two chances with each class.”

Avoiding illness and death

Researchers found that all participants held “a strong belief” in the effectiveness of their medication. They also acknowledged that adherence helped them to avoid illness and death. One interviewee said: “I’ve never had any strict regimen of anything like that...I take them knowing what the alternative is, what one of my friends tells me, it’s an early death...so that’s the reason I take them.... If I had a choice...I would not take them...I don’t consider that much of an incentive, but it’s all that I have at this time...it’s all that I have to hold on to.”

Problem solving

The researchers commented that these PHAs were able to take ownership of problems and celebrate solutions “transcending the suffering and self-blame for acquiring HIV.” Here are some statements from PHAs

that support this:

“...blaming yourself or being upset or whatever [for being HIV positive], that’s ridiculous, you know. You have HIV, move on, make something positive out of it.”

“You know, I have a crisis in my life all the time, it’s just that I decided that it’s not going to bury me and it’s not going to bury me to the extent where it’s going to interfere with me taking medications.”

Support can be both negative and positive

The team found that the PHAs were able to recognize “positive and negative” sources of support. Participants had learned to assess each potential source of support and stressful situations or people were avoided. One bit of advice for people about to start therapy was this: “Take [your medications] at a convenient hour, like when you first get up and before you go to bed...so it’s the first thing you do and the last thing you do.”

Other PHAs tied medication taking to common events in their lives, such as regularly scheduled TV shows or other activities. Some people used a beeper, pill box or written notes to themselves as reminders of pill time.

Connecting with other positive women: Aboriginal Women's Wellness Retreat

PWN will be hosting the 2nd Aboriginal Women's Wellness Retreat September 15 - 17, 2006 in Langley, BC. The retreat is open to all Positive Women's Network members but priority will be given to persons of Aboriginal ancestry.

If you are interested in learning more about your culture and heritage, healing paths and teachings or just

want to connect with other positive women in BC, please apply! Registration and information has been mailed to members. Applications will be due by Monday July 24th.

If you've moved, please call us with your new address. For more information, contact Gloria, the Retreat Coordinator at 604.692.3000.

"I appreciated being out of the city and away from the sickness that surrounds me daily."

--past retreat attendee

Adherence Secrets continued

Working with the health care team

Participants collaborated with their doctors, nurses and other members of their health care team. Moreover, the PHAs saw themselves as a key and active part of this team, as illustrated by this woman's comment:

"I try very hard to be one of these people that if a doctor says to me, 'I want to have this test done' or 'I want you to take this pill,' I say, 'Why?' I mean, doctors are doctors. They are not God. They are not all-knowing, so you should still be aware of what's going on with yourself, for yourself."

The results of this study are encouraging. Keep in mind that this was a small

study. Research into adherence is often complex, time consuming and expensive. But if these findings are confirmed in a larger study, then perhaps adherence educational efforts can be strengthened.

Another point is that the findings from this study may not apply to every PHA. For instance, because of differing circumstances, some PHAs may have other priorities, such as: finding a safe space for shelter, getting a regular source of food, searching for a supply of street drugs.

Unless the underlying reasons for these conditions are addressed, health enhancement with HAART will not become a priority for some newly diagnosed PHAs.

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Source: CATIE News, March 10, 2006

From Canadian AIDS Treatment Information Exchange (CATIE). For more information visit CATIE's Information Network at <http://www.catie.ca>

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Events and Program Information

Quick Calendar: go to www.pwn.bc.ca for updates

Monday	Tuesday	Wednesday	Thursday	Friday
Drop-in open 11:30-3:30	Drop-in open 11:30-3:30	Drop-in open 11:30-3:30	Drop-in open 11:30-3:30	Drop-in closed
	Lunch 12-2	(Closed on Cheque Issue Wednesdays)	Lunch : 12-2	
	Foodbank 12-2. No pick-up any other day.		Recovery Support Group starts soon. Call Sangam for details.	
Administration 9:00-4:00 Monday through Friday				

Drop In hours

The drop in is open Monday to Thursday from 11:30 to 3:30. The drop-in is closed Friday.

Recovery Support Group

A support group for women dealing with recovery will start in August. Contact Sangam for details: 604.692.3006.

If you can't come to see us...

... we may be able to come see you. Stacie is doing outreach on Fridays now. She goes to various programs and organizations to familiarize them with PWN. She also makes home visits when possible. If you would like to connect with her, call 604.692.3005.

Support group for positive transgendered women

Group starts in August. Leave a message for Angel at 604.692.3006



Foodbank Closures

The foodbank is closed the Tuesday before cheque issue. Days the foodbank will be closed in the next few months: July 25, August 22, September 26.

Events and Program Information

Aboriginal Women's Wellness Retreat

See the notice on page 9, and watch for your registration package in the mail.

Positive Spaces Project

Three drop-in lounges/resource centers have been established in the Fraser Health Region for persons living with HIV/AIDS. The project is called Positive Spaces: Peers Creating Supportive Environments. There are three lounge locations:

Abbotsford: Fridays from noon- 5 p.m. (Stacie from PWN is available)

New Westminster: Thursdays from 1p.m.- 4 p.m., Fridays from 1 p.m. to 4 p.m. (Stacie is here too!)

Surrey: (Set to open September 2006)

Services available at all locations include support groups, access to a food bank, social activities and more!

Volunteers for all three locations are needed ASAP.

Please contact project coordinator, Edoye Porbeni, at 604-526-2522 or edoye.porbeni@purposesociety.org.

AIDS Walk for Life September 24th

Join us for the AIDS Walk for Life on Sunday September 24th, sponsored by BC Persons with AIDS Society. PWN will be a community partner once again, and we hope to be the top money raising community partner (once again!). *To help with PWN fundraising efforts, you must specify that you want to join the PWN team when you register.* To make it simpler, you can contact Donna, our AIDS Walk for Life team captain, for more information: 604.692.3000 or donnat@pwn.bc.ca

Many thanks to Womyn's Ware and Lush for their donations to the May retreat. Members were very appreciative!

Next issue: reports from the sixteenth International Conference on AIDS (Toronto, August 13-18).

PWN Board of Directors 2006-07

The Annual General Meeting was held on Monday June 26th and a new Board of Directors was assembled. Newly elected members include:

Monique Desroches
Nash Dhalla
Peg Frank
Christine Iamonaco-Dagg
Margarite Sanchez
Kath Webster

Returning Board members:
Lisa Gifford
Teresa Jakubiak
Kurstin Leith
Yasmin Winsor

Board meetings are held every two months and are open to all. Call PWN for the upcoming schedule.



*Do you have something to share with other members?
Deadline for submissions to the next newsletter is September 6.
Send submissions to janetm@pwn.bc.ca or by mail (see last page).*

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Positive Women's Network, a partnership of women living with and affected by HIV/AIDS, supports women in making informed choices about HIV/AIDS and health. We provide safe access to support and education/prevention for women in communities throughout British Columbia. The Positive Women's Network provides leadership and advocacy around women's HIV/AIDS health and social issues in the national and local health care communities.

Thanks to our supporters!



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Unless otherwise noted, all materials in this newsletter are written by Janet Madsen, Communications Coordinator (janetm@pwn.bc.ca)

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